Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Act and Code Review consultation questions | Ngā pātai matapakinga

This document contains all the questions we are asking as part of the Act and Code Review consultation. Aside from the required questions, you can answer as many or as few as you'd like. When completed, please either email it to review@hdc.org.nz or post it to us at PO Box 1791, Auckland, 1140.

Please visit https://review.hdc.org.nz to answer these questions online.

Your details (required)

It's important for us to know a bit about you so that we understand whose views are being represented in submissions. It helps us to make sure that any changes we recommend will work well for everyone and have an equitable impact.

1. What is your name? Sal Faid

2. What is your email address? [redacted]

3. Are you submitting as an individual, or on behalf of an organisation or group?

☐ I am submitting as an individual

4. How did you hear about this consultation? (please select)

☐ HDC website ☐ News media X Social media ☐ Internet
X Through my job ☐ Word of mouth ☐ Other (please specify below)

____

Please answer the following questions **if you are submitting as an individual**. If you are submitting on behalf of an organisation or group, please go to page 3.

Which of these services do you engage with the most? (Please select all that apply)

[redacted] [redacted] [redacted]
[redacted] [redacted] [redacted]
[redacted]

What is your gender?

[redacted] [redacted]
[redacted]
[redacted]

How old are you?

[redacted] [redacted] [redacted] [redacted] [redacted]
[redacted] [redacted] [redacted]

What is your ethnicity? (Please choose all that apply)

[redacted] [redacted] [redacted] [redacted]
[redacted] [redacted] [redacted] [redacted]
[redacted] [redacted]
[redacted]

Do you identify as having a disability?

[redacted] [redacted] [redacted] [redacted]

If you are submitting on behalf of an organisation or group:

What is the name of your organisation or group?

What type of organisation/group is it?

- ☐ Consumer organisation/group (please specify below)
- ☐ Iwi/ Māori organisation/group (please specify below)
- ☐ Health and/or disability services provider (please specify below)
- ☐ Central Government
- ☐ Local Government
- ☐ University/Academic
- ☐ Other (please specify below)

Please feel free to provide any further detail:_______________________________

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Share 'one big thing'

This survey contains structured questions that ask for your feedback on each chapter in our consultation document. If you would prefer to give us your feedback as a whole, by telling us 'one big thing' – you can do so below.

If this is all you want to provide by way of your submission, that's fine by us. We will consider all the submissions we receive.

Thank you for this opportunity to provide my perspective on what I consider one of the most important pieces of legislation this country has in healthcare.

If implemented to the full extent the Code ensures people receive quality care and support that they deserve. Sadly, rights are violated daily and opportunities to thrive are lost.

Language Changes

I would like the HDC to consider re-wording the Code to be written in the first person and using complementary inclusive language.

Ngā Paerewa Health and Disability Service Standards 2021 sets a precedent by using the first person to demonstrate language and direction that puts people at the centre of care and support and provides ownership to tangata whaiora. I would like to see the Code re-written to 'I have the right to be treated with respect; I have the right to have my privacy respected; I have the right to have my needs taken into account…'

Specific Use of Language:

Preferred use of terms

- 'I' or person or person using services or tangata whaiora rather than Consumer

- Advanced preferences rather than advanced directives

The Following are specific suggestions to wording changes suggested in the Code

> *Right 4 Right to services of an appropriate standard*
>
> *(4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.*

I think this statement should be expanded to include whanau – who can also be impacted by sub care.

At the least 'that consumer' - sounds like an object – change to person or use I statements

> *Right 5 Right to effective communication*
>
> *(1) Every consumer has the right to effective and accessible communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary, and reasonably practicable this includes the right to appropriate supports and/or support people, including a competent interpreter.*

I am heartened to see accessible – included here.

Include in this right that the onus is on the provider to provide the interpreter – I do not think this is well understood by all parties.

