A Window on Disability

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Health Quality & Safety Commission
Te Tāhū Hauora

Cover artwork by Sasha Wells, Dunedin, 1986.

Sasha Wells is a Studio2 artist. Sasha likes to draw dogs and cats, using different colours to layer paint, pens, and coloured pencils. Sasha enjoys coming to Studio2 because it's fun – 'This is a picture of sleeping dogs.'

Studio2 is a creative studio space in Ōtepoti Dunedin, where disabled artists are supported to create artwork, experiment with a range of materials, and develop their own artistic styles and profiles.

Published May 2026 by Health Quality & Safety Commission Te Tāhū Hauora,

PO Box 25496, Wellington, 6146.

ISBN: 978-1-991122-44-5 (online)

Available online at www.hqsc.govt.nz

Enquiries to: info@hqsc.govt.nz

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Chapter 3

Life-course stage – Children and youth

This collection of life-course data is all about children and youth. Disability health experts shared that during the early years of a disabled child's life, a twin-track approach to health should lead to near-equitable health outcomes with non-disabled children. In a health setting, a twin-track approach means that a disabled person has access to, and choice between, both mainstream health services, as well as culturally aligned, disability-specific services, as well as choice to use either type of service.[32]

For disabled children and youth in particular, a twin-track approach should see them actively engaged with the wide range of public health initiatives targeting young children's health (such as dental and immunisation programmes), as well as paediatric care that is specific to their disability. However, disability health experts cautioned that as children age, challenges in accessing mainstream services start to emerge. Support for this trajectory comes from international evidence, which shows that the shift from paediatric to adult health care services is fraught. For example, it can involve poorly managed transitions, limited expertise in youth health among adult providers, loss of trusted paediatric relationships, and weak communication across adult care.[33]

The measures that we discuss for this life stage are immunisations, oral health, asthma, hospitalisations, unmet need and human papillomavirus (HPV) vaccinations.

A high-level summary of the findings

Broadly, the system appears responsive to disabled children. Before the COVID-19 pandemic, disabled children were vaccinated at similar rates to non-disabled children. It is likely that the pandemic led to some inequity, but we do not have data to support this. The IDI has to use older Census data, so we do not have information for babies born after the Census.[34] However, data for five-year-olds appears to support the suggestion that there has been a downturn in immunisation rates for disabled children – Māori and Pacific disabled children in particular.

Poor oral health is an early issue and recurs throughout the life course. Evidence comes from rates of dental hospitalisations for dental disease, which are higher for disabled children than for non-disabled children. Rates are higher again for Māori and Pacific disabled children.

Compared with non-disabled children, asthma in disabled children is less likely to be treated well, and higher rates of hospitalisation follow. Disabled children experience higher levels of potentially avoidable hospitalisations for different causes, including dental, gastroenteritis and constipation, than non-disabled children. Disabled children and young people, along with their whānau, report significant unmet need for primary care, assistive equipment, and medication.

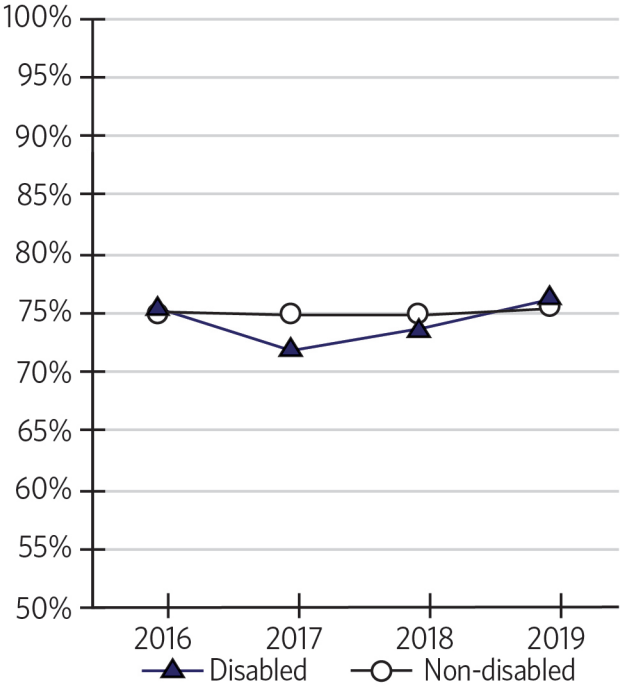
Immunisations for disabled children

Due to challenges in matching IDI data using the 2023 Census, data on the impact of the pandemic on disabled children's immunisation rates at six and 24 months is not available beyond 2019.

Reassuringly, available data indicates that immunisation rates for disabled and non-disabled children aged 6 months and 24 months were broadly comparable from 2016 to 2019, the most recent period for which disability-disaggregated data for young children is available (Figure 32 and Figure 33). However, other evidence, though not disaggregated by disability status, demonstrates that the COVID-19 pandemic had a significant negative impact on immunisation rates, particularly for minority, at-risk and marginalised communities.[35] [36] [37] [38] Given that intersectionality[39] has compounding effects, these findings raise concerns about immunisation uptake among young disabled children in the period following 2020, especially for those belonging to communities already experiencing disadvantage.

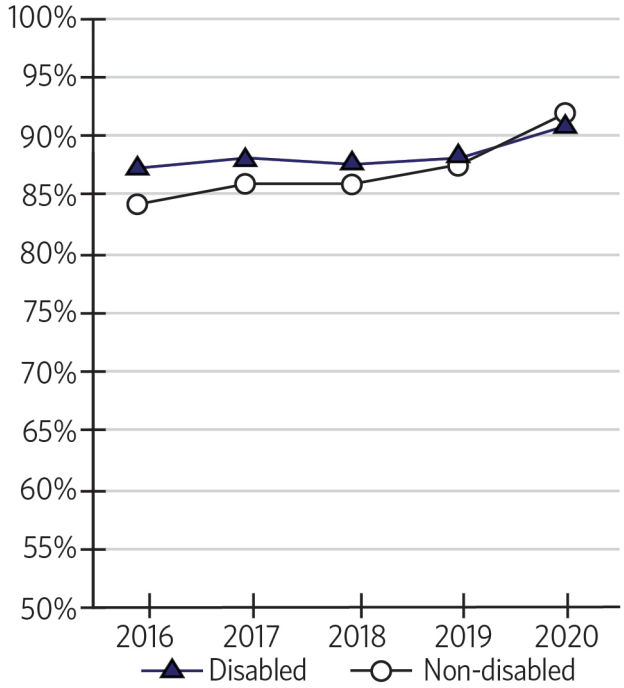
In summary, the years following the 2020 pandemic were characterised by impacts on immunisation rates affecting Māori and Pacific children especially. However, the impacts of the pandemic on immunisation of disabled children, and Māori and Pacific disabled children in particular, are not yet known.

Figure 32: Percentage of children fully immunised at 6 months, by disability status, 2016–2019



Source: IDI

Figure 33: Percentage of children fully immunised at 24 months, by disability status, 2016–2020

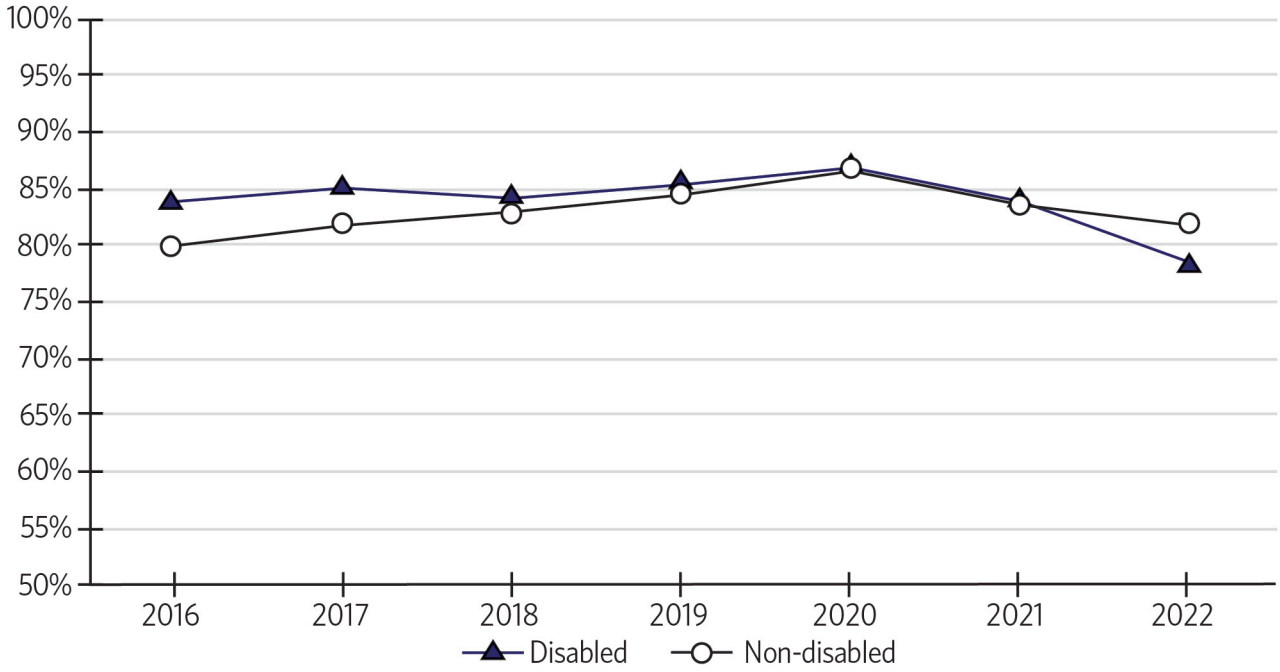


Source: IDI

However, by focusing on children who were at least five years old in 2022, it is possible to gain insights from analysing later data that incorporates the first two years of the pandemic.

