

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

This work is licensed under the Creative Commons AttributionNonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0). To view a copy of this licence, visit <https://creativecommons.org/licenses/by-nc-sa/4.0>



New Zealand Government
Te Kāwanatanga o Aotearoa



Chapter 2

Life-course stage – Maternity and birth

It is widely recognised that disabled people face an elevated risk of adverse health outcomes during pregnancy and childbirth. International research consistently demonstrates that barriers to accessing appropriate and timely maternity and perinatal health care contribute to higher rates of caesarean section, pre-eclampsia, pre-term labour and birth, and lower birthweights among disabled people compared with non-disabled people.¹⁵ These risks are particularly pronounced for some groups within the disability community, including pregnant Deaf people and people with learning (intellectual) disabilities.¹⁶

In New Zealand, recent initiatives aimed at improving equity within maternity and perinatal systems, such as Kahu Taurima¹⁷ and the Maternity Commissioning Framework, signal growing recognition of the need to better serve marginalised populations. However, significant data and knowledge gaps remain in relation to the service experiences and outcomes of pregnant disabled people, including those from minority communities. While limited, existing sources such as the Sixteenth Annual Report of the Perinatal and Maternal Mortality Review Committee and the Ministry of Health's Survey of Whānau and Families' Experience of the Maternity System provide important insights into how disabled people engage with, and are impacted by, maternity and perinatal services in New Zealand.

A high-level summary of the findings

In New Zealand, disabled people are less likely than non-disabled people to be enrolled with a lead maternity carer (LMC), such as a midwife, in their first trimester of pregnancy. People with multiple impairments are even less likely to be enrolled with an LMC.

Later, compared with non-disabled people, disabled people experience higher rates of pre-term birth, and report lower scores on their experience of maternity care and their satisfaction with the maternity experience.

Caveats on this maternity data

International evidence suggests disabled people are at greater risk of severe pregnancy- and birth-related complications.¹⁸ However, in New Zealand, we know little about the quality of care for pregnant disabled people giving birth due to the nature of our approach to data collection.

For instance, the New Zealand Maternity Clinical Indicators collection presents comparative maternity intervention and outcome data across a set of 19 indicators for pregnant people and their babies, by maternity facility and district.¹⁹ These data are collected and publicly reported via the Maternity Clinical Indicators web tool.²⁰ However, disability information is not collected.

IDI analysis allowed us to effectively compare disabled people with non-disabled people for some indicators, but many indicators were impossible to interpret. That is, some different proportions of complications or outcomes for disabled people versus non-disabled people may not represent differences in quality of care, but simply what was necessary for a patient with a certain kind of disability. Rates of caesarean section performed under general anaesthetic may be a meaningful indicator of quality of care for non-disabled people, for example, but in the absence of information about a disabled person, and the nature of their impairment(s), we cannot know if this intervention was appropriate or not.

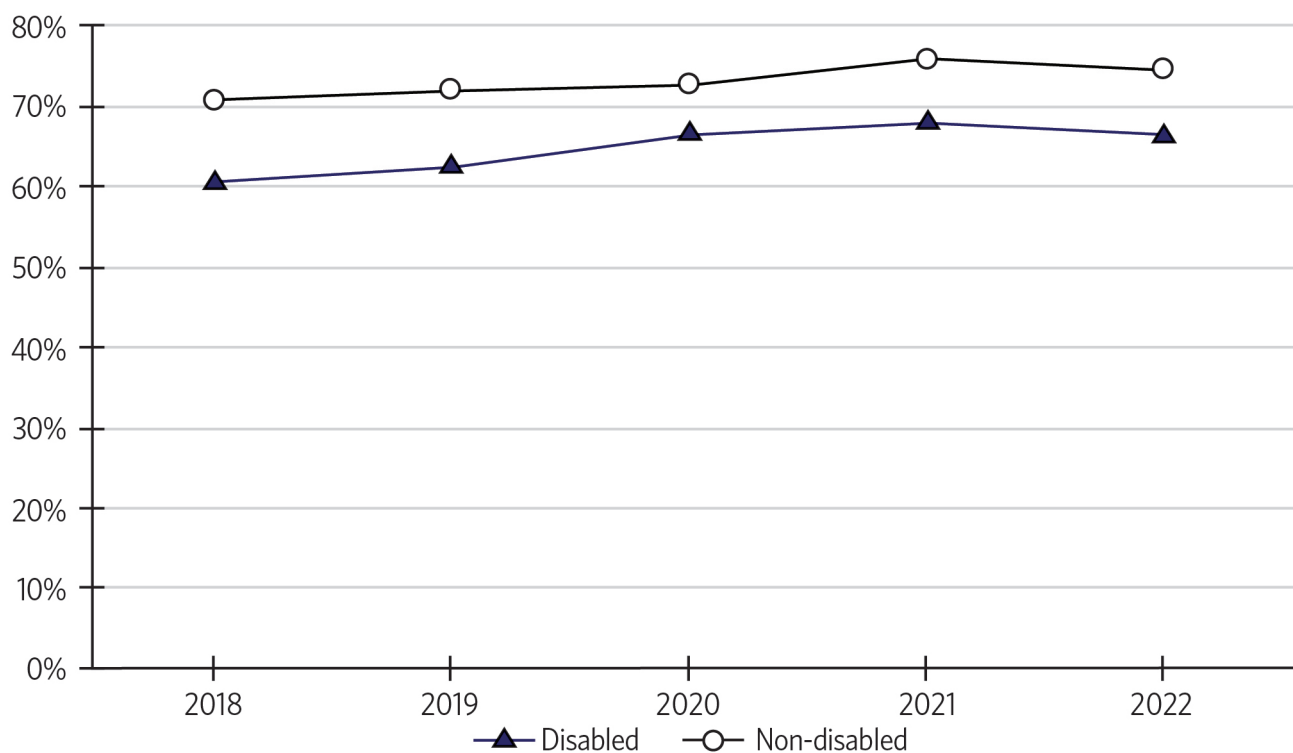
Therefore, we have selected indicators meaningful to disabled people and supplemented them with other sources of experience and satisfaction data that collect disability status.

Lead maternity carer enrolment

It is widely recognised that having a lead maternity carer is important for the health and wellbeing of both the birthing parent,²¹ and the baby.²² However, maternity data analysed for this report show that disabled people are less likely than non-disabled people to be enrolled with a lead maternity carer (LMC), such as a midwife, in their first trimester.

