Disabled People's | Tāngata Whaikaha Experiences of Health Services

Report on complaints to HDC

HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

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Feedback

We welcome your feedback on this report.
Please email any feedback to hdc@hdc.org.nz

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Tuia tō mana kia māia
Tuia tō mauri kia mau

Horahia te mātauranga
Kia puta ko te māramatanga

E whakakotahi ai te wairua
Kia tipu, kia hua, kia puāwai ngā mahi

Haumi e, hui e,
Tāiki e!

Retain and hold fast to your mana, be bold, be brave

Be widespread with knowledge to empower understanding

By working together we will grow, flourish and prosper

Join together, bind all together, let it be done!

Contents

Foreword

E ngā iwi, e ngā mana, e ngā karangatanga maha huri noa o Aotearoa nei, tēnā koutou, tēnā koutou, tēnā koutou katoa. Tangihia hoki ki te nunui, ki te roroa ki a rātou o te pō. E huri te oranga tonutanga e tātou. Tēnā anō tātou katoa.

E ngā whānau kua tau te mana kia tuia, ka nui te mihi, ka nui te mihi, ka nui te aroha.

Aotearoa New Zealand's health sector is under significant pressure. In recent years, there has been concern about its capacity to meet the demands placed upon it. There are ongoing staff shortages, service disruptions and geographical inequities in access to care. These challenges are reflected in complaints to the Health and Disability Commissioner (HDC) by disabled people | tāngata whaikaha, and their families, whānau and support people, about the accessibility and appropriateness of health services for disabled people.

Our health system is filled with highly skilled and compassionate people committed to delivering quality health services that uphold the rights and improve the health and wellbeing of all consumers, including disabled people | tāngata whaikaha. However, when systems are under pressure, healthcare professionals do not always have the resources or support to fully realise people's rights.

This report follows the publication of our recent Report on Complaints to HDC About Residential Disability Support Services. That report called for stronger oversight of the care and treatment of disabled people | tāngata whaikaha living in residential care, including the need to create a consistent quality framework across all funded disability service provision. It also sparked additional interest in what complaints to HDC might tell us about the experiences of disabled people engaging with health services.

HDC gained further insights from disabled people | tāngata whaikaha during our 2024 Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights. Disabled people and their families, whānau and advocates shared their experiences of barriers to health care, such as Deaf people not having access to New Zealand Sign Language interpreters and blind people having to navigate changing and inaccessible booking systems. Both providers and consumers expressed some concerns about providers not being able to meet accessibility requirements in a resource-constrained health system.

In our final report on the Act and Code Review, HDC committed to sharing feedback on accessibility barriers experienced by disabled people | tāngata whaikaha with the Ministry of Health | Manatū Hauora, Whaikaha – Ministry of Disabled People, and Health New Zealand | Te Whatu Ora to support quality improvement.

HDC is publishing this report concurrently with the Health Quality & Safety Commission Te Tāhū Hauora report, *A Window on Disability*. Their report presents an in-depth analysis of health outcomes for disabled people | tāngata whaikaha that demonstrates the need for changing practice.

HDC's focus with this report is to support service improvement and take a collaborative approach to improving the experiences of disabled people | tāngata whaikaha in the health system. By examining the concerns raised about the experiences of disabled people and making associated recommendations, it is our hope that, ultimately, consumer rights will be better protected.

Rose Wall.

Rose Wall
Deputy Health and Disability Commissioner

Executive summary and recommendations

The health sector is under significant pressure. People in the health system are working hard within a constrained environment, but further opportunities for the rights of disabled people | tāngata whaikaha to be fully realised remain.

Disabled people | tāngata whaikaha are frequent users of health services, yet explicit and implicit biases toward disability in health systems remain pervasive. Disabled people continue to experience significant inequities in health outcomes, which in turn exacerbate the barriers they face to experiencing ordinary life outcomes.

Gaining a better understanding of the experiences of disabled people | tāngata whaikaha in the health system, particularly when things have gone wrong, can improve our understanding of what is important to disabled people and their whānau or family.

This report presents insights from complaints made to the Health and Disability Commissioner (HDC) from 2023 to 2025 about the experiences of disabled people | tāngata whaikaha when using health services. The themes in this report can help identify where health systems can better support the rights of disabled people to be upheld.

Our analysis of complaints identified issues that were grouped into the following themes:

1. **Person-centred care**, including use of restraint, failures to provide reasonable accommodations, and failures to recognise disabled people | tāngata whaikaha as experts in their own lives.
2. **Cultural responsiveness**, particularly for tāngata whaikaha Māori and Deaf | Turi communities.
3. **Quality of communication,** including inaccessible communication, inconsistent recognition of communication needs and inadequate engagement with family, whānau and support people.
4. **Informed consent processes**, including concerns about bodily autonomy and supported decision-making.
5. **Quality of disability-related cares**, such as timely personal cares and appropriate support during hospital admissions.
6. **Quality of medical treatment**, including lack of provider knowledge about disability and diagnostic overshadowing.
7. **Continuity and coordination of care**, including delays in access to diagnosis and inadequate coordination within and between health and disability systems.

Recommendations

Many complaints made about care provided to disabled people | tāngata whaikaha can involve multiple providers and agencies across both health and disability sectors as well as other public sectors (such as education and social services). A multi-agency, cross-sector approach is crucial to improving health outcomes for disabled people and ultimately to ensuring disabled people's rights are upheld and protected. Although our recommendations are directed towards Health New Zealand | Te Whatu Ora (Health NZ) and Disability Support Services at the Ministry of Social Development | Te Manatū Whakahiato Ora (DSS), we acknowledge the responsibilities of other health agencies and funders of support services,[1] and we encourage them to engage closely with this work. We also acknowledge work already under way by agencies, including Health NZ and DSS.

In response to the identified issues, HDC makes the following recommendations:

1

HDC recommends Health NZ support people with communication barriers by:

1.1 considering opportunities for hospitals to increase the understanding, availability and use of augmentative and alternative communication tools, including in emergency departments (EDs) and mental health settings.

2

HDC recommends Health NZ continue work to reduce the use of restraint on disabled people | tāngata whaikaha and move towards eliminating restraint by:

2.1 reviewing restraint practices in hospital settings and considering what supports are needed to reduce the use of restraint on disabled people.

3

HDC recommends Health NZ work to support improving staff capability through:

3.1 the development of best practice resources and information (in consultation with disabled people | tāngata whaikaha) to support accessibility and inclusion in health settings, including, for example, environment and design, person-centred approaches, methods of communication and trauma-informed care (including medical trauma)

3.2 training for clinical and non-clinical staff, including the development of resources to improve disability understanding and capability (including a focus on 'hidden conditions' such as learning disability and neurodivergent conditions), with a particular focus on mental health and emergency care settings.

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[1] Including, for example, training institutions, professional colleges, regulatory authorities, ACC and Oranga Tamariki.

HDC acknowledges that Health NZ and DSS have begun early engagement on the following recommendations and is pleased they have committed to cross-agency work.

4

HDC recommends Health NZ and DSS as lead agencies work together on cross-agency issues related to:

4.1 ensuring clarification for disabled people | tāngata whaikaha about accessing funding for disability supports in hospital (noting that people have expressed concerns about who is responsible for the provision of disability support in this context)

4.2 coordination of discharge from hospital to community settings with disability support, including to community residential services

4.3 navigation support for disabled people with ongoing health needs, including clarification from DSS and Health NZ on eligibility for their respective funded supports and, where relevant, other funding streams, as well as navigation support within and between these funding streams (noting a recent cluster of complaints to HDC about a lack of clarity about and support to access funding for disabled people with health needs)

4.4 improvements to coordination of care and support during and following transition from paediatric to adult services for people with complex and coexisting health, disability and mental health conditions

4.5 support and information for families whose children are awaiting diagnostic assessment for neurodivergent or neurodevelopmental conditions in the public health system.

5

HDC supports the four areas for progress that the Health Quality & Safety Commission Te Tāhū Hauora identified in their *A Window on Disability* report:

5.1 the need for more disaggregated data related to disability

5.2 the need for disability training and professional development across the health workforce

5.3 the need for greater employment of disabled people | tāngata whaikaha across the health system

5.4 the need to develop supported decision-making frameworks and training across the health system.

6

HDC acknowledges and supports the work of Whaikaha – Ministry of Disabled People related to:

6.1 their launch of the *Whaimana – Support My Decisions* website

6.2 securing government commitment in the *New Zealand Disability Strategy 2026–2030* to ensure that tools for self-determination and supported decision-making are standard practice in health care.

Monitoring of recommendations

HDC will work with Health NZ and DSS to monitor the implementation of recommendations in this report. Health NZ has committed to developing, within three months of the publication of this report, a roadmap to implement our recommendations.

Introduction

This report presents insights and themes identified through a qualitative analysis of complaints to the Health and Disability Commissioner (HDC) about health services by disabled people | tāngata whaikaha over a three-year period from 1 January 2023 to 31 December 2025.

The health sector is under significant pressure. People in the health system are working hard to improve the accessibility of services and quality of care for disabled people | tāngata whaikaha within a constrained environment, but further opportunities for disabled people's rights to be fully realised remain. This report serves to highlight the key areas of concern that are raised with our Office and makes associated recommendations to improve the experience of disabled people in the health system.

Disabled people | tāngata whaikaha and the health system

Disabled people | tāngata whaikaha are high users of the health system; however, explicit and implicit biases toward disability in health systems remain pervasive.[2] In Aotearoa New Zealand, health outcomes for disabled people have improved slightly over time in some areas. However, disabled people continue to experience significant inequities in health outcomes, which in turn exacerbate the barriers they face to experiencing ordinary life outcomes. Gaining a better understanding of disabled people's experiences of the health system, particularly when things have gone wrong, can improve our understanding of what is important to disabled people and their whānau or family. Complaints also point to ways in which providers can improve their services to better support disabled people to live well.

HDC's role in the health and disability sector

HDC is an independent Crown Entity whose role is to promote and protect the rights of people using health and disability services as set out in the Code of Health and Disability Services Consumers' Rights (the Code). The primary way in which HDC does this is through the independent assessment and resolution of complaints about the quality of care provided to people by health and disability services.

HDC's complaint data is grounded in the consumer experience. We work with other agencies responsible for quality and safety to amplify the consumer voice, address areas of systemic concern and ensure that public safety issues are identified and addressed in a timely way.

HDC can highlight consumer rights issues, hold providers to account for the responsibilities they carry, make recommendations for improvement and monitor actions taken. However, we do not have direct oversight of, or powers in relation to, funding decisions, workforce planning and service design and planning — primarily these are matters for the Government and Health New Zealand | Te Whatu Ora (Health NZ).

HDC has a particular focus on communities that experience multiple barriers to accessing quality care and complaints processes, including disabled people | tāngata whaikaha. This report highlights the additional barriers that disabled people face in their interactions with the health system.

Barriers experienced by disabled people | tāngata whaikaha

Disabled people | tāngata whaikaha and their family and whānau experience multiple barriers to accessing or engaging with complaints processes, including fear of retaliation or withdrawal of service. Some disabled people may also face barriers, even with significant support, to raising concerns themselves and or may be without family and whānau or support networks to advocate on their behalf.

