Deafness Notification Report 2023

Rīpoata Whakamōhiotanga Turi

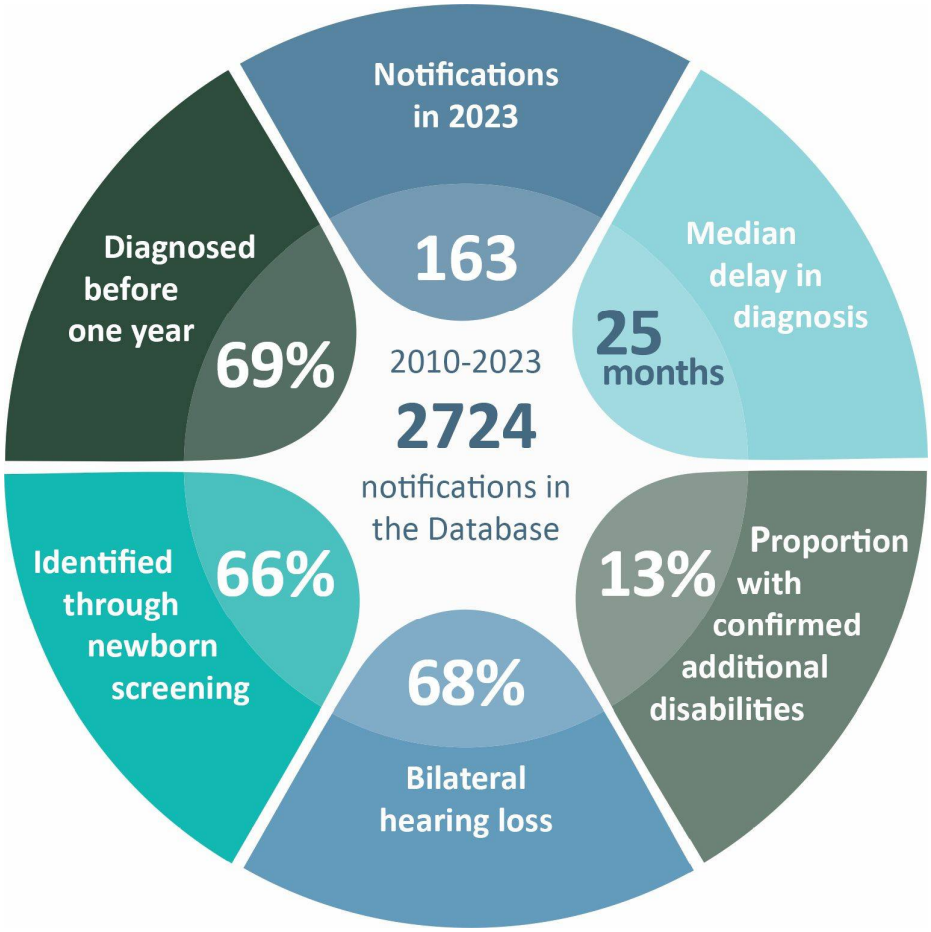
Janet Digby, Levare Limited

January 2025

Enable NEW ZEALAND

Summary

Whakarāpopoto



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This and previous reports are available on the New Zealand Audiological Society website.

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The Deafness Notification Database

Te Pātengi Raraunga Whakamōhiotanga Turi

- **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 whānau to benefit 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 2023.

Welcome to the fourteenth 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 2023 calendar year.

The New Zealand DND reports aim to provide detailed information about the children and young people being diagnosed with permanent hearing loss in Aotearoa New Zealand, their characteristics and those of their hearing losses, diagnosis and intervention. This is done to inform clinical practice and decision making around the motu to benefit children and their whānau.

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

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

Where parents (mātua) or care-givers (kaitiaki) provide consent for this information to be shared, audio-logists and audio-metrists 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.

The analyses contained in this report generally pertain to 2724 children and young people notified with a hearing loss diagnosed between the start of 2010, when the DND was relaunched, and the end of 2023[ii].

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

ii Additional notifications made for children diagnosed before 2010 have also been received, meaning the total number of notifications held is greater than 2,800.

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

For further information see the document's Glossary from page 84 and appendices from page 73:

- Sections within Appendix A relate to the DND: Making notifications, History, Completeness, Notifications and ethnicity, Terminology, Interpolation.
- Sections within Appendix B contain further information about specific topics: Māori hearing and health, Perspectives on hearing loss and hearing services, Newborn screening goals and history, Single-sided deafness, Severity codeframes, International severity comparisons, Cytomegalovirus, and Atresia and microtia.

Perspectives on hearing loss and hearing services

There are various perspectives or lenses used through which one can view hearing and deafness. Understanding these various perspectives can usefully inform clinical practice and decision making with a view to reducing inequities in access to and through the health (and education) system. This is particularly important for Māori and Pacific populations who suffer the greatest inequities and to consider different perspectives of hearing held within the Deaf community:

"There's the Māori world, there's the Western world, there's the Hard-of-hearing world, there's the Hearing world, there's the Deaf world," Alehandrea Manuel[1].

Two studies on perceptions are included in Perspectives on hearing loss and hearing services from page 79.

Acknowledgements

We extend our sincere and heartfelt thanks to the 163 parents (Mātua), caregivers (Kaitiaki) and young people (Rangatahi) who consented to share details with the Database in 2023.

As a result of this willingness to share basic diagnostic information, clinicians, service providers and other decision-makers 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.

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. (*See Making notifications from page 73 for details on how to notify a case.*) It is clear from how this is done, including by departments under strain, that diagnosing clinicians care deeply about the wellbeing of both their patients and whānau.

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

The primary author of these reports 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 Te Whatu Ora Te Toka Tumai Auckland. Their input into these reports is greatly appreciated. Ngā mihi nui ki a kōrua. The authors are grateful to Alexia Searchfield for additional analyses contained in this year's report to expand our understanding of notification data. Ngā mihi maioha Alexia.

i For those interested, comprehensive New Zealand Guidelines relating to children with APD were published by the New Zealand Audiological Society in 2019.

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 for 163 children and young people diagnosed during 2023, most of whom were born in Aotearoa New Zealand. The proportion of notifications for Asian children and young people has risen since 2010 and there has been a reduction in the proportion of European children being notified.**
- **Males are more likely than females to be diagnosed with a hearing loss and two thirds of notifications are for tamariki with bilateral hearing losses. Māori are more likely to have a bilateral hearing loss and more likely to have a mixed hearing loss than non-Māori, non-Pacific.**
- **In addition to poorer outcomes for those with more severe and bilateral hearing losses, current evidence suggests that mild and unilateral hearing losses (UHL) are also associated with poorer outcomes than for those without hearing loss.**
- **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 2023 had one or more confirmed 'additional disabilities' at the time their hearing loss was notified.**
- **Those with one or more additional disabilities are more likely to have a bilateral hearing loss, a mixed hearing loss or permanent conductive hearing loss, than those without. Pacific children are more likely to have one or more additional disabilities compared with children who are non-Māori, non-Pacific.**

Interpreting odds ratios and p-values

In this year's report we have included odds ratios (OR) to compare the likelihood of another variable being present in one group with the likelihood of it happening in another group.

For example, children with a bilateral hearing loss are 2.8 times as likely to have an additional disability when compared with those who have a unilateral hearing loss.

Where the odds are less than 1.0, this means there is a lower chance of a specific outcome, while those greater than one, like the example above, indicate a higher chance. In the example, this means tamariki Māori are nearly twice as likely to live in a Quintile 2 area than a Quintile 1 area. All odds ratios within the report are statistically significant.

Confidence intervals are all calculated at 95%, and p-values are provided when these ratios are described, so readers who are interested can have more detail. A large p-value means that the difference between the groups is not surprising and could easily have happened by chance, so we can't be confident in our findings. A small p-value (usually <0.05) means that the results are surprising and unlikely to have happened by chance, so we can be more confident that our findings are real.

In our report, p-values less than 0.05 are considered statistically significant. Those where the p value is less than 0.01 show even greater confidence and those with p values of less than 0.001 are the very highest level of confidence that the difference seen between two groups is real. In this report should findings reach statistical significance this is noted.

General information

Introduction

One hundred and sixty-three children and young people diagnosed during 2023, and whose hearing losses met the criteria for inclusion, had their information notified to the Database by the end of July 2023[i, ii]. There are now 2724 cases included in the main dataset that forms the basis for analysis in this report. These notifications were received from 18 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.

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

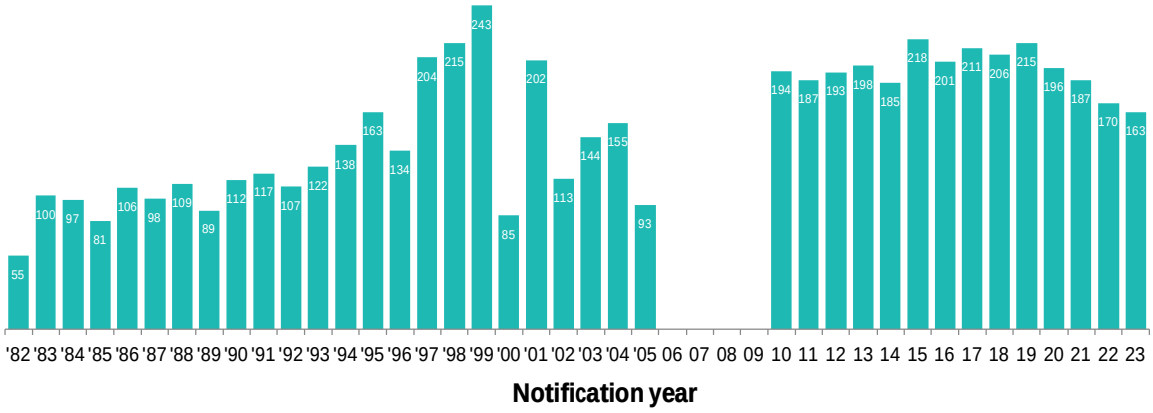

Figure 1: Notifications by year 1982-2005[iv] and 2010-2023

Overall, when considering notifications from 2010-23:

- when considering the size of various ethnic groups in the under 19 Census population (2013, 2018 and 2023) European children are under-represented and Māori over-represented;
- notification numbers are highly dependent on deprivation. Children from low deprivation areas have an average rate of notifications of 1.4 per 10,000 compared to 3.6 per 10,000 for those from high deprivation areas; and
- those for Māori and Pacific Peoples have comprised a steady proportion of notifications over time, while notifications among Europeans have fallen;
- the proportion of notifications for under 1-year olds has increased dramatically and there has been a decrease in the number for older children, including among 4-6-year-olds, the group most commonly diagnosed as a result of the B4 School Check (B4SC).

When compared with 2010, notifications in 2023 are:

i Reports prior to 2006 contained information about diagnoses notified during each calendar year, rather than those 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 several hours. However, many individual notifications took fewer than five minutes to enter using the online form, as was the case in previous years.

iii 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 generally been in mid-March the following year though for 2024 this was delayed to 2024 due to low notification numbers. 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.

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

- a bit less than half as likely to be for European children and young people[i], consistent with changes in their falling proportion within the population; and
- more than three times as likely to be for Asian children and young people[ii], in line with their growing proportion in the population.

Falling number of notifications

The falling number of notifications, particularly for 2022 and this year, is a concern as it may indicate a drop in the proportion of children who are hard-of-hearing being diagnosed.

Several factors are thought most likely to contribute to this decline:

- a fall in the number of births (down 4% on 2019 numbers[2]), particularly in Auckland, and subsequent reductions in the number of diagnoses during the period;
- a fall in the proportion of diagnoses notified to the DND due to increased pressure on public audiology services (potentially related to the private sector recovery from the initial phase of COVID and subsequent increased recruitment activities, meaning public sector vacancies are again harder to fill); and
- a reduction in the number of children being seen for screening (particularly 2–5-year-olds[iii]), monitoring and/or diagnostic appointments, potentially linked with poorer coverage rates and/or a reticence of whānau to engage with health services during and since the pandemic.

At the Health NZ Audiology Leaders Group meeting on the 21st of November 2024, there was a diversity of experience from District representatives, with some reporting very low or high numbers of diagnoses compared with typical levels, and others with expected numbers. No reasons for the drop in numbers is immediately apparent to this Group, including whether the issue is reduced notifications or reduced diagnoses.

Further potential causes of this fall in notifications are outlined in Falling notifications from page 73.

Gender

Background

In overseas research, males are commonly found to have higher rates of hearing loss than females. Reported figures range between 51.5% and 58% for males (1:1.06 and 1:1.38), as reported in the 2011 *Comprehensive Handbook of Pediatric Audiology*[3] 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[4].

Hearing Australia's data on those under the age of 26 who have hearing aids or cochlear implants show a similar pattern, with higher numbers of hearing loss among males (51.2%) than females (48.6%) and 0.1% as intersex, as at December 2022[5]. The 2021 Australian Hearing report noted a predominance of females among those among 21–25-year-olds. This analysis is not described in the current report and no 2023 report is available.

DND data

From 2018, a third option has been available for selection in the notification form, meaning the notifying professional can now select female, male or an additional gender option, such as non-binary.

Of the 2724 cases (2010-2023) contained in the main dataset, 45% of these are listed as female and 55% male, with one case listed as 'other', or non-binary. This represents a ratio of 1: 1.21 of females to males. This gender difference was particularly noticeable in 2016 and 2020, when it was near or above a ratio of 1:1.33.

A higher proportion of children and young people in the Database are male in all the ethnic groups: MELAA (58%), Asian (58%), Pacific Peoples (57%), Māori (55%) and Europeans (53%).

i OR 0.6, CI 0.4-1.0, p-value=0.05.

ii OR 3.2, CI 1.6-6.3, p-value=0.0004.

iii The B4SC has seen rates of coverage fall from 9% in 2010-11 to 18% in 2022-23, with even poorer coverage for Māori and Pacific tamariki.

Birthplace

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

Figure 2 shows the birthplace of cases notified by for the 2010-2023 period. During that time, 6% of children and young people notified were born overseas, with the birthplace of an additional 5% being uncertain.

The number of children about whom the notifying professional listed uncertainty about the location of their birth has dropped from a high of 12% in 2010 to 1-4% in 2017-2023. 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 163 notifications to the Database in 2023, 5% were known to be born outside Aotearoa New Zealand. Lack of certainty around birthplace was listed in a further 3% of cases.

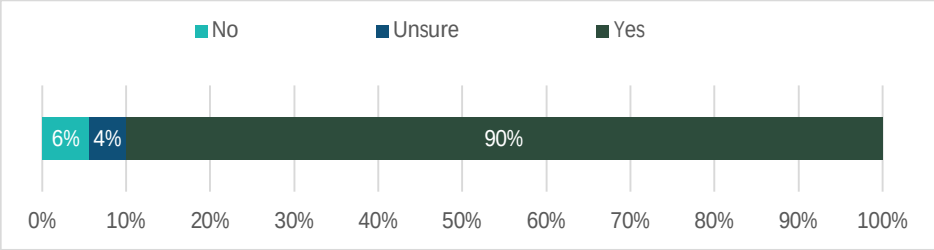

Figure 2: Proportion of children notified born in New Zealand (2010-2023)

Geographical representation

Table 1 compares the proportion of 2010-2023 notification with the percentage of the population under the age of 20 from the 2018 Census with the percentage of 2023 notifications from each district[i]. The percentage of notifications received for 2010-2023 from each district is also shown. This can be compared with the relevant percentage in the population for those under the age of 20.

This year we are reporting Hutt Valley and Capital and Coast notifications for the full period under one grouping, Capital, Coast and Hutt Valley, to reflect the newly formed District. There is currently one operations manager for audiology across both areas and the plan is for this to become one service.

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 1[6].

Notification levels

There has been downward trend overall in the number of notifications since 2019, with the lowest number of notifications reported in 2022 and 2023.

In addition to the ethnic distribution and natural fluctuations in the number of hearing losses diagnosed among tamariki in each year, other factors affecting 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 number of hearing professionals working within each district (some districts have made efforts to catch-up on notifications in recent years);
- the rates of deprivation within districts and other factors influencing the ability of whānau to engage with services;

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

District	Percentage of population under the age of 20 (Statistics NZ, 2018 Census[7])	Percentage of notifications received in 2023 (under 19 years)	Percentage of notifications received 2010-2023 (under 19 years)
Auckland	9%	3%	6%
Bay of Plenty	5%	8%	7%
Canterbury	11%	11%	12%
Capital and Coast	9%	9%	12%
Counties Manukau	13%	7%	13%
Hawke's Bay	4%	4%	3%
Lakes	3%	4%	3%
Midcentral	4%	0%	2%
Nelson Marlborough	3%	0%	3%
Northland	4%	5%	6%
South Canterbury	1%	4%	2%
Southern	6%	11%	7%
Tairāwhiti	1%	3%	3%
Taranaki	3%	3%	3%
Waikato	9%	20%	9%
Wairarapa	1%	2%	1%
Waitematā	13%	4%	5%
West Coast	1%	1%	1%
Whanganui	1%	1%	1%

Table 1: Estimated percentage of population under 20 years of age by district (2018 Census, using DHB populations) compared with percentage of notifications (2023) and (2010-2023)[i]

- the workload of hearing professionals and the level of commitment to notify notifications to the Database; and
- the date the child or young person was diagnosed, and whether the clinician decides it is appropriate to ask for consent 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.

A recent local study (unpublished, 2018), 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[8, ii].

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 in 2018 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. Of the 163 children and young people about 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.

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, particularly given differences between districts in their systems and who is informed about a request from a new provider[i].

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)[ii]. Individual children may have one or several additional disabilities (ADs) and these can vary between individuals in both presentation and degree, making both descriptives and comparisons challenging.

Estimates of the global burden of childhood disability from 2020, suggest that more than one in ten children and adolescents are affected by epilepsy, intellectual disability, vision, or hearing loss. When other conditions, such as developmental delay and cerebral palsy, are included, this figure will increase[9].