At first glance, the recent dip in immunisation rates among five-year-old disabled children appears small (Figure 34).

Figure 34: Percentage of children fully immunised at five years, by disability status, 2016–2022

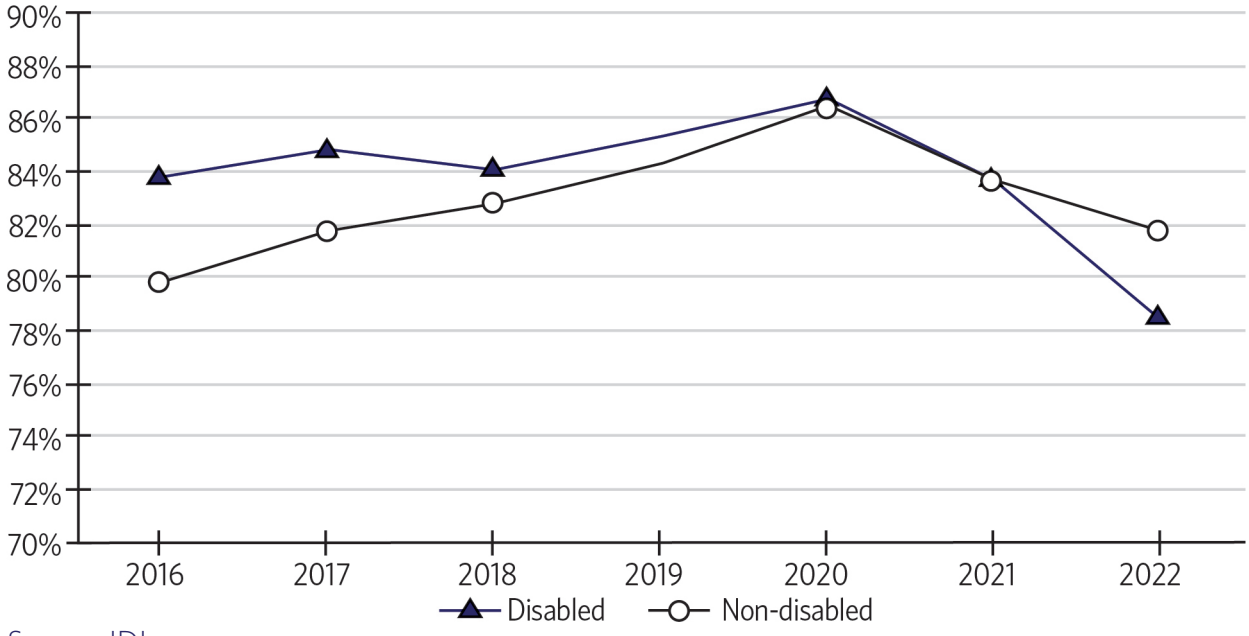


Source: IDI

However, looking closer, with a more fine-grained view of the percentages involved, recent trends are clearer and more alarming.

Following 2020, the pandemic appears to have affected immunisations for all children. However, the impact on immunisations for disabled children seems more powerful, with a drop of 9 percentage points in immunisations of disabled five-year-olds between 2020 and 2022 (Figure 35).

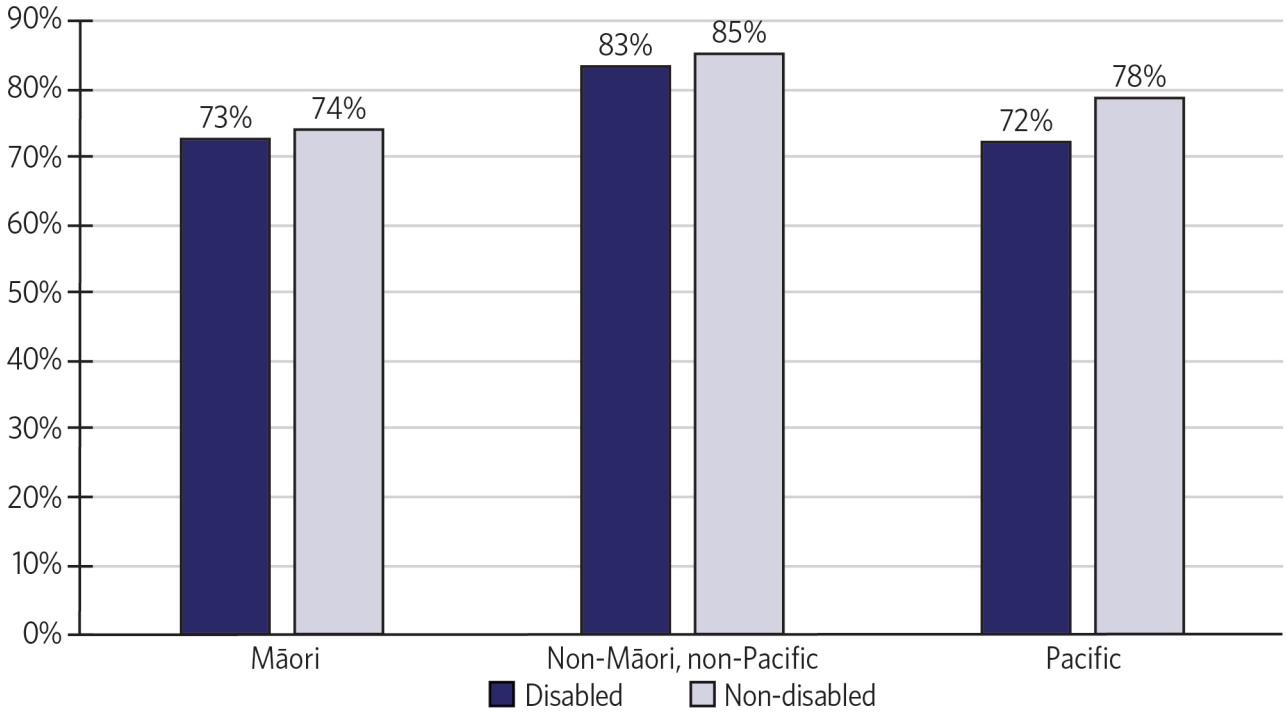
Figure 35: Percentage of children fully immunised at five years, by disability status, 2016–2022



Source: IDI

As of 2020, Māori and Pacific disabled children experienced the largest inequity, as compared with both non-Māori, non-Pacific disabled children and non-disabled children (Figure 36).

