A Window on Disability

New Zealand Government
Te Kāwanatanga o Aotearoa

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

New Zealand Government
Te Kāwanatanga o Aotearoa

Chapter 1

Disability, data and what we can know

Who is disabled in New Zealand?

The answer depends heavily on what questions are asked.

The New Zealand Census identifies disabled people using six domains of functional difficulty, known as the Washington Group Short Set on Functioning (WG-SS).[2] These domains are: seeing, hearing, walking, washing, remembering and communicating. If someone responds that they have a lot of difficulty doing one or more of these things or cannot do them at all, they are counted as "disabled". In the last Census, this approach identified that 5% of New Zealanders are likely to be disabled.

However, many disabled people do not view or experience disability in these ways. A short history of the distinctive ways in which we have counted disability in New Zealand is available at Appendix 1.

In 2023 Stats NZ ran the first Household Disability Survey in ten years.[3] The Household Disability Survey received 21,636 successful responses from a group of 25,000 people carefully selected from the Census to provide accurate estimates for key population groups who are typically undercounted: disabled, Māori, Pacific and others. While it has a smaller number of participants than the Census, the Survey has more, better and deeper questions about disability and impairment.* It also asks about fourteen, rather than six, domains.

The Household Disability Survey estimated that, in 2023, 17% of New Zealanders were disabled. This is a better, more comprehensive estimate of the prevalence of disability, and is the approach recommended by Stats NZ for these purposes. The 17% figure represents more than one-sixth of the population, and equates to 851,000 people, or 98,000 children and 753,000 adults.

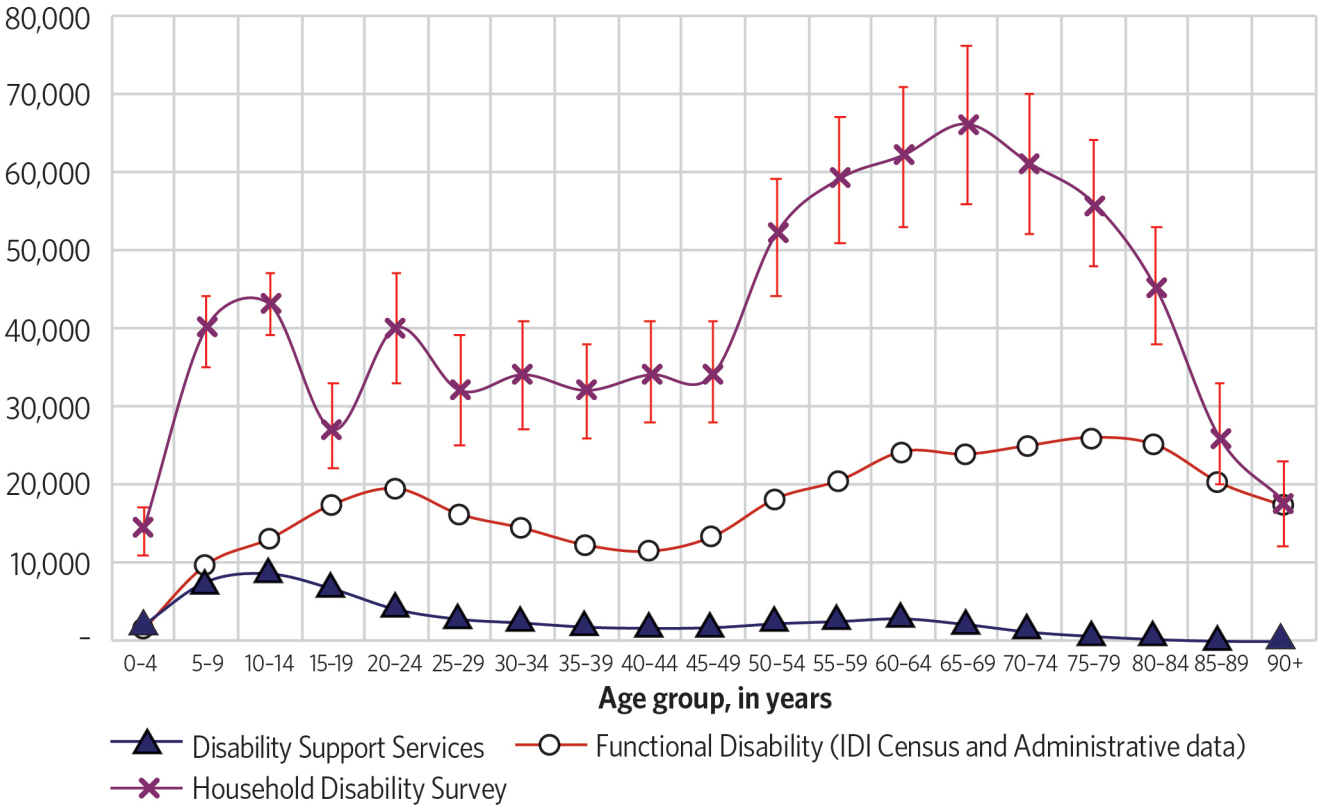
So there are the Census and Survey findings, and we also know that 51,500 people received Disability Support Services in 2023, representing less than 1% of the population.

* As reflected by the social and rights models of disability, 'disabled' and 'disability' are terms that have been used throughout this report when referring to individuals and communities that are disabled by socially constructed barriers. 'Impairment/s' is used when referring to one or more impairments that a disabled person lives with.

Figure 1 compares the measures of disability, showing how they differ depending on the questions asked and who was included. This graph compares the number of people in each age group who meet the criteria for the 2023 Household Disability Survey, who were determined to have functional disability using IDI sources, or received Disability Support Services in 2023.[4]

It demonstrates the extent to which disability data is affected by the questions asked, when they were asked and how they were asked, as well as who was asked the questions.

Figure 1: Disabled population from the Household Disability Survey (estimate), people who receive Disability Support Services and people identified as disabled within the Integrated Data Infrastructure (IDI), 2023



Source: IDI

The genesis of disability is also important.

In New Zealand, disabled people's health must be understood within the context of disability supports and service systems that are complex, restrictive, inaccessible, underfunded and often difficult to navigate.[5] These structural barriers are most starkly illustrated by differences in entitlements and resourcing based on the cause of a person's impairment – the Ministry of Health funds health-related and congenital disabilities, while the Accident Compensation Corporation (ACC) funds disabilities resulting from injury or accident.

Although there is a lack of comprehensive comparative data, available evidence highlights substantial inequities. For example, in its Briefing for Incoming Minister in 2017, the New Zealand Artificial Limb Service Peke Waihanga estimated that 'ACC patients on average get access to 214% more services and technology than a DHB patient.'[6] As it further stated in its 2023 Briefing for Incoming Minister:

> Having two different national prosthetic contracts presents significant health and safety risks. For the ACC artificial limb service, amputees receive an optimised prosthetic prescription and rehabilitation plan, while the Te Whatu Ora prosthetic service is bulk-funded and increasingly underfunded i.e. Te Whatu Ora funding has not increased despite the increase in amputees and the complexity of their care. This situation imposes suboptimal outcomes for patients and ongoing stress for staff.[7]

This disparity between support provided by ACC versus that of Health New Zealand | Te Whatu Ora is not limited to amputees. It is experienced across the disability community and has a direct and enduring impact on disabled people's health outcomes, safety and overall wellbeing.

Disability is almost invisible in our health care data

So the ways we count who is disabled are important. The first Window on Quality report was published in 2015 and the series has grown since then. We are usually able to rely on large, robust, national-level data sets to understand and tell a story about the quality of New Zealand's health care.

The large data sets we often rely on include the National Non-Admitted Patients Collection (NNPAC) and the National Minimum Dataset (NMDS). These data sets collect administrative data on hospitalisations, emergency department presentations and other publicly funded service interactions. They are used to understand service use and, often, quality of care. They do not collect people's disability status. In our Window reports, we also use other smaller, routinely and consistently collected data sets such as the Maternity Clinical Indicators, which tell us how well our maternity services are doing. We can examine these data sets to assess results by different ethnic groups, age groups and parts of the country. But they too do not collect disability status.

Every New Zealander who interacts with our health system has a National Health Index (NHI) number. The NHI is the unique identifier we use to make sure we have an up-to-date record of important information health care providers need, like contact details, but also information that is important for monitoring the quality of our health services such as information about on someone's gender and ethnic identity. The NHI does not record whether a person is disabled or what disability-related accommodations from health services they might require.

