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.

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Chapter 4

Life-course stage – Adults

Between the ages of 18 and 21 years, young disabled people transition from paediatric care into the adult health care system. This is a critical period in the life course, during which challenges often begin to intensify. It also typically coincides with ageing out of the education system – an environment that is often structured to notice, monitor and respond to the health and wellbeing needs of disabled children and young people – and into adult support services, where such oversight is far less consistent.

As highlighted by Kimberly and Finlay's story, together, these shifts across the education and health sectors can result in significant disruption to a disabled person's health and wellbeing. As responsibility for navigating care increasingly falls on the individual, young disabled adults, tāngata whaikaha and their whānau are expected to self-advocate within a system that is frequently confusing, inaccessible and fragmented. [56] Unsurprisingly, this transition period is also where disparities between disabled and non-disabled people's health outcomes begin to widen and become more pronounced.

A high-level summary of the findings

Patients' experiences of barriers to accessing primary health care indicate that wait times are a key issue. In terms of mental health, disabled adults experience higher rates of anxiety and depression, and use secondary mental health and addiction services more frequently, but still experience greater unmet need for mental health services.

The elective surgery cluster of indicators shows that the proportion of disabled people waiting longer than four months for their first specialist assessment after referral is similar to that for non-disabled people. However, the proportion of disabled people waiting more than four months for treatment once a treatment plan is committed to is higher than that of non-disabled people. Disabled people experience higher rates of post-operative complications for common surgeries. Moreover, the risk increases as the number of impairments increases, and is disproportionately higher for Māori and Pacific disabled people.

Like disabled children and young people, disabled adults experience higher levels of dental surgeries as oral health worsens over time, and significant unmet need particularly for primary health care. Disabled adults have a higher prevalence of diabetes than non-disabled adults. According to Health

New Zealand | Te Whatu Ora, many disabled adults under 64 years of age live in long-term care homes – that is, aged residential care (780 people in the first quarter of the financial year 2024/25), despite these settings not being designed for the needs of younger adults.[57] In this chapter, Box 6 gives details of cancer data from Te Aho o Te Kahu – Cancer Control Agency, which shows disabled people experience higher rates of major cancers – lung cancer in particular – than non-disabled people.

Patient experience – what working-age disabled people report about access to primary health care

Since 2016, the Health Quality & Safety Commission Te Tāhū Hauora has regularly surveyed adult patients about their experiences of primary care. Multiple survey questions relate to access, while disability status is captured through the WG-SS and self-identification.

Long-standing disparities in access to primary care for disabled people have been reported previously.[58]

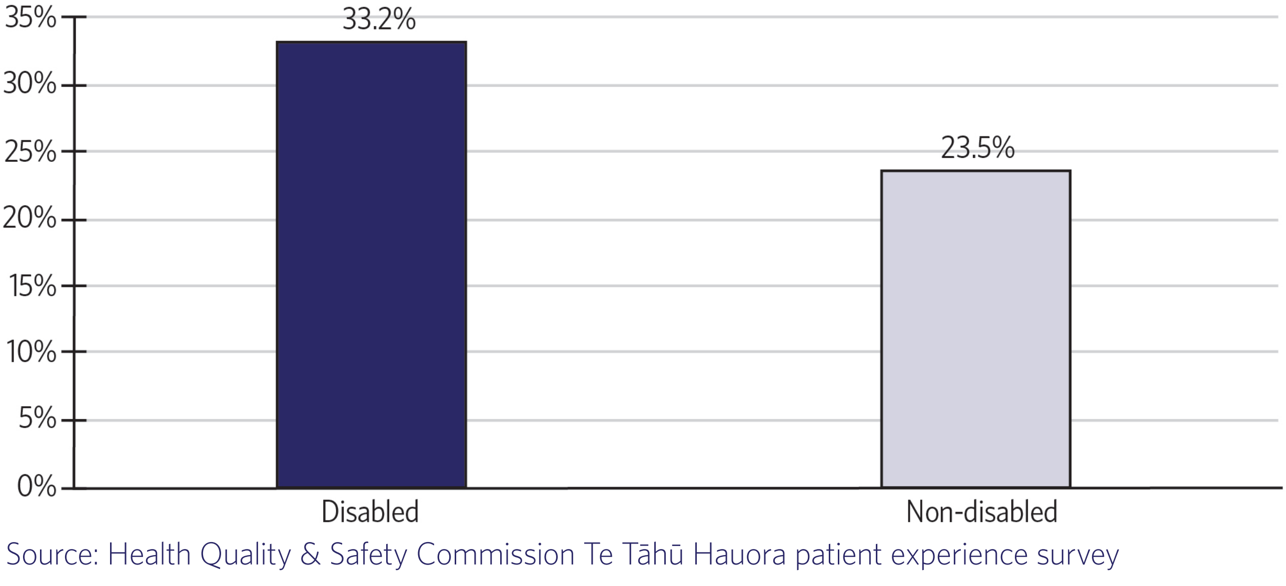
For the purposes of this Window report, patient experience survey results were analysed through the following key themes:

- barriers to accessing care
- wait times
- continuity of care
- alternatives offered by general practice.

Barriers to accessing care[59]

One-third (33.2%) of working-age disabled people (aged 19–64 years) reported a time when they were unable to access primary health care when they wanted it in the last 12 months. This compares with only around a quarter (23.5%) of working-age non-disabled people (Figure 49).

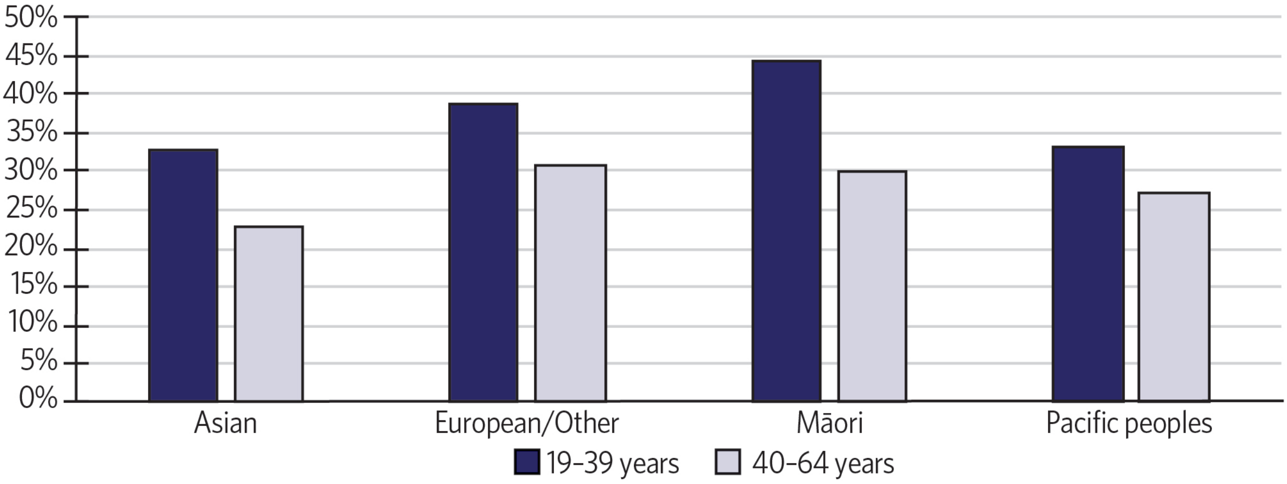
Figure 49: Percentage of people reporting a time when they couldn't access primary care when they wanted it in the last 12 months, ages 19–64 years, by disability status, May–August 2025



Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey

Disabled people aged 19–39 years were more likely to report an inability to access primary health care than those aged 40–64. Younger working-age Māori disabled people were more likely than other ethnicities in the same age group to report a time when they were unable to access primary health care when they wanted to in the last 12 months (44%) (Figure 50).

Figure 50: Percentage of disabled people reporting a time when they couldn't access primary care when they wanted to in the last 12 months, by age group and ethnicity, May–August 2025



Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey

Wait times

According to the patient experience survey, one in five (20.5%) of working-age disabled people were able to get an appointment on the same or next day from booking it. However, 14.1% had to wait longer than two weeks.

Where people reported that there was a time in the last 12 months when they wanted health care from a GP or nurse but were unable to get it, they were then asked about the reasons why they were unable to access this care.

For disabled people of working age, nearly a quarter (23.1%) reported that the wait time to get an appointment was too long. The wait time for an appointment was the most frequently reported barrier among all respondents, regardless of their demographic profile.

The next most common reasons why working-age disabled people were unable to access care were that the GP or nurse they wanted to see was unavailable (12.1%), the clinic was closed (eg, after hours) (5.9%), they were unable to contact the clinic to make an appointment (4.7%), and the appointment was too expensive (4.2%).

Continuity of care

The finding that 12.1% of respondents could not get care because their preferred clinician was unavailable suggests disabled people value continuity of care. While continuity of care is a known driver of improved health outcomes,[60] data from the 2024/25 New Zealand Health Survey reveals a concerning disparity: disabled people are twice as likely as non-disabled people to note an unmet need to see a GP due to fear, or a previous negative experience. [61] This was reiterated by survey data that showed 72.2% of working-age disabled people have one health care professional they usually see and, of those, most (84%) saw that professional in their most recent appointment. Continuity of primary health care is a protective factor for eliminating inequities for Māori and disabled people.[62]

Of the disabled people who were unable to access care, when asked what their reason for seeking care was, just over half (56.1%) perceived their health need as urgent. When respondents were unable to get either a timely appointment or one with their preferred clinician, they were asked whether their practice offered alternatives. Of those with an urgent health need, 67% were offered alternatives by their practice (eg, phone triage, an appointment with another GP or nurse, or a referral elsewhere).

Telehealth and patient portals can save practice staff time, improve access to care and support a patient-centred approach. Portal use has grown: 61.4% of working-age disabled people have heard of and use a portal. However, while telehealth has increased access to health services for some disabled people, others have reported increased barriers due to disabled people's experience of accessibility barriers and the digital divide.[63] [64]

Being involved in decisions about treatment and care relates to the ability to engage with care, a key element of access. Most (83.6%) working-age disabled people said their health care practitioner involved them as much as they wanted in making decisions about their treatment and care, but equity gaps persist.

Alternatives offered by general practice

Flexible health services are evidenced as essential for disabled people[65] and for reducing health inequities for Māori (Te Tiriti o Waitangi principle four, the principle of options, "requires the Crown to provide for and properly resource kaupapa Māori health and disability services"). [66] Of the two-thirds (67%) of working-age disabled people offered an alternative by their practice:

- 25% had a GP or nurse talk to them to assess their needs.
- 28.2% were offered an appointment with another GP or nurse.
- 23.2% were referred elsewhere.
- 9.8% were offered a different alternative.
- 33.0% were not offered any of the above.

Disabled adults' mental health

According to the United Nations' definition of disability, psychosocial disability is both a disability in itself and a comorbidity that many disabled people experience.[67] [68] Disabled people have a higher prevalence of anxiety and depression, and use specialist mental health services more than non-disabled people, but still report unmet mental health care need.

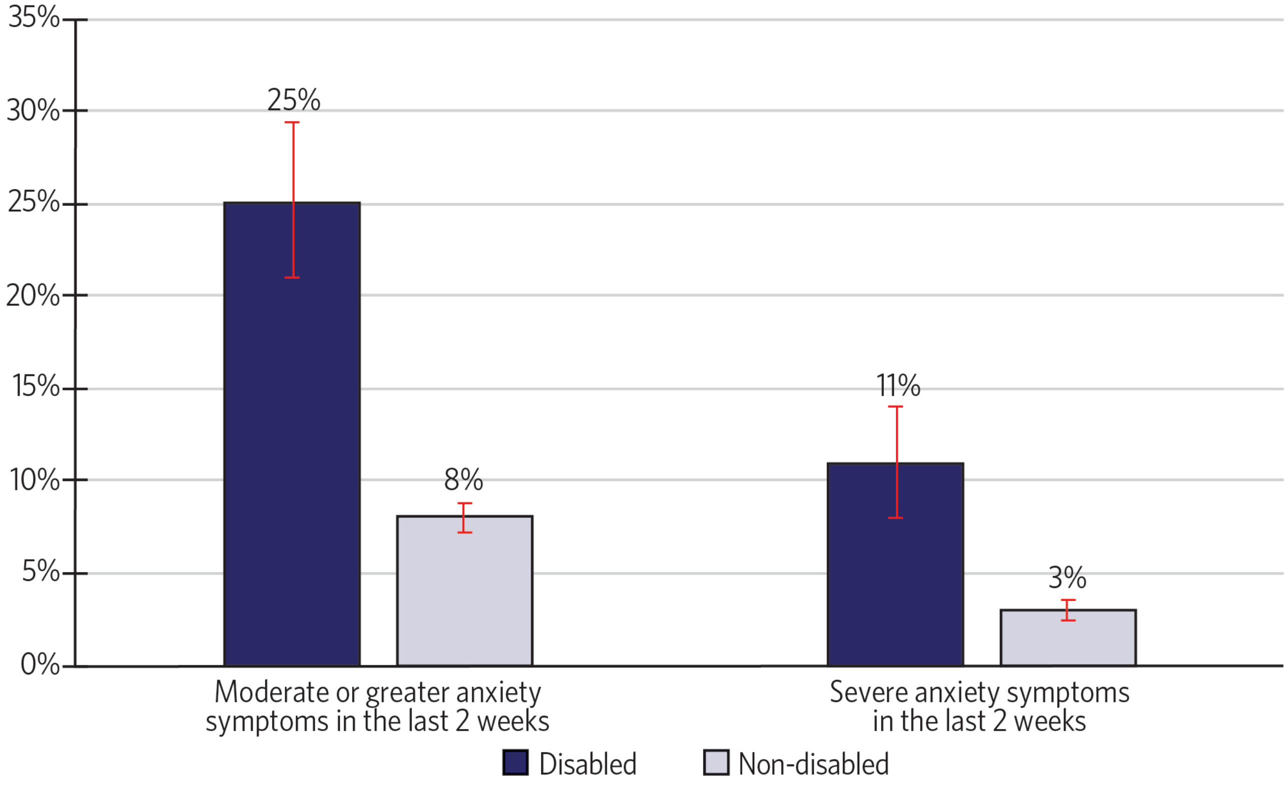
The prevalence of mental health issues in New Zealand was estimated using data from the New Zealand Health Survey 2021–2023.