Figure 36: Percentage of children fully immunised at five years, by disability status and ethnicity, 2022



Source: IDI

Oral health in disabled children

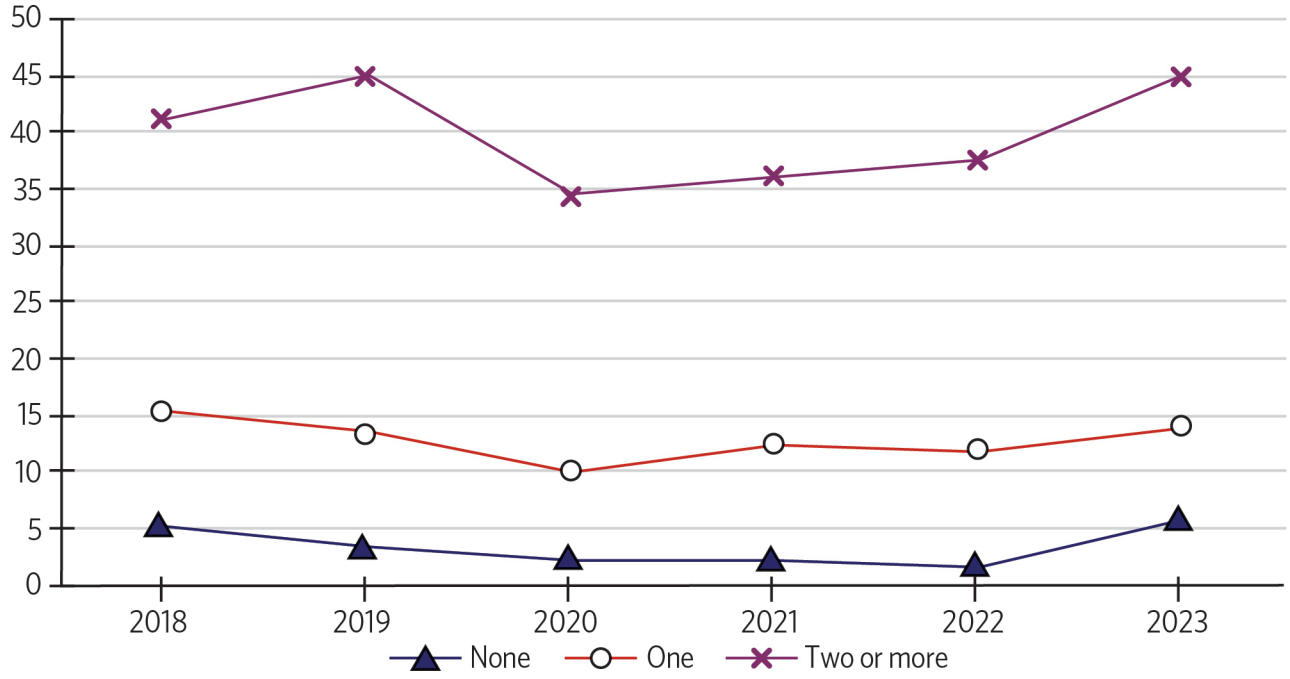
The next indicator investigated was the oral health of disabled children. The specific areas considered were decay that has worsened to levels requiring hospital care, rates of decay discovered in younger disabled children, and missed oral health checks for younger disabled children.

The hard end – hospitalisations of disabled children for dental issues later in life

Early decay contributes to significantly higher rates of hospitalisation for serious dental issues in disabled children and young people aged 5–18 years, particularly for those with two or more impairments. The hospitalisation rate of disabled children with two or more impairments approaches nine times higher than that of non-disabled children (Figure 37).

Note: These hospitalisations are counted using the ICD-10 codes for urgent dental issues, not routine services that may be difficult or unacceptable for some disabled people and are thus delivered in hospital. These urgent dental issues include dental caries, diseases of pulp and periapical tissues, gingivitis and periodontal diseases.

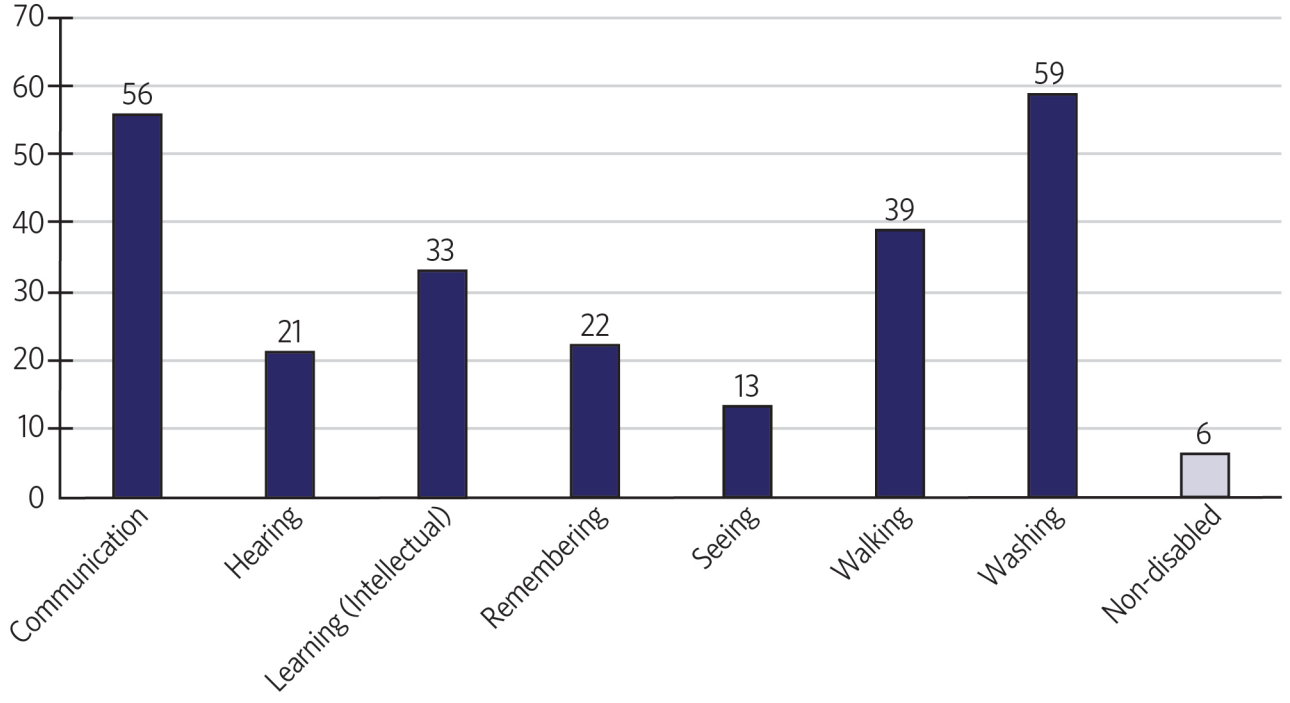
Figure 37: Rate of hospitalisations for dental surgery, per 1,000 population per year, ages 5–18 years, by number of impairments, 2018–2023



Source: IDI

Children and young people with communication and washing impairments are the most affected by dental hospitalisations (which occurred at more than 10 times the non-disabled rate in 2023). The groups that are second highest in representation in rates of hospitalisation for dental surgery are children with walking and learning (intellectual) impairments. Learning (intellectual) disability data was available from a different dataset (Figure 38). All of these differences from non-disabled children and young people were unlikely to be due to chance in 2023.

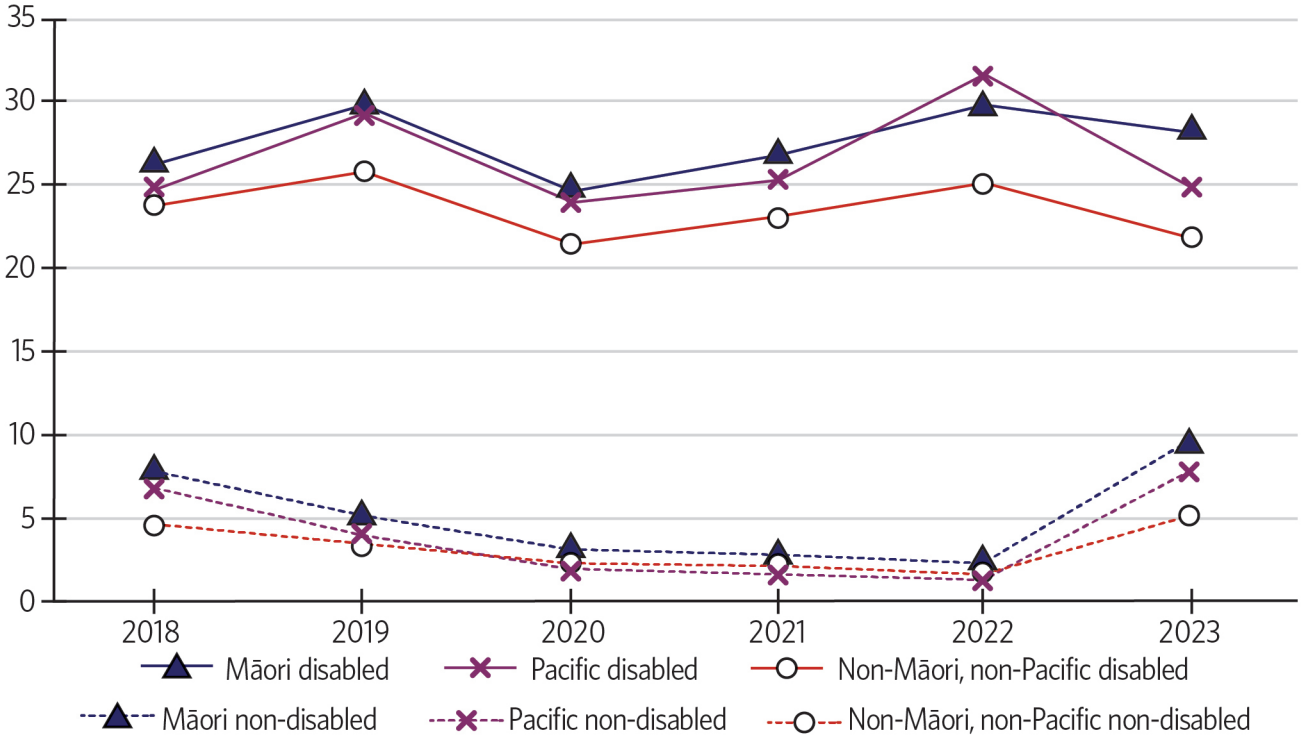
Figure 38: Rate of hospitalisations for dental surgery per 1,000 population, ages 5–18 years, by WG-SS disability domain, 2023



Source: IDI

The intersection of disability and ethnicity also impacted dental hospitalisations. For example, Māori and Pacific disabled children and young people were more likely than other disabled and non-disabled groups to have dental issues so severe that they required hospital treatment (Figure 39).