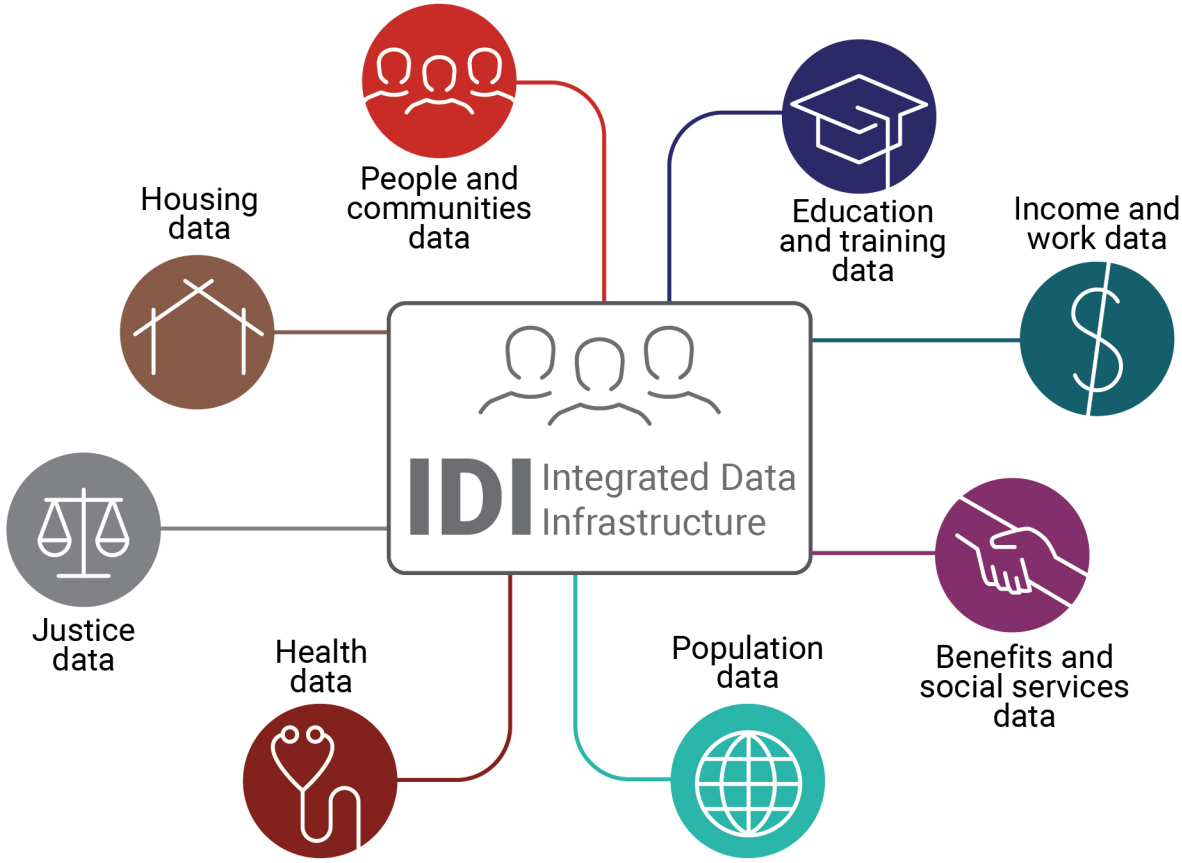
As a result of these limitations, this has been the hardest report to compile of all the Window on Quality series yet, because our usual ways of understanding the quality of New Zealand's health care exclude disability. We don't know from these usual sources who is disabled or what their health care is like.

So, what did we do? Innovative approaches to data

In New Zealand, we have something called the Integrated Data Infrastructure (IDI).

The IDI is an innovative data solution for connecting different, disconnected data sets. It is like a spine, or the trunk of a tree, providing a connection point for multiple data sets from different sources, including health care. These different data sets are like the branches while the IDI is the connection point, enabling the branches to be linked and used to tackle questions that have previously gone unanswered (Figure 2).

Figure 2: The Integrated Data Infrastructure (IDI)



Source: Stats NZ

All data in the IDI is de-identified, meaning information like names, dates of birth, and addresses has been removed. Any numbers that are used to identify people, like Inland Revenue Department (IRD) and NHI numbers, are encrypted (replaced with another number). Experts who undertake data analysis using the IDI also do so in closed labs. These labs are not connected to the internet, and no materials can be brought in or sent out until results pass through a formal, two-week process during which Stats NZ checks them. The checking process ensures no identifying information is accidentally included, and no errors have been made.

What the IDI allows us to do is see a cohort of people identified in the Census and administrative data as disabled, and connect that set with other data sources, like the usual ones we use to understand quality of care. In this way, we can compare disabled people's health care outcomes with those of non-disabled people.

But what of the Census disability estimate of 5%, and the well-documented undercounting of disabled Māori, Pacific and other marginalised communities? This question has been carefully considered throughout the development of this report, given the potential implications for health policy and practice. Following extensive discussion with disability health experts and data scientists, a consistent conclusion emerged: the primary focus of this Window report is not to establish the precise prevalence of disability, but to compare the quality of care experienced by disabled and non-disabled people. Crucially, these comparisons remain consistent across data sets, regardless of which disability prevalence estimates are used.

For this Window report, we have taken the approach of using the Household Disability Survey for a more accurate estimate of the actual numbers of disabled people, and using the Census through the IDI to compare their outcomes with those of non-disabled New Zealanders. As recommended by Stats NZ,[8] although this approach is imperfect, it is the best we have at this point in time.[9]

What this report does

In this introductory chapter, we describe the difficulties of data on disability in New Zealand, our approach, and a quick, high-level view of disabled people's use of health care.

In the following chapters, we dive into life-course stages to understand what we can (from the limited data available) about how being disabled affects quality of care at different stages of life:

- maternity and birth (Chapter 2)
- childhood and youth (Chapter 3)
- adulthood (Chapter 4)
- older age (Chapter 5)
- conclusion and recommendations (Chapter 6).

Importantly, this Window report demonstrates how health outcomes and service experiences change, and often worsen, over a disabled person's life course. This trajectory suggests the New Zealand health system is lacking the accessibility and accommodations necessary for disabled people to fully realise their right to the highest attainable standard of health and wellbeing,[10] and the vision of the Health of Disabled People strategy, which is for disabled people to 'live long, fulfilling and more independent lives in good health'.[11] In Chapter 6 we conclude and make recommendations on how to improve the situation this report describes.

Our collaborators

Throughout this report, stories from disabled people, tāngata whaikaha and their whānau who use New Zealand's health care services provide us with a sense of the lived, human experience of the data. We have also included commentary from health professionals working at the front lines of New Zealand's health system. We wish to thank the generous people who contributed their stories to this report.

This report was developed in a partnership between the Health Quality & Safety Commission Te Tāhū Hauora; the Donald Beasley Institute,[12] a leader in culturally diverse, disabled-led disability research (Figure 3); and Nicholson Consulting,[13] a data analytics group who specialise in IDI analyses and Māori and disability data (Figure 4). A group of disability health experts provided further contextual and statistical insights and feedback throughout the report.

Figure 3: Donald Beasley Institute representatives
L-R: Dr Robbie Francis Watene, Kairakahau Matua Whaikaha/Disabled Research Lead; Associate Professor Brigit Mirfin-Veitch, Kaiuruki Matua/Director

Figure 4: Nicholson Consulting representatives
L-R: Tori van Loenhout, Senior Data Scientist; Dr Sarah Underwood, Data Scientist; Dr Amjad Ali, Senior Data Scientist; Dr Todd Nicholson, Service Lead

An opening example

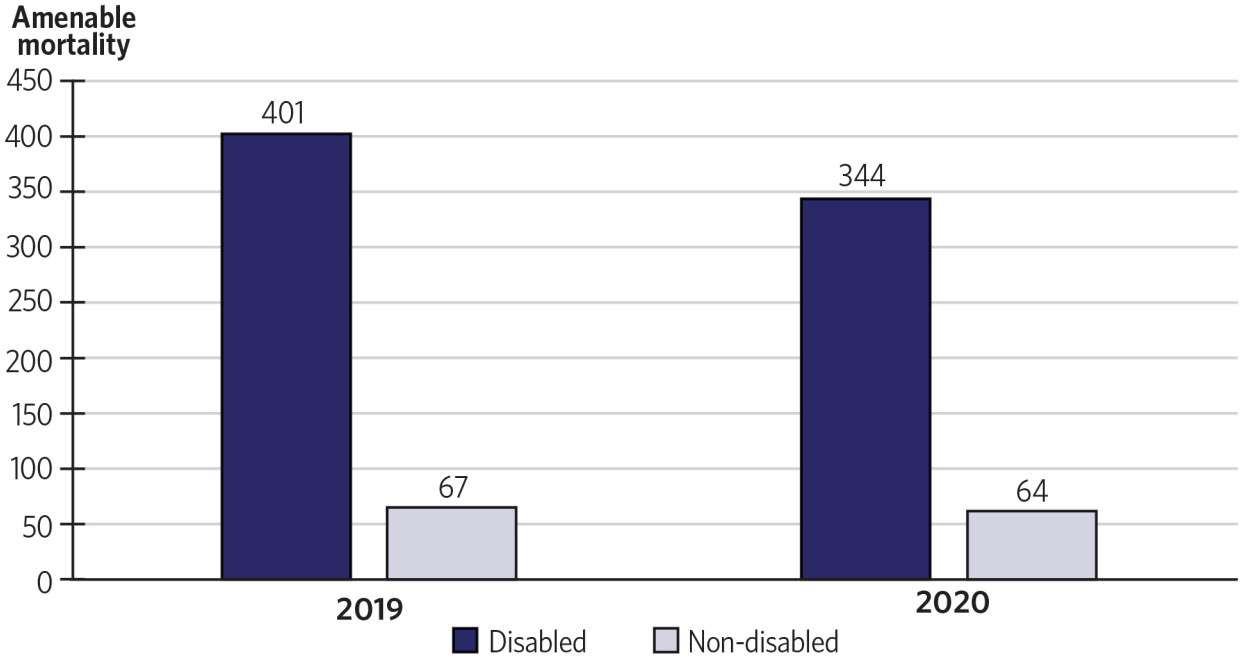
Before we begin to discuss data in more detail, we should acknowledge that much of the data in this report is newly generated from the IDI and has not been analysed before. However, it aligns with what many in the disability community say they have experienced in relation to their health and health care. They have told us it is good to be able to quantify, at last, what they have long suspected. Please also note that this data is confronting. It reveals many long-standing inequities for disabled people that have resulted in poorer experiences of care, unnecessary pain and shorter lifespans.

