

3 March 2023

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

Tēnā koe Rose

Feedback into the scoping of the next review of the Act and Code

Thank you for the opportunity to provide early input into the review of the Health and Disability Commissioner Act and the Code of Health and Disability Services Consumers' Rights.

You have asked me whether there are there any aspects of the Act or Code that we think are not working well, or not working well for everyone. You have also asked what changes to the Act or Code we think would best enhance the protection and promotion of consumer rights.

In response to these questions, I have outlined below the points that Te Hiringa Mahara would like to see taken account of in the scoping of your next review.

Language consistent with a 'social' rather than 'medical' framework

We would like you to consider whether provisions in the Act and Code need amending so that wording is consistent with a 'social' framework rather than a 'medical' framework for rights in health and disability care and treatment services.

Further to this point we encourage you to identify principles to guide consultation on substantive issues (as the Law Commission has done in their current consultation relating to their review of adult decision-making capacity law¹).

Risk and safety

We would like your review to consider issues of risk and safety from a wider perspective than the 'medical model' prevalent in the health sector. Current practices grounded in risk aversity can lead to decisions that harm people using mental health services.

¹ <https://huarahi-whakatau.lawcom.govt.nz/>

We note that the national conversation recommended in He Ara Oranga about mental health and risk has been limited,² but we think that is an important topic for your review to consider.

Privacy and information sharing

Related to the concept of risk aversity, we think that the impact of ‘the right to have his or her privacy respected’ as stated in the Code would benefit from review. Feedback we have received suggests that the right to privacy often overwhelms ‘the right to co-operation among providers to ensure quality and continuity of services,’ even if this results in negative impacts on the wellbeing of people using services.

Realising rights under the Code

Your review may benefit from considering the barriers that people face to understanding, acting upon, and realising their rights under the Code – and whether the Health and Disability Commissioner has the resources and powers to help overcome these. People who experience social discrimination and disadvantage face barriers to seeking health services, and to understanding and acting upon their rights. This is likely to be seen in inequities in the demographic makeup of complainants who reach out to you, when compared to the population as a whole. In short, structural discrimination and other disadvantages mean that some people are less likely to try to access services, and when they do, less likely to receive appropriate care, and then less likely to access advocates or review processes when their rights are not upheld. Focusing on complaints will miss the opportunity to make the greatest improvement in care.

Te Tiriti o Waitangi

We think it is essential to review the extent to which the Act and Code explicitly give effect to Te Tiriti o Waitangi in all processes. We are concerned that the Code and Act work for all cultures and enable the experiences, needs, and aspirations of tāngata whaiora³ to be understood in a variety of ways. This includes a te ao Māori understanding of whānau that encompasses hapū and iwi and ways-of-being that are drawn from taonga tuku iho (ancestral knowledge); and an individualistic view of people as separate beings with independent rights as described in the Code.

He Ara Āwhina

He Ara Āwhina is a framework that we have developed with people’s voices about what matters to them in mental health and wellbeing.⁴ It is based on the Institute of Medicine’s six domains of healthcare quality. We encourage you to consider the domains and concepts in He Ara Āwhina as you develop the scope for your review.

² We note the following document published on the Ministry of Health website as a discussion prompt: Changem Ltd. 2022. He Arotake ngā Tūrarū | Reviewing risk: He kohinga kōrero | A discussion paper. Wellington: Ministry of Health https://www.health.govt.nz/system/files/documents/publications/changem_reviewing_risk_discussion_paper_14.pdf

³ 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.

⁴ 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/>

Other points

To support the monitoring of equity in access to services and outcomes we would like to see total ethnicity used when reporting usage statistics by ethnicity. Total ethnicity reflects how people describe themselves. Prioritised ethnicity invariably reduces the proportion of Pacific peoples in reporting. This can be seen, for example, in the ethnicity reporting in the Advocacy Service's annual report.

Also, we think language in the Code should keep up with understanding of gender diversity. That is, using gender neutral terms such as they/them/person.

I hope the attached feedback is useful. I am of course happy to discuss this in person.

Ngā mihi nui



Karen Orsborn
Tumu Whakarae | Chief Executive

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

Who: Age Concern NZ
Karen Billings-Jensen, Chief Executive
Louise Rees, National Manager Social Connections Services
Joanne Reid, Manager Health Promotion and Policy
Hanny Naus, Professional Educator - Elder Abuse and Neglect Prevention

Date: 7 March 2023

Re: HDC Act & Code review

- Age persons is a growing and diverse population group and a one size fits all approach no longer works. It is important that health and disability service providers factor in the needs of Māori and Pacific Islands peoples, as well as migrants, refugees and the rainbow community, plus people with disabilities.
- Lots of issues around the use of Right 7(4) and consent and huge issues around the use of Enduring Powers of Attorneys.
- Age Concern advocates are constantly fighting for consumers with diminished competency to ensure that their voices are being heard and that they are not being ignored.
- It is really important to protect supported decision making.
- The move to online services is having a significant impact on older people. Things like traditional landlines being substituted with broadband lines impacts their ability to communicate and access services and emergency care when need (e.g. calling 111)
- Talked about the importance of 'digital inclusion' – that it is an ongoing problem, not just for older people now, but also for future generations, as tech is constantly evolving. Switching to broadband phone connections was one particular issue for older people and created issues for timely access to care including being able to call 111.
- Also noted concern about the rural/urban divide – lots of rural providers are closing down services and this is having a huge impact.
- Aged concern advocates can have difficulty accessing residential care facilities so having the National Advocacy Service is a good thing as it is a government funded service and providers are more willing to work with their advocates.
- Issues around consumers being able to access advocates it would be better if family members could help support them in making a complaint.
- Older people often do not feel comfortable in making a complaint, so when they do it is a big deal.
- There is a lot in the Code that is really good and it is important that this review doesn't throw the baby out with the bathwater.
- It is important to encourage older people to access and use the Code and it needs to be made as simple and accessible as possible. The cost of ordering the Code posters and other related materials was noted.
- The advocacy service is very important in this regard as it can help guide consumers through the process as well as weed out the vexatious complainants.
- The more early resolution with advocacy, the better and it is important that the advocacy service remain independent and not be "part of the system".
- There is an issue around accessing advance directives in emergency and hospital settings which needs to be addressed.

Key issues for older people included:

- Care needs to be affordable and timely – long waits for A&E, Hospital and GP care.
- Legitimate health issues should not be dismissed as 'just aging'
- Hospital discharges should not occur at 3am in the morning – people want to feel that there is a system that cares and that they are not just a number. It is important that aged consumers are seen in their contexts and that providers realise that many people are on their own.
- Important to have services joined up so that older people are not having to repeat themselves and it would also avoid communication breakdowns.
- It is hard for older persons to transition into care and it is question what does it look like to transition out?
- There are a lot of stresses and strains on carers, a lack of respite care for carers, many of whom say that they can't cope but have to continue despite burnout.

Age Concern very happy to help with promoting Act and Code review through their newsletters.

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and/or the Privacy Act 2020

13 March 2023

Rose Wall
Acting Health and Disability Commissioner
review@hdc.org.nz

Tēnā koe Rose

Thank you for the opportunity to provide input into the upcoming review of the Health and Disability Commissioner Act (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code).

As the peak industry body for the aged residential care (ARC) sector, the New Zealand Aged Care Association (NZACA) represents over 37,000 beds of the country's care home industry, or about 93% of the total supply. Our members' services include four categories of care – rest home, hospital, dementia and psychogeriatric, as well as short-term care, such as respite. ARC is also home to around 700 younger people with disabilities and the sector is the largest provider of end-of-life care, not only for older people but also for younger people unable to be cared for in a hospice due to lack of capacity.

New Zealand's population is ageing rapidly. In June 2022 there were 94,100 people aged 85 years or older; in 2042 it is estimated there will be 233,300. This major change, together with multiple factors reducing the number of potential family carers, means that there is a corresponding year on year increase in demand for long term aged care.

You have rightly identified that there has been significant change since the last time the Act underwent any major update, over 20 years ago. We recommend the following be considered as you scope this review.

Health equity/ Te Tiriti o Waitangi

A principle of the Pae Ora (Healthy Futures) Act 2022 is that the health sector should be equitable, which includes ensuring Māori and other population groups have a right to access to services in proportion to their health needs, to receive equitable levels of service and to achieve equitable health outcomes.

We suggest this be a consideration when updating the Code, however, it is important to note that the full onus of this cannot be put on healthcare providers, as insufficient government funding and policy settings are major barriers to the provision of care, particularly for private providers in rural and low socio-economic regions¹.

The Code of expectations for health entities' engagement with consumers and whānau, a requirement of Pae Ora, came into force in October 2022. This sets the expectations for how health entities must work with consumers, whānau and communities in the planning, design, delivery and evaluation of health services. While some overlap exists between the two codes, the Code of expectations incorporates Te Tiriti o Waitangi principles identified by the Waitangi Tribunal in its Hauora Inquiry, which should also be considered in the HDC review.

Ngā Paerewa Health and disability services standard NZS 8134:2021

The updated Ngā Paerewa Health and disability services standard came into effect in February 2022. Ngā Paerewa reflects the shift towards more person- and whānau-centred health and disability services. This is the Standard

¹ <http://nzaca.org.nz/news/equitable-access-to-arc-report/>

upon which ARC facilities, and other health and disability providers, are audited by the Ministry of Health. Ngā Paerewa should be considered when scoping this review to ensure that the standard to which healthcare providers are audited aligns with their responsibilities to consumers under the Act and the Code.

For example, the concept of cultural safety is one that could be included in an updated Code to align with both Pae Ora and Ngā Paerewa.

Technology

One learning for ARC from the pandemic has been the importance of keeping residents connected with whānau and loved ones. Unfortunately, during an outbreak (of COVID or other transmissible diseases), in person visiting may not be possible for a time, for the safety of both residents and staff. In such a circumstance, a provider could meet a consumer's right to support by facilitating a support person(s) to attend virtually. Likewise, some health services can be delivered virtually, and this is becoming more commonplace.

Technology of this type has a place in health but is it a careful balance between the rights and best interests of consumers and its necessity for the provider to continue delivering quality care. For example, in ARC we are seeing an increase in the use of virtual nursing, brought about by a severe shortage (around 25%) of registered nurses (RNs) in the sector. While having a nurse on site is preferable, where it is not possible, an RN who is familiar with the facility and its residents can be consulted virtually.

Advance directives

In the current review of adult decision-making capacity law by Te Aka Matua o te Ture | Law Commission, it has been identified that the legal status of advance directives in Aotearoa New Zealand is unclear. The review will consider whether the status and scope of advance directives should be clarified in law. The Ministry of Health's 'repeal and replace' of the Mental Health Act is also considering the use of advance directives.

The Law Commission review is considering several issues around advance directives including how they should be made, whether health practitioners should be required by law to follow them, and what happens if they haven't been updated in some time and may no longer be that person's wish. There is also the issue of how advance directives be accessed when they are needed and whether a central register would be useful.

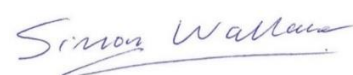
We note that that the majority of people entering aged care have not prepared advance directives or an advanced care plan. There appears to be a gap in education, with many New Zealanders being unaware of the existence of advance directives and their rights in these situations.

Other comments

We note that the code refers to consumers as his or her and that not everyone identifies with these pronouns.

Again, thank you for the opportunity to provide input to shape the review and we look forward to working with you throughout the process – please direct correspondence to Policy Analyst Rebecca Chapman at rebecca@nzaca.org.nz or [REDACTED].

Ngā mihi nui



Simon Wallace
Chief Executive

Information removed under section
9(2)(a) of the Official Information Act
and/or section 53(b) of the Privacy Act
to protect the privacy of the individual/s
involved



Kia ora Catherine,

I have a Grad Cert in Restorative Justice Practice from VUW, and recently completed the VUW Restorative Foundations in Healthcare. My prior role was coordinating restorative justice processes in the court system.

I refer to my VUW colleague's research and discussion document suggesting the potential for restorative approaches in the HDC process. <https://www.publish.csiro.au/hc/fulltext/hc21026>

I see the update of the Act as an opportunity to introduce restorative approaches. The benefits of restorative approaches is that it can be quicker and more meaningful for those involved (*if done properly and safely*). It can be adaptable to accommodate cultural needs, . and allows both sides to talk about all the events leading up to an event, address the harm caused, and 'restore' the relationship and the dignity and mana of all involved. There would need to concurrent upskilling of Advocates to be able to facilitate conferences (some of the records I have seen of advocate meetings have NOT been restorative for the parties). I know some DHB staff are completing training on how to hold restorative conferences.

Restorative 'justice' occurs in the court system due to s24A of the Sentencing Act: <https://www.legislation.govt.nz/act/public/2002/0009/latest/DLM6362000.html>

A restorative conference can be convened when the person who has caused harm has pleaded *or been found* guilty. The result of any restorative conference is then taken into account by the judge at sentencing. [I can personally speak to the risks, but also the good and bad outcomes of this process].

How could a restorative process be included in the HDC process?

Where a provider accepts a departure from the Code, there could be Commissioner's discretion to refer to a restorative process by Advocacy (or suitable DHB staff). If both parties willing, and it is safe to proceed, a meeting could be held.

To be clear a restorative process is not alternative dispute resolution (there is no dispute, there needs to be agreement that harm was caused, with an apology, and steps taken to prevent re-occurrence). However, dispute over some aspects of a complaint are not entirely fatal to a restorative process. A report from any conference held is then provided to the Commissioner for next steps. In severe departures, this would still require breach, publication of outcome and if necessary, referral to disciplinary tribunal. The purpose of the restorative process is to:

- fully explore all the factors that contributed to an event of harm (this can often go beyond what is provable from an adversarial legal process, but is complementary to a 'just culture')
- provides a safe space for both consumer and provider voice
- allow providers/consumer quick resolution within the formal HDC process

There is the potential for a restorative process at all levels of harm (for severe or mild departures). In the criminal process, it has proven to be more successful where there has been serious offending (yet is more likely to be referred for mild offending). Sometimes resolution can occur at the preconference stage without proceeding to a meeting (complainant is satisfied that provider has accepted they caused harm, and addressed causative factors). I note that the 'restorative process' for mesh (often used as an example) has simply provided circles for the voices of victims and is not a true restorative process - yet!

I note there is a section of the current Act for Mediation -

<https://www.legislation.govt.nz/act/public/1994/0088/49.0/DLM334135.html> In my opinion, this existing section is not appropriate for a restorative process and is unable to come within it under its current form (mediation is for a dispute, doesn't appear to be voluntary, includes expense payments).

I propose a dedicated new section, along the lines of (without being an expert legislative drafter!):

62. Restorative process

(1) Where the provider accepts there has been a departure from the Code, and the Commissioner is of the opinion that it would be appropriate to do so, taking into account the wishes of the complainant(s), the Commissioner may enable inquiries to be made by a suitable person to determine whether a restorative process is appropriate in the circumstances.

(2) Where a restorative process is held, a report of any meeting is to be provided to the Commissioner to be considered [alongside s45 outcomes - in appropriate legalese]

An alternative is to insert a restorative process within in s45 -

<https://www.legislation.govt.nz/act/public/1994/0088/49.0/whole.html#DLM333992>

I note something should be included in regards to reparations because providers should not see it as an opportunity to pay their way out of a breach (ditto from consumers). It would have to work alongside the ACC system.

In my experience, after a successful and safe conference, the harmed party often feels significant grace towards the person who caused them harm and is focused on a rehabilitative outcome.

Anyway, I don't have all the answers, just the ideas! I hope my email this initiates some deeper thought on how we can meaningfully incorporate restorative processes alongside our existing ones.

Nāku iti noa, nā

Alice Robinson (she/her/they/ia)

Investigator | Kaitūhura

Office of the Health and Disability Commissioner | Te Toihau Hauora, Hauātanga

Level 11, TechnologyOne House, 86 Victoria Street, Wellington 6011

Phone: 0800 11 22 33

Kia ora Catherine,

I have had another thought.

The Ministry of Education states:

"Schools providing health or disability services for their students, have responsibilities under the Code of Health and Disability Services Consumers' Rights (the code)."

<https://www.education.govt.nz/our-work/our-role-and-our-people/contact-us/regional-ministry-contacts/learning-support-services/making-a-complaint-about-a-learning-support-special-education-service/#sh-complaint%20health%20and%20disability>

The Ministry of Education then refers to supporting ākong with health conditions.

<https://www.education.govt.nz/school/health-safety-and-wellbeing/health-and-wellbeing/health-conditions-in-education-settings-supporting-children-and-young-people-2/>

<https://www.education.govt.nz/our-work/overall-strategies-and-policies/wellbeing-in-education/#sh-disability%20code>

Reading the existing Health and Disability Commissioner Act 1994, education disability services would fall under:

<https://www.legislation.govt.nz/act/public/1994/0088/latest/whole.html#DLM333589>

s2 Interpretation

"disability services includes goods, services, and facilities—

(a) provided to people with disabilities for their care or support or to promote their independence; or
(b) provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of the independence of such people"

For example this should include a teacher aide funded by the Ministry of Education Ongoing Resources Scheme to support a student with, for example, autism. However, it is currently a grey area. The Ministry (who holds a stewardship role, and no responsibility for what individual schools do) would refer to HDC, but HDC currently *has no process for education disability services*.

This is an opportunity to create clarity in HDC Act, but also to seek more funding and resources for HDC.

Anyway, again happy to discuss further!

Information removed under section 9(2)(g)(i) of the Official Information Act to maintain the effective conduct of public affairs through the free and frank expression of opinions by or between organisations and employees and the commissioner.

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Tēnā koe Rose and the HDC office

Thank you for the invitation to provide input into the HDC Act and Code Review. I am sending this email in my personal capacity as a lawyer who has had involvement with the Code, both in representing clients in the complaints process but also as a legal researcher with input on policy and research ethics.

In summary, the areas of the HDC Code which I consider are in need of review and changes to the Code are as follows:

1. Providing a definition of competence/capacity for decision-making, and giving effect to supported decision-making and the Convention on the Rights of Persons with Disabilities (CRPD). Any changes to the Code would need to interface with the Law Commission's review of adult decision-making capacity: Ngā Huarahi Whakatau.
2. Completing the review of Right 7(4) and non-consensual research. This review was not completed by the previous Commissioner, despite extensive input from a wide range of people in the health and disability sector. On my part, I interviewed key people and research institutions in the UK as part of my NZ Law Foundation International Research Fellowship in 2015.
3. Kia mōhio ai koe, I attach:
 - a. Chapter 6 – Research on people who lack capacity, from my report: Mental Capacity: updating New Zealand's Law and Practice (2016) www.alisondouglass.co.nz;
 - b. Article by myself and Angela Ballantyne in *Bioethics* (2018) From protectionism to inclusion: A New Zealand perspective on health-related research involving adults incapable of giving informed consent.
 - c. One of several submission sent by the New Zealand Law Society, Health Law Committee (when I was Chair) seeking to follow through on earlier recommendations from the previous Commissioner for proposed changes to the Code. In this regard you may wish to contact the law reform committee of the NZLS and current Health Law Committee for input into the current review.

