Te Hiringa Mahara
Mental Health and Wellbeing Commission

13 August 2024

Morag McDowell
Health and Disability Commissioner
Act and Code Review
PO Box 11934
Wellington 6142
By email: review@hdc.org.nz

Tēnā koe Morag

Feedback on the Review of the Health and Disability Commissioner Act and Code of Health and Disability Services Consumers' Rights

Thank you for the opportunity to provide feedback on the review of the Health and Disability Commissioner Act (HDC Act) and the Code of Health and Disability Services Consumers' Rights (Code). Overall, we are pleased to see our previous feedback on the review reflected in your suggestions for legislative changes to improve the HDC Act and Code.

Te Hiringa Mahara | Mental Health and Wellbeing Commission was set up to play a part in strengthening oversight of the mental health and addiction system. He Ara Āwhina | Pathways to Support is a framework that we have developed with people's voices about what matters to them in mental health and wellbeing.[1] We want to ensure that the Code and Act works for all cultures and enables the experiences, needs, and aspirations of tāngata whaiora[2] to be understood in a variety of ways. Following our function to advocate for the collective interests of tāngata whaiora and their supporters, our feedback supports legislative changes that will strengthen tāngata whaiora rights in practice.

1. Supporting better and equitable complaint resolution

a) We support inclusion of the term 'upholding mana' in the HDC Act's purpose statement (p22). We agree that this legislative change will help ensure a focus on people within the current objective of 'fair, simple, speedy and efficient resolution' of those complaints. We agree with the review focus on Māori and tāngata whaikaha | disabled people to access complaint resolution processes.

---

[1] There are two perspectives in He Ara Āwhina that describe what an ideal mental health and addiction system looks like: te ao Māori perspective, which was developed by Māori, with Māori, for Māori and a shared perspective, which is for everyone. See https://www.mhwc.govt.nz/our-work/assessing-and-monitoring-the-mental-health-and-addiction-system/

[2] Tāngata whaiora is used to emphasise 'whaiora' the desire to 'seek wellness'. The plural tāngata encompasses the individual and the people they determine as their whānau.

It is important that the HDC Act and Code are interpreted and applied to support better and equitable outcomes for Māori and all groups who experience disadvantage or poorer health outcomes. As part of the HDC Act's purpose, we would like to see non-legislative considerations that promote accessibility and cultural safety, for example in tāngata whaiora rights promotion, enhanced training for advocates, and increased options or pathways for complaint resolution.

b) The HDC Act must ensure that cultural responsiveness is inclusive of all cultures and relates to ethnicity, such as Pacific, Asian, Middle Eastern, Latin American, African and LGBTQIA+. We encourage a continued focus on strengthened approaches to complaint resolution under the HDC Act and Code for Pacific peoples, migrants, refugees, prisoners, veterans, Asian people, older people, LGBTQIA+, young people, children in state care and rural communities.[3] For some groups we have heard from such as prisoners and veterans, this could mean the HDC working more closely with central agencies such as Corrections and Veterans Affairs to ensure that consumers have equitable access to information and understand their rights to raise concerns and (or) complain about health and disability services.

c) We support a strengthened definition of 'whānau' in the HDC Act and Code, where whānau is both acknowledged from whakapapa kinship, and being determined, chosen, by the consumer. From our engagement with lived experience communities, there needs to be more consideration by service providers of the role of parents, legal guardians, and (or) whānau for consumers under the age of 16. In this context, the Māori concept and practice of whāngai, needs to be recognised and afforded consideration in the interpretation and application of the Code.

d) We are pleased to see suggested changes for inclusive language in the HDC Act and Code with use gender-neutral pronouns such as they/them/person.

e) We support the suggested inclusion of a non-retaliation clause in right 10, as an additional safeguard against a provider treating a consumer less favourably in response to a complaint made.

f) We agree that clearer and more transparent complaints processes from providers is important to ensuring rights in the Code can be realised. We heard that tāngata whaiora would like to see right 10 interpreted and applied as placing an obligation on providers to 'take seriously' consumer concerns and (or) complaints. We expand on this feedback in our comments below.