Disabled pregnant people were 8 percentage points less likely to be enrolled with an LMC in the first trimester (67%) than non-disabled pregnant people (75%) in 2022. The difference is consistent over time (Figure 19) and more pronounced for Māori and Pacific disabled people as well as people with multiple impairments.

Figure 19: Percentage of people enrolled with an LMC in trimester one of pregnancy, by disability status, 2018-2022



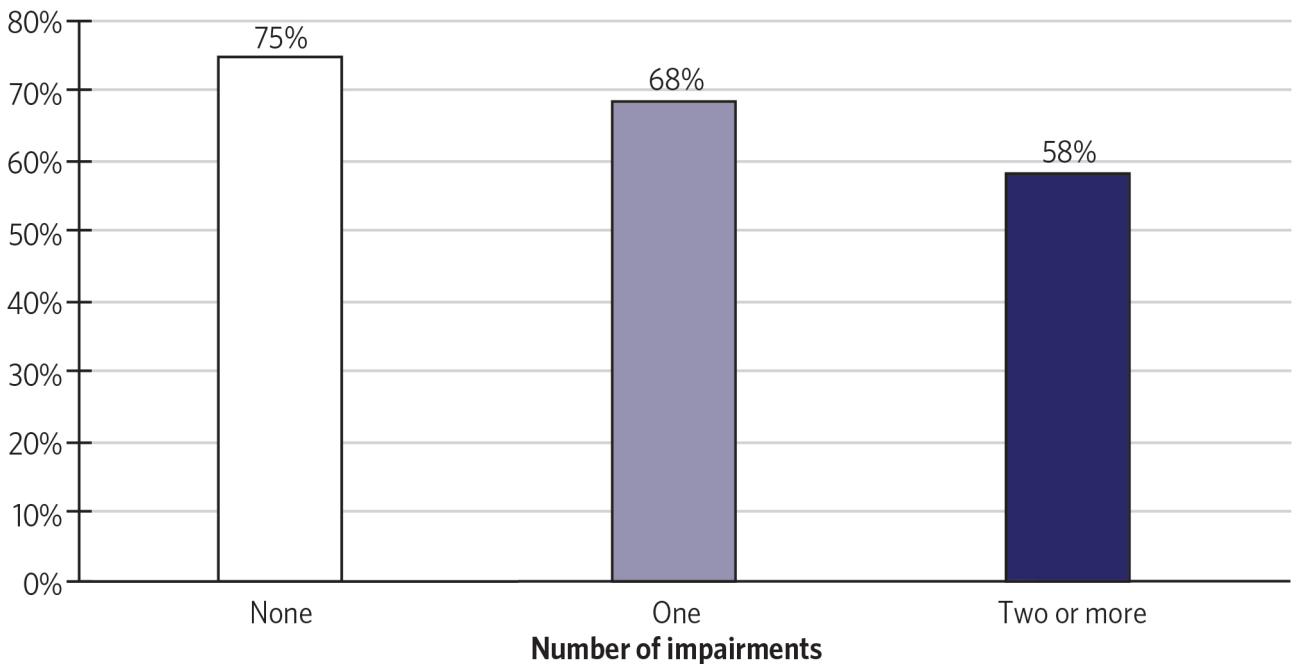
Source: IDI, Maternity Clinical Indicators

Multiple impairments - less likely to have an LMC or midwife

An 'inverse care law' was evident in the data: that is, those most likely to need maternity care were the least likely to receive it. More formally, the inverse care law is often expressed in this way: 'The availability of good medical care tends to vary inversely with the need for it in the population served.'²³

The more impairments a disabled person had, and thus the higher their need for early maternity care, the less likely they were to have the care crucial for planning and preparing for the birthing journey. Disabled people with two or more impairments were 17 percentage points less likely than non-disabled people (Figure 20) to have an LMC in their first trimester of pregnancy.

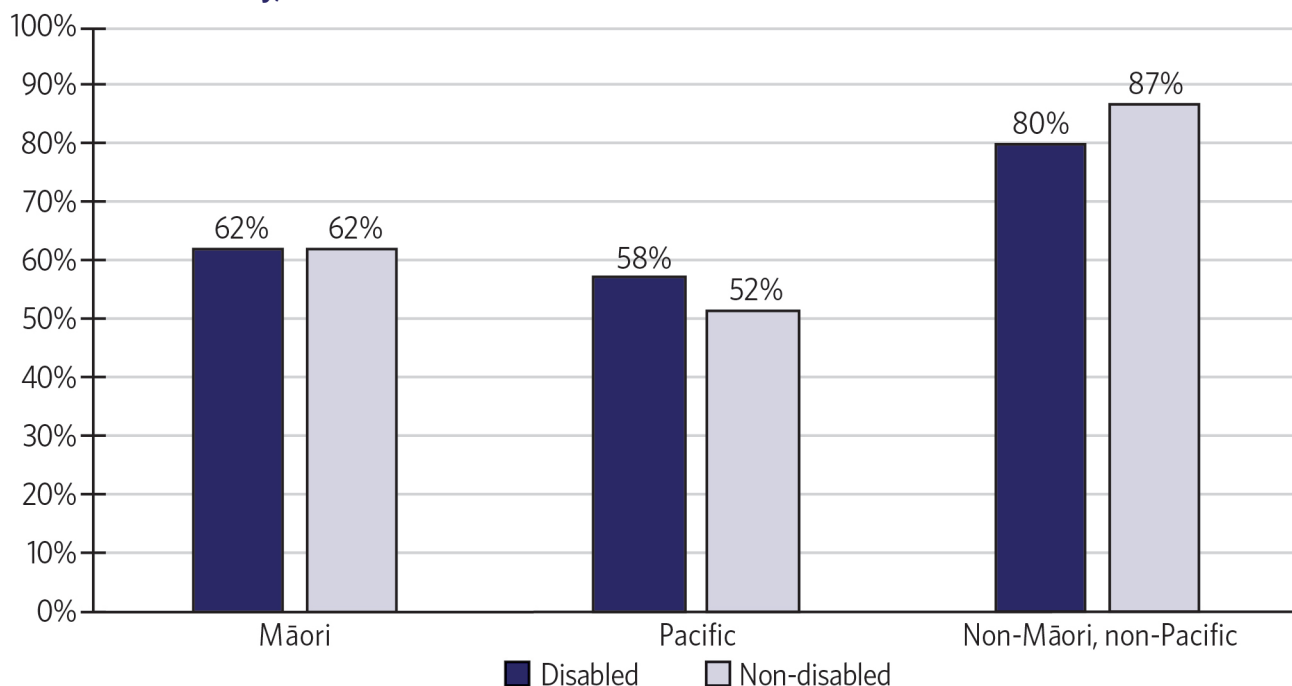
Figure 20: Percentage of people enrolled with an LMC in trimester one of pregnancy, by number of impairments, 2022



Source: IDI, Maternity Clinical Indicators

Pregnant Māori and Pacific disabled people were less likely than non-Māori, non-Pacific disabled people to be enrolled with an LMC in trimester one (Figure 21).