The presence of one or more disabilities can place an additional burden on families when compared with those tamariki and rangatahi without additional disabilities.

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 other conditions. Rates of additional disabilities among children with hearing loss are particularly high among those who have a syndrome.

As outlined in Nelson and Bruce's 2019 review paper on this topic[10]:

- 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, result in 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;
- 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 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 on the level of support they may require, particularly from *Learning Support Services*, Ministry of Education | Te Tāhuhu o te Mātauranga (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 definitions for both hearing loss and for disabilities differ and are not always described in journal papers. A selection of studies from various jurisdictions showing very large variance in rates of ADs (4-57%) was described in previous reports.

i Audiologists on the Paediatric Technical Advisory Group (PTAG) in 2023 noted that it is possible that districts that 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/ren or young people go on to receive 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.

ii 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.

Selected studies on hard of hearing children with one or more ADs show:

- 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 (Cupples *et al.* 2014[11]);
- the type of additional disability can provide an indication of expected language development where formal assessment of cognitive ability isn't possible (Cupples *et al.* 2018[12]);
- children with additional disabilities who had better language outcomes were more likely to: have had earlier fitting of HAs, lesser hearing loss, higher cognitive ability, use of speech for communication, and higher level of maternal education[13].

DND data

The widest definition of additional disability is used for the Database. Of the 2724 children and young people in the Database with hearing loss (2010-2023), the majority (75%) have no 'additional disability' listed. Eleven percent are listed with a possible although as-yet unconfirmed additional disability. Thirteen percent have one or more confirmed additional disability(ies)[i].

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[14, ii].

Additional disability	Number of tamariki	Percentage
Yes	360	13%
Unsure whether AD exists, no confirmed diagnosis	305	11%
No additional disability	2032[iii]	75%
No data	29	1%
Total	**2726**	**100%**

Table 2: Proportion of cases by additional disability status (2010-2023)

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%)[iv].

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[v].

Additional analyses completed for 2010-2023 notifications contain a number of findings, including that children with an additional disability are significantly more likely to have a bilateral hearing loss and to be Pacific Peoples:

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 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.

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 The authors of this report believe that the earlier identification of tamariki with hearing loss, since the implementation of newborn hearing screening nationwide, is 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.

v 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.

	More likely	Less likely
Children with an additional disability	2.8 times as likely to have a bilateral compared to a unilateral hearing loss[i] than those without 2.6 times as likely[ii] to have a permanent conductive hearing loss 1.6 times more likely to be Pacific compared to children who are non-Māori, non- Pacific[iii]. There is no significant effect seen for other ethnic groups. 1.6 times more likely[iv] to have a mixed hearing loss and/or a permanent conductive hearing loss in one or both ears than those without 1.6 times more likely to have a mixed hearing loss[v]	0.5 times as likely to have a sibling or parent with a permanent hearing loss[vi]; and 0.5 times as likely to have a sensorineural hearing loss[vii] 0.6 times as likely[viii] to have ANSD
Those listed as 'unsure' whether they have an additional disability	0.5 times as likely[ix] to have a deaf parent or sibling, compared to children who do not have an additional disability	

2023 data

Of 2023 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 17% of cases there was uncertainty regarding whether the child or young person had an additional disability[x].

The majority of those who were listed as having an additional disability had one additional disability listed, though some had no detail provided[xi].

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 DND data showing the proportion of children with an additional disability are 'point in time' figures at the time of the hearing loss diagnosis.

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 3 shows the total proportion of confirmed and unconfirmed cases with an additional disability. This figure is more consistent

i p<0.0001.

ii CI: 1.9-3.7, p<0.0001.

iii CI: 1.0-2.5, p=0.03.

iv Odds ratio of 1.6 for those with a mixed hearing loss, CI: 1.1-2.3, p=0.0055, and odds ratio of 2.6 for those with a permanent conductive hearing loss, CI: 1.9-3.7, p<0.0001.

v CI: 1.1-2.2, p=0.0055.

vi CI: 0.3-0.8, p=0.0073.

vii CI: 0.4-0.6, p<0.0001.

viii CI: 0.4-0.7, p<0.0001.

ix CI: 0.3-0.7, p=0.0027.

x 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.

xi Smaller numbers of children and young people had two, three, four or even five additional disabilities noted. A small number of 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'.

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 ('unsure')	Cases with additional disability (2002-2005) and total confirmed and possible (2010-2023)
2002	-	-	29%
2003	-	-	21%
2004	-	-	23%
2005	-	-	18%
2010	14%	11%	26%
2011	17%	5%	22%
2012	15%	11%	26%
2013	12%	12%	24%
2014	18%	9%	27%
2015	10%	11%	21%
2016	12%	9%	21%
2017	10%	10%	21%
2018	12%	11%	23%
2019	14%	9%	23%
2020	14%	14%	28%
2021	14%	16%	30%
2022	12%	14%	26%
2023	12%	17%	29%
Average 2010-2023	**12%**	**17%**	**29%**

Table 3: Proportion of cases with a known additional disability (2002-2005 and 2010-2023)

Even with a large drop in the average age at diagnosis, we can still see growth in the proportion of cases with a possible additional disability. The 2010-2023 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:

many parents were spending considerably longer with their tamariki than usual due to COVID-19 related school closures, meaning issues they noticed resulted in more prompt identification of additional disabilities compared with before the pandemic;

additional disabilities are now more likely to be diagnosed; and

reduced immunisation coverage, which has falling since before the pandemic.

Immunisation rates

In Aotearoa during recent years there has been concern expressed about falling immunisation coverage since it began dropping in 2016. Rates were particularly low for tamariki Māori and those who live in income poverty[15]. Since the start of the pandemic, further significant reductions in the number of children receiving immunisations were 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 exacerbated further drops in immunisation coverage in many countries[16].)

This fall in immunisation coverage rates has meant that immunisation has again become a focus for successive governments. The new target for 24-month immunisation coverage has been set at 95%[17].

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 specific notification forms corresponds to the categories selected by the notifying professional (e.g., normal hearing, sensorineural hearing loss etc.).

The proportion of 2010-2023 cases in the Database thought to be bilateral is between is approximately 68:32, or as low as 65:35, depending on the methods used to determine categories[i].

Immunisation coverage (including for conditions such as mumps that can result in unilateral hearing loss) in Aotearoa New Zealand has been falling, as described in the previous section. The number of cases resulting from these changes 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[ii] 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[18].

In our dataset, bilateral hearing losses are associated with significantly higher levels of sensorineural, mixed hearing loss and ANSD[iii] and significantly lower levels of permanent conductive hearing losses[iv].

Māori continue to have significantly higher rates of bilateral hearing loss than non-Māori and non-Pacific children in our current analysis.

Unilateral hearing losses

Background

Unilateral hearing loss prevents the auditory system from processing and integrating input from both ears. This is important for optimal understanding of speech in noisy situations and for sound localisation[19, 20].

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[21, 22, 23]. 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[24, 25, 26, 27].

To reflect the now acknowledged importance of unilateral loss, cases where these average more than 26 dB HL in the child/young person's hearing-

i From 2015, these reports have contained data for cases that contained completed audiometric data for all eight datapoints, as well as data for those which are interpolated. Manual determinations are made on those cases with fewer thresholds listed. 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.

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

iii Sensorineural hearing loss: OR 1.4, CI: 1.2-1.7, p<0.0001. Mixed hearing loss: OR 1.6, CI: 1.2-2.2, p=0.0011. ANSD: OR 2.7, CI: 2.3-3.2, p<0.0001.

iv Permanent conductive hearing loss: OR 0.3, CI: 0.2-0.4, p<0.0001.

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[28]. 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. Most 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[29].

Prevalence

Prevalence of unilateral hearing loss (UHL) is difficult to understand, not least because the definition used differs between studies, and samples often don't include the complete group being described[30].

Newborn hearing screening programme data from Finitzo *et al.* (United States) suggest around one in 1,000 babies are born with a UHL, about a third of the total babies identified with a hearing loss[31]. 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.*[32]

As described by Vila *et al.* in 2015[33], more than one in ten or more of the children diagnosed with UHL will see this hearing loss progress to affect their other ear[34, 35, 36].

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.'[37] 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

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, comparisons of the proportion of unilateral/bilateral notifications in the current dataset with previous DND data (prior to 2005) is not possible because reporting at that time was incomplete.

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

hearing loss benefit from some form of personal amplification device[38].

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[39].

In New Zealand, Project HIEDI (Hearing Impairment, Early Detection and Intervention, an advocacy rōpū formed to see the introduction of universal newborn screening and early intervention) 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[40].

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[28, i].

DND data

About a third of all notifications to the Database since 2010 (32%) are for children and young people diagnosed with unilateral hearing loss, similar to the birth prevalence rate within Finitzo (USA) noted above.

Here in Aotearoa New Zealand, a 2018 analysis of data provided for 163 of the 189 notifications to the DND in 2010 (unpublished)[8, 41], showed 32% of those children or young people with a unilateral hearing loss ended up with a bilateral hearing loss by the time follow-up data was provided seven to eight years later[ii]. This is higher than the 10% plus rate reported by Vila above.

The proportion of all 2010-2023 cases[iii] that met the criteria for SSD is 5.1%[iv]. *For further information about single sided deafness, a subgroup of those with unilateral severe or profound hearing losses, can be found in the appendix on this topic, beginning on page 80.*

i 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.

ii 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).

iii Based on determinations including interpolated data, where the worse ear has a severe hearing loss or worse from 1kHz to 8Khz.

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

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[i]', 'other' and 'don't know'. 'ANSD' (Auditory Neuropathy Spectrum Disorder) is offered as an option and is a subgroup of sensorineural hearing loss (SNHL).

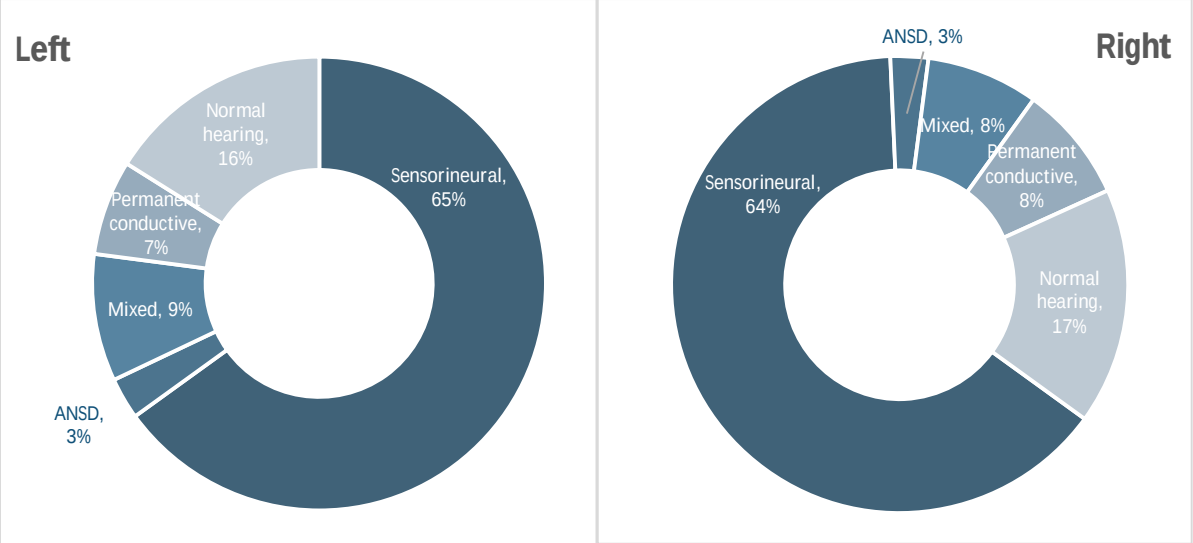

Figure 3: Type of hearing loss (2013-2023)

The 2013-2023 data for this question are contained in Figure 3. The most reported type of hearing loss contained in notifications was sensorineural, irrespective of ethnic group and deprivation level, followed by normal hearing. Please note that the cases with normal hearing in one ear relate to those children and young people with a unilateral hearing loss.

Cases of atresia and microtia fall into the permanent congenital hearing loss category. *See Aetiology subsection on Atresia and microtia which begins on page 33 for more information on these conditions.*

Error! Reference source not found. shows the groups most and least likely to have specific types of hearing loss based on data from 2013, when types of hearing loss were added to the notification form.

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 2013-2023 cases (right and left ears) in the Database were listed in the ANSD category. Overseas prevalence data[42, 43] suggests New Zealand may have lower rates of ANSD than other similar jurisdictions.

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

	More likely	Less likely
sensorineural hearing loss (In one or both ears)	*Children from Quintile 5* are 1.6 times as likely[i] - compared with children from Quintile 1 *Children with bilateral hearing loss* are 1.5 times as likely[ii] - than children with a unilateral hearing loss	*Children with an additional disability* are 0.5 times as likely - than children with those without an additional disability[iii]
permanent conductive hearing loss (In one or both ears)	*Children from Quintile 5* are 2.1 times as likely[iv] - than with children from Quintile 1 *Children with an additional disability* are 2.7 times as likely[v] - than children without an additional disability Children and young people with *bilateral hearing loss* are 1.7 times as likely - than children with a unilateral hearing loss[vi]	*Māori children* are 0.7 times as likely[vii] - than non-Māori, non-Pacific children
mixed hearing loss (In one or both ears)	*Māori children* are 1.6 times as likely - than non-Māori, non-Pacific children[viii] (this aligns with previous analyses in 2016 and 2021[ix]) *Children from Quintile 5* are 2.2 times as likely[x] - than children from Quintile 1 *Children with an additional disability* 1.6 times as likely[xi] - than children without an additional disability *Children and young people with bilateral hearing loss* are 1.7 times as likely[xii] - than children with a unilateral hearing loss	
ANSD (In one or both ears)	*Children with a bilateral hearing loss* are 2.7 times as likely[xiii] – when compared with children with a unilateral hearing loss	*Children with an additional disability* are 0.6 times as likely[xiv] – when compared with children without an additional disability
'unsure' listed under type of hearing loss (In one or both ears)	*Pacific children* are 3.0 times as likely[xv] - than non-Māori, non-Pacific children	

i CI: 1.1-2.3, p=0.009.

ii CI: 1.3-1.7, p<0.0001.

iii CI: 0.4-0.7, p<0.0001.

iv CI: 1.1-4.3, p=0.03.

v CI: 2.0-3.8, p<0.0001.

vi CI: 0.2-0.5, p<0.0001.

vii CI: 0.4-0.8, p=0.007.

viii CI: 1.2-2.1, p=0.0006.

ix Two previous analyses contained in the 2016 report found differences contained in the type of hearing loss between Māori and Europeans (Fishers exact test: p=.0037). More Māori had 'mixed' hearing losses than expected, and fewer Māori were recorded as having 'permanent conductive' hearing losses than expectedx. A repeat analysis of the type of loss by ethnicity for 2010-2020 data also found higher proportions of mixed losses among Māori.

x CI: 1.1-4.3, p=0.03.

xi CI: 1.2-2.3, p=0.0055.

xii CI: 1.2-2.3, p=0.0011.

xiii CI: 2.3-3.2, p<0.0001.

xiv CI: 0.5-0.8, p<0.0001.

xv CI: 1.4-7.5, p=0.005.

Table 4: Groups more and less likely to have specific types of hearing loss (2013-2023)

This difference could relate to our unique population, including lower proportions of severe and profound hearing loss and differences in whether auditory nerve hypoplasia or aplasia are included[44].

Sometimes auditory nerve insufficiency/deficiency, aplasia and hypoplasia, absent or poorly formed cochlea nerve terminology are used interchangeably in the literature, and in some cases they are included in the ANSD category[45, 46, 47]. In New Zealand, in cases where a scan confirms presence of these conditions, they may be categorised as sensorineural hearing loss rather than ANSD. As scans are routinely performed in New Zealand and this may be less common elsewhere, this may explain our lower ANSD rates.

Hearing loss present at birth

Of all 2010-2023 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 Aotearoa 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 66% in 2023. 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 report found that the proportion of Europeans *without* 'hearing loss thought to be present at birth' was significantly higher than for Māori[i].

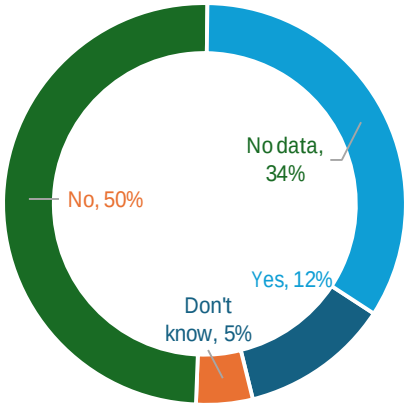

Figure 4: Immediate family member with hearing loss (2015-2023)

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?[ii] (or had a permanent hearing loss if they have died).' This question was introduced part way through 2014.

i CI: 0.1-0.1, p<0.0001. 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.

ii 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 grand-parent, and then about each specific relative. Between 13% and 24% of cases reported a 'family history of hearing loss' between 2010 and 2013.

The results for this question are shown in Figure 4[i]. That figure shows data from 2015-2023 notifications – years containing responses to this question for all cases.

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[48]. No studies have been undertaken to establish which groups in Aotearoa New Zealand have the highest prevalence of hearing loss related to genetic changes.

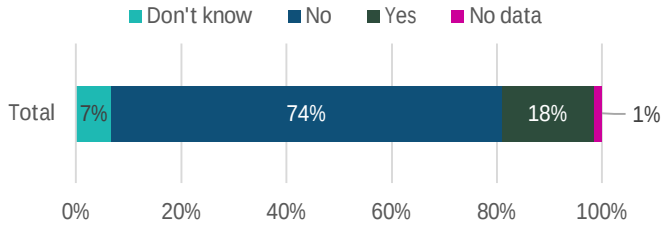

Figure 5: Immediate family member with hearing loss (2015-2023)

Table 5 shows the known presence of a family history of permanent hearing loss for an immediate family member. This is most common for Māori children (22%), then Pacific children (19%), and least common for Asian children (7%).