---

[3] These priority populations for better and equitable outcomes are identified in *He Ara Oranga* and listed in Schedule 2 of the Mental Health and Wellbeing Commission Act 2020.

We suggest provider accountability be strengthened under right 10 in the Code. We would like to see the obligation to provide information to the consumer to take effect from the earliest consumer contact or engagement. Such action can ensure consumers have the information on hand if or when needed, reducing barriers to request the information after issues arise, especially where relationships have broken down.

We propose changes to right 10 to simplify and set clearer expectations for provider complaint processes, including promoting the right to complain and effective promotion so that processes are accessible for tāngata whaiora. We have received feedback that current practices of displaying posters and pamphlets can be difficult to understand (e.g. people who are illiterate or cannot read or speak English) or information is not available (e.g. in prisons the Code is not widely promoted). We have heard that often consumers are informed that they have rights, without being informed what those rights mean or look like in practice.

There needs to be clearer pathways about the processes and what is involved at various stages. Our engagement suggests that sometimes Māori are not taking the step to complain because for them to navigate the process it is very difficult to undertake and to understand. From a Māori perspective, the process of making a complaint needs to enact tikanga that directs the right action at various stages. For example, ensuring access to advocates from a te ao Māori perspective who are available to assist whānau to navigate the complaints process and support the process being more respectful, mana enhancing and upholding, and meaningful for whānau.

We also recommend a finite period for complaint resolution is considered. We have heard that often Māori do not complain because the process is drawn out and lengthy and the benefits of the process and possible outcomes are not clear for whānau. Increased options as complaint resolution pathways could help support shorter timeframes for resolution. This would enable consumers to take up their complaints directly with providers more readily, an outcome that is beneficial for all those involved.

We would like to see restorative practice as part of a larger commitment versus a one-off episode. Having processes in place for restoring relationships when harm occurs, enables transparency, learning and improvement. Conditions for restorative practice includes physical places tāngata whaiora can feel safe to be heard, raise their concerns and resolve these directly with providers. Kaupapa Māori services and Peer Supports can provide culturally appropriate practice and guidance on ‘houhou te rongo’ restorative processes.

We recommend creating a ‘map’ of the resolution pathways the HDC Act and the Code aims to deliver for people and the possible outcomes of these processes. Feedback from our lived experience network engagement is that it is currently difficult to understand what outcomes and benefits a complainant might expect from engaging in the processes of complaining to providers, Advocacy services and the HDC. This uncertainty adds to the difficulties experienced by consumers to overcome the barriers that are real and significant to navigating complaints processes. It can also put the consumer and the provider in the position of being adversaries as there is ambiguity for all parties as to what to expect from the process. This can potentially lead to the providers approaching the complaint from a liability and risk aversive position and not the relational and restorative approach that is desired.

We also recommend that legal duties/obligations on providers that follow from the consumer rights in the Code are made more explicit in the HDC Act and Code operations. We have heard that descriptive examples of upholding rights in context showing “what good looks like” would help clarify the providers obligations, which would be helpful for consumers and providers alike.

g) On ways to strengthen the Advocacy service, we have heard tāngata whaiora would like advocates to have a deeper knowledge of how the HDC Act is applied in complaint resolution. We would like to see sustainable resourcing so advocates can continue to meet demand. Advocacy services need to be supported with ongoing training and resources in cultural safety and the developing approaches to supported decision making in practice.

h) We agree with the changes suggested to improve the language of complaint pathways in the HDC Act. We suggest using terms that are easily understood by people aged 12 or under (as the average literacy level in Aotearoa NZ), or by people whose first language is not English.

We would like to see language that outlines the possible outcomes in respect of each stage of the complaint resolution process(es). For example, the circumstances under which a complainant can challenge the HDC decision, so that complainants can be well informed throughout their involvement in the process(es).

