Submission to the Health and Disability Commissioner on Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights

14 August 2024

Submission of Te Kāhui Tika Tangata| Human Rights Commission

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Te Kāhui Tika Tangata

Introduction

1. In 2023 Te Kāhui Tika Tangata | Human Rights Commission appreciated the opportunity to provide input on the scope of the Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights ("**the Review**").[1]

2. We welcome the opportunity to now make a submission to the Health and Disability Commission ("**HDC**") on the consultation document for the Review.[2]

Our complaints data relating to health and disability issues

3. Based on data from Te Kāhui Tika Tangata | Human Rights Commission's complaints and enquiries records from the past 5 years,[3] and as seen in Figure 1, disability is the most cited prohibited ground of discrimination. Figure 2 shows the top ten issues on which people have sought information or support from Te Kāhui Tika Tangata | Human Rights Commission. This is consistent with HDC complaints data.[4]

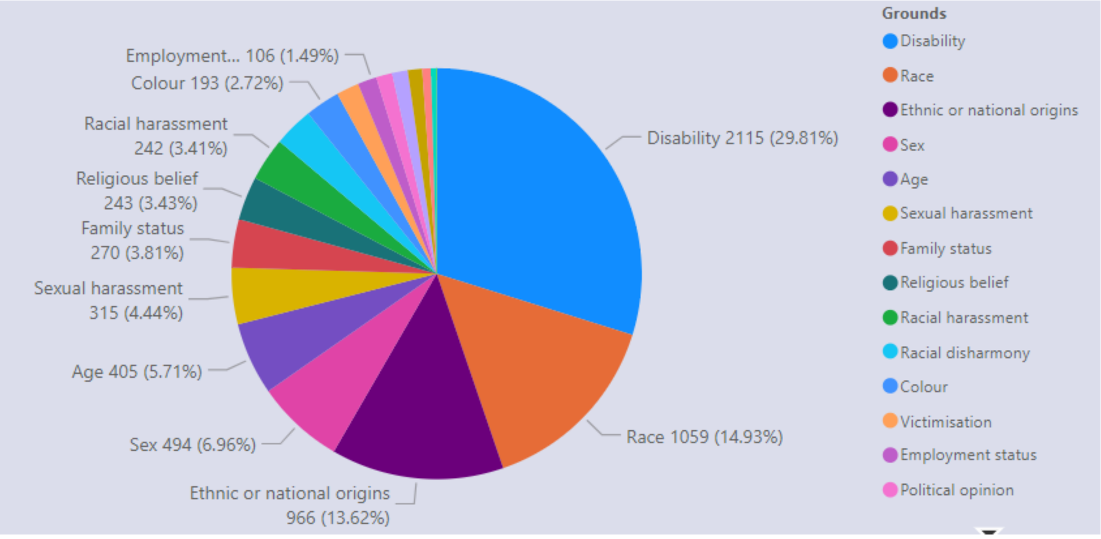

Figure 1: 2019-2024 – Prohibited grounds raised in contacts with complaints service (Note that one contact can raise more than one prohibited ground.)

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[1] Letter to Rose Wall, Acting Health and Disability Commissioner, dated 13 March 2023.

[2] Dated April 2024.

[3] from 1 January 2019 to 2024.

[4] As noted at p 35 of the consultation document, over 25 percent of the complaints received by HDC are about care provided to tāngata whaikaha | disabled people.

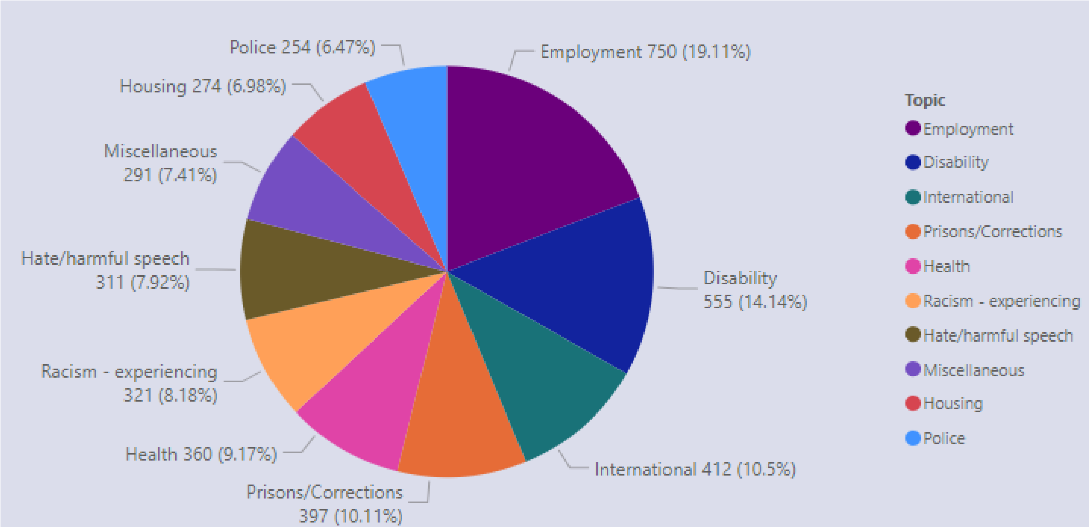

Figure 2: Top 10 issues that people cited when contacting Te Kāhui Tika Tangata | Human Rights Commission in the 2024 financial year