Compared with those children and young people who are non-Māori and non-Pacific, Māori are around twice as likely to have a parent or sibling with a permanent hearing loss and both Māori and Pacific are around twice as likely to be unsure if they have a deaf parent or sibling[ii].

Ethnicity	No	Yes	Unsure
Asian	87%	8%	6%
European (this includes NZ European)	77%	18%	5%
Pacific Peoples (includes Cook Island Māori)	71%	19%	10%
Māori	68%	23%	10%
MELAA	85%	15%	0%

Table 5: Likelihood of close family member with permanent hearing loss (2015-2023)[iii]

i 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.

ii Māori are 1.7 times more likely to have a parent or sibling who has a permanent hearing loss (OR: 1.7, CI:1.8-1.4 at 95%, p<0.0001). Māori are 2.3 times more likely to be listed as 'unsure' (OR: 2.31, CI 1.54-3.41, p<0.0001). Pacific Peoples are 2.2 times more likely to be 'unsure' compared with non-Māori, non-Pacific (OR: 2.3, CI 1.2-3.8, p= 0.0075).

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

Ethnicity

Mātāwaka

- **The DND collects only top-level ethnicity data for several reasons. It is important to be aware that this aggregation masks differences for subgroups – this is particularly for Pacific and Asian groups which are diverse in many ways.**
- **The largest number of notifications to the DND are listed as European, although there are fewer than would be expected within this group based on the size of their population.**
- **The number of notifications from those of Māori ethnicity are higher than expected based on their number in the population and this pattern is confirmed by other sources. 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.**
- **Māori have 1.5 times as many bilateral hearing losses as their non-Māori, non-Pacific counterparts.**
- **Pacific, Asian and MELAA children and young people are notified to the Database in proportions roughly equivalent to their relative population size for this group.**

Recording ethnicity

Background

The notification form for the DND 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].

It is important to note that relying on top-level ethnicity codes masks differences within subgroups. Subgroup differences are likely to be more significant for those New Zealanders from Pacific, Asian and MELAA groups, which are far from homogenous as they include children and young people from many different countries and ethnicities. In these reports, this aggregation is done to reduce the burden on notifying professionals. Below is some information on the challenges of using aggregated ethnicity information for Asian New Zealanders. *For further information on ethnicity coding in the Database, please refer to Notifications and ethnicity which begins on page 76.*

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

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

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.

Limitations in aggregating ethnicity

Asian New Zealanders

It is important to note that (as with Pacific Peoples) Asian New Zealanders are a particularly diverse 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.

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. From the 2018 Census, the Auckland region had 28% of its population identifying as having Asian ancestry and this number comprises 62% of the of the Asian population in Aotearoa[49].

The good health of those coming to live in Aotearoa New Zealand is often referred to as the "healthy immigrant effect"; however, the aggregation of such a large and diverse group can hide significant disparities. It is also worth noting that Asians report the highest rates of discrimination of all Level 1 ethnicity groups[52].

Overall, Asian New Zealanders tend to have mixed access to and through other parts of the health system, as demonstrated by their high vaccination rates[50], and low rates of enrolment with GPs[51] and for some screening services[52].

The proportion of tamariki listed as Asian among notifications to the DND and living in Aotearoa New Zealand has grown rapidly in recent decades, with the fastest growing subgroups moving here being those identifying with Indian, Chinese, Korean, or Filipino ancestry. These were also the most populous subgroups within the diverse Asian category[53].

Unequal health access and outcomes for Māori

Disparities documented in numerous areas of our health systems demonstrate Māori[i] have poorer access 'to, and through' the health system[54, 55,64], that they receive a poorer and slower service, and are less likely to receive appropriate levels of care[56], resulting in poorer health outcomes. Despite the presence of national policy frameworks, work to address disparities has often not been successful and educational disadvantage are often related, particularly for children.

In 2016, Māori young people and those most deprived had lower enrolment rates relative to their peers. Although young people's enrolment rate subsequently increased, especially during the COVID-19 pandemic, the enrolment rate for Māori and Pacific Peoples, and those most deprived, declined[57]. These groups already have higher needs and have increased vulnerability, including because of falling immunisation coverage.

Clinicians should be aware that whānau they see from in these groups are less likely to be enrolled with a primary provider. Enrolment with a primary provider has been shown to improve health equity[57].

Hearing service disparities

Limited research on disparities in hearing care has been conducted, and is described briefly below:

- 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 given that Māori are known to have a higher prevalence of hearing loss overall[58].
- 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, Pacific and Asian tamariki[59].
- 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 Pacific[60,ii].

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

ii It is worth noting there are differing views about the efficacy of grommets as a treatment for middle ear disease. Regardless, it is

- As described by Pokorny *et al.* (2022) referral rates for Māori do not reflect their increased rates of hearing loss and ear disease[61]. 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.
- Screening programme coverage rates 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 New Zealand by ethnicity and district. The results were 'incongruent with evidence that Māori and Pacific children in New Zealand experience a greater burden of middle ear disease than European children'[62].

The specific nature of the barriers to access are not generally described and research into whether such disparities exist for tamariki accessing 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[63].

(*Please see* Appendix B: Māori, hearing and health *from page 78 for more information.)*

Notifications

DND data

Ethnicity data and representation

Fewer than 1% of notifications are missing one or more ethnicity codes and this number has fallen over time. Most notifications (89%) contain one code, and a smaller proportion (9.5%, 0.7% and 0.04%) contain two, three or four codes, respectively.

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

Figure 6 shows the average notification rate for each ethnic group using population figures for under 19-year-olds from the 2013, 2018 and 2023 Censuses. The European ethnic group is the largest in the Census by a significant margin, at 66% of the population under 19 years of age, but comprise only 43% of notifications to the Database.

While the proportion of notifications from those of European ethnicity are considerably lower than one would expect based on the size of their population (see Figure 6), notifications from those of Māori ethnicity are higher than expected, comprising 38% of notifications and only 25% of the population under 19 years of age[ii].

Despite several sources pointing to higher rates of hearing loss among young Māori, this group may still be underrepresented in DND statistics[64, iii]. 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 and that these hearing losses are more common among Māori.

unlikely that differences in otologic treatment practices would be applied based on ethnicity.

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 Other sources supporting this conclusion include; Whakarongo Mai (1989), Greville (2001), UNHSEIP programme data and Household Disability services. Details of these sources can be found in Appendix D.

iii Reasons include, 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 suggest fewer cases may be found and/or notified when compared with those in the European population, for example. 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.

Children and young people of Asian or Pacific ethnicities are notified in approximately the same proportions as would be expected by their population under 19 years of age.

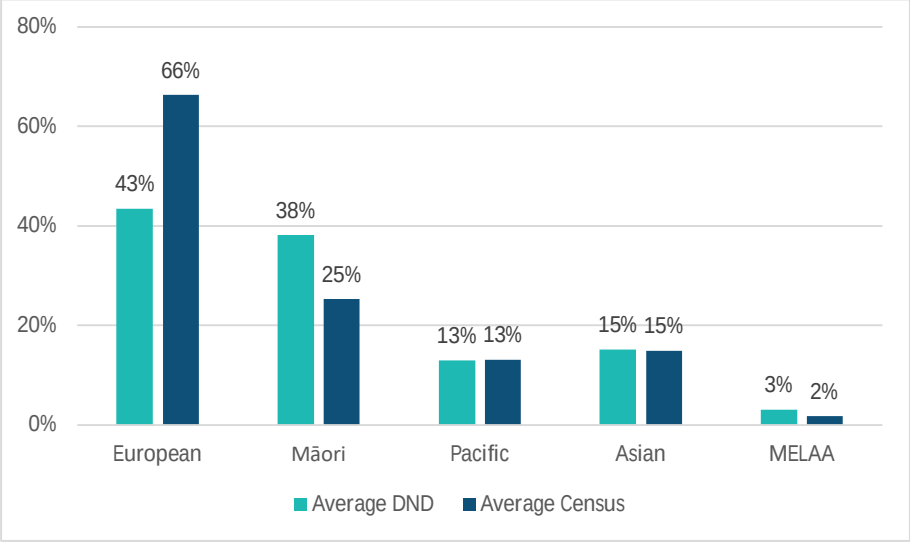

Figure 6: Average notification rate by ethnicity (for 2013, 2018 and 2023)[i]

Unilateral and bilateral hearing losses

Of 2010-2023 cases, including those with interpolated audiometric data, 68% are recorded as bilateral, while the remaining 32% are unilateral. MELAA children and young people have the highest proportion of bilateral hearing losses, at 76% in total, followed by Māori (75%) and Pacific children (69%). Asian and European children have fewer bilateral hearing losses (at 68% and 67% respectively)[ii] and therefore a greater proportion with unilateral hearing loss.

Tamariki Māori have higher rates of bilateral hearing loss than their European counterparts as described in previous reports and in the 2014 paper by Digby *et al.*[65]. This current analysis, now containing considerably more data shows that Māori children notified are 1.5 times as likely as their non-Māori, non-Pacific counterparts to be diagnosed with a bilateral hearing loss[iii]. While other ethnic groups have varying rates of bilateral to unilateral hearing losses, those differences did not reach significance.

Other differences

Keeping in mind the considerable subgroup diversity within the Asian category when compared with other ethnic groups commonly found in Aotearoa New Zealand, children in this group have a higher proportion of severe and profound hearing losses, though this difference does not reach significance.

Trends

Since the relaunch of the Database in 2010 there has been an increase in the proportion of Asian children being notified compared with all other ethnicities[iv], and a smaller but significant fall in the proportion of European children notified[v]. This change is supported by the changing proportion of ethnic groups in the general population.

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

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.

iii CI: 1.34-1.97, p<0.0001.

iv Note that there is a strong concentration of Asian families in Auckland and Waitematā districts (2010-2023), more than double the average proportion for the whole country.

v Asian children have 2.8 times greater odds of notification in 2023 when compared with 2010 (p<0.0001) and European children have a decrease in odds of notification by 0.9 times between 2010 and 2023 (p<0.0001).

Work to reduce disparities

Two recent projects 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 tamariki Māori and Pacific children, 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)[i].

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[66]) based on a survey and a series of virtual hui. It was clear that there is a collective desire among health and educational professionals to address inequitable outcomes in ear and hearing health for Māori and Pacific tamariki.

Five themes were identified from the virtual hui: *Ear and hearing healthcare and institutional racism*, policies maintaining status quo, practitioner-patient power dynamics, workforce issues and perspectives of hearing loss.

Paediatric ORL Pathway - Redesign for Equity

The goal of the Paediatric Otorhinolaryngology (ORL)[ii] 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 Pacific children in particular) to paediatric ORL services via end-to-end integrated care pathways that work seamlessly, ensuring consistent, high-quality care and support[67].

This redesign project has an associated rōpū working on developing National guidelines on Otitis Media with Effusion (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 are driving change across the pathway of care.

Recommendations of this project can be found within this groups 2023 report. They include giving effect to Health NZ | Te Whatu Ora’s Te Tiriti o Waitangi commitments, providing mobile ORL services, offering flexible appointment times and increased financial support for costs associated with attending appointments[68].

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

ii 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.**
- **Overall, the New Zealanders who are Māori, Pacific Peoples and under the age of 17 are more likely to be living in income poverty than those over the age of 65 years, and those with one or more disabilities are also more likely to live in areas of higher deprivation than those without.**
- **These effects are glaring among children notified to our Database, with Māori children being 16 times and Pacific children 40 times more likely to live in a Quintile 5 area compared with non-Māori, non-Pacific children**
- **The rate of notifications rise with increasing deprivation. Children from low deprivation areas have a prevalence of around 1.4 notifications per 10,000 children compared to a prevalence of 3.6 per 10,000 for those from high deprivation areas.**
- **Hearing professionals can expect to see a great number of families from deprived areas, particularly among Māori and Pacific, who experience the effects of that deprivation in many ways. Income and poverty are significant determinants of health; professionals can expect to see poorer health among families diagnosed with hearing loss as well as considerable barriers to engagement with services.**

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. The Index was created, and is revised regularly, by staff at the University of Otago (Wellington).

The 2018 Index draws on New Zealand Census data relating to unemployment, single parent families, qualifications, home ownership, internet access, household income, means tested benefit status, age and sex, and ethnicity, allocating a deprivation score to every meshblock (small area) containing 60-120 residents on average 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[69, 70].

The deprivation scores are provided for each National Health Identifier (NHI) by Te Whatu Ora | Health New Zealand[i]. Deprivation data has been included in our DND analyses since the 2016 report. Data for this report are based NZDep2013 and NZDep2018[ii, 70]. Of the 2724 tamariki now contained in the main dataset, 99% have deprivation data available[iii].

i Please note that NZDep scores relate to the addresses at which tamariki were living at the time the *Ministry* of *Health | Manatū Hauora* 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. Initially, the deprivation scores for NHIs in the database were NZDep13 but in recent years NZDep18 scores have been available. These are based on the 2018 Census and include updates to variables, boundaries and methodologies used.

iii Data were unavailable for tamariki whose: NHI was not valid, those who had no NHI listed, those whose notification were submitted after the deprivation scores were provided by Health NZ | Te Whatu Ora, and those who live outside New Zealand. For those whose NHI was not valid or missing, NHIs were sought but a small number were not provided, or not provided until after the analysis for a specific report was completed.

Quintiles

In the report this year we have included investigations of differences by quintile. Each quintile (fifth) represents 20% of the population across the whole country. This means Quintile 1 relates to children who live in areas scoring the lowest on the deprivation index (1 or 2), all the way up to Quintile 5 that relates to children who live in areas with the greatest deprivation scores (9 or 10).

Hearing, disability and deprivation

International data indicates prevalence of congenital hearing loss is lower in countries with higher incomes. This difference is thought by the WHO (2017) to be due to lower infection rates and better access to preventative measures and healthcare services[71].

The New Zealand Child Poverty Monitor reported in 2018 that, in Aotearoa New Zealand, children under the age of 17 were more than twice as likely to be living in income poverty than adults over the age of 65 years[72].

Statistics New Zealand reports that overall, 11% of children under the age of 15 have a disability[73]. For some years the link between disabilities and deprivation has been highlighted, including by The Treasury (2022[75]) and Child Poverty Action Group (NZ, 2015[74]). Children with disabilities in Aotearoa New Zealand are at a greater risk of living in low-income households than those without such disabilities. Children with hearing loss may face compounded disadvantages, including those associated with discrimination and social exclusion, reducing their access to resources and support systems necessary for their development and potentially resulting in long term consequences[75].

Once adjustments are made for differences in age profiles by population, Māori and Pacific groups are also more likely to be living with low incomes.

When considering rates of deprivation, hearing loss has also found to be correlated with higher rates of deprivation. For example, in the United States Boss *et al.* (2011) evaluated disparities in socio-economic status among hearing impaired children nationwide through the 1997-2003 National Health Interview Survey. Families of children with hearing impairment lived closer to the poverty level and used some medical services less frequently[76].

The connection between disability and deprivation is not inevitable, however. As noted by Child Poverty Action Group (NZ) cite the United Kingdom's much higher disability allowance is thought to be the reason there is no correlation between childhood disability and poverty in that country[77].

Notifications

Comparisons with the general population

Among notifications to the DND, we can see that deprivation is more common than in the Aotearoa New Zealand population at large. Thirteen percent of children in the Database are living in the lowest deprivation quintile, compared with 20% in the population at large; and 33% of children are living in areas that scored a 9 or 10 on the Index (Quintile 5 – the highest) compared to 20% in the population at large.

Deprivation and rates of notification

We can also see when examining rates of notification by deprivation, that children notified from the four lowest deprivation quintiles are all underrepresented when compared to their relative population sizes.

Population data by quintile are published by Stats NZ for 2013 and 2018 Censuses. This means we can calculate notifications by deprivation per 10,000 people under 19 years of age. Doing this shows that the chance of being in the DND is more than twice as great for those children and young people living in Quintile 5 compared with Quintile 1. Children notified for 2010-2023 from low deprivation areas (Quintile 1) have a prevalence of around 1.4 notifications per 10,000 compared to a prevalence of 3.6 per 10,000 for those from high deprivation areas (Quintile 5).

In addition, while identification below the age of one year is similar across quintiles, there is a greater chance of a child having their hearing loss detected later in life[i] (after the age of 6) for those living in high deprivation areas.

Deprivation and ethnicity

Figure 7 illustrates the distribution of children and young people within the Dataset by deprivation status, grouped by ethnicity.