Figure 21: Percentage of people enrolled with an LMC in trimester one of pregnancy, by disability status and ethnicity, 2022



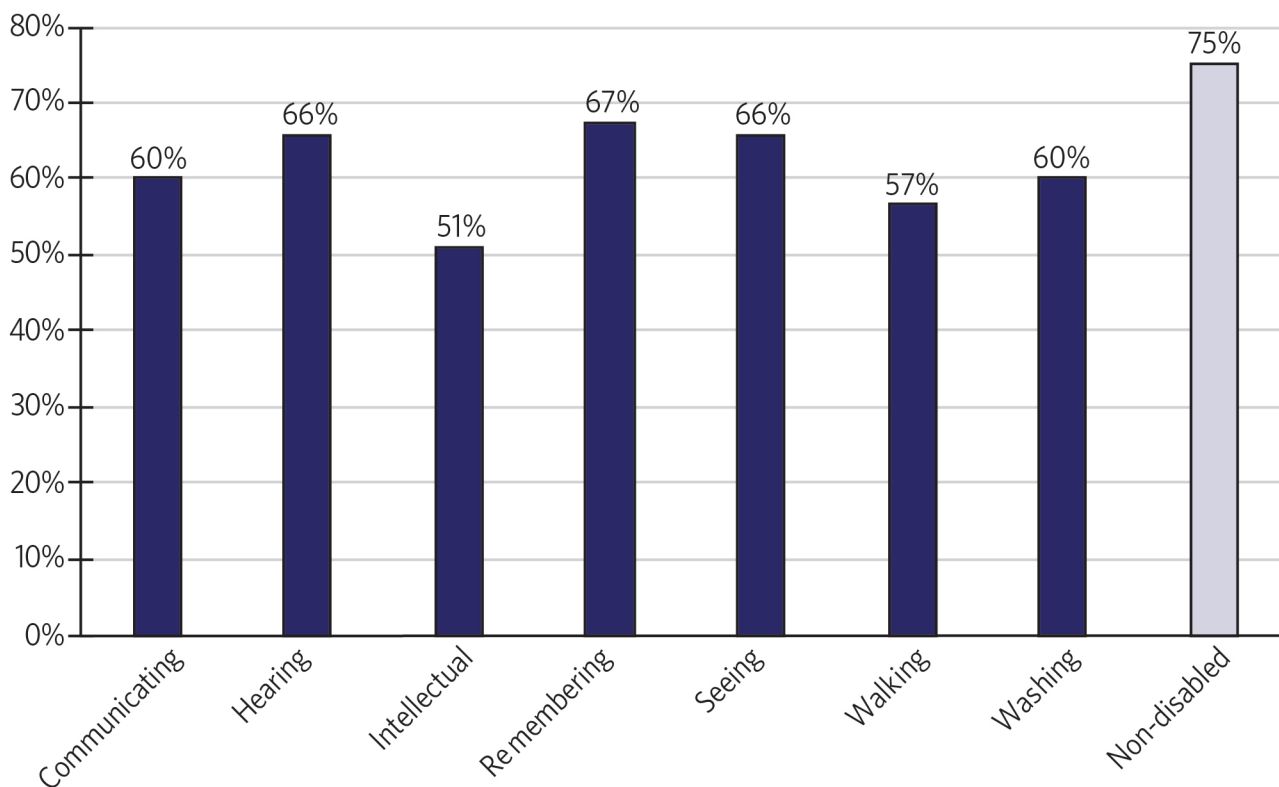
Source: IDI, Maternity Clinical Indicators

An analysis of the enrolment data across the WG-SS disability domains shows that rates of enrolment with an LMC were lower for disabled people. In four of the seven domains (intellectual disability was available through a different dataset), rates were lower than those of non-disabled people in ways that are unlikely to be due to chance. These domains were:

- intellectual (rate ratio (RR) = 0.69, 95% confidence interval (CI): 0.55-0.86)
- walking (RR = 0.76, 95% CI: 0.61-0.94)
- communicating (RR = 0.80, 95% CI: 0.64-0.99)
- seeing (RR = 0.88, 95% CI: 0.78-0.99).

People with a learning (intellectual) disability were least likely to be enrolled with an LMC in a timely way (Figure 22).

Figure 22: Percentage of people enrolled with an LMC in trimester one of pregnancy, by WG-SS disability domain, 2022



Source: IDI, Maternity Clinical Indicators

According to disability health experts, many factors contribute to the gaps between disabled people’s and non-disabled people’s adequate and timely maternity care. For example, people with a learning (intellectual) disability continue to be perceived as child-like and asexual, and are routinely excluded from sexual health education.^{24 25} Further assumptions include that they cannot be good parents and will therefore terminate their pregnancy, as well as experiencing substituted decision-making (decisions made for them by others) about their bodies, the information they receive, and access to services.²⁶ Due to these factors and pressures, people with a learning (intellectual) disability may conceal their pregnancies to avoid feeling pressured to have a termination, and then present to an LMC at a later stage than non-disabled pregnant people.²⁷

Other New Zealand studies have reported explicit discrimination towards pregnant disabled people. In 2021, research was conducted across the 3DHB collaboration of Capital & Coast, Hutt Valley, and Wairarapa District Health Boards (DHBs). The small qualitative study involved nine disabled consumers who had given birth, ten consumers who had given birth to disabled babies, and three midwives. The study showed that some disabled pregnant people were exposed to ‘a sense of being under surveillance and the need to prove their ability to care for their baby’.²⁸ Some disabled people who had just given birth experienced ‘a deep fear that their babies would be taken away from them’. Health care professionals disclosed details of their disabilities to Oranga Tamariki without their knowledge and with no explanation. One disabled woman interviewed had her baby uplifted soon after birth.