I would be happy to meet and discuss your review if that is of assistance. I do hope that there will be genuine action by the Commissioner to update the Act and Code.

Kia kaha

Alison Douglass

Ngā mihi nui | Kind regards

Alison Douglass

Barrister LLB, MBHL

Barristers Chambers | Level 3, Westpac Building | 106 George Street | PO Box 5117 | Dunedin 9058 | New Zealand

Phone 03 477 3488 | Fax 03 474 0012 | Mobile +64 27 549 6161

alison.douglass@barristerschambers.co.nz | www.alisondouglass.co.nz

Morag McDowell
Rose Wall
Office of the Health and Disability Commissioner
PO Box 11934,
Wellington 6142

13 March 2023

Regarding the early input into the HDC Act and Code of Rights Review

Tēnā kōrua Morag and Rose,

The Auckland Women's Health Council appreciates the opportunity to provide early input into your review of the HDC Act and Code of Rights.

As you may be aware, AWHC has had a sustained interest in the HDC and the Code of Rights. We made submissions on the Health and Disability Commissioner Act 1994, then once the legislation was passed and the first Health and Disability Commissioner appointed, we made submissions and participated in consultation meetings that occurred during the development of the 'Code of Rights'. We have also made submissions on previous reviews and other HDC topics when public/stakeholder feedback has been invited.

There are a number of issues that we believe should be considered in your review, as we set out in brief below. There are two major concerns that have arisen in the last few years; one that was discussed in Anthony Hill's review in 2019, and one that has been raised since then:

1. The 'recruitment' of incompetent/unconscious patients unable to provide consent in medical/health research. After a number of communications from our then Co-ordinator, Lynda Williams, to Anthony Hill, the former HDC issued a public consultation document on this issue, on which we made a [submission](#) in 2017. Mr Hill released a report in 2019 in which he recommended changes, and mentioned this in his 2019 HDC Act review report to then Minister of Health, David Clark. As far as we are aware, nothing further has been done about recruiting incompetent/unconscious patients for medical/health research. We believe that it is important that the Act and the Code does more to protect some of our most vulnerable citizens from medical exploitation.
2. In 2020 and 2021 we actively supported Renate Schütte's petition to Parliament requesting the right to appeal decisions made by the Health and Disability Commissioner, making written and oral submissions to the Health Select Committee. The Health Select Committee's recommendation was that this issue was best suited to consideration in the regular review of the HDC Act. We absolutely support the right for both complainants and providers to appeal HDC decisions and refer you to our [written submission in support of Ms Schütte's petition](#) on our website.

Other issues we believe should be considered as part of your review:

3. The delays and extraordinary amount of time it takes for decisions to be made, especially for complainants who ultimately receive a no further action decision. These delays fail to fulfil the promise set out on the HDC website to resolve "complaints in a fair, timely, and effective way."
4. That so few complaints are formally investigated and so many complainants receive no further action decisions, even when there have been serious consequences for a patient, and the fact that there is no

recourse for such complainants to have their complaint reviewed, as there is no appeals process. Between 2001 and 2019, investigated complaints as a proportion of closed cases dropped significantly from 40% in 2001 to under 5% in 2019.

5. The HDC Act needs to be amended to reflect a greater acknowledgement of te ao Māori and te Tiriti, as is the case in much recent legislation and health agency and Government documents, in particular the Pae Ora (Healthy Futures) Act 2022.
6. Research over recent years has shown persistent breaches of patients' informed consent rights, particularly in teaching hospitals. These breaches continue in the face of the 2015 consensus statement on medical students and informed consent, prepared by both the medical schools, CMOs of the district health boards and the Medical Council. These continued breaches of informed consent rights are a huge concern (see [AWHC August 2022 Newsletter, pp10-15](#)). We would like to see some legislative means to enforce informed consent rights, beyond the complaints process, as many health consumers are not aware of their rights and/or are too vulnerable to speak up, particularly when their care occurs in a teaching hospital. That consumers may not be aware of their rights is no justification for continued breaches by medical staff and institutions.
7. Amendment to the Code of Rights to specifically to include gender diversity in rights of dignity and respect; services that take into account the needs, values, and beliefs of gender diverse people; and freedom from discrimination, coercion and harassment, exploitation, etc. Gender diversity was a barely recognised issue when the Code of Rights was written. However, New Zealand and international research has found that discrimination and a lack of respect and dignity in health care is a significant issue for gender diverse people, and that their mental and physical health suffers as a result. Many in the queer community suffer poor physical health, in part because they are reluctant to see doctors when they need to because of past experiences. Many gender diverse New Zealanders report being misgendered, or having their gender identity dismissed, questioned or disrespected, and their health concerns trivialised or misunderstood, by health care professionals.
8. The need for information sharing on harm from medicines/drugs, medical devices and medical procedures between HDC, ACC and Medsafe (or the new Therapeutic Products Regulator when the Therapeutic Products Bill is passed into law). A number of OIAs AWHC have lodged with HDC, ACC and Medsafe over the last few years regarding treatment injury, has shown that these agencies are completely siloed and none of them appear to share information (anonymised or otherwise), so there is no comprehensive understanding of the level of treatment injury.

The above points are just a very brief outline of our concerns, and we look forward to having an opportunity to provide a more comprehensive submission on these at a later date, together with feedback we might be able to make on any other issues that are raised in the process of your review of the Act and the Code of Rights.

Ngā mihi nui



Sue Claridge
Communications Manager
For the Executive Committee
Auckland Women's Health Council

Dear Jane,

I write on behalf of the Cartwright Collective. Thank you for seeking our views on what we consider should be included in consultation in the review of the HDC Act and the Code of Rights.

On behalf of the Cartwright Collective, I submitted in written submissions to the Health Select Committee supporting the Mesh Downunder (Renate Schutte) petition seeking a right of appeal from adverse HDC decisions. The Select Committee recommended that the Commissioner consider this issue as part of her review of the Act and Code. Clearly that is a key issue to be included in the review.

We recommend that the following matters should also be included in consultation and be part of the review:

- The preliminary determination process, including the policy developed by the HDC to assist in making NFA determinations, adoption of which was recommended by the Ombudsman. The policy (see Factors relevant to taking no action on a complaint, on the website) has not been consulted on, and the review presents a good opportunity to fulfil that obligation.
- Consideration of providing an ability for complainants to influence the resolution pathway chosen for their complaint
- The investigation process – issues include repeated requests for the same information from the complainant, the fact that the complainant is not given a full copy of the provisional opinion, only the information gathered section, delays in reaching opinions on complaints.
- Seeking a legislative overruling of the Marks decision, to enable non-consumer complainants to take section 51 proceedings before the HRRT, as recommended by both Commissioners Paterson and Hill.
- Advocacy – consideration of the appropriate place of advocacy in relation to the HDC.'s resolution processes.

We look forward to being advised of the details of the review and the opportunities for consultation.

Ngā mihi nui | Kind regards,

Jo

22 March 2023

Rose Wall
Acting Health and Disability Commissioner
By email: Jane.Carr-Smith@hdc.org.nz

Tēnā koe Rose

Early scoping consultation – HDC Act and Code Review

Thank you for your letter of 3 February 2023 and the invitation to provide my input for the next review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code).

As you have sought my perspective for the purpose of informing your scoping considerations at this stage, I have endeavoured to keep my comments fairly high-level. This is on the understanding that there will be further opportunity to provide input as necessary once the review is underway.

At the outset, I note your observation that it has been over a decade since any substantial changes have been made to the Act or Code. As you say, much has changed in that time, both in terms of New Zealand's health and disability system and with respect to society's values and expectations more broadly. It is of course essential that the Act and Code remain fit for purpose in this evolving context. My impression from your letter is that this next review will be guided by recognition of such changes.

To that end, I anticipate that the review will consider whether the Act and Code, in their current form, reflect contemporary developments in key areas affecting people's rights, including in particular:

- gender and gender-neutral language;
- social models of disability, including understandings of competency, decision-making capacity, and supported decision-making;
- the right to reasonable accommodation; and
- the place of Tikanga and cultural considerations.

There are also a number of matters which have come to my attention in my role as Chief Ombudsman which I wish to highlight for your consideration which I have addressed below.

Mandatory notification requirements

As you will be aware, I appeared before the Health Committee in May last year in relation to a petition that requested that the House amend the Health and Disability Commissioner Act to give complainants, and those who are the subject of complaints, the right to appeal decisions made by the Health and Disability Commissioner (the HDC). In response to the petition, the Committee encouraged the HDC to *'address the complexities of creating a right of appeal'*, amongst other matters, as part of the next review of the Act and Code. At the time, I confined my comments to the Committee to clarifying the reach of the Ombudsman's jurisdiction with respect to HDC. I do not intend to depart from that approach here, but I understand that the question of a right of appeal is a matter which the HDC may be contemplating.

You will recall that my submission addressed the findings of my investigation into the HDC's assessment of three complaints.¹ These complaints were essentially concerned with the HDC's exercise of its discretion to take no further action on a complaint. In two of those cases, I formed an opinion that the HDC's decision to conclude its preliminary assessment by taking no further action under section 38(1) of the Act was unreasonable. I found that the HDC's preliminary assessment processes in those cases went beyond what the Act envisaged a 'preliminary' assessment should involve, in practice resembling a quasi-investigation, and that this had an undue negative impact on those involved.

While my conclusions in that investigation arose primarily out of issues relating to the HDC's policy and practice, this review may be an opportunity to consider whether the provisions of the Act may effectively encourage the approach taken in those cases.

For instance, the Act's requirement to notify the Medical Council on the commencement of an investigation in certain cases may have contributed inadvertently towards the HDC's preference to undertake prolonged 'informal inquiries' rather than a notified investigation as a means to avoid what the HDC saw as disproportionately adverse effects on a medical practitioner.

In these circumstances, it may be worth contemplating whether providing the HDC with statutory discretion to decide whether to make a notification to the Medical Council when commencing an investigation might remove any potential perverse incentive not to investigate an alleged breach of the Code. The Act could include guidance on what factors must be considered in respect of the threshold for notification, including imminent risk to patients or serious concerns about medical practice or competency.

Decision-making capacity and Right 7 of the Code

There is an issue that I wish to raise from a disability rights perspective with regard to the current Code and decision-making capacity. My comments in this respect reflect my role under the United Nations Convention on the Rights of Persons with Disabilities (the Disability Convention) as part of the Independent Monitoring Mechanism (IMM), constituted under Article 33(2), to protect and monitor disability rights in New Zealand.

¹ See: <https://www.ombudsman.parliament.nz/resources/investigation-health-and-disability-commissioners-assessment-three-complaints>

Supported decision-making is a key principle of the Disability Convention. This is highlighted in Article 12 of the Convention which recognises disabled people's right to exercise legal capacity on an equal basis with others. All measures must be taken to respect a disabled person's rights, will and preferences; and to prevent abuses, conflicts of interest, or undue influence over the exercise of legal capacity. Any restrictions on legal capacity must be of the shortest possible duration, and be subject to independent and impartial review and oversight.

Right 7 of the Code provides for the right of consumers to 'make an informed choice and give informed consent'. This right is subject to an exception, however, permitting health or disability providers to provide services without the consent of the recipient where they have reasonable grounds to believe that the person is not competent to make their own decisions. The exception to Right 7 does not appear to reflect a contemporary understanding of the right to access support to make decisions, or the shift to establishing a person's will and preferences rather than acting in a person's best interests.

Where this exception can be used is also not necessarily clear, and provides services providers with broad powers to give primacy to a substitute decision-making approach, rather than a supported decision-making approach. This may cause issues in, for example, mental health, intellectual disability and aged care areas.

The Law Commission's current review of how the law should respond where an adult's decision-making is affected reflects a wider conversation about the need for reform in this area. In my role as part of the IMM, I have stated that genuine fulfilment of Article 12 of the Disability Convention requires a transformational shift in domestic legislation and practice; moving from substitute decision-making to supported decision-making; and fully respecting disabled people's autonomy, and their right to appropriate decision-making support.

The United Nations Committee on the Rights of Persons with Disabilities (the Committee), in its Concluding Observations which were promulgated in September 2022 after New Zealand's review in Geneva, expressed concern about the lack of progress made to abolish the guardianship system and substitute decision-making regime in New Zealand, and the absence of a timeframe to replace this regime with supported decision-making systems. The Committee formally recommended that New Zealand:²

... repeal any laws and policies and end practices or customs that have the purpose or effect of denying or diminishing the recognition of any [disabled person] before the law, and implement a nationally consistent supported decision-making framework that respects the autonomy, will and preferences of [disabled people].

The HDC may wish to examine whether the Code is sufficiently clear about when these exceptions can be made so that primacy is given to the exploration of all kinds of supported decision-making practices. At a minimum, I suggest that the review examine whether there are adequate safeguards in place to ensure that any decision to engage the exception to Right 7 is properly exercised and that any risk of arbitrary detention or unconsented treatment is minimised.

2

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fC0%2f2-3&Lang=en

Complaints and feedback

It is of critical importance that consumers can raise concerns about both their experiences while accessing health services (i.e. to complain about instances where their rights may have been infringed), as well as decisions made about their medical treatment. This is especially important for consumers who are treated compulsorily under the Mental Health (Compulsory Assessment and Treatment) Act 1992, or under cl 7(4) of the Code.

It is similarly important that complaints can be dealt with to the satisfaction of a consumer at the lowest possible level.

Having said this, I have observed instances where potentially significant concerns about treatment have been triaged as 'feedback' at a service level, due to the manner in which the concerns were raised, as opposed to being triaged as a 'complaint'. In such cases, there is a risk that concerns raised may not be dealt with in the most appropriate manner. The HDC may wish to consider whether there are sufficient mechanisms in place to ensure that complaints are dealt with appropriately at a service level, no matter the manner in which the complaint is raised.

Finally, I understand that there is a common misunderstanding amongst the disability community about the HDC and what it can do. To some, the designation 'Health and Disability Commissioner' implies that a complaint can be made to the HDC about anything broadly health or disability related. While this may not come within the ambit of the present review, I thought it useful nonetheless to bring to your attention. There might be some value in the HDC examining whether the current name best communicates the scope of the HDC's functions. For instance, 'Health and Disability Services Commissioner' might arguably reflect more accurately the HDC's remit and help to avoid any misapprehensions. Of course, there may be other more practical ways to promote greater public understanding of the scope of the HDC's role.

Thank you for the opportunity to provide input at this early stage in your review process. I hope my comments are helpful and I look forward to being consulted further once the review is underway.

Nāku noa, nā



Peter Boshier
Chief Ombudsman

Who: Children's Commissioner:
Dr Kathleen Logan, Principal Policy Advisor, Advocacy
Kelsey Brown, Chief Policy Officer

Date: 1 March 2023

Re: HDC Act & Code review + CC's Code of Ethics

- Children's Commissioner currently working on an internal Code of Ethics following the recent legislative change.
- Advised that it has a lot of internal expertise on how to engage well with children and young people in a thoughtful and ethical fashion.
- Noted that HDC's Code did a good job at focusing on individual rights but questioned whether there was work to do when considering Te Tiriti and a focus on collective rights.
- Noted that the Oranga Tamariki Act contained s 7AA which imposed duties on the chief executive with respect to upholding OT's treaty obligations. This could be a good example for HDC to consider. Also consider the recent amendments to the Education Act.
- Important to never see children's rights in isolation – tamariki need to be seen in the context of their whanau, hapū and iwi.
- Consider the United Nations Convention on the Rights of the Child – which has a focus on children needing protection. Consider legislative reform to include express reference to this convention.
- Other important documents to consider include the Waitangi Tribunal report on the Uplift of a baby and the Royal Commission work re abuse in state care. Articles from Justice Joe Williams are also of importance particularly concerning the incorporation of tikanga.
- Consider Paula King's work – Oranga Mokopuna regarding ethical co-designing and the intersection between the individual and collective.
- Consider Right 7 in the context of the right of a child to participate in decisions made about them. Also consider Right 7 in light of Gillick competency i.e. that children may be able to consent if they have the competency to do so – it need not be bound by an age limitation if competency is present.
- All agreed that it was important to keep the conversation going.

Hi Catherine,

I gave this a little thought last night, and I'm not sure if there's a more official place we're meant to be sending submissions but I'm just emailing you if that's ok.

First off, I've always thought that the max fine for offences (s73) is a pretty paltry sum - \$3000. Not really an effective deterrent or penalty in my view for people that commit the offences listed. I looked at the Commerce Act, and it's max fine for an individual is \$100,000. Even though I am not even sure how often if ever s73 is invoked (but that's another story altogether), I would like to see the max financial penalty increased to at least \$10,000. While the max fine of \$3000 may be effective in dealing with the average, shall we say less well off providers, some providers will be very well off, and having a higher ceiling would enable a more appropriate fine in their case should offences be committed. Also, I tried to see if this number has ever been changed - I could not find the original Act, but in the 2007 version on legislation.govt, \$3000 is also the number. I think there's a good chance this number has never been changed, despite usual things like inflation causing that number to become less and less meaningful over the 30 years or so since the Act came to being. Perhaps this has never been looked at seriously because s73 is so infrequently, possibly never used, but I am strongly for the max penalty being increased to at least \$10k.

As for the Code. It's always struck me as a bit odd that there isn't something in the Code that specifically states the right of consumers/duty of providers to have care documented. I would say that in most cases, investigations are most about clinical treatment and the documentation thereof. 4(1) cover the care, and when there are gaping holes in clinical record keeping, we breach under 4(2). However 4(2) only talks about professional standards in various areas in a general way. I would suggest that documentation failures are by far and away the biggest reason why 4(2) is used, and so given this and the huge importance of clinical record keeping in care and HDC's work, I find it odd that it isn't specifically mentioned/emphasised! So I'd suggest some consideration be given to adding some detail about record keeping to the Code, given its significant prominence in HDC's cases!

Also, I acknowledge that some of the next stuff may or may not be relevant to the Act so much as it is to operational matters in how we apply the Act, but I'll let you be the judge of that, and for what it's worth....

I'm not sure that at HDC we regularly/consistently enough enforce the need for complainants to seek remedy by complaining to the provider initially. My feeling is that it is probably often the case that complainants haven't formally gone through that process with their providers, prior to HDC undertaking action on receipt of a complaint. If that is true, I think that causes problems for HDC. At the Ombudsman and IFSO, this is enforced and complainants are told no action will be taken as they haven't gone to the provider/agency first for resolution, and that if they do that and no resolution is achieved and they want investigation, they must provide a copy of the written response they receive along with the reasons they wish the provider/agency to be investigated. Section 38(2)(e) already provides for taking this approach, but I have a feeling that HDC might be a bit lenient or lax in applying it effectively? I think HDC should be utilising s38(2)(e) all the time to ensure that complainants have first sought a response from their provider first to try and resolve the complaint (where reasonable and practicable). This approach would mean that when the complaint comes in, there is more information to assess from the get go, as we can require the complainant to attach a written response from the provider, and the reasons they remain dissatisfied with it. And because a large proportion of consumer-provider complaints can result in resolution (some with advocacy assistance which they should be encouraged to use), a lot of the time this would help to reduce the number of complaints that HDC is having to assess and investigate. I think s38(2)(e) already enables us to do this (and maybe we are, but I don't think so!), but either it just needs to be applied better, or something specific could be added to the Act.