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[2] World Health Organization. (2022). *Global report on health equity for persons with disabilities*. https://www.who.int/publications/i/item/9789240063600

In an effort to mitigate the power imbalance between consumers and providers, HDC contracts the Nationwide Health and Disability Advocacy Service to assist people to resolve their concerns directly with providers or raise their complaints with HDC. However, we acknowledge that significant barriers remain.

HDC has taken careful note of the feedback we received during the Act and Code Review to consider our own accessibility, including our communication. We are incorporating this feedback into our quality improvement programme and the implementation of HDC's Disability Strategy. HDC has committed to actions to make our systems, processes and communications more responsive to the needs of disabled people | tāngata whaikaha, which in turn strengthens HDC's ability to contribute to quality improvements for disabled people. For example, HDC has developed a downloadable booklet called My Health Passport, which supports disabled people to easily share information with health and disability providers about their communication and support preferences. We are currently working with the creators of the Volition app to create a digital version of My Health Passport.

Cultural responsiveness

Tāngata whaikaha Māori and their whānau also face additional and compounded barriers in both their engagement with the health system and their engagement with HDC.

HDC provides an important platform for the consumer voice to be heard, equity issues to be raised and addressed and the sector to be held accountable for providing culturally responsive care and improving Māori experience of care. However, our ability to contribute to health outcomes within the health and disability sector relies on us making sure that the way we operate is accessible and culturally responsive. We acknowledge that Māori communities are not always supported to be aware of their rights under the Code and do not always have a high degree of trust in complaints processes as currently designed.

HDC is working on more responsive ways of listening to, and working together with, tāngata whaikaha Māori and whānau hauā to reduce barriers to our complaints process, including through work undertaken by our Māori Directorate to engage with hapori Māori and the use of tikanga-led processes within our complaints process.

However, it is important to acknowledge that the complaints HDC receives about services provided to disabled people | tāngata whaikaha likely represent the 'tip of the iceberg' and are unlikely to provide an overview of the experience of all communities.

Holding systems to account

For disability communities, who disproportionately experience poor health outcomes, it is critical that health systems continue to identify, monitor and address the barriers to accessing services, engaging with health professionals and navigating the health system itself.

Through an analysis of complaints about health services provided to disabled people | tāngata whaikaha, this report seeks to highlight the barriers to quality health services experienced by disabled people and their whānau, families and support people. The report and its recommendations also aim to promote continued collaboration and cross-sector approaches between agencies to identify and address areas of improvement within the health system and to ultimately strengthen the trust of disabled people in the health system and contribute to improved health outcomes.

It also highlights the value of mechanisms for monitoring the consumer experience in an environment where it is more difficult for consumers to express their concerns and complain.

Complaints to the Health and Disability Commissioner

The Code sets out 10 rights for consumers and places corresponding obligations on all providers of health and disability services, including both organisational providers and individual professionals.

HDC promotes and protects the rights of people using health and disability services by:

- resolving complaints about the quality of support provided to people
- promoting the Code through publicity and education
- improving quality and safety within the sector and
- where appropriate, holding providers to account.

HDC is independent of government policy and health and disability service provision. This allows us to be an effective watchdog for the protection of consumer rights.

Anyone may make a complaint to HDC about a health or disability service that has been provided to a disabled person | tangata whaikaha. It is not uncommon for HDC to receive complaints from third parties, such as whānau/family members, friends, staff or other providers involved in treatment or support, particularly for people with communication barriers and those living in residential care. The Commissioner may also commence an investigation on their own initiative, without having received a complaint, if they consider it appropriate to do so.

The Advocacy Service can assist people to resolve concerns directly with their provider. Advocates can also help people to raise complaints with HDC, and they play an important role in improving understanding of the Code at a community level.

Complaints and resolution pathways

The Code gives people the right to complain and requires every provider to facilitate the fair, simple, speedy and efficient resolution of complaints (Right 10).

HDC is focused on supporting the early resolution of complaints between the parties where appropriate and has a wide discretion as to the action it can take on a complaint. Supporting such resolution can be particularly relevant for people who have an ongoing relationship with the provider and/or are reliant on the care provided. On receiving a complaint, HDC undertakes a preliminary assessment and determines the pathway for resolution, considering the issues raised, the resolution needs of the complainant and the evidence available.

Following preliminary assessment, HDC can:

- refer the complaint to the provider, often with the assistance of the Advocacy Service, for direct resolution between the parties
- refer the complaint to other agencies where the issues raised are more appropriately dealt with by that agency or when a concern requires a timely response by that agency
- take no further action on a complaint where the preliminary assessment indicates that a formal investigation is not warranted; this may be accompanied by educational comment or recommendations
- conduct a formal investigation, which can result in the provider being found in breach of the Code, as well as recommendations
- refer a provider to the Director of Proceedings where the Commissioner has determined that the Code has been breached, to consider whether legal action should be taken; this option is reserved for the most serious breaches of the Code.

Value of complaints for quality improvement

Every complaint to HDC represents an opportunity for learning. Both local and sector-wide changes can result from the assessment and/or investigation of what went wrong in a particular case and an analysis of how such events can be prevented in future. HDC aims to take an educational approach to complaints and makes hundreds of recommendations on individual complaints each year. These recommendations have a high compliance rate: providers complied with 91% of recommendations made by HDC in 2024/25.

Complaints are grounded in consumer voice and experience and can often reflect the issues people care most about. Complaints provide unique insights into aspects of treatment and support, such as compassion and dignity, feelings of mistrust, and psychological harm, that are not always captured by other systems of healthcare monitoring. HDC's unique dataset therefore provides an additional perspective on the concerns and barriers disabled people | tāngata whaikaha face when navigating the health system and engaging with services.

Considered together, complaints can become an even more powerful tool for widespread quality improvement. Understanding trends and patterns in the complaints received allows for the identification of common issues, wider systemic issues and possible solutions.

Background

What we mean by disabled people | tāngata whaikaha

Language used in this report

HDC acknowledges the diverse experiences and identities people have related to disability. Some people, including those from Deaf | Turi and neurodivergent communities, reject the language and framing of disability or impairment, and others may simply prefer different terms.[3] We also acknowledge the critical role that whānau and family play in supporting disabled people | tāngata whaikaha and in navigating the experience of disability. In this report, unless discussing specific groups, we use the term 'disabled people | tāngata whaikaha' or 'disabled people'.[4]

HDC notes that a range of definitions of disability are used by individuals, organisations and legislation. For the purposes of this report, we use the United Nations' definition:

> *that disability is an evolving concept and that disability results from the interaction between … people who have long-term physical, mental, intellectual or sensory impairments that, in interaction with [attitudinal and environmental] barriers, may hinder their full and effective participation in society on an equal basis with others.*

When considering the experiences of disabled people | tāngata whaikaha in the health system, it is important to acknowledge the tension between understandings of 'disability' in medical and social terms.

Understandings of disability

Understandings of disability are and have always been contested, both nationally and globally. Western medical views of disability have been criticised for their deficit views of difference, whereas many contemporary models of disability increasingly favour strength-based or neutrality-based approaches to human diversity.

In te ao Māori, concepts of disability have, and continue to be, expressed in diverse and evolving ways.[5] For many Māori with lived experience of disability, their identity is Māori first, and some people may be reluctant to engage with the language and identity of 'disability', along with the implied responsibility on individuals to ask for specific accommodations while receiving health services.[6]

Māori have not historically been involved in the design and implementation of policies affecting tāngata whaikaha Māori. There has been insufficient opportunity for the perspectives, needs and preferences of whānau Māori to influence the design of health services and how they are delivered and monitored. As discussed later in this report, structural barriers within the health system, including barriers to self-determining identity, needs and preferences, affect how tāngata whaikaha Māori access and experience health services. This in turn affects health outcomes and creates additional barriers to accessing and engaging with te ao Māori.[7]

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[3] People use a range of terms to identify themselves and their collective identity, including, but not limited to, disabled people, tāngata whaikaha, tāngata whaikaha Māori, whānau hauā, tagata sa'ilimalo and their āiga-tele, people with disabilities, people with lived experience of mental distress | tāngata whaiora, d/Deaf | tāngata Turi, blind or low vision | tāngata kāpō and neurodivergent | kanorau ā-roro and autistic people | tāngata takiwātanga.

[4] The term 'disabled people' is used by the New Zealand Disability Strategy and aligns with the social model of disability by placing emphasis on the barriers created by society that disable people and places responsibility on society to remove barriers and create a less disabling world. Tāngata whaikaha is a strengths-based term meaning 'people who are determined to do well' and is a shift away from more deficit-focused language and approaches. 'Whaikaha' means to have strength, to have ability and to be enabled.

[5] Jones, B., King, P. T., Baker, G., Nikora, L. W., Hickey, H., Perry, M., … Ingham T. R. (2024). Karanga rua, karanga maha: Māori with lived experience of disability self-determining their own identities. *Kōtuitui: New Zealand Journal of Social Sciences Online, 19*(1), 45–64. https://doi.org/10.1080/1177083X.2023.2224422.

[6] Ibid.

[7] Ibid. HDC also note the importance of supporting national conversations about the language and conceptions of 'disability' among tāngata whenua so that tāngata whaikaha Māori are more likely to feel comfortable discussing their access needs and identification in datasets to monitor health outcomes.

The social model of disability was developed to shift the focus from individual circumstances and medical conditions to the barriers that societies and organisations create through inaccessible environments, information, attitudes and systems that hinder participation and inclusion. Under a social model approach, emphasis should be placed on removing barriers and creating tools and systems that enable disabled people | tāngata whaikaha to participate on an equal basis with others. Social and rights-based models of disability in health systems provide a basis for improving policy, service design and health professionals' knowledge and interactions with disabled people.

In 2008, the New Zealand Government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD acknowledges disability as a natural part of human diversity, and signatories made a commitment to progressively realising the rights of disabled people | tāngata whaikaha. This includes the right to the highest attainable standard of health and to accessing health services on an equal basis with others. The UNCRPD does not create new rights but clarified countries' existing human rights obligations in ensuring that disabled people enjoy equal rights.[8] Many of the articles of the UNCRPD align closely with the Code.

Health outcomes for disabled people | tāngata whaikaha in Aotearoa New Zealand

In Aotearoa New Zealand, health outcomes for disabled people | tāngata whaikaha have improved slightly over time in some areas. However, disabled people continue to experience significant inequities in health outcomes, which in turn exacerbate the barriers they face to experiencing ordinary life outcomes.