Mothers of disabled babies also described interactions with health professionals after the birth ‘that were informed by a deficit- and tragedy based model of disability’.

This meant that their babies were talked about in ways that were overly negative, with an undue emphasis on all the ‘problems’ associated with their impairment. When this happens, impairment and disability are constructed as inherently ‘wrong’ and tragic.

Outdated and discriminatory language was used about their babies. 'Examples of this included describing babies with impairments as "mentally retarded" and asking women what is "wrong" with their baby.' Those interviewed found this 'hugely upsetting and offensive'.

The research also reiterated that when pregnant disabled people did have access to an LMC, the relationship was important:

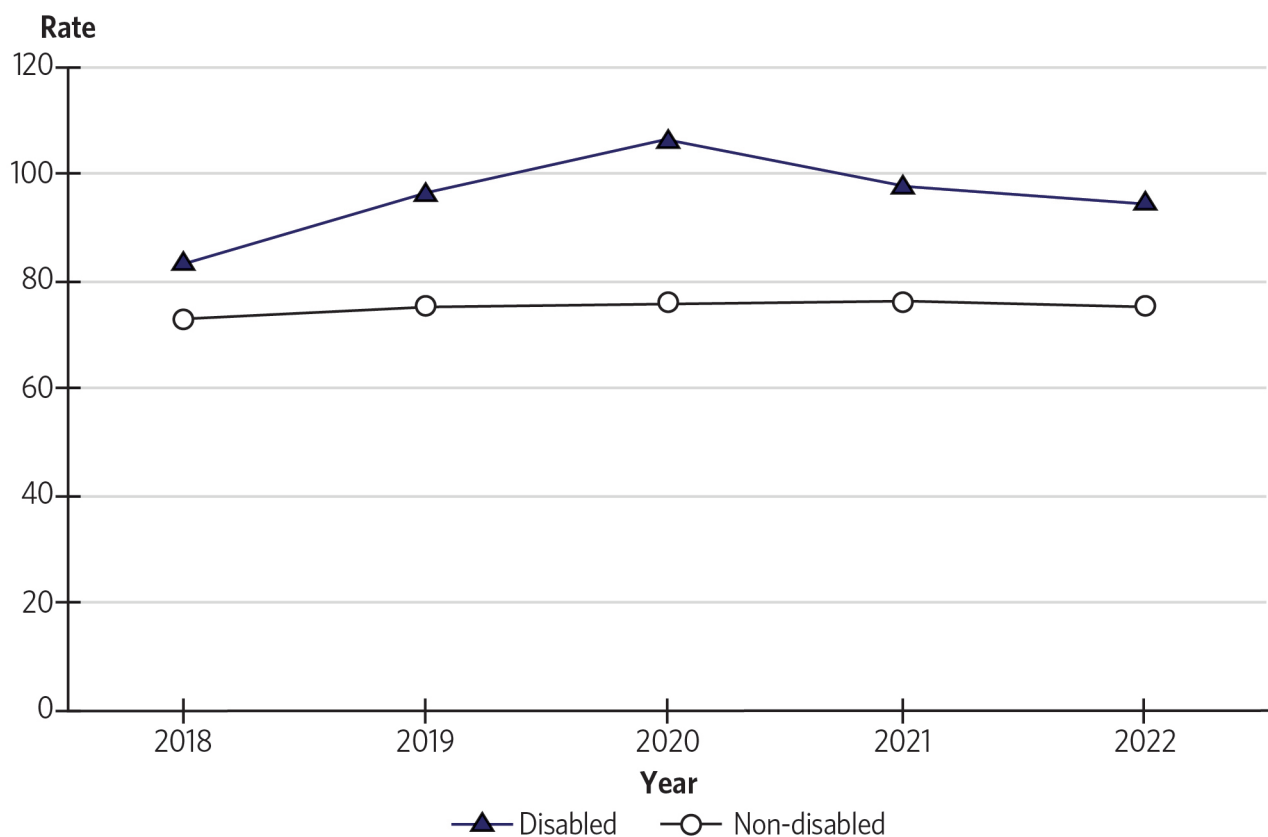
... there was a strong emphasis on the trust they built and the consistency of this relationship throughout their maternity journey. Having an LMC midwife meant they didn't have to repeatedly tell their story. Disabled women also talked about how midwives were reassuring and encouraging when they expressed concerns about parenting or worries about the future. This emotional support was important for countering some of the negative attitudes disabled women encountered early on in their maternity journey.

Pre-term births

Disabled pregnant people were more likely to deliver their babies pre-term (Figure 23). While acknowledging that there were a small number of cases each year between 2018 and 2022, pre-term births were particularly pronounced for people with learning (intellectual) disability, who were on average 1.4 (1.0-1.8) times more likely to experience a pre-term birth than other disabled people.

In general, pre-term births can be associated with immediate and long-term health issues for the child. A lack of data made it difficult to identify differences by ethnicity.

Figure 23: Rate of pre-term births per 1,000 births, by disability status, 2018-2022



Source: IDI, Maternity Clinical Indicators

Disabled people's experiences of the maternity system

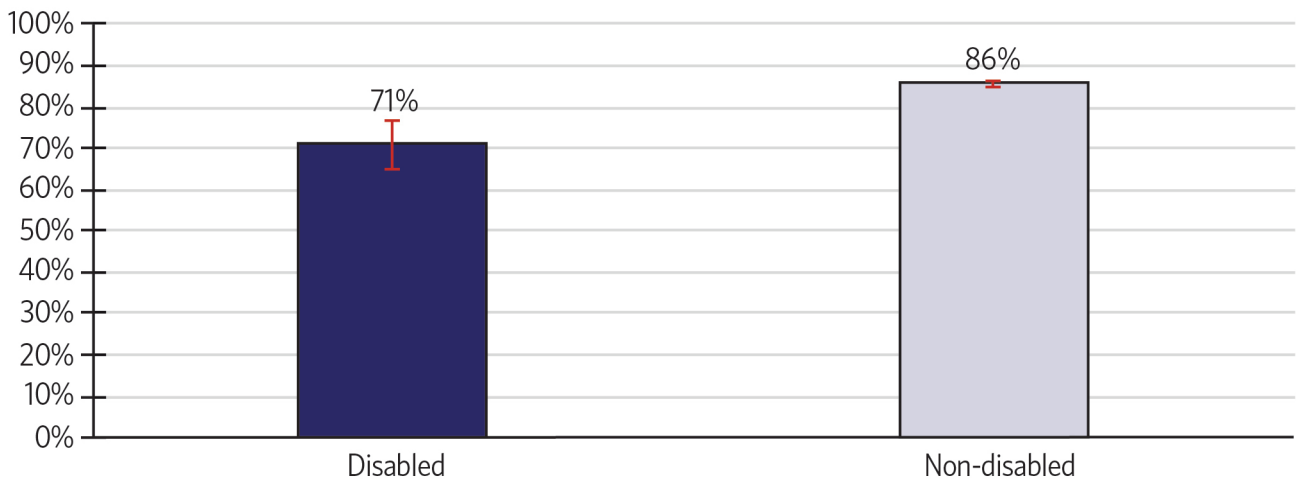
The Commission's adult hospital patient experience surveys are designed to find out what went well and what can be improved in patients' experience of their inpatient and outpatient care in New Zealand's public hospitals.^{29 30} They have collected data on disability status since 2019.