Lastly, with the same caveat as above re probably not being an Act issue, I have seen the Commerce Commission website which outlines firmly that it just won't/can't look into all complaints. With the pressure that hdc is under and to try to find a way through that to improve our process timeframes, i think serious thought should be giving to adopting this kind of approach, with similar wording/reasoning that that ComCom uses. <https://comcom.govt.nz/make-a-complaint/complaint-form>. For example, when I got in

touch with ComCom about a small matter one time, I just received a brief email back pretty much just saying 'thanks for raising the concern, but after looking at this we've decided we won't be taking any action', and reiterated some of the points on the above link. I was perfectly fine with that, and I'm sure that there might be space for HDC to similarly close some cases quickly and easily that way, instead of by letter.

Happy to discuss anything of the above, and thanks for reading (especially if not all is particularly relevant to your work right now and is more for other process redesign stuff!)

Cheers

Conor Clerkin ([he/him](#))

Senior Investigator | Kaitūhura matua

Office of the Health and Disability Commissioner | Te Toihau Hauora, Hauātanga

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

Who: Consumer Advocacy Alliance
Sue Claridge (who is also a committee member with Auckland Woman's Health Council)
Denise Astill (who is also the Executive Officer of Foetal Anti-Convulsant Syndrome NZ)
Charlotte Korte (anti surgical mesh advocate)

Date: 13 March 2023

Re: HDC Act & Code review

- Like that HDC is allowing for a long consultation period – this gives people an appropriate amount of time to provide their responses.
- It is important how HDC engages with consumers – some consumers will not engage with a large document. CAA would like to have a sit down meeting with HDC and other related consumer advocacy groups to get into “the nuts and bolts of things” and help these groups understand what the key issues are and for HDC to understand the consumer perspective on these issues.
- Would like HDC to be accountable to the Code of Expectations for health entities’ with consumers and whanau which was created under the s 53 of the Pae Ora (Healthy Futures) Act 2022. Would also like to know how this Code interacts with HDC’s Code and work.
- Would like the HDC code to be co-designed with consumers who are experts by experience.
- Concerned about the ongoing harm which consumers face and would like to find tangible solutions to prevent future harm. To that end, they discussed a ‘Red Flag’ alert which would alert HDC to issues with a particular surgeon or a particular area of practice.
- There needs to be a system, such as the ‘Red Flag’ alert, to help HDC collect data and follow up on providers and areas causing ongoing harm. This would also allow HDC to do a deep dive analysis on ongoing harm.
- Would like to know how HDC can legislate to track ongoing kind of harm. Options could include naming individual providers (although there was some reluctance around this) and publishing anonymized data and trends with the focus being on how to prevent future harm. HDC should have a function like this.
- Asked whether there was a Director of Advocacy as it is unclear if one exists, and if so they are not very visible. This role needs to have a focus on advocacy for consumers, and it needs to highlight ongoing harm.
- HDC needs to have powers to enforce change, it is not enough to provide guidance/recommendations.
- Concerned about informed consent breaches in teaching hospitals. There are still issues with students obtaining consent despite the 2015 consensus statement between the two medical schools. It doesn’t matter what comments the Commissioner makes on the matter because she has no enforcement powers. HDC needs the ability to enforce recommendations to ensure provider accountability.
- HDC needs to be better resourced to help with active monitoring of the system to ensure compliance with recommendations and informed consent.
- HDC needs to publish its guidelines for investigation – the current language on the website is not very clear and not in laypersons language.
- HDC should publish its interviews with providers in the interests of transparency – the more transparency the better, as this helps build trust with consumers.

- Real issue with consumers being fearful about lodging a complaint with HDC as it could result in ACC revoking its compensation.
- HDC takes too long to resolve complaints min of 3 years, given this delay consumers wonder if it is worth making a complaint.
- It was also noted that providers hold the balance of power and consumers are vulnerable to that. Accordingly, it should be written into the Code that there is an equal balance between consumers and providers.
- Consumers should also receive the same level of information as providers when being asked to respond to complaints.
- There should be clear criteria for the experts HDC uses, including that they have an appropriate level of experience/expertise. At the moment there are a whole bunch of surgeons providing advice who do not have the right credentials.

Information released under the Official Information Act 1982
and/or the Privacy Act 2020



Morag McDowell
Rose Wall
Office of the Health and Disability Commissioner
PO Box 11934,
Wellington 6142

13 March 2023

Regarding the early input into the HDC Act and Code of Rights Review

Tēnā kōrua Morag and Rose,

The Consumer Advocacy Alliance appreciates the opportunity to provide early input into your review of the HDC Act and Code of Rights.

Thank you so much for the opportunity to meet with Rose, Catherine and Michael on the 13th of March. We felt it was a productive meeting and helped to clarify for us what we include and how we present our views to you in this letter.

We have structured our submission starting with our recommended amendments to the HDC Act 1994 (Comments 1-13), including two comments on the role and functions of the Commissioner (14 and 15), followed by our concerns with the Code of Rights (comments 16-18). Comments 19 to 30 are important submissions on a range of issues within the HDC and the complaints process that are not issues that can or should be addressed through changes in the legislation. The order of our comments should not be taken to indicate priority or importance, and some issues we believe to be of utmost importance appear later in our submission (for example, our comments on the notification, reporting and analysis of harm and treatment injury; 19-21).

Amendments to the HDC Act

- 1. Right to appeal HDC decisions.** We believe that the Act should be amended to allow both complainants and providers to appeal HDC decisions. Both Charlotte Korte and Sue Claridge made submissions in support of Renate Schütte's petition to Parliament seeking the right to appeal decisions made by the Health and Disability Commissioner, and refer you to those submissions and others in support of Ms Schütte's petition.
- 2. Signatory to the Code of Expectations.** We believe that the HDC Act must be amended to require the HDC to be a signatory to, and act in accordance with, the Code of Expectations for health entities' engagement with consumers and whānau, as required of other health entities under sections 59 and 60 of the Pae Ora (Healthy Futures) Act 2022, and report annually on how it has given effect to the code.
- 3. Tiriti Te Tiriti o Waitangi.** The Act needs to be amended to reflect a greater acknowledgement of te ao Māori and Te Tiriti o Waitangi, as is the case in much recent legislation and health agency and Government documents.
- 4. Independent review of investigations.** The Commissioner has said that the rise in complaints to HDC is unprecedented and complaints are increasing in complexity. The final decision on what 'acceptable' practice is, relies heavily on ensuring the Commissioner 'gets it right' after receiving advice from HDC

'expert' advisors and assessors, both internal and external. In future, to mitigate any inconsistencies between decisions made by different Commissioners, we feel that independent review of investigations is warranted. Independent panels could be appointed to provide independent reviews of complaints and decisions. The structure and make-up of panels could be modelled on the HDECs in that: the panel would comprise medical experts, consumer representatives and medical ethicists; the panel would meet regularly (e.g. monthly) to review and discuss complaints and decisions, having been provided with all the (anonymised) paperwork pertaining to each complaint. An independent review panel should reduce the number of decisions appealed (see point 1).

5. **The creation of mandatory enforcement powers.** Where there are persistent breaches or infringements of the Code of Rights, particularly by institutions, the Commissioner needs the ability to ensure compliance. For example, ongoing breaches of informed consent rights in teaching hospitals and in the face of the 2015 Consensus Statement on medical students and informed consent rights. There should be provision for the Commissioner to have the power to mandate compliance with the Code of Rights.
6. **Negative implications of early, speedy efficient resolution of complaints.** The focus of the HDC and wording in the Act and Code needs to change from 'speedy efficient, early resolution', to 'a prompt and clear response, and comprehensive analysis'. Comprehensive analysis should not sacrifice timely resolution of a complaint. Investigations have taken as long as three years, during which time the complainant and their family/whānau have experienced greater distress waiting for resolution. Investigations, even for complex complaints, must be undertaken in less time.
7. **Delays in making preliminary assessments.** Delays in a preliminary assessment of a complaint, as well as being distressing and frustrating for the complainant, can also delay awareness of the HDC of potentially serious issues with providers, or unsafe therapeutic products (medicines, devices) or procedures. There should be a clear threshold detailed in the Act which prioritises serious/severe harm events so, if needed, the Commissioner can intervene earlier, and action can be taken to ensure further harm does not eventuate.
8. **Independence of the Advocacy Service.** We believe that if the Advocacy Service is to be truly independent, it should compile an independent, separate annual report to be submitted to Parliament, or to the Minister of Health. We fail to see how the Advocacy Service can be a truly independent body if it is included in the HDC's annual report. The Advocacy Service annual report, like the current HDC Annual report needs to be made publicly available.
9. **Patient choice in the resolution pathway.** Complainants have very little choice in the resolution pathway chosen for their complaint. The Advocacy Service works well for minor complaints, but not for complex ones or where serious harm is involved. We agree with the Commissioner, who has spoken about the need to include a Restorative Justice approach to complaints resolution; however, this should be as a separate optional service independent of the HDC.
10. **Visibility of follow up.** We recommend that the legislation is amended to ensure greater transparency from HDC regarding who is responsible/accountable for ensuring that improvements/ changes have occurred after recommendations have been made by the HDC, as part of the complaints resolution process. This is especially important for breach findings. The provider does have a responsibility to ensure they have complied with HDC recommendations. However, if recommendations are made, it must be mandatory for the HDC to ensure compliance, there should be audits of compliance with recommendations and results of audits should be published. These audits should be unscheduled so there is no possibility that providers can suddenly implement recommendations or alter notes or other documents. When there has been a breach of informed consent or informed choice a consumer should be included in this audit.
11. **Greater transparency regarding the communication between the HDC and other health related entities.** The HDC and other entities involved with collecting information on patient safety and treatment injury should be formally required to share information, including notifications/ complaints of harm and PROMs, including but not limited to ACC, HQSC, MoH/Medsafe/Pharmac (or, in time, the new Therapeutic Products Regulator). While we are aware that there will be privacy issues regarding both the complainant and providers, it must be possible to share data so that there is a clear

understanding across all Government health entities and agencies regarding the level of harm caused. To ensure proper surveillance and monitoring of the safety of therapeutic products, procedures and providers of health care services, amendments must be made within the Act, so such obligations are mandatory. It is vital that data and other information collected is not just collated into anonymised themes, but also on an individual practitioner level so repeat offenders can be identified, monitored, and if needed, contacted by the relevant agency to prevent further harm.

12. **Transparency of complaints process/inequitable access to relevant information.** There is a lack of transparency over how decisions are made, and what evidence is used to support a decision (process). Consumers need access to the same information that is shared with providers. The investigation process does not currently comply with the Code of Rights, because of inequity of access to information. The complainant is not given a full copy of the provisional opinion, nor all relevant documentation considered as part of their complaint. Providers should not have access to more comprehensive information than that which the complaint has access to. Not only is this unethical, but consumers are also unable to identify if all relevant information they deem is important has been included and considered as part of the inquiry/investigation.
13. **Ethics Committees.** There should be a clear overarching legal framework for research ethics committees; their role and function to be clearly set out in primary legislation and their accountabilities to support the National Standard for Ethics Committees and to maintain their independence. As a consumer group, we consider it is an essential role of ethics committees to protect consumers from harm and to benefit them and population groups previously disadvantaged by being excluded or harmed from research in the wide range of health and disability research, to be set out in legislation or through the HDC Code. This is a gap in our legal framework which has never been filled following the Cartwright Inquiry in 1988.

Alison Douglass would be a suitable person to work with HDC to put together a suitable policy, legal and ethical framework. Alison is a Deputy Chair of the Health Practitioners Disciplinary Tribunal; former Chair of the Wellington Ethics Committee; former Chair of ACART for the Minister of Health; established and was co-Chair of the ACC research ethics committee for 10 years ([Alison Douglass: ADLS](#)). Consumer Advocacy Alliance would be happy to put you in touch with her if needed.

Functions and Role of The Commissioner

14. **The role of Commissioner in publicly promoting and protecting consumer rights.** The Commissioner has a statutory obligation to publicly promote and protect consumer rights, and we believe the Commissioner needs to be more visible in the public domain, especially when serious issues become apparent and ongoing harm is occurring. It is important for the public to hear the voice of the Commissioner, to see that the Commissioner is visibly stepping up in public and making comment on serious issues, particularly systemic issues/breaches, repeat offenders (particularly institutions such as hospitals) and on devices, medicines and procedures that repeatedly cause harm. This also gives validation to those who are harmed, and misinformation can be reduced.
15. **Accountability/performance reviews of Commissioner.** Often a given Commissioner may have a long tenure, and the public have a right to be assured of competence in the decisions made. The public need more information on who the Commissioner is accountable too, how the position and performance is reviewed, and the KPIs for the Commissioner and how these are measured.

Concerns Regarding the Code of Rights

16. **Inclusivity and gender diversity.** Where appropriate, the Rights set out in the code need to include gender diversity in rights of dignity and respect; services that consider the needs, values, and beliefs of gender diverse people, and freedom from discrimination, coercion and harassment, exploitation.
17. **The right to fully informed consent.**
 - (a) There is ongoing inadequate provision of information to consumers about surgical mesh risks, and risks of medicines in pregnancy. These sorts of situations emphasise the need for all health agencies and individual health practitioners to be accountable for ensuring that all information shared or

published is accurate. Before any information is endorsed there must be stricter scrutiny of who is disseminating this information, whether their level of expertise enables them to provide this information, and if this information/training corresponds to best practice and international guidelines. Information must not be misleading as it would be interpreted by a consumer. Specifically, it must not mislead or minimise the amount and severity of harm that has happened or may occur. To obtain informed consent a patient must be provided with all treatment options. The BRAN^{1, 2} method should be endorsed by HDC:

Benefits – all the benefits of proceeding with the health care professional’s suggestion

Risks – all the risks explained to the consumer

Alternatives – advise the consumer if there are any alternatives available

Nothing – explain the likely outcomes to the consumer if they choose to do nothing

- (b) Currently there are significant issues with cognitive bias in current consenting practices, and not just with surgical mesh. The nature of cognitive bias is such that health professionals are unlikely to present comprehensive information about alternatives to the treatments they offer. There is also no requirement for practitioners to disclose if they are unable to provide specific treatment options themselves. We support amendments to make this a legal requirement.

18. **The right to be fully informed about breach findings.**

- (a) For the HDC to have the power to recommend or direct providers in certain decisions with breach findings, to advise future patients that they have previously been found to have breached the Code of Rights.
- (b) Consumers should be able to request information about the competency and expertise of health care providers, including details about any previous complaints before commencing treatment.

Notification, Reporting and Analysis of Harm and Treatment Injury

19. **The importance of a Red Flag alert.** The current harm reporting and identification system is not working, or in some cases not available. We suggest a 'Red Flag alert' to be developed and implemented within the HDC internal system, so HDC can use this early indicator to identify, track, and monitor repeated harm from individuals and more widespread harm from particular health disciplines, devices or medicines.
20. **HDC definition of serious harm.** The only recourse for patients to obtain 'justice' is the HDC complaints process as they do not have the ability to sue in New Zealand. Judicial hearings are traumatic and too expensive for the average consumer, and Ombudsman investigations are of limited benefit. HDC send few complaints to the Director of Proceedings for disciplinary action, and predominantly practitioners are likely to face prosecution in only cases of sexual misconduct, misuse of drugs or fraud. Therefore, we feel that HDC should closely consider what constitutes serious harm, and which type of complaints meet the threshold for disciplinary proceedings.
21. **Annual analysis of harm data.** A formal function of the HDC is to protect patients from harm. We believe that regular 'deep dives' into complaint data, and the release of subsequent formal, publicly available, reports are necessary. This includes looking at disparities in data between relevant health entities, and collating and analysing patterns of complaints, breaches of rights and physical harm. It is essential that the HDC be able to identify individual repeat offenders and vocational sectors of health care that are over-represented. If this is currently not possible, new systems and policy needs to be created to ensure repeat harm on an individual basis can be monitored.

1 BRAN Analysis at <https://qilothian.scot.nhs.uk/pc-resource-bran-analysis>

2 Choosing Wisely: Shared decision making resources at https://choosingwisely.co.uk/wp-content/uploads/2020/11/CWUK_patient_leaflet_100120-1.pdf

Other Issues, Concerns and Recommended Changes

22. **Published guidelines on threshold of HDC investigations.** More transparency is needed regarding what the threshold is for deciding whether a complaint goes to investigation. HDC should rewrite the existing guidelines so they contain more comprehensive, clear information that all consumers will understand. We also strongly encourage HDC to publish 'No Further Action' decisions, so the public have a greater of an understanding of the reasons why cases are not being fully investigated.
23. **Internal HDC reviews to be published.** We strongly recommend that HDC formalises and publishes internal HDC reviews. Such internal reviews need to be overseen by an independent body that can provide a 'fresh look' at the complaint from someone who has not seen or been involved previously in this process.
24. **Criteria for standards and expertise of HDC advisors/complaint assessors.** Outcomes of complaints are largely dependent on 'expert' opinions from advisors engaged by HDC. In our experience, and from the consumers we are hearing from, there are concerns about whether HDC internal and external advisors have the requisite knowledge to be able to provide a comprehensive expert opinion on some complaints. We suggest the HDC look at how these advisors are chosen and examine the current criteria for advisor knowledge and expertise prior to engagement. In the case of surgical mesh, many specialists (some of whom are currently engaged by HDC and deemed 'experts' in such procedures) may not be competent enough to offer expert opinion, especially if they have not met credentialing standards. This issue does not just pertain to surgical mesh but may be found in all vocational disciplines.

In the example of Foetal Anti-convulsant Syndrome (FACS) and individual syndromes, there are currently 'experts' who are relying on research that is more than ten years old, instead of the much more current information available. As well as criteria for standards, we also recommend that, in specialised cases such as FACS and surgical mesh, as well as assessors/advisors (that meet the criteria), expert consumers are involved in assessing the complaint. Additionally, it would be wise to ask 'experts by experience' which medical/clinical experts they would recommend to be advisors on specific issues. It is often the 'expert by experience' consumer who has significant knowledge of the medical condition at the heart of complaints, and know who are the most experienced and skilled or knowledgeable health practitioners or clinicians in that discipline.