Figure 39: Rate of dental surgeries per 1,000 population, ages 5–18 years, by ethnicity and disability status, 2018–2023



Source: IDI

Dr Michael Brosnan

Paediatric Dental Specialist, BDS MDentSci FRC, Paediatric Dentistry, Waikato Hospital

Neurodivergent children, as well as children with special needs and complex medical conditions, meet the acceptance criteria for oral health care at the Specialist Dental Unit at Waikato Hospital.

Due to limited staffing and limited access to theatres, we have a long wait time to be seen at our unit. This tends to result in acute episodes of pain and infection for some of our children.

This is frustrating for whānau and oral health care staff alike. A child with high needs deserves a ring-fenced service separate from non-disabled children. We aim to do this as much as possible but wait times and access to resources greatly impact dental staff and whānau. ■

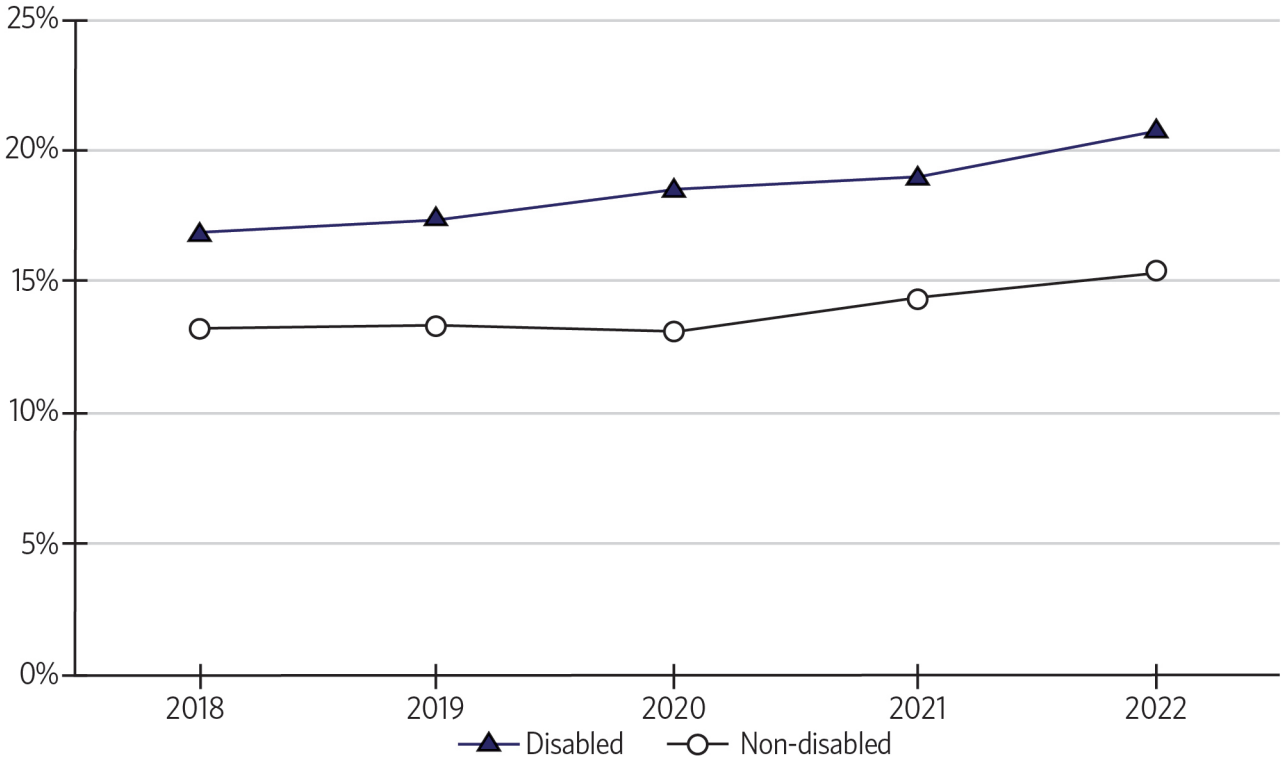
Rates of tooth decay in disabled children

The B4 School Check (B4SC) is a nationwide programme offering a free health and development check for four- to five-year-olds.[40] It aims to identify and address health, behavioural, social and developmental concerns, such as hearing problems or communication difficulties, that could affect a child's ability to get the most benefit from school. It includes checks for general health and development, height and weight, teeth, social and emotional wellbeing, and immunisation status.

B4SC dental checks are commonly referred to as 'lift the lip' tests. Children's teeth are given a score from 1 to 6. A score of 1 means no decay, while scores of 2 to 6 are considered concerning.

In 2022, one-fifth of younger disabled children who received their dental checks had tooth decay already. Between 2018 and 2022, the percentage of disabled children who had dental decay was consistently higher – by almost 5 percentage points – than non-disabled children even at the age of 4–5 years (Figure 40).

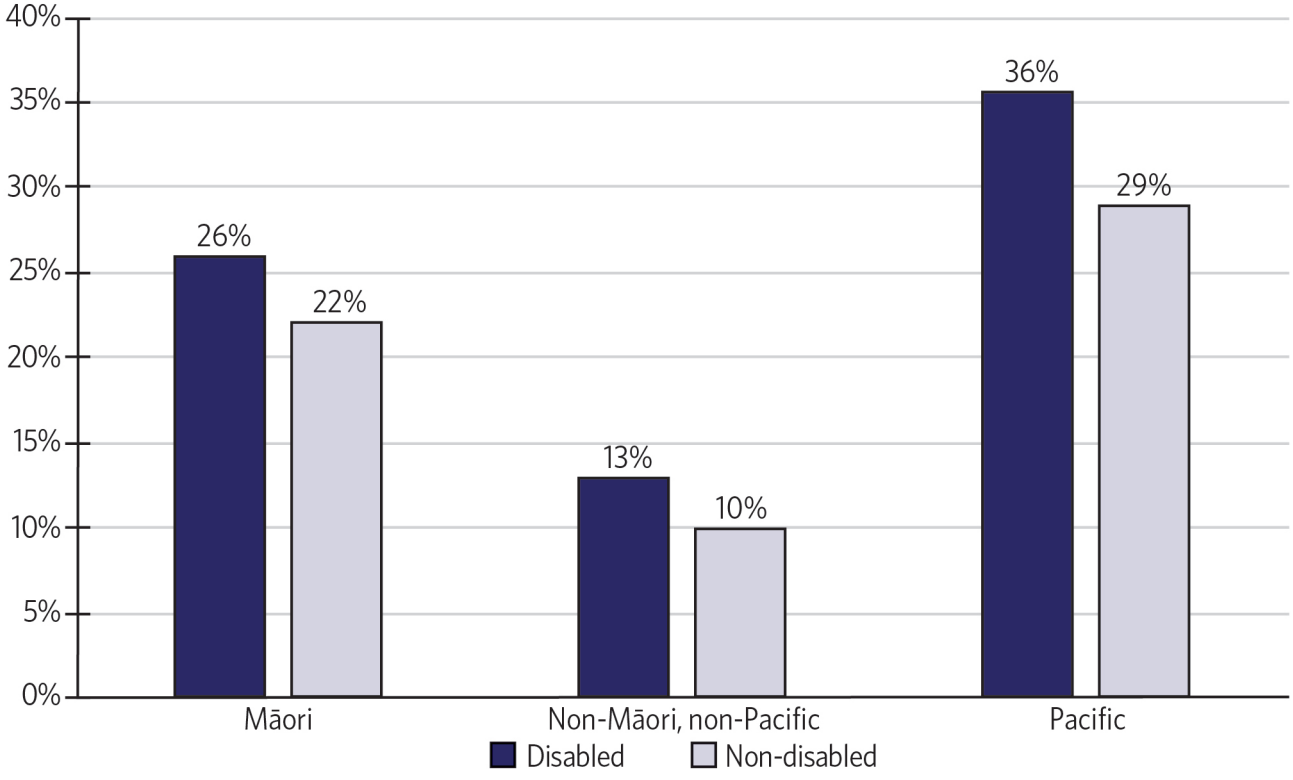
Figure 40: Percentage of children with scores of 2–6 (more tooth decay) on the 'lift the lip' dental decay test at B4SC, by disability status, 2018–2022



Source: IDI

A quarter of Māori disabled children and more than a third of Pacific disabled children (nearly three times the percentage of non-Māori, non-Pacific disabled children) had tooth decay detected at their B4SC (Figure 41).