This section presents results from the adult hospital inpatient experience survey specifically for people who received maternity care, including people with and people without a community LMC. Disabled people responded less positively to a number of key questions than non-disabled people, and Māori disabled people had the least positive experiences. We focus on findings here only where differences were unlikely to be due to chance.

Involvement with care

Disabled people in maternity care were less likely than non-disabled people to feel as involved as they wanted to be in making decisions about their treatment and care. Only 71% of disabled people responded they were involved as much as they wanted to be, compared with 86% of non-disabled people (Figure 24). The percentage of Māori disabled people who felt involved as much as they wanted to be was comparable with the wider disabled population (69%).

Figure 24: Percentage of people who responded 'Yes, always' to the question, 'Were you involved as much as you wanted to be in making decisions about your treatment and care?', by disability status, 2021-2024

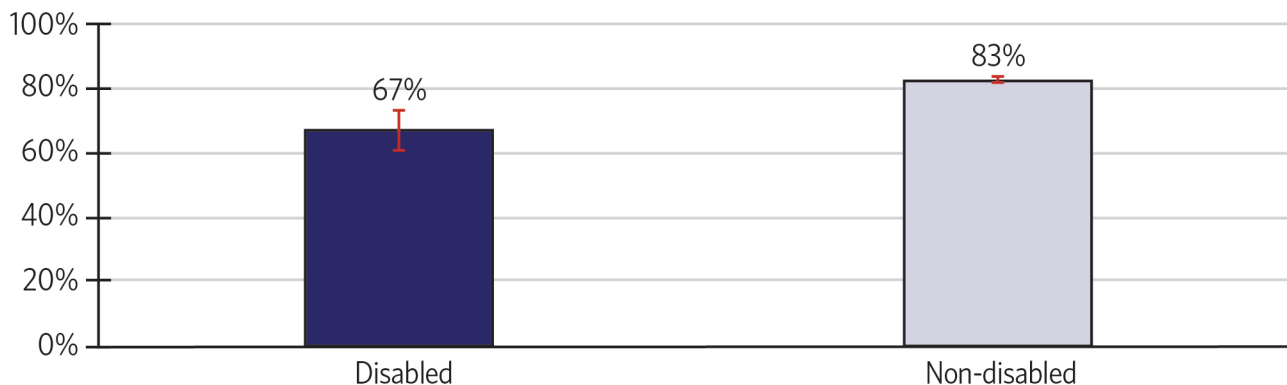


Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey, maternity care

Including family and whānau in discussions

Disabled people were 16 percentage points less likely than non-disabled people to say that staff included their family and whānau in discussions about the maternity care they received (67% versus 83%) (Figure 25). Māori disabled people were less likely to report this important consideration - only 56%, compared with 83% of non-disabled people who were non-Māori, non-Pacific.

Figure 25: Percentage of people who responded 'Yes, always' to the question, 'Did hospital staff include your family/whānau or someone close to you in discussions about the care you received during your visit?', by disability status, 2021-2024

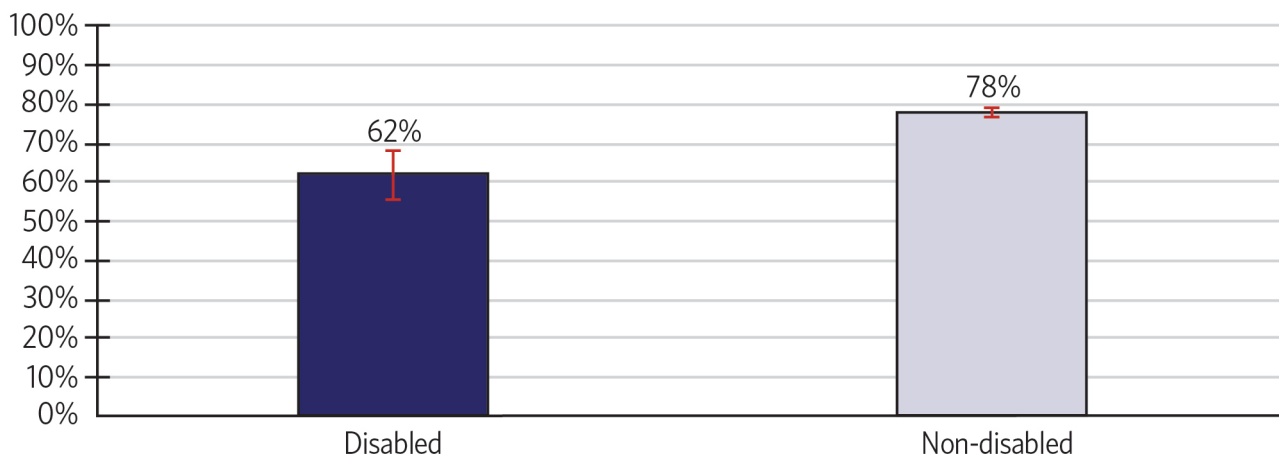


Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey, maternity care

Individual needs met

Only 62% of disabled people responded that they felt their individual needs were met during their maternity care, compared with 78% of non-disabled people (Figure 26).