25. **Imbalance of power between complainants and providers.** There is an imbalance in the weighting given to consumers/complainants and the information they provide compared to that submitted by the provider; essentially more trust or belief is placed in what healthcare professionals say compared with what complainants say. A healthcare professional who has caused harm might have seen a consumer years ago and have seen hundreds of patients since, yet they are believed ahead of the consumers. This imbalance of power has a flow-on effect, causing more harm, and leading to consumers having even less faith in a system they already mistrust. The Code of Consumer Expectations places consumers on a level footing with their health practitioner; consumers are experts by experience.
26. **Consumer fear of lodging a complaint with the HDC.** Some consumers are afraid of lodging a complaint with the HDC if they are receiving supports through ACC, as they believe they will have their ACC revoked. This fear is exacerbated if this has occurred in the past. We know of a situation in which a family/whānau had their child's ACC entitlement revoked as a result of going to HDC, and the whānau then had to fight through the court to get ACC back. The family won, but at what cost? There needs to be a guarantee that, irrespective of the HDC decision, there will be no revocation of their ACC entitlements. For example, an HDC decision may find that a treatment injury complaint does not meet the threshold of a breach of rights, but this does not mean that a treatment injury has not occurred, and meets the criteria for ACC entitlement.
27. **Broaden the HDC definition of disability.** The current definition of disability and criteria for who fits this category must be changed to ensure it is inclusive of all people living with a disability. The HDC must adopt the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); New Zealand is a signatory to the UNCRPD and the HDC must comply with this convention.

28. **Post decision feedback and communication with the complainant.** It would be advantageous, after receiving the provisional decision letter from HDC, that a video call between the complainant and HDC is undertaken. This would make the complainant feel more human, valued, and respected and would be particularly beneficial when it is a complex complaint that has taken some time to properly investigate.
29. **Customer satisfaction:** To ensure the HDC is fulfilling its obligations to protect and promote consumer rights, and that the complaints process meets the needs of consumers, engagement with consumers in a variety of ways on a more regular basis is needed. We don't believe that only surveys and "exit interview" style assessments of consumer satisfaction are adequate. While they may provide some limited understanding of the consumer experience, we recommend a more focussed "listening circle" style of forum to review consumer experience of the complaints process, perhaps facilitated by a neutral party to ensure that consumers feel able to speak freely about their experience.
30. **That the HDC is adequately resourced** (financially and in terms of staffing and expertise) to ensure that the volume of complaints can be dealt with in a timely manner for the benefit of both complainants and providers, to enable other critical work (such as research into patterns of complaints) can be undertaken, and to enable the monitoring/auditing of past breaches.

We believe that the Office of the Health and Disability Commissioner, the Code of Rights and the complaints process are a vital and integral part of our health system. They have a critical role in not only upholding consumer rights in the provision of health and disability services, but ensuring improved patient safety, and contributing to positive changes in culture within our health system, and health institutions and provider organisations.

We hope that any apparent criticisms we may have of the HDC, the Act and the Code of Rights, are taken as our genuine desire to work with the HDC as consumer advocates; to participate in ensuring that the complaints system, and all its parts, offer New Zealanders the very best opportunities to address breaches of their rights and help create a better, safer health system.

Ngā mihi nui

Consumer Advocacy Alliance

Co-founders:

- Charlotte Korte | Patient Advocate
- Denise Astill | Foetal Anti-Convulsant Syndrome New Zealand
- Kat Gibbons | Pelvic Floor Dysfunction Support NZ
- Sue Claridge | Auckland Women's Health Council

13 March 2023

Rose Wall, Acting Health and Disability Commissioner
Office of the Health and Disability Commissioner
PO Box 11934
Wellington 6142

By email: review@hdc.org.nz

Tēnā koe Rose,

Thank you for the opportunity to provide early input into the scoping considerations for your review of the Health and Disability Commissioner Act (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code). I have detailed below several areas that I believe could be considered under the scope of your review. The identified areas are typically the areas we engage with most regularly.

One area for review that you might consider in both the Code and Act is the inclusion of Te Tiriti o Waitangi considerations and principles, as Te Tiriti is currently not explicitly considered in either. For instance, you could consider how this legislation is aligned with the Pae Ora Act 2022 and shifts occurring in the wider Health Sector. Similarly, the Act and Code could explicitly identify consumers from an equity and Te Tiriti o Waitangi lens and ensure advocates have a sound understanding of Te Ao Māori.

Areas of the Act that could be considered in your review.

I note that, unlike the legislation for the Chief Ombudsman or the Office of the Privacy Commissioner, there is no provision in the Act which explicitly protects information obtained by the Health and Disability Commissioner during an investigation from release to those who request it. I understand this is a matter that has been raised before, and we would welcome the consideration of an equivalent provision in the Act.

Areas of the Code that could be considered in your review.

This relates to the 'Right to Complain section' in the Code. I note that the Corrections Act 2004 and the Corrections Regulations 2005 include provisions for managing complaints from people in prison or on community sentences or orders. For the most part, these provisions align well with the requirements in the Code. However, the Corrections Act 2004 also includes objectives which allow for complaints to be dealt with informally or elevated to a formal stage if the complainant chooses. The Ombudsman's guide on effective complaint handling appears to anticipate that agencies resolve complaints informally where possible (refer to page 9). You could consider amending the Code to allow for complaints to be resolved informally where possible if this would be the most appropriate avenue while still allowing complaints to be treated with the gravity required.

The Code also expects providers to assess whether a complaint is justified or unjustified. The Department of Corrections (Corrections) has moved away from a binary type of complaint categorisation, as Corrections consider it needs to recognise the nuance required for complaint responses. The Ombudsman's guide on effective complaint handling for agencies also does not include this binary complaint categorisation and instead refers to updating the complainant on the outcome. The HDC could consider amending the Code to remove the justified/unjustified categorisation.

This feedback related to timeframes for responding within the Code (Right 10), which currently include the requirement to acknowledge the complainant within 5 working days of receipt (Right 10(6)(a)), provide an update within 10 working days of acknowledgement (Right 10(7)) and give further updates at monthly intervals (Right 10(4)). I note that these timeframes can be confusing, particularly the expectation that the provider gives an update 10 working days after written acknowledgement of a complaint. This means that the timing of the first update will change depending on which of the 5 working days after receipt of the complaint was acknowledged. You could consider amending the Code, so the timeframes are all linked to the date of receipt. If changes to the timeframe are considered, we would appreciate further discussion about them and for your team to consider alignment with the timeframes in the Corrections Act and Regulations.

The Code also requires that within 10 working days of a complaint, the provider must (if they decide more time is needed to investigate the complaint, and that time is more than 20 working days) inform the consumer of that determination and the reasons for it.

The timeframe of 'more than 20 working days' appears to be arbitrary, as (Right 10(7)(b)(i)) already requires the provider to determine how much additional time is needed in all cases. It might be simpler if this was re-framed, so the provider must inform the consumer of the timeframe determination and the reasons in all cases (rather than just the subset of cases where the determined time is longer than 20 working days).

It may also be helpful to look at re-framing the language in this section to clarify that the other timeframe is an estimate. Investigating a complaint can often uncover other lines of inquiry, which may not have been anticipated when providing the original timeframe estimate. This suggests that responders to complaints cannot reasonably be expected to determine the exact amount of time required to respond to every complaint.

Thank you again for engaging me as a key stakeholder in this work, please do hesitate to reach out to discuss any of the feedback, and I look forward to engaging on this work further as the review progresses.

Ngā mihi nui



Dr Juanita Ryan
Deputy Chief Executive Health



Health and Disability Commissioner's review of the Health and Disability Commissioner Act and the Code of Health and Disability Services Consumer's Rights.

Our views on the review on the Health and Disability Commissioner Act and the Code of Health and Disability Services Consumer's Rights (the 'Code') (we will be focusing on the Code) are detailed below. Our views are informed by previous projects that have focused on access to justice and supported decision-making as well as decades of providing support and advice to disabled people and their family, whānau and disability support professionals who are engaged in health and disability systems in Aotearoa New Zealand.

The review of the Health and Disability Code is timely. The Code must have a louder voice for disabled people than it currently does. The lived experiences of disabled people should be considered throughout this review, with the disability community being consulted on all elements of the review. Below we will consider aspects of the Code and changes that could be made to improve it in order to enhance the protection and promotion of consumer rights, particularly those of disabled people.

1. Consumers have rights and providers have duties:

- It notes under this section that every provider must take action to – (a) inform consumers of their rights; and (b) enable consumers to exercise their rights.
- This Right should consider the unique communication needs of disabled people and therefore include: "inform consumers of their rights in a format they understand including where practicable through use of a competent interpreter, augmentative and alternative communication technology and accessible formats".

2. Rights of consumers and duties of providers:

- Right 1: Right to be treated with respect:
 - Under this Right, every consumer has the right to be treated with respect, have a right to have his or her privacy respected and to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values and beliefs of Māori.

- Right 2: Right to freedom from discrimination, coercion, harassment, and exploitation:
 - This right should include “ableism” and “disablism” in the list of experiences consumers have a right to be free from. This would explicitly recognise the experiences of disabled people and enhance protection from ableist and disablist assumptions, actions and attitudes, within the health and disability system.

- Right 3: Right to dignity and independence:
 - Right 3 focuses on the independence of the individual. Whilst independence is important, to align with Te Tiriti o Waitangi and the views of tāngata sai'ilimalo – Pasefika disabled people, this Right should also include whānau, aiga and family in order to move away from ableist conceptions of personhood, which emphasise individual abilities and capacity. Many disabled people wish to include their natural supporters and support systems when engaging with the health system and making decisions related to their health and disability.

 - To recognise the lived experience of disabled people relating to the need for support, Right 3 could be reworded to say:
 - “Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual as well as the individual’s place within their support system”.

- Right 4: Right to services of an appropriate standard:
 - This section notes that “every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.”

 - Alignment of the United Nations Convention on the Rights of Persons with Disabilities (‘UNCRPD’) with the Act and Code should be considered within this review. Right 4 should highlight the importance of services complying with the UNCRPD in order to overtly acknowledge the rights of disabled people who are significantly impacted by the Code of Health and Disability Services Consumer’s Rights.

 - We believe that Right 4 should therefore be amended to include a subsection stating the following:
 - “Every consumer has the right to have services provided in a manner which is consistent with the United Nations Convention on the Rights of Persons with Disabilities”.

 - Incorporating the UNCRPD in domestic regulations would significantly enhance the rights of disabled people within health and disability systems. It would also create incentive for more health and disability providers to engage in education and training relating to the treaty,

understanding their services through a disability lens, and disability rights generally.

- Right 5: Right to effective communication:
 - The specific communication needs of the disability community should be considered in the review. Right 5 should include mention of accessible formats as well as augmentative and alternative communication technology. The use of such formats is crucial for successful communication with many in the disability community.
 - To respond to this gap, Right 5(1) could be amended to say:
 - “Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and practicable, this includes the right to information provided in accessible formats and through augmentative and alternative communication technology, as well as the right to a competent interpreter.”
- Right 6: Right to be fully informed:
 - This Right requires that every consumer have the right to information that a reasonable consumer, in that consumer’s circumstances, would expect to receive.
- Right 7: Right to make an informed choice and give informed consent:
 - Right 7 provides a process by which a consumer can be identified as lacking competence or having only a certain level of competence (diminished competence). Others (whether it is a supporter or the service provider) can then consent on the consumer’s behalf where it is “in the best interests of the consumer”; and “reasonable steps have been taken to ascertain the views of the consumer”. Right 7 therefore enables substituted decision-making to take place. This means that the consumer is not involved in the decision-making process.
 - Substituted decision-making does *not* protect disabled people’s rights and denies a person their legal capacity and personhood. Personhood has been associated with values such as choice, self-determination and autonomy.¹ It is our experience that when *supported* decision making takes place, which is underpinned by a focus on a person’s rights, will and preference (as opposed to an approach which presumes what a person’s ‘best interests’ are) then positive outcomes will be the result.
 - Supported decision-making should therefore replace substituted decision-making, even in cases where someone’s views are difficult to obtain. This approach is advocated for by article 12 and 13 of the UNCRPD, which require states parties to recognise the legal capacity

¹ Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse*, 37(1), 1 – 15.

of all disabled people and to ensure access to justice for disabled people, including through the provision of procedural and age-appropriate accommodations. Further information regarding supported decision-making can be found in an integrative literature review we completed on this subject.²

- The New Zealand Government has ratified the UNCRPD in 2008 and its Optional Protocol in 2016 and therefore has an obligation to provide accommodations to support disabled people to exercise their legal capacity through supported decision-making processes. When examined by the UN Disability Committee in 2014 and 2022, in both reporting sessions the New Zealand Government was challenged to address its failure to replace substitute decision-making in all its forms, including in the health and disability sector.
- We believe that in this review you should be considering how the Health and Disability Act and Code can shift from a substituted decision-making regime to a supported decision-making regime. In order to make this transition, the following revisions could be considered:
 - Right 7(2): “Every consumer must be presumed competent to make an informed choice and give informed consent”.
 - Right 7(3): “Where a consumer has affected decision-making, that consumer retains the right to make informed choices and give informed consent.”
 - Right 7(4): “Where a consumer is deemed to have affected decision-making, that consumer has the right to make their decision with the help of a formal decision-making supporter and / or whānau, aiga, family and firends.”
- “Affected decision-making” should be defined in the definitions section of the Code and could replace “diminished competence” or “lacking competence” as it recognises that though some may require support to make decisions, they retain their legal capacity.
- Right 8: Right to support:
 - This Right states that consumers have the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer’s rights may be unreasonably infringed.
- Right 9: Rights in respect of teaching or research:
 - Right 9 states that the rights in the Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research. Therefore when someone is deemed as lacking competence and are viewed as being unable to give

² Mirfin-Veitch, B. (2016). *Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review*. Donald Beasley Institute: Dunedin.

informed consent and when it is seen as being in their “best interests”, Right 7(4) of the Code allows the person to be enrolled as a participant in research. This is problematic, as this substituted decision-making process allows other people to decide for disabled people whether they are enrolled in research or not, denying that person autonomy.

- As noted when discussing Right 7, we believe that through supported decision-making strategies disabled people with affected decision-making can be supported to make decisions, this includes whether they consent to engagement in research.
- The National Ethical Standards on Health and Disability Research and Quality Improvement (the ‘Standards’) note that protection of disabled people from exploitation and undue influence in research must take place but must be proportional to the degree to which it affects a person’s ability to act on their will and preferences. The Standards support the use of a person-centred, supported decision-making model regarding informed consent to participate in research, stating the following (p. 54):
 - “As a default position, researchers should take all people, regardless of disability, as having the capacity to provide informed consent.”
 - “Where researchers have reasonable grounds to believe that a disabled person cannot by themselves give informed consent, they should provide that person with access to the support required to do so. It should be noted that almost any person, with the right support, is capable of providing informed consent.”³
- The Standards do however, note that there is a group of people who cannot provide informed consent to participate in research. We believe that when research aligns its conduct with the UNCRPD (specifically the principles laid out in Article 3 and Article 12 and 13) there is a way forward, however the level of reform this requires appears to have been deemed out of scope for the review.

³ National Ethics Advisory Committee. (2019). *National Ethical Standards Health and Disability Research and Quality Improvement*. Wellington: Ministry of Health.

- Right 10: Right to complain:
 - Right 10 states that consumers have the right to complain about the provider in any form appropriate to the consumer. The communication needs of the disability community should be considered when reviewing this Right as disabled people need to have access to complaints procedures. We believe that Right 10 should include an additional subsection stating the following:
 - “Every consumer has the right to effective communication throughout the complaint process, in a form, language, and manner that enables the consumer to understand the information provided. This includes the right to information in accessible formats, information that utilises augmentative and alternative communication technology as well as the right to a competent interpreter”.

From: "Rachel Hargreaves" <rachel.hargreaves@deaf.org.nz>
To: "Jane.Carr-Smith@hdc.org.nz" <Jane.Carr-Smith@hdc.org.nz>
Cc: "Lachlan Keating" <Lachlan.Keating@deaf.org.nz>
Date: 07/03/2023 08:49 a.m.
Subject: HDC Review - Deaf Aotearoa's feedback

CAUTION: This email originated from outside of the organisation. Exercise caution when opening attachments or clicking links, especially from unknown senders.

Hi Jane,

Thank you for asking for Deaf Aotearoa's early input into the scoping of the review of the Act and Code. Our key points are as follows.

We note that the purpose of the Act is 'to promote and protect the rights of health consumers and disability services consumers...'

Our main comment on the Act is that the 'promotion' aspect is not working well. We haven't seen any promotional activity, and if there has been any, we haven't seen it in NZSL. It is safe to say that many people in the Deaf community have little or no awareness of the Act and its purpose. Similarly with the 'protecting of rights' aspect, the Act has had little impact on Deaf people's right to full access to information on an equal basis with others.

We note that the Commissioner must have the ability to recognise 'the social, cultural, and religious values of different cultural and ethnic groups in New Zealand'. And yet resources do not reflect Deaf culture or Deaf worldview.

In terms of the Code, the rights remain valid. However, there are gaps in implementation. For Deaf people, the key ones are:

- Right 2: the right to freedom from discrimination, coercion, harassment and exploitation
- Right 5: the right to effective communication
- Right 7: the right to make an informed choice and give informed consent.

We have many examples of discrimination on the basis of communication barriers, lack of on-call qualified interpreters to ensure effective communication is upheld in all situations, especially those where consent is being sought. Deaf people have to explain their rights over and over again each time they attempt to access health and disability services because staff do not know, or dismiss, the importance of timely and effective access to information.

We recommend that these issues are in the scope of the review. New Zealand's health and disability services workforce must upskill themselves to demonstrate Deaf cultural competency, in the same way as tikanga Maori is being considered across the system.

Is the role of the Health and Disability Advocacy Service included in the scope of the review? If so, we recommend the re-establishment of the Deaf Advocacy roles.

Thank you. We look forward to seeing the results of this scoping exercise.

Rachel Hargreaves |

Policy & Advocacy Manager

Level 9, 342 Lambton Quay, Wellington, New Zealand

Mobile [REDACTED] | Web www.deaf.org.nz

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Preliminary Thoughts on Health and Disability Review 2023

From Death Without Debt

1st of March, 2023

Dear Catherine,

Thank you for your email of 19th December 2022, inviting Death Without Debt to send through any thoughts on what Commission should consider in it's review by March 10, 2023

Attached is a simplified briefing on the issue. In short:

One After-death duty of care appears to be a grey area for the Commission and a little considered. Commission HQ has advised Death Without Debt the Commission can indeed cover after-death care but this is contradicted by Commission advocates on the ground who tell people they have no remit to help people in these cases.

There is a clear case the Commission should explicitly include after-death duty of care within it's remit.

Two Currently standard practice constitutes a significant failure on the part of the health sector. This failure has occurred slowly and over time but nevertheless has had serious consequences. There are also Treaty of Waitangi implications.

Three The essential problem is simple. Government paperwork requirements coupled with neglect and disinterest on the part of the medical profession are trapping the public in the funeral industry's business model and this leads to funeral debt. Claims by the Ministry of Health, to Death Without Debt, that their proposals for a reformed medical referee system will address our concerns contradict both common sense and research by ourselves and Health Literacy NZ. It also contradicts the experience of NGO's dealing with poverty and funeral industry entrapment.

