

Executive Summary | Whakarāpopototanga

Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights | Ko te arotakenga o Te Ture Toihau Hauora, Hauātanga 1994 me te Tikanga o ngā Mōtika Kiritaki mō ngā Ratonga Hauora, Hauātanga

March 2025 | Poutū-te-rangi 2025



Introduction | He kupu whakataki

The Health and Disability Commissioner (HDC) is an independent Crown entity charged with promoting and protecting the rights of all people in New Zealand who use health and disability services. We are required to regularly review the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code) and make recommendations to the Minister of Health. It is then up to the Minister and Government to decide whether to progress those changes.

These reviews are an opportunity to ensure that the Act and Code remain effective in protecting and promoting the rights of everyone using health and disability services. Reviews can also help us to improve how things are done at HDC and identify changes to improve the health and disability system.

Our latest review was initiated following the enactment of the Pae Ora (Healthy Futures) Act, and focused on how the HDC Act and the Code of Rights could better meet the needs of all New Zealanders. This review comes at a time of significant change for and pressure on the health and disability sector and increasing demand for HDC's services.

When consulting on this review we had a particular focus on hearing from those communities who may experience a greater power imbalance when engaging in care and are less likely to raise concerns, including Māori and tāngata whaikaha | disabled people.

Overall, most people and organisations we heard from supported the issues we set out and the principles behind our suggestions for change. Generally, people and organisations were united in wanting a fair, accessible, and responsive Act and Code and more timely, people-centred complaints resolution.

This document provides a high-level summary of the 'Recommendations Report | He Tuhinga Taunaki. Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights'. You can find the full report at review.hdc.org.nz.

Approach | Te Tukanga

Initial engagement with stakeholders found substantial agreement on the priorities for the review. These were shaped into five focus areas:

- Supporting better and equitable complaints resolution;
- Making the Act and the Code more effective for and responsive to the needs of Māori;

- Making the Act and the Code work better for tangata whaikaha | disabled people
- Considering options for a right of appeal of HDC decisions; and
- Minor and technical improvements

We wanted to make sure that anyone who wanted to, could have a say in this review. We used a mix of engagement approaches and had a particular focus on hearing from priority populations as outlined in the Pae Ora (Healthy Futures) Act — including Māori, tāngata whaikaha | disabled people, and Pacific peoples. We also ensured Māori, tāngata whaikaha | disabled people and Pacific representation in the analysis and interpretation of feedback.

Given the different barriers faced by tangata whaikaha | disabled people, we made sure we were hearing from different groups within the disability community, including people with a learning disability, the Deaf community, and people with lived experience of mental distress.

We received a record number of submissions (259) during the public consultation period and met with hundreds of people and organisations over the course of the review.

Our findings and recommendations | Ngā whakataunga kōrero

Overall, we found that the Act and the Code are generally working well and that most of the changes people wanted to see are best addressed operationally. However, some changes to the Act and the Code are needed to align with modern expectations, help shift practice in the sector and improve the way HDC operates.

Making the Act and Code more responsive to Māori and disabled people

While the Code is flexible enough to adapt to a changing context, we found that small changes are needed to make people's rights clearer and ensure the Code is inclusive of all communities.

For Māori and tāngata whaikaha | disabled people in particular, this means being more explicit about existing obligations on providers in order to address systemic barriers and embed cultural safety. Our recommendations include changing language in the Code to reinforce accessibility and support inclusion; and adding the right for people to have tikanga taken into account when care is being provided to them.

These changes would reinforce current expectations of practice while helping people to see the Code as more reflective of their needs and values. Some of these changes will need to be supported by guidance for the sector.

Stakeholders considered that ensuring the Act provided for appropriate leadership within HDC was essential to ensuring HDC's ability to protect and promote the rights of all communities. We heard this is particularly important in relation to HDC's capability to

understand, embed and demonstrate tikanga and to ensure the rights of disabled people are understood and upheld. We therefore recommend introducing collective requirements for the appointment of Deputy Commissioners into the Act. These would include attributes relating to knowledge, experience and expertise of ao Māori, including but not limited to tikanga Māori, and reo Māori; and an understanding of the rights of disabled people and the operation of the disability support sector.

There was significant support for the Act to provide specific provisions to give practical effect to Te Tiriti o Waitangi, with people wanting to see both general and specific provisions included in the Act. While ensuring appropriate leadership within HDC was seen as the most important change that could be made, people also wanted the Act to require effective engagement with Māori, particularly in relation to reviews of the Act and Code and advocacy guidelines, and to account for the importance of engaging with representatives that have been determined by mātauranga Māori | Māori knowledge systems. People also wanted provision for the promotion and protection of tikanga in complaints management, including in the delivery of hui ā-whānau¹ and hohou te rongo².

We agree that there is substantial scope for the Act to give practical effect to Te Tiriti o Waitangi and recommend both general and specific provisions are included in the Act, informed by the submissions we received during consultation. We share stakeholders' views that this will benefit all New Zealanders.

People-centred complaints resolution

People agree that a well-functioning complaints system is an important mechanism for highlighting and addressing quality and safety issues and improving patient experience. However, we also heard how fear of being treated differently or losing access to services can prevent people from speaking up, how challenging complaints processes can be to navigate, and how sometimes they add to the distress of those seeking resolution, whether as a consumer, a whānau, or a provider. For many communities, existing processes are also not well-aligned to how they resolve issues and restore relationships.