4. In the past five years we received 165 enquiries and complaints referring to the Health and Disability Commission. Of these, 33 alleged unlawful discrimination (including by the HDC itself). A large number of complaints related to: health care for people in prison; ACC; mental health services; and covid measures. Some of the contacts were from people referred to us by HDC, or were people wanting to pursue both agencies' processes. Others include people complaining about HDC or its processes, or dissatisfied with the result of HDC processes.

5. We believe this data demonstrates at a high level that issues relating to health and disability services are a significant concern in our communities. Particularly in more marginalised communities. The issues are perceived by many people as being intertwined with human rights, such as freedom from discrimination. This can create confusion for complainants in navigating which agency to contact.[5] As such, the issues covered by the Review, and the opportunity to improve the functioning of our health and disability consumer watchdog, and improve promotion and protection of human rights, are of vital importance to both of our agencies.

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[5] The Royal Commission has noted in its final report Whanaketia that "There were barriers to people in care raising concerns or complaints including a lack of access to whānau, communities and advocates." At p 208 of Part 7.

Kaupapa 1: Supporting better and equitable complaint resolution

Te tautoko kia pai ake te whakatatū amuamu, kia mana taurite hoki

6. We support the following proposals in the consultation document:[6]

    a. Inclusion of the concept of mana in purpose section of the Act, for example including a purpose to 'protect the mana and dignity of the person'.

    b. Making it clear that cultural responsiveness by providers includes recognising and respecting the values and world views of different cultures, and the right to bring those into their health and disability services. The need for this was recognised as early as the Cartwright Report, which led to the original Code and agency being developed.[7] However ongoing disparities suggest that the wording of the right needs strengthening, and more promotion and enforcement.

    c. Making it clear that the requirement for culturally competent services includes for groups such as the rainbow community and tāngata whaikaha.

        - We note that 'cultural competency' practices must be careful not to embed oversimplified or stereotypical interpretations, or to treat all people of a certain culture as homogenous. Cultural safety may be a better concept to use.[8]

        - "Cultural humility" also usefully recognises that achieving cultural competence, especially for the diverse range of consumers a practitioner may work with, is a journey that takes time. There is a need to have approaches that support the practitioner with cultural safety whilst on this journey.[9]

    d. Updating the Act and Code with gender-inclusive language.

    e. Clarifying the right to have whānau or other support people (as defined by the consumer) involvement, even if they cannot be present physically.

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[6] As an entity that also handles complaints, we appreciate many of the challenges faced by the HDC. Our submission is made as a National Human rights Institution with a responsibility to promote human rights, and as a dispute resolution provider in the hope that a rising tide lifts all boats

[7] See Cartwright et al. (1988) 'The Report of the Cervical Cancer Inquiry' at p 214.

[8] Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S.-J. and Reid, P. (2019) 'Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition', *International journal for equity in health,* 18(1), pp. 174-174.

[9] See for example: Dorothy E. Stubbe (2020), Practicing Cultural Competence and Cultural Humility in the Care of Diverse Patients.

  - We note that many people's closest relatives or supports live overseas or in other parts of the country and travel is not always possible – whether due to a pandemic or other significant event, or simply the resources of the whānau. As much as possible, technology that allows face-to-face involvement should be used, but it is acknowledged that due to time zones, email and other messaging may be more practical.

f. Making it explicit in Right 10 that complaints can be made by support people. The primary consumer of the service may not be in a position to make the complaint themselves for many reasons.