Figure 41: Percentage of children with scores of 2–6 (more tooth decay) on the 'lift the lip' dental decay test at B4SC, by disability status and ethnicity, 2022



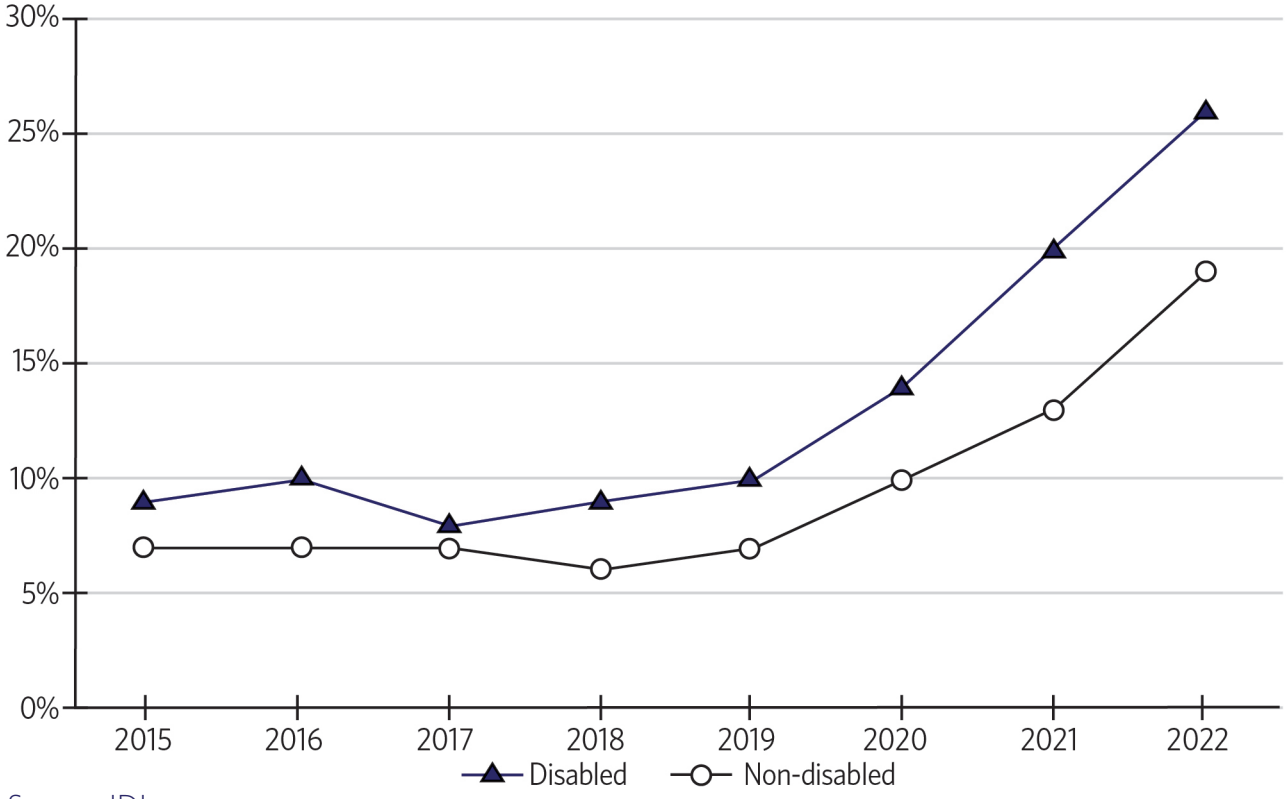
Source: IDI

B4 School Check

Data shows that, historically, a higher percentage of disabled children than non-disabled children miss their B4SC dental checks. In addition, both the percentage missed and disparity with non-disabled children have risen since the pandemic. By 2022, one in four disabled children did not receive their dental check, compared with one in five non-disabled children (Figure 42).

The data on preventative health care must be viewed with caution. B4SC clinicians may refer many disabled children directly to specialist or hospital care without first performing a check, so those referred, while potentially getting appropriate care, will be counted as having no B4SC here.

Figure 42: Percentage of children with no recorded B4SC dental check, by disability status, 2015–2022



Source: IDI

Even allowing for variations on the referral process, disability clearly affects B4SC checks. The percentages of missed checks were analysed by disability domain and ethnicity, but it was not possible to make any consistent statistically significant interpretations with confidence. That is, the data was not strong enough to confirm any relationships between B4SC, disability and ethnicity.

It has also been suggested that the B4SC may not be the best solution to strategies for prevention of dental decay in disabled children, and in particular for children with learning (intellectual) disability.

One example comes from a 2025 population-based cohort study that linked records of hospital dental admissions with records of caries experience among children with neurodevelopmental disabilities (NDD). It found higher hazard ratios for the presence of caries and for hospitalisation. The authors conclude:[41]

> Targeted preventive strategies and adaptation to primary oral health services are needed to meet the needs of neurodiverse children and redress this substantial inequity. However, targeting children with NDDs at the B4SC is unlikely to mitigate these oral health inequities.

As disability health experts note, a range of intersecting factors shape poorer dental outcomes among disabled children. These factors include the effects of medications, dietary restrictions, sensory sensitivities, communication, socioeconomic disadvantage, limited access to accessible information, and, in some cases, the nature of the impairment itself. In more medically complex cases, clinicians may also be reluctant to intervene until treatment is unavoidable, particularly where sedation is required. This raises critical questions for the public health system.

- How should it respond to the complexity and diversity of disabled children's dental needs?
- What would an effective twin-track approach look like in practice?

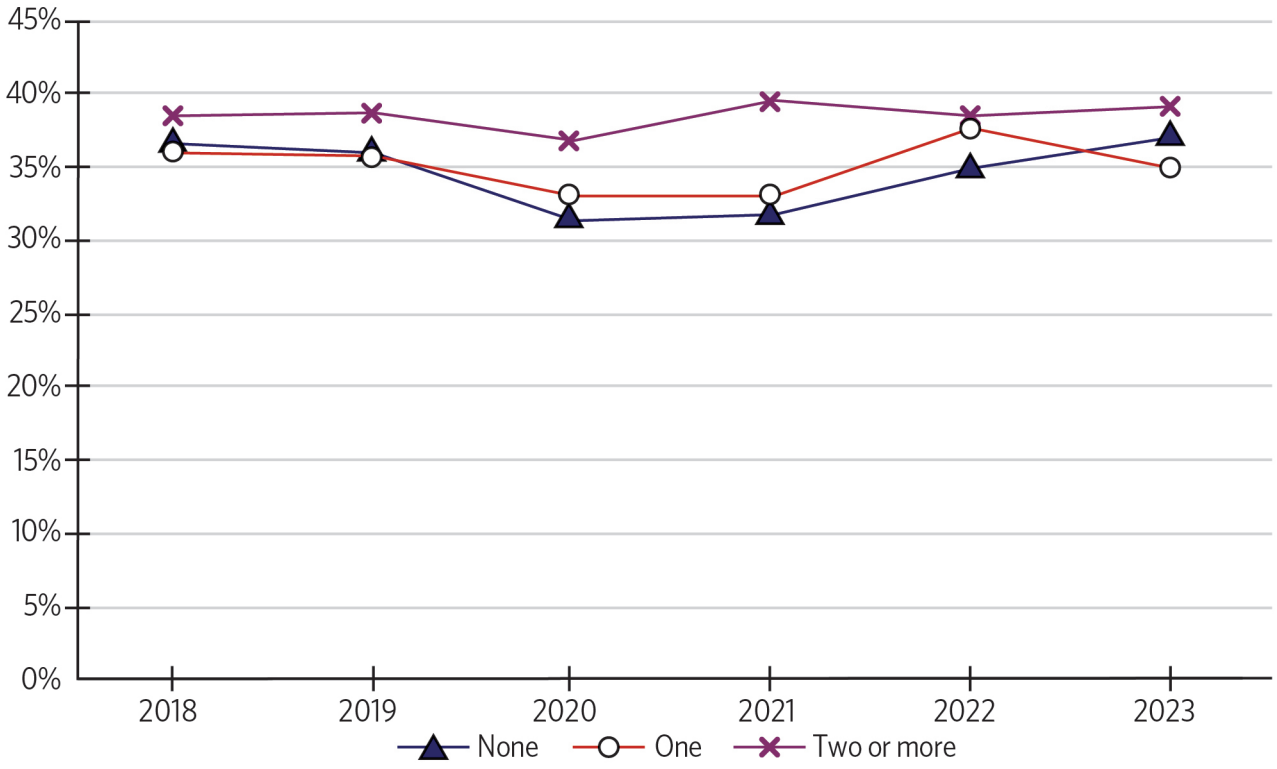
Asthma in disabled children – management and hospitalisations

Management of asthma – children whose asthma is not managed well

The next indicator analysed for this life-course stage was disabled children's experience of asthma. Good management of asthma should involve little use of SABA (reliever) medication and regular use of preventers.[42] (A combined treatment is now available, but only became so after the period our data covers. [43]) However, some disabled children are only dispensed a reliever, indicating they may be receiving less than optimal asthma management.