Anxiety

The New Zealand Health Survey estimates 9.8% of the New Zealand population experienced moderate or greater anxiety symptoms in the last two weeks[69] – about 408,000 adults over the age of 15. For disabled adults, this estimate was 25.4% (about 92,000 disabled adults), three times the rate for non-disabled adults, at 8.3% (about 315,000 non-disabled adults).

An estimated 41,000 disabled adults (11.2%) experienced severe anxiety in the last two weeks.[70] This is over four times the rate for non-disabled adults (2.5%) (Figure 51).

Figure 51: Prevalence of moderate or greater and severe anxiety symptoms, by disability status, 2021–2023



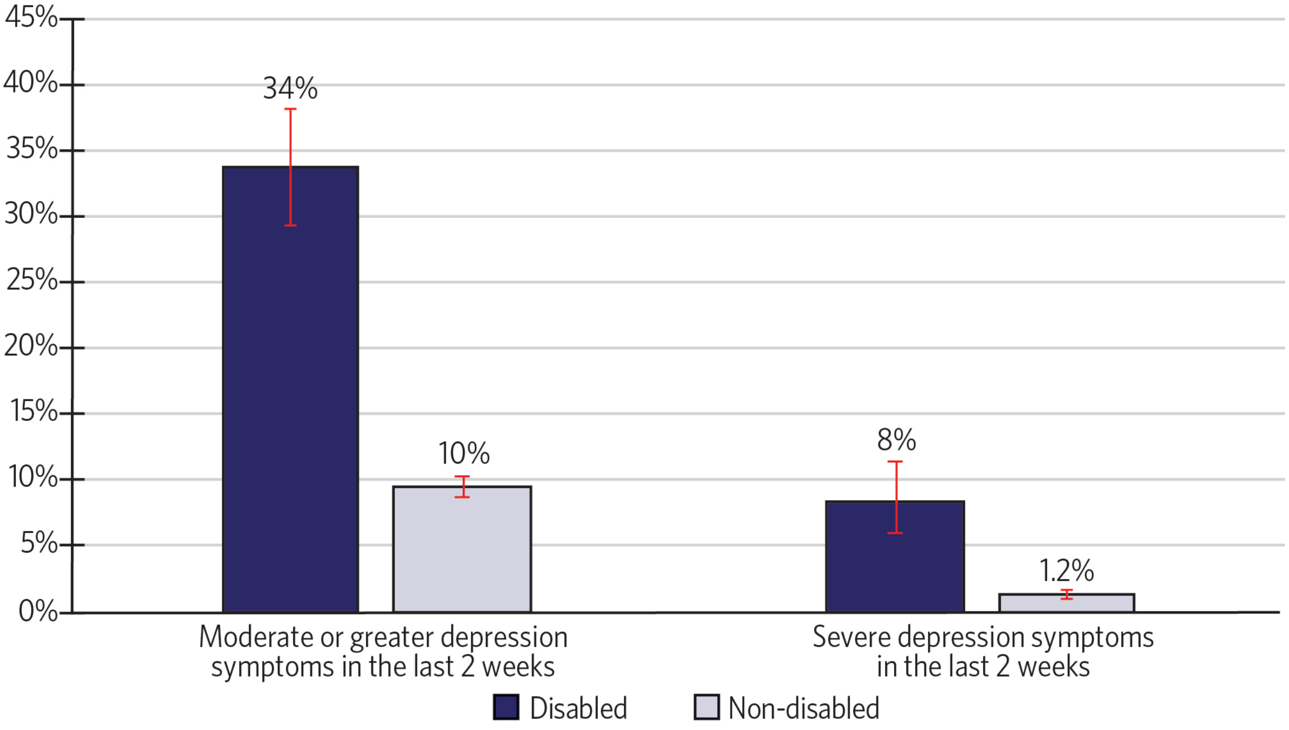
Source: New Zealand Health Survey

Depression

The Health Survey estimates 11.6% of the New Zealand population experienced moderate or greater symptoms of depression, or about 484,000 adults over 15. For disabled adults, this estimate was 33.6% (about 123,000 disabled adults), over three times the rate for non-disabled adults, at 9.5% (about 361,000 non-disabled adults).

An estimated 30,000 disabled adults (8.3%) experienced severe depression in the last two weeks. This is almost seven times the rate for non-disabled adults (1.2%) (Figure 52).

Figure 52: Prevalence of moderate or greater and severe depression, by disability status, 2021–2023



Source: New Zealand Health Survey

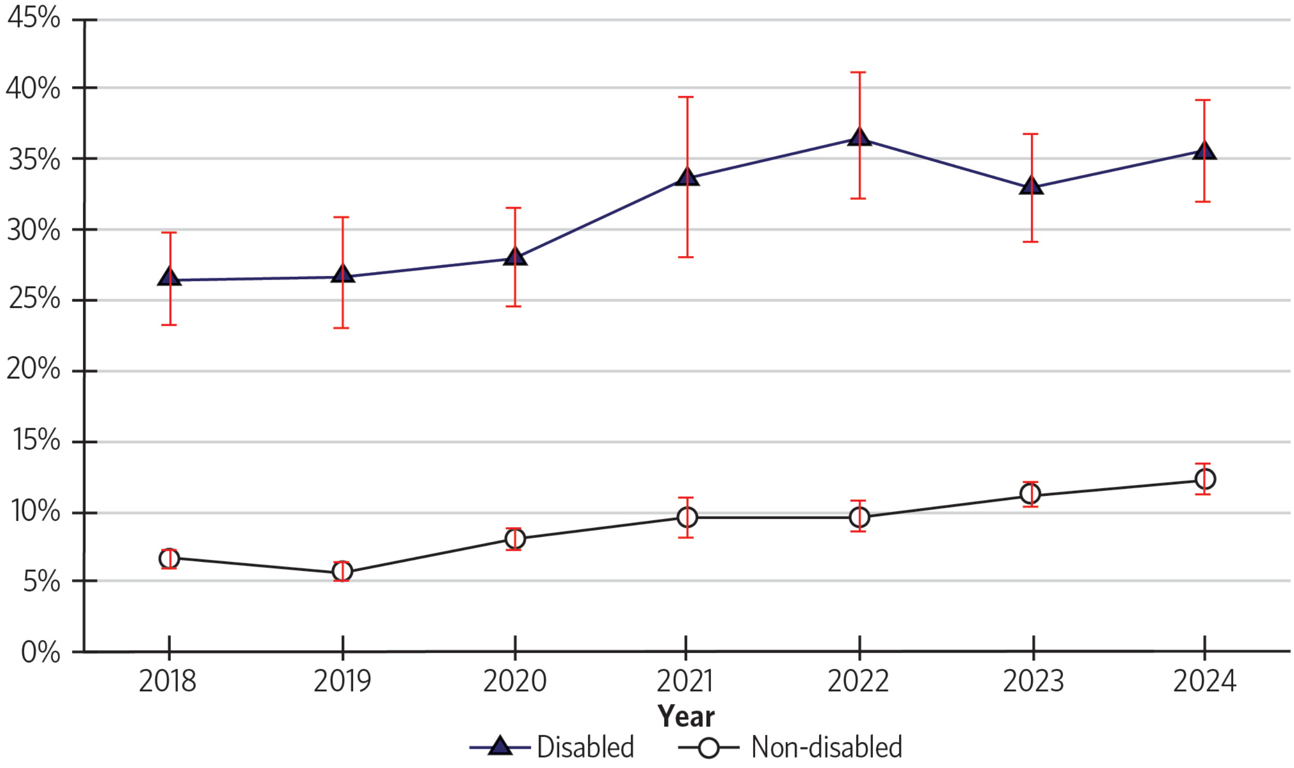
Increasing rates of psychological distress over time

The NZ Health Survey collects data about whether people experience psychological distress and a measure of how severe that distress is.[71]

The estimated percentage of disabled adults experiencing high or very high levels of psychological distress in the past 4 weeks was 26.4% in 2018, rising to 35.5% in 2024. Over the same time period the percentage was 6.7% for non-disabled people in 2018 rising to 12.2% in 2024. That is, the estimated percentage of disabled people who experienced high or very high levels of psychological distress in the past 4 weeks was approximately three times higher than that of non-disabled people.

While the rate for the non-disabled population has almost doubled in this time, the rate for disabled people rose quickly between 2020 and 2022 and has since stabilised, with the result that in 2024 over one-third of disabled adults experienced high or very high psychological distress (Figure 53).

Figure 53: Prevalence of high or very high levels of psychological distress, by disability status, 2018–2024

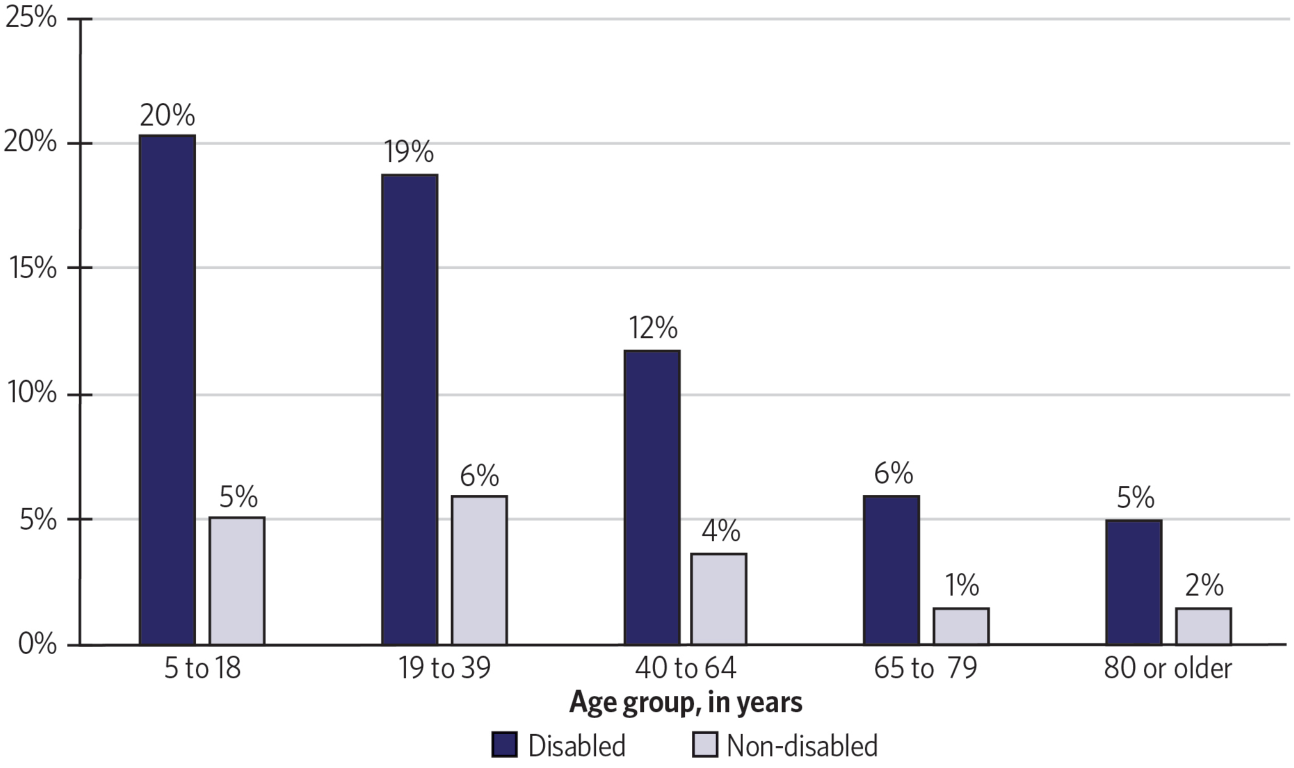


Source: New Zealand Health Survey

Mental health service use and disability

Disabled people draw on specialist mental health and addiction services at much higher levels than non-disabled people. This higher use is especially evident among younger age groups (Figure 54).

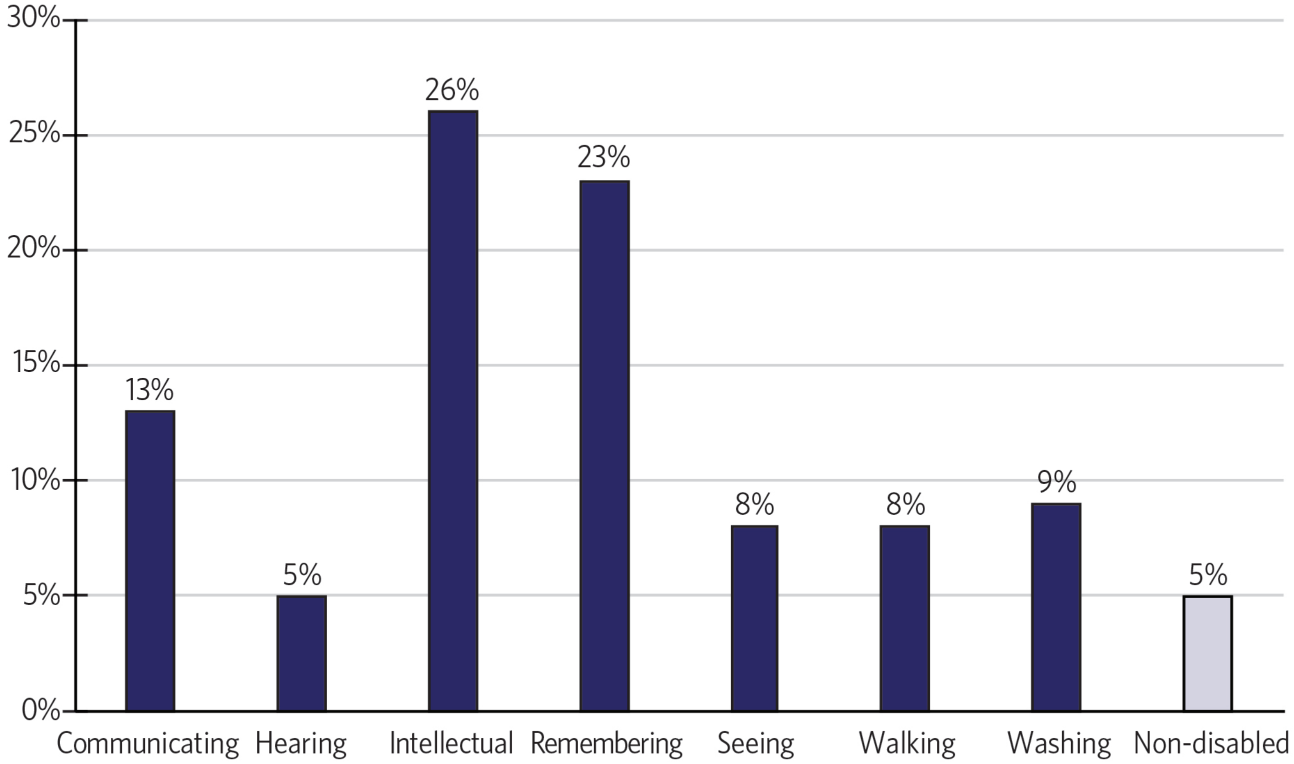
Figure 54: Percentage of population that has contact with specialist mental health and addiction services, by age group and disability status, 2023



Source: IDI

The highest users of specialist mental health and addiction services were people with intellectual, remembering or communicating impairments (Figure 55). For all of these groups, their differences from non-disabled people were unlikely to be due to chance.