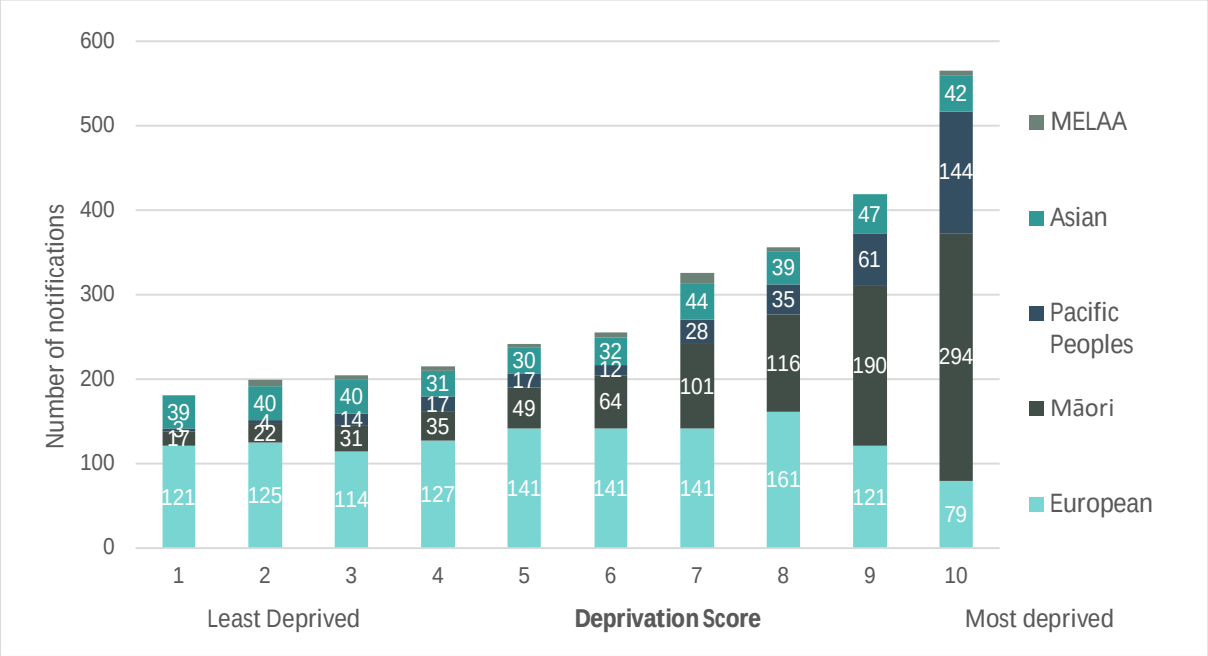

Figure 7: Deprivation scores (NZDep2013) of tamariki in the DND by ethnicity (2010-2023)

European children are relatively evenly distributed across all five quintiles, however there are glaring differences in the distribution of deprivation by ethnicity, with:

- Māori children and young people being 16 times more likely to be in a Quintile 5 area compared with non-Māori, non-Pacific children[ii].
- Pacific children being 40 times more likely to be living in a Quintile 5 area compared with non-Māori, non-Pacific children[iii].

Implications

These data demonstrate that audiologists (and other professionals working with young people who are hard-of-hearing) are much more likely to diagnose children from families living in deprived areas and therefor experiencing the effects of financial hardship. The odds go up enormously for families who identify as Pacific and/or Māori.

Professionals should keep in mind that income and poverty are significant determinants of health[78]. As a result, many of the families they see are more likely to experience poorer overall health[78] (including greater barriers to accessing health services[79] and lower housing stability[80]) and higher rates of stress and mental health issues for adults[81], young people and children[82, 83] than those in less deprived areas. These factors are likely to result in greater barriers for families to engaging with services, including screening, audiology, education and specialists such as ENTs.

i This doesn't indicate these hearing losses are delayed as some will have hearing losses than are acquired or progressive and were not present when they were younger.

ii CI: 11.3-23.3, p<0.0001.

iii CI: 17.4-91.6 (this range is large as it reflects the small sample size for the Pacific Peoples ethnic group within each deprivation quintile), p<0.0001.

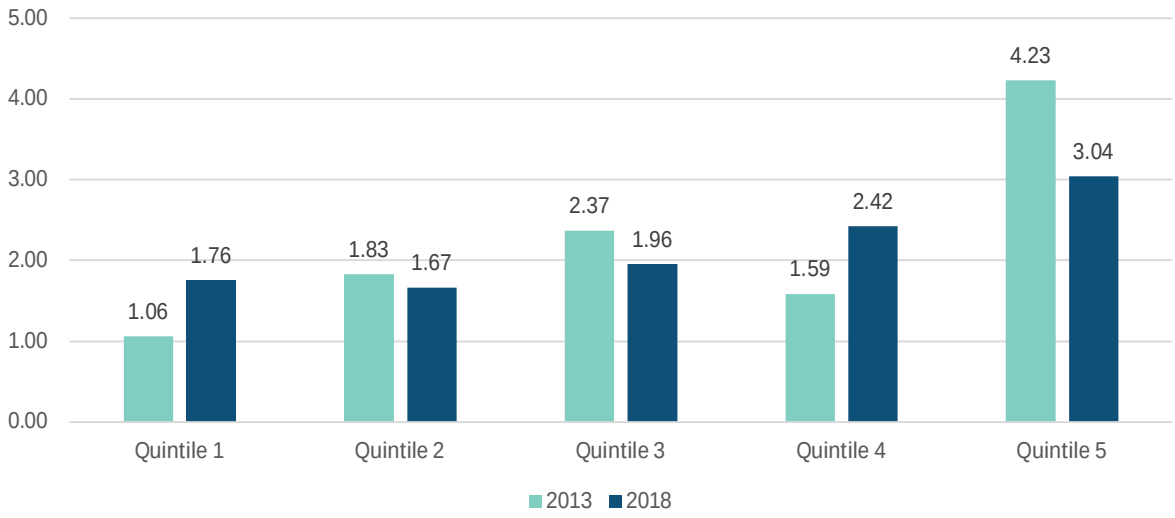

Figure 8: 2010-2023 notification rates by deprivation (quintile) per 10,000 from the under 19 Census population[i]

Deprivation and type of hearing loss

When examining the type of hearing loss by quintile from 2010-2023, some further patterns emerge, with children from:

- Quintile 5 (the highest deprivation areas) being 1.6 times more likely to have a sensorineural hearing loss and 2.1 times more likely to have a mixed hearing loss when compared with those in Quintile 1.
- Quintile 4 being 2.1 times more likely to have a permanent conductive hearing loss than children in Quintile 1.
- Quintile 3 being 1.6 times more likely to have a sensorineural hearing loss than children in Quintile 1.

Families living in deprived areas are also more likely to be diagnosed with Congenital CMV (cCMV). A recent analysis of the National Minimum Dataset by Jeong (2023) found that approximately 40% of all cases diagnosed with cCMV resided in the most deprived quintile[ii, 84].

i Census data by deprivation for 2023 has not yet been published.

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

Aetiology

Ngā pūtake

- **A little over 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 a little under nine in ten 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 basis is rising as more genes are found to have an association with this condition.**
- **Of those with a known aetiology at the time of notification, congenital hearing losses are the most common (6%), followed by acquired and genetic (4% each).**
- **Just over 3% of the children and young people in the Database are reported to have one of 39 specific syndromes recorded, the most common being Down Syndrome followed by Pierre Robin/Stickler, Goldenhaar, Noonan and Charge syndromes.**

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 general aetiology of hearing loss can be found in the 2021 report, and estimates of the proportion of prelingual hearing losses thought to be genetic are likely to sit at 50% with 30% of those (15-20% overall) associated with a recognised syndrome[85]. A significant proportion of late onset hearing loss is due to genetic causes[86].

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[87]. Those who are pregnant and have no antibodies may pass on infection to their babies. This condition is of particular importance for those whānau living in the most deprived quintile, and it may not have been diagnosed.

Grosse *et al.*'s systematic review (2008) found that approximately 14% of children with cCMV infection develop a sensorineural hearing loss[88]. Universal screening is starting to emerge for this condition, and this will improve understanding of prevalence.

Some professionals have suggested that it is possible Aotearoa New Zealand has a greater prevalence of progressive hearing losses because of our high rates of CMV. New Zealand data on CMV is limited though seroprevalence in Aotearoa is thought to be highest among Pacific Peoples[89] and local rates of cCMV disease are thought to be highest among Māori and Pacific populations[90]. A seroprevalence study in is underway.

Please see the Appendix section on Cytomegalovirus beginning on page 82 for more detail on this condition and its implications.
Sincere thanks to Associate Professor Holly Teagle for sharing her knowledge on this topic.

Mumps, measles and meningitis

Mumps, measles and meningitis were previously often considered by audiologists as potential

causes of hearing loss; however, this had become less common, likely due to generally increased immunisation coverage. Immunisation coverage levels have recently fallen considerably since 2016.

It is worth noting that the current concern regarding mumps incidence in 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[91]. The impact of the recent measles epidemic[92] is not yet known.

Atresia and microtia

Microtia is a congenital difference where the external ear is underdeveloped. It affects one rather than both ears in most cases[96]. 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[93].

Microtia usually occurs with aural atresia (AA), a condition where the auditory ear canal is underdeveloped or closed. Unilateral atresia is more common than bilateral, in the order of three or four cases to one[94].

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[95].

A 2011 review by Luquetti *et al.* of microtia-anotia prevalence found these conditions were more common among in American Indians or Alaskan Natives, Hispanics and Asian or Pacific Islanders and a lower prevalence among non-Hispanic Black or Africans as compared to non-Hispanic Whites[96].

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

Patterns from the research includes that:

- children with microtia or anotia are more likely to be male, and mothers were more likely to have health conditions associated with obesity and/or pre-pregnancy diabetes, and less likely to be taking folic acid containing supplements[97];
- high rates of speech therapy were common among those with AA as were educational interventions, particularly those with bilateral AA, and that children with right sided or bilateral AA may be at increased risk of speech and learning challenges[98]; and
- older and younger children alike benefit from audiometric improvement resulting from atresia repair[98,99].

For further information on treatment options for microtia and atresia please see the appendix from page 83.

DND data

Known vs unknown causes

A little over 99% of the 2724 records in the dataset (2010-2023) 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.

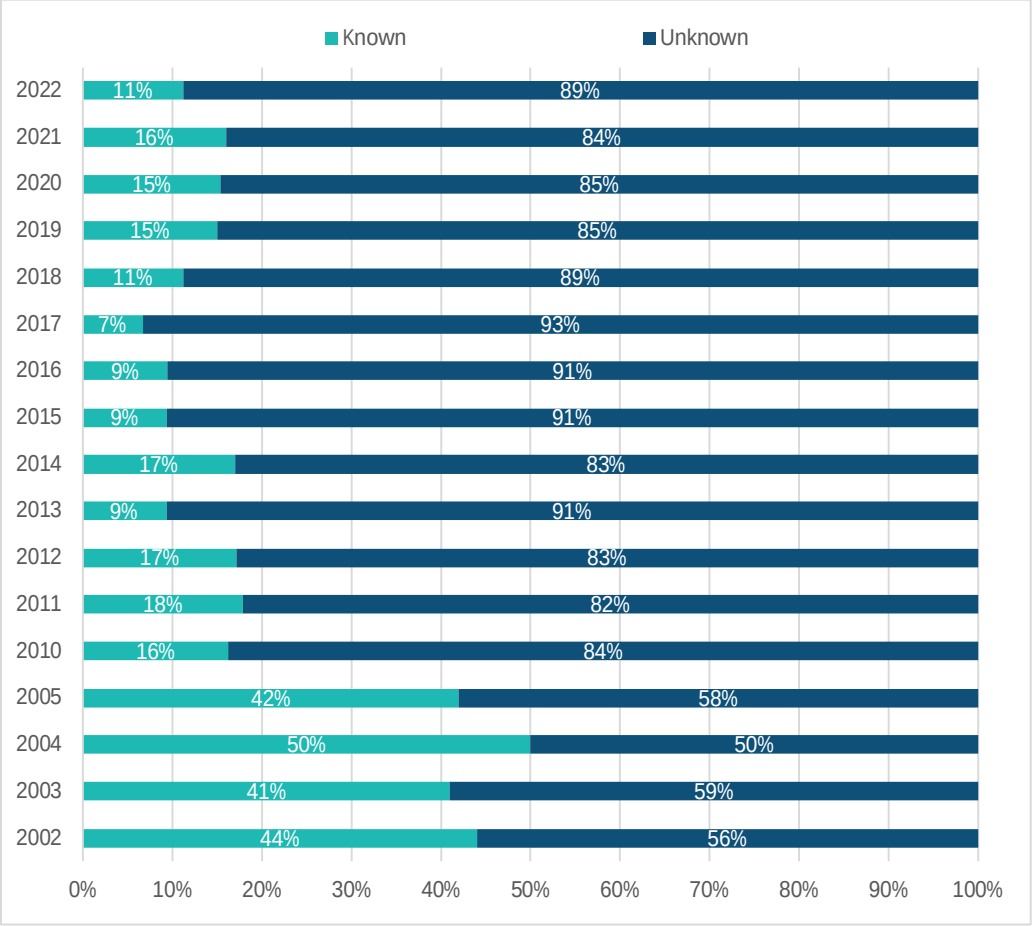

Figure 9: Aetiologies known and unknown (2010-2023)

A change on historic levels

For the 2002-2005 period, the proportion with an unknown cause was between 50 and 59%, with 2001 at 70%[100]. 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 11-16%.

Higher rates of unknown aetiology since 2010 are very likely to reflect our significantly reduced average age at identification since the introduction of nationwide newborn hearing screening. As a result of this screening, more tamariki are being diagnosed with hearing loss earlier.

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 conditions is established, perhaps reducing the likelihood of hearing losses that are part of a syndrome being identified at the time of notification.

Other findings

During the 2010-2023 period, those children and young people with bilateral hearing losses that were recorded as severe or profound 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% for Māori, 10% for Pacific Peoples, 9% for MELAA and only 7% for those children and young people of Asian ethnicity.

Aetiologies by type

Of all notified children during 2010-2023, 5.7% have a congenital hearing loss (with most of these having atresia/microtia or both), 4% have an acquired hearing loss, and 3.4% have a syndrome. A further 0.7% have hearing loss of genetic cause that is not syndromic in nature.

Those with acquired hearing loss could include progressive hearing losses that were undetected through newborn hearing screening. These hearing losses are often genetic in nature[86].

Row Labels	All cases
Unknown aetiology/no data	86%
Total congenital	6%
Congenital (non-atretic)	1%
Congenital (atresia)	4%
Acquired hearing loss	4%
Genetic causes	4%
Genetic cause (non-syndromic)	1%
Genetic cause (syndromic)	3%
Total	**100%**

Table 6: Aetiology types (2010-2023)

Though sample sizes are too small to test for significance, some patterns do emerge within 2010-2023 data, including that children and young people:

- with bilateral hearing losses are less likely to have an acquired hearing loss (4% compared with 7% for those with unilateral hearing losses);
- with bilateral hearing losses are less likely to have a congenital hearing loss (4% compared with 9% for those children with unilateral hearing losses);
- with acquired hearing losses appear most commonly among children identified as MELAA, Māori or European and are least likely among Asian children;
- who are Pacific are more likely to have congenital hearing losses when compared with non-Māori and non-Pacific children (and mostly result from atresia); and
- who have genetic hearing losses that are non-syndromic are more likely among European and Asian children and young people.

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

Atresia and microtia in the DND

Among notifications, 3.9% of children and young people are listed as having atresia/microtia or both. The majority (63%) have atresia only and this is the case among children in each ethnic group. Twenty-two percent have both atresia and microtia and 14% have microtia only. Atresia in the right ear is most common. Microtia by itself is also a relatively uncommon occurrence, as is bilateral microtia and atresia.

Non-Māori, non-Pacific children are predominantly affected by atresia alone, while Māori and Pacific children are more commonly affected by either combined atresia and microtia, or by microtia alone.

As found by Luquetti (2011) and noted above[96], Pacific children have relatively high rates of these conditions. This pattern holds in the DND dataset when comparing Pacific children with our other ethnic groupings.

Compared to non-Māori, non-Pacific children, Pacific children are:

- 4.7 times as likely to have both microtia and atresia, and microtia or atresia[i].
- 3.7 times as likely to microtia alone[ii]; and
- 2.1 times as likely[iii] to have either microtia or atresia; including when adjusting for deprivation level[iv].

Children and young people with syndromes

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

Among the 2724 children and young people in the Database, 39 specific syndromes had been

i Pacific children are 4.7 times more likely to have both microtia and atresia (CI: 1.5-14.3, p=0.0053) when compared with non-Māori, non-Pacific children. They are 2.1 times more likely to have microtia *or* atresia only, compared with non-Māori, non-Pacific children (CI: 1.2-3.8, p=0.0090).

ii CI: 1.0-13.2, p=0.43.

iii CI 1.2-3.5, p=0.0045.

iv CI 1.2-3.8, p=0.009.

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

confirmed, affecting 97 children and young people. This number represents 3.6% of the children and young people in the main dataset. The most common syndromes listed are Down Syndrome (affecting 26 children and young people) followed by Pierre Robin/Stickler Syndrome, Goldenhaar Syndrome, Noonan and Charge Syndrome.

The proportion of DND cases listed as genetic is considerably lower than the proportion expected from the literature. This is likely to be because 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 referral rates and/or availability of genetic testing for children with hearing loss could also be a factor.

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 with atresia in Aotearoa New Zealand. Children with atresia 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.

For further information on treatment options for microtia and atresia please see the appendix from page 83.

Identification of hearing losses

Te tautuhi i ngā take i turi ai

- **Hearing loss may be present at birth or develop at any time. Newborn hearing screeners are the group most likely to first suspect a hearing loss among children notified to the DND.**
- **There are two peaks for identification of hearing losses among New Zealand tamariki – those identified as a result of newborn hearing screening mostly diagnosed 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, Māori and Pacific children, those with milder degrees of hearing loss, bilateral hearing loss and/or acquired hearing loss and those living in the most deprived areas are significantly more likely to have their hearing losses identified later.**
- **Pacific children and young people have seen dramatic falls in their ages at identification, though they still have the most diagnoses after the age of 10, are still on average diagnosed later than non-Māori, non-Pacific children and still have longer delays than non-Māori, non-Pacific children.**
- **Eighty percent of the 108 children notified in 2023 as a result of a newborn screening referral were diagnosed by the internationally recommended age of three months.**
- **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. 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.**

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 2023.

Table 7 shows the top three groups that first suspected the hearing loss among notified cases *during selected years* since 2010.

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 [101, 102, 103].

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.