Please take care of yourself while reading this Window report. Take breaks, and reach out for support if and when you need it.

As an opening example, we first share Figure 5. This shows amenable mortality for disabled people compared with non-disabled people. 'Amenable' means 'capable of being acted upon' – that is, something could have been done to stop something from happening. For 'amenable mortality', this means something that could have been done to stop a death from happening at that time. There are a number of conditions that can cause death, but that can be helped by good health care at the right time. Amenable mortality measures the rate of deaths of disabled and non-disabled people aged 0–74 years that could have potentially been avoided if they had been given effective and timely health care.

Figure 5 shows that the rate of deaths from conditions that can be treated is more than five times higher for disabled people than non-disabled people. It is a stark reminder, at a very high level, that New Zealand's health care is not working well for more than one-sixth of the population.

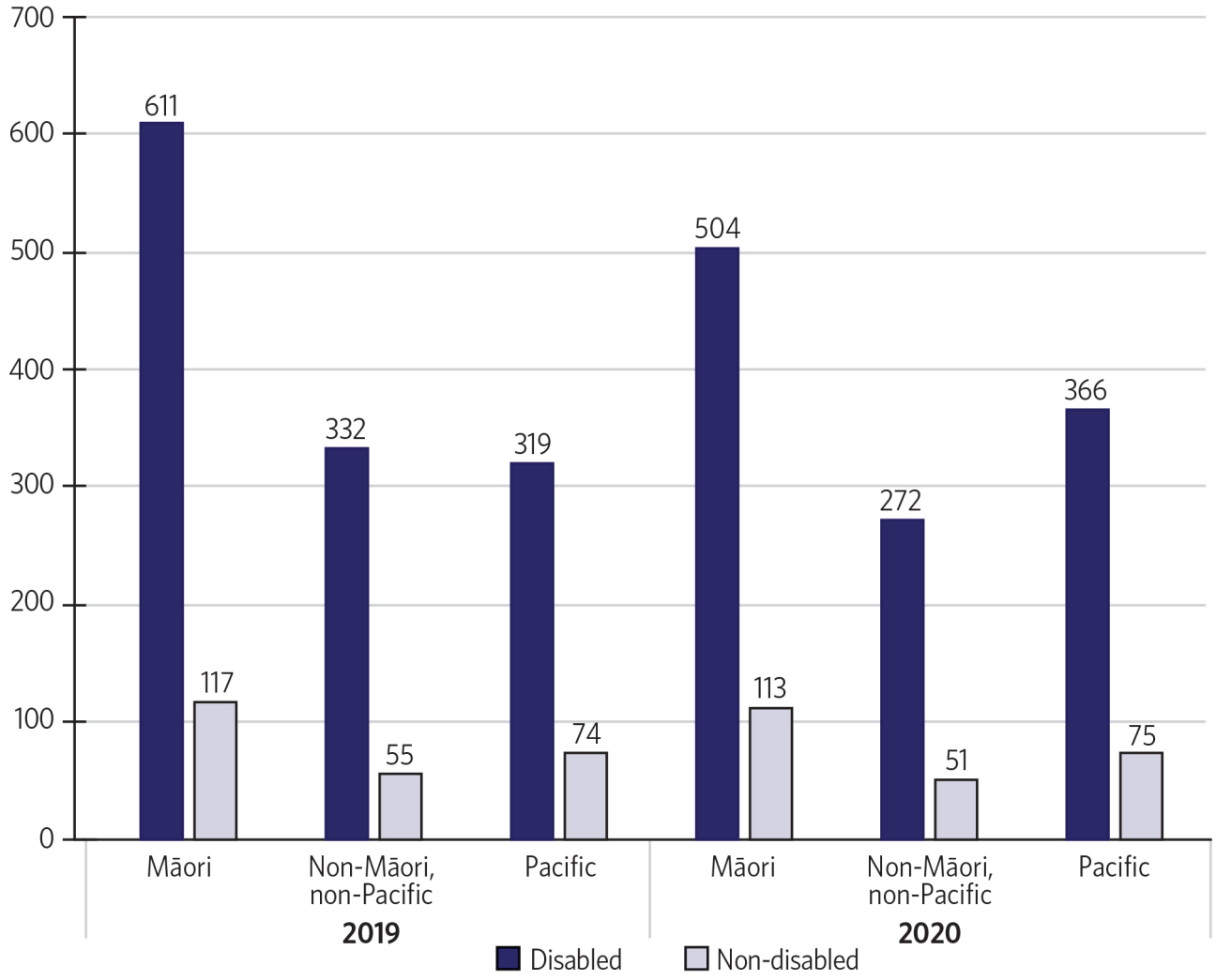
Figure 5: Amenable mortality rate per 100,000 population, ages 5–64 years, by disability status, 2019 and 2020



Source: IDI

The intersection of ethnicity and disability in relation to amenable mortality is also powerful. In 2020, Māori disabled people died from amenable causes at nearly 10 times the rate of non-Māori, non-Pacific people who are not disabled: 504 deaths per 100,000, compared with 51 per 100,000. Pacific disabled people died at nearly 7 times the rate of non-Māori, non-Pacific people who are not disabled (Figure 6). These differences provide another confronting reminder: New Zealand's health care is not working well for Māori and Pacific disabled people.

Figure 6: Amenable mortality rate per 100,000 population, ages 5–64 years, by disability status and ethnicity, 2019 and 2020



Source: IDI

An important note: This is not a compendium

Amenable mortality is a high-level measure and serves mostly as an alarm bell. Although it doesn't tell us what can and can't be fixed, it does tell us there is a serious issue. It is not the intention of this report to be a complete compendium of the data that could be analysed – IDI processes are rigorous and slow. Instead this report presents a curated selection of measures that give a view on more specific aspects of the quality of care for disabled people throughout the life course.

Important contexts, models and strategies underpin the thinking, framing and choices made in writing this report. In particular, we draw on: common models of disability, including both Māori and Pacific models of disability and health (including tāngata whaikaha, whānau hauā and Tagata Sa'ilimalo

models); Te Tiriti o Waitangi; the United Nations Convention on the Rights of Persons with Disabilities, to which New Zealand is a signatory; the Health of Disabled People Strategy; and the New Zealand Disability Strategy 2026–2030. For more information on these sources, see Appendix 2.

All of these contexts are important. It is also noteworthy that not every aspect of health care for disabled people can be analysed, and not every experience reflected. Disability is a large, complex space, and not well-measured.

In other words, this report is only a window, necessarily partial and incomplete, on the quality of care disabled people receive in New Zealand.

A quick, high-level view of health care use by disabled people

From a very broad perspective, disabled people are actively trying to access our primary health care system. This is demonstrated through primary health organisation (PHO) enrolment rates, which are consistently higher for disabled people than for non-disabled people. Despite this, disabled people struggle to access primary care, and subsequently rely heavily on secondary care – disabled people use emergency departments at higher rates than non-disabled people, are hospitalised more and stay longer in hospital once they are there.