Inequities across broader social determinants of health[9] play an important role in disabled people | tāngata whaikaha experiencing inequitable health and wellbeing outcomes. The 2023 Household Disability Survey found that disabled people were less likely than non-disabled people to be doing well across many areas of their lives, and disabled people also face significant barriers to accessing quality health care, with tāngata whaikaha Māori and other marginalised communities experiencing compounding inequities. [10,11]

The most recent New Zealand Health Survey data indicated that disabled adults were less likely than non-disabled adults to report being in good, very good or excellent health; were more likely to experience high or very high levels of psychological distress; and experienced multiple additional barriers to accessing primary care, including the cost of seeing a general practitioner (GP) and filling prescriptions, as well as access to transport to attend appointments.[12] The Cancer Control Agency recently found that disabled people were 22% more likely to be diagnosed with cancer than the non-disabled population, with even higher rates (34%) for those aged 45–65 years.[13]

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[8] Quinn, G., & Degener, T. (2002). The moral authority for change: human rights values and the worldwide process of disability reform'. in G. Quinn & T. Degener (Eds.), *Human rights and disability: the current use and future potential of human rights instruments in the context of disability* (pp. 13–28). United Nations. https://www.ohchr.org/sites/default/files/Documents/Publications/HRDisabilityen.pdf

[9] Social determinants of health include housing, employment, education and involvement with the justice system, among many others.

[10] McLeod, K., Stone, G., Beltran-Castillon, L. (2025). The cost of exclusion: hardship and people with intellectual disability in New Zealand. IHC. https://www.ihc.org.nz/publications/the-cost-of-exclusion-report

[11] Public Health Advisory Committee. (2025). Determining our future – social, cultural, economic and commercial determinants of wellbeing in Aotearoa New Zealand: Actions to improve our health and wellbeing. Ministry of Health | Manatū Hauora. https://www.health.govt.nz/publications/determining-our-future

[12] Ministry of Health | Manatū Hauora. (2025). New Zealand Health Survey 2024–25. https://www.health.govt.nz/monitoring-statistics/surveys/new-zealand-health-survey

[13] Te Aho o Te Kahu – Cancer Control Agency. (2025). The burden of cancer among disabled people: Diagnosis insights. He taumaha te mate pukupuku ki ngā tāngata whaikara: Ngā kitenga. https://teaho.govt.nz/application/files/1717/6420/6615/Disability_Cancer_Diagnosis_Insights_Te_Aho_o_Te_Kahu_Cancer_Control_Agency_27_November_2025_3.pdf

Figures for tāngata whaikaha Māori reflect compounding inequities. Data released from the 2013 Disability Survey (2019) show that disabled Māori aged 25 years and over were more likely than disabled non-Māori to develop cancer and chronic conditions and to be admitted to hospital for diabetes, high blood pressure, heart disease and motor vehicle accidents. The 2013 Disability Survey also found that tāngata whaikaha Māori had worse self-reported health and lower trust in the health system than their non-disabled peers.[14,15]

Research on groups of disabled people | tāngata whaikaha in Aotearoa New Zealand with specific conditions is limited. However, research on the health of people with learning disability[16] reflect the deeply concerning inequities this group faces. People with learning disability are likely to die significantly younger, have much higher potentially avoidable hospitalisations and are much more likely to be treated for a psychosis, including being medicated when they have not received a diagnosis that features psychosis.

See the box on page 14 for insights on health outcomes from the Health Quality & Safety Commission Te Tāhū Hauora (HQSC) concurrently released report, *A Window on Disability*.

Health versus disability services

Health systems play a critical role in the prevention, diagnosis and treatment of, and rehabilitation from, acute and chronic illnesses and injury. Receiving an accurate diagnosis can play an important role in supporting a person's understanding and management of their health conditions and bodily differences. However, many disabled people | tāngata whaikaha have experienced physical and psychological harm or medical trauma during their engagement with the health system. There is a long history of medical approaches that have 'othered' and/or attempted to 'cure' disabled people. This has included, for example, subjecting them to unnecessary or unconsented treatments (eg, forced sterilisation) rather than supporting their overall wellbeing, self-determination and inclusion in society as they are. These experiences can have a significant effect on disabled people's trust in the 'medical system'.

For many decades, disabled people | tāngata whaikaha, their families, whānau and allies have made social and political efforts to realise equal rights across society. Independent living movements in many parts of the world have championed disabled people being supported to live ordinary lives in their local communities. The success of these movements has seen long-term formal/paid supports move from hospitals and institutions to the community.

In Aotearoa New Zealand, this has also included a separation between health and long-term, community-based disability supports, most notably in the deinstitutionalisation of people from large-scale hospitals and institutions into the community. This deinstitutionalisation supports people's rights and inclusion in society. However, a lack of structures supporting information sharing and connection between health, disability and other government settings has created barriers for many disabled people | tāngata whaikaha who have significant engagement with multiple systems and often do not receive the support they need to navigate between them.

Community-based disability supports are tasked with responsibility for developing in-depth understanding of a disabled person's individual needs and circumstances to be able to support them (potentially every day), with a focus on consistent, ongoing relationships. Community disability supports are not responsible for the provision of medical care, but they do play a role in supporting the delivery of some care (such as wound care or the administration and supervision of medication) and health monitoring (such as wound care monitoring or alerting health providers to changing symptoms).

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[14] Cited in Kaiwai, H., & Allport, T. (2019). *Māori with Disabilities (Part Two). Report Commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575)*. https://www.abuseincare.org.nz/__data/assets/pdf_file/0023/28364/kaiwai-h-allport-t-maori-with-disabilities-part-two-report-commissioned-by-the-waitangi-tribunal-for-the-health-services-and-outcomes-inquiry-2019-1.pdf

[15] StatsNZ | Tatauranga Aotearoa. (2024). 2023 General Social Survey. https://datainfoplus.stats.govt.nz/

[16] In this report, we use the term 'learning disability' as a community-preferred term. We acknowledge that the term 'intellectual disability' is used in legislation and by other organisations and individuals.

Health Quality & Safety Commission Te Tāhū Hauora report

The following is a short synopsis of the Health Quality & Safety Commission Te Tāhū Hauora report, *A Window on Disability* ('the report'). The report noted that disabled people in Aotearoa New Zealand are among the most frequent users of the health system yet experience poorer health and safety outcomes than their non-disabled peers, with disparities further compounded for Māori and Pacific disabled people. Many disabled people report poorer health service experiences and outcomes as they age. For this reason, the report adopted a life-course approach to presenting its data.

Disabled people who become pregnant are less likely to enrol with a lead maternity carer during their first trimester, have a higher prevalence of pre-term births and generally report lower satisfaction and poorer overall experiences with maternity services.

Health outcomes for disabled children are broadly comparable to those of non-disabled children. However, disparities begin to emerge as disabled people age. These inequities become particularly pronounced as young disabled people transition out of paediatric services and into adult health care, which the report has identified as a critical point of failure within the health system.

Disabled adults experience higher rates of chronic conditions, mental health distress and major cancers and encounter significant systemic barriers. These inequities are most acute for Māori and Pacific disabled people and are compounded by a critical unmet need for primary, mental and oral health care. Consequently, some disabled adults are prematurely placed into aged residential care, and others experience avoidable health declines due to delayed or inadequate support.

The report identifies that significant data gaps persist relating to the health experiences of older disabled people. Some disparities are evident in home and community support outcomes between disabled and non-disabled older populations. Most critically, disabled people face significantly lower life expectancy than their non-disabled peers.

The report identifies four priority areas to progress:

1. The need for more disaggregated data related to disability, meaning disability must be accurately reflected in national health data.
2. The need for disability knowledge to be embedded into all stages of education, training and professional development of the healthcare workforce.
3. The need for health agencies and services to employ disabled people and tāngata whaikaha who understand the disability experience.
4. The need to embed self-determination and supported decision-making as core principles in the New Zealand health system.

The full *A Window on Disability* report is available at www.hqsc.govt.nz.

Conversely, although health providers diagnose conditions and deliver medical treatments, they are not generally involved in the day-to-day support of disabled people | tāngata whaikaha and may not have an understanding of the individual's preferences, circumstances or support needs. This lack of familiarity with an individual's disability support needs can be a problem when health systems have to respond to a person's health needs, particularly in acute settings.

There are also key intersections between health and disability services. For example, receiving disability supports can, at times, be reliant on a diagnosis via medical specialists, and – in turn – gaps in disability support can place further pressure on health systems to provide care. It is therefore likely that disabled people | tāngata whaikaha are disproportionately affected by the significant constraints across both health and disability systems. For example, there can be delays in discharging disabled people from hospital because of difficulties accessing and coordinating disability supports in the community. Disabled people can also face avoidable hospital admissions because of a lack of support. This has a negative impact on disabled people's health and wellbeing and places the health system under further pressure.

Recent health and disability reforms in Aotearoa New Zealand

International acknowledgement of health system inequities for disabled people | tāngata whaikaha has been increasing.[17] In Aotearoa New Zealand, several significant government reforms and key developments across the health and disability sectors have identified disabled people | tāngata whaikaha as a focus population and set out new expectations for the health sector to improve outcomes, including through:

- Pae Ora (Healthy Futures) Act 2022
- HQSC's code of expectations for health entities' engagement with consumers and whānau 2022
- Health of Disabled People Strategy 2023
- Government Policy Statement on Health 2024
- New Zealand Disability Strategy 2026–2030
- New Zealand Health Plan 2024–2027.

These developments set out the Government's priorities and objectives for the publicly funded health and disability sector in Aotearoa New Zealand. Individually and collectively, these documents set expectations around improving the experiences of disabled people | tāngata whaikaha in the health and disability system, including expectations in relation to:

- promoting equity for disabled people
- promoting the self-determination of disabled people
- ensuring services and supports are accessible
- improving connections and coordination between systems
- improving workforce capacity and capability to support disabled people
- improving the collection and visibility of data, research and evidence about the experiences and outcomes of disabled people.

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[17] World Health Organization 2022, *op. cit.*

Current actions by health and disability agencies to improve health outcomes for disabled people | tāngata whaikaha

We are aware of important work happening across several agencies to respond to the health needs of disabled people | tāngata whaikaha.

Whaikaha – Ministry of Disabled People

Whaikaha has recently launched the refreshed New Zealand Disability Strategy 2026–2030,[18] which established 'disabled people achieving the highest possible attainment of health and wellbeing' as one of its five priorities. The health actions that the Government has committed to in the Strategy include:

- reviewing and improving policies and practices, so disabled people's health journey is equitable, accessible and inclusive
- training the health workforce to deliver services that are inclusive, culturally safe and easy to navigate
- building disabled people's skills and knowledge to take up health system roles
- identifying disabled people in national health data
- putting a system in place so disabled people can record their accessibility needs against their National Health Index (NHI) number.

Health NZ

Health NZ is also working to improve data on disabled people | tāngata whaikaha accessing health services within the public system, while also improving staff capability. Work includes:

- developing a Patient Profile NHI project to collect, monitor and respond to quality issues and health outcomes across all health services, as well as to provide information about individual access needs when someone is engaging with the health system
- improving the capture of disability status in complaints and feedback data
- undertaking analysis of national disability data sets to understand health quality and outcomes
- improving training and development opportunities, including e-learning modules, wānanga and workshops
- improving processes such as booking systems, developing and supporting safeguarding policies and guidelines and ensuring disability expertise input into service design and clinical pathways
- building capability around patient and whānau access to New Zealand Sign Language (NZSL) interpreters, including through training and development of resources
- engaging with disability community stakeholders across business units within Health NZ.