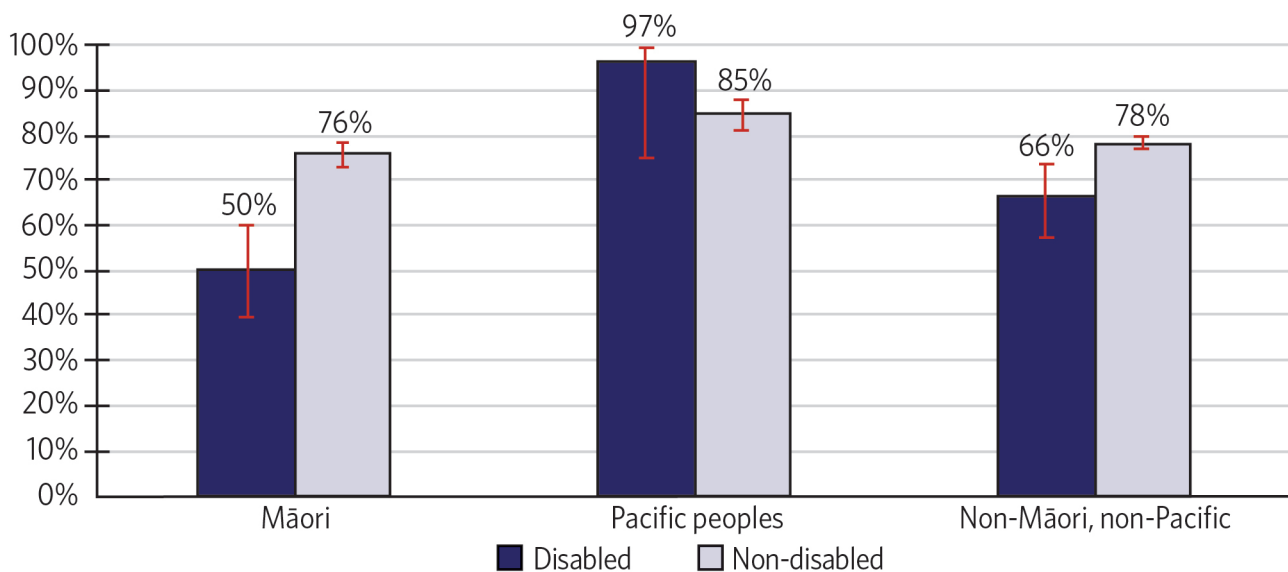
Figure 26: Percentage of people who responded 'Yes, definitely' to the question, 'Did you feel your individual needs were met?', by disability status, 2021-2024



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

Just 50% of Māori disabled people felt their individual needs were met. This was a statistically significant difference from Māori non-disabled people (76%) and non-Māori, non-Pacific people who were not disabled (78%) (Figure 27).

Figure 27: Percentage of people who responded 'Yes, definitely' to the question, 'Did you feel your individual needs were met?', by ethnicity and disability status, 2021-2024

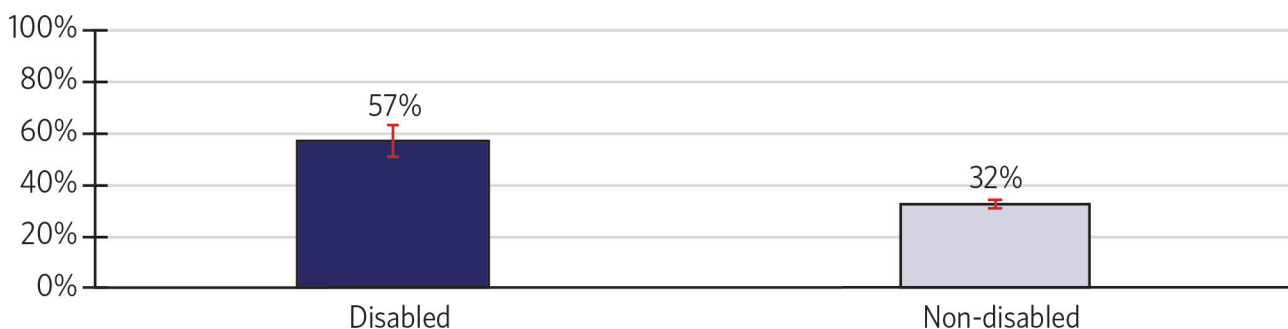


Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey, maternity care

Conflicting information

More than half (57%) of disabled people felt they were given conflicting information by different doctors or staff involved in their maternity care. This compares with 32% of non-disabled people (Figure 28).

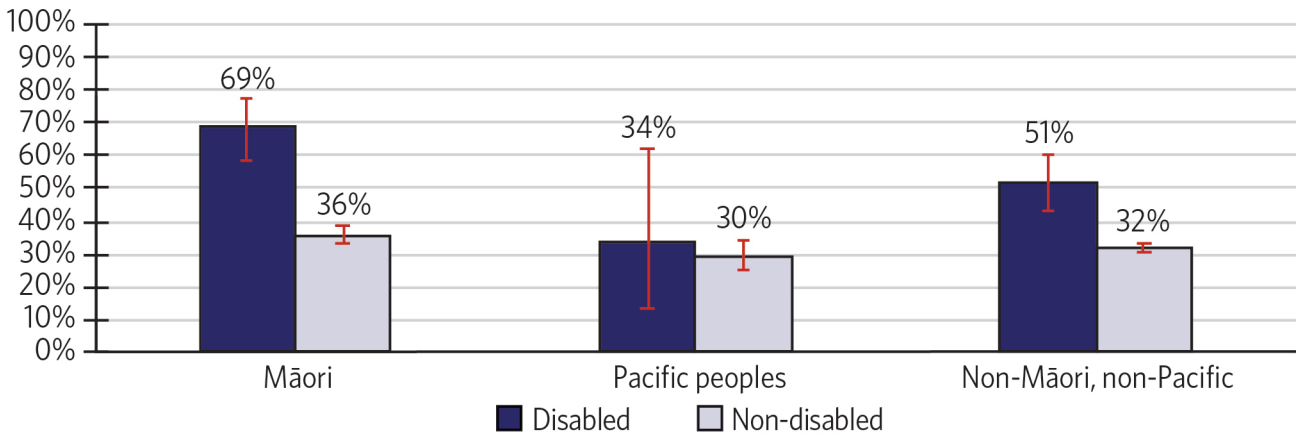
Figure 28: Percentage of people who responded 'Yes' to the question, 'Were you given conflicting information by different doctors or staff involved in your care, e.g. one would tell you one thing and then another would tell you something different?', by disability status, 2021-2024



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

Nearly 70% of Māori disabled people said they were given conflicting information by staff during their maternity care. This compares with 36% of Māori non-disabled people and 32% of non-disabled people who were non-Māori, non-Pacific (Figure 29).