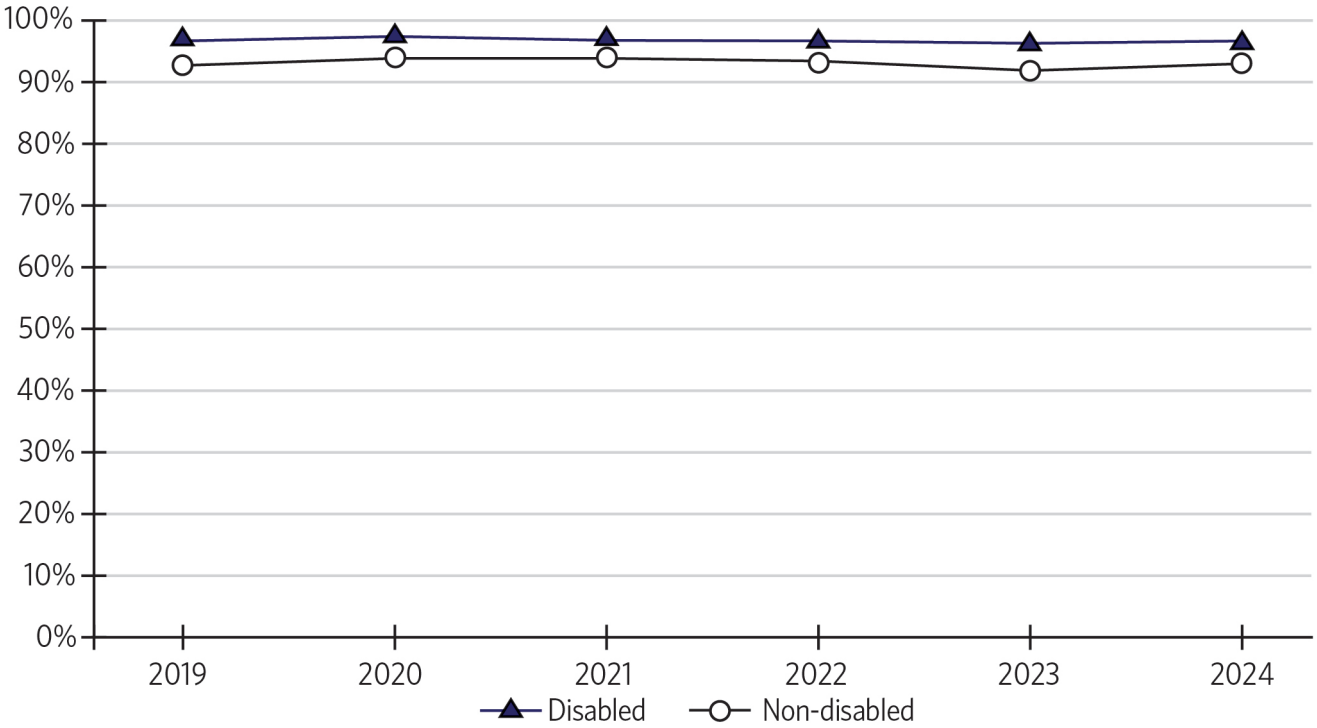
A lack of primary care access drives many disabled people into secondary care, with costs to people and to the system.

Primary care enrolment

Disabled people are trying to engage with the health care system and are enrolled with general practitioners (GPs) at consistently higher rates than non-disabled people – 97% versus 93% in 2024 (Figure 7).

Disabled people with two or more impairments are more likely to be enrolled with a GP than those with one or no impairment, across all ages. Māori and Pacific disabled people are more likely to enrol with a GP than Māori and Pacific non-disabled people too.

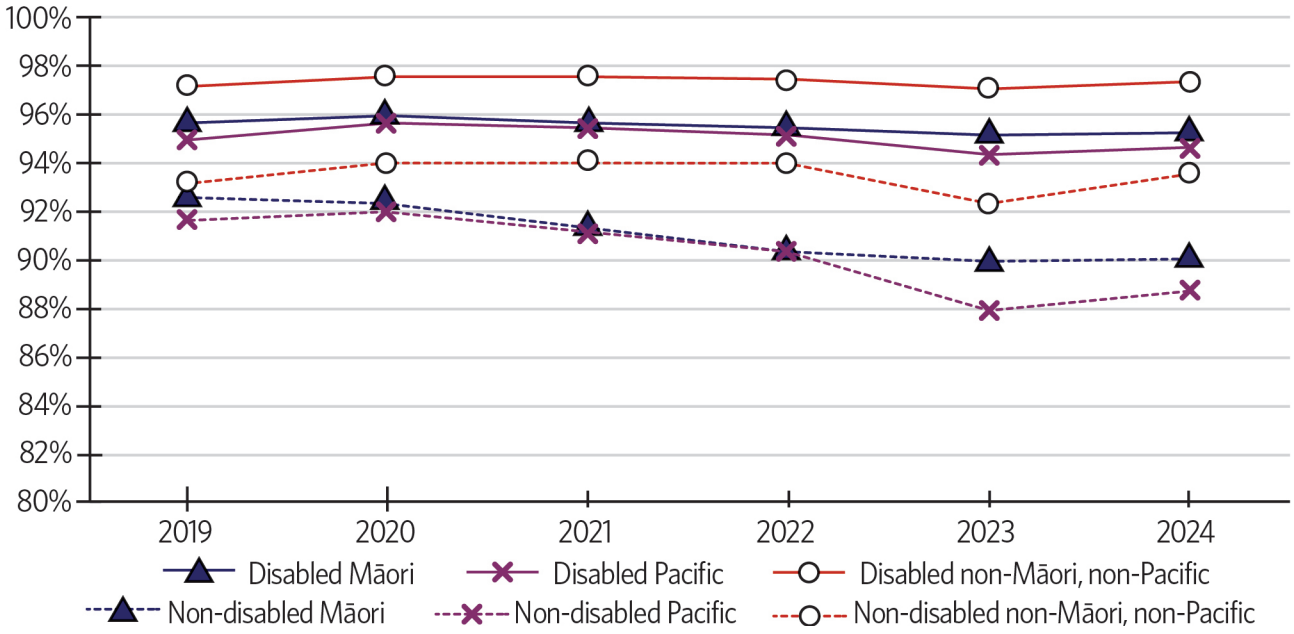
Figure 7: Percentage of people enrolled with a GP, by disability status, 2019–2024



Source: IDI

However, Māori and Pacific disabled people are less likely than non-Māori, non-Pacific disabled people to be enrolled with a GP, even though the percentage is still very high, and nearly five percentage points higher than for Māori and Pacific non-disabled people. Disabled people of all ethnicities had higher enrolment with a GP than non-disabled people (Figure 8).

Figure 8: Percentage of people enrolled with a GP, by ethnicity, 2019–2024



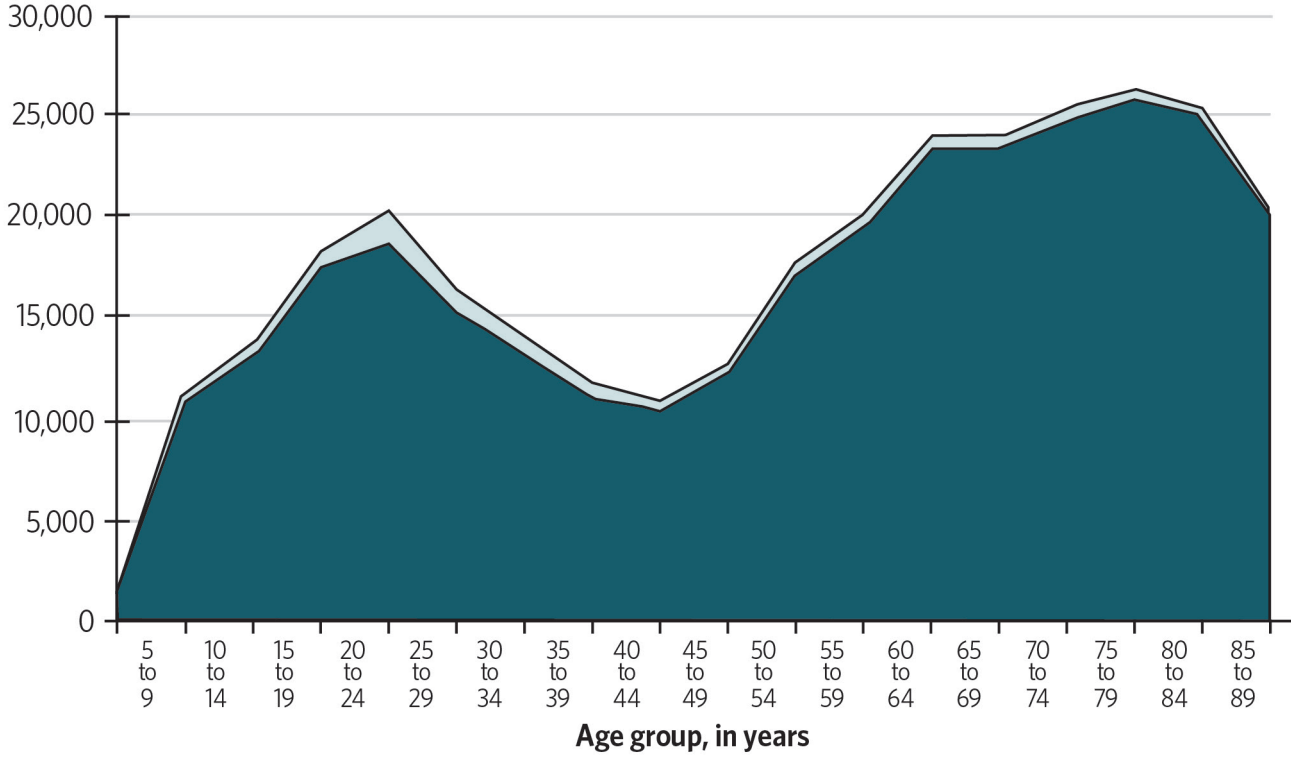
Source: IDI

Disabled people with seeing and hearing impairments are less likely to be enrolled with a GP than those with other impairments but the differences are small. Intellectually disabled people over 40 years are less likely to be enrolled with a GP than those with other impairments.