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[18] Whaikaha – Ministry of Disabled People. (2025). New Zealand Disability Strategy 2026–2030. https://www.whaikaha.govt.nz/about-us/our-work/new-zealand-disability-strategy-2026-2030

Ministry of Health

The Ministry of Health has been undertaking a range of both targeted and systemic work to improve disabled people's health outcomes and experiences. Targeted work by the Ministry of Health includes improving disability data and developing a 'health of disabled people' outcomes framework. Broader system changes have seen adjustments to the way primary care is funded, including weighting for people with coexisting conditions. The Government has also introduced targets for and monitoring of the delivery of health services. Other work includes:

- strengthening patient voice and support for disability leadership within the health workforce
- developing a health sector workforce monitoring framework, including disability competence and cultural safety, disability employment trends and training
- improving research and evaluation, such as engagement with primary and community care for tāngata whaikaha Māori māmā and pēpi across the first 2000 days of life
- developing an outcomes and measurement framework for the health of disabled people to support national monitoring.

DSS

Disability Support Services (DSS) at the Ministry of Social Development | Te Manatū Whakahiato Ora is improving quality management systems to identify and respond to incident report trends related to health issues in disability support services, particularly in residential disability services. DSS has also established an interagency role to support disabled people | tāngata whaikaha to access more seamless and appropriate care between health and disability agencies.

Data used in this report

Currently around 25% of complaints to HDC are about the care provided to a person who identifies as having a disability. However, we know that groups within disability communities are under-represented in complaints and face multiple barriers to raising their concerns, including people with learning disability and people in residential support services. Around 4% of complaints to HDC each year are about *disability support providers*, meaning that most of the complaints about services provided to disabled people | tāngata whaikaha involve providers of *health services*.

Between 1 January 2023 and 31 December 2025, HDC received around 1,800 complaints about care and treatment provided to disabled people | tāngata whaikaha under the age of 65 years by healthcare providers.

To develop the themes for this report, a coding methodology was developed through internal workshops. A close analysis was then undertaken of a subset of 176 complaints about the care provided to disabled people | tāngata whaikaha covering a range of health settings and experiences using an approach similar to constructivist grounded theory.[19] The themes in this report detail the common issues raised in complaints about disabled people's experiences in the health system, as well as some issues where the impact of the issue was significant despite the small number of complaints.

We have excluded residential and community disability services and Needs Assessment Service Coordination services because we recently published a report outlining the themes in complaints about residential disability support services.[20]

Complaints involving care provided to people over the age of 65 years were also excluded for the purposes of this report. The experiences of older disabled people and people with age-related disabilities were detailed in the Aged Care Commissioner's 2024 monitoring report *Amplifying the voices of older people in Aotearoa New Zealand*. The themes in complaints about residential aged care will be the focus of a future report, including the experiences of younger disabled people in aged residential care.

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[19] Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage Publications.

[20] See Report on complaints to HDC about Residential Disability Support Services – Health & Disability Commissioner

In our analysis and reporting of complaint themes, we have placed a particular focus on the experiences of neurodivergent people, people with learning disability and the Deaf community. This is in consideration of the significance of the issues raised in complaints about the experience of these groups, the communication barriers faced, current knowledge gaps within the health system and inequitable health outcomes for these groups. Although experiences of the mental health system by disabled people | tāngata whaikaha did form part of the analysis of this report, we have not focused on the experiences of mental health consumers in the mental health system. This will be the focus of a future report, including an analysis of disability.

Our thematic analysis revealed several recurring themes that were then grouped into seven thematic 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.

Where appropriate, illustrative examples and quotes from complainants have been included in this report, alongside HDC's analysis. The quotes have been anonymised, and in some cases edited, to ensure anonymity while maintaining the voice and intention of the person.

The complaints analysed for this report provide unique insights into aspects of treatment and support and directly reflect concerns raised by disabled people and their families. However, it should be noted that people can experience multiple barriers to making complaints and that the themes presented here are not a measure of the prevalence of any given issue. It is therefore important that the information presented in this report is examined alongside other forms of data, such as experience surveys, incident reporting mechanisms and health outcome data.

It should also be noted that complaints to HDC about services provided to disabled people | tāngata whaikaha can raise complex and contested issues. For example, in some cases there may be a difference between the views of family and whānau, who have a deep interest in the disabled person's safety and wellbeing (and may potentially be their legal guardian), and the views of the person, who has the right to self-determination. At times, the examples within this report may reflect these and other complexities.

Themes identified in complaints

Person-centred care

The Code sets the benchmark for person-centred care in Aotearoa New Zealand's health system.

The Code requires health providers to deliver an appropriate standard of care that is consistent with a person's needs, optimises their quality of life, takes into account their values and beliefs and ensures they are provided with the information they require in their individual circumstances to make an informed choice. The cornerstone of person-centred care is respect for people and their families and whānau, and the Code requires that every consumer is treated with respect and dignity.

It is important to note – particularly within te ao Māori – that person-centred care may also be defined as whānau-centred care, depending on the needs, values and beliefs of the consumer.

Notwithstanding the expectations of the Code, complaints to HDC can highlight concerns from disabled people | tāngata whaikaha that health services are not structured in a way that is consistent with their needs and that at times does not treat people as experts in their own experience.

Reasonable accommodations

The term *reasonable accommodation* refers to necessary and appropriate modification and adjustments to support disabled people | tāngata whaikaha to live their lives on an equal basis with others.[21] Reasonable accommodations are dependent on the needs of the person and include accessible modes of communication, physical changes to infrastructure (such as stepless access and automatic doors) and more individualised accommodations such as those to account for sensory differences.

The concept of reasonable accommodations goes hand in hand with that of universal design: creating environments and systems that are as useable as possible by all people. Hospitals and other medical environments are bright, loud and unpredictable and can be extremely stressful, particularly for neurodivergent people and people with learning disability.

> *I took myself to the emergency department … I had anxiety due to the overwhelming sensory and busy social environment … There was 'reception' and 'triage nurse' with different coloured floor mats under each. It was overwhelming.*

> *Verbal communication, especially in social and sensorily overwhelming environments, is incredibly challenging for me and makes it hard to think and process clearly, especially when I'm feeling vulnerable and the person I am talking to doesn't seem to understand my autism and/or they are a stranger.*

Although some providers have recognised the importance of reasonable accommodations and introduced environmental adaptions to decrease stimulation, in general, complaints to HDC highlight the distress some people experience in health settings, particularly EDs and shared ward environments. Care plans for disabled people | tāngata whaikaha who may frequently need to use health settings can help to ensure that adaptions are made to improve their experience and reduce distress.

> *There has never been a plan for* [consumer] *to get medical support for* [chronic health condition] *other than having to deal with the emergency department,* [which] *means a six-hour wait at the hospital – at least … She is often placed in noisy corridors … they put her in the hallway next to a baby that was literally screaming for more than two hours. After the two hours, I reminded them that* [consumer] *had sensory sensitivity, and this should be on her file.*

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[21] New Zealand Independent Monitoring Mechanism on the UNCRPD. (2023). Removing barriers: A guide for reasonable accommodation of disabled people in Aotearoa. https://www.ombudsman.parliament.nz/sites/default/files/2023-02/Reasonable%20Accomodation%20Guide%202023.pdf

For some disabled people | tāngata whaikaha, previous distressing experiences in hospital and other medical settings have led to the development of significant medical anxieties or fears, such as needle phobias. Sensory sensitivities can also require adjustments to the ways in which medical treatments are delivered (eg, the form in which medication should be provided).

> [Consumer] *has autism and a fear of needles. On* [consumer's] *medical notes, there are two red flags noted by a psychologist and a psychiatrist which highlights the difficulty for him when receiving treatments in hospital. Nursing staff have been informed of* [consumer's] *triggers on admission. Staff ignored these triggers during an admission to ED and proceeded to attempt to treat* [consumer] *without further discussion and input from the family.*

In addition to creating environments and systems that reduce distress, reasonable accommodation occurs where individual needs are recognised and adjustments to care are made:

> *After hours, another nurse came in and tried to speak to me. She quickly realised I was nonverbal and asked if I could answer by shaking or nodding my head – I could. It took her one minute to do this and to find out she could call one of my emergency contacts to tell her what had happened …*
>
> *I was then moved to a quieter place in ED, given a cup of water with a straw so I could actually drink, was given the medication I had waited hours for.*

Reasonable accommodations related to communication needs are detailed in the communication section.

Experts in their own experience

A stated aim of the Provisional Health of Disabled people Strategy,[22] the New Zealand Disability Strategy 2026–2030[23] and the Enabling Good Lives approach[24] is that of self-determination and the acknowledgement that disabled people | tāngata whaikaha and their families and whānau are experts in their own lives, needs and preferences. Acknowledgement of this fact by health providers, and by the system more broadly, is another core component in the provision of person-centred care.

For disabled people | tāngata whaikaha (and, where relevant, their family) who may have lived with a condition from birth or for many years, their knowledge of health complications that can arise from their disability is often based on extensive lived experience, ongoing treatment and personal learning. Complaints to HDC illustrate how failing to acknowledge disabled people and their families as experts in their own experience can result in harm and negatively impact on the consumer–provider relationship and engagement in care.

> *As a result of* [recent surgery]*, and as a usual consequence, I got a UTI* [urinary tract infection] *three days after surgery. I made contact with* [GP] *in a phone appointment and told him the symptoms and explained it was the usual UTI … Every diagnosis report came back clear and every conversation between appointments, I had reemphasised I had a UTI but was not listened to. Finally … four months after I first suggested I had a UTI; a renal scan was done which triggered an immediate referral to* [specialist] *… the damage was now irreversible.*

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[22] Ministry of Health | Manatū Hauora. (2024). Provisional Health of Disabled People Strategy. https://www.health.govt.nz/strategies-initiatives/health-strategies/health-of-disabled-people-strategy

[23] Whaikaha – Ministry of Disabled People 2025. *op. cit.*

[24] Enabling Good Lives – www.enablinggoodlives.co.nz.

Disabled people | tāngata whaikaha and their families may have had to spend a significant amount of time upskilling professionals in relation to their health conditions and disability support needs. Ensuring a consumer's disability-specific needs and experiences are captured in their clinical notes and care plans where relevant can help reduce the burden of having to repeat the same information across multiple settings and ensure that their expertise is captured and communicated.

> *When we arrived* [the doctor] *had oral medication waiting for her even though I had informed them multiple times she wouldn't take any orally. After* [consumer] *refused the medication* [the doctor] *stated there was no point in getting* [the procedure] *as … she wouldn't take medication so there was no point. I feel like* [the doctor] *completely failed with her obligation of patient care and left me feeling absolutely let down.*

> *Despite my* [autistic] *son's clear distress …* [the provider] *yelled at him, 'Be brave!' very loudly.*

Use of restraint

Evidence emerging internationally suggests that neurodivergent people, and particularly neurodivergent children, are more likely to experience physical and pharmacological restraint in hospital settings.[25,26] HDC has received a cluster of complaints that underscore the impact of the use of restraint on neurodivergent children and their families in the inpatient setting. These complaints can reflect a lack of understanding of neurodivergence among health staff, a lack of individualised care planning and a failure to adequately engage family in treatment.