  - Providing that making a complaint is not against the will and preferences of the person receiving the healthcare or disability service.
  - It may also be appropriate in certain cases to consider defining the "complainant" as the affected whānau, hapū, or family group. Rather than a sole individual.
  - In cases where there is an ongoing relationship, efforts to safeguard against any retaliatory or negative impact should be taken.

g. Including a non-retaliation clause.[10] However, we note that this could be difficult to assess and monitor, so further guidance for health practitioners and consumers could be beneficial.

h. Strengthening the advocacy service so that it can meet the needs of the diverse people accessing it, or those wishing to do so. This may include having the ability to attend meetings with consumers and ensuring there are advocates with expertise relating to different groups and communities.

i. Using terms, in letters to consumers, that better convey that improvements and insights have been achieved as part of the complaint process - even if no further action is taken beyond a certain point. Letters to consumers should appropriately acknowledge the contribution that their bringing forward a complaint has had, as for many people it takes a lot of courage and personal resource to do so. Even where official breaches are not found, there are often learnings for both parties, and ideally

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[10] One survivor advised the Abuse in Care Royal Commission of Inquiry that he was "secluded as retaliation for a complaint he made against staff" at p 239 of Part 4 of Whanaketia.

with restorative practices, relationships between consumers and providers (and their mana) can be upheld by the process. In other words, their mana is protected.

7. We also suggest that consideration needs to be given to:

    a. Including an explicit requirement (possibly in the purpose section) for the HDC to protect, promote and uphold human rights obligations in Aotearoa in the context of health and disability services. In particular, the right of all people to the highest attainable standard or physical and mental health;[11] and to assist NZ in meeting its obligations under te Tiriti, the Convention on the Rights of Persons with Disabilities ("**CRPD**") and the Universal Declaration on the Rights of Indigenous Peoples ("**UNDRIP**").[12]

        - If there is not also a commitment to te Tiriti and UNDRIP, then incorporating concepts such as mana and tikanga into the Act and Code will be incomplete – as these go hand in hand. You cannot uphold a person's mana, and respect tikanga, if you are not also honouring the rights set out in te Tiriti and UNDRIP.
        - There is international evidence that applying human rights concepts and frameworks helps to strengthen health systems, achieve equity, reduce suffering, and save lives.[13]

    b. Improving the accessibility of the advocacy service and complaints process. We acknowledge the different formats for explaining how to make a complaint on the website, and that complaints can be made in any language. Accessibility must also continue on into the rest of the process.

    c. Expanding the scope of the HDC's jurisdiction to cover not only complaints about the quality of services, but complaints about access to services. Whilst access can sometimes be a resourcing issue beyond the provider's control, it is nevertheless

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[11] See Universal Declaration on Human Rights (UDHR) (adopted 10 December 1948), art 25(1); International Convention on the Elimination of all Forms of Racial Discrimination (ICERD) (adopted 21 December 1965, entered into force 4 January 1969), art 5(e)(iv); International Covenant on Economic, Social and Cultural Rights (ICESCR) (adopted 16 December 1966, entered into force 3 January 1976), art 12(1); International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (adopted 18 December 1979, entered into force 3 September 1981), arts 11(1)(f), 12 and 14 (2)(b); International Convention on the Rights of the Child (UNCROC), (adopted 20 November 1989, entered into force 2 September 1990), art 24 (1989); and United Nations Convention on the Rights of Persons with Disabilities (CRPD), (adopted 13 December 2006, entered into force 3 May 2008), art 25.

[12] See for example the long title of NZBORA 1990 and s 5(1)(b) of the Corrections Act 2004 which refer to the intention to meet or comply with certain international human rights instruments commitments.

[13] See further resources list for more information and further reading at: www.tikatangata.org.nz/ourwork/guide-to-the-rights-to-healthcare-and-health-protection.

often a critical contribution to poor outcomes in healthcare. It is also one of the rights under UNDRIP and te Tiriti. The ability to investigate this and highlight it to the public, Te Whatu Ora and Ministry of Health would be a beneficial further check to promote consumer safety and obligations under te Tiriti and UNDRIP.

d. Given the overlap with Te Kāhui Tika Tangata | Human Rights Commission for many complaints, establishing a choice of procedures (with the Code defining its scope in relation to complaints of discrimination), or through greater co-ordination between our agencies through a memorandum of understanding including the option for co-mediation of discrimination complaints.[14]

e. Offering restorative alternative dispute resolution processes, including offering a more person-centred complaints process and a tikanga-based complaints process – noting the recent hui ā-whānau and hohou te rongo options implemented by HDC.[15]

f. Introducing an ability for HDC to undertake and publish thematic investigations and recommendations to improve the health and disability sector.[16]

g. Strengthening annual reporting requirements covering the following data - in order to assist the HDC to better understand and respond to people's needs:[17]

    - Disaggregated data on barriers to accessing health and disability services;
    - Disaggregated data about barriers to accessing the HDC's complaints and investigations procedures.

h. Providing the equivalent of a clinical navigator for disability (non-health) contexts.

i. Implementing processes that can achieve faster resolution, where that is appropriate. Even six months is a long time for resolving a matter that may affect day to day living and public safety – including the potential for serious harm or death. Delays also affect public confidence in both the HDC and health system.