Across all ages, disabled people are working hard to access primary care. Figure 9 shows a small drop-off in enrolments as disabled people transition into adulthood, but the difference in level of enrolment compared with non-disabled people (Figure 10) is clear.

The proportion of disabled people unenrolled in primary care (shown in light grey) is small ...

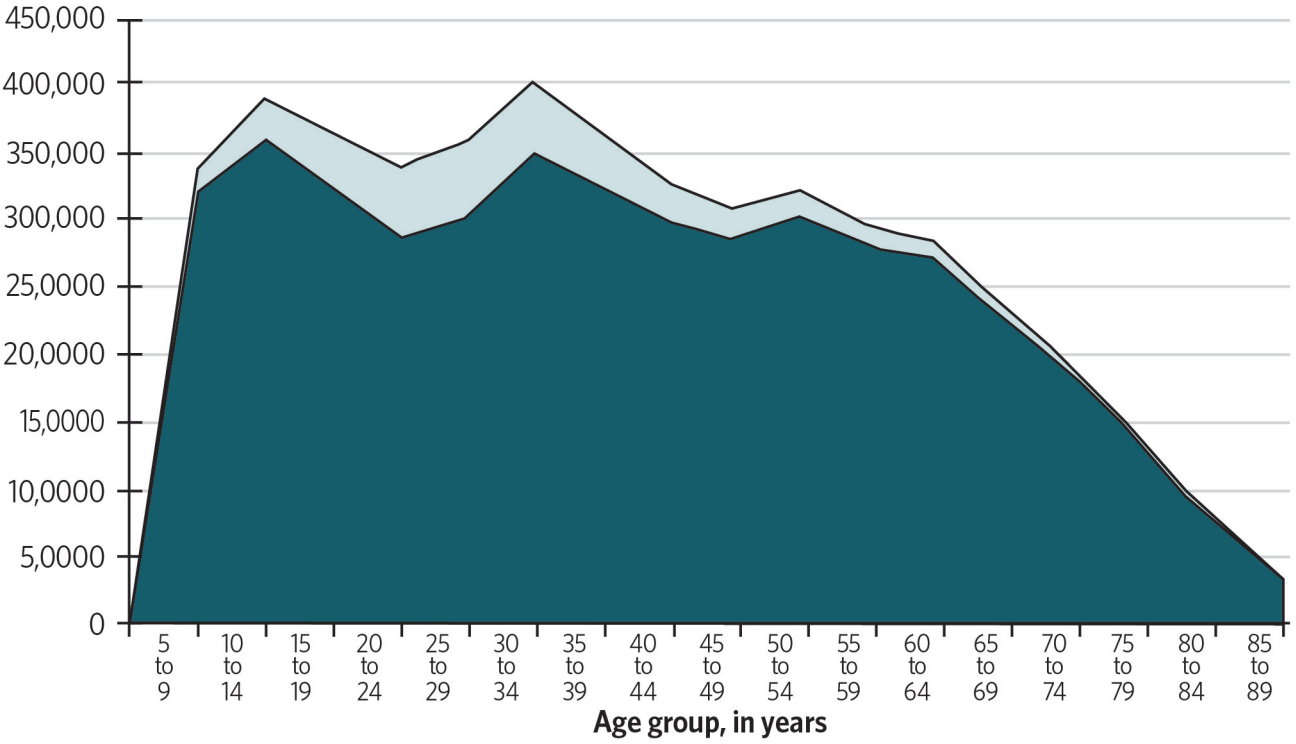
Figure 9: PHO enrolment of disabled people, by age group, 2023



Source: IDI

... and clearly smaller than the proportion of non-disabled people unenrolled with a PHO.

Figure 10: PHO enrolment of non-disabled people, by age group, 2023

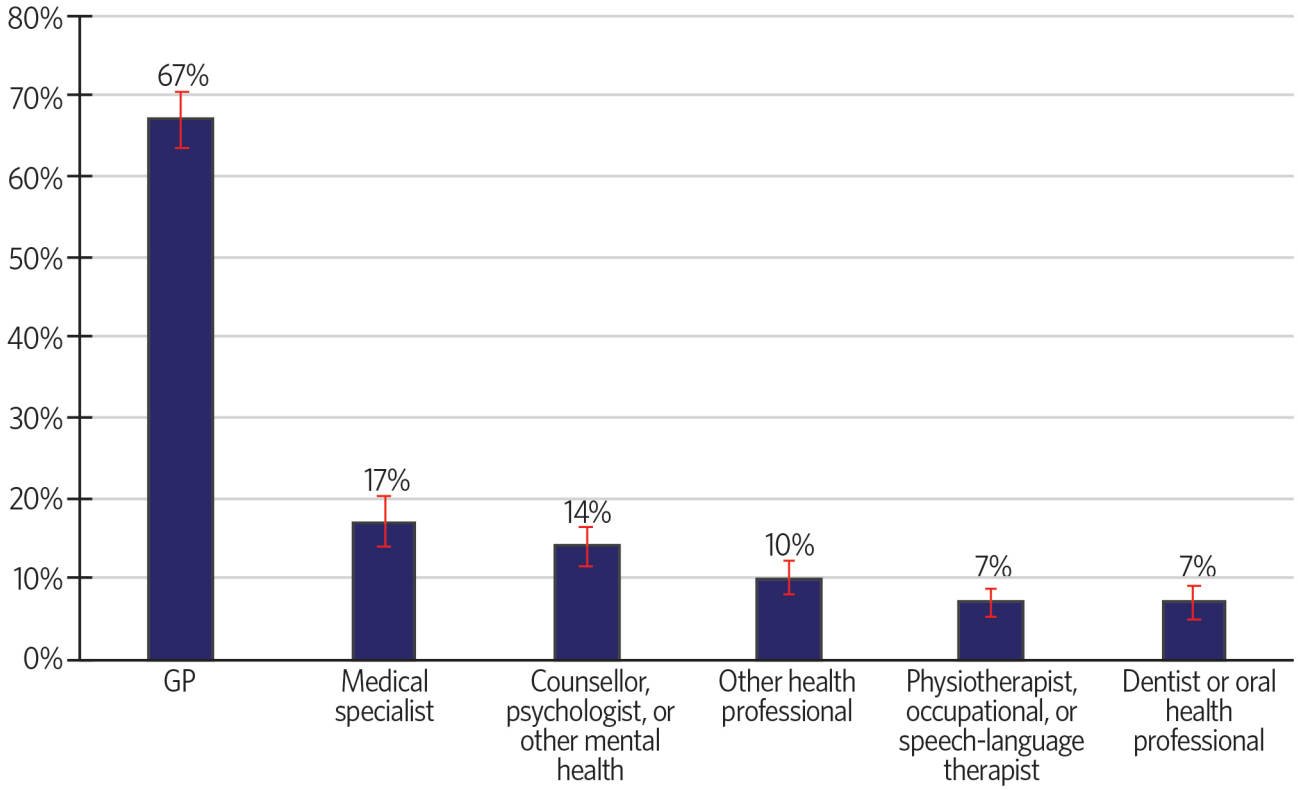


Source: IDI

Unmet need for care

Despite these efforts to access primary care and strong levels of enrolment, one-third of disabled people reported an unmet need to see a health professional in the last 12 months. Of those, the majority reported an unmet need to see a GP (Figure 11). This is critical when we consider how general practice referrals are often the gateway to secondary care, diagnostic services, funding, and disability supports and services.