Among non-disabled children and disabled children with one impairment, the percentages of those not optimally managed over time are similar. In contrast, those with two or more impairments are much less likely to receive optimal management than non-disabled children – by a difference of between 5 and 8 percentage points. That is, as the number of impairments a disabled child has increases, so too does the likelihood that they are not receiving optimal asthma care (Figure 43).

Figure 43: Percentage of asthma patients who were dispensed a reliever but not a preventer in at least two quarters of the year, ages 5–18 years, by number of impairments, 2018–2023



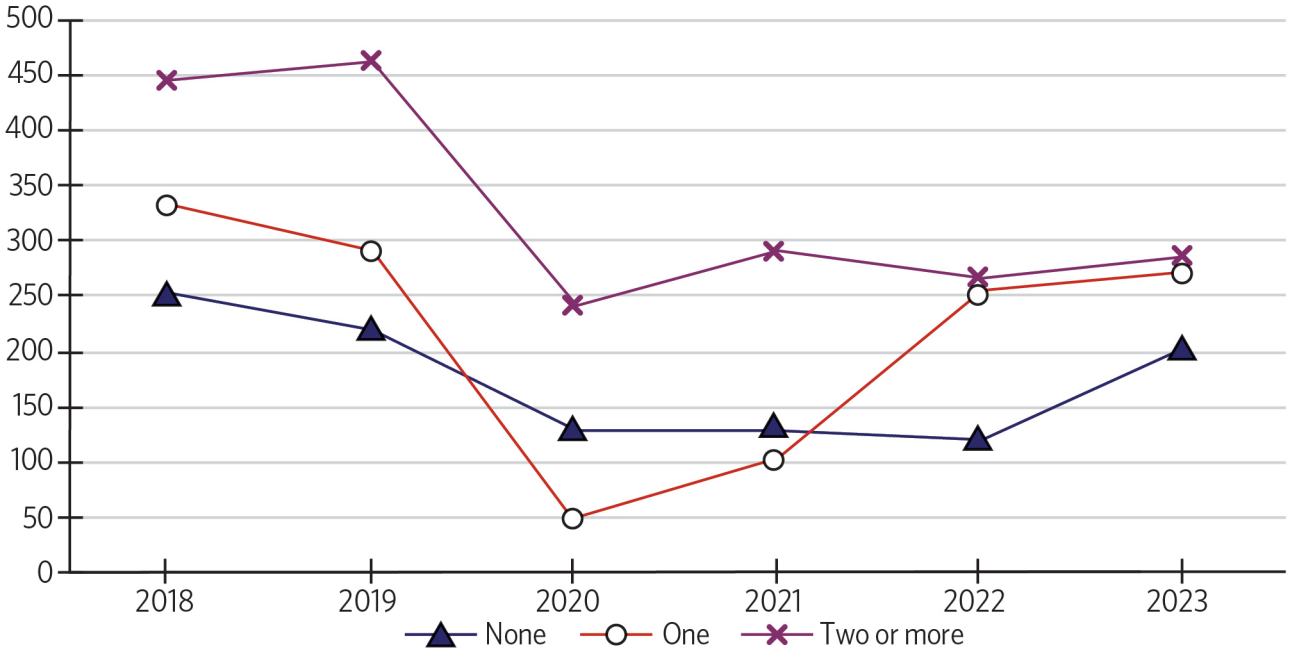
Source: IDI

While the differences are small, they suggest that clinical decision-making may differ for disabled children with multiple or complex impairments. In reflecting on these patterns, disability health experts pointed to research indicating that marginalised populations, such as Māori, are at times assumed to be less likely to engage with preventative care and, as a result, are less likely to be offered preventative interventions.[44] However, targeted research is required to better understand clinical decision-making processes and their implications for equity in health care.

Hospitalisations of disabled children for asthma

Disabled children with one impairment who were aged 5–18 years had a higher hospitalisation rate for asthma than non-disabled children (with the exception of the first two years of the pandemic). Consistently, even during the height of the pandemic, disabled children with two or more impairments had a higher rate of hospitalisation for asthma (Figure 44).*

Figure 44: Hospitalisation rate for asthma per 100,000 population, ages 5–18 years, by number of impairments, 2018–2023

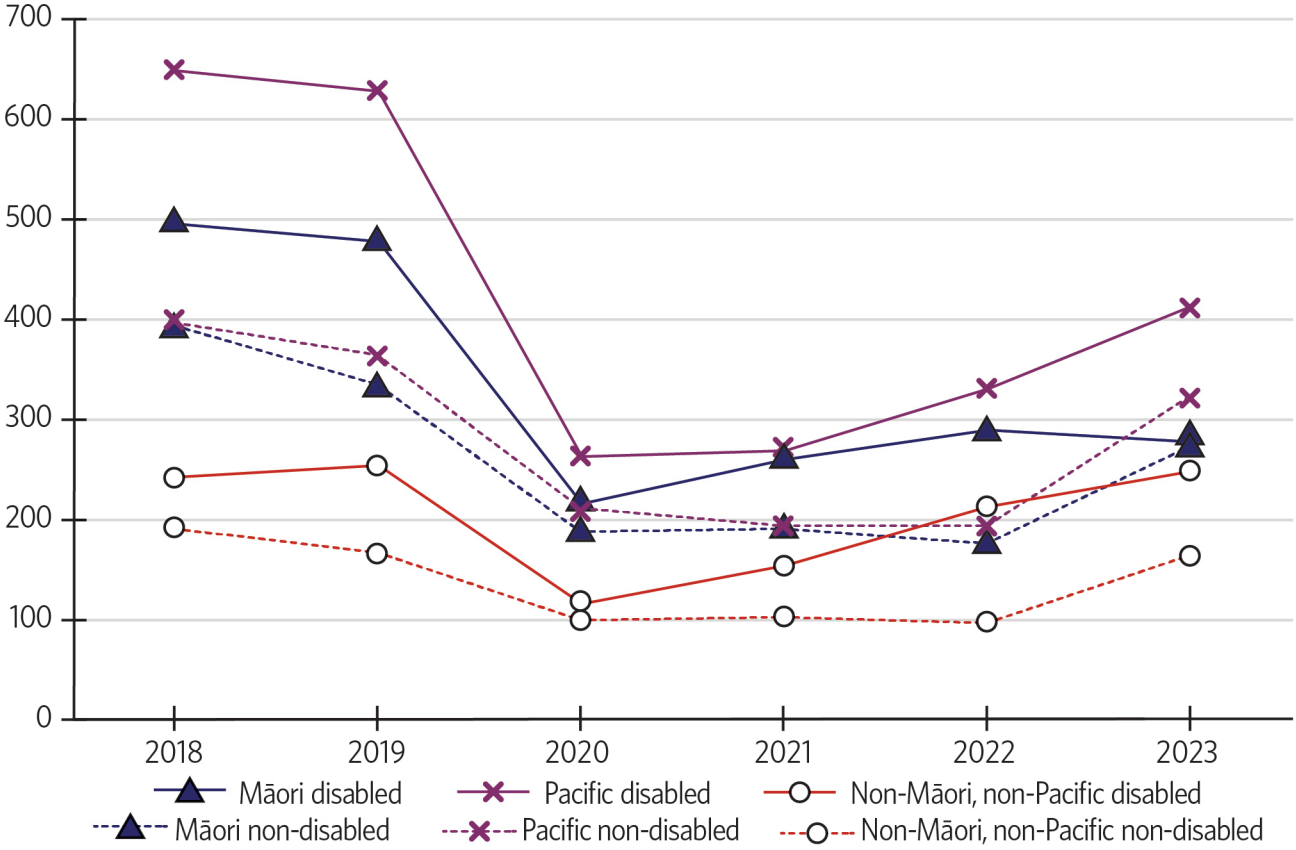


Source: IDI

From 2018 to 2023, Māori and Pacific disabled children had higher rates of hospitalisation for asthma than disabled children of other ethnicities. The dips for all groups in 2020, as shown in Figure 45, coincide with decreases in respiratory illnesses associated with pandemic restrictions.