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[14] The Royal Commission has noted in its final report Whanaketia in a section on "Functions of different entities in future care system" that the Independent Oversight Bodies (the Ombudsman, Te Kāhui Tika Tangata Human Rights Commission, Health and Disability Commissioner, Mana Mokopuna) should "work collaboratively to proactively investigate care providers, hospitals and schools, and investigate and report on complaints brought by users of supports and services." At p 52 of Part 9.

[15] Te Kāhui Tika Tangata | Human Rights Commission recently developed an internal tikanga based complaints guide and is happy to meet to discuss this with the HDC to share learnings and insights if that would be helpful.

[16] See for example the recent report from Te Hiringa Mahara: Achieving equity of Pacific mental health and wellbeing outcomes May 2024.

[17] See OHCHR (2018) A Human Rights-Based Approach to Data for more information on the "general guidance and elements of a common understanding on a Human Rights-Based Approach to Data (HRBAD), with a focus on issues of data collection and disaggregation."

  - Making the advocacy service more proactive and practical could assist in this regard. Delays in resolving complaints, or proceeding with a prosecution, can have significant impacts on access to justice (for all parties); and can increase stress levels in marginalised complainants, as well as overburdened healthcare and disability workers.
  - Consideration should be given to how case management systems could be improved. We acknowledge that in the current environment resourcing such can be very challenging, but in the long term it could be cost-saving, and some measures can be implemented without additional expenditure.

j. The importance of using and analysing complaint information at a more strategic level - to identify patterns or recurring issues in order to promote measures that will avoid future breaches of the Code.

k. How the framing of the Act could be changed to have more emphasis on protecting and upholding rights, and promoting a more person-centred and whānau-centred approach to healthcare and disability services.[18] This would nicely flow into a person-centred and whānau-centred approach to complaints processes and dispute resolution, and to a Code which has as a central purpose the promotion of human rights. Person centred-care is a rights-consistent approach to health and disability services, and as such has many benefits, including reducing complaints.[19] Under te Tiriti, it is also appropriate to take a whānau-centred approach for some complainants.

l. Using the term "rainbow people", rather than "LGBTQIA+". "Rainbow people" appears in the recent Integrity Sport and Recreation Act 2023, and is defined in s 4(1) as:

> people whose sexual orientation, gender identity, gender expression, or variations of sex characteristics differ from majority binary norms, for example, people who are takatāpui, lesbian, gay, bisexual, intersex, transgender, queer, non-binary, and fa'afafine

Some minor changes and improvements could be made to this definition. For example, placing "transgender" before "intersex" in the list and including other Pacific

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[18] The key principles of person-centred care are that the person is treated with dignity, compassion and respect; and their care is personalised, coordinated and enabling. For a brief overview of person-centred care see: https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf

[19] Ibid, p 13, 29.

> Rainbow terms:- māhū (Hawai'i and Tahiti), vakasalewalewa (Fiji), palopa (Papua New Guinea), fa'afafine (Samoa and American Samoa), 'akavaine (Cook Islands), fakaleitī or leitī (Tonga), and fakafifine (Niue). These terms are captured in the acronym MVPFAFF+.

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

Ka whakaritea Te Ture me Te Tikanga kia mauritau atu, kia urupare atu hoki ki ngā matea o te Māori

8. We share the concerns about the low level of Māori accessing the complaints and advocacy services, and the flow on and compounding effect this can have into inequities in the health system for Māori. Opportunities for learning, improving, and associated improved outcomes, are lost if complaints are not made by affected tangata whai ora Māori.[20] As noted recently by the Productivity Commission:

> Until these inequities are resolved, health and education systems in Aotearoa New Zealand are more likely to reinforce advantage, rather than acting as interventions through which equity can be achieved.[21]

9. The Code is an important legal instrument to protect health rights, but it is very much framed from a Western norms and legal system perspective. This is likely to be behind some of the low level of engagement by tangata whenua, including bringing claims that relate to a breach of right 1(3). The Waitangi Tribunal has recognised that the lack of recognition in legislation and policy contributes to the inequities in health outcomes for Māori.[22] As the consultation document notes, the universalist approach reflected in the current code is not resonating with Māori service users. Nor is it appropriate in the context of a nation State formed under te Tiriti.

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[20] See for example: Report on Opinion - Case 97HDC8872.

[21] New Zealand Productivity Commission (2023). A fair chance for all: Breaking the cycle of persistent disadvantage at p 29.

[22] Waitangi Tribunal, (2023), Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (Wai2575), 34, 55. See also Palmer, S. C., Gray, H., Huria, T., Lacey, C., Beckert, L. and Pitama, S. G. (2019) 'Reported Māori consumer experiences of health systems and programs in qualitative research: a systematic review with meta-synthesis', *International Journal for Equity in Health,* 18(1), pp. 163; Came, H. A., Herbert, S. and McCreanor, T. (2021) 'Representations of Māori in colonial health policy in Aotearoa from 2006-2016: a barrier to the pursuit of health equity', *Critical public health,* 31(3), pp. 338-348.