> *(2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.*

I think the term *environment* should be strengthened or provide guidance on what this means – include adequate time and the need to repeat information.

Right 10 Right to complain

(1) Every consumer and/or their representative has the right to complain about a provider in any form appropriate to that the consumer and/or representative.

A definition of *representative* would be helpful – when whānau complain are they a representative or are they seen in their own right.

(*9) A provider may not treat or threaten to treat less favourably than other people in the same or substantially similar circumstances —*

(a) any consumer of services that are or may be the subject of a complaint;

I like the intent of this section and agree that it is necessary.

I feel that (a) is worded ambiguously – is the complaint made by the consumer or have they been complained about. Or both. If the person is complained about they are not covered by the Code – perhaps using complainant to make it clear.

Education and Training of Providers

I would like the Commission to do it a snapshot of training each discipline or field receives in the Code. Not just in the Code itself (although this is sadly lacking) but an assessment of training provided in the elements of the Code – esp, regarding Communication and the right to support.

There is a huge difference in the understanding and implementation of the Code between health professionals – some disciplines receive extensive training as a foundation of their practice – others receive very little.

Although, training is expected through mandatory training schemes, by service providers, it is very brief and often in the form of online self-directed modules that are very light touch – I would say tick box.

The main message of these courses is that you must adhere to the Code of Rights not how to go about it. In fact I have serious concerns regarding the MOH online course which uses a RN in a forensic unit that I think misses the

point completely.

Topic 1: Supporting better and equitable complaint resolution

1.1: Did we cover the main issues about **supporting better and equitable complaints resolution**?

The document talks about outcomes – I feel it is important to state that the outcome is defined by the person who made the complaint.

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

Although the Code states that complaints should also be able to be received and taken seriously if received in any formats this is often not adhered to in practice. There is a strong reliance on written complaints.

People have the right to be taken seriously no matter what form it takes. – eg, in video format. I think that there needs to be a strengthening of process regarding verbal and anonymous complaints – that there is an expectation that services will investigate these complaints similarly to written complaints.

Anonymous complaints are often dismissed and do not enter the quality system because investigations often focus on reading clinical notes, interviewing people – the focus is on the tangata whaiora making the complaint however anonymous complaints should be investigated and taken seriously and managed as a system or service quality improvement.

Provision to make complaints should be made to ensure children and young people can also complain – processes need to be in step with technology and the current nature of what young people are experiencing.

It has been my experience on a number of occasions that a young person is happy to put their complaint in writing but once the complaint has been sent they do not want to know what happens next – this is challenging for the system because resolution of the complaint – timeframes and pinning down what was done as a result of the complaint is driven by the requirements of reporting back/letters back to the complainant. Therefore I agree with the changes to the complaints process but feel it needs to be stronger.

Processes should be in line with the culture (including the need for interpreter services) of the person or person's making the complaint

Complaint resolution can be complicated with regard to employment law and performance management. Often complainants want to ensure this can't happen to someone else and when that means it is escalated to performance management that cannot be discussed with the complainant – guidance regarding this is important. The HDC has an obligation to ensure processes include situations where staff cannot or will not be part of a complaint resolution/restorative process. There must be options and complaints processes need to ensure they are not an all or nothing approach – that although staff may not engage in a restorative approach the service still can and that there is an expectation that they will.

Complaints by whānau need special mention – whānau need to be allowed to follow the complaint process in their own right. I have seen whānau complaint management severely compromised because their loved one does not give consent. This is similar to my above statements. Complaints processes that rely on reading notes and interviewing staff rely on access to the clinical notes therefore when the notes cannot be read because consent is not given the complaint hits a brick wall. I consider a complaint is a complaint and it should enter the complaint process and that there is an expectation that resolution is found.

In summary I think it is important that complaints that do not need a resolution process are still seen as important and are investigated, led to quality improvement and are reported to the appropriate level of the service.