The intersection of tāngata whaiora rights under the HDC Act and Code with rights under other Acts, such as the Mental Health Act, needs to be clearer. We have heard that there is not enough understanding among tāngata whaiora of the District Inspector role and function, and District Inspectors need to be more prominent in processes upholding rights, including those rights under the Code. We acknowledge that the Director of Mental Health and Addiction, Manatū Hauora, is reviewing and updating the current Guidelines for District

Inspectors. Across health and disability services legislation, we support clearer guidance for consumers and providers so there is coherence in the law underpinning the shift to a new human rights framework based on supported decision making.

In the broad context of changing language, ongoing dialogue on risk and mental health is relevant to the review of the HDC Act and Code, as envisaged by recommendation 35 of He Ara Oranga, which was accepted in full by the Government[4]. A paper on attitudes, beliefs and evidence about risk has been written to contribute to that discussion.[5] It sets out what risk is in the context of mental health, how it can affect people who use services, and how a more strengths-based approach to risk to shift societal attitudes and behaviours could be progressed in the future. Among the topics suggested, we consider HDC is well positioned to influence and shape discussions “focusing on accountability and less blame, recognising that fear is toxic to both safety and improvement. A strong focus on improving services, with more time spent asking ‘what makes things go right’, rather than just focusing on ‘what went wrong’”.

2. Making the Act and the Code effective for, and responsive to, the needs of Māori

a) We acknowledge the Law Commission’s view that tikanga needs to be enabled to function on its own terms without seeking to statutorily specify what that might mean.[6] We support changes to the HDC Act and Code where tikanga can be broadly defined as that which is accepted generally by Māori and (or) localised individual Māori groups, iwi, hapū, marae or whānau, with necessary legislative protections, education, and guidance for enacting tikanga in practice (p29). We encourage the HDC consider any changes to the HDC Act necessary to strengthen existing or establish new relationships for collaborating and coordinating with Māori (and non-Māori) provider workforce networks, professional bodies, and tertiary training institutions.

We would like to see increasing investment in HDC’s options for complaint resolution, especially hui ā-whānau process led by tikanga and hohou te rongo, using principles and values from Te Ao Māori. In our monitoring of mental health and addiction services we advocate to increase investment in Kaupapa Māori approaches and Peer Support responses in commissioning and delivery of services to achieve better and equitable outcomes for Māori.

---

[4] Government Inquiry into Mental Health and Addiction. (2018). He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction. Government Inquiry into Mental Health and Addiction: Wellington

[5] Changem Ltd.(2022). He Arotake ngā Tūraru | Reviewing Risk: He kohanga kōrero | A discussion paper. Wellington: Ministry of Health.

[6] Law Commission chapter 5 Tikanga

b) We support the suggested changes for the HDC Act and Code to explicitly give general effect to Te Tiriti o Waitangi in the Act's preamble and give specific effect to the principles, so that the articles can be interpreted and adapted in contemporary localised health and disability service contexts. We agree that both general and specific changes will support the Crown honour its obligations under Te Tiriti | The Treaty (p31).

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

a) We support the recommendations to strengthen disability functions under the HDC Act to add a legislated role under the HDC Act focused on disability issues and to include the HDC reporting to the Minister for Disability Issues. We note the review document includes reference to HDC relationships with agencies including Te Hiringa Mahara | Mental Health and Wellbeing Commission (p37). Our understanding is that the current scope of our 'statutory relationship' includes the Mental Health and Wellbeing Commission among the agencies that must be consulted in the HDC's preparation and review of the Code (s23 HDC Act). For clarity we suggest an additional sentence in the final report that describes the scope and nature of our relationship in the context of statutory amendments that were made because the role and function of Mental Health Commissioner was repealed under the HDC Act.[7] We suggest describing our current relationship in terms of close liaison and sharing information as part of our collaborative approach to systemic concerns and improvement (p36).

b) We agree with changes to updated definitions of disability in line with contemporary understandings of human rights. Our engagement with disabled people suggests strengths-based and affirming definitions of disability as follows. **Disability services** support disabled people and whānau to participate in society and communities and improve the health and wellbeing of disabled people by responding to their needs and aspirations. A **disability services consumer** is a disabled person who accesses disability services.