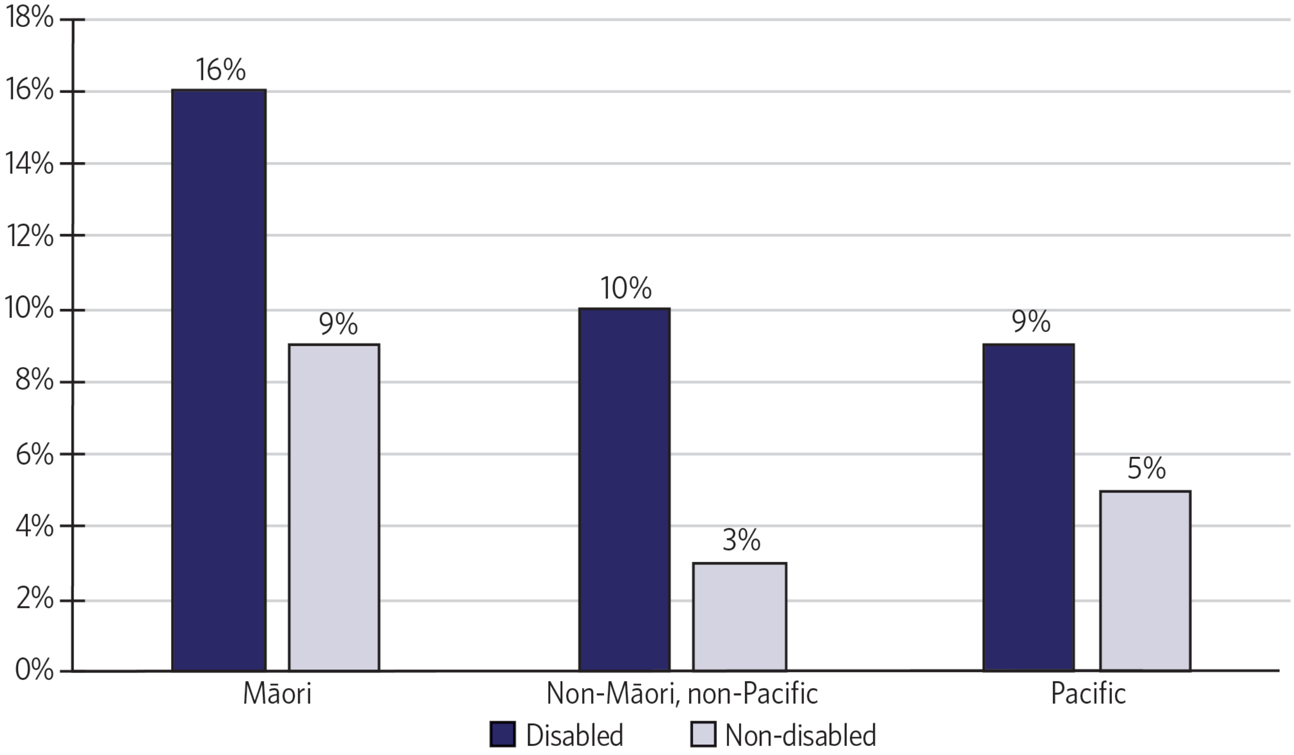
Figure 55: Percentage of population using specialist mental health and addiction services, by WG-SS disability domain, 2023



Source: IDI

Across all ethnic groups, disabled people used specialist mental health and addiction services more than non-disabled people (Figure 56).

Figure 56: Percentage of people using specialist mental health and addiction services, by ethnicity and disability status, 2023



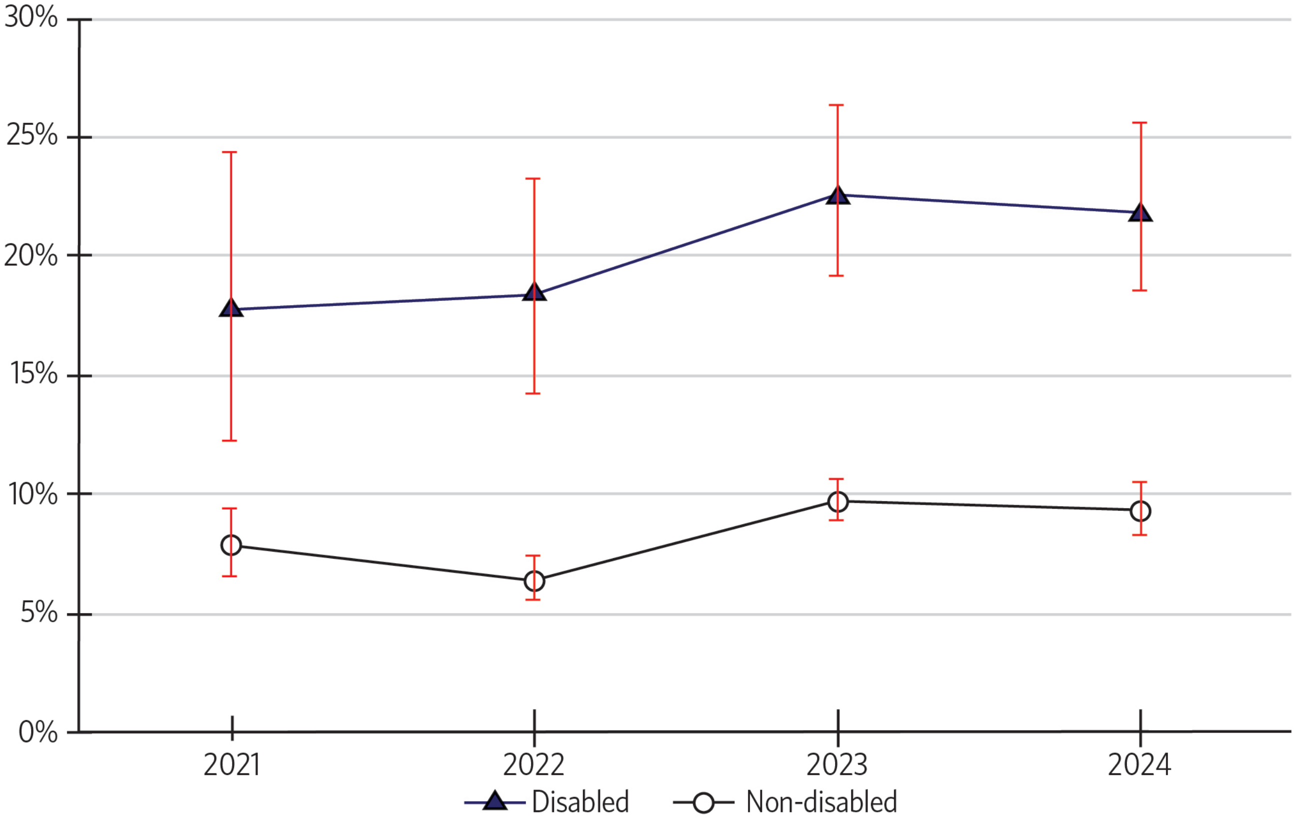
Source: IDI

High unmet need for mental health care

Despite this higher use of secondary mental health services, more disabled people report unmet need for mental health care. This unmet need has increased over the past four years.

The NZ Health Survey, 2024/25, estimated 10.5% of the New Zealand population, or 456,000 adults aged 15 and over, had unmet need for professional help for their mental health in the past 12 months. For disabled adults, this estimate was 21.9% (about 85,000 disabled adults), over twice the rate for non-disabled adults, at 9.4% (about 370,000 non-disabled adults) (Figure 57).

Figure 57: Unmet need for professional help for their mental health in past 12 months, by disability status, 2021–24



Source: New Zealand Health Survey

Māori disabled people in New Zealand experience significantly higher rates of poor mental health, psychological distress, and socioeconomic deprivation compared to non-disabled people. In 2023/24, Māori had the highest rates of unmet need compared to other ethnic groups (14.7%, about 95,000 people), followed by Pacific (12.7%, about 37,000 people).[72]

In New Zealand, qualitative research examining disabled people's experiences of health and wellbeing suggests that 'diagnostic overshadowing' may contribute to the high prevalence of anxiety and depression among disabled people.[73] Diagnostic overshadowing refers to a health professional's bias whereby they over-attribute symptoms to an individual's disability and so overlook co-existing health conditions unrelated to the disability.[74] Other factors contributing to the high rates of psychosocial disability among disabled people and reports of unmet need include: inaccessible mental health services (eg, for D/deaf people and people with a learning (intellectual) disability); the stress and anxiety of engaging with the health and disability system; lack of 'mental access'[75] due to the ongoing impact of medical trauma; loneliness and isolation; stigma; lack of appointments and wait times; financial barriers to non-funded services; and a lack of cultural responsiveness within mental health services, including limited awareness of disability culture.[76]

Abel, Tāne Maori, He tangata turi (Māori Deaf male)

As a Māori male, the health system has been hard to navigate. Even harder, as a tangata turi (Deaf person), accessing mental health support in the Aotearoa health system has felt like pushing against a door that was never built with my needs in mind.

Early help that never quite fit

My first experience with mental health support happened when I was about 13, in high school. Like many teenagers, I was struggling with depression and trying to understand what was happening to me. I reached out for help because that's what you're told to do. But from the very beginning, it didn't feel right.

The counsellors and psychologists I saw could sometimes sign a little, which people often assume is enough. But none of them understood what it meant to be Māori, or what it meant to be a Māori man. They didn't understand the dynamics of my whānau, especially my relationship with my father. Most of them were Pākehā, and while they may have had training in Deaf spaces, they had little understanding of Māori realities. I was expected to open up about deeply personal things in a system that didn't fully see who I was.

At school, things became more complicated because of how Deaf support was organised. Interpreters worked across multiple students, and information often got mixed up. I remember being there to manage my depression and being given information about suicide that actually related to another Deaf student. Suddenly, I knew about someone else's suicidal thoughts. At that age, we didn't have the tools or language to deal with that. We didn't know how to talk about suicide, let alone process someone else's pain alongside our own.

When support stops and survival begins

One thing school did have was funding. Mental health and wellbeing services were supported, likely through the Ministry of Education. But once I left school, that safety net disappeared. As an adult, especially at university, there was no clear funding for interpreters. Suddenly, the question wasn't just 'Can you help me?' but 'Who will pay for me to communicate?'.

Often, when I contacted services, my background information would get passed from one person to another. There was a panic – about me being Deaf, about me being Māori. Layers of complexity that didn't exist for others. I'd be moved along because someone else had 'more experience with Deaf people', or because another person 'knew a bit of sign'. Each time, I had to start again. Each time, I had to explain myself again. Eventually, it becomes exhausting.

Continued over

During university, I was supporting a partner through a very serious health situation. They were hearing, so they had access to services and a support system. I didn't. When we went to appointments together, medical professionals would often ask my partner if it was okay for an interpreter to be present, for me. That decision wasn't given to me. Because of privacy concerns, the answer was often no. So I sat there, unable to fully understand what was happening, unable to support them properly, while dealing with heavy emotional topics in silence.

The hidden labour of being Deaf

This wasn't really about money. It was about awareness. Many professionals didn't understand that interpreters work under strict ethical codes, or that Deaf people are used to navigating these spaces. What feels new and uncomfortable to them is normal for us. Eventually, I stopped caring and brought an interpreting student along just so I could have some access. It wasn't ideal, but it was better than nothing.

Over time, I learned that I had to prepare before seeking help. I learned to introduce myself carefully, explain that I'm Deaf, explain how interpreters work, and reassure professionals before we could even begin talking about my actual problems. Deaf people do this all the time. It's extra emotional labour before you even get to your pain.

A few years ago, after another relationship breakdown, I tried again to get counselling. This time, I specifically asked for a Māori man. He didn't need to be Deaf – I just wanted someone who understood part of my world. Even then, I got passed around. I was told someone else would be better, then someone else again. Eventually, I went back to the first person I asked for. When we finally sat down together, the worry disappeared. He saw me as human first. The communication difference was just that – a difference, not a barrier.

What happens when access is denied

One of the hardest experiences of my life was supporting a long-term partner through a serious, lifelong illness. For months, I went with them to doctors and hospitals, trying to understand what was happening so I could support them. I never once had an interpreter. I missed crucial information. I couldn't fully grasp their diagnosis or what it meant for our future. It wasn't until after the relationship ended that I realised how much that lack of access had affected me, and how much I needed support myself.

I am aware that I carry privilege. I've had access to education. I can read, write and explain myself. I can advocate. Many Māori and tangata turi don't have that same access. They come to me asking for help, asking how to navigate systems that have never welcomed them. Too many have suffered alone, unable to express what they're going through because language is everything. Without it, support feels impossible.

What doing it right can look like

This is why training matters. Counsellors, psychologists and other health professionals need real education about Deaf and disabled experiences. They need to understand when passing someone along is harmful, not helpful. They need to know that trust is fragile when you're constantly redirected.

I have had one example of care done right. Growing up, my family GP took the time to communicate with me properly. He wrote things down, explained terms and made sure I understood. Because of that, I grew confident enough to go to appointments on my own. That relationship showed me what good care can look like.

Continued over

But it shouldn't depend on luck or one good person. It should be built into the system.