Four The needed reform is simple. Doctors would simply complete the relevant pre-disposal paperwork on behalf of the family and inform the whanau or executors adequately about the processes and the choices available to them. This process takes mere minutes. We know, we've had doctors trial it. Doctors and nurses Death Without Debt have approached with this solution are supportive.

Sub-standard after-death care, by definition, affects all New Zealanders, yet the Commission are unfamiliar with this issue.

Because most people, even, perhaps especially those engaged in policy analysis, are operating on incorrect assumptions on this issue, a review team relying on voluminous by correspondence is likely to fail.

We therefore propose a seminar where the Commission can put faces to the issues and

hear from people dealing with the fallout from the medical fraternity's oversight.

Face to face time will allow a common understanding to be built up. Your questions, reservations and clarifications to be dealt with smoothly and quickly in a way that email and documents simply don't allow.

We propose, after such a presentation, to supply a full written submission which will then have a wider, and, vitally, a human context.

We look forward to your acknowledgement of this letter and to your engagement.

Please note I am away from the 3rd of March to April 2nd and will only occasionally be checking my email.

Fergus Wheeler
Convenor
Death Without Debt
www.deathwithoutdebt.org
fbwheeler@proton.me

The need for the Health and Disability commission to explicitly include after-death care in it's remit

A brief outline

Contents:

- 1) Summary:
- 2) About Death Without Debt
- 3) Why after-death care should sit within the health and disability code's remit.
- 4) Background:
 - a) Entrapment by official paperwork requirements
 - b) Case studies
 - c) Failings of current after-death care relative to the H and D code
 - d) The significance of the problem and the Treaty of Waitangi
 - e) Why the current MoH review of legislation does not address the basic issue

1) Summary

Current standard practice by the attending medical professional at a death fails the Health and Disability Code on multiple points. That this failure is universal doesn't make it acceptable.

The argument, put forward by H and D advocates that the Code only extends up to death but not beyond is not sustainable. In any case the Health and Disability Commission H.Q. itself accepts the code can cover after-death duty of care.

The current sub-standard level of after-death care constitutes a likely breach of the Treaty of Waitangi.

Steps required of the Health and Disability Commission to put the wider, but also the Treaty-specific issues right include:

1. *Explicit inclusion of (limited) after-death care in the Health and Disability Code*
2. *Engagement with the legislative process as the Burial and Cremation bill makes its way through the house*
3. *Active guidance and training for all Health and Disability Commission staff and advocates on what adequate after-death care looks like.*
4. *Engagement with the medical fraternity over what adequate after-death care looks like from their point of view.*
5. *Engagement with the Ministry of Health on the part they need to play in bringing the medical profession after-death care up to standard.*
6. *Engagement with the public, including different ethnic communities, NGO's and churches as to what they are entitled to expect with after-death duty of care.*
7. *Engagement with Maori as to what they are entitled to expect.*
8. *Engagement with both independent and industry-aligned undertakers, funeral directors, funeral guides etc as to their role in protecting the rights of patients and their families.*

About Death Without Debt

Death Without Debt was formed in 2020 to address the root causes of funeral debt. Our committee consists of health professionals and people working on poverty issues. Supporting organisations include Community Law, Salvation Army and Grey Power.

Our first action was to submit to the Ministry of Health's review of Burial and Cremation Law.

Why after-death care should sit within the Health and Disability Commission's remit.

In the field of common sense, which is where the expectations of the public lie, the issue is simple: The public should not be forced, by difficult or unfamiliar official paperwork requirements to become dependent on the funeral industry for negotiating those paperwork processes.

Arguments against answered:

- a) The Health and Disability Code only addresses *individual* patient' rights. Whanau and/or close friends are advised of individual patient's post-operative results, of births, are asked to act in situations where the individual patient is unable to communicate or make decisions themselves, and so on. The medical fraternity and Commission need to be consistent when applying the Code and include after-death care despite it not being strictly a patient issue. The Commission is often involved in cases where the treatment of the family by the profession is at issue.
- b) The Code only covers strictly medical practices. As above. At birth, it is naturally assumed the health-profession will support the whanau in arranging birth certification and so on.
- c) The medical profession and the Code don't cover currently cover after-death duty of care. After-death duties are in fact part of doctors' and nurses' job description. These duties include confirmation of death and certification of cause plus advice to the family and/or executors about how to proceed once the doctor or nurse leaves. Should a doctor or nurse fail to adequately execute these basic tasks, it is unimaginable that they would get away with it under the current Code. All that is proposed here is for existing after death care to be extended by a couple of minutes and done properly.
- d) After death duty of care has never been an issue before now. The public are unaware of what they *should* be entitled to because of poor current medical practice. Most have no idea there could be any alternative to the current practice of being referred automatically to the funeral industry. Therefore it does not occur to most people to complain. In the rare event they do, they are turned away by H and D advocates.

Since death is unavoidable, and the after-death paperwork requirements compulsory, the onus should be on the state to ensure individuals and family/whanau are not forced by these requirements into a position where they can be exploited.

When a patient dies their rights need to be transferred (albeit briefly) to the family, executor, friend or whoever is responsible for the body.

Background

Entrapment

At present, the public have, effectively, no choice but to engage the funeral industry to complete basic pre-disposal paperwork requirements. Pre-cremation paperwork is particularly problematic. Pre-burial paperwork requirements, while easier to negotiate, are seldom attempted because of a systemic bias towards funeral directors and against any attempts by the public to organise the legal and practical sides of the funeral processes themselves. Most professions and agencies have defaulted entirely to the funeral sector.

How the system is currently experienced

The need for an extension of medical duty is best understood by simply reading DWD's submission to the Ministry of Health's Review of Burial and Cremation Legislation - in particular case studies #2 and #3. These are available on our website:

<https://www.deathwithoutdebt.org/resources>

How current after-death care measure up against the Health and Disability Code

Current standard practice fails on nine of the Code's ten points.

Right 1

The right to be treated with respect. Currently those attempting to bypass the funeral industry by attempting to fulfil paperwork requirements themselves are often regarded with hostility by workers in the health and social work sector. More importantly, respect implies consideration, and very little consideration or support is currently given to whanau attempting to avoid funeral debt by avoiding the funeral industry.

Right 2

The right to freedom from discrimination, coercion, harassment, and exploitation. As above; the public should have the right to be protected from predation by the funeral industry, by,

- a) *Not being put in a position of dependency on them by official paperwork requirements,*
- b) *Not having to engage with unregulated businesses at a time of great vulnerability*
- c) *Receiving adequate information on the funeral process.*

Right 3

The right to dignity and independence. People should have the right to be free of the funeral industry for official paperwork requirements because research clearly shows that once funeral directors are engaged to do the paperwork, very few families succeed in regaining independence for the rest of the funeral process. Official paperwork requirements entrap people in the funeral industry's business model.

Right 4

The right to services of an appropriate standard. At present no support or information is normally offered regarding the funeral process other than a referral to the funeral industry. Although this is standard behaviour on the part of the medical profession, this behaviour nevertheless fails to provide duty of care

Right 5

The right to effective communication. No information on the funeral processes and the financial risks of engaging the funeral industry are currently provided to patient's families

Right 6

The right to be fully informed. Ditto.

Right 7

The right to make an informed choice and give informed consent. Ditto

Right 8

The right to support. Ditto

Right 9

Rights in respect of teaching or research. N/A

Right 10

The right to complain. Complaints about after death care cannot at present be made to the Health and Disability Commission as advocates claim after-death care is not covered by the Commission. Complaints to medical professionals themselves are turned down or ignored.

The significance of the problem and the Treaty of Waitangi

According to Stats NZ's Household Economic Survey for the year ended June 2019, more than one-third of Maori households (37%, or 88,000 Maori households) and nearly half of Pasifika households (47%, or 36,000 Pasifika households) would not be able to pay \$1,500 as an unexpected expense, let alone a full funeral and associated costs in the region of \$10,000. The corresponding figure for non-Maori non-Pasifika households is 16%.

These figures are sourced by Commissioned Research from Stats NZ.

Given Maori households are clearly disproportionately affected, there are clear Treaty implications.

Why the current moh review of legislation will not address the basic issue

The Ministry of Health is reported to have finished its review of the burial and cremation legislation.

The review was begun by the Law Commission in 2010.

Both the Ministry of Health and the Law Commission looked at possible regulation of the funeral industry, but missed the fundamental question which should have preceded that work: "Why are the public so dependent on the funeral industry in the first place?" The answer is equally simple: To bury or cremate someone, the public are forced by a number of obstacles into a relationship of dependency with the funeral industry.

The issue was likely overlooked because NZ's medical community and social agencies

and staff have, almost without exception, defaulted to the funeral industry. Hiring a funeral director is simply people are supposed to do. It is the only thing advised.

If the Law Commission and the MoH did look into the issue of people DIYing (DIY = Do-It-Yourself) their own funeral processes at all, they would have found assured bypassing funeral directors is, in fact, possible en-route to burial. Actually, only a tiny number of New Zealanders:

- Are aware of this
- Confident enough to actually do it
- Have the necessary support.

In any case, 70% of New Zealanders opt for cremation. Bypassing funeral directors for cremation is almost impossible and this has cemented in current attitudes and practice for both cremation and burial.

Although government and private publications and websites say organizing your own funeral process is entirely possible, this is seldom the case. There are very real obstacles in the process that are glossed over.

It is believed that while the Ministry of Health, have, in their review gone some way, with their proposals, to fix problems with the medical referee system. However the MoH have not addressed the fundamental problem of duty-of-care for whanau/family etc.

In the past the MoH argued (to Death Without Debt) that a public register of medical referees will ensure anybody who wants to DIY a funeral process will be able to do so without being dependent on a funeral director.

This flies in the face of the experience of grass-roots poverty campaigners, Death Without Debt's research interviews and the findings of Health Literacy NZ which show most New Zealanders will have no chance of knowing about, let alone executing their supposed choices in the after-death setting.

In other words, the need for the Health and Disability Commission to advocate for sufficient after-death duty-of-care remains despite the partial reforms proposed by the MoH.

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

From: "Deon York" <Deon.York@hqsc.govt.nz>
To: "review@hdc.org.nz" <review@hdc.org.nz>
Cc: "Jane Carr-Smith" <Jane.Carr-Smith@hdc.org.nz>, "Janice Wilson" <Janice.Wilson@hqsc.govt.nz>
Date: 09/03/2023 03:58 p.m.
Subject: Seeking early input into HDC's Act and Code Review

CAUTION: This email originated from outside of the organisation. Exercise caution when opening attachments or clicking links, especially from unknown senders.

Kia ora Rose,

Thank you for your correspondence of 3 February 2023: Seeking early input into HDC's Act and Code Review. The Health Quality & Safety Commission (HQSC) welcomes the invitation to comment early.

An early observation would be that the review of the HDC code offers an opportunity for both the HDC and HQSC to have clear guidance about the differences between the Code of Rights and Code of Expectations. To date there have not (to our knowledge) been any complaints about breaches of the code of expectations and wonder whether this new code has been referenced in any complaints your office receives?

Appreciating that you are not at the public consultation phase yet, I shared the questions posed in your correspondence to Te Kāhui Mahi Ngātahi, our consumer advisory group (CAG) to the board and we discussed it briefly at our last meeting. I have summarised early thoughts from the CAG (these centre on provision of mental health and addiction services):

- A critique of mental health care in Aotearoa is that the UNCRPD isn't always honoured. The Code seems like an appropriate place to be explicit on this point. *Section 6. Other Rights* could be strengthened in this regard.
- How is this review considering the Law Com review of adult decision-making capacity (closed 3 March)? Right 6 and Right 7 both have inconsistencies with the current decision-making capacity approach and the Mental Health Act (MHA). Particularly, Right 7 (2) as we know in practice the MHA takes a biased and medically orientated approach to competency, and Right 7(7) is not aligned with the current MHA at all.
- Right 7(5) regarding advanced directives could be expanded. Again the Law Com review could be a valuable addition here but at a minimum this should require advanced directives to be honoured.
- Under Right 8 (Support) and 10 (Complaints) there could be a greater emphasis on peer support or peer governance.
- Challenges with mental health care not meeting the code of rights, and a lot of the conversations about risk, and practitioner-perceived risk, is reinforced by Section 5 – Other enactments. This essentially makes the Code optional if a practitioner justifies their actions by following the interpretation of another act. Core complementary legislation such as the current MHA, or a future revised MHA should be referenced and

integrated explicitly. Again, Section 6 could be written to strengthen a consumer's understanding of rights.

I welcome further conversations. Please let us know how we can be of further assistance.

Ngā mihi,
Deon

Deon York ([he/him/ia](#))
Director | Tumu whakarae – He Hoa Tiaki
Consumer and whānau engagement
Health Quality & Safety Commission
DDI: [REDACTED]
M: [REDACTED]
deon.york@hqsc.govt.nz
www.hqsc.govt.nz

Information removed under section
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and/or section 53(b) of the Privacy Act
to protect the privacy of the individual/s
involved

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

Who: Disabled Persons Assembly NZ
Mojo Mathers, Policy Coordinator
Paul Brown, Policy Advisor
Chris Ford, Regional Policy Advisor

Date: 7 March 2023

Re: HDC Act & Code review

- Lots of confusion regarding the overlapping roles between HDC, HRC and the Ombudsman's office.
- People with disabilities are often traumatized by the health system, so if they actually make a complaint it is a big step for them, which explains why there are not many disability complaints.
- Distinction between HDC and Advocacy is very confusing and there is a real need to clarify the structure as part of the refresh. Disabled people don't often understand the distinction making it harder for them to make complaints. People often think they have made a complaint to HDC when in fact it has been lodged with Advocacy.
- Advocacy could still remain independent but it should come under HDC's umbrella rather than the current contracting out model. It is important to give advocates experienced with disability issues job security as this would make it easier for disabled persons.
- Advocates are good and it was queried whether HDC misses out on their experience and knowledge of the disability sector under the current model. The advocate who works with deaf people is really good.
- However, it was questioned if there was an internal complaints process about advocate performance, particularly if the advocate was seen to be taking the side of the provider. There may be some mistrust of advocates if they do this (take the side of the provider).
- When considering reform to the Act and Code, HDC should have regard to principles of equity, accessibility and mana.
- Re accessibility, it is really important providers ensure that their facilities and activities are wheel chair accessible.
- Big issue disabled complainants experience is the slowness of complaint resolution.
- Disabled persons are reluctant to make complaints as they don't want to upset the relationship with their providers as they are very dependent on them and depending on the service there is often very few providers to choose from.
- Discussed the distinction between individual complaints and wider/group/systemic complaints. The later is very important and there are a number of big issues which confront disabled consumers including:
 - sexual health, bowel screening (disabled people falling off the radar), cervical smears, and blind people being able to read prescription instructions from pharmacists (i.e. via braille).
- People with learning disabilities have the lowest healthcare outcomes and it is important for HDC to talk/consult with them on the review. The big issue that they face is that they don't get long enough at medical consultations in order to properly understand the care that is being provided to them. Barriers to this type of consumer are even higher when considering

making a complaint to HDC. HDC should factor these barriers in when consulting with this consumer group and do easy read consultation documents and possibly a video.

Responses to question about what HDC is doing well:

- Videos around the Code are good/impressive but there is a need for HDC to revisit whether more education is needed to make disability consumers aware of their rights under the Code. Also disability providers need to be aware of their obligations under the Code. HDC does not have much social media presence and this could assist with education around the Code.
- Code is generally pretty good and by in large covers what it should. It is still something disability consumers go to when they are facing an issue with their provider.
- Re-emphasized that the principles of dignity, autonomy and choice should be present within the Code as they stand the test of time. Consider whether the definitions in the Code could be updated for this.
- Questioned whether HDC should have broader powers around the monitoring and site visits of disability service providers.
- Concerns that lots of prisoners have disabilities and the care provided to them should be viewed through a disability lens.
- Don't like the reference to the word "consumer" as it implies disabled persons have choice when often they do not. The term "service user" may be a better term.
- How does the "Enabling Good Lives?" initiative fit in with the Code?
- Where does the UN Convention on the Rights of Persons with Disabilities fit in with the Code? There should be express reference to it.
- There should be an express legislative requirement that HDC has to consult with disabled persons on matters impacting them.
- There is a perception that HDC only focuses on health and this is evidenced in the Act where the responsible minister is the Minister of Health. This should be broadened to include the Minister for Disability Issues.
- It is really important that HDC's consultation is accessible to persons with disabilities and Disabled Persons Assembly NZ can help with promotion of the Act and Code review.



email support@aim.org.nz

www.aim.org.nz

Supporting families, preventing tragedies

26 February 2023

Ms Rose Wall

Acting Health and Disability Commissioner

Thank you for your invitation for us to contribute to your review work.

Alongside the current work of the HDC, our view is that there should be a new and newly-funded cross-sector **Adverse Preventable Outcome Database (APOD)**. This should operate under the auspices of the HDC but include (with appropriate cross-sector legislation changes) close communication with:

- Coronial inquiry processes where these relate to healthcare
- Te Whatu Ora regional mortality and morbidity review systems
- ACC Treatment Injury team
- ACC Risk of Harm team
- PMMRC and other national mortality databases

This Adverse Preventable Outcome Database can collect information from all adverse preventable health outcomes to ensure the following:

- (1) Consistent family / whānau support and advice**, for example, a family who has been through a Coronial process where poor health care practices were identified then being advised about making a claim to ACC under treatment injury provisions. Coronial services have never seen it as their duty to inform families where substandard care was identified in their loss, that ACC treatment injury claiming is a potential pathway for them. Similarly, the PMMRC does not inform families of this option. We have also noted that the HDC does not consistently inform families about this option where breaches of the Code are found.
- (2) Practice themes** leading to poor outcomes which can become evident across several complaints, but which involve different practitioners in each case. An example from

the maternity sector would be poor or absent fetal monitoring along with flawed CTG interpretation. We also expect that weekend under-staffing of hospital midwifery and registrar rosters in maternity units may emerge as a theme across many poor preventable outcomes. Further, it is our view that the human factors deficiencies in the Section 88 regulations (such as open-ended hours of attendance in labour by the one midwife) will lead to detectable poor outcome patterns.

- (3) **Risky practitioners** who are the subject of repeated adverse findings about their standards of care could be identified so that the relevant registration bodies can respond. To give you an example of our concerns: an obstetrician formerly employed at Hutt Hospital whose care of one of our AIM families there was found by internal and external investigation processes to be deficient. Tragically that deficient care led to the death of the baby girl involved. Some time later, that same practitioner, now working at Middlemore Hospital, has been directly involved with another of our AIM families. This time it has led to a brain injured baby who will have lifelong impairment from that birth. ACC's Risk of Harm team do not collect and compare practitioner names over time and across multiple Risk of Harm notifications. They simply deal with each avoidable poor outcome in an isolated manner. In our view this blinkered approach is a hugely lost opportunity to strengthen the health sector and to protect the public. An Adverse Preventable Outcome Database would ensure that this type of information can be captured so that repeatedly deficient standards of care can be rectified.