> *… I, his mother, was not listened to as this specialist thought he knew what was 'better', and now we are left to pick up the pieces, manage his traumatised behaviour and now work through an even more severe dislike for doctors and hospitals.*

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[25] Williams G., Corbyn, J., & Hart, A. (2023). *Improving the sensory environments of mental health in-patient facilities for autistic children and young people. Journal of Child Care in Practice*, 29(1), 35–53. https://doi.org/10.1080/13575279.2022.2126437

[26] Salvatore, G. L., Simmons, C. A., & Tremoulet, P. D. (2022). *Physician perspectives on severe behavior and restraint use in a hospital setting for patients with autism spectrum disorder. Journal of Autism and Developmental Disorders, 52*(10), 4412–4425. https://doi.org/10.1007/s10803-021-05327-8

Reasonable accommodations in the physical environment

Physical access to many buildings has improved in recent years with accessibility requirements for new buildings under the Buildings Act 2004 and some older buildings retrofitted to increase accessibility for disabled people | tāngata whaikaha. However, the health infrastructure in Aotearoa New Zealand is aging and, in some cases, not fit for purpose. Physical access issues remain a barrier to accessing care for some disabled people.

> *The clinic … had no accessibility, meaning any time I visited I had to bring my own ramp for my wheelchair.*

Ensuring physical accessibility to health services for disabled people | tāngata whaikaha requires not merely ensuring physical access through the door but also that buildings and equipment are designed to promote inclusivity. Complaints to HDC illustrate how a lack of access to inclusive or universally designed equipment can result in inequitable access or delayed diagnosis and treatment.

> *I am unable to access a mammogram machine. Due to this* [consumer was removed from screening list]*, so I no longer receive reminder notifications. As 'normal' women are still accessing standard mammograms, it is unfair that I cannot have an ultrasound mammogram. … I want to see wheelchair users accessing the same level of health care as non-disabled people.*

Cultural responsiveness

Right 1(3) of the Code gives people the right to be provided with services that take into account the needs, values and beliefs of different cultural, religious, social and ethnic groups, including the needs, values and beliefs of Māori. This means that, where relevant, a person's cultural needs should be considered alongside their other support needs.

Aotearoa New Zealand society is diverse, and so too are disability communities. Disabled people | tāngata whaikaha must be provided opportunities to express their cultural identity and to receive culturally responsive services and support on an equal basis with others. To this end, a stated principle of the New Zealand Disability Strategy 2026–2030[27] is the upholding of equity, culture, identity, non-discrimination and inclusion. This principle acknowledges:

> *that disabled individuals belong to diverse whānau, communities and cultures, each with their own unique identities, values and practices. It recognises people should not face barriers because of the different parts of their identities.*

However, the Strategy acknowledges the many barriers disabled people | tāngata whaikaha currently face in their interactions with healthcare providers and their navigation of the wider system, including negative social attitudes toward disabled people. These concerns are also reflected in complaints to HDC.

Health providers' cultural awareness and competence in relation to disabled people | tāngata whaikaha requires the recognition that consumers and their whānau may identify with multiple communities, shaping their identity and sense of self. These identities may stem from their ethnicity, religion, nationality, sexuality, gender identity and socioeconomic background, alongside their identity and experiences as disabled people.

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[27] Whaikaha | Ministry of Disabled People, 2025. *op. cit.*

Tāngata whaikaha Māori

Many tāngata whaikaha Māori identify as Māori first. Where individuals and whānau of tāngata whaikaha Māori (Māori with lived experience of disability) raise concerns with HDC, it is frequently around models of care that do not reflect te ao Māori and are not whānau-centric. Complaints to HDC also often highlight how intergenerational experiences have reduced whānau Māori trust in the health system, and this distrust can be even greater for Turi and tāngata whaikaha Māori and their whānau who have experienced compounding inequities.

Studies suggest Māori and Pacific Peoples also experience under-diagnosis of neurodivergence and other conditions that may require disability support,[28,29] an issue that may be due to both systemic barriers and diagnostic models that lack cultural understanding of non-Western cultures. Just as knowledge, training and understanding in the diverse needs, preferences and experiences of disabled people | tāngata whaikaha are essential tools for providers to enable quality, person-centred care and treatment, so too is knowledge, experience and expertise in relation to te ao Māori, mātauranga, tikanga, kawa and reo Māori in the care and treatment of tāngata whaikaha Māori.

Complaints to HDC from tāngata whaikaha Māori and whānau highlight concerns around lack of understanding of whānau-inclusive and tikanga-led care.

Deaf and Turi Māori culture

For Deaf people | tāngata Turi, cultural responsiveness goes beyond linguistic knowledge, requiring an understanding of Deaf | Turi ways of thinking and social norms. When healthcare providers demonstrate cultural responsiveness, consumer and whānau trust and engagement increases. It is therefore important that healthcare professionals seek to better understand Deaf culture and identity in recognition of the Deaf community's shared history, language and lived experience.

Complaints from Deaf people | tāngata Turi starkly illustrate the failures of such understanding, for example, concerns around health professionals ending appointments and/or refusing further appointments where they have misinterpreted verbal directness and speaking voices that are louder than average as aggression.

Although many Deaf | Turi individuals who speak sign language identify as a linguistic minority with unique cultural traditions, health systems strategies to promote greater inclusion often approach Deafness under disability frameworks, which do not always capture the nuanced needs of diverse Deaf communities. Complaints to HDC also highlight the barriers Turi Māori can face when the health system fails to recognise their multiple identities. As the *New Zealand Disability Strategy 2026–2030* states,

> *Turi Māori walk in both the Deaf and Māori worlds, identifying as members of the Deaf community and as Māori. Many Turi Māori use NZSL as their first language. However, Turi Māori face barriers accessing te ao Māori, including that NZSL does not always reflect Māori concepts.*[30]

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[28] Tupou, J., Kewene, F., Morrison-Young, I., Wi-Hongi, A., Sporle, A., Diamond, T., Theodore, R., & Bowden, N. (2026). Identification of autistic Māori in Aotearoa New Zealand: A national cross-sectional study. *Autism*, 30(2): 362–374. https://doi.org/10.1177/13623613251380927

[29] Ruhe, T., Kolose-Pulefolau, B., Foliaki, S., Bowden, N., Richards, R., & Kokaua, J. (2022). Examining case complexity among Pasifika with autism/Takiwātanga in Aotearoa New Zealand: A national cross-sectional study. *Pacific Health Dialog*, 21(10): 673–682. https://pacifichealthdialog.nz/index.php/phd/article/view/149

[30] Whaikaha – Ministry of Disabled People, 2025, *op. cit.*

Communication

Under Right 5 of the Code, people have the right to open, honest and effective communication in a form and manner that allows them to understand the information provided. Almost all complaints to HDC raise communication issues to some extent, and inadequate communication is one of the most common themes identified in complaints about services provided to disabled people | tāngata whaikaha.

Effective communication and information sharing between the consumer, their family/whānau or support people (where appropriate) and their health provider is essential to being supported to make informed decisions about their treatment, maintaining positive relationships with providers and improving the consumer's health and wellbeing.

Poor communication can leave disabled people | tāngata whaikaha and their whānau and support people feeling as though they do not have a voice, and it affects their decision-making and sense of control about their care and treatment. Furthermore, the consequences of miscommunication can be very serious, leading to missed diagnoses, missed opportunities for preventive measures, reduced trust, lack of adherence to treatment plans, a reluctance to engage with future treatment and, ultimately, poor health outcomes.

Common concerns include a lack of accessible communication; inadequate communication with family, whānau and support people; inadequate access to interpreters; and issues of informed consent.

Accessible communication

Ensuring accessible communication is about respecting the diverse communication needs and preferences of disabled people | tāngata whaikaha and engaging and conveying information in a mode and manner that works for the consumer. For example, although the use of plain language is an important aspect of accessibility, the depth and type of information each person requires to make an informed choice will differ.

Although some Deaf people | tāngata Turi may primarily use sign language for communication, others use lip-reading or written language as their primary means of communication. However, studies have shown that only around 30–40% of spoken English language can be understood through lip-reading alone, a figure that drops further when the individual is unwell.[31] Not being able to access comprehensive sign language communication in health settings adds to existing barriers to health literacy and understanding of and compliance with prescribed treatments for Deaf people.[32] Deaf people may also face barriers to accessing family health history, which further disadvantages them in respect of health outcomes.

Similarly, people who are blind or low-vision | tāngata kāpō may use Braille where possible but may prefer to have important information about their health communicated to them verbally, particularly where Braille formats may only be available as generic information, as opposed to more complex, person- or disease-specific information. For people who experience social and communication barriers, effective communication may necessitate additional consultation time, as well as the assistance of alternative or augmentative communication. For others, the availability of and time for an interpreter or family member or other support person may be critical to ensuring the person's effective communication with the provider. This can be difficult for individual providers to achieve within a pressured system.

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[31] Payne, D. A., Terraschke, A., Yoshida, K., & Osasah, V. A. (2023). Aotearoa New Zealand Deaf women's perspectives on breast and cervical cancer screening. *New Zealand Medical Journal*. 136(1576): 40–48. https://doi.org/10.26635/6965.5995

[32] Witko, J., Boyles, P., Smiler, K., & McKee, R. (2017). Deaf New Zealand Sign Language users' access to healthcare. *New Zealand Medical Journal*, 130(1466): 53–61.

For people's rights to effective communication and informed consent to be upheld and to allow them to participate as partners in their own care, the system must facilitate people with specific communication needs to use their preferred means of communication in their interactions with health providers.

> *Due to his hearing disability,* [consumer] *had to learn to 'read' people (body language, micro expressions and lip movement). However, his condition has worsened progressively in time, and now unless he can see the full face of the person he is conversing with, he cannot understand them.*

Complaints to HDC illustrate how people can face barriers to accessing care when accessible forms of communication are not offered in a way that meets the individual's needs.

> *As a profoundly deaf individual, traditional methods of communication, such as phone calls, are not accessible to me. Consequently, I rely on email as my primary mode of communication. Unfortunately, I have noticed delays in responses to my appointment requests via email … This delay not only impacts on my access to timely healthcare but also adds unnecessary stress and uncertainty.*
>
> *… I am now required to disclose personal information to the Practice Manager or receptionist – who are not medical experts – to relay to my GP, compromising my privacy and dignity.*

Importantly, difficulties in communication can increase anxiety and distress for disabled people | tāngata whaikaha and contribute to disengagement from health services.

> *Psyching-up to make a phone call to book an appointment or resolve an issue can be really hard work. Having to do it repeatedly just to get through is even harder work … So, I didn't make those appointments I needed to make and I'm now just trying to manage those health issues myself.*

Complaints also highlight the difficulties people face when their providers do not have a consistent understanding of their communication needs. A lack of information sharing between providers or consistent documentation also means that people's communication needs can be easily misunderstood or overlooked. It is frustrating to have to advocate for your own communication needs across multiple health settings.