10. It is notable that the first draft of the Code incorporated a higher recognition of "the special needs of Māori including recognition of their status as tangata whenua in the Treaty of Waitangi". However, this was changed to the current wording in Right 2(3) – due in part to concerns that Māori would receive preferential treatment and that the Crown's treaty duties were not yet sufficiently defined by the courts or Waitangi Tribunal.[23] Such concerns were not justified at the time and represent a misunderstanding of the rights and obligations under te Tiriti, and of measures that promote equity.[24]

11. In any event, there is now extensive jurisprudence to draw upon, in particular from the Waitangi Tribunal,[25] but also: proceedings under the Human Rights Act and New Zealand Bill of Rights Act; and comments from international human rights bodies. For example, the Expert Mechanism on the Rights of Indigenous Peoples[26] which has specifically stated in relation to Aotearoa:

> The right to health of the Māori people is effectively affirmed in the Treaty of Waitangi, which provides for the protection of self-determination and cultural possessions (tangible and intangible), shared decision-making and equal participation in society without discrimination."[27]

12. Various reports from the Waitangi Tribunal state that the rights protected in te Tiriti need to be actively recognised and protected in all laws of Aotearoa.[28] In the context of health and

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[23] Ministry of Health (1996) "Amendments to the draft code of health and disability services consumers' rights Wellington" Office of the Minister of Health.

[24] Te Tiriti obligations are upheld by international human rights standards and guidance. Tino rangatiratanga reflects the fundamental human right to self-determination – the right of peoples to make decisions for themselves. UN human rights bodies stress the importance of the right to self-determination, the need for special protection of indigenous communities, and for states to work in partnership with indigenous peoples in health-related interventions. See Anne Nuorgam (April 2020) *Statement by the Chair of the United Nations Permanent Forum on Indigenous Issues: Ensure indigenous peoples are informed, protected and prioritized during the global covid-19 pandemic*. Accessible at: https://www.un.org/development/desa/indigenous-peoples-es/wp-content/uploads/sites/34/2020/04/UNPFII-Chair-statement_COVID19.pdf.

[25] See Waitangi Tribunal, (2023), Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (Wai2575), 34, 55.

[26] https://www.ohchr.org/en/hrc-subsidiaries/expert-mechanism-on-indigenous-peoples. For example the thematic report on *The right to health and indigenous peoples, with a focus on children and youth* by the Expert Mechanism on the Rights of Indigenous Peoples (**EMRIP**) highlighted that partnership between States and indigenous peoples is paramount to ensuring adequate and equitable health outcomes for indigenous peoples.[26] It found health was a fundamental element of indigenous peoples right to self-determination[26] and that decision making processes around health needed to include indigenous peoples.[26]

[27] EMRIP Thematic Study (2016) *Right to health and indigenous peoples with a focus on children and youth,* UN Doc A/HRC/33/57. Accessible at: https://www.undocs.org/a/hrc/33/57 at 19.

[28] See for example: Waitangi Tribunal, (2023), Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry, (Wai2575) at 34, 55.

disability services, kāwantatanga, ōreitetanga, and tino rangatiratanga are particularly relevant.

13. As the Waitangi Tribunal has found: “Tino rangatiratanga of hauora Māori is necessary to pursue health equity. Tino rangatiratanga of hauora Māori will not be possible without more active support from the Crown”.[29]

14. The Waitangi Tribunal’s Hauora (Stage 1) report found pervasive inequities and Tiriti breaches, including failures to give effect to tino rangatiratanga regarding hauora Tangata Whenua. The report highlighted institutional racism, chronic underfunding of Tangata Whenua health, and a lack of accountability in relation to Tangata Whenua health equity. Two overarching recommendations made by the Tribunal were for legislative amendments to: adequately recognise and provide for te Tiriti and its principles in the health and disability system; and to expressly commit the Crown and the health system to achieving equitable health outcomes for Tangata Whenua.

15. Further, it is widely recognised by experts in disciplines such as public health and medicine that respect, recognition and incorporation of a service user’s culture results in better health and social outcomes.[30] This is particularly important for Māori consumers in light of Māori health statistics.[31] Tāngata whaikaha Māori are particularly impacted,[32] as are their whānau.[33]

16. In light of this background, we support the following proposals and actions already underway, as outlined in the consultation document:

    a. Actions being taken to increase the attractiveness and accessibility of HDC services to Māori consumers and communities.

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[29] Waitangi Tribunal, (2019), Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry, (Wai2575).