	2011	2016	2023
Most likely to suspect	Parent or caregiver (37%)	Newborn hearing screener (56%)	Newborn hearing screener (77%)
Second most likely to suspect	VHT (14%)	VHT (15%)	VHT (6%)
Third most likely to suspect	Medical professional (19%)	Medical professional (19%)	Parent or caregiver (5%) Medical professional (5%)

Table 7: Groups most likely to first suspect hearing loss (Selected years, tamariki born in Aotearoa New Zealand)

Since the widespread implementation of newborn hearing screening, 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 (37% in 2010 and 2011) – to being first in an average of 7% of cases during the last six years (2018-2023). Newborn hearing screeners were not in the top groups to suspect a hearing loss in 2010 or 2011, but by 2013 they became the most likely to first suspect more cases than any other group – rising to a high of 77% of all cases in 2023.

Age at diagnosis

Figure 10 shows the proportion of children whose hearing loss is identified within each age group[i] between 2010 and 2023. Over time, there has been a very distinct increase in the percentage of notifications made for children under the age of one, and a decrease for all other age groups.

The peak in the number of notifications during the first year of life is undoubtedly in large part the because of nationwide implementation of the newborn hearing screening programme. One hundred and thirteen tamariki (69%) received a diagnosis during their first year of life in 2023, compared with only 12% in 2010. This means children diagnosed in 2023 were 57% more likely to have their hearing loss identified before the age of one than those diagnosed in 2010.

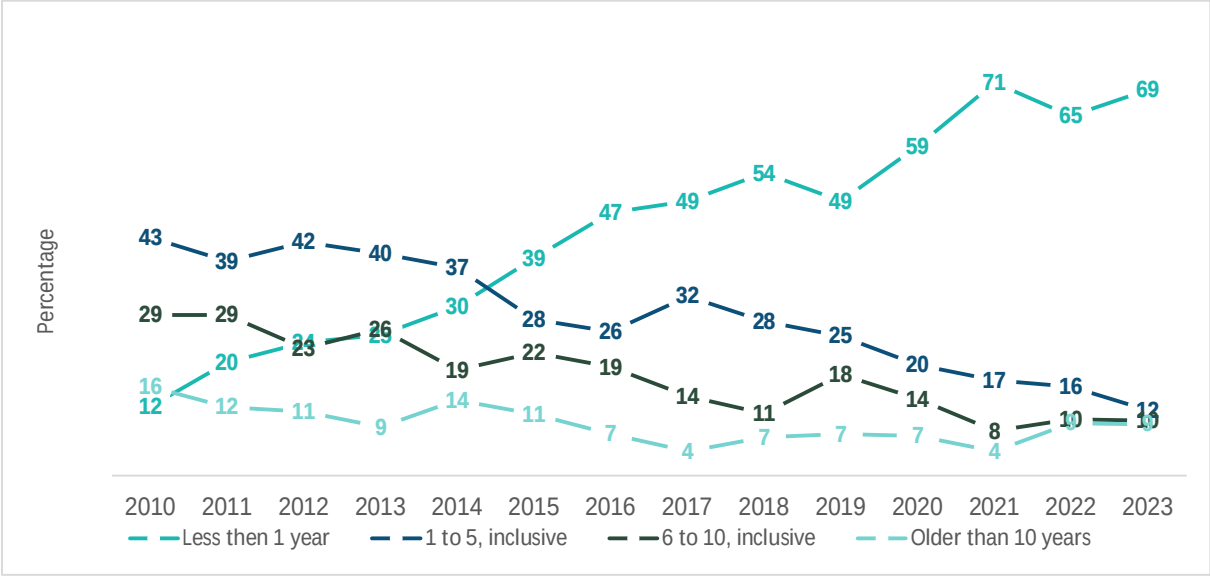

Figure 10: Number of children diagnosed by age group (2010-2023)

i 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.

The *number* of notifications before the age of one is down from highs in 2020 and 2021 (n=116, 132) and has likely been affected by the smaller number of children notified during the last two years, though it's not clear if that drop was caused by lower rates of notification or lower rates of diagnosis.

One hundred and eight of this year's cases were listed as having their diagnosis made as a direct result of newborn hearing screening, down from a high of 119 in 2021.

A further, smaller peak in diagnoses has been seen among four and five-year-olds; this peak is very likely to correspond to the B4 School Check[i]. The number of tamariki being identified between the ages of four and six years has fallen from an average of 58 in the years 2010-2016 to 33 in 2017-2023. This drop may reflect that some children who were previously being identified by *B4 School* Check *which begins on page 47 for further information.]*

childhood hearing screening at or around school age are now being identified through newborn hearing screening.

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 nationwide implementation of universal newborn hearing screening. It seems likely that some children identified well after the newborn period previously (when the average diagnosis age was very late) are now being identified in the first months of life.

Coverage rates for the B4SC had been thought to be high in previous data, though revised figures in recent years show the proportion of children not checked is significant and has risen to 18% in 2021/2 and 2022/3. *[See the section on the*

Children aged between four and six years (the ages when the B4 School Check is most likely to identify children with a hearing loss) comprised 33% of 2010 notifications but in 2023 make up only 11%[ii].

Table 8 shows groups more likely to be identified later among those notified to the DND.

The following groups are likely to be identified significantly later:
Those born overseas
Māori and Pacific children and young people
Those with mild bilateral losses and less severe (mild to moderately severe) unilateral losses
Those with acquired losses
Those living in areas with a 9 or 10 on the deprivation scale (the most deprived areas)

Table 8: Later ages of identification (2010-2023)

Age at diagnosis and severity of hearing loss

Table 9 shows the average age at diagnosis (identification of hearing loss) for children and young people with bilateral hearing loss in each of

i 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.

ii This equates to a 22% reduced chance of being diagnosed in this age range CI -0.30- -0.13, p value <0.0001.

the American Speech-Language-Hearing Association (ASHA) severity categories. As expected, as severity increases hearing losses are identified earlier.

Children under the age of four are more likely to be missing some severity data[i], meaning some cases could not be classified for Table 9.

The greatest variability in the age at diagnosis is for mild and moderate hearing losses, which is understandable given that these losses can be difficult to identify regardless, and as not all mild hearing losses present at birth are detected because of newborn hearing screening[ii].

i Several factors may influence this pattern, including that babies can wake during testing and that younger tamariki can be difficult to test.

ii The notification form does not include information about the proportion of losses that are thought to be progressive in nature.

Degree of hearing loss (ASHA, Clark, classification system)	Average months at diagnosis (2010-2023)	Median months at diagnosis (2010-2023)
mild	66	68
moderate	37	57
moderately severe	30	47
severe	29	22
profound	13	3

Table 9: Average age at diagnosis, in months, for *bilateral* hearing losses by degree (ASHA codeframe) using interpolated data with manual checks (2010-2023)[i, ii]

Age at diagnosis, deprivation and ethnicity

When analysing 2010-2023 data, children in higher quintiles are diagnosed later than those in lower quintiles. This difference is significant for those in Quintile 5 who are 24.5 months later based on their median age of diagnosis when compared with Quintile 1 children[iii].

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 average and median ages at diagnosis may not be a direct reflection of how systems are performing for each group.

Table 10 shows the median and average at identification (2010-2023, 2023) for each ethnic group[iv], for all children and young people notified.

Looking at changes in medians over time by ethnic group, every ethnic group shows improvements (decreases) in these ages between 2010 and 2023, particularly since 2020[v]. This is pleasing to see given the service disruptions clinics faced during initial part of the pandemic.

Ethnic Groups	Median months at diagnosis (2010-2023)	Median months at diagnosis (2023)	Average months at diagnosis (2023)
European	32	3	42
Māori	32	3	34
Pacific Peoples	33	2	34
Asian	3	2	16
MELAA	4	2	10[vi]
All groups	26	3	32

Table 10: Average and median months at diagnosis by ethnicity (2010-2023 and 2023)

Changes within ethnic groups

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

Non-Māori, non-Pacific children show a steeper decline in these ages than Māori and Pacific, however the difference in rates compared with non-Māori, non-Pacific was not significant. We can also see that progress in reducing ages at diagnosis has plateaued.

Māori tamariki

Māori children and young people have a higher proportion of mild hearing 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 the analysis by Digby *et al.* (2014)[104]. 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).

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 This year, average ages at diagnosis are being calculated differently. During 2010 and very early in 2011, no date of diagnosis was being collected on the notification form. We have opted this year to remove those records from analysis in favour of those containing this date, meaning we can very accurately describe averages in tables like the one below. As a result, these figures are not directly comparable to those reported in reports for 2010-2022.

iii This model looked at the independent effect of deprivation. P=0.0057.

iv When viewing data on ethnicity, please keep in mind that Table 10 is based on multi-code data, hence several cases are in two or more ethnicity groups at one time.

v Medians are less sensitive to outliers than averages, indicating a larger presence of extreme values in the 2023 data.

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

vii 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 Pacific tamariki.

These opposing effects make it difficult to understand how the system is performing to detect hearing losses early among Māori tamariki and rangatahi.

This could be an indication of some improvement in accurate coding of ethnicity, or of improvements in the health system's functioning for Māori, although we have no evidence to support these suggestions. With this in mind, this fact doesn't in itself indicate that systems are working well for Māori whānau.

Māori tamariki and rangatahi were identified at an average age of 34 months over the full period, earlier than their European counterparts whose average was 42 months. Across the 2010-2023 period, the median difference in age at diagnosis was 10 months later for Māori than for non-Māori, non-Pacific children[i].

Pacific Peoples

On average, in 2015 Pacific children's 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 considerably. For this group this is an enormous shift in averages 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.

- It is worth noting that before the introduction of nationwide universal newborn hearing screening Pacific tamariki were identified later than any of the large ethnic groupings.
- Pacific children have also seen pleasingly large reductions in median age at diagnosis during the most recent years, though these weren't visible until around 2020, about two years later than other groups. These reductions may, in part, be related to changing characteristics within the cohorts identified over time, or they may reflect delayed system improvements for this group over time.
- Across the 2010-2023 period, those who are Pacific have later median ages by 12 months compared with non-Māori and non-Pacific[ii]. However, by 2023 we can see the median age of identification for Pacific children has fallen and is now below for those for European and Māori (see Table 11).

Asian tamariki

When examining the average age at identification over time, children and young people in this group seem to have benefitted quickly from the implementation of newborn hearing screening when compared with other groups. It is also worth noting that the median age at diagnosis for Asian tamariki across the full period (2010-2023) is the lowest of all ethnic groups, at three months. However, figures do fluctuate from year to year, and 2022 saw a rise in the age at diagnosis for this group.

Asian children and young people are the most likely group to have their hearing loss identified under the age of one year.

MELAA tamariki

MELAA children and young people have had a high average age at identification over the years, at 54 months. It is worth keeping in mind that this group are commonly born overseas and not diagnosed in New Zealand – this is a common contributor to late diagnoses. It is also worth noting that this group is historically very small and large variations exist in the averages for this group over time.

Newborn hearing screening

The Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) is jointly led by Health New Zealand | Te Whatu Ora and the Ministry of Education|Te Tāhuhu o te Mātauranga. In Te Whatu Ora the UNHSEIP is one of the Antenatal & Childhood Screening Programmes within the Prevention Directorate, National Public Health Service. Information about the UNHSEIP is now on the Health NZ | Te Whatu Ora website.

i p=0.017.

ii p=0.0262.

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[105, i, ii, iii].

Screening status

Table 11 shows the screening status of Aotearoa New Zealand-born children notified to the Database (and therefore diagnosed) for selected years between 2010 to 2023. This table has been simplified from the one used in previous years to make it easier to read.

Was newborn hearing screening offered, and if so, were they screened and what was the outcome?	2010	2015	2019	2020	2021	2022	2023	All years
Service was not available at the time	62%	23%	7%	4%	2%	3%	2%	**15%**
Unsure whether screening was offered	8%	8%	7%	6%	3%	4%	5%	**6%**
Screened and referred but follow-up did not occur at the time - a delayed diagnosis	1%	2%	3%	4%	4%	2%	6%	**3%**
The child was screened and passed (in New Zealand)	2%	15%	19%	12%	13%	18%	12%	**13%**
This diagnosis is a result of a refer on the screening test	18%	38%	49%	54%	64%	64%	66%	**49%**
Yes, screening was offered but this child was not screened	1%	2%	2%	2%	2%	0%	1%	**1%**
Other (screened overseas and passed, referred and passed diagnostic test, born/screened overseas, referred directly to audiology due to atresia, born overseas, screened and referred didn't pass ABR and monitored)	6%	8%	12%	16%	12%	7%	9%	**10%**
No data	3%	4%	2%	2%	1%	1%	0%	**2%**

Table 11: Newborn screening status of children born in Aotearoa New Zealand and diagnosed, selected years[iv]

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

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, some are not severe enough to be detected, and as not all childhood hearing losses are present at birth.

Other findings include:

- as deprivation increases, families are less likely to be offered/or take up the offer of screening. For families living in Quintile 1 this rate is 66%, and drops down to 58% for those living in Quintile 5 areas[v];

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 See the 2021 DND report on the goals of the screening programme and Appendix G: Key screening goals on page 87 for more information.

iv 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 that don't fit the codeframe and the inclusion of the proportion of cases that didn't contain data for this question.

v Quintile 5 (children living in the most deprived 20% of areas) are 0.72 times as likely to have their hearing screened compared to Quintile 1 children (CI: 0.55-0.95, p=0.02).

- loss to follow-up is least common among Asian children (2%), followed by MELAA (2%) and Europeans (2%) and most common among Māori (6%) and Pacific (4%); and

UNHSEIP monitoring data

No officially published UNHSEIP annual monitoring reports were made available during 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].

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.

Te Whatu Ora | Health New Zealand released a monitoring report[106] in 2022 relating to babies under three 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. Despite the challenges of the COVID-19 pandemic, the overall results were positive. Key points from this report were described in the 2022 report.

The 2020 report shows that most metrics were similar or better compared to 2017, although the proportion of cases categorised as DNA, lost contact, or declined rose from 7.4% to 10.6%. Rates of hearing loss detected by the programme were higher for Māori and Pacific babies than in 2016[106].

However, the UNHSEIP 2020 coverage rates were lower compared to some similar programmes, such as Australia's Healthy Hearing Programme[107]. There is concern about progress for Māori and Pacific babies, who are more likely to have hearing loss, less likely to be screened, and less likely to complete their audiological assessment.

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.

This UNHSEIP data to 2017 demonstrated our rates of hearing loss at birth are somewhat higher than those reported in similar jurisdictions overseas[ii] at around 1.2 cases of bilateral hearing loss for every thousand babies screened, plus an additional 0.8 cases of unilateral hearing loss[43]. 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 district.

It is a great pity that annual published programme data has not been consistently available for this nationwide screening programme.

International benchmarks

The Joint Committee on Infant Hearing (JCIH) recommended in 2000 that all children should be screened by one month of age, have a diagnosis by three months and begin intervention by six months of age[108]. This advice was extended in 2019 to indicate those meeting this 1-3-6 benchmark should attempt to get to 1-2-3[109].

Thangavelu *et al.* (2023) in Germany note "…both the 1-3-6 and the newly amended 1-2-3 quality criteria are very demanding and can only be

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.

ii Overseas, several 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.

achieved with considerable financial and infrastructural expenditure."[110]

DND data

During 2023, a total of 108 of notifications were for babies born in Aotearoa New Zealand who were diagnosed as a direct result of newborn hearing screening, a huge increase since 2010.

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 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 2023.

Of the 108 cases in the DND notified in 2023 that were identified as a direct result of newborn hearing screening in Aotearoa New Zealand, 80% were diagnosed by the internationally recommended age of three months[i]. This is the highest proportion reported to date, with the previous highest figures being 74% in 2021 and 73% in 2018

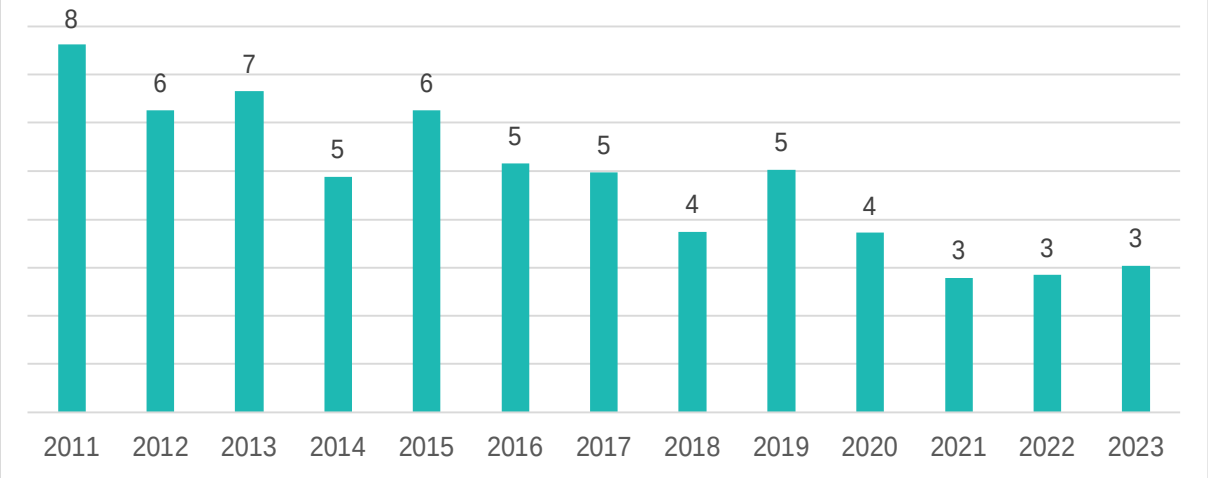

Table 12: Average months at diagnosis for children referred from and diagnosed as a direct result of the newborn hearing screening programme (2011-2023)[ii]

Identification of false negatives

The DND provides the only method for identifying potential false negatives from the newborn hearing screening programme[111].

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 Aotearoa New Zealand context.

In 2023, one case notified to the Database was 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. That notification contained no further detail around that case. This is not to say that one or more additional babies diagnosed in 2023 were

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 Please note that this graph excludes cases without an exact date of diagnosis. This means no 2010 cases are included and only some 2011 cases.

not incorrectly passed at their newborn hearing screening, just that none notified to the Database were recorded as such.