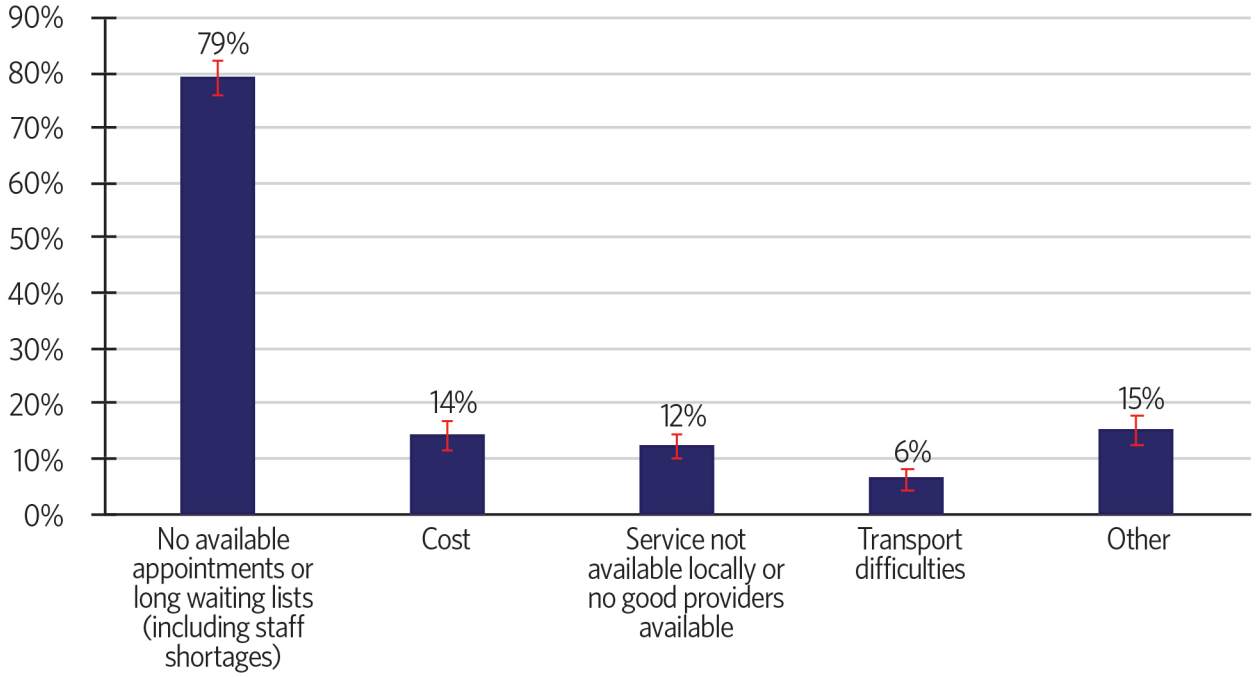
Figure 11: Percentage of disabled people who had unmet health care needs, by health care profession, 2023



Source: Household Disability Survey

The most common reason for this unmet need was that a GP was not available (Figure 12).

Figure 12: Reasons for disabled people's unmet need to see a health professional, 2023



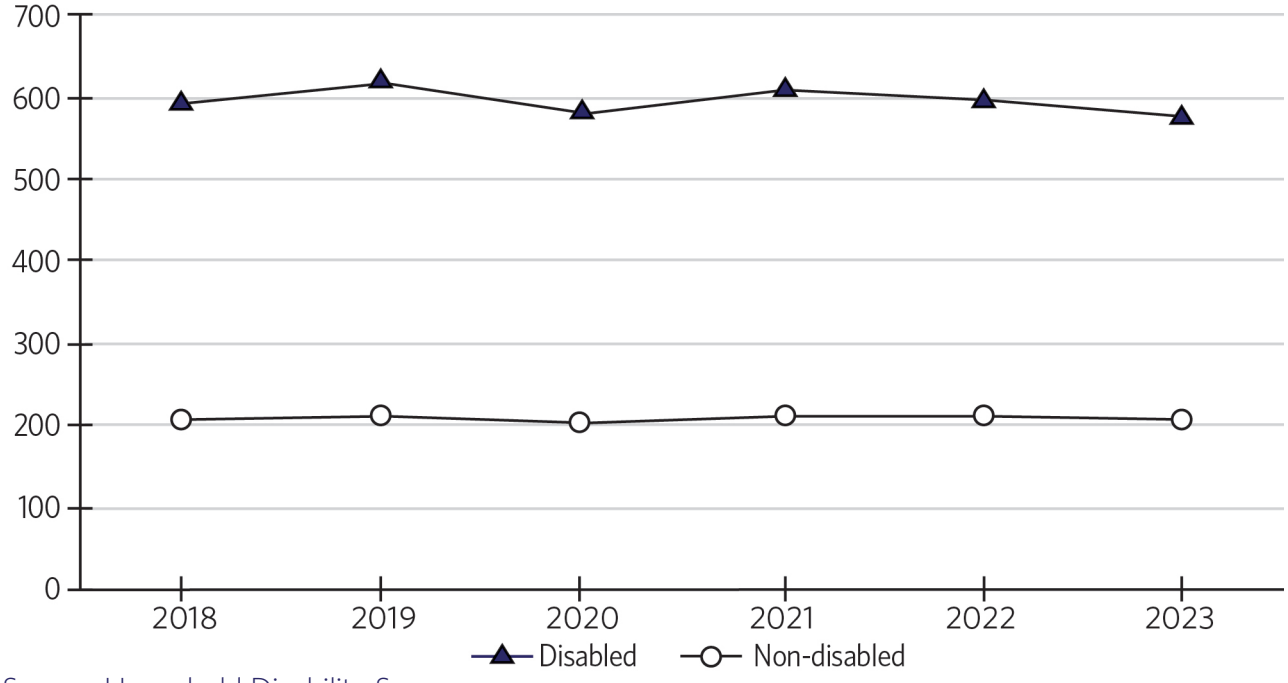
Source: Household Disability Survey

Despite strong levels of GP enrolment, disabled people have higher rates of emergency department presentations.

Emergency department presentations

Disabled people presented with acute conditions to emergency departments (EDs) at almost three times the rate of non-disabled people, consistently over time (Figure 13).

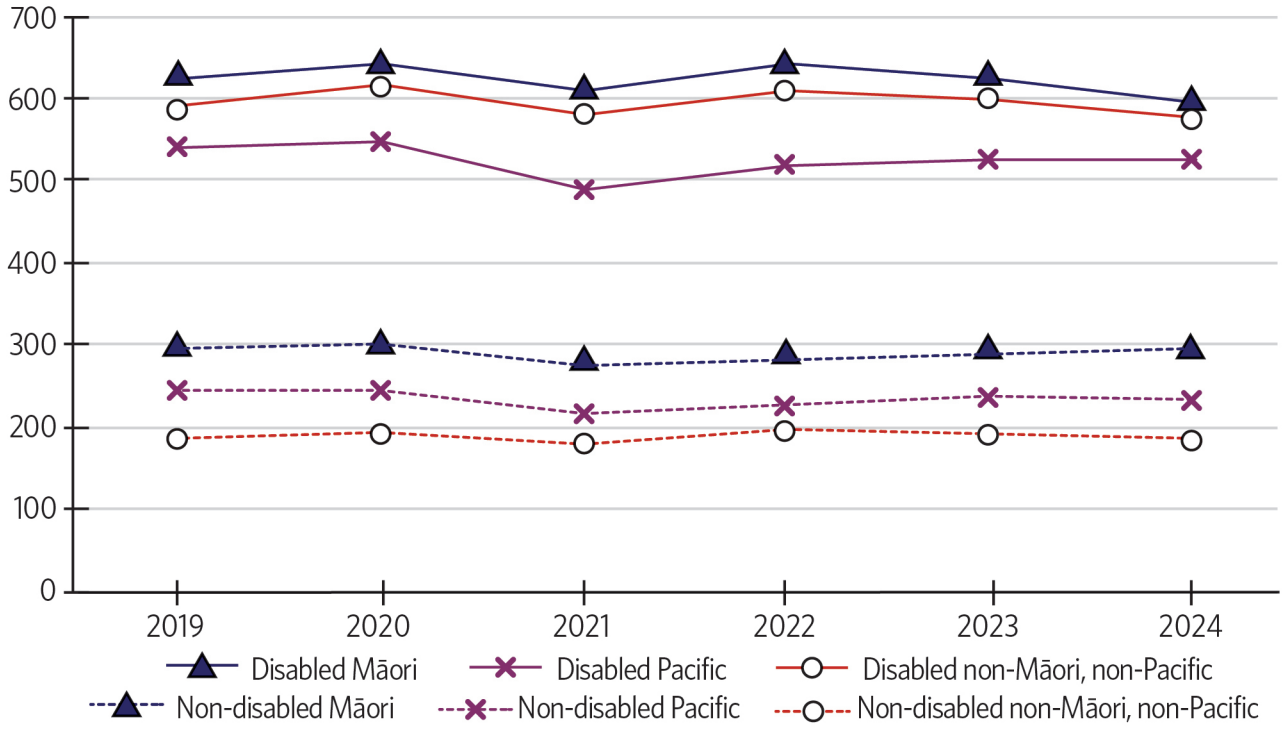
Figure 13: Rate of ED presentations per 1,000 population, by disability status, 2018–2023



Source: Household Disability Survey

The rate at which Māori disabled people presented to EDs was higher than the rate of non-Māori, non-Pacific and Pacific disabled people (Figure 14).