> *As I am severely deaf, I was wearing hearing aids in both ears, which help me to better understand speech. My hair is very short, and my hearing aids are quite large. They are easy to see when I am wearing them. I was also wearing a vivid blue lanyard with 'Hearing-Impaired' in large text, to make sure all staff were aware … Throughout the whole appointment* [doctor] *rarely made any eye contact with me … so I could not lipread him. I do not really know what he was saying to me at this point.*

> *I told the nurse who admitted me to the ward* [for surgery] *I was very hearing impaired. She wrote on my information whiteboard that my language was 'lip reading' … I am not a good lip reader, it requires intense concentration and skill, and after surgery there was no hope of me lip reading … I was relying on Google Live Transcribe to understand what people were saying to me.*

> [Following discharge] *I was sent an appointment letter for a 'phone or zoom' to take place … Zoom/Phone is not an ideal way for me to communicate. However, my husband and I made a plan to try to make it work … No phone call ever came … a nurse had called me and left a voice message, expecting an app on my phone to transcribe it to text …* [the next appointment] *was cancelled because* [doctor] *was not sure they could make captions work on Zoom … They were unable to give me any assurance of an accessible mode of communication and deferred my already deferred appointment to an even later date.*

Even when communication barriers are known and understood by a provider, systems, including access to appropriate tools and flexibility around time constraints, may not be in place to support communication needs to be met.

Communication with family, whānau and support people

Right 8 of the Code gives people the right to have support people of their choice present during their interaction with a health or disability provider. For many disabled people | tāngata whaikaha, the right to have a support person present, whether that be a family member, a legal or welfare guardian, friend or support worker, is also essential to upholding their right to effective communication.

Family, whānau and support people may also play a more central role in the care and treatment of disabled people | tāngata whaikaha if they hold legal guardianship or for decisions where the disabled person would benefit from support (eg, where decision-making capacity may be affected).

However, it is important that, where possible, the person remains at the centre of discussions and decisions about their health and wellbeing. Complaints to HDC highlight how, even when disabled people | tāngata whaikaha may require support to communicate or make decisions, the consumer must still be at the centre of these discussions. This includes being given the opportunity to ask follow-up questions and to ensure they have control over decisions made in relation to their care.

> *I also feel I am not taken seriously … I am aged 20, and I have been asked 'are you okay speaking to me without your dad here' over the phone, all because there is 'Autism' and 'ADHD' on my file, and my dad came with me to support me at a face-to-face appointment. This automatic assumption is degrading and insulting. Regardless of my other diagnoses, I deserve to be treated with the respect and care shown to every other patient.*

It is important to consider the wider experiences of disabled people | tāngata whaikaha and their whānau. Many disabled people may be coming to health settings having previously had their value, capability or decision-making capacity questioned or having not been offered a full range of treatment options, more frequently than their peers.

Complaints to HDC can also highlight the impact on disabled people's engagement in their care where medical professionals do not understand or facilitate the consumer's needs and preference for involvement of support people. For some disabled people | tāngata whaikaha, their family, whānau and carers are central to their wellbeing, and complaints underscore the importance of, where appropriate, listening to those most familiar with a person's needs and preferences.

> *Her carers were explaining to the doctor that my daughter was unwell; however, the doctor looking after her seemed uninterested about the information being given to her by my daughter's carers. This left them feeling unheard and disrespected.*

> [Consumer] *was placed in a taxi as arranged by the hospital without her next of kin advised, as well as being driven home by a driver whose details were not disclosed to her next of kin … the driver just drove away and left a blind, sick woman in the early hours of the morning to find her own way to the front door.*

> *I am my father's welfare guardian. It was extremely difficult to speak with the medical team to get information regarding my father's treatment plan and actual diagnosis … I phoned each day asking to speak with my father's medical team … and every answer I got was they would call me back, and they never did … How am I meant to be my father's welfare guardian and assist him in appropriate medical care if I am not told his diagnosis?*

CASE STUDY

Management of patient with complex physical and mental health needs by GP

The Deputy Commissioner found a GP in breach of the Code for multiple failings in the care of a patient with complex physical and mental health needs. The Deputy Commissioner noted that the patient was clearly an at-risk health consumer and had complex health and social needs. She was concerned that the GP made assumptions about the treatment (or lack of treatment) of her conditions without seeking specialist advice or input, and without any discussion with the patient or her support person.

Access to interpreters

Right 5(1) of the Code states that every consumer has the right to effective communication in a form, language and manner that enables them to understand the information provided. Where necessary and reasonably practicable, *this includes the right to a competent interpreter*.

Printed health information and easy-read formats can be useful communication aids, but gaps in both health and English literacy can mean readable communication modes are not always effective, particularly when a person does not have the support of a family member or other support person, or – for instance – when a Deaf person | tāngata Turi has NZSL as their first language.

Qualified NZSL interpreters act with neutrality, and although a professional NZSL interpreter may make suggestions about how to improve communication between the parties, they only interpret the discussion and do not provide any advice to the Deaf | Turi consumer on matters related to their health care or treatment.

There are risks related to written or printed communication and lip-reading, as well as issues with relying on non-professional NZSL communicators (fluent or semi-fluent family, whānau or friends), including skill level, potential for breaches of privacy and opportunity for coercive control. The availability and use of professional interpreters can therefore be a vital means of ensuring effective communication and consumers' understanding, compliance and engagement with treatment and services.

Although some health professionals remain unaware, many providers understand that NZSL is an official language of Aotearoa New Zealand, distinct from spoken and written English in both grammar and vocabulary. Although considerable efforts are being made to improve access to NZSL interpreters, there remain several reasons why interpreters may not be available to consumers in health settings, including issues of urgency, regional variations in access and demand, and funding and contracting pressures.

Informed consent

The right to informed consent sits at the heart of the Code and is central to the provision of person-centred care. Under the Code, informed consent has three essential elements:

- Right 5 – the right to effective communication
- Right 6 – the right to be fully informed
- Right 7 – the right to make an informed choice and give informed consent.

Effective informed consent processes serve not only to protect the rights of disabled people | tāngata whaikaha but also to promote autonomy, self-determination, engagement and trust within the clinical relationship and ultimately better health outcomes and improved consumer experience. However, complaints to HDC suggest that disabled people, particularly people with learning disability and Deaf people | tāngata Turi, are not always adequately supported to make an informed choice about their treatment.

Bodily autonomy

Our right to make choices over our body is essential to our sense of self. Bodily autonomy can be particularly important for disabled people | tāngata whaikaha who are likely to feel as though they do not have complete control over their bodies or senses or over their interactions with providers and institutions. Disabled people can also have a history of medical trauma, some of which may be due to a loss of bodily autonomy (eg, a sense of being 'manhandled').

> [I have a history of being] *treated with disrespect, manhandled, left in undignified positions, treated very badly as I am vulnerable being a tetraplegic.*

Inadequate communication and informed consent can impact decisions and interactions most people take for granted, including control over one's own body. Whether touching or pushing a consumer's wheelchair or when assisting the disabled person | tangata whaikaha with their personal cares, any physical contact, including pushing a wheelchair or use of other mobility aid, that has not been specifically consented for can be experienced as invasive and disrespectful.

> *Because she is in a wheelchair, she could not safely transfer herself to and from the wheelchair with her hand in a cast, and so she was staying in the hospital … Early next morning she* [woke up] *to find a nurse undressing her. She was practically naked from the waist down by the time she was fully aware of what was going on. She now suffers from anxiety and can't go into the hospital without having anxiety attacks.*

Capacity assessment and supported decision-making

The Code is clear that every consumer must be presumed competent to make an informed choice unless there are reasonable grounds for believing they are not competent. Complaints to HDC highlight a concerning level of variation in health professionals' understanding of capacity and their capability to undertake capacity assessments. Research also suggests that the application of capacity tests is currently inconsistent, and many people who make capacity assessment decisions are unaware of existing guidance.[33]

From time to time, disabled people | tāngata whaikaha, families and whānau raise concerns that underlying implicit assumptions and biases about disabled people can impact on assessments of their capacity to make informed decisions (eg, incorrect assumptions that people who are non-verbal may lack capacity).

It is important that providers put in place processes to facilitate supported decision-making where appropriate. Complaints to HDC highlight variable understanding among providers about supported

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[33] Hickling, N., McCann, C., Tippett, L., & Cheung, G. (2024). Examining the approaches used to assess decision-making capacity in healthcare practice. *New Zealand Medical Journal,* 137(1598): 22–32. https://doi.org/10.26635/6965.6474

decision-making and the application of Right 7(4), including their obligations to take reasonable steps to ascertain the views of the consumer, where decision-making capacity is affected, including by consulting with people who have an interest in the welfare of the consumer.

Whaikaha – Ministry of Disabled People has recently launched a website, *Whaimana – Support My Decisions*, to promote understanding and practice around supported decision-making.[34]

The recent publication of Te Aka Matua o te Ture | Law Commission's Review of Adult Decision-Making Capacity Law, makes recommendations to reform legislation and focus decision-making on a person's 'wishes' and 'values'. The recommendations are currently being considered by the Government.

Quality of nursing and other cares

A central concern for disabled people | tāngata whaikaha and their families and whānau is that they receive support and care that promotes their physical and mental health, ensures their safety and wellbeing and upholds their dignity and mana.

All consumers using health services have the right to an appropriate standard of care that meets their needs. For many disabled people | tāngata whaikaha, the provision of effective care and support by health providers is very important, particularly for those who require support with daily living but may face barriers in communicating their needs and those with complex comorbidities requiring hospital admissions.

Common concerns expressed by complainants in respect to care and support are delayed personal cares and a reliance on family and whānau to provide support in health settings.

CASE STUDY

Disabled man died when his dietary plan was not followed

Health NZ was found in breach of the Code for failing to document a disabled man's dietary needs clearly and consistently and not communicating these needs when the man's care was being transferred between staff and hospital wards.

The man was at risk of choking and aspiration from eating and drinking. He had a comprehensive eating and drinking plan, which outlined that he was to receive only puréed or liquid foods and that he had to be supervised at all times while eating. On his arrival at the hospital, the residential care provider provided hospital staff with the man's medical history, including information about his dietary plan. However, the man was transferred to another hospital ward, and handover notes for his transfer did not contain information about his dietary plan or feeding requirements.

While admitted to hospital, the man was given non-puréed food, contrary to his dietary plan. He was left unattended after his meal delivery and was then found to be in distress. Sadly, despite attempts to revive him, he subsequently died.

Delayed/inadequate attendance

Delayed personal cares and support can have a significant impact on the dignity, mana and wellbeing of disabled people | tāngata whaikaha in health settings. Such delays can also pose a risk of harm to the consumer, particularly where the disabled person may face barriers to communication, significant mobility issues or other risks to their safety. Timely personal cares have an important role to play in patient safety, including reducing the risk of choking, falls, infections and pressure injuries.