I whole heartily support the process for joint complaints – where whānau or tangata whaiora who are experience similar issues be able to raise a joint complaint and groups can request HDC investigations on specific issues - eg people using the CORS, whānau bereaved by suicide, people held in solitary confinement for extended periods (please see next section for more detail)

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

I agree with the restorative approach and I think it important that complaints lead to quality improvement.

The Ngā Paerewa states that As Service providers – *'We have a fair, transparent and equitable system in place to easily receive and resolve or escalate complaints in a manner that leads to quality improvement'*

However, there is no expectation that this quality improvement is mandated throughout the organisation or system.

Historically, (Health and Disability Sector Standards – NZ8134.1:2008) complaints were seen as a core component of the quality and risk management system (1.2.3.5), Ngā paerewa does not detail this but directs services to a risk based quality system with a focus on outcomes.

My concern is that complaints will be individually focused and service improvements only made where that individual interacted with the unit or service – there is no expected mechanism that large services need to manage and review complaints across the organisation and escalate them to the appropriate level – complaint management should continue to be monitored be every level including governance.

I know that this is best practice however if this is not a requirement then I'm concerned that complaints will not lead to broader quality improvements. Boards of Trustees have a responsibility to monitor complaints if these reporting mechanisms are not mandated then there is a huge risk.

One could say that complaint management is inherently important to a good quality system however I fear that unless it is mandated services will not voluntarily report and respond to them systemically.

Complaints are one of the few areas the tangata whaiora voice can be heard – there needs to be strong safe guards and processes to ensure that when we speak up it is heard and something is done about it. History would tell us that we cannot rely on the good will of services to maintain systems and processes that ensure we effect change.

I feel there is a need for more advocacy and peer advocates to ensure people are supported to access services and complaints processes

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

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

I am encouraged to see the tikanga process the Commission has in place for managing complaints from Māori.

I would like to see it legislated that all Health and Disability services must offer ta au Māori process for tangata whaiora and their whānau.

This process should be available for all who wish to make a complaint and services should ensure staff are proficient in tikanga and the protocol.

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

I whole heartily agree that the Code must be more responsive to Māori and that we must do better but as non-Māori I feel I cannot provide any more thoughts other than we need to give Māori the pen so that they can write what is needed.

We need to truly listen and the HDC needs to be leaders by demonstrating Pātuitanga.

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

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

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

I agree that you have captured some of the issues faced by tāngata whaikaha re language, complaint processes etc and would like the role of Deputy Commissioner Disability to have an expectation of having lived experience of disability – please see the following section.

I think that there is a need to enhance the visibility of the Code for people – ensuring resources are accessible is a first step but I think there is a lack of knowledge regarding some of the more detailed elements of the Code. – eg, having a support person present, asking for or having interpreters services offered.

A request for a HDC investigation

I think more works and investigations should be made to protect the rights of differently abled people who are held in restricted, locked or highly medicalised services such as forensic mental health facilities, intellectual disability mental health units and residential facilities. Tāngata whaikaha in these facilities are restricted in their access to choice and independence – often due to short staffing – it is difficult for them to complain or to have their complaints taken seriously.

I would like to see the HDC work with the Ombudsman who visits these services regularly to collectively improve the outcome for people using these services.

I think people in forensic and acute mental health facilities regularly have their rights breeched with regard to seclusion and restraint. There has been movement to eliminate seclusion however progress has been slow. The focus has been on systems, attitude and resourcing – some effective, some not so much. A lot of work has been done in this space and the system and services has a commitment to change however this is one of the first things to fall away when the system is under pressure.

I feel that the focus has fallen away from people who the system has failed and continues to fail. They are caught in very challenging circumstances. I would like the HDC to focus some attention on the individuals who are experiencing prolonged seclusion events – solitary confinement. Those that are in seclusion for weeks and sometimes months at a time. I would like HDC to proactively be aware of these situations and put in place mechanisms to ensure you know about these events and that these individuals are not hidden in the general statistics of seclusion data – that HDC proactively protects their human rights, provides advocacy as required and holds services and the system to account.