For too long, Māori and tangata turi men like me have been in survival mode. We adapt, we prepare, we advocate – not because we want to, but because we have to. It shouldn't be this hard to be seen, heard and supported in our own health system. ■

Disability and elective surgery

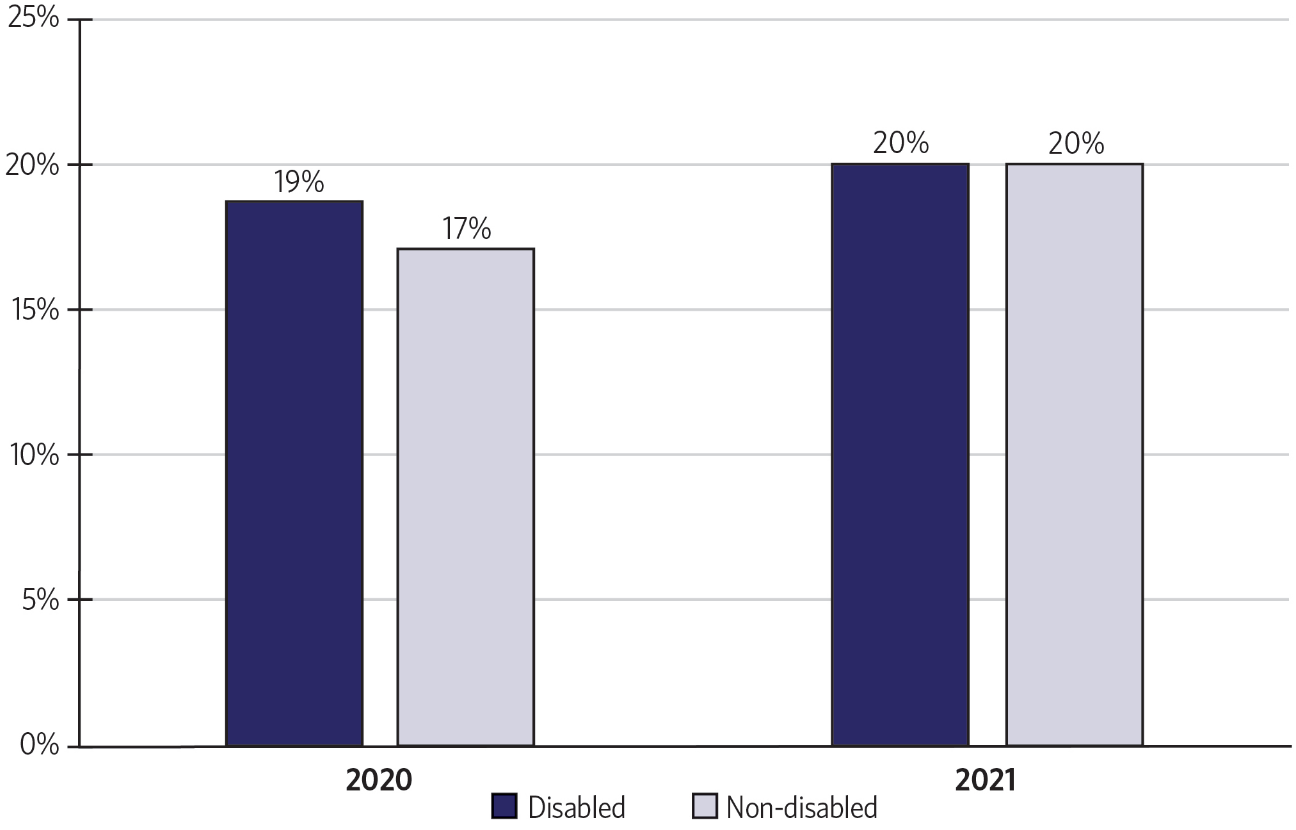
This section examines the following key indicators for elective surgery of:

- delays in getting specialist assessment after a referral is made
- delays in getting actual treatment after a specialist assessment
- post-operative complications after the elective surgery.

Getting a specialist assessment after a referral is made

Pleasingly, the percentage of people waiting more than four months from their referral to getting their first specialist assessment was very similar in 2020 and 2021 for disabled people and non-disabled people. (Figure 58).

Figure 58: Percentage of patients, ages 19–64, waiting more than four months for first specialist assessment after being given referral, by disability status, 2020–2021



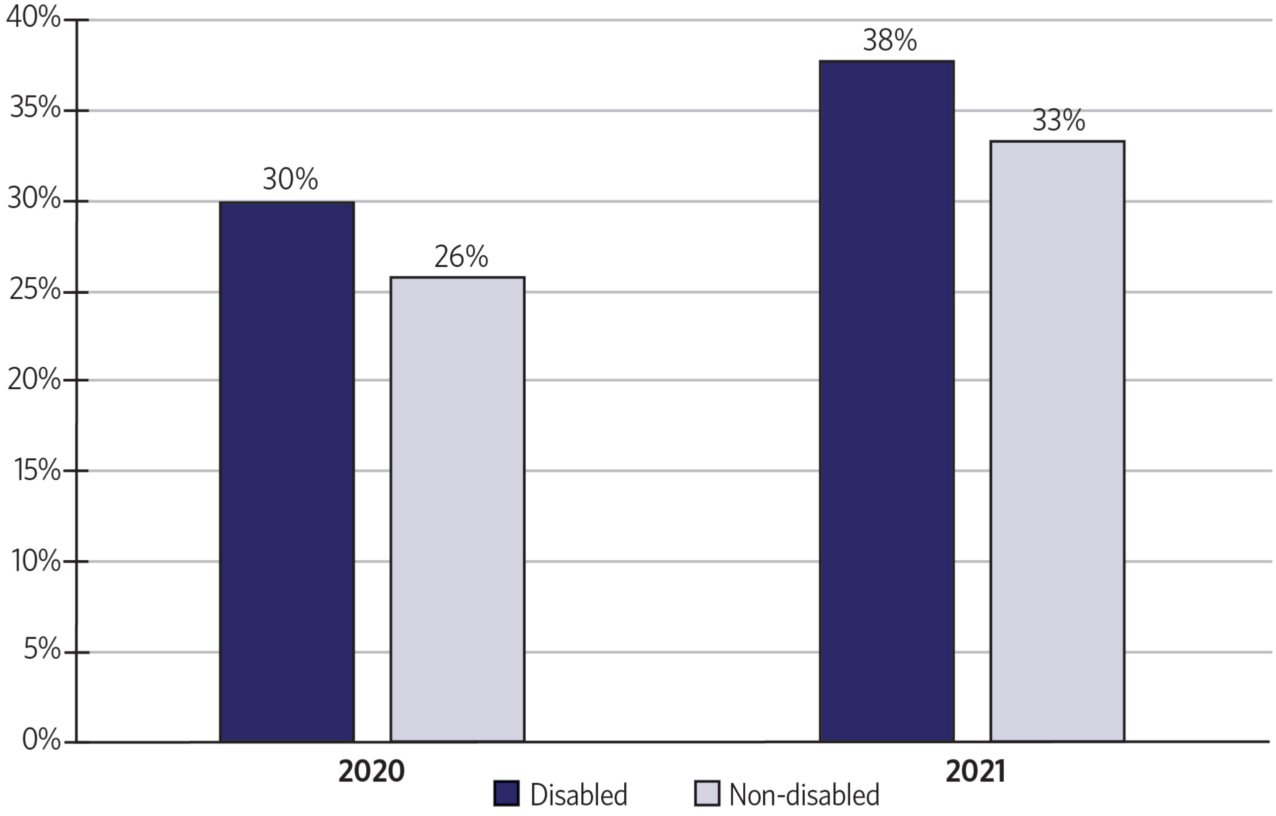
Source: IDI

Getting actual treatment after the specialist assessment

However, after being given a commitment to treatment, a greater proportion of disabled people than non-disabled people waited more than four months to receive that treatment. This raises questions about barriers to accessing treatment services and whether the health system is effectively rationing care by prioritising non-disabled people who may be perceived as less complex to treat, over disabled people with more complex needs.

As the number of disabled people waiting more than four months for treatment grew between 2020 and 2021 and into the pandemic, the gap between disabled people and non-disabled people also grew. By 2021, 38% of disabled people and 33% of non-disabled people waited more than four months to get their elective surgery performed (Figure 59).

Figure 59: Percentage of patients waiting more than four months for treatment after being given commitment to treatment, by disability status, 2020–2021

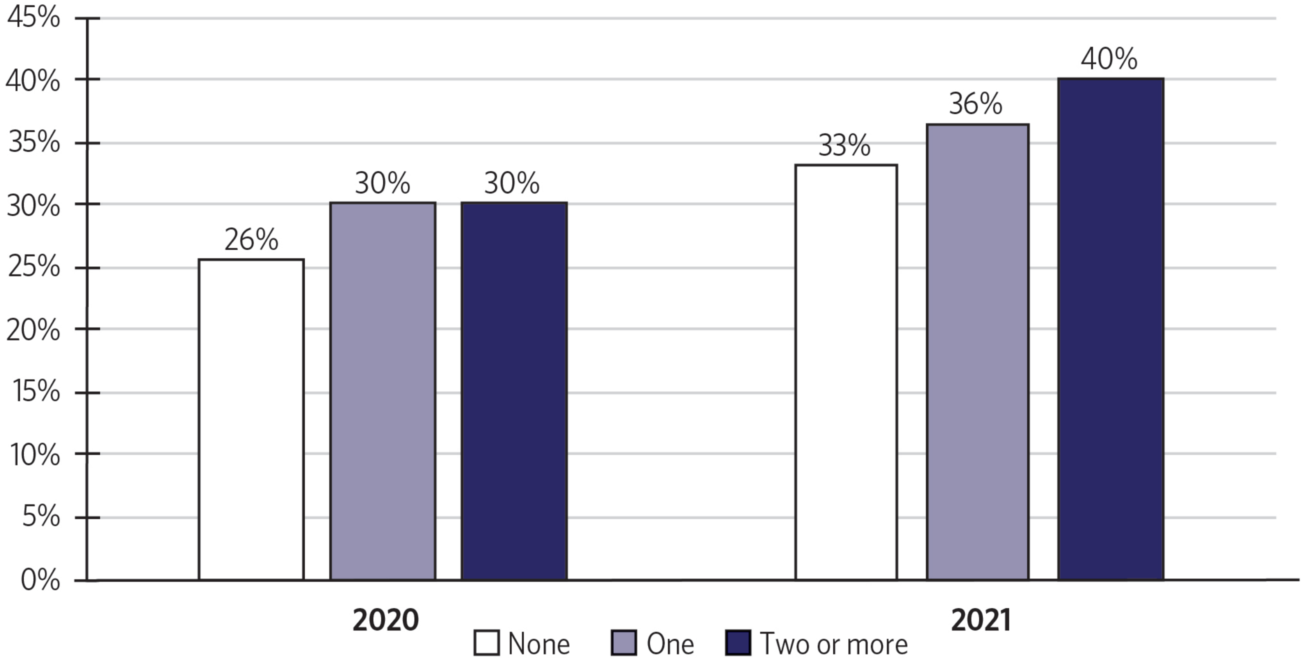


Source: IDI

The more impairments a disabled person had, the more likely they were to wait more than four months for their treatment.

In 2021, 33% of non-disabled people, 36% of disabled people with one impairment and 40% of people with two or more impairments waited more than four months to get treatment (Figure 60).

Figure 60: Percentage of patients waiting more than four months for treatment after being given commitment to treatment, ages 19–64 years, by number of impairments, 2020–2021



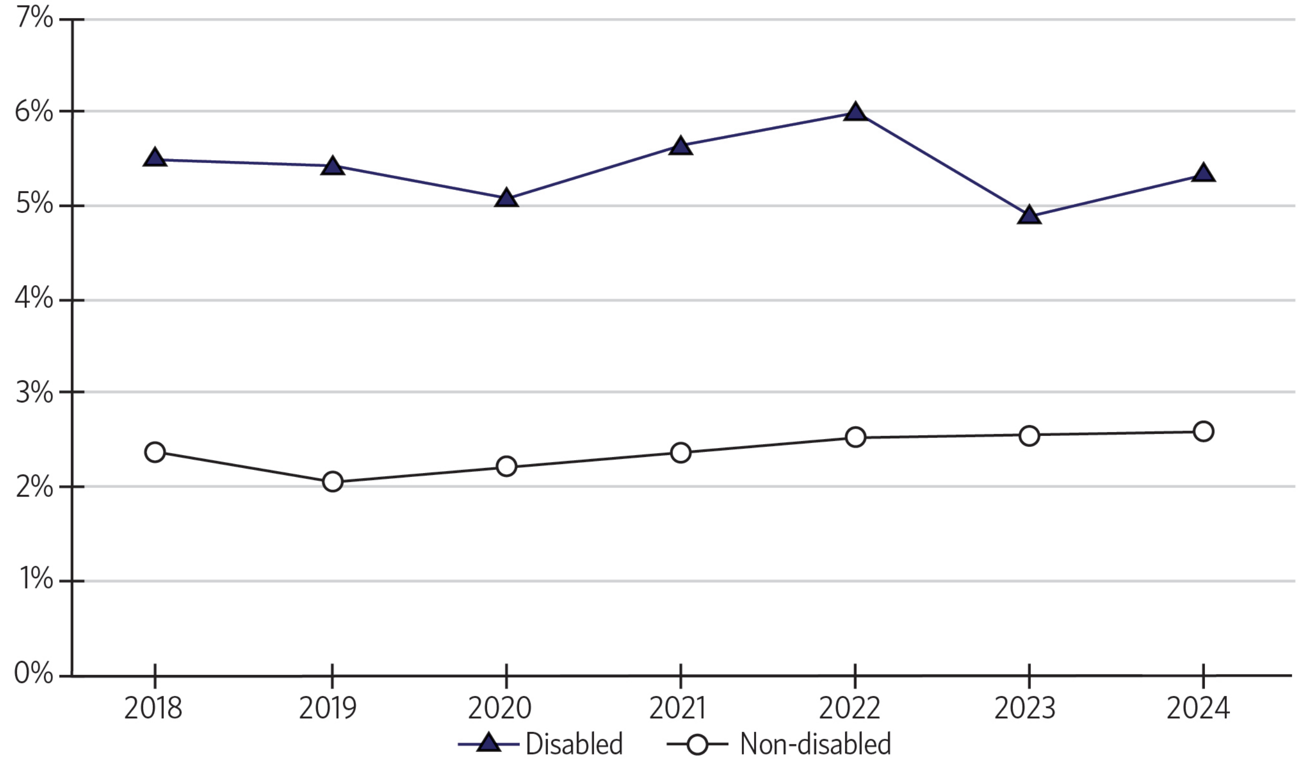
Source: IDI

More post-operative complications

After elective surgery, disabled people were more likely than non-disabled people to experience post-operative complications.