[30] See for example Hector Kaiwai and Dr Tanya Allport *Māori with Disabilities (Part Two): Report Commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575)* June 2019 at p 52. See also Angelique Reweti (2023) Understanding how whānau-centred initiatives can improve Māori health in Aotearoa New Zealand ; Heather Came, Dominic O’Sullivan, Jacquie Kidd, and Timothy McCreanor *The Waitangi Tribunal’s WAI 2575 Report: Implications for Decolonizing Health Systems* Health and Human Rights Journal Volume 22/1, June 2020, pp 209 – 220.

[31] See Waitangi Tribunal, (2019), Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry, (Wai2575), 34, 55.

[32] Ingham, T.R. et al. (2022) ‘The Multidimensional Impacts of Inequities for Tāngata Whaikaha Māori (Indigenous Māori with Lived Experience of Disability) in Aotearoa, New Zealand’, *International Journal of Environmental Research and Public Health*, 19(20).

[33] See *Te Rina’s story: ‘I struggled behind closed doors’* (n.d.) Accident Compensation Corporation. Available at: https://www.acc.co.nz/newsroom/stories/te-rinas-story-i-struggled-behind-closed-doors/

b. Including provisions that recognise the importance of, and give practical effect to, the commitments encapsulated in te Tiriti o Waitangi, including the options for incorporating this set out at pages 32-34.

c. Explicitly incorporating tikanga into the Code, in a way that allows for transgressions of such to be investigated and legally enforced.

    - We defer to experts (mātanga tikanga) on how tikanga should be incorporated, but note that tikanga varies amongst different iwi. Any incorporation of the concept needs to be duly flexible to accommodate this.
    - In *Ellis v R* [2022] NZSC 114 the Supreme Court noted that tikanga is the first law of Aotearoa and still applies today - regardless of whether the context is specifically te ao Māori. The Chief Justice stated at [169]: "Tikanga is both social and legal in nature and its force as a source of regulatory principle will be dependent on context. Moreover tikanga is not fixed, but changes and evolves across time, to meet new situations. What is "tika" (right) in any situation may need to be discussed and negotiated between those expert in tikanga. As is stated in the Tikanga Statement "[d]ecisions about mātāpono (principles) are always subject to variables such as concepts, practices, and values, as relevant to the circumstances". What this means is that while the core principles and values of tikanga are enduring and readily identifiable, the particular manifestation of those principles in any given context is subject to change."
    - We note that whilst there may be good reasons for leaving a provision general (including because tikanga is not static across time and space), this rationale must be balanced against a risk that generality could leave a provision vulnerable to interpretation that may not uphold rights of tangata whaikaha Māori in the way envisioned. Careful consideration is required around the level of generality and the aims of the provision.

17. We also suggest:

a. Including reference to the relevant rights set out in the United Nations Declaration on the Rights of Indigenous Peoples ("**UNDRIP**").[34] In particular, the rights of indigenous peoples to:

  - enjoy the highest attainable standard of physical and mental health;[35]
  - determine and control their own health policies and practices;[36]
  - maintain and develop their own traditional medicines, health care practices and medicines relevant to their cultural practices;[37]
  - participate in decision-making processes that affect their health and wellbeing;[38] and
  - have access to and use and control of their traditional lands, territories, and resources, which are critical for their health and well-being.[39]

b. HDC undertaking meaningful engagement with Māori communities, in consultation with Māori communities, to promote use of its services and development of them to better serve Māori.

c. Ensuring that the inclusion of Māori concepts such as mana and tikanga, and honouring of te Tiriti, is done in an authentic manner. These concepts and commitments should be incorporated not just into the legislation, but also into the processes of the organisation, so that they do not become 'window dressing' or 'lip service'.

d. Considering how to protect and promote Māori data sovereignty in the context of health and disability, and to ensure the ethical use of data to enhance the wellbeing of tangata whenua, their language and culture.[40]

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[34] Although not a treaty, the Declaration has "significant normative weight" and can be taken into account in assessing the Crown's obligations under Te Tiriti o Waitangi: Waitangi Tribunal *Whaia te Mana Motuhake - In Pursuit of Mana Motuhake*: *Report on the Maori Community Development Act Claim* (Wai 2417, 2015) at 34 and 39.

[35] United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (adopted by UNGA 13 September 2007, signed by New Zealand 20 April 2010), at 24.

[36] UNDRIP, art 23.

[37] UNDRIP, art 20.

[38] UNDRIP, art 18.

[39] UNDRIP, art 14.