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

I feel that what has been proposed does not reflect contemporary thinking of co-design (please refer to the Code of Expectations – Pae Ora (Healthy Futures) Act 2022). There is an expectation that all health entities engage with consumers and whānau in the planning, design, delivery and evaluation of health services.

Mental Health and Addiction legislation has had the need for lived experience within its Acts and Standards for over 25 years (1998 MH and Addiction Service Standards). I think it a reasonable expectation the HDC do the same.

Adding a 'legislated role focused on disability issues' is doing to and doing for – we want to do it for ourselves.

Therefore - I would like to see lived experience included in the legislation and within the Code – that people with lived experience - tāngata whaikaha be named within the Act as key partners – they will lead or co-lead any review of the Act and the Code and is an integral part of the Commission – especially with regards to complaints.

As it stands *tāngata whaikaha has relationships, provides advice and the commission collects data regarding concerns* – I feel we need to be leading these projects and should have a place within the Commission.

At the very least it should talk about 'partnership with decision making influence' rather than the '*focus on rights….support trust in and engagement with HDC'*

Ministerial reporting should also include the Minster for Mental health.

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

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

4.1: Did we cover the main issues about **considering options for a right of**

appeal of HDC decisions?

I agree that there needs to be a right of appeal – this is an important mechanism to ensure people feel that they have been heard and provided with opportunities to seek resolution.

4.2: What do you think about our suggestions for **considering options for a right of appeal of HDC decisions**, and what impacts could they have?

4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

Topic 5: Minor and technical improvements

5.1: What do you think about the issues and suggestions for **minor and technical improvements**, and what impacts could they have?

5.2: What other **minor and technical improvements**, both legislative and non-legislative, should we consider?

5.3: What are your main concerns about **advancing technology** in relation to the rights of people accessing health and disability services?

5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

Publishing and data protection

This section provides important information about the release of your information. **Please read it carefully.**

You can find more information in the Privacy Policy at hdc.org.nz.

Being open about our evidence and insights is important to us. This means there are several ways that we may share the responses we receive through this consultation. These may include:

- **Publishing all, part or a summary of a response** (including the names of respondents and their organisations)
- Releasing information **when we are required to do so by law** (including under the Official Information Act 1982

Publishing permission

May we publish your submission? (Required)

X Yes, you may publish any part of my submission

☐ Yes, but please remove my name/my organisation/group's name

☐ No, you may not release my submission, unless required to do by law

Please note any parts of your submission you do not want published:

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Reasons to withhold parts of your submission

HDC is subject to the Official Information Act 1982 (The OIA). This means that when responding to a request made under the OIA, we may be required to disclose information you have provided to us in this consultation.

Please let us know if you think there are any reasons we should not release information you have provided, including personal health information, and in particular:

- which part(s) you think should be withheld, and
- the reason(s) why you think it should be withheld.

We will use this information when preparing our responses to requests for copies of and information on responses to this document under the OIA.

Please note: When preparing OIA responses, we will consider any reasons you have provided here. However, **this does not guarantee that your submission will be withheld.** Valid reasons for withholding official information are specified in the Official Information Act.

☐ Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.

I think these parts of my submission should be withheld, for these reasons:

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Follow up contact

If needed, can we contact you to follow up for more detail on your submission? (required)

x Yes, you can contact me

☐ No, do not contact me

Further updates

Would you like to receive updates about the review?

x I'd like to receive updates about the review

x I'd like to receive updates from HDC about this and other mahi

Thank you

We really appreciate you taking the time to share your thoughts with us. If you have provided your details, we'll keep you updated on progress. If not, feel free to check our consultation website https://review.hdc.org.nz for updates or to contact us if you have any questions. We can be reached at review@hdc.org.nz.