In 2024, about 3% of non-disabled people experienced post-operative complications, while 5% of disabled people did (Figure 61).

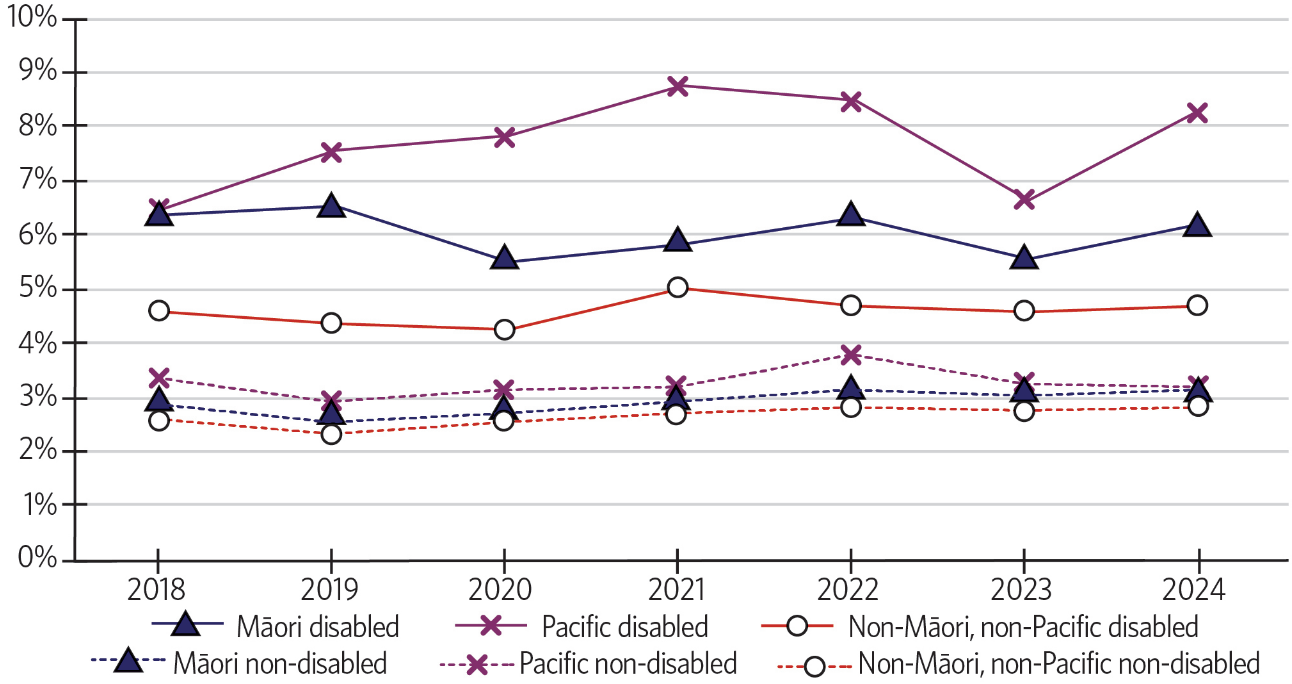
Figure 61: Percentage of complications in common surgeries, ages 19–64, by disability status, 2018–2024



Source: IDI

Māori and Pacific disabled people were more likely than non-Māori, non-Pacific disabled people to experience post-operative complications (Figure 62). The gap was greatest for Pacific disabled people, with a percentage roughly double that of Pacific non-disabled people.

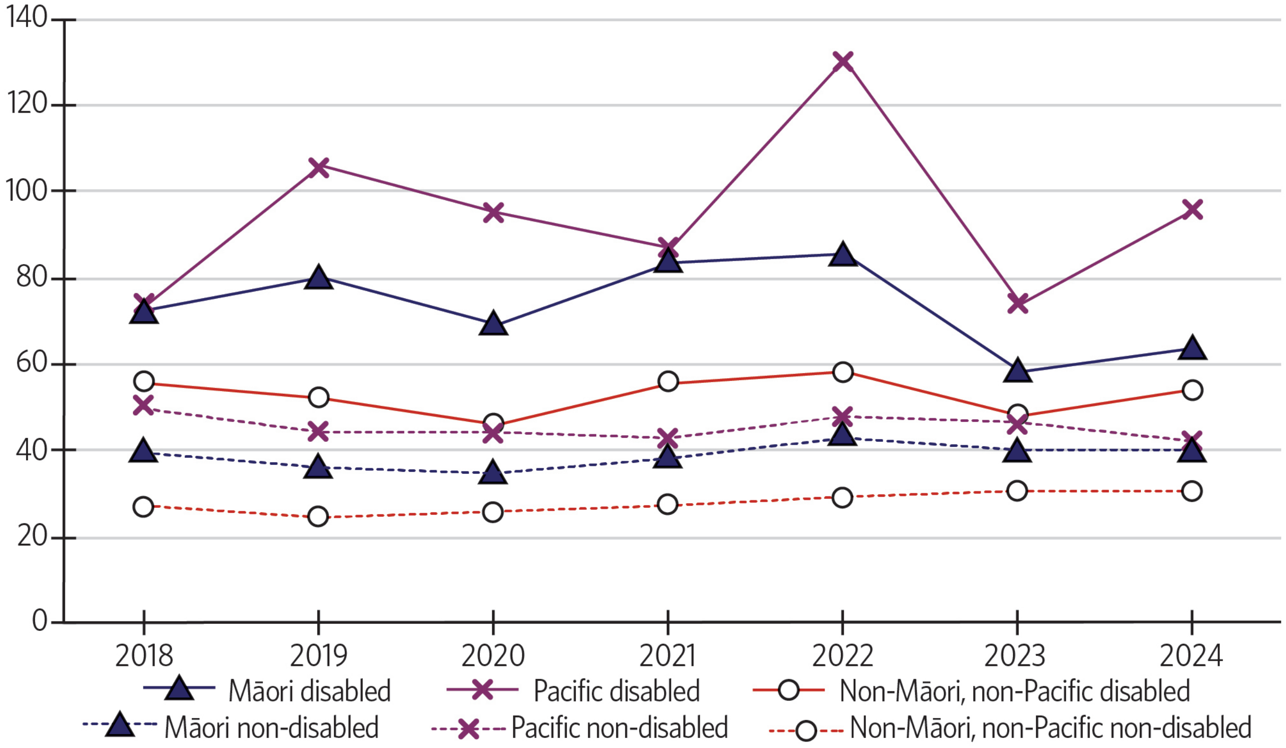
Figure 62: Percentage of complications in common surgeries (all ages) for disabled people, by ethnicity, 2018–2024



Source: IDI

Focusing only on adults aged 40–64 years, the relationships between disability status and ethnicity are clear. As Figure 63 shows, Pacific disabled people aged 40–64 years have the highest post-operative complications rate (solid green line), while non-Māori, non-Pacific adults aged 40–64 years who are not disabled have the lowest complication rate of all (dashed dark red line).

Figure 63: Post-operative complications rate per 1,000 surgeries, ages 40–64 years, by ethnicity and disability status, 2018–2024



Source: IDI

Disability and oral health

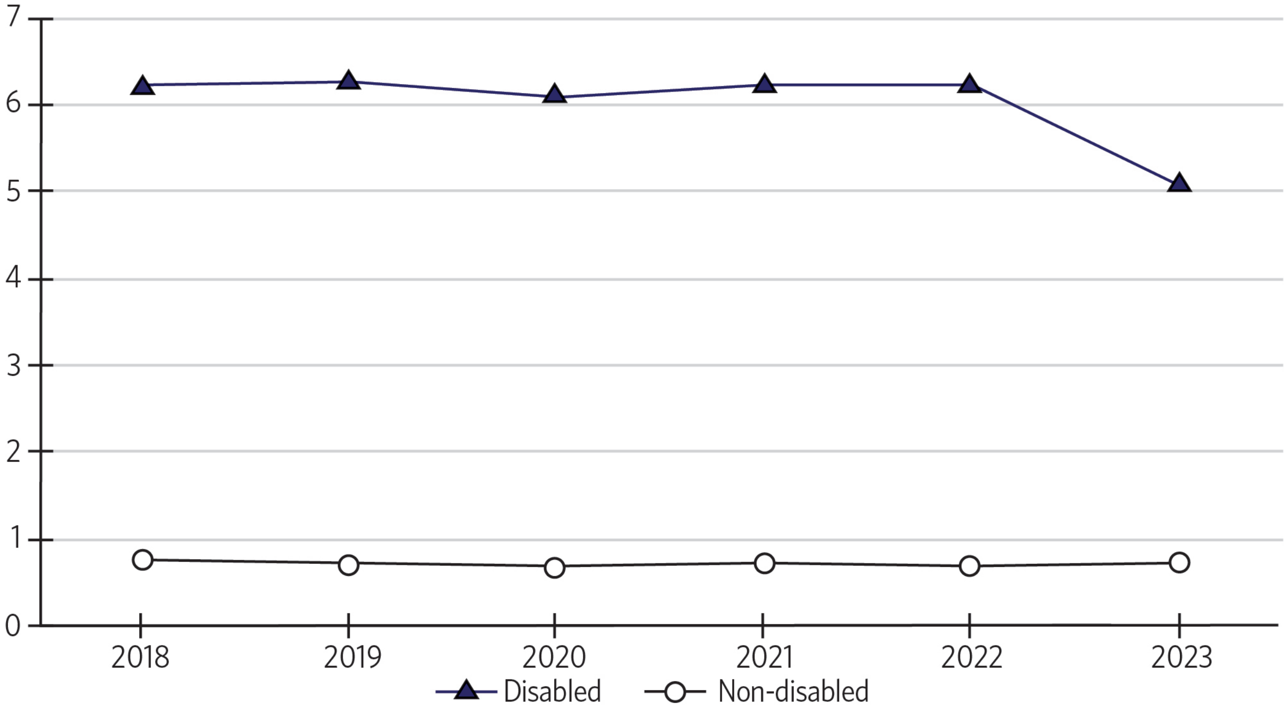
Chapter 3 reported early inequities in rates of decay in disabled children, and higher rates of dental surgeries in disabled children aged 5–18 years. Unsurprisingly, the path of oral health worsens as disabled people progress through adulthood. Access to dental care for people with multiple and complex disabilities is challenging, as is the accessibility of dental clinics.

Possibly one of the biggest contributors to the inequity is that many disabled adults simply cannot afford the dental care they need. The New Zealand Health Survey found disabled adults were 1.33 (CI 1.23–1.43) times as likely as non-disabled adults to report unmet need for dental health care due to cost in the past 12 months.

Data is hard to come by, but it is possible to measure the number of dental surgeries performed on disabled adults for serious issues such as dental caries, diseases of pulp and periapical tissues, gingivitis and periodontal diseases.

The rate of dental surgeries per 1,000 population a year in disabled adults is approximately eight times higher than that of non-disabled adults (Figure 64).

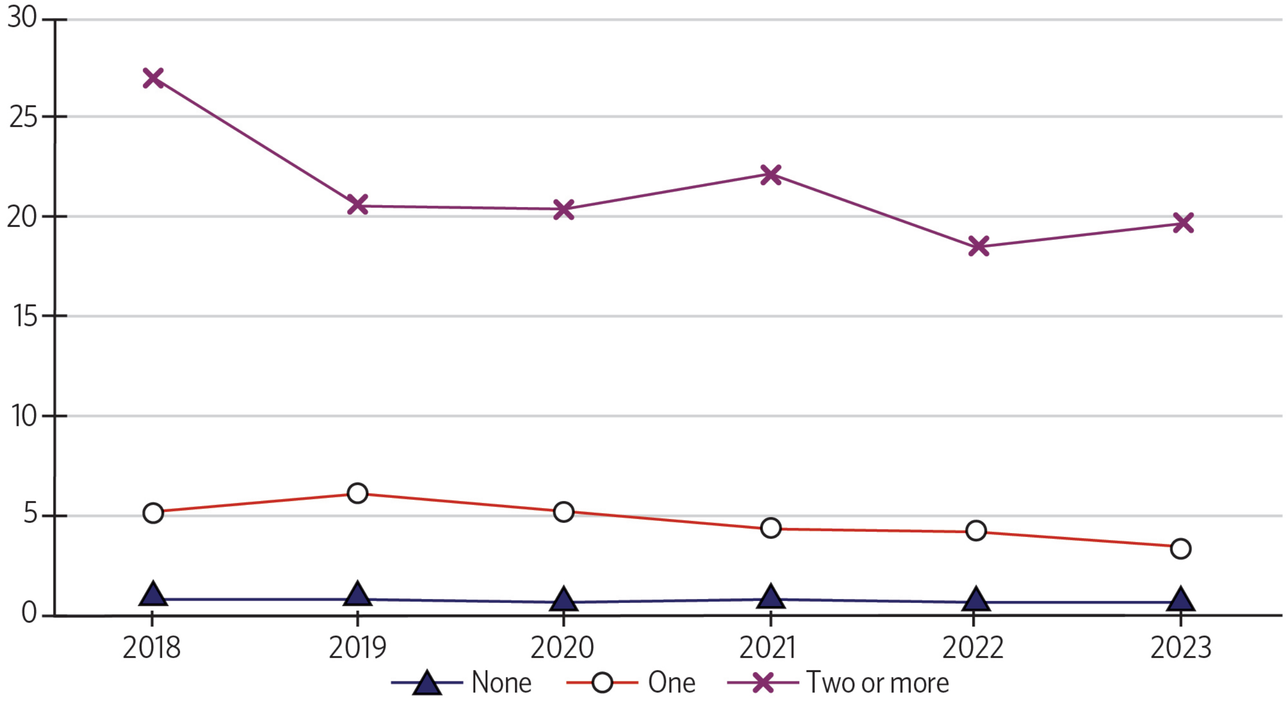
Figure 64: Rate of dental surgeries per 1,000 population per year, by disability status, 2018–2023



Source: IDI

Again, the more impairments a person had, the worse their dental outcomes were. Disabled people aged 19–39 with two or more impairments had a rate of 20 dental surgeries per 1,000 population in 2023 (Figure 65). People with two or more impairments were 28 times more likely than those with no disability to end up in hospital for dental issues. For people with a single impairment, the rate was 3, and for people with no disability, it was 0.7 per 1,000.