Nineteen of the tamariki who were born in Aotearoa New Zealand and identified with hearing loss during 2023 had been screened previously as part of the UNSHEIP and passed this screening. This figure is not necessarily a concern, as many tamariki develop hearing losses after their initial diagnosis. One would expect over time that, as newborn hearing screening programme coverage rose after the start of implementation, there would be a rise in the number of children and young people who *could* be possible false negatives from the screening programme.

In addition, this figure was likely to rise for some period following the discovery of 2,064 incorrectly conducted screenings in 2012[i]. Of the 485 children who attended the recall in the Counties Manukau District Health Board, two children with bilateral profound hearing loss were identified and received cochlear implants at age three years[112]. The implications of false negatives can be significant for children and their whānau.

By removing those listed as born outside Aotearoa New Zealand, those with acquired hearing losses[ii], and those where the hearing loss was not thought to be present at birth, we can see that seven cases in 2023 remain. This is the lowest number since 2013. Of those *potential* false negative cases, the age of identification for these tamariki ranged from one and a half, to nearly seven years of age.

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.

Programme coverage

B4 School Check hearing screening data for selected cohorts from selected years are shown in Table 13 (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 | Manatū Hauora* since 2020-21 shifted to include more children in the denominator and so data below 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.

This is the third year we describe multi-coded ethnicity data provided by the Ministry of Health. This aligns to how we describe ethnicity for

i 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.

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

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

iv From 2020/21, the data source 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 | Manatū Hauora* reports this is a change from previous reports 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. Further detail about this change and its advantages can be found in the previous two DND reports. The B4SC database is a national information system for capturing and storing information about children receiving their B4SC.

children and young people within our own database.

Outcome	Description	2010/11	2018/19	2020/21	2021/22	2022/23
Pass Bilaterally	The child was screened and passed.	71%	74%	74%	71%	68%
Referred	The child was screened and referred to a relevant service.	6%	5%	3%	3%	5%
Rescreen	The child was unable to complete the screen, so a rescreen has been booked, normally in around 6 months.	9%	5%	5%	5%	6%
Under care	The child is already under the care of a relevant service.	1%	3%	3%	2%	3%
Decline	The hearing check was declined by the caregiver.	5%	1%	1%	.5%	1%
Not Checked[i]	The child did not receive a hearing check.	9%	12%	14%	18%	18%

Table 13 B4 School Check Hearing Screening data (tamariki screened in selected years)[ii, 113]

Outcome	Description	*All cases*	Māori	Pacific Peoples	Asian	MELAA	European
Pass Bilaterally	The child was screened and passed	***68%***	62%	58%	66%	65%	74%
Referred	The child was screened and referred to a relevant service	***4.5%***	5.2%	6.3%	3.6%	3.7%	4.0%
Rescreen	The child was unable to complete the screen, so a rescreen has been booked, normally in around 6 months	***6.2%***	8.8%	7.3%	5.1%	5.3%	5.2%
Under care	The child is already under the care of a relevant service	***2.6%***	3.1%	3.1%	2.4%	1.9%	2.5%
Decline	The hearing check was declined by the caregiver	***0.5%***	0.8%	0.5%	0.3%	0.2%	0.5%
Not Checked	The child did not receive a hearing check	***18%***	20%	24%	22%	24%	14%

Table 14 B4 School Check Hearing Screening data by ethnicity (2022/2023)[iii, iv, 113]

Insights

There is no national reporting framework that helps us understand the efficacy of hearing screening done as part of the B4 School Check. As a result, key information is unknown[115], 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, and
- 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 Pacific

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 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 them in this table. The children in this category are listed as 'not checked' in 21.3% of cases.

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

Peoples) are not benefiting equally from this screening programme when compared with Europeans. Without any basic measures of programme efficacy, it is not possible to confirm the degree of inequity or its cause(s).

A recent presentation at the ORL 2024 Conference[114] shed some light on data from the B4SC via a retrospective cohort study, finding glaring differences, with Māori, Pacific, and children living in more deprived areas less likely to have B4SC and hearing screening and having higher rates of hearing loss with flat tympanograms (likely indicating middle ear dysfunction). These groups also had significantly poorer access to primary healthcare to enable appropriate follow-up and management. There are differences in rescreen and referral outcomes which needs further evaluation.

Programme coverage

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

- has increased in recent years since 2016-17 (see Table 13) 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*-European groups, particularly children recorded as Māori or Pacific (See Table 14).

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

For example, the new data from *Ministry of Health | Manatū Hauora* shows the overall referral rate for tamariki completing the hearing screening as part of the B4 School Check is 4.4% (2021/2022). As with previous years, Māori and Pacific tamariki have higher referral rates (5.3% and 5.3%), with European, Asian and MELAA tamariki having lower rates than the average (3.8%, 3.4% and 3.7%).

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.

In Aotearoa, there is a growing body of evidence suggesting Māori and Pacific children particularly would benefit both from screening programmes that focused more on reducing disparities, and on screening at additional points in childhood to identify chronic middle ear disease, as yet unidentified permanent hearing loss and auditory processing difficulties.

There are signs that current screening protocols/instruments may exacerbate rather than narrow pre-existing inequalities for these groups of children (due to thresholds set for referral, for example). In addition, systems and practices that are Euro-centric may reduce the chance that hearing losses are identified promptly when they develop outside the two- or three-points during childhood at which hearing is currently screened.

Given this understanding, it is therefore disappointing that Pacific Peoples 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 14 and in the previous section.

Recent local sources describe some of issues that exist and recommendations to address those:

Source and focus	Findings and recommendations
A) Reviews	
A 2019 Better Start –evidence review examining Well Child Tamariki Ora hearing screening after the newborn stage (2019)[115]	A lack of prevalence or efficacy data for the B4 School Check. 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. School screening could be considered for Tauira in Year 3 and Year 5.
***Ministry of Health*|*Manatū Hauora* review of the Well Child Tamariki Ora framework in 2020[116]**	A redesign of the framework needed to support all tamariki and whānau to flourish, including nurturing Māori partnership and leadership to fulfil Te Tiriti obligations and enabling funding and commissioning approaches to support equity.
The Growth, Development and Screening Technical Advisory Group (and its Childhood Hearing Screening Technical Advisory Group) on the Well Child Tamariki Ora National Schedule. Considered evidence from the Better Start Evidence review above in 2002[117]	Recommended all hearing screening activities be transferred to the National Screening Unit. It also suggested strengthening Well Child Tamariki Ora engagement with 2–3-year-olds and retaining pure tone audiometry in four-year-olds with secondary use of DPOAE and tympanometry.
B) Studies	
Paterson *et al.* (2006) Pacific Island Families analysis among 1,001 two-year-olds screened in Auckland[118]	Found very high prevalence of chronic middle ear disease as 25% of children affected by OME. Concluded that consideration of national screening for this condition and other ontological disorders was warranted. *[Authors note: Serious cases of chronic middle ear disease can cause permanent hearing loss.]*
Leversha *et al.* (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 Pacific[119]	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 children and the authors indicate it is therefore inappropriate in the Aotearoa New Zealand context.
Burge's 2018 thesis (2018) examined development and wellbeing of children starting school in Tāmaki[120]	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[i].
Dickinson *et al.*'s study (2018) on 485 South Auckland children aged 2-3 years of age attending a screening recall due to a problem with their newborn hearing screen[112]	Being of Māori and/or Pacific ethnicity was significantly associated with hearing loss, concluding 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".
Su *et al.*'s *study* (2021) examined the feasibility of a hearing screening programme using otoscopy and DPOAEs, and conducted tympanometry in an area of high economic deprivation in Auckland[121]	Hearing screening in early childhood centres for three years olds was feasible, but more work is needed to ensure efficient and effective community-based follow-up of screening referrals.
Gibb *et al.*'s paper (2019) published in the *British Medical Journal* examined the hearing and ear status of 920 Pacific children aged 11 years living in New Zealand as part of the Pacific Island Families Study[122]	High prevalence of hearing loss, abnormal tympanograms and processing difficulties mean Māori and Pacific children were less likely to have completed checks when compared with non-Māori and non-Pacific 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].

i In addition, some children who were not enrolled with a PHO were actually 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.

In 2011, the American Academy of Audiology (AAA) recommended preschool screening frequency as prescribed by our Well Child Tamariki Ora schedule in New Zealand, *plus* screening at ages 5, 6, 7, 10 and 12 or 14 years at a minimum[123].

In 2021, the WHO's World Report on Hearing noted "Late onset, or progressive, hearing loss associated with some of these conditions, is commonly missed during early childhood screening."[124]

Organising for change

Perceived and ongoing failures of our nationwide screening programmes, particularly for Māori and Pacific children, have resulted in independent organising by groups of concerned individuals and organisations.

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. This group intends to expand their services within the Counties Manukau District. Many children with various stages of otitis media, as well as some with newly diagnosed permanent hearing loss, have been identified and followed up as a result of this and rates of undiagnosed hearing issues have been concerning to their team.

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 eight months, an increase on the previous two years but an improvement on historical levels. This is undoubtedly, in large part, due to nationwide implementation of the newborn hearing screening programme.**
- **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 being diagnosed, and intervention begun.**
- **Average delays to diagnosis are greatly improved over historic levels though reductions seem to have stalled.**
- **Children and young people with an additional disability, with a unilateral hearing loss, who live in the most deprived quintile and those who are Māori and/or Pacific Peoples have the longest median delays. Asian children have a lower median length of delay when compared with other ethnic groups.**
- **'Audiologists having difficulty getting a confirmed diagnosis' was the most commonly mentioned reason for delays in diagnoses across 2010-2023. When restricting notifications to those from 2021-2023, 'parents did not attend appointments/ delayed or rescheduled these (for any reason including service failed to engage family)' became the most common. 'Child was born overseas/lived overseas and hearing loss not diagnosed there', or 'follow-up not provided' were both associated with the longest delays, at eight months each.**

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 associated with improved 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[125]. Early diagnosis seeks to maximise benefit during sensitive periods of neurological and linguistic development and limit children from falling behind their peers[126, 127, 128, 129, 130].

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 often 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.

Screening newborns for hearing loss has proven overall to be successful overseas and in Aotearoa New Zealand at reducing diagnostic delays within newborn hearing screening. 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 15 months in 2021 before rising again to 24 months in 2023[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; and
- 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.' [131].

McLean *et al.* (2014) examined qualitative and quantitative evidence use of reminders and notifications in healthcare settings in the UK, resulting in the development of six themes influencing patient attendance[132]. 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) looked at major barriers to paediatric hearing health care and found that public health information and communication between families and professionals can ameliorate the role of socio-economic status in 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[133]. 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 more detail on approaches to reducing diagnostic delays. Considering various perspectives on hearing (from page 6) and the associated Appendix on page 79 may also be helpful to clinics and decision makers focused on reducing delays.

Presence and length of delays

Presence of delays

Overall for 2010-2023, 45% of all notifications contained one or more reasons for a diagnostic delay. This figure was highest for those of Māori and MELAA ethnicity (54% and 60%), followed by Pacific Peoples (46%) and then European (29%) and Asian (35%) children and young people.

In 2023, the proportion of cases that have no reasons for delay[ii] has risen, from an average of 59% over 2017-2021 to, to 71% in 2022 and 2023.

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 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.

Length of delay

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

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

Median delays

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

Groups at significantly increased risk of longer median diagnostic delays include children and young people who:

- have an additional disability (or for whom the presence of one is unclear) than children without an additional disability[ii];
- have a unilateral hearing loss than children with a bilateral hearing loss[iii];
- live in a Quintile 5 area (the highest deprivation), compared with those who are in Quintile 1[iv]); and
- are Māori or Pacific Peoples when compared with non-Māori, non-Pacific.

Asian children have a lower median length of delay when compared with other groups. Keep in mind that the 'Asian' group is far from homogenous and these overall figures likely mask differences between subgroups. This may reflect their:

- higher proportion of severe and profound hearing losses;
- lower likelihood of not attending appointments or to have 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 more successful access to and through at least some specific parts of the health system, as demonstrated by their high rates of participation in other health promotion efforts, including COVID-19 vaccination[134].

Average delays

The average delay in 2023, between first suspicion and confirmation of the child or young person's hearing loss (*including* those born overseas), and mild, acquired, or unilateral hearing losses[v], was eight months. Figures varied considerably between districts, with a delay range of 0-31 months reported among children and young people diagnosed in 2023.

While average delays in the last five years have greatly improved on the previous high of 17 months[vi] it is worrying to see that reductions in the length of delays have stalled since Covid, and are still static compared with those in 2020 and 2021, given that both of these years included considerable lockdowns and therefore disruptions to hearing services.

i This change excludes 203 cases from the analysis of the length of delay.

ii p= 0.0003.

iii p < 0.0001.

iv p=0.03.

v 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.

vi 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.

The child being born or having lived overseas was at least part of the cause of the lengthiest delays, at eight months, followed by suspicion of something other than hearing loss and then difficulty getting a referral to audiology; follow-up or referral lost in the system or didn't occur was next most common.

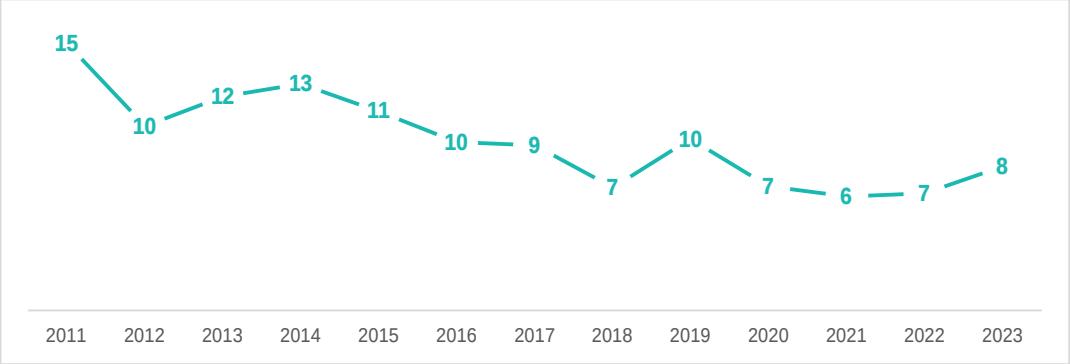

Table 15: Average delay in months by year of notification (2011-2023)[i]

Causes of delay

2010-2023 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, including some for which there was a delay calculated.

The analysis 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 date the hearing loss was first suspected until the time when the hearing loss was diagnosed[ii].

Keeping in mind that some children and young people had a number of reasons listed, the left column in Table 16 shows the various average and median delays by cause, showing which reasons contributed to the longest delays. The second shows the most commonly mentioned delays from 2010-2023 and the last shows the most common delays during the last three years. The authors of the report hope that this information might be helpful to focus the efforts of clinics and decision makers.

Ethnicity

When delays in diagnosis are examined for 2011-2023, several patterns emerge:

- for all groups except MELAA, difficulties getting a confirmed diagnosis was the most mentioned cause of delay to diagnosis and waiting time to see a hearing professional was second. For MELAA children the top reason for delay was that they were born or lived overseas;
- Māori were less likely than other groups to have no reasons listed for their delay;
- Māori and Pacific families and those living in areas of higher deprivation were more likely than European or Asian groups not to attend appointments or to have delayed these for any reason;
- European, Asian and Māori families/parents/child/carers or educators (not health professionals) suspected something other than hearing loss or had no concern were more likely to have suspected something other than hearing loss.

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

ii Delays for children and young people born overseas are included in this table, as are those from 2010 where no date of diagnosis was requested on the notification form, meaning no precise length of delay can be calculated. The pattern of the 5 most commonly mentioned reasons is the same whether data from 2010-2023 or the 2011-2023 years is considered. It is only possible to include data from 2011 when a specific date of diagnosis began to be recorded.

Cause of delay by median and average delays for cases with reason included (both rankings are the same and are shown in brackets)	Most common delays across the dataset (2010-2023)	Most common delays 2021-2023 in recent years
'child was born overseas/lived overseas and hearing loss not diagnosed there', or 'follow-up not provided' (both 8 months)	'audiologist had difficulties getting a confirmed diagnosis'	'parents did not attend appointments/ delayed or rescheduled these (for any reason including service failed to engage family)'
'parents/child/carers or educators suspected something other than hearing loss or had no concern' (6-7 months)	'parents did not attend appointments/ delayed or rescheduled these (for any reason including service failed to engage family)'	'audiologist had difficulties getting a confirmed diagnosis (e.g. conductive overlay, child unwell)'
'difficulty getting a referral to audiology (e.g. VHT referral not accepted by DHB, GP or other health professional dismissed parent concern and no referral was made)' (6-7 months)	'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)'	'waiting time to see hearing professional or accessing services in their area'
'child not screened for any reason/multiple screenings (both 5 months)	'child was born overseas/lived overseas and hearing loss not diagnosed there'	'child or young person had other medical issue(s) which took precedent (e.g. feeding issues, medically fragile)'
'waiting time to see hearing professional (both 5 months)	'difficulty getting a referral to audiology (e.g. VHT referral not accepted by DHB, GP or other health professional dismissed parent concern and no referral was made)'	'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)'

Table 16: 2010-2023 reasons for delay (ranked and median, average, most common)

When considering the ability of educators to identify children with hearing loss it is important to note there are significant challenges in timely identification of hearing loss among children using subjective methods, including for teachers[135] and also parents[136, 137, 138]. These challenges prompted the introduction of newborn and other childhood screening programmes in many parts of the world to reduce the age of identification and inter-vention for children with this condition, aiming to improve their outcomes. Even when successful these programmes will not mean all cases are identified in a timely way, including for those with mild hearing loss or those that develop or progress later in childhood.

Educators have many calls on their attention, including providing support for children who have English as a second language and those with other conditions such as ASD. Additional teacher education and resources to aid identification and support for these groups may reduce the proportion of children who are identified later when parents or educators don't suspect a hearing loss.