Following our 2009 submission to Parliament, the Government response to the Health Committee recommendation about assisting families and whānau with poor care outcomes noted that,

The Government supports the need for better coordinated support for families affected by adverse birth events...

Across the many intervening years since our submission, sadly none of that better coordinated support has taken place. We see this HDC review is a golden opportunity to try something new.

About the same time as we made this first Parliamentary submission all those years ago, the Maternity Quality initiative (MQI) was established across the DHBs. The most recent PMMRC report released in December 2022 shows that there has **been no improvement in maternal and perinatal deaths and other poor outcomes over the last 15 years**. Clearly, all the millions of dollars spent annually on the MQI and all other maternity improvement measures have achieved no benefit (we have some thoughts as to why this is so which we would be happy to discuss).

Once again, **this HDC review is a golden opportunity to try something new.**

Kind regards and thank you again for the opportunity to contribute

Dr Lynda Exton

AIM Kaitiaki

Who: Health Research Council of NZ
Dr Sunny Collings, Chief Executive & Consultant Psychiatrist

Date: 9 March 2023

Re: HDC Act & Code review

- Explained background on HRC's role in funding research and how it has its own Act – the Health Research Council Act 1990. It was noted that under that Act the HRC had a duty to advise government on health research into issues that affect Māori, it also makes reference to tikanga which was quite progressive for the era (1990s). Something HDC could look to as an example.
- The big issues facing NZ health research are climate change and health inequality.
- Climate change in terms of disruption of services and the mental health impact it has on people.
- Health inequalities in terms of the fact that our health system is “not in the best of health” and is failing some people. Backroom functions of the health system are not great including things like data sharing.
- Often research needs to take place in larger settings (such as old DHBs) but they are not well set up for research and this was an opportunity lost in the current reforms to the health care system.
- It is important to recognize that research is critical to help improve care and services.
- Right 9 : “The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research” – queried what does “it is proposed” mean?
- Wondered whether a document supporting the Code would be helpful and could emphasis the relationship between researchers and consumers.
- Right 5 – every consumer has the right to effective communication – it needs to be clear that this is not just getting information but rather a discussion between the provider and consumer.
- Consent to research on “vulnerable consumers”
 - not all mental health consumers are the same and some actually want the right to participate in research and make a difference.
 - people feel positive that they can make a contribution and this has therapeutic benefits in and of itself. For example, in mental health research, some participants feel like it is the first time they are really heard and can open up, without the fear of consequences.
- Noted that it is increasingly difficult to get people to participate in research – which is an important social good. Possibly a hangover from the vaccine issue.
- Advance directives – it would be good if consumers could make advance directives about their willingness to participate in research and this could be stratified into non-invasive research and invasive research.
- Would also be a good idea to relax the prohibition on EPOA's not being able to consent to experimental treatment.

Dr Collings wanted to make it clear that the views expressed were her own and not the formal position of the HRC.

13 March 2023

Rose Wall
Acting Health and Disability Commissioner

By email to review@hdc.org.nz

Tēnā koe Ms Wall,

Feedback on Health and Disability Commissioner's Act and Code Review

We write in response to your letter dated 3 February 2023, in which you invited the Human Rights Commission (the Commission) to provide preliminary feedback to inform the scoping of your review of the Health and Disability Commissioner Act 1994 (the Act), and the Code of Health and Disability Services Consumer's Rights (the Code).

At the outset, we wish to thank you for this opportunity on behalf of the Commission. We welcome the opportunity to be engaged this early in the process and look forward to contributing further as your review progresses.

As noted in your 3 February letter, we appreciate that the Act and Code have not been updated in a long time, and the health and disability sector in Aotearoa is now operating in a vastly different environment than when these instruments were drafted. Notably, the government has since ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and adopted the Enabling Good Lives approach to disability support; the Pae Ora (Healthy Futures) Act 2022 has transformed the structure of our primary healthcare system, including through the establishment of the Māori Health Authority; and the Covid-19 pandemic compounded healthcare issues whilst also seeing the success of whānau and hapū-based support for communities.

In this letter, we first make some general observations about access and engagement with the Act and Code across different communities, before setting out four high-level recommendations which we consider could better enhance the protection and promotion of human rights.

General observations

You have asked the Commission to comment on whether there are aspects of the Act or Code that we consider are not working well, or not working well for everyone. While we cannot speak to the direct experience of individuals, we make some observations based on our engagements with communities and their representative organisations, as well as

consistency with human rights law, including Te Tiriti o Waitangi obligations.

Having reviewed the data from the Health and Disability Commissioner's (HDC) latest Annual Report,¹ we understand there is inequitable access to, and engagement with, the complaints processes established by the Act and Code across different communities in Aotearoa. As discussed further below, the HDC has specific obligations to Tangata Whenua under Te Tiriti o Waitangi. However, there is well-established evidence of pervasive inequities and barriers affecting Māori access to health and disability services, including through language, cost, racism and a range of other systemic barriers.²

There are additional population groups in Aotearoa who are more likely than others to experience inequity in their ability to access and engage with the Act and the Code. For example, Pacific peoples and other ethnic communities, disabled people, and rainbow communities.³ In its [Talanoa Report](#) the Commission found long-standing health inequities experienced by Pacific peoples in Aotearoa.

Despite the known barriers faced by Tangata Whenua and Pacific peoples in particular, these communities are under-represented in complaints received by the HDC. Your 2020/2021 Annual Report shows that 11 percent of the HDC's complaints were received from people who identified as Māori, and only 2 percent from people who identified as Pacific, whereas 40 percent of complaints were received from people who identified as Pākehā. The Commission recommends that your review focus on how the Act and Code can better serve and connect with communities that face inequities in health and disability services.

We are also aware of general feedback that the Act and Code could better respond to resolving relational issues between service providers and consumers. We have heard that the Act and Code are more equipped to respond to complaints about the quality of health and disability services. However, as people are increasingly being recognised as partners together with their providers in matters relating to health and disability, there is an expectation that whakawhanaungatanga and manaakitanga be respected and upheld. There is an inherent power imbalance between health and disability service providers and consumers, who often rely on providers for their essential daily needs. The Commission recommends that an increased focus on how providers can better engage with and treat people at a systemic level, and how people can exercise their right to complain without adverse consequences, should be considered as part of the Act and Code review.

¹ HDC Annual Report 2021, accessed at <https://www.hdc.org.nz/media/6046/hdc-annual-report-2021.pdf>.

² Palmer et al., (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, 2. Waitangi Tribunal, (2019), *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*, (Wai2575), 34, 55. Accessible at: <https://waitangitribunal.govt.nz/news/report-on-stage-one-of-health-services-and-outcomes-released/>.

³ For discussion of difficulties experienced by SOGIESC communities in the health system refer to: [To Be Who I Am](#).

Recommendations for change

You have also asked the Commission to provide preliminary advice on potential changes to the Act and Code which we consider would better enhance the protection and promotion of health and disability services consumers' rights. We set out four recommended areas for change below.

1. Embedding Te Tiriti and human rights obligations

In their current form, the purpose provisions of the Act and the rights contained in the Code do not reflect and embed the need for the HDC to ensure health and disability service providers comply with human rights obligations, including those contained in Te Tiriti o Waitangi.

Te Tiriti and UNDRIP obligations

The Act and the Code do not explicitly refer to Te Tiriti o Waitangi, or tikanga and mātauranga Māori. The Act and Code should contain provisions which require the HDC to ensure health and disability service providers act in a manner that is consistent with Te Tiriti o Waitangi. In *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*, the Waitangi Tribunal found that "the Crown is obliged to ensure that all primary health care services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care."⁴ However, the Commission is aware of at least one complainant who was advised that the HDC could not address the aspects of her complaint that related to Te Tiriti issues.⁵ There is an urgent need to consider what health and disability services should look like in te ao Māori and how tikanga is and should be understood and applied across these contexts.

In addition to Te Tiriti, the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) affirms and reinforces the rights of indigenous peoples to:

- enjoy the highest attainable standard of physical and mental health;⁶
- determine and control their own health policies and practices;⁷
- maintain and develop their own traditional medicines, health care practices,

⁴ Waitangi Tribunal, *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*, WAI 2575 (2019), p 163.

⁵ See <https://www.stuff.co.nz/national/health/130534797/specialist-censured-for-obtaining-consent-while-patient-was-on-sedatives>. We understand the HDC initially referred the complainant to the Commission to address the Te Tiriti aspects of her complaint. After the Commission notified the complaint, the complainant reverted to the HDC process because the discrimination and Te Tiriti issues were interconnected to the HDC issues and the solutions she sought, but this was only after she challenged/escalated matters within the HDC.

⁶ 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.

⁷ UNDRIP, art 23.

- and medicines relevant to their cultural practices;⁸
- participate in decision-making processes that affect their health and wellbeing;⁹ and
- have access to and use and control of their traditional lands, territories, and resources, which are critical for their health and well-being.¹⁰

Coupled with Te Tiriti obligations, these UNDRIP articles highlight the importance of upholding Tangata Whenua rights to self-determination through the provision and regulation of health and disability services in Aotearoa. The Commission recommends that exploring how these rights and obligations can be actively embedded and advanced should form a key consideration of the HDC's review.

Wider human rights obligations

The Commission recommends that the Act and the Code also be updated to require the HDC to ensure that health and disability services providers act in a manner that protects, promotes, and upholds human rights.

As a party to international human rights instruments, Aotearoa is legally bound to respect, protect and fulfil the right of everyone to the highest attainable standard of both physical and mental health.¹¹ This right is established by article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR),¹² and has been subsequently recognised in article 24 of the Convention on the Rights of the Child (CRC)¹³ and article 25 of the CRPD. The right to the highest attainable standard of health entitles everyone in Aotearoa to both healthcare and health protection, administered through an effect health system.¹⁴ The Commission recommends that the HDC builds on these legally binding foundations to elevate the right to healthcare and the right to public health in their future work.

The right to the highest attainable standard of health is underpinned by fundamental

⁸ UNDRIP, art 20.

⁹ UNDRIP, art 18.

¹⁰ UNDRIP, art 14.

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 Committee on Economic, Social and Cultural Rights ' [General Comment no.14 on the highest attainable standard of health](#) ' (2000).

¹³ See Committee on the Rights of the Child ' [General Comment No.15 on the right of the child to the highest attainable standard of health](#) ' (2013).

¹⁴ See Human Rights Commission [Guide to the rights to healthcare and health protection in Aotearoa New Zealand](#) (8 February 2023).

rights to equality and non-discrimination recognised in both domestic and international law.¹⁵ Equitable health and disability services require effective, responsive and integrated systems of good quality that are accessible to all.¹⁶ For disabled people, failure to provide reasonable accommodation through appropriate individualised modifications, adjustments and supports is also a form of discrimination and interferes with the exercise of their right to health on an equal basis with others.¹⁷

There is international evidence that applying human rights concepts and frameworks help to strengthen health systems, achieve equity, reduce suffering, and save lives.¹⁸ The Commission considers that the Act would be strengthened by an explicit requirement for the HDC to protect, promote and uphold human rights obligations in Aotearoa, and that human rights principles should be embedded throughout the rights contained in the Code.

2. Language and understandings

Since the Act and Code were drafted, there has been a significant shift in the way we understand a number of concepts which are fundamental to the health and disability sector. The Commission recommends that through your review, the language in the Act and Code be updated to reflect these changes. In particular:

- *Consumer rights* – The Act and the Code were drafted in an era which conceived of “consumer rights”. However, the work of both the HDC and the Commission is primarily concerned with human rights, grounded in binding domestic and international human rights law. The Commission recommends that as part of its review the HDC focus on replacing the language of “consumer rights” with “human rights”, which recognises people as rights holders rather than consumers.
- *Disability* – Definitions under the Act and Code currently reflect a medical model of disability. Ratification of the CRPD in 2008 signalled a shift away

¹⁵ Recognised domestically in the New Zealand Bill of Rights Act 1990 (NZBORA), s19 and the Human Rights Act 1993 (HRA), s21 as well as in the ICERD; CEDAW; International Covenant on Civil and Political Rights (ICCPR), (adopted 16 December 1966, entered into force 23 March 1976), article 26; ICESCR, article 2(2); CRC, art 2; and CRPD, art 5.

¹⁶ Hunt and G Backman “Health systems and the right to the highest attainable standard of health” (2008) 10(1) *Health Hum Rights* 81 at 81–92. See also C Williams et al “The right to health supports global public health” in R Detels et al (eds) *Oxford Textbook of Global Public Health* (7th edn, Oxford University Press, Oxford, 2021); see also P Hunt and S Leader “Developing and Applying the Right to the Highest Attainable Standard of Health: The Role of the UN Special Rapporteur (2002-2008)” in J Harrington and M Stuttaford (Eds), *Global Health and Human Rights Legal and Philosophical Perspective* (Routledge, New York, 2010).

¹⁷ CRPD, art 5(3). See also [‘Removing barriers’ – an updated guide about reasonable accommodation of disabled people in Aotearoa](#). Jointly published by the Chief Ombudsman, Human Rights Commission and Disabled People’s Organisations Coalition.

¹⁸ See further resources list for more information and further reading at www.tikatangata.org.nz/our-work/guide-to-the-rights-to-healthcare-and-health-protection.

from the medical model, toward a social model of disability.¹⁹ The social model of disability moves the focus away from a pathological understanding of disability (the medical model) and onto the barriers within society that prevent disabled people from being able to participate in society and develop their full potential, consistent with the right to freedom from discrimination and the right to health.²⁰ We consider the rights contained in the Code could also more clearly recognise and reflect the right of disabled people under article 19 of the CRPD to live independently and be included in the community, as engaging with service providers is often central to disabled peoples' ability to participate in many aspects of home and community life.

- *Healthcare and disability service providers* – The definitions relating to service providers and practitioners under the Act and Code do not account for the less formal way many health and disability supports and services are provided in Aotearoa. Consistent with article 19 of the CRPD, we have moved toward a more family and whānau-centred provision of care, and the Enabling Good Lives model reflects an expectation that people should be treated as equal partners in matters to do with health and disability. A balance also needs to be struck between the need for regulation to uphold the quality of services being provided, while avoiding over-prescription in how much we expect from family and whānau-based carers. As part of its review, the Commission recommends that the HDC engage with community members about how best to bring them in line with the regulatory requirements under the Act and Code.
- *Informed consent* – The requirement for all consumers to provide free and informed consent for the provision of health and disability services is consistent with human rights obligations. The Commission notes that right 7(3) of the Code upholds the right of consumers with diminished capacity to give informed consent. However, it does not expressly recognise or account for supported decision-making by consumers. Article 12 of the CRPD requires that “those who lack capacity should not have decisions made for them (substituted decision-making) but should rather be supported and helped to make decisions for themselves.”²¹ We would therefore recommend that attention is given to incorporating supported-decision making principles within this part of the Code to reflect the requirements of the CRPD. We also consider that right 7(4) of the Code, which provides for “best interests” decision-making on the behalf of consumers who lack competence, provides for a form of substituted decision-making and therefore requires

¹⁹ CRPD, art 2.

²⁰ See *Report of the Special Rapporteur on the rights of persons with disabilities* UN Doc A/HRC/52/32 (28 December 2022) at [18]-[20] which notes that the medical model of disability “focus[ed] on the impairment, not the person” whereas “[s]ervices of the future should primarily be about enabling one to self-actualize in the world”.

²¹ *TUV v Chief of New Zealand Defence Force* [2022] NZSC 69 at [95] citing CRPD, art 12, and See UN Committee on the Rights of Persons with Disabilities *General comment No 1 (2014) Article 12: Equal recognition before the law* UN Doc CRPD/C/GC/1 (19 May 2014).

reconsideration in order to align with the principles of the CRPD. We note that right 7(4) is engaged in a range of circumstances, including emergency care when a patient may be unconscious. We also note that right 7(4) does make some provision for the ascertaining the will and preferences of the consumer, either directly or through others with an interest in their welfare. However, we nevertheless recommend that right 7(4) is reviewed with a view to ensuring that it fully reflects the primary focus on the will and preferences of an individual required by the CRPD.²² In its Concluding Observations, the CRPD Committee has recommended that New Zealand laws are revised to ensure substituted decision-making is replaced with supported decision-making.²³ The Commission considers that any legal framework which provides for informed consent should be predicated on a person's right to supported decision-making, where appropriate.

3. Complaints and investigations

The Commission recommends that several changes to the scope and procedures for bringing complaints and investigations under the Act and Code are needed to better protect human rights.

In relation to scope, the Commission considers that the rights under the Code should be extended to include a right to access health and disability services in Aotearoa. This would then allow people to complain to the HDC when they are unable or have barriers to access these services. Accessibility of healthcare is a fundamental principle of the right to health. As reflected in the HDC's latest Annual Report,²⁴ and discussed in our general observations above, there is clear evidence that people from different communities in Aotearoa experience inequity in their ability to access health and disability services. Expanding the scope of the HDC's jurisdiction to cover not only complaints about the quality of services, but complaints about access, would promote a greater focus on the unmet needs of these communities.

The Commission also understands that greater cultural and disability responsiveness is needed in the supports provided to people throughout the HDC's complaints and investigation processes. This aligns with the HDC's obligations to Tangata Whenua under Te Tiriti o Waitangi and UNDRIP, to ensure pathways for resolution of complaints and investigations recognise and respect tikanga and te ao Māori. Obligations regarding accessibility and reasonable accommodation under the CRPD²⁵ would be better protected through an explicit right to accessible communication under the Code, with more detail about the alternative formats to ensure disabled people can exercise their right to complaint under the Code on an equal basis with

²² *TUV v Chief of New Zealand Defence Force* [2022] NZSC 69, at [99].

²³ Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities (New Zealand)*, CRPD/C/NZL/CO/2-3, 27th session (26 September 2022) at [22].

²⁴ HDC Annual Report 2021, at pp.14, 15, 24, 26.

²⁵ CRPD, arts 2 and 9.

others.²⁶ Equally, avenues which better accommodate SOGIESC communities, and are culturally responsive to the needs of Pacific and other ethnic communities, would improve the ability for these population groups to access and engage with the HDC's complaints procedures.