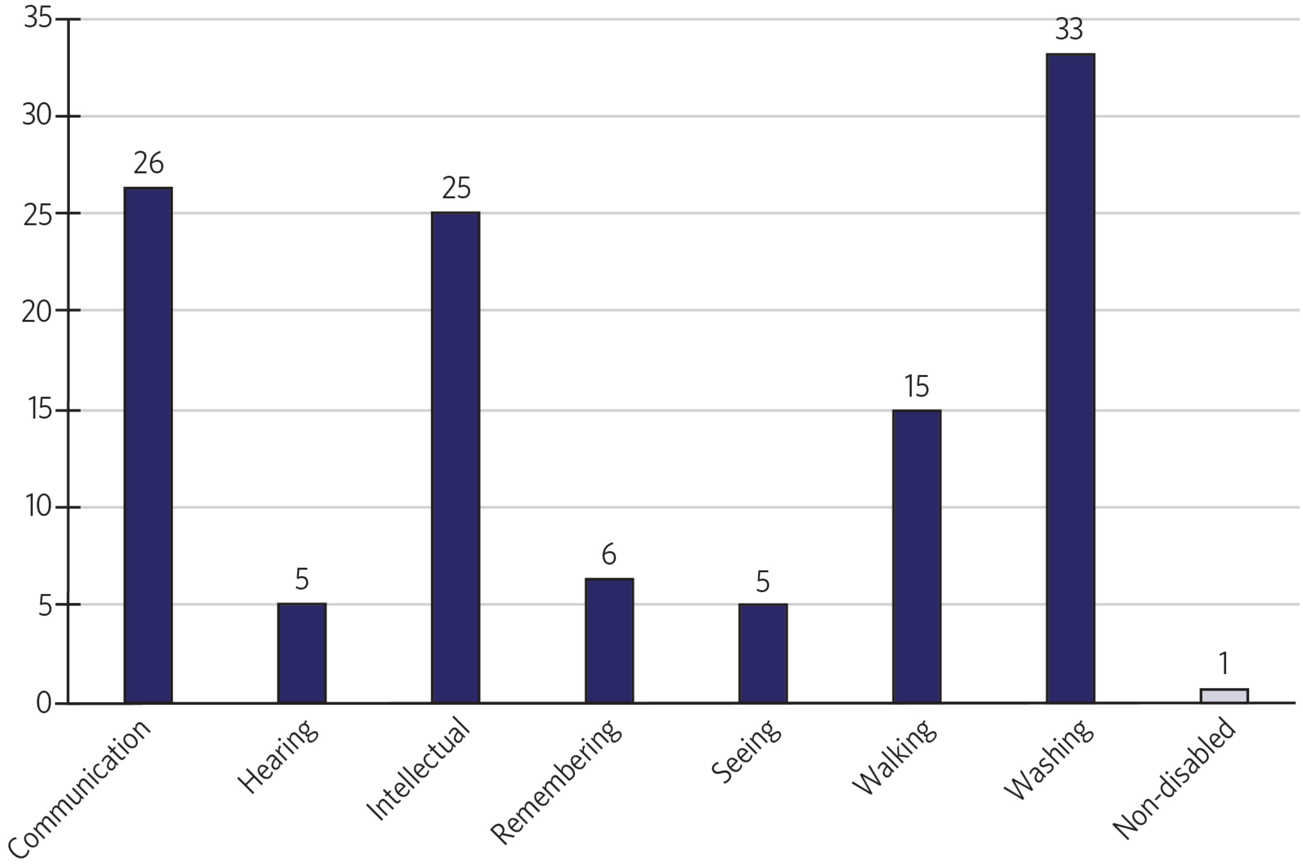
Figure 65: Rate of dental surgeries per 1,000 population per year, ages 19–39 years, by number of impairments, 2018–2023



Source: IDI

People in the washing, communication and intellectual disability domains were hospitalised for dental surgery more than any other group among those aged 19–39 years (Figure 66). These differences from non-disabled people are unlikely to be due to chance.

Figure 66: Rate of dental surgeries per 1,000 population per year, ages 19–39 years, by WG-SS disability domain, 2023



Source: IDI

Dr Sunethra Tennekoon

BDS, DClinDent (SND), Adult Special Needs Dentistry, Waikato Hospital

Adult patients with behavioural, intellectual or physical disabilities make up a significant proportion of our patient cohort.

Access to dental treatment in the community or private sector is usually not possible and wait times for a consultation in the dental department can take between 300 and 600 days.

These unsatisfactory wait times are due to limited specialist dental staff, limited dental support staff and limited hospital resources, including clinic availability and further wait times for a general anaesthetic waitlist.

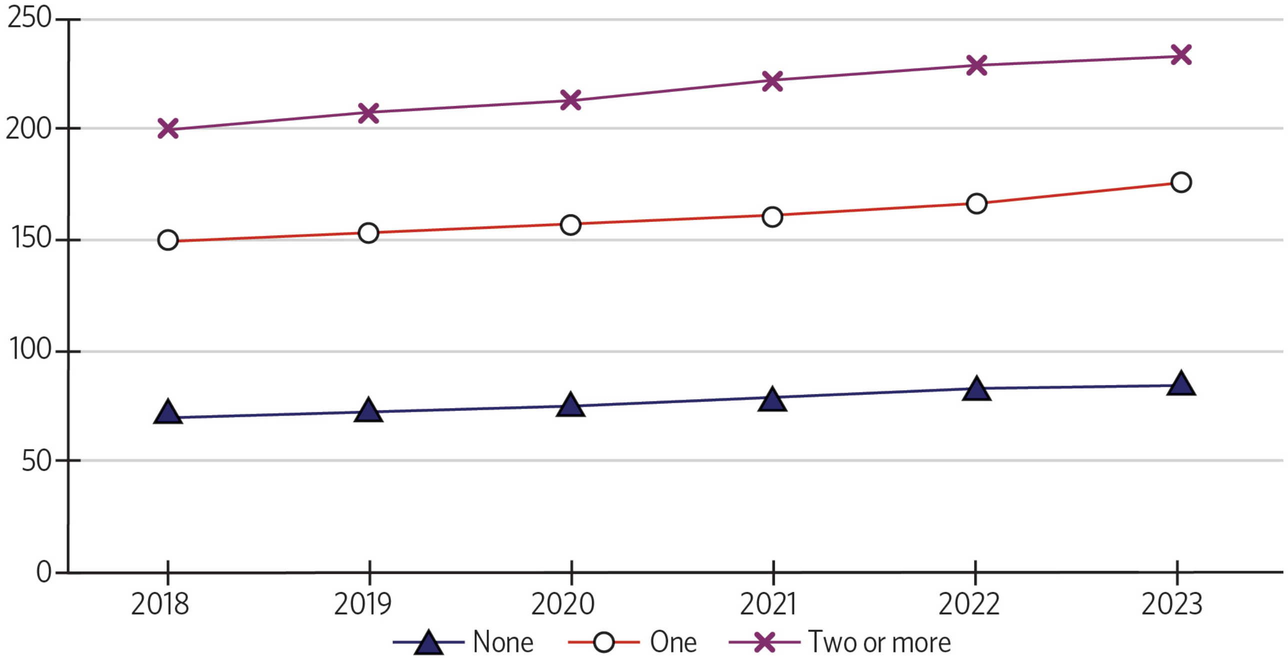
There is always pressure to see these high-need and vulnerable patients as efficiently as possible and the recognised delays are stressful for patients, their whānau, their support staff and for the dental staff, also. ■

Disability and diabetes

Diabetes is both a leading cause of disability and a chronic condition managed by people already living with disability. While both Type 1 and Type 2 diabetes can appear at any age, Type 1 diabetes often appears in children and younger adults, while the risk of Type 2 diabetes increases with age. People who develop diabetes are at increased risk of disability.[77] [78] Research also shows that people with existing disabilities experience higher rates of diabetes, particularly people with mobility or learning (intellectual) disabilities, due to a wide range of factors such as genetics, lifestyle, medication use and misuse, barriers to appropriate medical care, comorbidities, and more.[79]

In New Zealand, there is a higher diabetes prevalence among disabled people compared with non-disabled people (over 170 per 1,000 versus about 60 per 1,000). Diabetes is more common among disabled people with more than one impairment. In 2023, the rate of diabetes for non-disabled people aged 40 to 64 years was 84 per 1,000 population. For people with one impairment, the rate doubled to 175 per 1,000, and for people with two or more impairments the rate almost tripled: 232 per 1,000 (Figure 67). In some cases, diabetes will be a cause of impairment, so the picture is muddied, but the burden is clear.

Figure 67: Prevalence of diabetes per 1,000 population, ages 40–64 years, by number of impairments, 2018–2023



Source: IDI

Māori are approximately 2.5 times more likely to have type 2 diabetes than non-Māori/non-Pacific people. These disparities are not merely due to genetics or lifestyle but are strongly driven by systemic racism, the intergenerational impacts of colonisation, and socio-economic deprivation.[80] For those aged 40–64, Pacific disabled people have the highest diabetes prevalence (about 390 per 1,000) followed by Māori disabled people (around 250) and then disabled people of other ethnicities (around 150). Non-Māori, non-Pacific people have the highest percentage of regular dispensings of hypoglycaemic medication (73.9%), followed by Pacific disabled people (71.8%) and then Māori disabled people (69.6%).

Cancer and disability

In 2021, Te Aho o Te Kahu – Cancer Control Agency (the Agency) identified a lack of research on cancer incidence and cancer outcomes for disabled people in New Zealand.

TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY

The Agency worked with lived experience advisors, Hei Āhuru Mōwai Māori Cancer Leadership Network, He Ara Tangata – the Agency's Consumer Advisory Group, Whaikaha – Ministry of Disabled People, Health New Zealand | Te Whatu Ora and the Ministry of Health – Manatū Hauora to review the available data, evidence and insights available on how disabled people experience cancer services and care.

The information has been collated in two reports that the Agency released on 27 November 2025. These new reports aim to highlight issues or attitudes that can make it harder for disabled people to access timely, high-quality cancer diagnosis and care. The reports highlight the:

- need to maintain a continued focus on providing accessible, inclusive and equity-focused cancer services
- importance of having robust data, collaboration and co-design of health services with disabled communities.

The team compared cancer diagnosis rates for those identified as having a disability with those of the total population. They looked at overall cancer diagnosis and the diagnosis rates for the four most common cancer types in New Zealand: lung, breast, bowel and prostate cancer.

Their findings are summarised below. For the full methods and results, with important caveats related to the difficulties presented by the lack of reliable data on disability status, please see the full reports, and frequently asked questions, available on the Agency's web page, Disability and Cancer reports (https://teaho.govt.nz/index.php/our-work/disability-and-cancer-project/disability-and-cancer-reports).[81]

Major findings on cancer and disability

These results are not official statistics. They have been created for research purposes from the IDI, which is carefully managed by Stats NZ. For more information about the IDI, visit stats.govt.nz/integrated-data on the Stats NZ website. More information on the methodology of this research project is available in the report.[82]

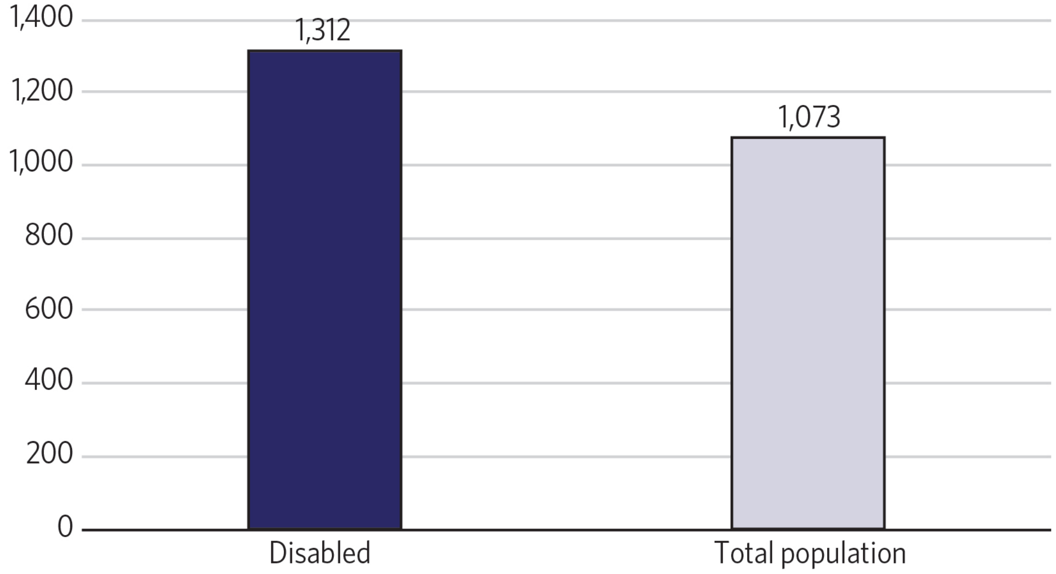
Cancer diagnosis was more common among disabled people than among the total New Zealand population. After adjusting for age differences, disabled people were 22% more likely to be diagnosed with cancer than the total population (RR 1.22; 95% CI 1.20–1.24) (Figure B1).

Disabled people are diagnosed with cancer more often than the general population, including for lung, bowel and breast cancers. However, the report explains that being disabled does not by itself make someone more likely to get cancer. Instead, disabled people might have a higher risk because they are more likely to be exposed to cancer-

Continued over

causing factors, like smoking. They may also face challenges linked to lower income, poor housing, and problems getting to doctors or cancer screening. These structural issues can make it harder to stay healthy and get cancer diagnosed early.