Other patterns

Clinics, decision makers and screening programmes may also wish to note:

- parents did not attend appointments/ delayed or rescheduled these (for any reason including

service failed to engage family) has moved to the most common reason for delay during the 2021-2023 period, and this coincides with various reports of reduced engagement with health services since the start of the pandemic. Keep in mind that this issue not associated with the longest delays overall; and

- even the presence of items low down in the median/average age rankings, including 'difficulties getting a confirmed diagnosis', which affected more than 400 children, resulted in a 3-month median delay or a 4-month average delay and addressing this delay is worth the attention of clinics and screening programmes.

Local research and efforts to improve equity and reduce wait times

Recent analyses of audiology data by Waikato DHB as part of their Equity Project were included in the DNDs 2021 report. Within their families, 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 by Pokorny, Hislop and Holt 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. A retrospective audit at Counties Manukau found that there were no differences in attendance rates between those who had participated in telephone consultation and those who had not[61].

"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."

That 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 Pacific whānau, these groups are generally not well represented within the audiology workforce. They suggest approaches to improve cultural safety could assist, as could finding ways to introduce the clinician when making 'cold' calls to whānau.

Broader issues contributing to delays

Staffing and delays

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

'Waiting time to see hearing professional or accessing services in their area' is one of the key causes of delays in Aotearoa New Zealand, including during the last three years.

Internationally there is a health workforce shortage, including a shortage of allied healthcare workers and hearing professionals[140]. There is also a growing concern that, like many countries, our aging population will require greater hearing care, exacerbating these shortages. The length of waiting times is a known contributor to reduced attendance at appointments.

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 the public sector has dropped back to more typical vacancy levels, meaning there is more limited capacity to

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

provide diagnostic, intervention and monitoring services to tamariki and rangatahi.

Hearing care for children and young people in Aotearoa New Zealand is generally provided by the public health system, through district services, including following the establishment of Health NZ | Te Whatu Ora. At times districts, particularly those outside the main centres, struggled to fill vacancies for audiologists and there are some reports that vacancies are not able to be filled currently due to district funding limitations. This can result in long waiting times, which are thought to be associated with lower attendance levels[141].

Efforts to improve engagement

Parents did not attend appointments/delayed or rescheduled these (for any reason including service failed to engage family) has become the most common reason for delay in the last three years, and this coincides with various reports of reduced engagement with health services since the start of the pandemic.

Cases where the whānau or young person did not attend the appointment have 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" while retaining the same acronym. This shift places the onus on the service to do what's needed so whānau/patients can attend appointments, thereby reducing delays in diagnosis and the start of intervention. This work also has positive 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'."[142]

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

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

Common factors thought to be important in reducing barriers to health service access include removing cost barriers, addressing transport and childcare issues[143], knowing the client population, personal engagement, a non-judgemental approach[144], strengthening cultural safety, and flexibility in service arrangements[145].

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."[146]

Māori and Pacific whānau have higher rates of non-attendance and are also more likely to live in areas of high deprivation when compared with European whānau, meaning there are further barriers to their engagement.

It has also been suggested that higher rates of middle ear issues among Māori (and Pacific) children may require multiple appointments when there is an underlying SNHL and that this can result in delays in diagnosis[147]. 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 2023 of 2.4 months, an increase on the previous two years average delay of 1.2 and 1.7 months respectively, but a fall from 2020's 2.8 months.

During 2023, the following patterns were visible among reasons for delay:

- fifteen children and young people had their diagnosis delayed because of non-attendance at appointments. COVID-19 has contributed to the higher number of whānau delaying non-

urgent hearing care appointments in recent years, including because some could not or did not feel comfortable engaging through telehealth options[148] and some may not have wanted to visit hospitals or clinics during earlier stages of the pandemic;

- "Audiologist had difficulties getting a confirmed diagnosis" was the most commonly mentioned cause of a delay in children's diagnoses for 2023, with 16 cases noted as being affected by this type of delay;
- this was followed by "parents did not attend appointments/delayed or rescheduled these, for any reason" in 15 cases, and "Waiting time to see hearing professional or accessing services in their area", with 12 diagnoses delayed for this reason; and
- in 2023, no cases where one or more reasons for a delayed diagnosis was provided specifically mentioned COVID-19.

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

Other causes

Audiologist had difficulties getting a confirmed diagnosis:

"Required 2 assessments as baby did not sleep for all testing at first appt."

"Several ABRs required as baby did not sleep well."

"This child was seen for hearing tests over several months in a private clinic with inconclusive results. Was then referred to us and hearing loss identified."

"Possibly given an incorrect diagnosis from an audiologist…."

"Difficult to obtain separate ear information due to ongoing middle ear problems."

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

"Child DNA'd f/u screening and discharged from program. Referred back to [redacted] from [name of clinic]"

"Family declined a GA ABR when he was younger - also DNA ABR appts."

"Family lives in rural area [area redacted] hence late second screening and referral to Audiology."

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

"Limited staff availability given staff shortages and delays over Xmas/New Year break."

"I assume the lack of full time Audiology at the time (When born) might have also affected attendance and FU."

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

"…and parental hearing concerns disregarded by other medical professionals."

Difficulty getting a referral to audiology

"…and parental hearing concerns disregarded by other medical professionals."

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)

"No concerns about hearing, picked up at B4 school."

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.**
- **New Zealand DND data suggest a relatively higher proportion of children and young people with mild and/or moderate hearing loss, and fewer with severe/profound hearing loss than in other similar jurisdictions 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 Pacific 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 69% in 2023, with a high of 72% 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.

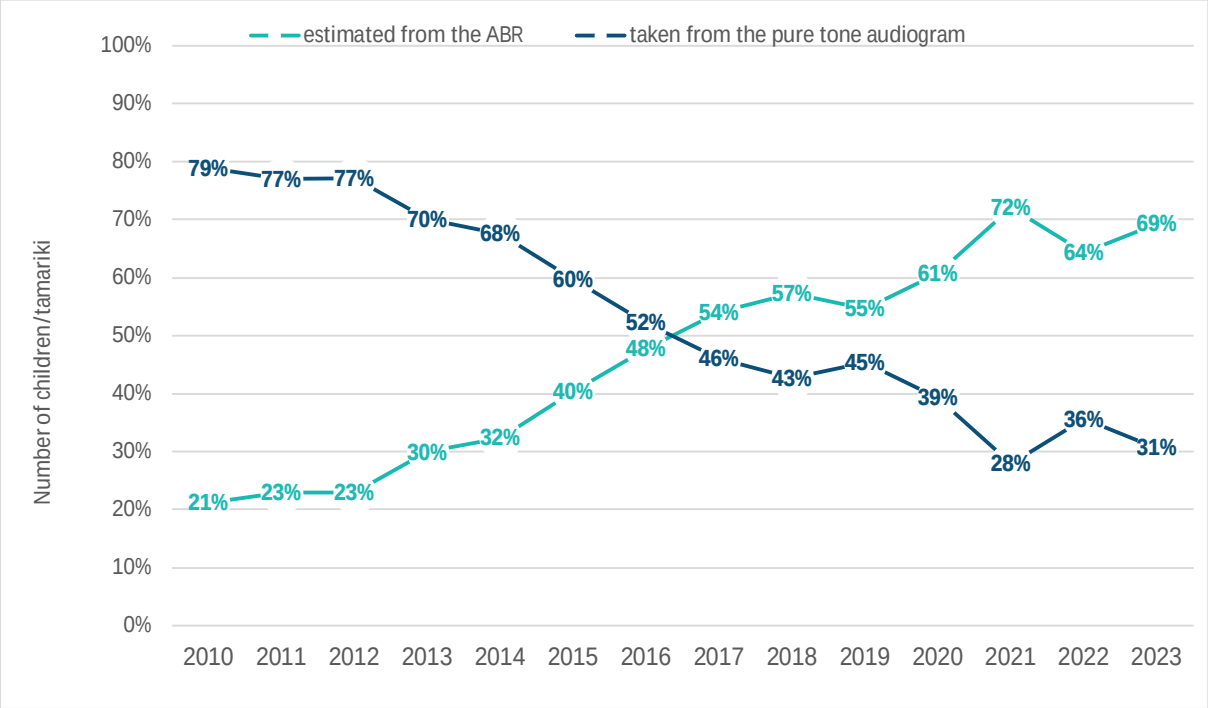

Figure 11: Proportion of cases containing thresholds from ABR and the Pure Tone Audiogram, by year, 2010-2023

Classifications

In Aotearoa New Zealand, the Clark (ASHA) codeframe is most commonly used in clinical settings. Therefore, this is the codeframe chosen for most analyses in this report.

Degree of loss	Clark 1981 (ASHA)[149]
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 17: Clark's 1981 ASHA severity codeframe

Further information about severity classifications can be found in Severity codeframes from page 81.

Single sided deafness in the DND

Severe or profound unilateral hearing loss can be referred to as single-sided deafness (SSD). *For more information please refer to the section titled* Single-sided deafness *from page 80.*

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.

The proportion of all 2010-2023 cases that met the criteria for SSD is 5.1%.

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

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

Cochlear implants in Aotearoa New Zealand

Children and young people in this category 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.

It is likely a good number of these tamariki will not have a robust auditory nerve[200] meaning implantation is not valuable for them. This indicates that an early scan is useful for those in this rōpū, to manage whānau expectations.

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* begins on page 81.

Of the 2724 cases within the main dataset (2010-2023), 78% contain enough data to calculate severity. This means for those children and young people with bilateral hearing loss all eight datapoints were provided or could be interpolated, while for unilateral cases there were four datapoints.

Table 18 shows the proportion of cases in unilateral and bilateral categories in each severity (degree) grouping.

Degree of loss using ASHA severity codeframe	Unilateral 2010-2023	Bilateral 2010-2023
Mild	49%	52%
Moderate	16%	29%
Moderately severe	12%	8%
Severe	8%	4%
Profound	17%	7%

Table 18: Comparison of severity distributions for children with bilateral and unilateral hearing losses, 2010-2023

By categorising notifications using the DND severity codeframe (1996-2005) and applying exclusion criteria from the original database[ii], 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 over time 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[iii], [150]. 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[23, 151] though much of the data in this area focuses on children with hearing losses in the upper end of the mild range[150].

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[152]. 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 hearing technology and are more likely to be Māori and Pacific Peoples. 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

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 which did not contain all eight-audiometric data-points, or whether interpolation or averaging was used for records with fewer tested frequencies.

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

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

effects of additional temporary conductive hearing loss'[105]. 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 European counterparts from the UNHSEIP.

Ethnicity and severity profiles

Bilateral hearing losses

Within the 2010-2023 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 European and Māori children have the greatest number of diagnoses, and that milder degrees of hearing loss are more commonly reported among Māori[153]. These findings have been confirmed by separate analyses of 1982-2005 data[i] and 2010-2016 data[ii]. Māori tamariki also have higher rates of unilateral hearing loss than their European counterparts as described previously.

Later analyses of cases that were listed only as Māori or European (rather than both) were also completed for those with bilateral hearing losses, showing the proportion of cases of 'severe'[iii] or greater severity was lower among Māori children and young people. This difference for the 2010-2023 period is 14% for European children, 6% for Māori and 13% for those both Māori and European.

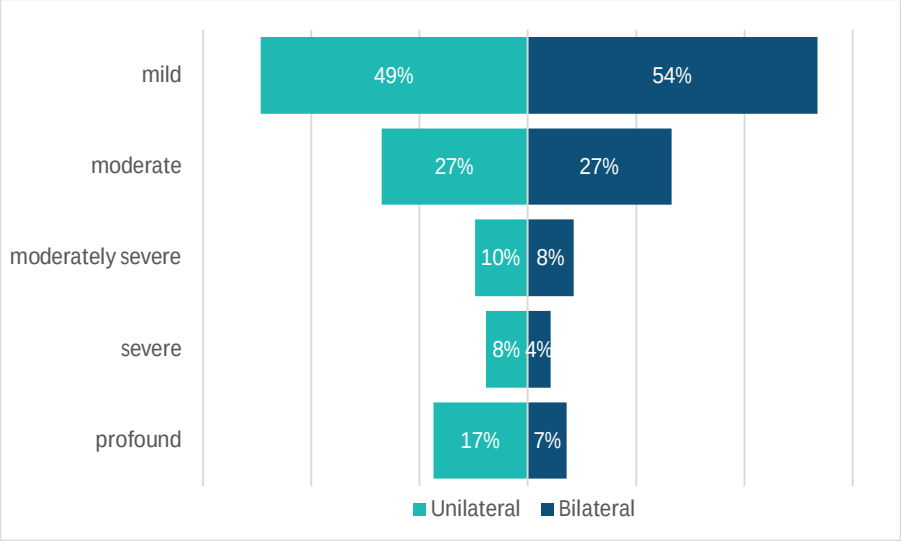

Figure 12: Degree of hearing loss by tamariki for bilateral and unilateral hearing losses (better ear, worse ear; 2010-2023, including interpolated values)

Other ethnic groups

There are a greater proportion of mild or moderate bilateral hearing losses among Pacific children (80%) and young people, and Māori tamariki (85%) in the Database than other groups. Seventy-seven percent of hearing losses among European children are mild or moderate in nature. Children and young people from the Asian and MELAA ethnic groups are least likely to have mild or moderate bilateral hearing losses, at 76% and

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

ii 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.

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

71% respectively. Seventy seven percent of European children and young people have these less severe bilateral hearing losses. Asian, 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 the 2010-2023 cases for children and young people with *unilateral hearing losses*, severity profiles are somewhat different between 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.

Pacific children and young people with a unilateral hearing loss have a lower likelihood of mild or moderate hearing losses (49%) than their Pākehā (European) counterparts (67%). MELAA tamariki are even less likely to have mild and moderate unilateral hearing losses, at 25% of the total.

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 Pacific children and young people.

See

International severity comparisons *on page 84 for further information.*

Intervention and support

Wawaotanga me te tautoko

- **The Ministry of Education | Te Tāhuhu o te Mātauranga provides services to students who are deaf and hard-of-hearing through groups such as Advisors on Deaf Children and other specialist educators. In 2023, they provided services to approximately 1,882 children under the age of eight, including 807 babies and young children identified as a result of the UNHSEIP.**
- **In the 2023 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 programmesand habilitation support; and Ko Taku Reo - Deaf Education NZ.**
- **At the time of diagnosis, professionals notifying cases expected 56% of the children and young people diagnosed in 2023 would receive two hearing aids. In total, 1,982 children and young people received hearing aids provided through MOH funding during the year.**
- **Forty-nine children and young people around the country received publicly funded cochlear implants during the 2023 calendar year, an increase on 2022.**

Ministry of Education | Te Tāhuhu o te Mātauranga

In the 2023 calendar year, the *Ministry of Education, Learning Support* provided service to approximately 1,882 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[154].

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 807.**
- 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 294.**
- 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 917.**
- For the calendar year 2023 the Ministry of Education, Learning Support provided service to approximately 150 children identified with hearing loss through the Universal Newborn Hearing Screening and Early Intervention Programme:
  - 74% of children and their whānau were contacted within 10 working days of receipt of a request for support;
  - 95% 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 from birth to Year 13 at school through:

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

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, and in 2023 had 127 students enrolled in Term 1 and 116 enrolled by the end of Term 4. Auckland has the greatest number (n=81), followed by Christchurch (n=39) and then Wellington (n=7). Students can access residential accommodation between 11 and 21 years of age at Kelston (Auckland) and Sumner (Christchurch)

2. 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 (Resource Teachers of the Deaf) under the moderate needs contract.

3. 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.)

4. 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

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.

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 2023, NZSL@School funding was provided to 121 students nationwide as top-up funding to increase the hours of their Communication/Education Support Workers (C/ESW's). A further eighty-nine students received support from an NZSL Tutor.

Continuing change

NZSL Immersion Day Schools (Hubs, Outreach) continue to meet the needs of students who would benefit from delivery of the New Zealand Curriculum through an immersive NZSL service one day a week, complimenting their regular mainstreamed schooling.

In 2023, there were 63 students enrolled at NZSL Immersion Day Schools across five locations. One location is currently on hold while the programme is reset. There are 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 2023, a project to set up and start a virtual playgroup has been targeted after a successful visit to Australia to see a similar model. Work with Australian colleagues is ensuring that the foundations we are setting for this are strong and we prepare for success. 0.4 FTE staffing is being allocated to set these up and get these running as a regular service. 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 163 cases notified to the Database in 2023, 159 contained information about whether hearing aids were to be fitted.

Figure 13 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. For 2023 the pattern has changed again, showing the lowest proportion being expected to receive two hearing aids, and the highest proportion with the hearing professional being unsure at this time about whether hearing aids are likely to be fitted.

When data for all children and young people notified from 2010 to 2023 were considered, the audiologist's intention was to:

- fit 75% of bilateral losses with one or two hearing aids, while 7% were not expected to receive any aids and the notifying clinician was unsure in 17% of cases; and
- fit 16% of unilateral hearing losses with one hearing aid, 54% two hearing aids[i], while 11% were not expected to receive any aids and the notifying clinician was unsure in 18% of cases[ii].