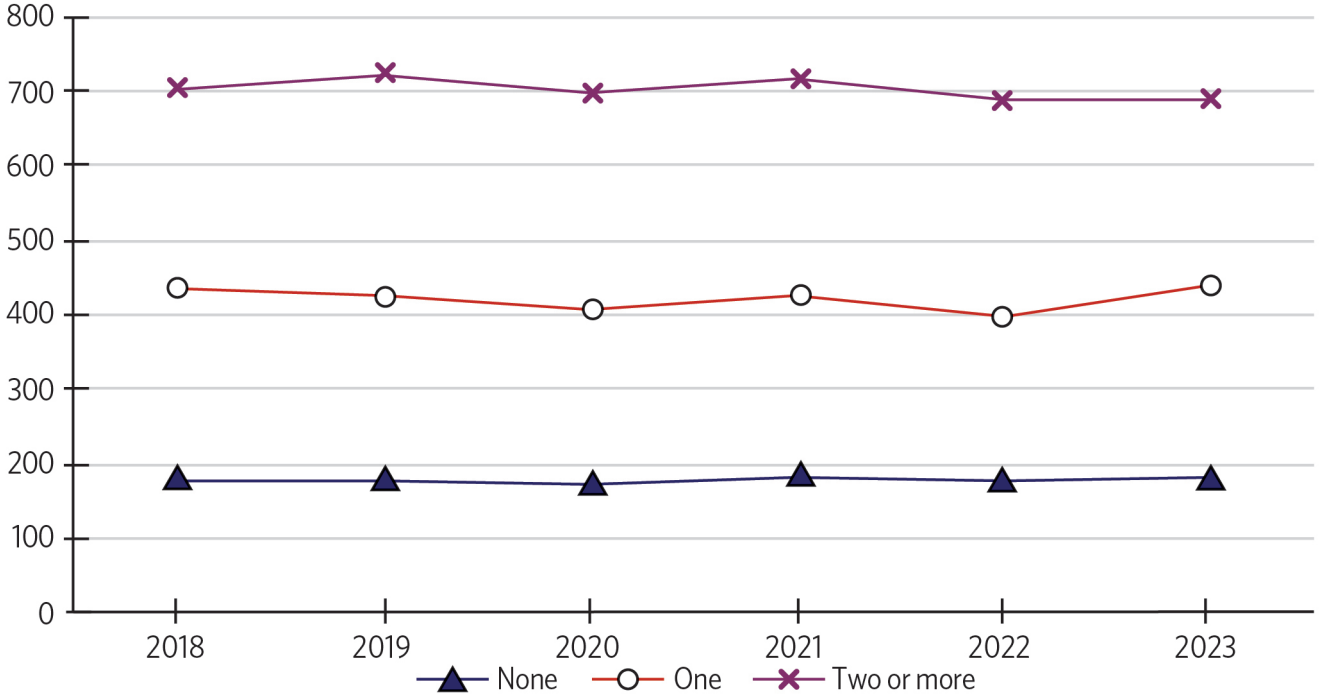
Figure 14: Rate of ED presentations per 1,000 population, by ethnicity, 2018–2023



Source: IDI

As might be expected, disabled people aged 64 years and older with more than one impairment presented more often to ED than those in their age group with one or no impairments. However, among those of later working age (40–64 years), the rate of presentations of disabled people with more than one impairment is also extremely high – almost four times the rate of non-disabled people in their age group (687 versus 183 per 1,000 population) (Figure 15).

Figure 15: Rate of ED presentations per 1,000 population, ages 40–64 years, by number of impairments, 2018–2023



Source: IDI

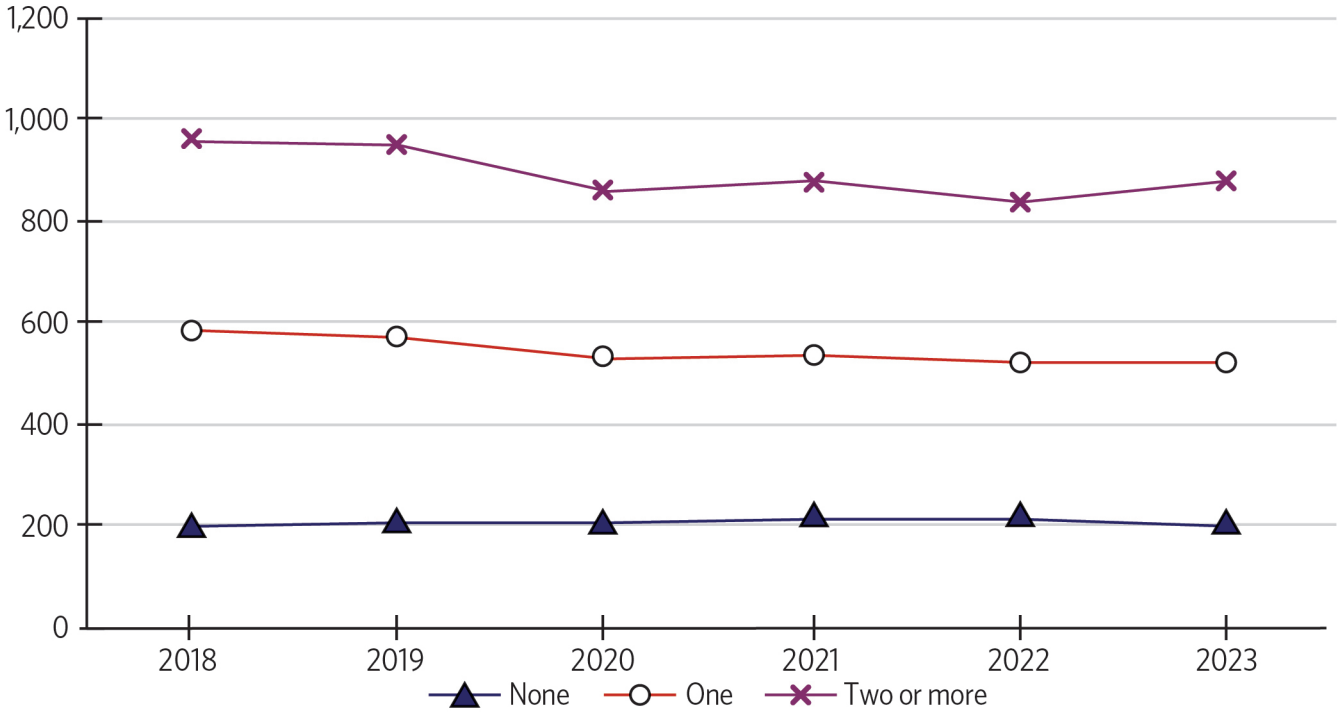
The Health Quality & Safety Commission's patient experience survey, which surveys users of primary care about their experiences of care,[14] asks about the reason for the patient's last visit to an emergency department. Data shows that 80% of disabled people said their condition was serious or life-threatening, or that they were sent by a health professional. This compares with 75% of non-disabled people.

Hospitalisations

The data shows that disabled people – especially those with multiple impairments – are admitted to hospital more often than non-disabled people.

In 2024, non-disabled people were hospitalised at a rate of 200 times a year per 1,000 population. People with one impairment were hospitalised at a rate of 520 times a year per 1,000 population, and people with two or more impairments 883 times a year per 1,000 population – that is more than four times the rate of non-disabled people (Figure 16).

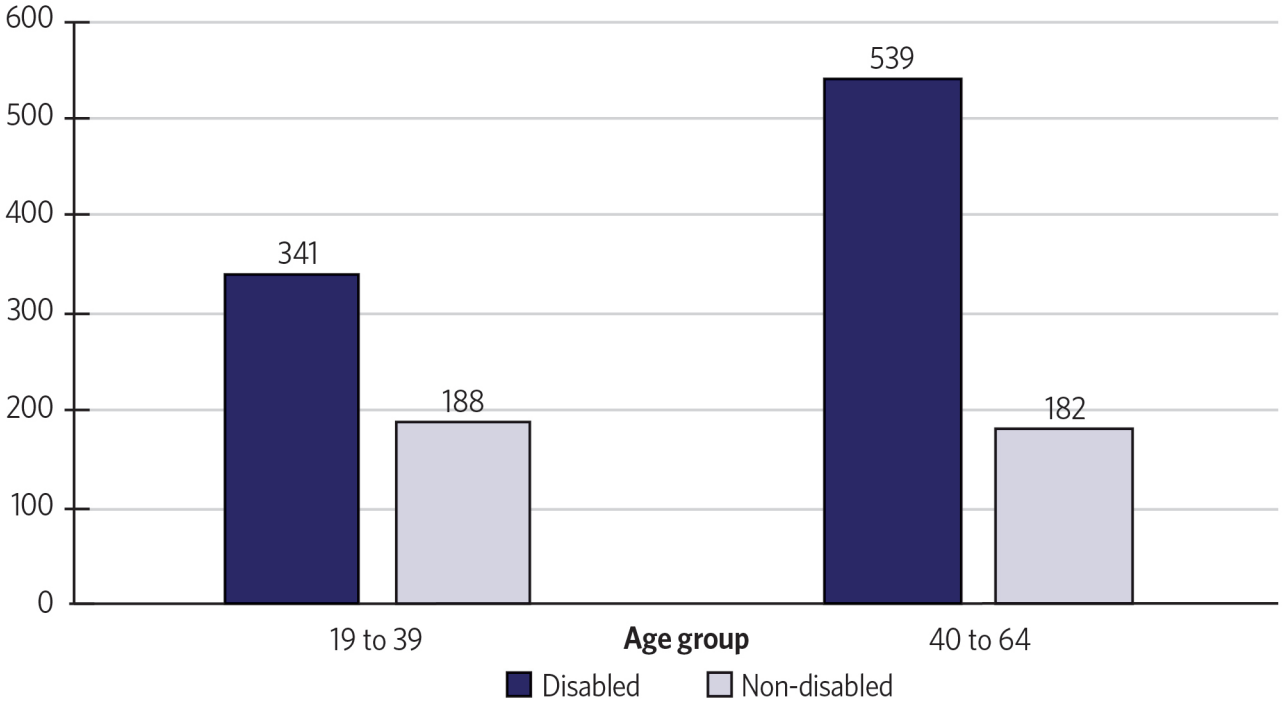
Figure 16: Rate of hospitalisations per 1,000 population, by number of impairments, 2018–2023