Figure B1: Age-standardised cancer incidence rate among disabled people and the total population per 100,000 person-years, 2018–2022

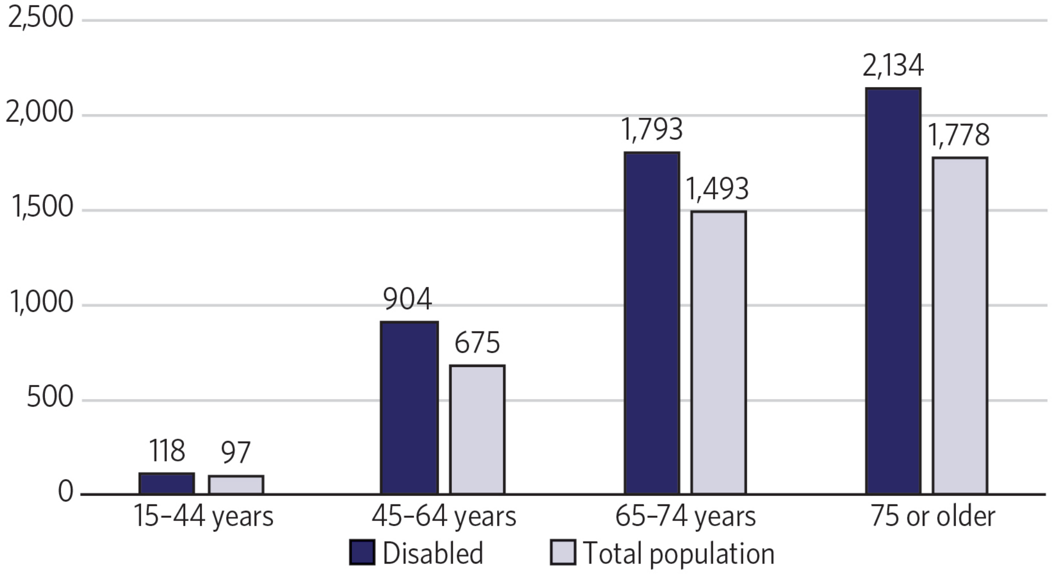


Source: IDI, 2025

Note: Rates are expressed per 100,000 person-years and age-standardised to the disabled population.

The highest difference was seen in the 45–65 years age group, where disabled people were 34% more likely to be diagnosed with cancer than the total population of the same age (Figure B2).

Figure B2: Age-standardised cancer incidence rate among disabled people and the total population per 100,000 person-years, by age group, 2018–2022

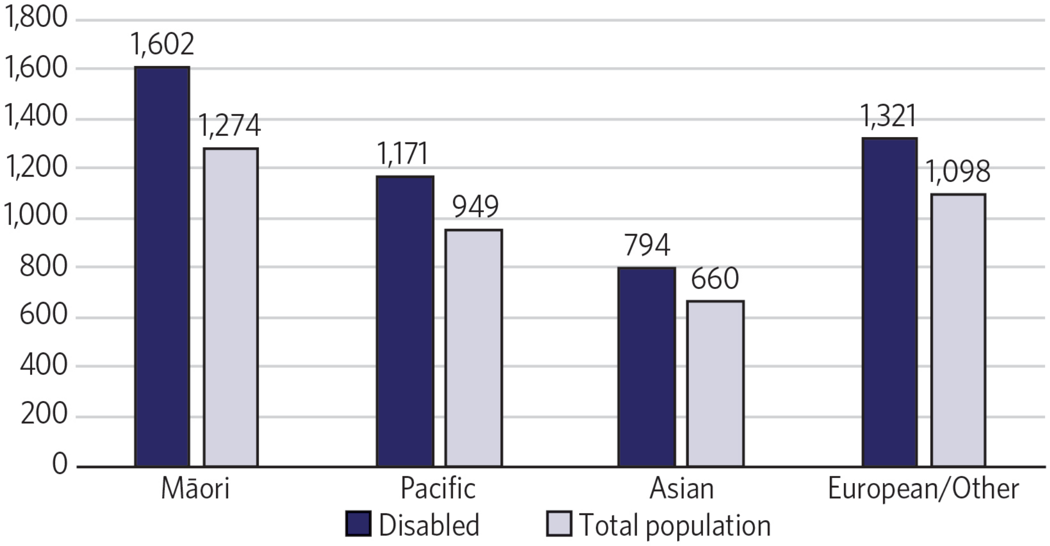


Source: IDI, 2025

Note: Rates are expressed per 100,000 person-years and age-standardised to the disabled population.

Tāngata whaikaha Māori | Māori disabled people had the highest incidence rate of any group within the disabled population (1,602 per 100,000 person-years) (Figure B3). Disabled males, disabled people living rurally and disabled people living in areas of high deprivation (Figure B4) were other subgroups within the disabled population that had a higher incidence of cancer.

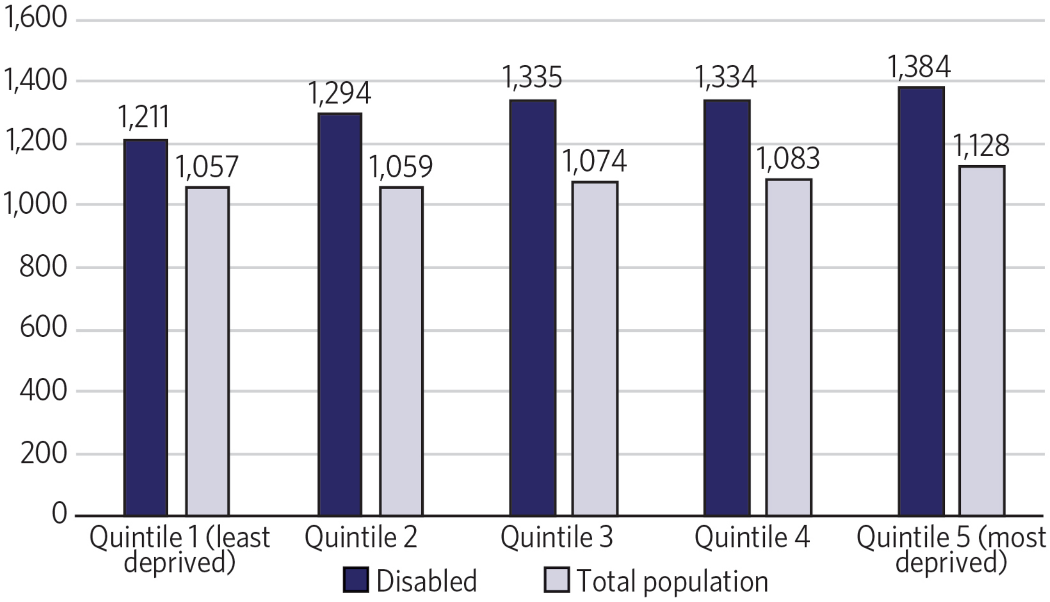
Figure B3: Age-standardised cancer incidence rate among disabled people and the total population per 100,000 person-years, by ethnicity, 2018–2022



Source: IDI, 2025

Note: Rates are expressed per 100,000 person-years and age-standardised to the disabled population.

Figure B4: Age-standardised cancer incidence rate among disabled people and the total population per 100,000 person-years, by deprivation quintile, 2018–2022



Source: IDI, 2025

Note: Rates are expressed per 100,000 person-years and age-standardised to the disabled population.

Screening

Studies from around the world show that disabled people are less likely to get screened for cancer, especially breast and cervical cancer. This means cancer may not be found early, making it harder to treat and leading to worse health.

There are many reasons why disabled people face challenges with cancer screening and treatment. These include clinics and appointment times that do not meet their needs, not having enough help to use health services, unclear or hard-to-read information for patients, and health staff who may not have enough training about disability.

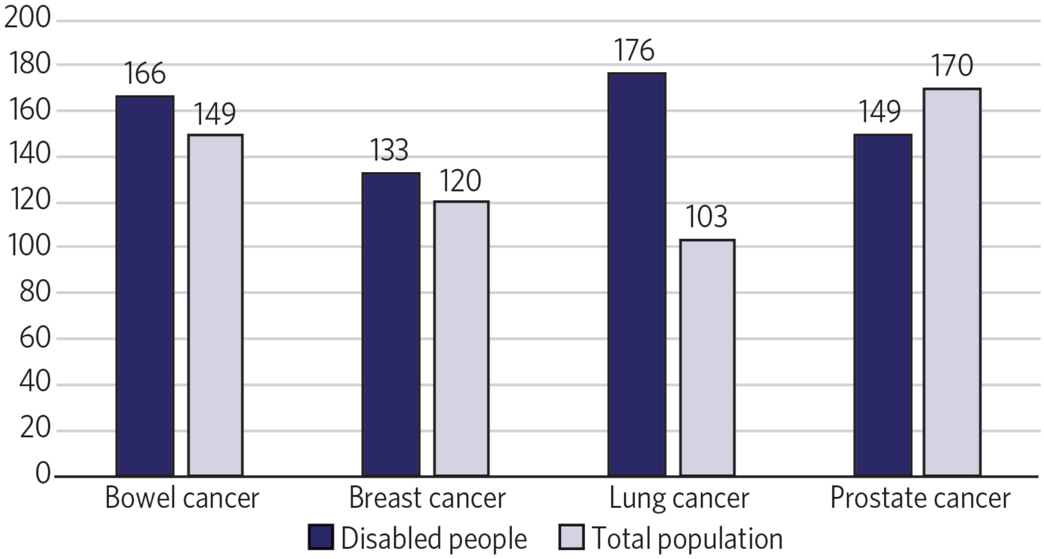
Prevention interventions (especially smoking cessation), screening programmes (including lung cancer screening) and cancer services all need to be accessible and acceptable to disabled people, with appropriate models of care.

Different types of cancers

Lung cancer

Overall, disabled people were found to have a 71% higher rate of lung cancer diagnosis compared with the total population (RR 1.71; 95% CI 1.62–1.80) (Figure B5). Among disabled people, tāngata whaikaha Māori experienced the highest incidence of lung cancer. This increased risk of lung cancer mirrors increased smoking rates among disabled people, who are 1.76 times as likely as non-disabled adults to be daily smokers.

Figure B5: Age-standardised cancer incidence rate among disabled people and the total population per 100,000 person-years, by cancer type, 2018–2022



Source: IDI, 2025

Note: Rates are expressed per 100,000 person-years and age-standardised to the disabled population.

The greatest difference was seen in the 45–65 age group, where disabled people were overall 34% more likely to be diagnosed with cancer than the total population.

Bowel cancer

Disabled people were found to have a 12% higher rate of bowel cancer diagnosis compared with the total population (RR 1.12; 95% CI 1.06–1.18). Disabled people living rurally were 20% more likely to be diagnosed with bowel cancer than the total rural population.

Breast cancer

Disabled people had an 11% higher rate of breast cancer diagnosis compared with the total population across all age groups (RR 1.11; 95% CI 1.05–1.18). Disabled people over the age of 75 were 24% more likely to be diagnosed with breast cancer than people of the same age in the total population.

Prostate cancer

Prostate cancer demonstrates a notably different pattern to the other cancers included in this review. Disabled people were less likely to be diagnosed with prostate cancer than the total population (RR 0.88; 95% CI 0.83–0.93).

This lower rate of prostate cancer diagnosis is seen among other population groups that have an overall higher rate of cancer diagnosis, such as Māori and people living in areas of higher deprivation. This is possibly related to differences in the likelihood of accessing PSA testing in primary care.

How the report was prepared

The Burden of Cancer among Disabled People: Diagnosis insights report used two data sources to identify disabled people in New Zealand. These are:

- Census and other household surveys that use the WG-SS to identify people with specific impairments
- health record data, including needs assessment data to also identify people with these same functional impairments.

Using these methods, the team compared the disabled cohort with rates in the total population. Person-years is a measure that combines the number of people and the amount of time they are observed. For example, 100,000 person-years could mean 100,000 people followed for one year. Reporting cancer rates per 100,000 person-years allows fairer comparisons across groups and time periods, and accounts for the dynamic nature of disability status over time.

More detail on the methods, including some important limitations, are described in the report. ■

The unmet need of disabled adults

Unmet health professional service need – large numbers, difficulties accessing primary care due to lack of appointments and long waiting lists

The 2023 Household Disability Survey found that a third (29%) of disabled adults had an unmet need to see a health professional in the past 12 months (27% male, 31% female). That is about 245,000 people.

By ethnicity, nearly two-fifths (37%) of Māori disabled people, a third (32%) of Pacific disabled people, 29% of European disabled people and 23% of Asian disabled people experienced difficulty seeing a health professional when needed.

By age, 37% of disabled people aged 15–44 years, 32% of those aged 45–64 years, and 18% of those older than 65 had an unmet need to see a health professional in the past 12 months.