c) We agree with proposed changes to explicitly reference accessibility in right 5 (effective communication) and right 10 (right to complain). It is important to ensure that the Code clearly articulates that disabled people and whānau have the right to have support to access and understand information. Where relevant to the HDC Act procedure for managing complaints, accessibility may also need to be explicitly referenced under the HDC Act itself. We have heard that tāngata whaiora are told of the existence of their rights without information to understand how those rights relate to the services and support provided to them. We would like to see this aspect of provider obligations strengthened under the Code.

---

[7] Section 18 of the Mental Health and Wellbeing Act 2020.

d) We agree with strengthened wording for supported decision making in the Code. There is a role for the HDC Act and Code to lead legislative reform in this area by redefining terms of use for tools that are designed to enact supported decision making in practice, such as Advance Directives in right 7(5) for documenting wishes about future care and treatment. Other terms of use include Advance Preferences Statements and the Law Commission's recommended non-legally binding Statements of Will and Preferences. We are concerned about tools such as Advance Directives in right 7(5) being elevated to a higher status than honouring the wishes for whānau when they are unable to make an informed decision for themselves in the moment. The Law Commission falls short of reforming the law on Advance Directives as it is beyond the scope of its review focused on the PPPR Act. We encourage coherence in law reform that builds on the principles recommended in the Law Commission consultation relating to their review of adult decision-making capacity law. We also encourage best practice approaches that are informed by research that identifies the conditions and qualities for implementation of supported decision making in practice.[8] We would like to see increased education and promotion of supported decision making among providers and consumer advocacy groups[9].

e) As a general comment about the HDC recommendations regarding unconsented research, we support representation of people with lived/living experience relevant to disability research on the specialist ethics committee and across all stages of research. This is consistent with our advocacy to strengthen lived experience leadership across the mental health and wellbeing system.

4. Considering options for a right to appeal HDC decisions

We acknowledge the resource implications and longer timeframes associated with, and consequential to, introduction of additional processes for review and appeal of HDC decisions, regardless of the take-up of new options by complainants and providers under option (a) and (b) (p45-46). In response to suggested options to challenge HDC decisions, accessibility (for consumers) that is aligned with the CRPD would be an important requirement of additional processes adopted.

On balance, we advocate for HDC continued effort and resources to be focused on promotion and prevention and early intervention of complaints resolution (to use health services terminology). This would include strengthened Advocacy services and

---

[8] Gordon et al (2022) From substitute to supported decision making: practitioner, community and service-user perspectives on privileging will and preferences in mental health care. https://doi.org/10.3390/ijerph19106002

[9] Lenagh-Glue et al (2020) Help and Hindrances to Completion of Psychiatric Advance Directives https://psychiatryonline.org/doi/full/10.1176/appi.ps.202000080

increased options or pathways for complaint resolution embedded in the HDC Act and operations, including Kaupapa Māori and other cultural approaches.

5. Minor and technical improvements

We are generally supportive of the minor and technical improvements that are listed under (a) – (f) and have no specific comments on impacts (p48-50).

We would like to comment on the intersection of (i) research and (j) advancing technology (p50-52). We encourage inclusion of collaboration with relevant lived experience/expertise in the interpretation and application of the Code's definition of research. In the example of digital mental health technologies, recent commentary calls for collaboration with lived experience in research to mitigate risks, alongside realising potential benefits, in this rapidly expanding area across the mental health and addiction system[10]. Lived experience leadership, including collaboration in research, contributes to evidence-informed policy and best practice that are essential for system improvements leading to better and equitable outcomes for people.

We hope our feedback is useful in preparation of your final report and recommendations and happy to discuss further.

Ngā mihi nui

[redacted]

Karen Orsborn
Tumu Whakarae | Chief Executive

---

[10] Gilbert et al (2024) Digital futures in mind: Why lived experience collaboration must guide digital mental health technologies. https://doi.org/10.1002/ajs4.355