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 0.5, 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, this is because although the average threshold for the better

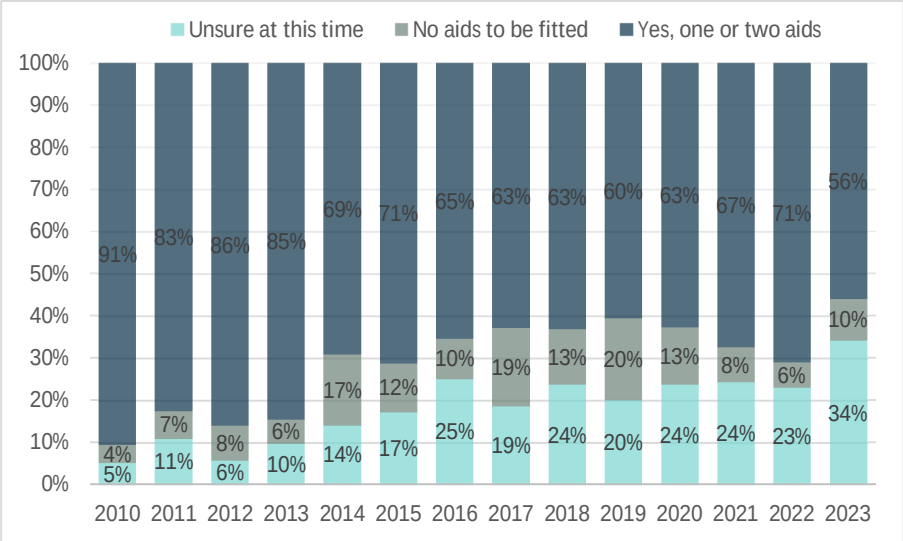

Figure 13: Hearing aids to be fitted by notifications (2010-2023)

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 are 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).

We will repeat these analyses for the 2024 data in the next in our series of reports.

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 19[i].

Ethnicity	0-3 years	4-5 years	6-15 years	16-18 years	Grand total
Māori	110	81	439	62	687
European	123	62	427	87	694
Pacific Peoples	34	20	117	20	190
Other	74	62	245	40	418
Total	340	225	1225	209	1982

Table 19: Whaikaha funding of Children's Hearing Aids, Calendar Year ending 31 December 2023, EnableNZ[ii, 155]

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 that 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.

i 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.

ii 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.

These data show health funded hearing aids for tamariki under the age of nineteen, and those in fulltime education and under the age of 21 during the 2023 calendar year[i, ii].

A total of 1,982 unique service users (tamariki and rangatahi) received hearing aid(s) during this period, slightly up on the previous two years.

International research

A selection of papers from overseas jurisdictions relating to hearing aids and factors contributing to improved outcomes is provided below:

Paper details	Findings
Tomblin *et al.* (2015) examined language outcomes for 290 children in the United States between two and seven years of age with mild to severe hearing loss[156]	Children fitted with hearing aids had better early language achievement than those fitted later. Those children fitted after 18 months improved in their language abilities as a function of the amount of hearing aid use. 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.
Ching *et al.* (2017) explore how intervention timing influences 5-year language in children with PCHL within the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study in Australia[157]	Earlier device fitting (HA or CI) is associated with higher global language scores (summarising language ability, speech production and speech perception evaluated using a range of measures). The impact of later fitting increased with the degree of hearing loss.
Cupples *et al.* (2018) describes speech and language outcomes for a cohort of 146 five-year-old children with hearing loss and additional disabilities[158]	Authors concluded that early hearing aid fitting was important for those children with additional disabilities. Children wearing HAs, those with less severe hearing loss, use of oral communication and a number of other factors were correlated with better language outcomes.
Ching *et al.* (2019) outline findings of the LOCHI study and its implications[159]	The earlier children receive their first fitting with a hearing aid or cochlear implant the 'better their speech, language and functional performance outcomes'. Psychosocial development was also associated with better language and functional performance.
Munoz *et al.* (2019) surveyed parents from around the world with children under six on their experiences with hearing aids[160].	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.
Visram *et al.* (2020) surveyed caregivers of eighty-one infants with a hearing loss in the United Kingdom[161]	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.

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

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

The 2021 Demographics report from Australian Hearing shows that fitting rates (for both hearing aids and cochlear implants) remained stable for those with moderate and greater degrees of hearing loss but increased for those who have less severe degrees of hearing loss. 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 to be due, at least in part, 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.

Prescribing, usage and data in Aotearoa New Zealand

A 2021 analysis by Waikato DHB (now Waikato District) found that for both Māori and non-Māori with moderate or greater hearing loss, hearing aid fitting occurred on average approximately six weeks after diagnosis, though medians for Māori were considerably higher at 19 weeks[139].

An Aotearoa New Zealand study followed up 163 of the 189 children and young people notified to the DND in 2010, seven-eight years later. For those where data was available, 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[8].

Readers should also be aware that while information was available from the UNHSEIP before 2015, no annual monitoring reports have been published since that time, though some data were made available during 2023 for the 2020 year. This means data on the proportion of children screened by one month and who have diagnosis by three months, are dated and we do not have any 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 helpful to enable us to understand whether screening is resulting in appropriately early intervention for those tamariki and rangatahi who receive hearing aids.

Cochlear implants

While 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 Whaikaha – Ministry for Disabled People 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 candidacy criteria for children and young people who are assessed by the cochlear implant teams[i].

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 and normal or near normal in the lower frequencies.

i 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.

During the 2023 calendar year there were 38 publicly funded cochlear implant devices provided in the Northern Region and 37 in the Southern Region, to children and young people under the 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. This year's numbers are a significant rise on those for 2022 for the Southern Region. A summary showing this change can be seen in Table 20.

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
2023	23	26

Table 20: Number of *children* receiving cochlear implants by year, split by cochlear implant programme (2016-2023)

Children receiving cochlear implants	Southern Cochlear Implant Programme[162]		Northern Cochlear Implant Programme[163]	
	Ears	Children	Ears	Children
ACC cases	1	1	2	2
Public Funding - (1 Jan to 31 December)	30	9	51	29
Private procedures	1	1	1	1
Re-implants – recalled devices, failed integrity tests, or soft failures	3	3	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)	2	2	1	1
	37	**26**	**38**	**23**

Table 21: Publicly funded cochlear implants provided in Aotearoa New Zealand during (2023)[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 which is not tracked by the Database.

Appendices

Ngā āpitihanga

Appendix A: DND related information

Making notifications to the Database

The authors of this report would like to extend their sincere thanks to all hearing professionals who have completed notifications for the Database. Your contribution to our understanding of permanent hearing loss among Aotearoa New Zealand's children and young people is greatly appreciated.

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

Audiometrists are warmly encouraged to make notifications for cases of hearing loss where they were the first to make a diagnosis that met the criteria among those who are over the age of 16 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 after a consent has been signed by the parent or caregiver, or for older rangatahi, by the young person themselves. This form should be kept on file by the diagnosing clinic.

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

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

Falling notifications

Table 22 outlines potential causes of the recent decline in notifications.

While in 2022, the fall in the number notifications in recent years showed some crossover with the fall in the number of cochlear implants provided by the Northern and Southern programmes, particularly in the Southern region, this year cochlear implant numbers have risen again to more typical levels. *These levels are described further in the section titled Cochlear implants on page 93.*

Disruptions to services are now much less common than during the first years of the pandemic, though widespread COVID-19 infections across the population remain common. The additional load on whānau is difficult to quantify though some services report less engagement from the public with health services, and this is reflected in coverage data for things like childhood immunisation. The high cost of living is also likely to be putting additional strain on families, including some not experiencing hardship previously. See 2020-2022 reports for further details relating to COVID-19 disruptions during past years.

Possible cause	- A fall in the number of children diagnosed (several districts are reporting this is the case for them) – this may be the result of the lower levels of engagement with health services by the public - A fall in the proportion of children being seen for monitoring or diagnostic appointments - A fall in the proportion of children whose diagnosis was reported to the database: Increased pressure on public audiology services as the private sector recovers from COVID and increases recruitment activities, meaning public sector vacancies are again harder to fill - A fall 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[164]. 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.
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 we don't understand programme coverage rates for 2022.

Table 22: Consideration of possible causes for the drop in notifications

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. It was managed by the National Audiology Centre on behalf of the Ministry of Health, and later by the Auckland District Health Board.

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

The original criteria during this period, 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 Aotearoa New Zealand and have a congenital (non-acquired) hearing loss. The data presented in reports to 2006 contained notifications made 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.

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, as nationwide implementation of the Universal newborn hearing screening and early intervention programme had begun. The DND was known to provide an important measure of changes in the age of identification and as the only way to identify potential false negatives within the newborn screening programme.

When the Database was restarted in 2010, the criteria were broadened to include children with hearing loss in one ear, those with acquired hearing losses, and those born outside Aotearoa New Zealand. 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 messages to members calling for notifications.

The authors of this report were delighted that the Ministry of Health began funding the DND from the start of 2012. The Database is now managed through a contract with *Enable New Zealand* (who have a contract with Whaikaha – Ministry for Disabled People) 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.

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

This history has implications for the longitudinal data 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; and
- notifications were reported for each calendar year throughout 1982-2005 and since the Database's relaunch, from 2010 to the current year.

Changes to consenting and notifications processes

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 through amendments to the newborn hearing screening consent, which also includes consent from whānau to have their child's data included in the Database.

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)[165]."*

The criteria for inclusion were modified for the 2010 re-launch of the Database, based on feedback from a small working group[i]. There was a strong view among audiologists consulted that this previous definition (above) 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 current criteria include 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]

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 an unknown but likely small proportion were being notified, we have not described this group in recent years, and we are no longer seeking notifications for these cases.

Potential renaming of the Database

Over the years, feedback on the name of the Database was sought from parents of deaf and hard-of-hearing tamariki, Advisors on Deaf

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.

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

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 likely that the Database has been receiving notifications for between 70% and 90% of all new cases diagnosed each year, though in the last couple of years it's unclear whether the proportion may have dropped or whether fewer children are now being diagnosed.

The authors continue to work on ways to maintain or increase the proportion of notifications received, improving the ability of the Database to inform stakeholders (including Health New Zealand | Te Whatu Ora, the Ministry of Health | Manatū Hauora, Whaikaha | Ministry for Disabled People, Ministry of Education | Te Tāhuhu o te Mātauranga, clinicians, educators and other service providers) about newly diagnosed permanent hearing losses among Aotearoa New Zealand children and young people.

Notifications and ethnicity

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

While it would be greatly preferable to collect more detailed information on ethnicity, we understand this information may not be available for all cases and 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 to the time taken to complete the form.

Historically, the proportion of notifications in each ethnic group was initially coded 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.

The method now 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[166]. 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 recorded under both these groups. This method 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 that were self-prioritised[167].

Terminology used in this report

There are several terms used by young people with a hearing loss and their families/whānau. Those whose information is included in this report range from those whose hearing losses are unilateral and mild in severity, through to those whose hearing losses are bilateral or profound. The terms commonly used differ both within these groups as well as between them.

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

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

Use of interpolation

Table 18 on page 63 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 also rely on interpolated datapoints, to provide a more complete picture of the severity of hearing losses reported among children and young people notified to the Database[i].

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

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.

Interpolation offers several benefits, including:

- 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.

i 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.

Appendix B: Further information about specific topics

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, with further marginalisation through cultural oppression and the introduction of new social systems based on European norms and values[168, 169, 170, 171, i].

Disparities documented in many areas of health demonstrate Māori have poorer access 'to, and through' the health system[64, 54,172,] 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 are some recent indications 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 inequities.

Several district health boards/districts 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.* for Constructions of Māori medical compliance (2011)[131] and Graham and Masters-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 sustainability within a connected system of care, and that future planning should involve First Nations communities at every age 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. Two percent or more of the children tested had a bilateral sensorineural hearing impairment[184].
- Household Disability Surveys:
  - *1991-2006 Surveys[185] 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[186]. (For*

i An introduction to this topic can be found in King *et al.*'s 2009 paper in *The Lancet*. (King M, Smith A, Gracey M. Indigenous health part 2: the underlying causes of the health gap. Lancet. 2009 Jul 4;374(9683):76-85. doi: 10.1016/S0140-6736(09)60827-8.)

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.

information about the limitations of these data please see the 2011 DND Report[187].)

- *The 2013 Survey continues to suggest Māori had higher unmet need for technology and equipment when compared with non-Māori[188] but also that they now have lower rates of hearing disability compared with their European counterparts[189], 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[190].*

- Greville (2001) found higher prevalence of temporary and permanent hearing loss among Māori children[191].
- 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%)[192] and this pattern still holds with 2020-2021 B4SC data showing 4% referral rates for Māori, compared with 3% for European children and young people as shown on page 49[ii].*
- Findings from Digby *et al.* (2014) indicated young Māori have higher rates of permanent hearing loss than their European peers, based on the previous and post re-launch DND datasets, which included notifications from 1982-2005 and 2009-2013[193].
- Diagnoses from the newborn hearing screening programme (2017) show that Māori infants who are screened, and for whom diagnostic information is available, have higher rates of hearing loss[194].

Perspectives on hearing loss and hearing services

Below are selected papers describing perspectives on hearing loss and hearing services in Aotearoa New Zealand. Please note that barriers for younger people and whānau/'aiga accessing care may differ from those for older people.

Manuel *et al.* (2021) conducted a review of literature on the experiences of hearing loss and hearing services among older Māori and whānau between 1985 and 2020. It used a Kaupapa Māori approach and PRISMA guidelines[195]. Five themes were described: societal stigma around hearing loss, hearing being a taonga for older Māori, hearing health care barriers, whakawhanaungatanga, and whānau centred care. Cost and poor patient-provider interactions created barriers to hearing services for Māori with hearing loss, and whānau.

Approaches to creating equitable, whānau-centred, culturally safe services are described including: the need for cultural safety training, increasing Māori and Pacific Peoples in the hearing workforce, more affordable services and technology and ones based in people's communities, including Māori voices in service improvement processes, and improved communication regarding follow up appointments. Whānau-centred care, destigmatisation efforts around hearing loss and care, education of students, and improving access to information and more Kaupapa Māori centred research were also noted.

Ready *et al.* (2019)[196] examined barriers to accessing hearing care services among older Pacific Peoples in Aotearoa New Zealand. This study was conducted using the Health Care Access Barriers model. The study found several barriers applied: community norms and attitudes; limited awareness of hearing care services; resulting cognitive barriers; communication limitations; financial, structural, family support barriers; and the absence of care for hearing available from general practitioners. The authors recommended work to eliminate or minimise modifiable barriers to hearing care including development and/or improvement of culturally responsive models of hearing care, particularly given how underserved Pacific Peoples are currently in Aotearoa.

Community norms may also slow care seeking for hearing:

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.

"The participants described a culture of diffidence among Pacific people, where they regard themselves as shy and reserved. Their lack of engagement with hearing health services could be because of the perceived fear of stigmatisation, being mocked and having perceptions of criticism or rejection."

"There was also the emergence of a sub-theme that explored religious beliefs about impairment among older Pacific people. There is a belief that it is God's will that one has hearing impairment and that only God can fix it."

Key newborn screening goals and history

New Zealand's UNHSEIP was implemented to reduce the length of time between birth or when a hearing loss develops and the start of intervention, for children born with hearing loss, 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 districts 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-standing advocacy from groups like Project HIEDI and the work of clinicians and managers in several district health boards, who worked to introduce local screening programmes.

Single-sided deafness

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[197, 198]. 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[199].

A study by Dewyer *et al.* (2022) found SSD was rare (0.36%) among the 52,878 children and young people within 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 as having SSD had the aetiology of their hearing loss confirmed as cochlear nerve deficiency (hypoplasia or aplasia), as found through MRI and/or CI. Sixty-six percent of those with SSD were categorised as able to benefit from cochlear implantation[200].

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[201].

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

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.

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).

Cochlear implants in Aotearoa New Zealand

Children and young people in this category[i] are not eligible for publicly funded cochlear implants except in the case of meningitis, but can opt for privately funded implants or receive implants if cover is provided by ACC[202].

It is likely a good number of these tamariki will not have a robust auditory nerve[201] meaning implantation is not valuable for them. This indicates that an early scan is useful for those in this rōpū, to manage whānau expectations.

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 23 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)[203]	World Health Organisation[204]	CDC[205]	Proposed code from Davis and Davis[3]
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 23: Comparison of audiometric severity classification systems

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); and
- Colorado data with New Zealand data 2010-2015 (2015 report).

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

Potential contributing factors include:

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

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 23.

- That Māori have a different severity profile to other ethnic groups.
- Information about individual tamariki are collected at the time of first diagnoses[i].
- Some cases with audiometric datapoints 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[ii].
- 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[206]. However, more recently, coverage rates have fallen.

A number of viral infections can cause hearing loss, which can be congenital or acquired, unilateral or bilateral and is typically sensorineural[207], although mumps, for example, almost always causes single-sided deafness. Any reduction in the number of more severe cases due to meningitis is likely to be small.

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[208], 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[209, 210], and that those families with children who have cochlear implants are managing and promoting device use more than those with hearing aids[211].

Cytomegalovirus

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 the loss will continue to deteriorate[212]. 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 that is bilateral and moderate to profound in nature[88]. 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[213].

Minnesota (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 Aotearoa New Zealand blood donors in 2009. The highest prevalence was found among Pacific Islanders (93.2%) and the lowest in Caucasians (54.8%) [214]; and
- a recent analysis of cases of cCMV disease was conducted by Jeong utilising the National

i 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.

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

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[84].

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

Atresia and Microtia

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 Aotearoa 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 Health NZ | Te Whatu Ora. Once rangatahi reach adulthood they are eligible for the universal hearing aid subsidy, which is $1022.22 every six years.

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

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

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.

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 Ko Taku Reo. Implementation of changes proposed in the Wilson Report (2011) were completed in 2015, meaning AODCs 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.

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

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

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

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

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

B4 School Check: The B4 School Check is a 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.

Districts: These are organisations established to provide health and disability services to populations within a defined geographical area. The previous name for these organisations was district health boards, and these were disestablished in 2022 under the Pae Ora (Healthy Futures) Act 2022 and replaced with 19 districts in four Regions within Health NZ | Te Whatu Ora.

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 Taupo northwards until 2019. Since 2020, Ko Taku Reo has provided services nationwide, replacing van Asch and Kelston Deaf Education Centres.

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

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

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

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.

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;
- provide referrals via audiology; and
- 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.

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

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

Taupō southwards until 2019. Since 2020, Ko Taku Reo has provided services nationwide, replacing van Asch and Kelston Deaf Education Centres.

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