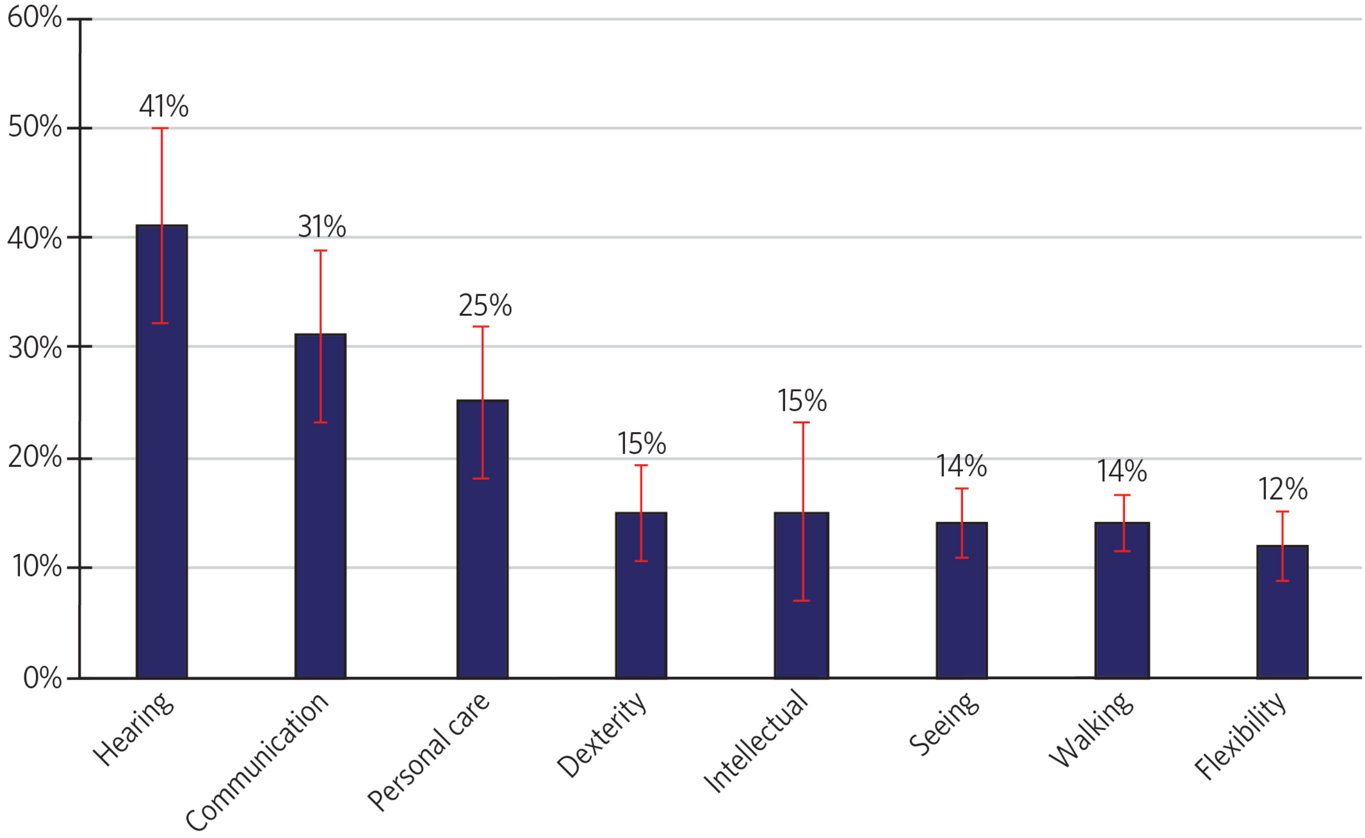
Unmet assistive equipment need – funding and information gaps

Assistive devices, such as crutches, glasses and hearing aids, can help reduce the limiting effects of some impairments. For example, recent research shows that assistive devices and technology are associated with improved quality of life; increased functional capabilities and independence; better management of chronic conditions; improved psychosocial wellbeing; and reduced physical and psychosocial stress.[83] [84] As highlighted by the World Health Organisation, "Assistive products help maintain or improve an individual's functioning related to cognition, communication, hearing, mobility, self-care and vision, thus enabling their health, well-being, inclusion and participation."[85]

The Household Disability Survey found 62% of disabled people (about 526,000 people) use assistive equipment or technology. Of these, only a third (33%, or 164,000 people) received government-funded equipment or technology. The rest, 67% or 336,000 people, received no government-funded equipment or technology.[86]

The survey found 28% of disabled people (about 212,000 people) had an unmet need for assistive equipment. Those with impairments in the domains of hearing, communication and personal care were the most likely to experience unmet need for assistive equipment (Figure 68).

Figure 68: Percentage of disabled people reporting an unmet need for assistive equipment, by disability WG-SS domain, 2023



Source: Household Disability Survey

As Figure 69 shows, lack of information and cost were the primary barriers to accessing assistive equipment across most disability domains investigated in the survey.

Of those with unmet need for assistive equipment, 62% (121,000 people) cited cost or ineligibility for funding as the main reason. In addition, 40%, or about 78,000 people, cited a lack of information about what equipment or funding was available or where to get it from.*

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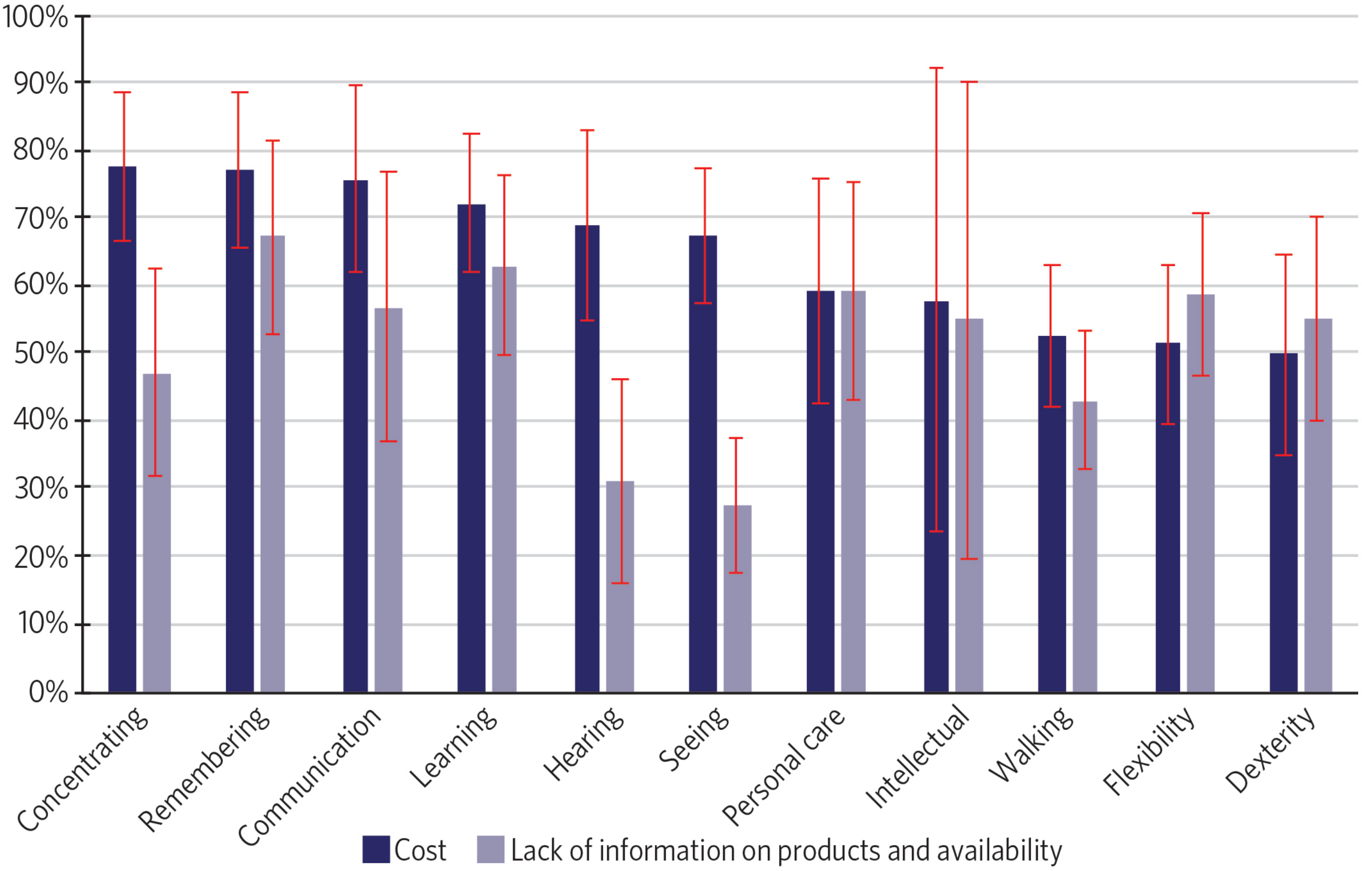
* Estimates for cost and information barriers for intellectually disabled people have a relative sampling error (RSE) of 30 to 49.9 percent. These estimates should be viewed with caution.

Figure 69: Percentage of disabled people reporting an unmet need for assistive equipment, by barrier and domain of disability, 2023



Source: Household Disability Survey

Further data on unmet need for assistive equipment

- Among disabled people, 14% reported difficulty in accessing assistive equipment and technology. Barriers to access included cost (71%), not funded (28%), long wait times (29%) and lack of information (29%).
- Unmet need was highest for sensory equipment (all ages), communication and cognition (aged five years and over) and pain/fatigue (adults only).
- By ethnicity, 63% of European, 60% of Māori, 57% of Pacific and 58% of Asian disabled people used assistive equipment or technology.
- By age, 46% of disabled people aged 0–14 years, 64% aged 15 years and older, 62% aged 15–44, 61% aged 45–64 and 68% aged over 65 use assistive equipment or technology. The differences reflect the changes that occur over life course.
- Assistive equipment and technology are most commonly used for sensory assistance (glasses, hearing devices, contact lenses) for 81% disabled people. Of those aged two years or older, 45% use assistive equipment to help with walking. Of those aged five years or older, 40% use assistive equipment to help with communication or cognition.
- By ethnicity, 36% of Māori, 38% of Pacific, 34% of Asian and 25% of European disabled people noted an unmet need for assistive equipment.
- By age, 35% of disabled people aged 0–14 years, 37% aged 15 years and older, 30% aged 15–44, 31% aged 45–64 and 21% aged over 65 had unmet need for assistive equipment and technology.

Adult disabled people in long-term care facilities

A further concern identified by disability health experts, as well as in health and wellbeing human rights monitoring, is the practice of placing adult disabled people (under 65 years) in aged residential care facilities. In many cases, this occurs because of the lack of accessible and age-appropriate facilities for younger disabled adults.[87] Health New Zealand | Te Whatu Ora data suggests that in 2025, 780 people aged under 65 years resided in long-term aged care facilities.[88] As highlighted by a young disabled woman who was interviewed for the 2020 Disabled Person-Led Monitoring report on disabled people's access to housing, being placed in an aged-care facility had a significant impact on her mental wellbeing, recovery and autonomy:[89]

> "there are no options out there for younger people with a physical disability [...] NASC presented me with basically three rest homes that took younger people [...] The next youngest person without an intellectual disability would probably be sixty. [...] I'd quite like some peace and quiet and not have to listen to not so nice entertainers. I don't join in the activities an awful lot 'cause I have physio or something on most days and I don't really wanna play bingo and I don't want to sit with 90-year-olds who can't talk when I'm having my meal. So, I eat in my room. [...] It's just... yeah, it's just not what a 30-something-year-old woman should have to do. The activities are not suitable for me. The food's not suitable for me and I'm kind of in a very, very cramped room. Yeah and I would like to be a lot more independent but there's constraints you have to fall within when you're living in this kind of situation. You know, what times you have a shower, times you eat, times when staff are available to help you with things."[90]

Health and Disability Commissioner complaints and disability

The Health and Disability Commissioner's (HDC's) 'Disabled People's | Tāngata Whaikaha Experiences of Health Services: report on complaints to HDC' has been published at the same time as this Window report. The full report is available on the HDC website, but we summarise main themes below.

Currently around 25% of complaints to the Health and Disability Commissioner (HDC) are about the care provided to a disabled person. Between 1 January 2023 and 31 December 2025, HDC received around 1,800 complaints about care and treatment provided to disabled people | tāngata whaikaha and the HDC report undertook a close thematic analysis of around 180 complaints, which revealed several recurring themes that were then grouped into seven categories:

- Provision of person-centred care
- Cultural responsiveness
- Quality of communication
- Informed consent processes
- Quality of disability related cares
- Quality of medical treatment
- Continuity and coordination of care across and between health and disability systems.

Continued over

Key findings in HDC's report include:

- the need for health providers to increase their understanding and use of augmentative and alternative communication tools, particularly in Emergency Departments and mental health settings;
- the need for health providers to continue to reduce their use of restraint for neurodivergent people in hospital and general medical settings;
- the need for improvement of staff capability through best practice resources, information and training for clinical and non-clinical staff; and
- the need for cross agency work to improve coordination, navigation, and support across and between health and disability services and funding streams.

HDC's report highlights the persistent and significant inequities in health outcomes for disabled people and underscores the need for further action to be taken for disabled people's rights to be fully realised and upheld in the health system. HDC has made recommendations to improve disabled people's experience of health services and will work with agencies to monitor their implementation.

More information and the full report is available at: https://www.hdc.org.nz/our-work/research-and-data-reports/health-experiences-of-disabled-people-report/ ■

Waata Houia – treat us as equal

Ko Tainui te waka

Ko Kapuārangi te maunga

Ko Wainui te awa

Ko Tōrerenui-a-Rua te tipuna whare

Ko Manaakiao te whare kai

Ko Tōrere te marae

Ko Ngāitai te iwi

Ko Ngāitai te hapū

Ko Waata Houia ahau.

My name is Waata. I am a 41-year-old tāne Māori, and I have a learning disability. Doctors told mum to put me in an institution when I was a baby, but she said no!

Continued over

When you ask me whether having a learning disability affects my healthcare and how I get treated in the health system, the first thing I would say is this: often health professionals don't listen. They don't treat me as a person – they don't ask me questions, they probably ask my mum. But I can answer my own things. Good doctors, they ask questions. They treat me as normal – not just as a person with a disability. One thing mum and I have noticed, is that the good doctors I have had, are mostly from overseas. I think they might have worked more with people with a learning disability. And they have had more disability training when they are learning to be doctors or nurses. I like it if I get a Māori doctor too.

One of the worst times I have had in hospital is when I was sore and upset, but the nurse wasn't listening to me. They thought I was being bolshie, but I was in pain and they were not listening. I wouldn't stay there, and since then, I don't like staying in hospital. So, sometimes when I have been really sick instead of staying in hospital, I stay home and mum looks after me. I am lucky that mum is a nurse and can do that. But lots of people don't have someone to look after them when they are sick. A time that was hard for me was when I changed from children's to adult health services. My paediatrician let me stay with him for longer than I should have, but when he retired I had to move into the adult system. That is harder, because you don't just have one doctor who knows you well.

I have had some good experiences in the health system too.

The GP I have now is amazing – sometimes it can be hard to get in but she always fits me in quick and sorts out what I need. She referred me to the hospital for something that was making me sore and affecting what I could do, but the hospital wouldn't do it. The letter said that I didn't meet the criteria. I think it was because I had a learning disability. My GP helped me instead but she thought I really should have had it done in the hospital. I have a great relationship with her because she knows me and I know her.

So this is what I say should happen to make the health system better. Teach the doctors and the nurses to learn more about disability – like we're the same as everyone else, but we've got a learning disability. We know what we can do, we know what we want to talk about, and we know what they need to learn so they can be accessible to us as who we are. We won't be changing! Treat us as equal – just treat us as same as how you treat everyone else. ■

New Zealand Government
Te Kāwanatanga o Aotearoa

Health Quality &
Safety Commission
Te Tāhū Hauora