Through their engagements with the HDC, the Commission's Dispute Resolution team understands that changes could also be made to better support avenues for alternative dispute resolution services under the Act (including early resolution, facilitation, mediation and conciliation). While the Act provides for "mediation conferences" in s 61, we recommend that there be statutory recognition of alternative processes. Other considerations related to complaints resolution include:

- We have heard that complaints from disabled people, where there is an expectation of an ongoing relationship with the provider/practitioner, are more often referred to an advocate for early resolution²⁷ compared with complaints by non-disabled people. While we understand the preference to maintain relationships, a balance needs to be struck with avoiding the preservation of harmful relationships. The preferences of the complainant should remain the priority at the initial assessment phase.
- Consideration should also be given to whether referring complaints back to providers for resolution is appropriate in some instances as opposed to actively investigating or using alternative dispute resolution processes. Some shared contacts have expressed frustrations when a matter has been triaged to the Nationwide Health and Disability Advocacy Service, where the process may involve seeking a written response from the medical practitioner against whom the complaint relates. In some cases that has been the end of the process. This has left complainants feeling dissatisfied, with no ability to take their complaint further.
- The intersection between the roles of the HDC and the Commission in addressing discrimination complaints requires consideration. As you are aware, discrimination complaints may fall under both right 2 of the Code as well as the Human Rights Act 1993. This overlap could be clarified through 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.
- The Commission understands the difficult balance to be struck between giving fulsome consideration to the issues raised in a complaint, while

²⁶ See CRPD, art 2 which defines "Communication" as including languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

²⁷ In accordance with s 37 of the HDC Act.

ensuring matters progress toward resolution in a timely manner. Introducing statutory timeframes, similar to those contained in the Official Information Act 1982, for the HDC to complete initial assessments of complaints and for parties to provide their responses, could assist with efficiency.

We recommend that also you consider how the outcomes of complaints and investigations could be strengthened to better address systemic issues in the health and disability sector. The complaints and investigation processes currently contained in the Act²⁸ focus solely on outcomes as between affected individuals and providers/practitioners found to have breached the Code through agreed resolutions, specific recommendations, or referral to disciplinary or Human Rights Review Tribunal proceedings. As part of your review, we recommend you consider how the HDC could be empowered to address cultural or structural issues arising more broadly across the sector, such as through the ability to undertake and publish thematic investigations and recommendations.

4. Increased transparency and accountability

Finally, we recommend that as part of the HDC's review you consider how to support increased transparency and accountability in respect of the health and disability system in Aotearoa. We consider that strengthened annual reporting requirements covering the following data would assist the HDC to better understand and respond to the peoples' needs:

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

As discussed in the Commission's recent submission on the Accident Compensation (Access Reporting and Other Matters) Amendment Bill,²⁹ it is critical that active steps be taken to address disparities and barriers to accessing health and disability services in Aotearoa, as well as complaints and investigation mechanisms designed to protect human rights. The HDC should also consider how to increase transparency around the solutions it considers and implements to address identified disparities and barriers to access.

Next steps

We hope the Commission's general observations and preliminary recommendations set out in this letter are helpful to informing the scope and process for your review of the Act and Code. We look forward to continuing to engage with you and provide feedback as your review progresses.

²⁸ In particular under ss40 – 50 of the HDC Act.

²⁹ Accessible at https://www.parliament.nz/resource/en-NZ/53SCEW_EVI_130009_EW9960/f383578df54e69c6b6ec175bc32a36112816e1db.

We strongly recommend that the HDC also consult directly with the Office of Human Rights Proceedings, which is independent from the Human Rights Commission.

As you enter the next phase of consultation with consumers and other stakeholders, we understand you will have a range of established contacts and networks to reach out to. We would also be happy to share our contacts from affected communities and representative organisations. The Commission has relationships with individuals and groups representing Tangata Whenua, hapū and iwi, disabled people and tāngata whaikaha Māori, Pacific peoples and ethnic communities, and rainbow communities. We would welcome the opportunity to facilitate further connections between the HDC and these communities.

Nāku noa, nā



Philippa Moran

Senior Human Rights Advisor to the Chief Commissioner | Kaitohu Tika Tangata ki te Amokapua

New Zealand Human Rights Commission | Te Kāhui Tika Tangata

Cc: Catherine McCollough, Principal Advisor, Health and Disability Commissioner
catherine.mccullough@hdc.org.nz

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

Ms Rose Wall
Acting Health and Disability Commissioner
Tower Centre
Level 10/45 Queen St
Auckland 1010
New Zealand

Re: proposed review of the Health and Disability Commissioner Act 1994 and the Code of Consumers' Rights.

Tēnā koe Commissioner Wall,

Thank you for the opportunity to provide input regarding the upcoming review of the Health and Disability Commissioner Act 1994 and the Code of Consumers' Rights.

While I think the Code continues to be an effective and functional regulation, there are two substantive issues that I think the Commissioner may wish to consider in a review of the Code (or at least which may be raised by interested parties), and one procedural issue that I would like to raise.

1. UNCRPD: supported decision making

The first substantive issue is whether the concept of 'supported decision making', as referenced in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹ should be explicitly referenced in Right 7 of the Code.

In suggesting this, I want to stress that while I would argue supported decision making is consistent with the spirit of the Code, I strongly disagree with the UN Committee's subsequent General Comment on Article 12² and the assertion that all substitute decision making regimes should be abolished is not tenable or desirable in a rights-based society.

In previous work, myself and my colleague Alison Douglass analysed Right 7 of the Code in the context of the contemporary rights-based shift to supported decision making.³ I have included the following extract in case it is of interest:

Right 7(1) emphasises the importance of individuals giving informed consent, but it also contemplates exceptions to that principle 'if any statute or the common law, or other provision of the Code, provides otherwise'. Right 7(2) reiterates the common law presumption of competence and that not all healthcare decisions require the same

¹ UN General Assembly *Convention on the Rights of Persons with Disabilities and its Optional Protocol* GA Res 61/106 (13 December 2006).

² Committee on the Rights of Persons with Disabilities, *General Comment No 1*, 2014.

³ J Snelling and Alison Douglas "Legal Capacity and Supported Decision Making" in I Reuecamp and J Dawson (eds) *Mental Capacity Law in New Zealand* (Thomson Reuters, 2019).

degree of capacity. Right 7(3) adds that a consumer with diminished competence “retains the right to make informed choices and to give informed consent, to the extent appropriate to his or her level of competence” – a rule that might even be read as requiring that appropriate support for decision-making be provided whenever such support is necessary and reasonably available.

Nevertheless, the Code still permits services to be provided without consent. Regarding a person considered to lack capacity to consent, Right 7(4) provides that health services may still be provided when this “is in the best interests of the consumer”, *and* “reasonable steps have been taken to ascertain the views of the consumer”, *and either*:

- (i) the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent *or*,
- (ii) if the consumer’s views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

These provisions implicitly suggest that best interests’ determinations should be consistent with reasonable beliefs about the patient’s preferences. Hence the Code clearly endorses the so-called “subjective” or patient-centred approach to determining best interests, which is consistent with the spirit of the CRPD and CRPD-GC which requires respect of a persons ‘rights, will, and preferences’. The Code does not provide guidance as to what constitutes reasonable steps to obtain a consumer’s views, but a genuine attempt to ascertain such views seems required whenever possible.

To make the approach even more rights-centred, the Code might stipulate that no-one should be considered to lack competence to consent unless all practical measures have been taken to support them to make their own decision, and those measures have not succeeded.⁴ In addition, the Code might provide that third-party decisions under Right 7(4) should be consistent with an impaired individual’s will and preferences, as far as possible, unless that would result in significant harm.

However, there will still be difficult cases where decisions must be made on behalf of an impaired person, when their will and preferences are not discernible, and no suitable person is available to provide advice.

2. Research involving adults who lack capacity to consent – Right 7(4) of the Code;

I understand this particular issue is not a new one for the Commissioner, but it remains an important issue yet to be resolved. I was part of the HDC’s Expert Advisory Group when the former Commissioner undertook a review of the issue—and would very much like to see reform in this area.

⁴ Cf Mental Capacity Act 2005 (UK), s 1(3).

3. Access to justice

I share some of the concerns previously raised by Professor Joanna Manning regarding the degree to which the Code is providing health and disability consumers' with access to justice.⁵ I think that a review of the Code could helpfully include an inquiry into the degree of satisfaction with the HDC process for both providers and patients as a means of identifying areas for improvement. (I wonder if there could be an independent review mechanism introduced for consumers if there is a decision that No Further Action is necessary or appropriate; or that there has not been a breach of the Code after an investigation (as currently occurs with ACC reviews) with the option of appealing to the HRRT.

Best wishes,

Dr Jeanne Snelling

Senior Lecturer | Pūkenga Matua
Faculty of Law | Te Kaupeka Tātai Ture
University of Otago | Te Whare Wānanga o Otāgo

⁵ Jo Manning "Fair, simple, Speedy and efficient"? Barriers to Access to Justice in the HDC's Complaints Process in New Zealand" (2018) NZ Law Review 611.



22 March 2023

Health and Disability Commissioner
Act and Code Review
PO Box 11934
Wellington 6142

By email: catherine.mccullough@hdc.org.nz

Tēnā koe Morag

Re: Seeking early input into HDC’s Act and Code Review

Thank you for your letter of 3 February 2023 seeking the Te Kaunihera Rata o Aotearoa the Medical Council of New Zealand’s (Council’s) input into the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers’ Rights (the Code). We appreciate the opportunity to provide input at this early stage.

I apologise for the delay in replying to you.

To assist you with your scoping of your review we have identified a number of areas of the Act and the Code that you may wish to consider and we have also made some preliminary notes on rationale:

Area of the Act	Rationale
s 9 and 10 Te Tiriti o Waitangi and the principles of Te Tiriti o Waitangi	<p>Consider creating consistency with the Pae Ora Act 2021 and the principles of Te Tiriti o Waitangi derived from WAI 2575.</p> <p>Consider s 9 Deputy Commissioner Kaitiaki Mana Māori or similar role to lead the organisations partnerships with the Iwi and the Māori community, and advance kaupapa Māori initiatives. We note that a senior Māori staff member has been appointed.</p> <p>Consider changing the language of clauses to reflect New Zealand values today and cultural safety (which now includes religious and ethnicity): For example:</p> <p><i>10 (1) (g) the person’s recognition of the social and cultural, and religious values of different cultural and ethnic groups or communities in New Zealand, which includes but is not limited to ethnicity, national origin, religion, diverse sexual orientations, gender identities and expressions, variations of sex characteristics, or disabilities</i></p>

s 14 (2)(a) s23 and s 29 consider specifying Māori communities and Māori health providers.	Tailoring the Act to reference Māori communities more specifically (as it does the disability community)
Section 20 re: content of Code	s20 (1) (c) (iii), consider specifying the provision of services that take into account the needs, values, and beliefs of different social groups or communities in New Zealand, which includes but is not limited to ethnicity, national origin, religion, diverse sexual orientations, gender identities and expressions, variations of sex characteristics, or disabilities.
s 23 Consultation on preparation and review of Code	Consider of consultation with disabled people's organisations under 23 b refer: Disabled People's Organisations - Office for Disability Issues (odi.govt.nz) Alternatively there may be the opportunity for an the independent disability voice informed by lived experience.
s 25 Advocacy services	Consider including a function to ensure that advocacy services are made available to diverse communities.
Section 31 of the Health and Disability Commissioner Act 1994 states that any person may complain orally or in writing to an advocate or to the Commissioner alleging that any action of a health care provider or a disability services provider is or appears to be in breach of the Code. This is also reflected in Right 10 of the HDC Code about every consumer having the right to complain about a health or disability provider.	The Code of Rights is available in different languages on HDC's website. This is an excellent initiative. This may not require amendment but more promotion to non-English language communities to promote access to HDC resources.
s 33(1) Preliminary assessment	Consider having a time limit inserted and replace – <i>"as soon as reasonably practicable"</i> ? Consider how a triage system for certain classes of cases (sexual boundary cases) that may assist to reduce risk to public safety due to delay.
S 34 (1) Referral of complaint to agencies involved in health or disability sector	Consider having a time period around referral of complaint back to appropriate authority if it appears from the complaint that the competence of a health practitioner or his/her fitness to practise or appropriateness of conduct may be in doubt - To replace 'At any time'.

	Timely notification of concerns about the safety of a doctor's practice or conduct is imperative so the Council can take interim action (if necessary) to protect the public.
34(2) Commissioner may consult with agency before referring a complaint. 34(5) Reference of a complaint does not preclude Commissioner from taking action on the complaint	The Council would like clarity around the criteria for referral or acting and referring complaint to Council under s34(1) – The Medical Council of New Zealand is unable under HPCAA to investigate conduct while the Commissioner is doing so. There may be some instances where Council (through its Professional Conduct Committees) are best placed to investigate conduct rather than the Commissioner. See also comment above around establishing a triage system for certain classes of cases (i.e., sexual boundary cases) and whether these are best placed with Council to reduce risk to public safety.
Code of Rights	The right to Cultural Safety we included within Right 1, for example Into Right 1, (3) <i>Every consumer has the right to be provided with services that are experienced by that consumer as culturally safe and aligned with that consumer's needs, values, and beliefs; this applies to all social groups or communities in New Zealand, including but is not limited to those based on ethnicity, national origin, religion, diverse sexual orientations, gender identities and expressions, variations of sex characteristics, or disabilities.</i>

We would be happy to input into the review at later stages, and expand on any of the points raised in this letter. We wish you all the best with your progress and thank you again for the opportunity to provide early input.

Ngā manaakitanga



Kiri Rikihana
Manukura Tuarua/ Deputy CEO



133 Molesworth Street
PO Box 5013
Wellington 6140
New Zealand
T+64 4 496 2000

Morag McDowell
Health and Disability Commissioner
c/o jane.carr-smith@hdc.org.nz
review@hdc.org.nz

Ref. H2023019867

Tēnā koe Morag

Health and Disability Commissioner Act and Code review

Thank you for your letter of 3 February 2022 seeking input to inform consideration of the review of the Health and Disability Commissioner Act (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code). I apologise for my delay in responding to you.

I appreciate the opportunity to provide input on this important review and would like to address the following for consideration. As your review progresses, it will be important to:

1. Demonstrate commitment to Te Tiriti ō Waitangi and obligations under Pae Ora Act, 2022. specifically:
 - a. acknowledging the new Pae Ora Act 2022, and the health principles are an obligation for the whole of the health system
 - b. the relationship with the New Zealand Health Charter under the Pae Ora Act 2022
 - c. purposeful and meaningful engage with Māori hapori, including whanau, hapū, and iwi to ensure the Act and Code's implications are able to accommodate their needs and aspirations
 - d. consideration of the functional role of the new Iwi Māori Partnership Boards (IMPBs) under the Pae Ora Act 2022, they may provide monitoring oversight in the future review processes
2. recognise the needs and aspirations of whānau Māori
3. show commitment to the Government's Accessibility Charter to ensure all New Zealanders can understand their rights and the review supports improved health literacy, specifically Outcome 5 - Accessibility
4. evaluate the Act and Code's benefits for Māori and other groups, with a focus on clinical engagement and a systems approach to complaints

5. address concerns about complaints management ensuring that there is robust and recent clinical engagement
6. strengthen collaboration between your office and teams in the Manatū Hauora, eg, the Quality Assurance and Safety Group and the Mental Health and Addiction Group
7. consult with other regulatory authorities to obtain their input on the review process taking a relational approach informed by restorative practice principles, collective rights, and recognise the intersection between regulatory authorities and the Health and Disability Commissioner (HDC)
8. assess how the Code affects health and disability research ethically, particularly when involving adults who cannot provide informed consent
9. clarify the list of health providers subject to the Code and ensure those providers and their clients understand their obligations, in order to effectively implement the code
10. consider changes that would enhance consumer rights protection and promotion, such as modifying the test for enrolling participants in health research without consent and removing the written consent requirement
11. consider how the Code works alongside the new role of the Aged Care Commissioner and their team.

In accordance with legislation requirements, the Director of Mental Health and Addiction has held a meeting with the HDC to provide feedback on the scope of the review. Their specific points for added below for completeness:

1. ensuring a clear process for direct referral of complaints to the HDC for investigation
2. establishing a formal mechanism for the Director of Mental Health or District Inspectors to refer complaints to the HDC for review
3. creating a mechanism for referral back to the HDC if outstanding matters are outside the jurisdiction of the Mental Health Act
4. implementing a formal mechanism for loop closure between HDC and District Inspectors
5. clarifying the authority and power of District Inspectors in sending investigation outcomes to HDC
6. ensuring consistency between the Code and provisions related to compulsory treatment in the Mental Health Act.

In light of the fundamental changes in the health system mentioned in your letter, I would like to further acknowledge our delay in addressing your request. As stewards of the health system, we take this matter seriously and are committed to working with our health system partners.

We openly welcome the opportunity to collaborate with you specifically on this important work addressing the issues raised in your letter in a timely and constructive manner.

Additionally, our Office of the Chief Clinical Officers and Quality Assurance and Safety team are available to meet to discuss their feedback in more detail.

Thank you again for the opportunity to provide input to this review. I look forward to continuing to work with the HDC to improve the health and wellbeing of all New Zealanders.

Nāku noa, nā



Dr Diana Sarfati

Director-General of Health

Te Tumu Whakarae mō te Hauora

14 / 4 / 23

cc: Rose Wall, Deputy Commissioner, Disability

Information released under the Official Information Act 1982
and/or the Privacy Act 2020

Ms Jordana Bealing (Co-Chair)
On behalf of NAMHSCA
(National Association of
Mental Health Services
Consumer Advisors)

13 March 2023

Rose Wall
Acting Health & Disability Commissioner

By email: review@hdc.org.nz

Kia ora Rose

RE: INPUT INTO HDC's ACT AND CODE REVIEW

Thank you for the opportunity to provide feedback into the HDC Act and the HDC Code. We have put this to our members and have collated this to give to you in the contents of this letter. Overall, our members did not have specific feedback about the Act and Code per se, however we wanted to take this opportunity to raise some issues with the HDC. Collectively, we have concerns regarding some areas that we hope the HDC will look into and consider and we wanted to make the most of this opportunity. Some issues are wider strategic operational issues, while others are more frontline.

- A lack of knowledge in the general public regarding basic health and disability rights, and also human rights more generally.
- More robust structures in place (or greater publicising of existing processes) regarding breaches of these rights – particularly in terms of where people can go.
- Compulsory Rights training for government services – sitting alongside many organisations Privacy training.
- Greater visibility and wider public facing initiatives of the HDC regarding disability issues
- MSD's partner means testing for disability benefits – currently our people are being incentivised to die alone, as entering into a relationship results in guilt of their partner having to take on greater financial responsibilities.
- The cost of disability parking permits which results in those with disabilities having to pay for free parking and pay more for paid parking.

Once again, thank you for this opportunity to provide feedback and for the excellent work that the HDC does. If you need any further feedback or input into any of these issues listed above (or any others) please do not hesitate to get in touch.

Ka tū tonu koe i roto i te aroha

Jordana Bealing

(Co-Chair NAMHSCA)

Compiled by: Sherida Davy, Dianne Black, and Dave Snell.

Information released under the Official Information Act 1982
and/or the Privacy Act 2020



13 March 2023

Morag McDowell
Health and Disability Commissioner
Act and Code Review
PO Box 11934
Wellington 6142

Email: review@hdc.org.nz

Tēnā koe Morag

Thank you for asking the National Advocacy Trust's early input into HDC's Act and Code Review.