[40] As noted by the Māori Data Sovereignty Network | Te Mana Raraunga in 'Tūtohinga | Our Charter' available at https://www.temanararaunga.maori.nz/tutohinga

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

Kia tika Te Ture me Te Tikanga mō ngā tāngata whaikaha

18. We endorse the feedback from tāngata whaikaha outlined on p 35, which is consistent with what we hear from our stakeholders. We support the following proposals and actions already underway outlined in the consultation document:[41]

    a. The intention to update the Act and Code and make it more aligned with CRPD and the social model of disability that this represents.

    b. Improving data collection in order to better analyse and report on issues for tāngata whaikaha.

    c. Actions to improve resources – ensuring they are modern, accessible and culturally appropriate, particularly for groups such as people in residential services or who are legally detained.

    - As part of the updating of resources, we suggest avoiding suggesting a strictly medical approach. For example, a recent video on the Code featured people in white coats – something which few medical providers now wear.

    d. Including a reporting requirement to the Minister for Disability Issues.

    e. Strengthening references to accessibility.

    f. Removing the words reasonably practicable in right 5 (right to an interpreter).

    - The right to communication goes beyond provision of a competent interpreter, unless interpreter is defined very liberally as provision of a range of communication support. Right 5 should reflect this, in a way that reflects and accommodates the particular context and what is reasonable and possible or practical. For example, in an emergency situation it may not be possible to provide the same level of communication support as in a consultation appointment with a specialist.

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[41] At pp 34 – 41.

- This right is closely connected to the right to supported decision-making discussed below.[42]

g. Updating language in right 7 as suggested on p 39 of the consultation document.

  - However in right 7(4) the change to "views" should include "rights, will, and preferences".

h. Updating the definitions relating to disability. We note however:

  - There is a need to consider how this can include a person who is the employer of the person providing the service, when they are also the person receiving the service. For example, in Individualised Funding situations.
  - Is the term 'any person' future proofed - for when services may in part be provided by 'entities' – such as AI or other technological supports?
  - Remove references to "care" and just use "support", as per other language changes. Change references to "independence" to "autonomy".
  - Ensure that wording, phrasing and framing is consistent with the social model of disability encapsulated by the CRPD.

i. Incorporating a clear right to supported decision-making, consistent with the CRPD. This should include the right to have this facilitated. This should align with the changes likely to be made to the PPPR Act.[43]

j. Creating a legislated role focusing on disability services issues. Ideally this role would be performed by a disabled person. We would also support a disability specific team within HDC. However care would need to be taken to ensure that there is not confusion in the community about this role, with the separate role of Disability Rights Commissioner, under the Human Rights Act 1993.[44]

19. In addition, we suggest:

a. Regarding the 2019 review relating to participation in research:

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[42] Equal recognition before the law (art 12 of CRPD) includes ensuring disabled people have legal capacity, including by seeking informed consent to medical treatment and the provision of support to give informed consent if required. The CRPD Committee has emphasised that the existence of an actual or perceived impairment of mental capacity does not change a person's standing before the law.

[43] https://www.lawcom.govt.nz/our-work/review-of-adult-decision-making-capacity-law/

[44] See s 8.

    - The 2019 recommendations are not explicitly clear on how they apply for non-health/medical related research – such as qualitative experiential research.
    - A high level of caution needs to be applied when extending circumstances when participation in research can occur without consent. Any changes in this area should ensure that they comply with human rights including in the field of bioethics, such as the United Nations Educational, Scientific and Cultural Organization (UNESCO), (2006) *Universal Declaration on Bioethics and Human Rights*.[45]
    - If a person is not able to consent, then the threshold and means of establishing 'potential for direct benefit' should be cautiously construed, with a precautionary principle approach.

b. Incorporating articles 23 - 25 of the Convention on the Rights of the Child, that relate to human rights specifically for disabled children.

c. Considering how to reflect and incorporate the purpose of supporting participation in community on an equal basis with others – in order to better align better with the CRPD.

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

Kia whakaaro kōwhiringa mō tētahi mōtika hei pīra i ngā whakatau a te HDC

20. We support the following proposals in the consultation document:[46]

a. Creating an appeal right, with a leave-like application process to triage out obviously vexatious and frivolous complaints.

    - It may be useful to consider the principles for strike out applications, which set a high threshold for stopping legal proceedings from continuing to a substantive hearing.[47]
    - Providing an appeal right is consistent with the right to access the courts and right to justice, and will also be more consistent with the Privacy and Human Rights Act jurisdictions.

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[45] Available at: https://unesdoc.unesco.org/ark:/48223/pf0000146180

[46] At pp 41 – 45.

[47] For the principles of strike out see *Attorney-General v Prince* [1998] 1 NZLR 262 (CA) at 267; and *Couch v Attorney-General* [2008] NZSC 45 at [33].

- Whilst there is currently the ability to apply for judicial review, consistent with s 27 of NZBORA, this is a complex and expensive jurisdiction to exercise rights in, making it prohibitive for many people. A more accessible option of review is needed.