Figure 29: Percentage of people who responded 'Yes' to the question, 'Were you given conflicting information by different doctors or staff involved in your care, e.g. one would tell you one thing and then another would tell you something different?', by ethnicity and disability status, 2021-2024

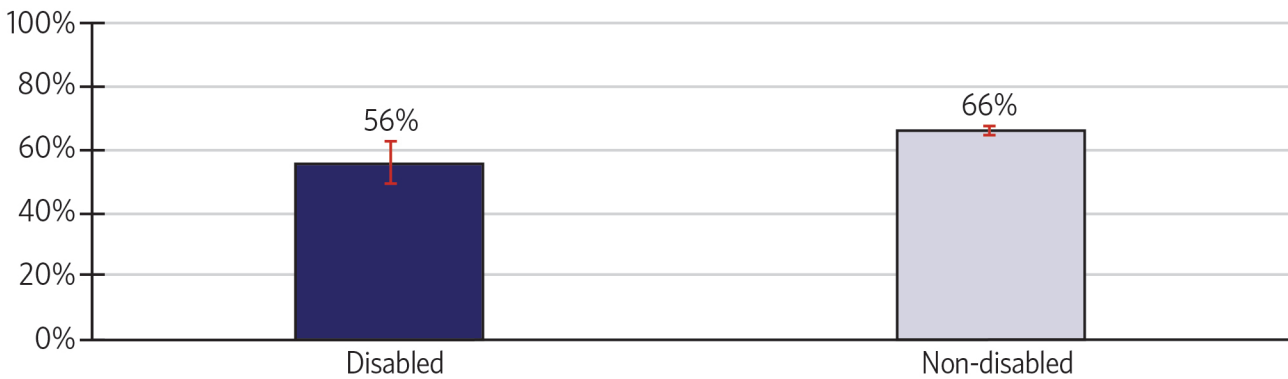


Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey, maternity care

Assistance with discharge

Despite potentially greater need for support after discharge, only 56% of disabled people in maternity care responded that hospital staff talked with them about whether they would have the help they needed when they left the hospital. This compares with 66% of non-disabled people (Figure 30).

Figure 30: Percentage of people who responded 'Yes' to the question, 'Did hospital staff talk with you about whether you would have the help you needed when you left the hospital?', by disability status, 2021-2024

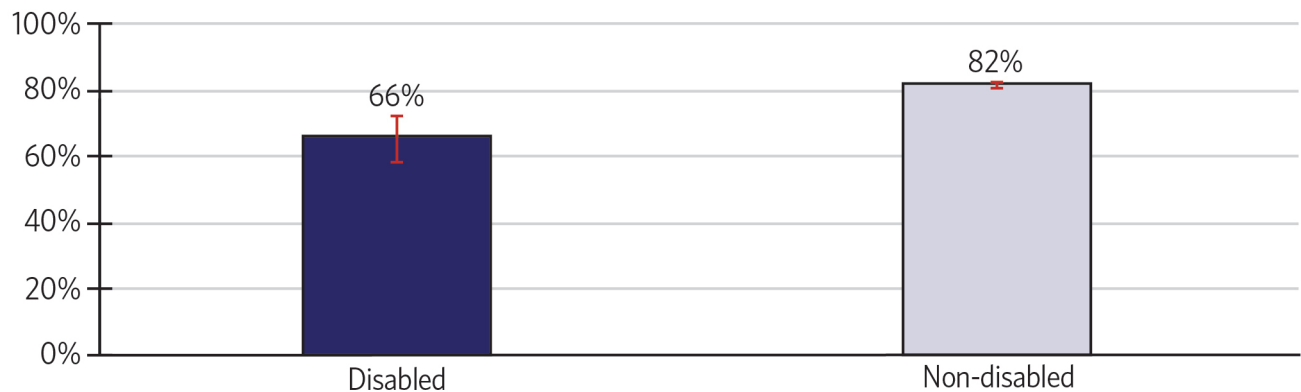


Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey, maternity care

Helped to use the bathrooms

Only 66% of disabled people were helped to use the bathroom or bedpan as soon as they wanted during their maternity care. This compares with 82% of non-disabled people (Figure 31).

Figure 31: Percentage of people who responded 'Yes, always' to the question, 'Did hospital staff help you to get to the bathroom or to use a bedpan as soon as you wanted?', by disability status, 2021-2024



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

Disabled people's satisfaction with maternity care

Following on from their experience of maternity care, disabled people had lower satisfaction scores for their maternity care.

The Triennial Maternity Consumer Survey, now run by Health New Zealand | Te Whatu Ora, has provided a regular assessment of consumer satisfaction with primary maternity services in New Zealand since 1999.³¹ The 2023 survey invited 12,000 people to complete the survey and achieved a sample of 4,355 mothers and birthing parents who had given birth between January and November 2021. Of these, 251 disabled mothers and birthing parents responded (based on their response to the WG-SS questions).

We only report differences here when those differences were unlikely to be due to chance.

Disabled mothers and birthing parents reported lower levels of satisfaction than all other respondents on all five stages of the maternity and perinatal journey, which is the care received from:

- their LMC while they were hapū/pregnant
- their LMC during labour and birth
- the hospital/birthing unit during labour and birth
- the hospital/birthing unit after the birth, and
- their midwife during pēpē/baby's first few weeks.

Overall satisfaction

Across all respondents, 79% were 'satisfied' or 'very satisfied' with the overall level of care they received during their pregnancy, labour and birth, and in the first few weeks after the birth. However, only 62% of disabled mothers and birthing parents gave this response.

Some key inequities

Disabled people were less likely than non-disabled people to report being satisfied or very satisfied with their care on 24 of the survey's questions, covering the birthing journey from antenatal education to the labour and birth process and into postnatal care. The differences between the two groups ranged from 6 to 20 percentage points. A few of the key differences are highlighted below.

Antenatal care

Disabled mothers and birthing parents were more likely than respondents overall to report issues with accessing ultrasounds, specialists and telehealth (25% versus 19%). They were also more likely to report travel constraints as a reason for these access issues (34% versus 18%).