* Some data suppressed due to small numbers for those 5 to 18 year olds with one disability for 2020 and 2021. The true hospitalisation rate for this group will be higher than shown here.

Figure 45: Hospitalisation rate for asthma per 100,000 population, ages 5–18 years, by ethnicity and disability status, 2018–2023



Source: IDI

There is progress. A 2024 study, which included Māori disabled people, found a 32% reduction in asthma hospitalisations among Māori aged 12 and over between July to December 2023 and July to December 2019. This compares to a 23% reduction for non-Māori.[45]

Dr Matire Harwood (Ngāpuhi), a co-investigator on the study and a GP, commented on the importance of these findings:

> "The substantial drop in asthma hospitalisations for Māori demonstrates the impact of equitable access to optimal care. However, the persisting inequities remind us of the urgent need to address the root causes of these health disparities. Solutions that empower Māori—through accessible, culturally safe care and systemic change—will help create sustainable improvements in respiratory health outcomes."[46]

Children and ASH

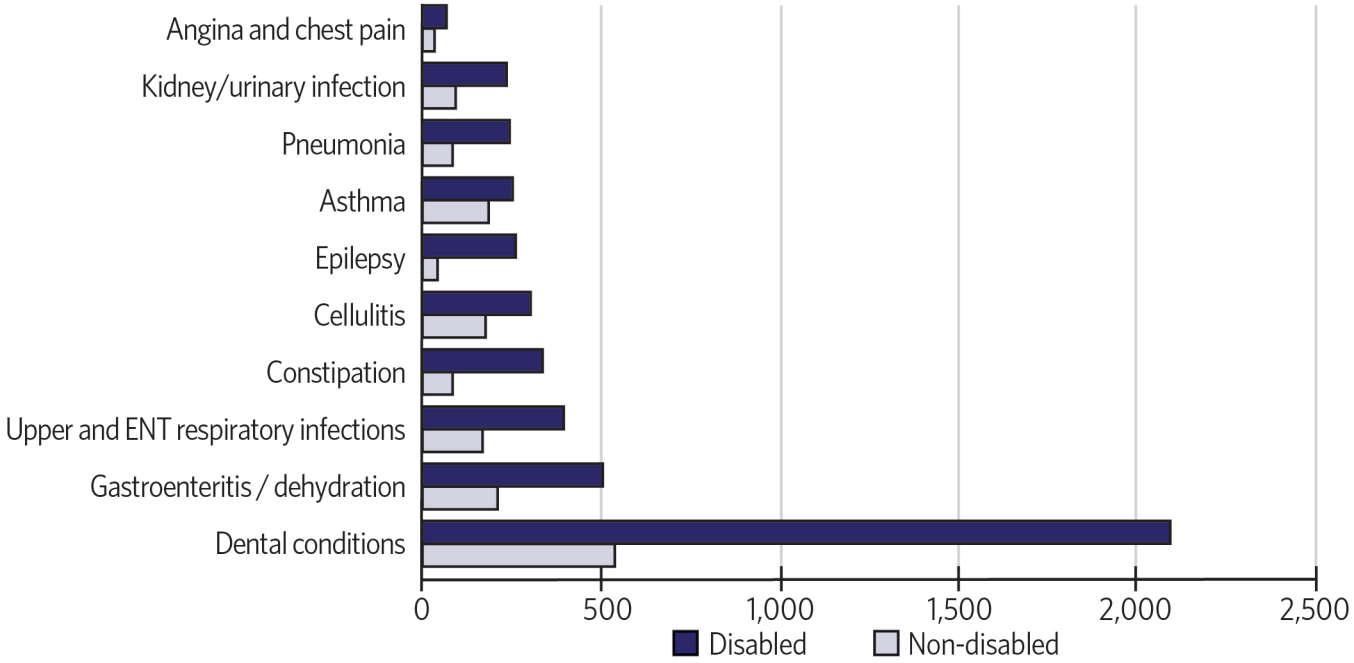
Ambulatory sensitive hospitalisations (ASH) here measure hospitalisations of disabled and non-disabled children aged 5–18 years for conditions that could be managed in primary or community care.

For disabled children, the data on the top five conditions for hospitalisation that could be treatable in primary care is markedly different from that for non-disabled children. Notably, their ASH rates are much higher than for disabled children, and some of the conditions in the top five differ between the two groups.

As Figure 46 shows, dental hospitalisations are the dominant reason for both groups but disabled children were hospitalised at nearly four times the rate of non-disabled children. Gastroenteritis/dehydration was the second most common reason (where ASH for disabled children was more than double the rate of non-disabled children). The remaining conditions in the top five for disabled children were:

- upper and ear, nose and throat (ENT) respiratory infections (again, with disabled children at more than double the rate of non-disabled children)
- constipation (not in the top five for non-disabled children, while the rate for disabled children was more than four times higher)
- cellulitis (with disabled children more than one-and-a-half times the rate of non-disabled children).

Figure 46: Ten ASH conditions with highest rates per 100,000 population, ages 5–18 years, by disability status, 2023



Source: IDI

Children, disability and unmet need

In the New Zealand Household Disability Survey, unmet need refers to situations in which a disabled person requires a health- or disability-related service or support but does not receive it, or does not receive enough support to meet their needs. In the 2023 Household Disability Survey, disabled children consistently report high levels of unmet need. When a disabled child experiences unmet health professional, medication and assistive equipment need, the consequences for their health, development and wellbeing can be significant.

Unmet need for health professional service

A third (33%) of disabled children aged 0–14 years reported an unmet need to see a health professional in the past 12 months,[47] as compared with 28% of disabled people 15 and over.

Unmet need for medication

More than one in ten (12%) of disabled children aged 0–14 years reported unmet need for medication in the last 12 months.

Unmet need for assistive equipment[48]

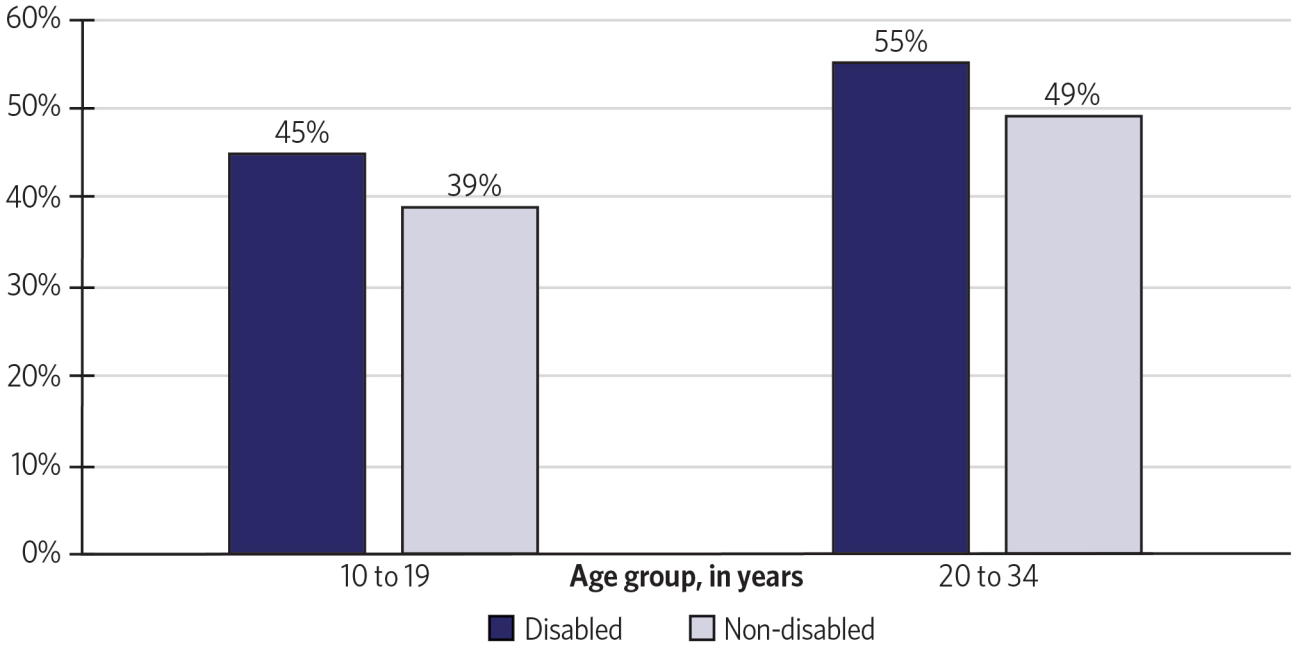
Nearly half (46%) of disabled children aged 0–14 years use assistive equipment or technology, but 35% reported unmet need for assistive equipment and technology.