- It has been posited that "unacceptable barriers to accessing justice are embedded in the complaints process" and that there may be inconsistency in how substantively similar complaints are dealt with by HDC.[48] This could mean that valid issues are not being explored, valid rights breaches not being held to account,[49] and the benefits gained to the health system and jurisprudence from doing so are lost.

- Currently people are prevented from accessing the HRRT if there is no finding of a breach by HDC.[50] There is thus no accessible check on the exercise of this power by HDC. This can be compared to Privacy Act and Human Rights Act complaints. Under those regimes, there is no comparable barrier to accessing the HRRT.[51]

- Increasing access to HRRT would mean that there would need to be a significant increase in resourcing so that cases are not further delayed. Existing delays for cases to be heard after filing suggest increased resources are needed in any event. This is particularly important given that in the HDC jurisdiction there are public safety issues involved: practitioners may continue practicing in the meantime; complainants may be of ill health and pass away before the proceeding, and they may be a key witness; and also the pressure and stress delay places on health practitioners waiting to have their complaint resolved.

21. In addition, we suggest consideration should be given to:

    a. Adjusting the bar on damages in s 52 so that health rights breaches are eligible for damages even where there is an indirect association with an injury covered by ACC.

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[48] Joanna Manning "Fair, Simple, Speedy and Efficient"? Barriers to Access to Justice in the Health and Disability Commissioner's Complaints Process in New Zealand. [2018] New Zealand Law Review pp 611 – 656.

[49] Accountability is a key principle of taking a human-rights approach. See Ysaline Reid (2024) The Principle of Accountability in Human Rights-Based Approaches to Development: Towards a New Understanding.

[50] Health and Disability Commissioner Act 1994, ss 50 – 51.

[51] Under the Human Rights Act there is a requirement that a complaint "has been made" with Te Kāhui Tika Tangata|Human Rights Commission – see s 92B of the Human Rights Act 1993. Under the Privacy Act there is a requirement that the Privacy Commissioner's office must have investigated the aspects of the complaint that the complainant wants the Tribunal to consider – see s 98 of the Privacy Act 2020.

For example, if a Māori person felt that their right to tikanga, incorporated in the new Code, was breached – they should not be prevented from claiming damages in the HRRT, if they also suffered a treatment injury[52] at the same time.

b. Clarifying that ACC cover is not a barrier to proceedings being brought under the HDC Act. Despite some overlap, the ACC scheme serves a sufficiently distinct purpose to that of the HDC Act to justify separate proceedings.

Kaupapa 5: Minor and technical improvements

He whakapai itinga, mea hangarau hoki

22. We support the following proposals in the consultation document:[53]

    a. Increasing the timeframe for reviews of the Act and Code, but with earlier reviews still possible if deemed necessary. An earlier review could be necessary if there were significant developments in healthcare.

    b. Increase of the maximum fine under s 73, to allow for inflation and bring it into line with comparable offences.

    c. Giving the Director of Proceedings a power to require information from providers. Given the important public safety function of the office, this is justified.

    d. Allowing people other than complainant (for example the estate or whānau) to have access to the tribunal.

    e. Allowing substituted service.

        - However, it should be noted that marginalised complainants may be more likely to frequently change contact details. It would be concerning if 'reasonable attempts' was interpreted narrowly as simply making one attempt to contact the person. Consideration could be given to including a section to provide alternative contact information in the initial complaint form, if it doesn't already. This could for example be a person's family member, GP or via their MSD case manager.

        - Permission should be sought in the initial complaint form, for contacting a person via social media accounts.

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[52] See Accident Compensation Act 2001, ss 32 – 33.

[53] At pp 47 – 51.

23. We agree with the raised concerns about new technologies such as Artificial Intelligence being used in health and how this impacts the upholding of health rights. Whilst there is potential for such technologies to enhance health access and outcomes, there is also potential for detrimental impacts – representing a significant ethical, legal and practical challenge for humanity.[54] The impacts of bias in medical research (such as from disproportionate use of Europeans and males as study subjects) are already an issue for example, and there is a risk that Artificial Intelligence may further embed such.[55]

Concluding comments

24. The Review represents a much needed opportunity to embed human rights into the Health and Disability Commissioner Act and Code of Health and Disability Services Consumer Rights, such as those found in CRPD, te Tiriti, and UNDRIP.
25. We would welcome being contacted for clarification on any of the points raised in this submission.

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[54] See Rowena Rodrigues (2020) Legal and human rights issues of AI: Gaps, challenges and vulnerabilities Journal of Responsible Technology Volume 4, December 2020, 100005

[55] Candace Makeda Moore (2022) The challenges of health inequities and AI Intelligence-Based Medicine Volume 6, 2022, 100067.