Disabled mothers and birthing parents were less likely to be 'satisfied' or 'very satisfied' with seven of the eight aspects of antenatal care that were measured. Examples of these aspects are:

- satisfaction with the care they received from specialists (73%, compared with 85% of all respondents)
- satisfaction that the people involved in their care were responsive to all of their needs (71%, compared with 85%)
- how easy it was to get the services they needed (67%, compared with 82%).

Labour and birth

Disabled mothers and birthing parents were less likely to be 'satisfied' or 'very satisfied' with the overall care they received from their LMC during the labour and birth (79%, compared with 87% of the total sample). They were also less likely to be 'satisfied' or 'very satisfied' with the overall care they received from the hospital and birthing unit staff during their labour and birth (60%, compared with 77% of the total sample).

These differences were particularly striking when it came to the choices available to them as to where they could have their birth, and satisfaction with the location and surroundings where they gave birth. Disability health experts noted that many disabled people are automatically classified as high risk and are offered no alternative to hospital birth. Disabled people reported lower satisfaction scores on whether their visitors and support people were able to be with them when they wanted, while disability health experts similarly report paid support workers are often not allowed to support disabled people in hospitals. This is despite support workers being disability trained and knowing an individual's needs, while hospital staff typically lack disability training, awareness, resources and capacity.

Postnatal care

Disabled mothers and birthing parents were less satisfied overall with the care they received from their LMC at home (82%, compared with 88% of the total sample). Disabled mothers and birthing parents were less likely to report being 'satisfied' or 'very satisfied' in relation to all 10 of the more granular aspects of postnatal care measured. The largest differences related to:

- information received about what care their pēpē/baby was entitled to (68% of disabled mothers and birthing parents were 'satisfied' or 'very satisfied' with this, compared with 83% of the total sample)
- the LMC's responsiveness to their needs (75%, compared with 87%)
- the way in which respondents' decisions, views and choices were respected (81%, compared with 91%).

Conclusion

Disabled people were less likely to be enrolled with an LMC in a timely way to assist them with their pregnancies and more likely to experience a pre-term birth. Their scores for experience and satisfaction with their maternity care are lower than those of non-disabled people.

Tamara Grant

(Ngāti Tūwharetoa, Ngāti Tama, Ngāi Tahu) - giving birth as an autistic mother with fibromyalgia

Tamara is autistic, dyslexic, an artist, activist, disability advocate, speaker, CEO and founder of Xabilities (supporting neurodiversity in Aotearoa), and mother of two.

Ko Aotea te waka,
Ko Ruapehu te maunga,
Ko Whanganui te awa,
Ko Uenuku te iwi,
Ko Ngāti Tamakana te hapū,
Ko Makaranui ki Raetihi te marae,
Ko Te Piki Kotuku rāua ko Tukaiora āku tūpuna,



Ko Ngāti Tama ki Whanganui-A-Tara me te Atihaunui a Pāpārangī me Tūwharetoa me Ngā Rauru me Ngāti Hikairo te taha hoki o tōku pāpā.

Ko Tamara Grant ahau.

My story of pregnancy as an autistic woman with fibromyalgia

When I think back on my pregnancy journey, I always start with this: I was lucky.

Not because the system worked for me, but because one midwife cared enough to bend the rules. She knew me from my first birth, when I was 17, and even though she was already full, she took me on again for my daughter in 2023. Without that, I honestly think I would have slipped straight through the cracks.

Continued over

What a lot of people don't understand is that pregnancy changes your autism. Just like puberty can intensify things for autistic kids, pregnancy does the same – but nobody talks about that. My senses were already high from autism, and then pregnancy dialled everything up until it felt unbearable. Add fibromyalgia on top – constant pain, fatigue, brain fog – and you get a very intense mix.

Through all of that, my midwife was the one person who didn't pretend to know everything. She'd say, 'I don't know how autism and fibromyalgia work together in pregnancy. Let's figure it out together.' That honesty was the best care I got the entire time. We tried different ways to manage anxiety and sensory overload. We even tried medications that weren't ideal, because some could affect the baby – but I literally couldn't go outside without shutting down.

Still, most days it felt like we were just surviving the pregnancy rather than being supported in it.

My experience with hospitals: One of the things that hurt the most was how often the hospital misunderstood me. I went in several times (not pregnancy related) with real physical symptoms – severe stomach pain, then an infection, then low iron – but every time, the staff fixated on my behaviour instead of my body. Because when I'm overwhelmed, I can go non-verbal, I use my hands and gestures. I look 'distressed'. And instead of asking about autism, they assumed mental illness or domestic violence.

Another time, despite messages from my midwife saying my bloods were off, I was held in a waiting area for a whole day, then sent to mental health services. I spent a day waiting on a couch, heavily pregnant, crying from exhaustion, and they just kept asking if I was 'okay'. A couple of days later someone casually called to say I needed iron. I was actually anaemic. It made me feel invisible – like they only saw their assumptions, not me. They were just trying to put me in a box they understood.

Giving birth, though, was the easy part. I live in pain every day, so labour was familiar territory. And even though my midwives weren't rostered on, four of them showed up, plus students. The room was full of support and calm. It was magical.

Postpartum was harder. I couldn't use services like Plunket. I didn't have the energy to explain autism to yet another stranger and have them tell me it's 'just hormones' or 'just being young'. I also had old trauma that made breastfeeding complicated, and nobody ever warns autistic mothers how common that is.

In the end, I did almost all of postpartum alone, with help from my family and my support workers. My mum organised all my carers, schedules, emails. Everything. People see me public speaking, flying for disability advocacy, talking clearly, and think I'm 'fine'. But behind that is a huge support system. Without it, none of this would work.

Continued over

This support isn't extra support, it's just meeting our basic needs to get what everyone else gets through the system.

What the health system could do better

- **Believe autistic women the first time.** If we say something is wrong with our body, check our body before our mind.
- **Ask about autism as quickly as you ask about mental health.** If someone is non-verbal or distressed, don't assume the reason.
- **Make space for sensory needs.** A quieter room, dim lights or clear communication can change everything.
- **Let us bring support people everywhere.** They're not 'extras'. They're the reason we can access care at all.
- **Stop making us fight the system while we're pregnant.** We are already using all our energy to exist and keep a baby safe.

I share all this because I don't want other autistic mothers with chronic illnesses to go through what I did. We deserve a health system that sees us, listens to us and believes we know our own bodies. ■



New Zealand Government
Te Kāwanatanga o Aotearoa

**Health Quality &
Safety Commission**
Te Tāhū Hauora