Youth – human papillomavirus (HPV) vaccinations

Data related to older disabled children and young people is sparse, but data regarding vaccinations was again a useful source of information on the health of disabled young people. The Ministry of Health recommends HPV vaccination and funds it on the National Immunisation Schedule for children and young people aged 9–26 years. A school-based vaccination programme is available in most areas. The incidence of genital warts has decreased by 75% since the vaccine became available in New Zealand in 2008. The vaccine is 'highly effective' in preventing infection with the most common types of HPV, including variants of the virus associated with oral and genital cancers (including cervical cancer).[49]

HPV immunisation rates are low. Younger disabled females (aged 10–19 years) were 6 percentage points more likely to be immunised against HPV than non-disabled females in the same age group in 2023. Disabled women aged 20–34 years were also 6 percentage points more likely to be immunised against HPV than non-disabled females in their age group (Figure 47).

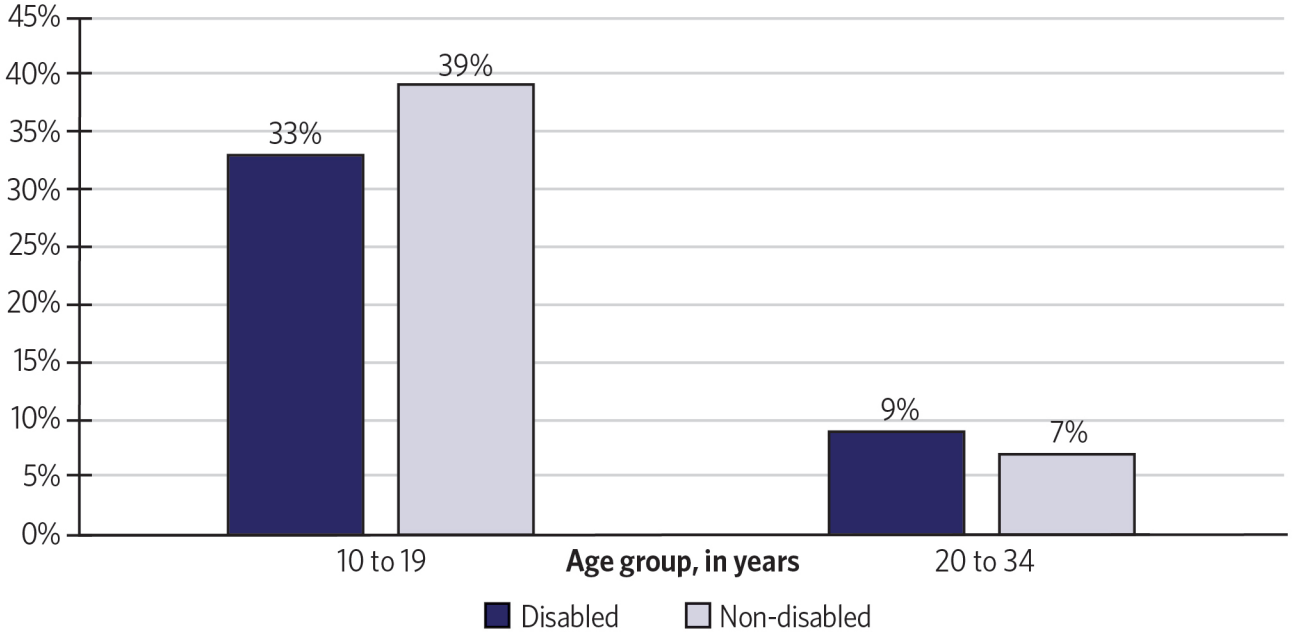
Figure 47: Percentage of eligible females fully vaccinated with HPV vaccine, ages 10–19 and 20–34 years, by disability status, 2023



Source: IDI

In 2023, younger disabled males were 6 percentage points less likely to be immunised against HPV than non-disabled males (Figure 48).

Figure 48: Percentage of eligible males fully vaccinated with HPV vaccine, ages 10–19 and 20–34 years, by disability status, 2023



Source: IDI

While at first glance these findings appear positive, particularly for younger disabled women and disabled women, international research provides important context.

With regard to young males, research consistently shows they are much less likely to receive the HPV vaccine than young females.[50] This gap is even larger for young disabled males. A recent population-based survey indicated that the parents of disabled boys often know less about HPV and its vaccine, and vaccine providers, such as doctors, are less likely to recommend it to them compared to the parents of girls.[51] This pattern has been attributed to a lack of awareness about HPV vaccination among young disabled males, their families, and healthcare providers.[52]

In contrast, research consistently has shown that disabled females experience more sexual abuse and victimisation,[53] but have less access to sex and sexual health knowledge and education.[54] These factors may partly explain the higher rate of HPV vaccination for young disabled females in New Zealand, with parents and close supporters, and vaccine providers responding to these risks by becoming more vigilant in seeking and recommending HPV vaccination. However, further targeted research is needed to understand these differences within the New Zealand context.

When faced with these early inequities in young people's lives and health care, we should emphasise that the WHO's recommendation on adolescent health applies equally to disabled young people as well as those who are non-disabled:

> "To grow and develop in good health, adolescents need information ... health services that are acceptable, equitable, appropriate and effective; and safe and supportive environments. They also need opportunities to meaningfully participate in the design and delivery of interventions to improve and maintain their health. Expanding such opportunities is key to responding to adolescents' specific needs and rights."[55]

Kimberly and Finlay's story – the transition from paediatric to adult care

Kia ora, I'm Kimberly Graham, and this is my son Finlay Butcher. For nearly 21 years, we've navigated life together with love, determination, and the complexities that come with high and complex needs. We also share a deep love of travel, using our adventures to show what access and inclusion can look like for families like ours. As Finlay enters adulthood, we're facing a transition many will recognise. Here's what this looks like for us.

Our experience is similar to what many other parents and young people go through during this transition phase. In my view, the challenges are widespread and affect almost every area – education, respite services, equipment clinics, therapists, medical supplies, and hospital or allied health specialists. Instead of the steady, familiar support we used to have from long-term paediatric specialists, every service now seems to require constant and persistent advocacy.

A major turning point happens when the paediatrician discharges a young person from their care. Families often find themselves in a service gap at that point. For example, when we were under hospital-based paediatric specialists, our prescriptions were covered. Now, we have to pay to see our GP for appointments and prescriptions, which adds a financial strain.

We also faced a long delay before my son could see his adult neurologist at Greenlane Hospital, almost a year after leaving paediatric services. During that time, his seizures and spasms worsened, and we had to return to Starship Hospital to speed up an appointment so his medication could be reviewed. Since that first visit, we've seen the adult neurologist only once, and it's now been almost another year with no follow-up. These long gaps between appointments create unnecessary risk for people who need ongoing neurological care.

The wheelchair clinic process has also been extremely slow. Often, by the time the assessment and fitting process is finished, the equipment no longer matches the person's needs. While this isn't only a transition issue, it's even harder for adults who are no longer regularly reviewed by occupational therapists. Without consistent monitoring, postural problems can get worse, leading to more health complications and putting all the advocacy back on families.

Continued over

We've also had problems with getting essential medical supplies. Under paediatric services, my son's feeding supplies arrived at our home on time and were always correct. Now, through Adult Community District Nursing, the deliveries are often missing important items. This means we have to go to the community health centre to pick up the rest, which adds stress and inconvenience.

Another concern is the limited understanding of high and complex needs at our local hospital. When my son was under paediatric care, he was always taken to Starship Hospital, where the staff were experienced with complex cases. Now, we must go to North Shore Hospital, which doesn't seem to have the same level of specialist expertise. This creates a lot of anxiety about the quality of care he'll receive in an emergency.

There's also a major gap when school-based supports end. My son will finish school at the end of the year, which means he will no longer receive regular physiotherapy, speech-language therapy or occupational therapy. We chose his specialist school specifically for the consistent access to therapies that mainstream schools couldn't offer. Losing this support leaves families unsure about the next steps.

When we were with Starship and the school system, my son's dental health was regularly monitored. Since leaving paediatric services, that oversight has dropped off, with fewer checks or referrals.

Adult community therapy services – nursing, physiotherapy, speech-language therapy, dietetics and occupational therapy – are available, but only on an as-needed basis. There are no regular reviews or proactive follow-ups.

Overall, this transition shows the lack of continuity between child and adult services and highlights the need for structured, accessible and ongoing support for young people with high and complex needs. ■

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