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[34] Whaimana – Support My Decisions: www.supportmydecisions.nz

> *Staff would not answer* [the call bell] *in good time … They wouldn't let mum borrow a wheelchair to enable her to do anything … Even if they had done so, they wouldn't assist anyway. Mum had not been cleaned at all. No sponge bath, nothing.*

> *He was left, not turned for up to 7 hours. His paralysis unfortunately means he doesn't have the strength or ability to turn himself in bed and relies on nursing staff or carers to help him with this. It is widely understood that a person that is paralysed needs to be turned every 2 hours minimum, including throughout the night. Pressure sores are preventable and this is a treatment injury due to lack of nursing care.*

> *In the two days* [consumer was in hospital] *she had not had her* [continence] *product changed by the medical staff, a shower, or had her teeth cleaned. I am not even sure if she ate any food! … The fact that someone of* [consumer's] *limited mobility and speech and that she had no family spokesperson with her and she was left like this is clearly unacceptable.*

Complaints about delayed personal cares often highlight capacity constraints and staffing issues. However, other contributors include inadequate assessment and care planning, inadequate engagement with family and support people and poor communication between staff (particularly at shift handovers).

HDC has also received complaints about inadequate personal cares and disability support for disabled people | tāngata whaikaha in ED waiting rooms. This is a particular issue in the context of significant waits for medical review within EDs and an increase in people being assessed and managed within waiting rooms and corridors. We note that, in response, some districts have introduced support staff to deliver personal cares within ED waiting rooms.

> *When the caregiver visited her following her admission she was found in a 'heavily overfilled* [continence] *product' … Her call bell was not working, but she would not have the comprehension how to use this. I also understand food/drink was put in front of* [consumer]*, but no one checked to see if she ate this.*

Reliance on family and whānau for support and personal cares

Family, whānau and other support people can often have expert knowledge of their loved ones' health and disability support needs. As such, involving family, whānau and support people in the care and treatment of disabled people | tāngata whaikaha is an important aspect of providing person-centred care and can improve both patient experiences and health outcomes.

However, relying on family, whānau and support people to provide care and support in a hospital setting should be explicitly discussed and agreed on as part of care planning. For some whānau or support people, assisting with cares while a consumer is in hospital will be important to both them and the individual. However, for others, providing such support at an already anxious time may cause further distress.

Complaints to HDC can reflect whānau concern or frustration where they believe they have to step in to provide care, to address staff shortages or knowledge gaps, without explicit agreement. Such agreement, including clear boundaries between the roles of hospital staff, whānau and carers, can also assist to manage expectations and reduce complaints.

> *If it was not for one of her excellent caregivers looking out for her and visiting her, I am not sure what would have happened.*

> *After arrival to the CT scan area, a radiologist and a health care assistant came to find me to ask whether I could help transfer* [my brother] *from his wheelchair to the CT imaging bed. My response was ‘no’, and I explained he needs to be transferred safely by properly trained staff … particularly given he was preparing for a spinal operation.*

> [Over the following days, consumer’s wife] *was found cleaning* [consumer] *as he had an accident, as he was unable to get to the toilet or call for help.*

Quality of treatment

Disabled people | tāngata whaikaha often have multiple, interconnected and compounding care and support needs encompassing their physical, social, cultural and economic wellbeing. In general, disabled people are more likely to experience multiple comorbidities associated with their disability and are at higher risk of experiencing mental distress. For example, people with a learning disability are at increased risk of chronic disease and are more likely to live with mental distress. However, despite high rates of enrolment in primary health care, people with learning disability experience inequitable health outcomes and are overrepresented in ED presentations and potentially avoidable hospitalisations.[35]

A number of complaints to HDC relate to the quality of treatment provided to disabled people | tāngata whaikaha, which can contribute to poor health outcomes. The most common themes in these complaints relate to health providers’ understanding of disability and to diagnostic overshadowing.

Lack of provider knowledge and understanding

Providers being trained and supported to develop knowledge and skills in disability, including the diverse experiences of disabled people | tāngata whaikaha, is essential to disabled people receiving quality, safe care and improving health outcomes. Such knowledge is crucial to providers having the tools they require to accurately assess, diagnose and safely treat disabled people and to improve patient experience and uphold their rights.

Studies indicate that providers often feel unprepared and unsupported to increase their knowledge of disability because of a lack of professional training, specific skills, and expertise regarding neurodivergence, co-occurring disabilities and neuro-affirming care.[36]

Complaints to HDC also highlight a lack of health sector expertise in disability and the impact this has on the quality of treatment that disabled people | tāngata whaikaha receive. For example, in the case of neurodivergent people and people with learning disability, a lack of understanding of the differences in the ways in which people communicate and experience pain, and a failure to consider the impacts of restricted diets or sensory sensitivities on illness and treatment, can significantly impact on quality of treatment.

> *His brain often does not communicate with his body for signs and symptoms of illness. This makes* [health issues] *hard to see or treat as he often doesn’t communicate what he is feeling … Vomiting or gagging is his body’s response to the pain. He will go pale and feel warm but not always run a fever. His behaviour goes out of control/violent, which can make it seem as if nothing is wrong.*

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[35] Beltran-Castillon, L., & McLeod, K. (2026). From data to dignity 2026: Health and wellbeing indicators for New Zealanders with intellectual disability. IHC. https://www.ihc.org.nz/publications/from-data-to-dignity-2026

[36] Chu, J. T. W., Wilson, H., Pi, S., McCormack, J. C., Marsh, S., Newcombe, D., Bullen, C. (2025). Knowledge, attitudes and practices towards fetal alcohol spectrum disorder among healthcare workers in New Zealand. *Journal of Intellectual & Developmental Disability. 50*(1): 10–20. https://doi.org/10.3109/13668250.2024.2404167

> *We argued that she has a different response to pain and will even laugh when something hurts. He replied that even* [a person or child with learning disability] *would guard a sore tummy when touched.* [Consumer] *lay on her back silent with very high blood pressure and sweating for a week in the ward while doctors puzzled as to what was wrong and denied her the tests or scans she so desperately needed. We told them we thought she must have a blockage … Eventually they agreed to do an ultrasound. They said they had found a tumour the size of an orange.*

Complaints to HDC also illustrate how providers' knowledge of the needs of an individual disabled person | tangata whaikaha can be improved via effective documentation and coordination of care between providers. These complaints also further highlight the positive impact that treating disabled people, and their family, whānau and support people, as experts in their own experience can have on quality care provision.

> *… she needs a large banner alert on her GP and hospital medical files warning that her pain threshold is high, and her response may not be as per medical textbook because she is brave beyond comprehension. Medical school needs to teach the doctors and nurses to have an abundance of discretion and very low threshold for more tests for* [people with learning disability] *where something more sinister may be at play.*

Diagnostic overshadowing

Diagnostic overshadowing, in the context of the provision of health services to disabled people | tāngata whaikaha, refers to when symptoms of medical or mental health conditions are misattributed to a person's disability, with clinically relevant alternative or differential diagnoses not adequately considered. This can contribute to disabled people not receiving the care they need in a timely manner.

> *For the past six years I have experienced abdominal issues which I have sought medical care for. However, I feel that I have been brushed off and ignored by multiple doctors from both general practice and the hospital … These interactions have left me feeling as though the doctors I have seen have not cared to further investigate my issues and are assuming that my issues are either exaggerated or imagined. It is like the doctors look at my file, see that I have been in for this several other times, see that other doctors have done nothing, then see that I have autism and ADHD, then assume it is all in my head and that there is nothing wrong so they do nothing also … Regardless of my other diagnoses, I deserve to be treated with the respect and care shown to every other patient.*

Coordination within and between health and other support systems

The Code gives people using health and disability services the right to cooperation among providers to ensure quality and continuity of services.

Disabled people | tāngata whaikaha must navigate across multiple systems and government agencies to obtain the support they require, including, for example, the health, education, disability support and social services systems. Although these systems have a direct impact on one another (eg, a diagnosis in the health system may assist people to receive support in the education system), they can operate in silos with limited information sharing between them. This means that disabled people and their whānau are often required to bridge the gap between systems themselves with little or ad hoc navigational support.

In addition, for disabled people | tāngata whaikaha with complex health conditions, navigating between services within the health system and obtaining assistance for both their disability support and health needs can be particularly challenging.

Access to diagnosis

Many of the current complaints to HDC reflect people's concerns about delayed access to care in the context of current constraints on the health system, including access to diagnosis for disabled people | tāngata whaikaha. For example, families of disabled children have raised concerns with HDC that significant waits for diagnostic assessments in services such as paediatrics impact on their access to disability support services. In theory, families may be able to access disability support based on need rather than diagnosis. However, concerns raised by whānau and families indicate that, in practice, disability support can be difficult to obtain in the absence of a diagnosis or that information about appropriate support services or referral to needs assessment services was not provided until their child received a diagnosis. Whānau and families note the economic consequences of such delays, which at times can require them to seek private diagnoses at significant cost.

> *I'm waiting for a developmental assessment for my daughter, to determine if she has an autism spectrum disorder … my daughter is really struggling and I'm not getting consistent messages from* [the provider]. *Initially they told me that I'm on a 12-month waiting list and today its changed to 18 months. In the meantime, she is struggling so much, and we are not sure how or what we need to do. Why do our children have to wait so long before we can get help?*

Timely diagnosis plays an important role in the long-term health and wellbeing of disabled people | tāngata whaikaha. Early diagnosis in children, for example, can help families and whānau receive the support they need to thrive and improve the child's health and life outcomes. Early diagnosis and intervention can also put disabled people and family or whānau in a better position to articulate their needs and request reasonable accommodations when receiving health care.

> [Specialist services] *declined a second referral from our GP without undertaking a face-to-face assessment or requesting comprehensive clinical information, including her history and comorbidities. Instead, we were advised to seek private support.*

> [Multiple providers] *failed to listen to, act on, and respond to my concerns about my son's development and possible autism. This failure has resulted in a significant delay in diagnosis and access to appropriate support. Rather than my developmental concerns being appropriately explored, they were dismissed. I was told, 'He will grow out of it,' 'Boys develop much slower than girls,' 'He will snap out of it,' and so forth … no meaningful developmental assessment, referral, or follow-up was undertaken.*

Information sharing between health providers

Disabled people | tāngata whaikaha are more likely to live with chronic health conditions and comorbidities that require frequent engagement with health services and treatment across multiple providers and specialties. A lack of information sharing between health providers is a recognised barrier to disabled people accessing and engaging with services. As the New Zealand Disability Strategy states, this lack of coordination means 'disabled people have to retell their stories every time they engage with a different health service'.

Complaints to HDC illustrate the difficulties disabled people | tāngata whaikaha face because of gaps in information-sharing between providers, particularly in respect of their medical history and disability support needs. The requirements for disabled people and their whānau and family to repeat their medical history and advocate for disability support needs to be met across multiple services can take a toll, add to their distress and increase risks that important information will be missed.