We believe the Act and the Code provides an important Pou for the New Zealand health and disability system. With the new legislative changes coming into practice, in particular the New Zealand Health Charter proposed in Sections 50-52 of the Pae Ora (Healthy Futures) legislation, the Code and Act still play a vital role in ensuring systemic, organisational or individual health professionals are held to account in delivering fair and equitable services to all health and disability consumers. The promote and protect of the rights of health and disability consumers.

There are definite opportunities to improve the Act including:

- Mandatory education and ongoing professional development for all health and disability professionals on the Act and the Code
- testing the efficacy of the Code with Māori, Pacific, ethnic, disability, rural and other key consumers of health and disability services across Aotearoa

We believe the free and independent role of the National Health and Disability Advocacy Service is an asset for the health and disability sector. The role of Advocacy needs to be strengthened within the Act to continue to empower consumers at the front end to access the appropriate support by having someone work with them, to ensure their rights are protected and promoted. As Drage (2013) states many of the points that may well be put on the table for discussion have been considered in previous reviews of the Act. (Drage, J., (2013). New Zealand's National Health and Disability Advocacy Service: A successful model of advocacy, *Health and Human Rights Journal*)

We welcome to opportunity to feed into this process in more depth and look forward to hearing from you.

Ngā mihi nui

Sarah Hutchings
Chair
National Advocacy Trust

13 March 2023

Rose Wall
Acting Health and Disability Commissioner
By email: review@hdc.org.nz

Tēnā koe Rose,

Thank you for your letter of 3 February regarding your regular review of the Health and Disability Commissioner Act (HDC Act) and the Code of Health and Disability Services Consumers' Rights (the Code).

I would like to thank you for asking for my thoughts at this early part of the process. Given the similarities in our roles as oversight agencies, I understand the need for our respective legislation to be fit-for-purpose and up to date.

At this early stage, my comments are limited to two minor suggestions that may warrant further consideration. I look forward to my Office being more engaged as your review continues.

Secrecy provisions

I understand that the HDC Act does not contain secrecy provisions. The Privacy Act 2020 includes a secrecy provision at section 206. I rely on this provision to ensure that my Office's correspondence between complainants and respondents are kept secret. You may wish to consider whether a similar provision would assist with your complaints processes.

Health information privacy and our working relationship

I am aware that the 2014 review into the HDC Act and Code noted that the then-Commissioner was satisfied with our current system where my Office considers matters relating to privacy in relation to health information. As you are aware, the current system provides that I may consult with you under s 208 of the Privacy Act on any matter relating to my functions, and similarly you can (and do) refer complaints to me pursuant to s 36 of the HDC Act. I consider that there may be benefit in us working together to ensure that where possible, operational matters such as complaint transfers are addressed consistently across our Offices. This would provide greater clarity and transparency for complainants and regulatory parties in relation to our respective processes. While I do not consider that a legislative solution is required, I suggest that you consider whether a Memorandum of Understanding or similar would further strengthen our Offices' working relationship.

Once again, I thank you for the opportunity to provide comment. I look forward to hearing more from your team as the Review progresses, and I am happy to provide advice on any privacy-related issues as required.

Ngā mihi nui



Michael Webster
Privacy Commissioner

13 March 2023

Rose Wall

Acting Health and Disability Commissioner

Act and Code Review

PO Box 11934

Wellington 6142

By email: review@hdc.org.nz

Tēnā koe Rose

Feedback into the scoping of the next review of the Act and Code

Thank you for the opportunity to provide input into the review of the Health and Disability Commissioner Act and the Code of Health and Disability Services Consumers' Rights.

We have detailed specific areas for consideration with regards to input and views of tangata whaiora:

Te Tiriti o Waitangi

We ask that the scoping review explore how the principles of Te Tiriti will be given effect in the Act and the Code of Rights as well as the processes and approach the commission adopts during the review. In particular with regard to the public consultation including:

- Partnership with Māori to design the approach and engagement with Māori with lived and living experience of accessing mental health services
- Ensuring feedback from Māori is analysed by Māori with recommendations that are informed by our communities and disseminated to our communities who have been involved in the process
- Equitable access and a range of options that suit the needs of the community to provide feedback

Further describe each of the rights

An exploration of what these mean to tangata whaiora so that there is a common understanding of the rights, the Act and the processes and support available if people have concerns about their rights being upheld. People often describe feeling 'let down' and 'unheard' when complaining and it is often due to an incongruence with what is 'allowed for' to establish there has been a 'breach'.

There is little education for tangata whaiora on their rights and typically many are fearful of 'rocking' the boat so will not raise any concerns. For Māori and Pasifika in particular this also highlights the potential for discriminatory practices not being reported for fear of not being heard or taken seriously.

We would like to see increased commitment and accountability to ensuring tangata whaiora can access education and support on the code of right and the role of HDC. Raising awareness now about the existing rights and The Commissioners Act may also have the added benefit of people who may be most impacted by the changes being able to better inform during the consultation process.

Inclusion of restorative processes

Feedback from tangata whaiora and people who have advocated on their behalf have often stated challenges with raising complaints whilst receiving service and the impact this has on their care and support received. In some cases it was a fear of repercussions later down the track if they were to seek support in the future.

Exploring the role of restorative practices that uphold the mana of tangata whaiora, particularly when there is a disagreement in the final decisions would be something we would like to see included in the scoping review.

Thank you again for the opportunity to provide some input in to this process.

Ngā mihi nui



Kerri Butler

Director

CAUTION: This email originated from outside of the organisation. Exercise caution when opening attachments or clicking links, especially from unknown senders.

Kia ora Rose,

I refer to your letter of 3 February to our Chief Executive, Margie Apa, regarding the upcoming review of the Health and Disability Commissioner Act, and the Code of Health and Disability Services Consumers' Rights (the Code) to consider whether any changes are necessary or desirable.

Thank you for the opportunity to comment.

Te Aka Whai Ora

We were unsure whether or not Te Aka Whai Ora had been invited to contribute, but would suggest that they would make an important contribution to this korero.

Legal Comment - Pae Ora

As you are aware, the Pae Ora (Healthy Futures) Act 2022 seeks to protect, promote and improve the health of all New Zealanders, and achieve equity in health outcomes among our population groups, including by striving to eliminate health disparities, in particular for Māori. The Act requires all health entities to be guided by the health sector principles, which give effect to the principles of the Treaty of Waitangi (including tino rangatiratanga (self-determination), ōritetanga (equity), whakamaru (active protection), kōwhiringa (options) and pātuitanga (partnership), and are aimed at improving the health sector for Māori and improving hauora Māori outcomes. At a high level, we would suggest that it would be useful for the HDC to run a tikanga lens over the Code (and "content of the Code" requirements in s 20 of the Act), and to consider whether the HDC should be guided by the health sector principles.

Section 7 (health sector principles) is set out in full below, and while many intentionally go beyond the point of delivery of services by providers (you will be aware of the recent mahi done by the HQSC in developing the Code of Expectations setting out how health entities must work with consumers, whanau and communities in the planning, design and delivery and evaluation of health services and incorporating the health sector principles), it would appear that in many respects, the Code of Rights could also speak to the health sector principles directly.

7Health sector principles

(1)

For the purpose of this Act, the health sector principles are as follows:

(a)

the health sector should be equitable, which includes ensuring Māori and other population groups—

(i)

have access to services in proportion to their health needs; and

(ii)

receive equitable levels of service; and

(iii)

achieve equitable health outcomes:

(b)

the health sector should engage with Māori, other population groups, and other people to develop and deliver services and programmes that reflect their needs and aspirations, for example, by engaging with Māori to develop, deliver, and monitor services and programmes designed to improve hauora Māori outcomes:

(c)

the health sector should provide opportunities for Māori to exercise decision-making authority on matters of importance to Māori and for that purpose, have regard to both—

(i)

the strength or nature of Māori interests in a matter; and

(ii)

the interests of other health consumers and the Crown in the matter:

(d)

the health sector should provide choice of quality services to Māori and other population groups, including by—

(i)

resourcing services to meet the needs and aspirations of iwi, hapū, and whānau, and Māori (for example, kaupapa Māori and whānau-centred services); and

(ii)

providing services that are culturally safe and culturally responsive to people's needs; and

(iii)

developing and maintaining a health workforce that is representative of the community it serves; and

(iv)

harnessing clinical leadership, innovation, technology, and lived experience to continuously improve services, access to services, and health outcomes; and

(v)

providing services that are tailored to a person's mental and physical needs and their circumstances and preferences; and

(vi)

providing services that reflect mātauranga Māori:

(e)

the health sector should protect and promote people's health and wellbeing, including by—

(i)

adopting population health approaches that prevent, reduce, or delay the onset of health needs; and

(ii)

undertaking promotional and preventative measures to protect and improve Māori health and wellbeing; and

(iii)

working to improve mental and physical health and diagnose and treat mental and physical health problems equitably; and

(iv)

collaborating with agencies and organisations to address the wider determinants of health; and

(v)

undertaking promotional and preventative measures to address the wider determinants of health, including climate change, that adversely affect people's health.

(2)

When performing a function or exercising a power or duty under this Act, the Minister, the Ministry, and each health entity must be guided by the health sector principles—

(a)

as far as reasonably practicable, having regard to all the circumstances, including any resource constraints; and

(b)

to the extent applicable to them.

(3)

*In subsection (1)(d), **lived experience** means the direct experience of individuals.*

Clinical Comment – Right 10 – Right to Complain

We would like more clarity of the meaning of Right 10 – the right to complain, in particular subsection 7.

Staff can take the view that they have 20 working days to respond to a complaint, without proper consideration of the 10 working day review. Confusingly, Paragraph 4 states that there must be at least monthly progress updates – which leads some staff to infer that they have a month to respond. It is also noted that paragraph 4 deals in calendar months, while paragraph 7 deals in working days. There has been a suggestion from our clinical people that Right 10 could be clarified for both consumers and providers if the timetable and complaint process milestones were stated more explicitly,

I hope the above is helpful, and look forward to talking more as this work continues.

Ngā mihi nui,
Tara

Tara McGibbon ([she/her](#))

Interim Chief Legal Counsel

Office of the Chief Executive

Īmēra: tara.mcgibbon@health.govt.nz

Ph: [REDACTED]

42-52 Willis Street, Wellington

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10-Mar-23

Community Alcohol and Drug Services
Pitman House
50 Carrington Rd
Point Chevalier
1022

Kia ora HDC

Thank you for the opportunity to make this submission on behalf of the consumer team at Community Alcohol and Drug Services in Auckland.

Community Alcohol and Drugs Services (CADS) Auckland is the largest provider of alcohol and other drug treatment services in NZ. Our services include CADS Counselling Service, CADS Medical Detoxification Service, CADS Auckland Opioid Treatment Service, CADS Dual Diagnosis Service, CADS Youth Service and the CADS Pregnancy and Parental Service. CADS provide daily low threshold easy access clinics at five locations and 23 regular satellite clinics.

The consumer team work with CADS clients, leadership, and teams, to ensure CADS is responsive to the needs of the people using the services. Our work rests on important foundation documents including Nga Paerewa: Health and Disability Services Standard and the Health and Disability Code of Consumer Rights.

We make The Code available in all reception areas: we have framed posters on our walls and brochures are given to all clients at their first presentation when clinicians explain to clients that they have rights including the right to be fully informed about how and why their information is collected, stored and shared.

Embedding The Code into CADS' practice has had a number of positive outcomes, perhaps the most significant being that over the years it has become apparent that more clients seem aware that they have rights! Not only that they have them but that they will be supported to enact them.

Dividing The Code into 10 rights makes it easy to remember and easy to describe to others.

Simple headings like Mana/ Respect, Manaakitanga/ Fair treatment etc makes it easy to work out exactly what issue one is dealing with. For example, if a client phones unhappy with some aspect of their treatment it is easy, while they speak, to determine which right may have been breached and then to help the client work out how they would like the issue addressed.

Knowing they have the right to complain and that the service will actively support them through the process reassures people that their complaint will be taken seriously and will not affect their current or future relationship with the service. Although all staff members can hear and record a client complaint it is common for this to be undertaken by the consumer team. We explain to people their rights and the complaint process. This is reiterated to the complainant once the complaint is entered into the e-system as the complainant is sent an acknowledgement of receipt and a written outline of the process.

The main challenge when working with the Code and clients is when the client's issue pertains to a clinical decision they are unhappy about; on these occasions it can be difficult to see how their complaint fits with the ten Rights.

Our team has been working with the Code for over 20 years and continue to find it easy to work with, easy to explain to clients and whanau, and easy to support. Simplicity is the key.

We acknowledge that awareness of The Code varies around NZ. People are better informed in some places than others and few AOD services have consumer roles that work alongside clinical and management teams to support the embedding of Rights in daily practice and support clients to ensure those Rights are met. Many clients do not feel confident to use the complaints process of their local service or of the HDC; just because there are few complaints coming from this sector does not mean people are satisfied with all aspects of their care and service delivery.

Perhaps more active promotion of the Code is required – not just to existing clients but wider – a public campaign would be one way to light the spark of knowledge.

Thank you for the opportunity to contribute to this process. We hope this information will be useful.

We can be contacted on (09) 815 5830.

Ngā mihi



Sheridan Pooley

Regional Consumer Advisor

CADS Auckland

Ph (09) 815 5830 ext [REDACTED]

DD [REDACTED]

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[TeWhatuOra.govt.nz](https://www.TeWhatuOra.govt.nz)

PO Box xxx, City, Postcode

Waea pūkoro: +64 21 123 4567

Te Kāwanatanga o Aotearoa
New Zealand Government

Level 4, 56 The Terrace
Wellington 6011
New Zealand

14 March 2023

Ms Rose Wall
Acting Health and Disability Commissioner
By email: review@hdc.org.nz

Tēnā koe Ms Wall

Health and Disability Commissioner Act and Code of Health and Disability Services Consumers Rights

Thank you for the opportunity to provide feedback in shaping the scope and structure of the review of the Act and the Code. This is a pivotal time in history with significant changes in Health and Disability systems, providing a unique opportunity to consider change to align with contemporary practices and contexts.

We welcome an ambitious review informed by pertinent literature and data. This will include consideration of your Te Tiriti obligations, recent observations from the UNCRPD examination, interim recommendations from the Royal Commission of Inquiry into Abuse in Care, and insights from the ongoing Waitangi Tribunal Health Services and Outcomes Inquiry (Wai 2575).

We would anticipate a thorough exploration of the current Code and the Act, and the consumer experience, so that future approaches can achieve greater effective advocacy and resolution by disabled people, whether their issues relate to disability support services or health.

We would expect to see the Principles of Enabling Good Lives ([Principles - Enabling Good Lives](#)) considered throughout the review process, and reflected in future changes to the Code, Act and associated procedures.

The voices of disabled people need to be heard and we encourage the inclusion of a range of stakeholder and consultation processes, particularly for tāngata whaikaha Māori and others with intersectional experiences (ie the rainbow community).

In summary, Whaikaha offers the following key considerations as you look to establish the scope of your forthcoming review:





Visible alignment of review structure with the articles of Te Tiriti o Waitangi and relevant UN Conventions

Tāngata whaikaha Māori and whānau whaikaha Māori will expect the review and subsequent changes are framed by Te Tiriti and meets the needs of Māori.

Authentic disabled voice must be included in the scoping and review process. This will require a range of approaches, including online and face to face consultations.

Additionally, the following international instruments have relevance:

[Convention on the Rights of Persons with Disabilities \(CRPD\) | United Nations Enable](#)
[Convention on the Rights of the Child | OHCHR](#)
[United Nations Declaration on the Rights of Indigenous Peoples | United Nations For Indigenous Peoples](#)

Exploration of systemic relevance to disabled people

It is acknowledged that disabled people will have cause to raise complaints in a range of settings. At this time, given the separation of disability support services from health, consideration should be given to how relevant and effective the Code and complaints resolution practices has been for disabled people, their whānau and allies.

This includes reviewing the relevance and effectiveness of the processes for resolution and investigation of complaints by disabled people, whether they be about health or disability services. This should include reviewing any data available about the number and types of complaints by disabled people and the outcomes of such.

Consideration should also be given to how the principles of Enabling Good Lives underpin how disabled people interact with the HDC, and how these, in turn, are reflected in the Code.

Mapping the Code of Health and Disability Services Consumer Rights alongside the principles of Enabling Good Lives would enable exploration of this alignment.



The Royal Commission of Inquiry into Abuse in Care, the High Needs Review in education, and the ongoing Waitangi Tribunal Health Services and Outcomes Inquiry (Wai 2575) are relevant to the review process:

[Home | Abuse in Care - Royal Commission of Inquiry](#)
[Highest Needs Change Programme – Education in New Zealand](#)
[Wai 2575 Health Services and Outcomes Kaupapa Inquiry | Ministry of Health NZ](#)

The voices of disabled people in the review process

Again, it is noted that authentic disabled voice must be included in the scoping and review process. Consideration needs to be given to a range of approaches, including online and face to face consultations.

The voices of disabled people are separate from the voices of whānau and advocates, who should also be considered stakeholders in a review process. A review of advocacy, representation and decision-making processes will also be relevant, including discussions about the options for substituted and/or supported decision making arrangements.

Role of the Advocacy Service within the Health and Disability Commission

It will be timely to review the access that disabled people have had historically to the Health and Disability Commissioner and the Nationwide Health and Disability Advocacy Service.

Accessibility

The review process needs to be equitable and accessible.

The review process needs to be supported by alternate formats [Alternate formats - Ministry of Social Development \(msd.govt.nz\)](#). It is noted that the timeframe and costs associated with this will need due consideration.

Looking forward, improvements need to be made to the accessibility, streamlining and ease of use of HDC process.

Timeframes for engagement and response also require review.



Independent complaints mechanism

Given the separation of the health and disability systems in 2022 it is timely to review the scope of complaints that come to HDC. The current HDC system reviews complaints of health services and complaints of disability services.

Over the last few years members of the disability community have asked for an independent complaints mechanism for the disability support system, claiming that the HDC process does not adequately enable disabled people and their whānau to report breaches of rights, abuse, and neglect in a timely and effective fashion.

We recommend that the HDC review considers this request, either as an opportunity to strengthen the HDC approach to better meet the needs of disabled people, or to recommend the establishment of a separate independent complaints mechanism for the disability support system.

With the enactment of the EGL principles and increased access to personalised budgets we will have a new service delivery climate that may well benefit from an independent complaints mechanism for the transforming disability support systems.

Whaikaha welcomes this opportunity to provide input and will continue to be available for further discussions as appropriate. We recognise there are always financial and time constraints to any review and remain interested to work with you to maximise the voice of disability community in addition to providing input from Whaikaha officials.

Ngā mihi



Brian Coffey ([he/him](#))

Acting Deputy Chief Executive Policy Strategy and Partnership

Whaikaha | Ministry of Disabled People

 | [Whaikaha.govt.nz](https://www.whaikaha.govt.nz)

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