This feedback reinforces the need for a more people-centred approach to complaints one that is timely, accessible, responsive, and keeps people safe. We recommend changes to the Act to provide HDC with more flexibility to respond to complaints in a way that better meets the needs of all parties, including the use of more restorative and culturally

¹ A tikanga-led process where whānau (inclusive of the consumer) are the experts of their experience and are supported to determine what resolution looks like for them.

² Hohou te rongo describes methods of resolving disputes using principles and values from te ao Māori (Māori world views). Hohou te rongo provides an opportunity for the nawe (wrongdoings of a person(s)) experienced by whānau to be acknowledged by the providers and for whānau to seek peace in the experience within a culturally safe and appropriate environment.

appropriate processes, and to make the overarching principles of complaints resolution for both HDC and providers more people-centred. We're also using the feedback we received about HDC's processes to make improvements.

We also recommend changes to the Code which reinforce people's right to protection against retaliation for making complaints. This would not create new obligations or rights but would provide a more explicit signal to support people to feel safe to raise concerns.

While mindful of the need to safeguard people's rights as individuals, people told us they wanted greater recognition of the role that family, whānau and others play in supporting people to uphold their rights. This is particularly important for those who require support to communicate, make decisions, and to raise and resolve issues. We recommend changes to the Code to strengthen the right to support to make decisions; allow support people to be involved when they can't be physically present; and give people the right to support to make complaints.

Given the role of advocates in supporting people to understand their rights and resolve their concerns, the Director of Advocacy and HDC are also considering the feedback provided and identifying opportunities to respond within current resourcing. This includes a focus on building relationships with local/community organisations to increase engagement with diverse communities.

Challenging HDC decisions

HDC was asked to consider options to 'appeal' HDC decisions following a petition to the Health Select Committee. The two changes to the Act we consulted on to allow for greater challenge of HDC opinions were to introduce a statutory provision for HDC to review its decisions, and to lower the threshold for access to the Human Rights Review Tribunal (HRRT)³. While there was general support for the intent of such changes, there was a range of views about what this would look like in practice.

In considering the options for appeal people saw benefits to fairness and access to justice, to people feeling heard and to the quality of HDC's decision making. However, people also shared concerns about the potential for increased delay, cost, stress and inequity. Many thought changes to HDC's existing complaints process would make the biggest difference.

The option to incorporate a statutory requirement for HDC to review decisions had the most support, with people stressing the need for a review process to be accessible, transparent, trauma-informed, independent from the previous decisionmaker, and equally

³ Currently a breach finding by HDC is required to access the HRRT.

available to providers and consumers. People were split on the option to lower the threshold for access to the HRRT, with most of those who supported this option only wanting the threshold to drop slightly – requiring an HDC investigation to have been completed. Many also felt that any lowering of the threshold should occur alongside the ability to have decisions reviewed.

We recommend incorporating a statutory requirement for HDC to review decisions into the Act, with a time-limit and criteria to limit the scope and circumstances of a review in the interests of finality. Given the small number of submissions on this issue, we have not adopted a position on whether access to the HRRT should be lowered. There are important arguments both for and against this option and we consider this issue is better addressed by the Ministry of Health in consultation with others. However, if a decision is taken to lower the threshold, we do not support it being lowered to capture all complaints to HDC.

Minor and technical changes

HDC consulted on and made recommendations in relation to a variety of minor and technical changes, including recommending that:

- The Act's requirements for reviewing the Act and the Code are aligned and timeframes for reviews are shifted to 'at least every 10 years';
- The maximum fine under the Act is increased to \$10,000;
- The phrase 'aggrieved persons' is replaced by the phrase 'the complainant (if any) or the aggrieved person (if not the complainant)' in relevant provisions from s52 of the Act (Remedies that may be sought) onwards; and
- The phrase 'under general anaesthetic' in Right 7(6)(c) of the Code is replaced with 'given medication designed to alter their level of consciousness, or awareness or recall, for the purpose of undertaking the procedure'.

HDC also recommend that two changes proposed by others during consultation are progressed by the Ministry of Health, in consultation with others:

- Clarifying that Code Rights extend beyond death in limited situations; and
- Changing the wording of section 72 of the Act (Liability of employer and principal) to make accountability clear, fair and aligned with current practice.

Conclusion | Whakakapinga

Changes to the Code are focused on shifting practice across the sector, strengthening the focus on person-centred care that responds to the diverse needs of our communities and

supports issues to be addressed early. The changes we propose to the Act are designed to improve how HDC operates. They are focused on ensuring that our processes are more flexible and that we have the mandate and capability to perform our role in a way that works well for everyone.

Central to these recommendations is a focus on relationships — between consumers and providers, between providers and the wider system, and between HDC and the communities we serve.

Throughout the review we have been mindful of the intersection of our review with reviews of other legislation, particularly the Health Practitioners' Competence Assurance Act and the Mental Health Act, the Law Commission's review of adult-decision-making capacity law as well as the Government's response to the Royal Commission of Inquiry into Abuse in State Care. Our view is that changes to the Act should be progressed alongside this work to ensure consistency and cohesion, with changes to the Code finalised once the policy direction is clear.

While we agree that changes to the Act and Code are needed, we found that changes to HDC practice and processes, and sector guidance, education and promotion can resolve many of the issues people raised. This review has identified priority actions to make further improvements within HDC's current resources.

The review also highlighted some areas that require further work by the sector to better uphold people's rights. As well as making specific recommendations to others in relation to these issues, we will work with the sector to share learnings from the review, including the issues people have raised that are outside the scope of HDC.