> *I reminded them that* [consumer] *had sensory sensitivity, and this should be on her file.*

> *On* [consumer's] *medical notes there are two red flags noted by a psychologist and a psychiatrist, which highlights the difficulty for him when receiving treatments in hospital …* [consumer's father] *relayed this information to the ED consultant but the information was ignored and resulted in* [consumer] *becoming anxious, aggressive towards staff …* [consumer's father] *wanted* [consumer] *to remain in hospital but felt, with the low level of acceptance and acknowledgement about* [consumer's] *autism and the recorded notes by specialists being ignored, it was in the best interest of* [consumer] *to take him home.*

> *I expected* [the GP] *to read all my personal history files, so I don't have to explain myself and how traumatising it is to repeat that over and over each time. She didn't read any information … Each time I go I'm seeing someone different and when it's a new doctor, they don't read my personal history, and it feels rushed and traumatising with only fifteen minutes of time to talk.*

Transition, discharge and coordination between services

HDC's *Report on Complaints to HDC About Residential Disability Support Services* previously highlighted the importance of Residential Disability Support Services assisting and enabling disabled residents to access support for their health and other needs. The report illustrated how transitions of support can be particularly prone to error and how documentation and systems must support important information about the consumer's health and social needs being transferred between services.

Similarly, complaints can illustrate the difficulties faced by disabled people | tāngata whaikaha with complex health and/or mental health needs in accessing and navigating the health and disability systems, including navigating between medical specialties. This can leave disabled people and their families or whānau feeling as if they are being pushed between services or put in the 'too hard basket'.

> [Provider] *has identified that there is no singular point of oversight for* [consumer's] *care and that the system has 'gaps' that need addressing … With no solutions, no attempts to plug gaps or provide oversight,* [Consumer] *continues to have to muddle along with no one prepared to take responsibility for his overall care or polypharmacological oversight or for any medical care at home … If every person in* [consumer's] *medical journey says there are gaps in the system, why does no one show enough initiative to find ways to address the issues of adolescent and adult, medical and disability, and specialists with multidisciplinary interests who might explore his case for better answers? … He remains in a limbo of the system's making.*

> [Consumer] *was under child and adolescent mental health services. She has also been under a paediatrician since birth. Mental health services then discharged* [consumer]. *Our GP has been trying to have her referred back to them as she is still severely depressed … They refused to take the referral because she has been diagnosed with ASD and said we need to go to* [specialist disability and mental health services], *but they have also refused the referral as they say her problem is caused by mental health. We are currently in limbo and worry for our daughter's life on a daily basis and don't know where to turn to from here.*

> [We] *are concerned there is no end to this* [three-year psychiatric] *hospital admission for* [consumer with learning disability and no diagnosed mental health condition] *and* [we] *are uncertain he is being prioritised in terms of a pathway for* [him] *to be successfully integrated back into the community.*

Transitions, including timely discharge from hospital to the community, can be affected by capacity challenges across health and disability systems, including delays in identifying, coordinating and approving funding for appropriate disability supports in the community.

Gaps in care

Complaints to HDC also highlight a gap in care and support for people who are neurodivergent or have a learning disability and are in crisis but do not meet diagnostic criteria for a mental health disorder. At times, people with these conditions can be placed in mental health settings because of a lack of disability support options. However, mental health staff do not have the skills required to meet disability support needs, and mental health settings can be detrimental to the person's wellbeing.

CASE STUDY

Care of disabled consumer in mental health unit

The Deputy Commissioner found Health NZ in breach of the Code for systemic issues that culminated in a disabled person being seriously injured during a restraint. The Deputy Commissioner commented that it was clearly problematic that a client was residing in a psychiatric ward when they were not diagnosed with a mental health condition.

They should have been in a disability setting with staff who were trained to support people with learning disability and fetal alcohol spectrum disorder (FASD). The staff in the psychiatric unit outlined that they had limited orientation, knowledge and understanding of how to work with someone with [a learning] disability and FASD.

The Deputy Commissioner highlighted:

This highlights a theme in complaints, of the difficulties disabled people with coexisting problems face in accessing care. The client was not able to reside in a setting that provided intellectual disability care. Similar difficulties arise for people who are neurodivergent or have a learning disability and are in crisis, but do not meet diagnostic criteria for a mental health disorder. Where people with these conditions are placed in an inpatient psychiatric unit due to a lack of disability support options, as the client was, the facilities are not well suited to their needs and can in fact be detrimental to their wellbeing.

HDC has also received a cluster of complaints that highlight a gap in coordinated service provision for disabled adults with complex health or mental health needs. This gap can become particularly apparent for families when they move from the more holistic family-centred model of paediatric care/child development services (where families and whānau can be supported to access both health and disability supports) to the care of more siloed adult services where no one clinician has responsibility for coordinating their care or assisting them to navigate between services.

> *While in hospital, meetings were arranged between medical professionals and* [consumer's parent] *to establish the plan of action to where* [consumer] *could go to be provided with care and treatment.* [Consumer's parent] *asserted* [consumer] *was in between paediatric and adult services due to his age and size, to the point where there was a battle between inpatient psych consults and* [community youth mental health] *because neither wanted to take on the responsibility for oversight of* [consumer's] *medication … medical professionals argued whether* [consumer] *is a paediatric or adult patient.*

In addition, people have raised concerns about a lack of support to navigate available funding streams for people with co-existing disability support needs and ongoing health needs. People have reported to HDC that they have been abruptly told by needs assessment services that, because of their co-existing health conditions, they no longer meet criteria for disability support funding and must instead seek funding for their health needs through Health NZ. The way in which these decisions have been communicated to disabled people | tāngata whaikaha and the lack of support to navigate funding streams is concerning. It is also unclear the degree to which seeking funding through Health NZ will assist people's existing disability support needs to be met.

Conclusions

We acknowledge the pressure the health sector is currently under and that people working within the health system are committed to improving the accessibility and inclusivity of the system within a constrained environment. However, persistent and significant inequities in health outcomes for disabled people | tāngata whaikaha, together with the themes from this report, underscore the need for further action to allow disabled people's rights to be fully realised and upheld in the health system.

Important work is currently under way across several Government agencies, including Health NZ and DSS, focused on improving health outcomes for disabled people | tāngata whaikaha. It is our hope that the themes from this report and our associated recommendations will provide a timely contribution to the work programmes of agencies to improve health services for disabled people in line with the Code, the Health of Disabled People Strategy, the New Zealand Disability Strategy and Aotearoa New Zealand's commitment to the UNCRPD.

Recommendations

Through the making and monitoring of recommendations, HDC holds the system accountable to ensure that learning and change occur. Common themes in HDC's recommendations to health service providers in response to the complaints analysed for this report included:

- strengthening pathways and processes in the health system to better support disabled people with complex health and disability needs
- ensuring appropriate initial assessment of support needs while disabled people are waiting for further assessment and treatment in EDs
- strengthening informed consent processes and documentation
- providing training to staff to address knowledge gaps in relation to disability
- improving policies and processes in respect of reasonable accommodations in health settings
- encouraging discussions and learnings among healthcare providers about reducing barriers to care for disabled people and improving practice.

Many complaints made about care provided to disabled people | tāngata whaikaha can involve multiple providers and agencies across both health and disability sectors. A multi-agency, cross-sector approach is crucial to improving health outcomes for disabled people and ultimately to ensuring disabled people's rights are upheld and protected. While our recommendations are primarily directed towards Health NZ and DSS, we acknowledge the responsibilities of other agencies, including ACC | Te Kaporeihana Āwhina Hunga Whara, Oranga Tamariki | Ministry for Children, Department of Corrections | Ara Poutama Aotearoa and the Ministry of Education | Te Tāhuhu o te Mātauranga, and we encourage them to engage closely with this work.

We note that professional standards and guidance to support culturally competent and culturally safe practice already exist within the health and disability workforce; however, existing and future standards and guidance should be reviewed to ensure the unique needs and preferences of disabled people | tāngata whaikaha, particularly Deaf | Turi people, and tāngata whaikaha Māori, are met.

Although the recommendations in this report are focused primarily on Health NZ, we acknowledge that some of the issues, including around staff capability, communication barriers and restraint, are also seen in primary care and other health settings outside of Health NZ. As such, HDC will work closely with regulators, professional bodies and training institutions to ensure the themes in this report are communicated and to explore further training opportunities for the health workforce.

Finally, we urge Health NZ to ensure disabled leadership is embedded in its governance structures and that the voices of a diverse range of disabled people | tāngata whaikaha and providers are central in shaping the responses to the issues and recommendations in this report.

HDC's recommendations

1

HDC recommends Health NZ support people with communication barriers by:

1.1 considering opportunities for hospitals to increase the understanding, availability and use of augmentative and alternative communication tools, including in emergency departments (EDs) and mental health settings.

2

HDC recommends Health NZ continue work to reduce the use of restraint on disabled people | tāngata whaikaha and move towards eliminating restraint by:

2.1 reviewing restraint practices in hospital settings and considering what supports are needed to reduce the use of restraint on disabled people.

3

HDC recommends Health NZ work to support improving staff capability through:

3.1 the development of best practice resources and information (in consultation with disabled people | tāngata whaikaha) to support accessibility and inclusion in health settings, including, for example, environment and design, person-centred approaches, methods of communication and trauma-informed care (including medical trauma)

3.2 training for clinical and non-clinical staff, including the development of resources to improve disability understanding and capability (including a focus on 'hidden conditions' such as learning disability and neurodivergent conditions), with a particular focus on mental health and emergency care settings.

HDC acknowledges that Health NZ and DSS have begun early engagement on the following recommendations and is pleased they have committed to cross-agency work.

4

HDC recommends Health NZ and DSS as lead agencies work together on cross-agency issues related to:

4.1 ensuring clarification for disabled people | tāngata whaikaha about accessing funding for disability supports in hospital (noting that people have expressed concerns about who is responsible for the provision of disability support in this context)

4.2 coordination of discharge from hospital to community settings with disability support, including to community residential services

4.3 navigation support for disabled people with ongoing health needs, including clarification from DSS and Health NZ on eligibility for their respective funded supports and, where relevant, other funding streams, as well as navigation support within and between these funding streams (noting a recent cluster of complaints to HDC about a lack of clarity about and support to access funding for disabled people with health needs)

4.4 improvements to coordination of care and support during and following transition from paediatric to adult services for people with complex and coexisting health, disability and mental health conditions

4.5 support and information for families whose children are awaiting diagnostic assessment for neurodivergent or neurodevelopmental conditions in the public health system.

5

HDC supports the four areas for progress that the Health Quality & Safety Commission Te Tāhū Hauora identified in their *A Window on Disability* report:

5.1 the need for more disaggregated data related to disability

5.2 the need for disability training and professional development across the health workforce

5.3 the need for greater employment of disabled people | tāngata whaikaha across the health system

5.4 the need to develop supported decision-making frameworks and training across the health system.

6

HDC acknowledges and supports the work of Whaikaha – Ministry of Disabled People related to:

6.1 their launch of the *Whaimana – Support My Decisions* website

6.2 securing government commitment in the *New Zealand Disability Strategy 2026–2030* to ensure that tools for self-determination and supported decision-making are standard practice in health care.

HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA