

a. Amend purpose statement

An option for improving the Act is to broaden its purpose statement for complaint resolution from 'fair, simple, speedy, and efficient' to also focus on people-centred practice. This could involve adding the concept of upholding mana into the purpose statement. Mana is a concept from te ao Māori that describes a spiritual force or power that resides in all people(s), in objects, or the environment, and includes respect and autonomy.

Recommend: Articulate the desired outcome or actionable consequence

- Culturally Safe
- Inclusive
- Fit for purpose
- Joint / Partnered
- Annually reviewed
- Resolution based
- Whānau centered
- Evidence based

b. Clarify cultural responsiveness

We propose rewording Right 1 (Respect) of the Code to be more inclusive and set expectations of cultural responsiveness that align with sector standards. This includes acknowledging the right of Māori to bring te ao Māori (Māori worldviews) to health and disability services. Cultural responsiveness also recognises the needs, values, and beliefs of groups, such as tāngata whaikaha | disabled people, people from LGBTQIA+ communities, as well as people from diverse ethnic groups.

Recommendation:

- Strengthen beyond responsive / recognition to include Culturally Safe (this is whānau informed)
- Hauora Māori (This identifies the special relationship of Māori as tangata whenua - reduces the risk of inappropriately grouping minorities together)

c. Clarify the role of whānau

We propose the following changes to the Code, to clarify the role of whānau in the consumer–provider relationship and to help providers provide for whānau participation appropriately.

- Changing the wording in Right 3 (Dignity and Independence) from ‘independence’ to ‘autonomy’ to recognise the interdependence people often have with whānau and support networks.
- Strengthening Right 8 (Support) to include the right to have whānau involved, even where they cannot be present physically.
- Clarifying Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer.

Recommendation: Right 10 (Right to Complain) Strengthen the role of HDC to enhance transparency and accountability of all health and disability services.

- That an unbiased / independent complaints process be available.
- That service MUST report and evaluate this process annually.
- That reporting to HDC must include themes, number, time taken to resolve, corrective actions and quarterly resolution status “dashboard” SAC 1-4

d. Ensure gender-inclusive language

We propose changes to the Code to update the language to be gender inclusive by replacing ‘him or her’ with inclusive language.

Recommendation: “Service User”

e. Protect against retaliation

We propose changes to Right 10 to include a non-retaliation clause to help people to feel safe to complain.

f. Clarify provider complaints processes

We propose changes to Right 10 to set more explicit expectations for provider complaint processes, including promoting the right to complain.

Recommendation: Visible and accessible external anonymous complaints process and internal complaints process.

g. Strengthen the Advocacy Service

We want to hear from you about the opportunities you see to strengthen the role of the Advocacy Service to better meet the needs of people and communities and enhance collaboration with HDC.

Recommendation: Apply national standards for minimum expectations/training/outcome/response time/ cultural capability / uptake eg disestablish service or staff if it is poorly used or fails to meet standards.

h. Improve the language of complaint pathways in the Act

We want your thoughts on changing the language of the complaint resolution pathways:

- Changing 'no further action' to, for example, 'no investigative action' to be empowering and reflective of the work undertaken to assess and resolve the complaint;
- Changing 'mediation conference' to, for example, 'facilitated resolution' to encourage broader forms of resolution such as restorative practice and processes led by tikanga.

Questions

- 1.2: What do you think of our suggestions for **supporting better and equitable complaint resolution**, and what impacts could they have?

Recommendation: State the desired outcome (Better than what?)

- Risk assessed
- Timely / efficient
- User friendly / fit for purpose
- Clearly guided
- Assistance provided
- Data monitored
- Efficacy evaluated

- 1.3: What other changes, both legislative and non-legislative, should we consider for **supporting better and equitable complaint resolution**?

Recommendation: Strengthen HDC role in complaints process

- To many ways to complain - dilutes the valuable insights.

Topic 2: Making the Act and the Code more effective for, and responsive to, the needs of Māori

Issues

Māori aren't benefiting equitably from the Act and the Code.

- Māori engage less with HDC and the Advocacy Service than expected given the experiences of, and outcomes for, Māori in the health and disability sector.
- Promotion of the Code is not reaching Māori communities. When it does, many feel that Code rights and complaint processes are not designed for them.
- Complaint processes and interpretation of rights often don't reflect te ao Māori values and tikanga.
- Te Tiriti | the Treaty and its practical application is also largely absent from the Act and the Code.

When te Tiriti | the Treaty is honoured, it helps Māori thrive. Making the Act and the Code effective for, and responsive to, the needs of Māori will support the Crown to honour its obligations under te Tiriti | the Treaty and lead to better outcomes for Māori using health and disability services.

What we're already doing

Recently we created a Director Māori role in leadership, along with a small team, to make HDC more responsive to the needs of Māori, help providers to be more responsive, and raise awareness of HDC in Māori communities.

Question

- 2.1: Did we cover the main issues about **making the Act and Code more effective for, and responsive to, the needs of Māori?**

Suggestions

We want to hear your thoughts on our suggestions for changing the Act and the Code to be more effective for, and responsive to, the needs of Māori.

a. Incorporate tikanga into the Code

We want to hear whether tikanga should be incorporated into the Code and what needs to be in place to protect how tikanga is understood and applied. We're aware that tikanga is interconnected, and tikanga cannot be viewed in isolation.

We've heard that if we were to incorporate only one element of tikanga then 'mana' captures the essence of other elements and would have the strongest impact. As a starting point for feedback, we propose to add to Right 1 (Respect) that every consumer has the right to have their mana upheld.

Recommendation: Kia tūpato.

- Process needs to be explicitly offered as an outcome of a regulated complaints process for the benefit of whānau Māori. Protections are required eg the ability to decline said applications from non-Māori.
- Hauora Māori Directorate have no health professionals on staff - putting your team and mahi at risk of failing to partner with the sector - consider partnership models.

b. Give practical effect to te Tiriti | the Treaty in the Act

Adding protections into the Act to give practical effect to te Tiriti | the Treaty will help make sure te ao Māori values and tikanga are applied with integrity. Our suggestions for the Act to give practical effect to te Tiriti | the Treaty include amendments to provide for:

- Processes to ensure equitable Māori engagement and leadership in the operation of the Act and the Code. For example, requiring HDC to make and maintain effective links with iwi/Māori and engage with iwi/Māori when reviewing the Act and the Code, and in the development of Advocacy Service guidelines.
- Māori values and worldviews, overseen by Māori. For example, including the promotion and protection of tikanga in the functions of HDC and the appointment of a Deputy Commissioner Māori.

- Māori to benefit equitably from health and disability rights as Māori. For example, changing complaint processes to better align with tikanga.

Questions

- 2.2: What do you think about our suggestions for **making the Act and the Code effective for, and responsive to, the needs of Māori**, and what impacts could they have?

Recommendation: Strengthen Protections for Māori.

- Provide a tool for Māori to understand how their complaint should be handled.
- Strengthen the outcomes based resolutions
- Improve accountabilities to Māori - regional monitoring / reporting / evaluation - these themes and findings could be used by Hauora Māori Partners to reduce the impact of unsafe systems / services / practices - “What matters to whānau”

- 2.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code effective for, and responsive to, the needs of Māori**?

Recommendation: Strengthen Protections for Māori.

- Legislate the costs of resolution based complaints process - make it a requirement
- Strengthen the codes protections for Mātauranga Māori / Customary Title (proof of uninterrupted use - to manage the frauds)
- Strengthen the codes protections against exaggerate claims of benefit eg no evidence of clinical practice benefit
- Include Expert Advisory Group composed of Māori Health Practitioners by dicipline eg Maternity and Early Years, Primary Community, Hospital & Specialist Services, Allied, Oral Health.

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

Issues

- Since the Act and the Code were first developed, there have been shifts in understanding of the rights of tāngata whaikaha | disabled people and the provision of supports and services, including in relation to mental health and addiction. The Act and the Code can be strengthened to reflect a modern understanding of disability rights, including the rights of tāngata whai ora, and of service provision.
- HDC is also seeking feedback on an earlier review, which looked at whether adults unable to consent should be able to participate in research, and, if so, what safeguards should be in place.

Updating the Act and the Code to support tāngata whaikaha | disabled people would support the Government to uphold its commitments under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Updates to the Act and the Code would also contribute to better and more equitable outcomes for tāngata whaikaha | disabled people when they access health and disability services.

What we're doing already

Traditionally, HDC has had a Deputy Commissioner, Disability and a dedicated delegation for mental health and addiction complaints. Recently, HDC made changes to improve how we work for tāngata whaikaha | disabled people, including:

- Improving how we measure and report on disability issues;
- Monitoring the experience of tāngata whaikaha | disabled people in our complaints processes to improve accessibility and responsiveness;
- Responding to trends from complaints about disability support services and opioid substitution treatment; and
- Reviewing and updating our resources to ensure they are accessible, modern, and culturally appropriate.

Question

- 3.1: Did we cover the main issues about **making the Act and the Code work better for tāngata whaikaha | disabled people?**

Suggestions

We seek feedback on the following suggestions for the Act and the Code as they relate to tāngata whaikaha | disabled people. We also seek feedback on HDC's draft recommendations for unconsented research.

a. Strengthen disability functions

Adding a legislated role focused on disability issues could strengthen oversight of complaints from a disability perspective, enhance HDC's focus on the rights of tāngata whaikaha | disabled people and promote trust and engagement with HDC. This could include adding a reporting requirement to the Minister for Disability Issues as well as the Minister of Health.

Recommendation: Create a glossary of terms

- Create for national consistency and to reduce inappropriate variations - in consultation with the Disability Community.
- Provide insight regarding physical disability and the broadening scope of disability now including Mental Health / Neurodiversity and the implications - be explicit!

b. Update definitions relating to disability

The definitions of 'disability services' and 'disability services provider' in the Act could be revised to reflect modern strengths-based concepts of disability, aligned with the CRPD.

c. Strengthen references to accessibility

We propose changes to the Code to explicitly reference accessibility in Right 5 (Effective Communication) and in Right 10 (Right to Complain). We also propose removing the words 'reasonably practicable' in Right 5 in relation to the right to a competent interpreter.

Recommendation: Strengthen the accountability function of HDC

- Breach of code requires action eg recognition of a publicly funded privately operated primary health sector. Where services fail to provide accessible care they should be required to resolve the issue e.g. Waikato Dental Service upstairs (no elevator for wheelchair access) - should not access public funding.
- The provider MUST provide a Accessibility Plan (in order to attain/maintain funding) identify issues, manage issues and create a service plan to resolve these issues.

d. Strengthen and clarify the right to support to make decisions

We propose the following changes to clarify that a person should be supported to make decisions about their care to their fullest decision-making ability.

- Strengthen Right 5 (Effective Communication) in the Code to explicitly reference the right to support to understand information.
- Update the language in Right 7 (Informed Choice and Consent) relating to ‘competence’ and ‘incompetence’ to decision-making capacity to align with the Law Commission’s review of adult decision-making capacity law.
- Strengthen Right 7(3) to reference the right to support to make decisions.
- Update the language in Right 7(4) from consumer’s ‘views’, to ‘will and preferences’, to align with the language of the CRPD.
- Strengthen Right 7(4)(c)(ii) to make sure that the will and preferences of people who will never have legal decision-making capacity are taken into account.

e. Progress consideration of HDC’s draft recommendations relating to unconsented research

A review by HDC in 2019 recommended that some health and disability research that is not currently permitted should be allowed, in limited circumstances and with robust safeguards. The intent was to support greater knowledge of specific conditions and improve treatment and services for groups affected by those conditions. The next step for this review was to seek public feedback on HDC’s recommendations.

The test HDC recommended for research when people could not consent was that research could go ahead only if it posed ‘no more than minimal foreseeable risk and no more than minimal foreseeable burden’ on the consumer. Recommended safeguards included that suitable people who cared about the person could prevent their participation in the research; and that specialist ethics committees would oversee the research. We would like to know what you think of these recommendations.

You can read the full 2019 report at <https://tinyurl.com/unconsented-research>.