Source: IDI

In the working-age brackets of 19–39 and 40–64 years, non-disabled people were usually hospitalised at a rate of approximately 200 times a year per 1,000 population. Disabled people aged 19–39 were hospitalised at twice that rate. As disabled people move into the older working-age bracket, the hospitalisation rate rises to almost three times the rate of non-disabled people (Figure 17). These trends have a significant impact on disabled people's ability to work, learn, parent, and participate in their community.

Figure 17: Rate of hospitalisations per 1,000 population, by age group and disability status, 2018–2023

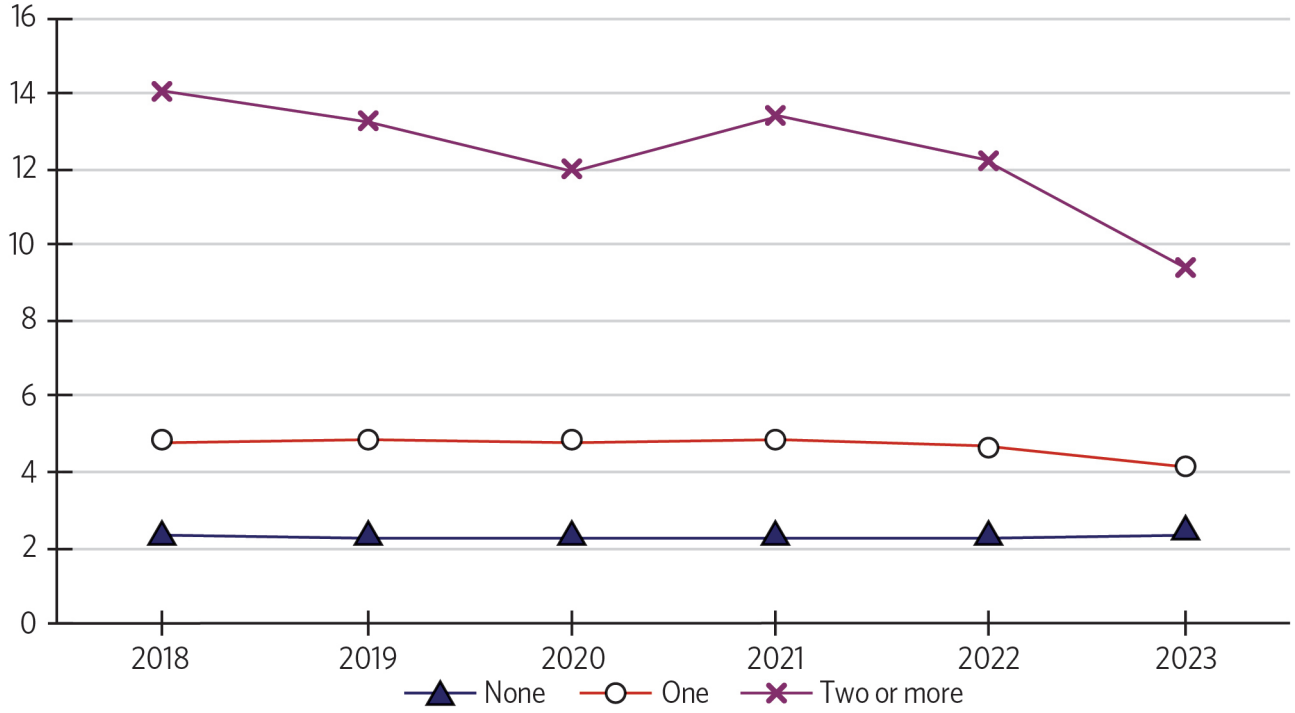


Source: IDI

Average number of days spent in hospital

Once in hospital, disabled people spend a longer time there. In 2023, non-disabled people spent an average of two days in hospital, compared with an average of nine days for disabled people with more than one impairment (Figure 18). These longer stays in hospital are mostly due to higher rates for disabled people aged 65 years and older.

Figure 18: Average length of stay in hospital in days, by number of impairments, 2018–2023



Source: IDI

What does this high-level view of disabled people's health care use mean?

In sum, despite the efforts of disabled people to access primary care, difficulties in accessing a GP appear to drive many to the ED, contribute to higher rates of hospitalisations at comparatively younger ages, and lead to longer average hospital stays than the non-disabled population.

All of this comes at a cost to people's lives and to the health system in dollars.

Over the next four chapters, we dive deeper into some of the factors contributing to this situation, analysing data that can tell us more about the quality of health care that disabled people receive at different life-course stages: maternity and birth; children and youth; adults; and older adults.

Jacinta Tevaga

Talofa lava. My name is Jacinta Tevaga. I am a proud Samoan woman, born Tangata Te Tiriti, who came from Samoa to Aotearoa in the early 1990s. I have trained and worked in mental health and addiction, and disability, and I am now a researcher focused on Disabled Person-Led Monitoring of the United Nations Convention on the Rights of Persons with Disabilities. I spend my days working to understand how our systems can better support D/deaf and disabled people. Many of my strongest lessons have come from my own experiences inside the health system.

Not being listened to

Today I have good primary care, and I'm grateful for that. But there was a time in my life when getting help felt almost impossible. I kept going to my GP because I was having severe stomach pain. They repeatedly told me it was probably just a tummy bug. Deep down I knew something wasn't right. The pain got worse and worse, and one day at work I almost collapsed. Because my primary care was closed, I went to an after-hours emergency clinic. It was expensive, and even then no one could tell me what was wrong. I felt like no one was taking my pain seriously.

For months I went back and forth trying to get answers. I kept saying I couldn't move properly and I was missing work because of the pain. Finally – after three

Continued over

more GP visits, one visit to after-hours, and a lot of money spent – I was referred for an ultrasound. That scan showed a cyst on my ovary the size of a tennis ball. By then it was so large I needed surgery. I was shocked that something so serious had been dismissed for so long.

A system that makes disabled people carry the burden

The process leading up to surgery was stressful. I had to fast and prepare multiple times because my surgery kept getting delayed. Each delay meant more pain. When I was finally admitted, my experience in the hospital was horrible. Even though I am blind, nothing in my notes signalled this. Every new nurse or staff member would ask me to 'show' them things or read paperwork I couldn't see. I had to explain again and again that I had a vision impairment and I was blind. That constant burden of reminding people was exhausting.

One health care assistant treated me especially badly. When I asked for guidance to the shower, she questioned why I couldn't walk there myself. She asked if she should just leave me, as if my need for support was an inconvenience. She refused basic tasks like helping to clean my bed, telling me I could just do it myself. The way she spoke to me felt condescending, almost like she didn't see me as a person who deserved care.

After surgery I faced complications and couldn't breathe properly, so I had to stay an extra two weeks. I requested that my sister be allowed to stay with me because I did not feel safe. I made a complaint about the way I had been treated, but nothing happened. It was acknowledged, but then there was no outcome.

Two years later, during a routine GP visit, I found out by accident that the surgeons had discovered endometriosis during my operation. No one had told me. For two years I walked around with pain, not understanding the cause. This lack of communication was frightening and unacceptable – the disconnection between primary care and the hospital.

Through all of this, I learned how heavy the burden is on disabled people to carry information between services. I was constantly repeating my history, my disabilities and my needs. The systems don't talk to each other, so we are forced to act as our own messengers, even when we are sick and overwhelmed.

What true accessibility should look like

What the health system needs is simple, but essential. Disabled people deserve to be listened to. We need staff who are trained in disability awareness – not just nurses, but health care assistants, doctors, everyone. Accessible communication must be normal, not something we have to beg for. And the system must understand that disabled people have other health conditions too. We are whole people, not just our primary disabilities.

My story is only one example, but I know many others who have had similar experiences. I share it because I believe our system can do better – and because every disabled person deserves care that respects their dignity, their voice and their life. ■

New Zealand Government
Te Kāwanatanga o Aotearoa

Health Quality &
Safety Commission
Te Tāhū Hauora