Questions

- 3.2: What do you think of our suggestions for **making the Act and the Code work better for tāngata whaikaha | disabled people**, and what impacts could they have?

- 3.3: What other changes, legislative and non-legislative, should we consider for **making the Act and the Code work better for tāngata whaikaha | disabled people?**

The glossary of terms could clarify is tāngata whaikaha = māori disabled or all populations.

Topic 4: Considering options for a right of appeal of HDC decisions

Issues

A petition to the Health Select Committee argued that there are limited options to challenge HDC decisions and that introducing a right to appeal HDC decisions would strengthen the promotion and protection of the rights of people accessing health and disability services. Considerations for assessing the value of an appeal include the potential costs and impacts of delay; the importance of reaching final resolution; and the expertise of the initial decision-maker.

What we're doing already

Over the last few years, HDC has reviewed and improved our 'closed file review'/internal review process and clarified decision-making guidance relating to taking no further action and notifying an investigation.

Question

- 4.1: Have we covered the main issues about **considering options for a right of appeal of HDC decisions?**

Recommendation: Right to appeal must meet a criteria

- Include the right to decline an appeal that is deemed harmful to priority populations.
- Professionally endorsed decision

Suggestions

We seek feedback on the following suggestions for the Act to challenge HDC decisions.

a. Introduce a statutory requirement for review of HDC decisions

Currently, HDC can undertake internal reviews of decisions if requested. The Act could be amended to require such reviews. This option could include a requirement that the original decision-maker is not part of the review or that there is peer involvement. Another variation of this option could be for an entirely independent review panel or body.

b. Lower the threshold for access to the HRRT

The HRRT considers breaches of rights concerning the Privacy Act 2020 and the Human Rights Act 1993 in addition to our Act. The threshold for accessing the HRRT is highest under our Act, which requires a breach decision by HDC to be made following an investigation.

The threshold could be lowered to the equivalent level of the Privacy Act, which generally requires a complaint to be investigated, or reduced further to the equivalent level as the Human Rights Act, which requires only that a complaint be made to the Human Rights Commissioner. Different thresholds would require different levels of resourcing for the HRRT.

Questions

- 4.2: What do you think about our suggestions for **considering options for a right of appeal of HDC decisions**, and what impact could they have?
- 4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

Topic 5: Minor and technical improvements

Issues and suggestions

The Act and the Code review provides an opportunity to identify minor and technical improvements. Suggestions for the Act and the Code are listed below.

- a. Revise the requirements for reviews of the Act and Code.**
- b. Increase the maximum fine for an offense under the Act from \$3,000 to \$10,000.**
- c. Give the Director of Proceedings the power to require information.**
- d. Introduce a definition for ‘aggrieved person’.**
- e. Allow for substituted service.**

- f. Provide HDC with grounds to withhold information where appropriate.
- g. Expand the requirement for written consent for sedation that is equivalent to anesthetic.
- h. Clarify that written consent is required when there is a significant risk of serious adverse effects.
- i. Clarify the Code's definition of 'teaching' and 'research'.

Questions

- 5.1: What do you think about the issues and our suggestions for minor and technical improvements, and what impacts could they have?
- 5.2: What other minor and technical improvements, both legislative and non-legislative, should we consider?

j. Respond to advancing technology

We also want to hear your views on how the rights of people accessing health and disability services can be promoted and protected in the context of advancing technology, including artificial intelligence and related changes to service provision.

Questions

- 5.3: What are your main concerns about **advancing technology** and its impact on the rights of people accessing health and disability services?
- 5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

Recommendation: Consider and create protections

- for Data Sovereignty, right to decline, withdrawal from service use / misuse.
- Exaggerated claims of benefit
- Evidence based practice
- Realizing the aspirations of Te Tiriti
- Inequity management eg those able to afford technology or procure the knowledge that technology offers in health care
- Manage the commercial sensitivities of technology in publicly funded services particularly for screening and diagnosis by reasonable access of all providers to technology

- Manage the clinical breaches of data sovereignty being used to formulate algorithms for example the perinatal institute estimating “Small for gestational of all fetal weights” using that data to generate a population based weight range for New Zealand - all software must remain free for use or the research open sourced for NZ duplication.