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? [redacted]

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
x☐ I am submitting on behalf of an organisation or group x 3

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

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

____

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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]

What is your gender?

[redacted]

How old are you?

[redacted]

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

[redacted]

☐ I don’t know my ethnicity ☐ I don’t want to state my ethnicity

☐ Other/s (please state):____

Do you identify as having a disability?

[redacted]

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

What is the name of your organisation or group? X 3

[redacted]

What type of organisation/group is it? See above.

T [redacted]

group.

☐x 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:

[redacted]

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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.

What is your ‘one big thing’?

All three groups have expressed similar views:

While great to have the HDC Act and the Code of Health and Disability Services Consumers Rights, too often disabled consumers are daunted by the process of making a complaint. It has become slow and difficult.

Linked to this and despite posters and pamphlets and now on-line information, we as consumers are often not familiar enough with the Code of Consumer’s Rights and what falls under it (e.g. our right to informed consent, dignity and respect) and what doesn’t (e.g. ACC), and how to make a complaint and how to access people such as HDC Advocates who can help us do this. **Consumers and Providers and their staff need repeated mandatory training on the HDC Act and Code**.

The HDC Act was passed in 1994, 30 years ago. **Is it time for a real burst of active promotion of the Code especially within the disability community as well as information and workshops on the Act and how to make a complaint and who can help you do this? The disability community should to be a partner in any promotion.**

The Review of the HDC Act and Code makes some good suggestions which would address some of the above, e.g. 1.1 g Strengthen the Advocacy Service, however related to that we are also concerned:

- **Some suggestions e.g. changes to the Act, could increase complexities,** and
- **how and when** many good proposals will be implemented, and
- **by whom and how**?

Do you anticipate New Funding? Don’t over promise.

Topic 1: Supporting better and equitable complaint resolution

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

complaints resolution?

By and large, yes e.g. by ‘Helping all New Zealanders to speak up for themselves and raise concerns directly with providers, including with the help of advocates’. But getting an advocate now is not easy – you need to know how to do this and their role.

The term ‘Clinical navigators’ is limiting – will you also have Support Navigators for matters that are not clinical? You should.

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

We support your suggestions:

A Amend purpose statement – but define ‘people centred practice’. Not all understand what this is.

B Clarify cultural responsiveness –but there needs to be a separate section for recognising the needs, values and beliefs of groups such as disabled people, LBTQIA and diverse ethnic groups. Some groups see themselves as a sub-culture, but not all do e.g. older people who have age-related disabilities may not identify as a sub culture (elsewhere you say they are included)

C Clarify the role of whanau –In some senses Right 3, Dignity and ‘Independence’ is still appropriate (e.g. disabled people may want to live independently), in others ‘Autonomy’ is the better word. Be careful. Right 10, Right to complain – yes support people can be able to make some complaints, but need for care here. The disabled person needs to give permission for them to do this if possible.

E Protect against retaliation, definitely yes but how?? We feel providers are unhappy when we complain externally

F Clarify provider complaints processes, but who will do this?

G Strengthen the Advocacy service, but how and who?? Need more staff.

H Improve the language of complaint used in the Act, but who will do this?

Our concerns are with how and who does these things. Will you have new staff, including qualified disabled staff?

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

Not sure what other changes, both legislative and non-legislative, are needed. Need to show the Act, broken down into understandable chunks, for those interested, to comment further.

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**?

Good that you now have a Director Maori and a small team. They need to consult widely on these issues. Our Maori member of CAG Karori and Capital Support's Consumer Advisory Group was not available to comment – he has just shifted South.

A Incorporate tikanga into the Code

B Give practical effect to the Treaty, including a Deputy Commissioner Maori sounds sensible, as does Maori to benefit equitably from health and disability rights as Maori, so complaints processes better align with tikanga. There will be issues re benefiting equitably from' rights' as opposed to 'services'. The current Government does not seem to support measures to achieve equity within health and disability services for Maori.

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?

Need to consult with Maori, including widely with disabled Maori. See above.

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**?

Need to consult with Maori, including widely with disabled Maori. See above.

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**?

Mostly yes.

You refer to ‘tangata whai ora’ – define here, the first time you use it, as well as ‘Words we Use’
Combining people with physical and other disabilities and people with drug addictions and mental illness is often difficult.
Many issues related to adults unable to consent, as well as participating in research. Under UNCRPD (which should be spelt out and defined in your ‘words we use’), all people can consent to some things, with support (see the Law Commissions recent review).

You say you have made improvements. Have you publicised these? I haven’t seen reports. Publicise reports and improvements e.g. through DPA’s Information Exchange.

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?

A Strengthen disability functions – still not sure what this fully means. Yes to reporting to the Minister for Disability Issues, as well as to the Minister of Health. Can we make complaints about Whaikaha? How often would you report, and with how much information? Made public?

B update definitions relating to disability but be careful, the definitions need to be widely understood, so publicity is needed, or confusion. Not everyone will know about current thinking and the UNCRPD.

C Strengthen references to accessibility, including how HDC and Advocates work. Is any advocate proficient in sign language? Good to take out 'reasonably practicable', I remember the storm over this in 1994; the Deaf Community will now be pleased. Are there now enough interpreters?

D. Strengthen and clarify the right to support to make decisions, under Code Right 5, 7, 7 (3), 7 (4), 7 (4) (iii). These are all critical, and must align as you say with the Law Commission's Adult Decision-making Review. It is all very well to say this, but how will you see it is implemented and understood?

Remember people who retain decision-making ability but cannot express their views. Some people can no longer speak, or move any part of their bodies. It is not just people with learning disabilities/ dementia affected. And it is not only caregivers and providers who will need help to understand and implement changes, other professionals such as doctors and lawyers will need help (a lawyer EPOA told me how difficult it has been supporting a client).

E. Unconsented research. We agree some research may be allowed, if it poses minimal foreseeable risk and a minimal burden on the consumer. Good that 'suitable people who cared about the person' could prevent participation, with ethics committee approval, but how do you judge someone is a 'suitable person' (are there any criteria?)? I don't have time to read the full 2019 report. You could have put critical pages in an addendum to this Review.

Some in the disability community may be against this suggestion.

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**?

We think you need some small working groups of disabled people and their families/ whanau familiar with these issues, to workshop this whole area, including disabled lawyers, if you have not already done so. People who have been through the complaints and advocacy processes and are familiar with the complex issues involved could point to areas needing improvement.

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**?

This is another complex issue. The HDC could find well-funded providers appealing, and it could be costly. Theoretically there could be the right of appeal by way of natural justice, but it could further delay an already protracted complaints process and decision-making, and be hard on the appellant.

[redacted]

[redacted]

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?

a. Introduce a statutory requirement for review of HDC decisions – Theoretically yes, but consider staff and legal ramifications carefully. You will need Govt. support.
b. Lower the threshold for access to HRRT – spell out what HRRT is. This is complex issue from my experience.
    - Presumably well qualified lawyers have developed and supported this proposal? Theoretically lowering the threshold sounds sensible, but there is a need for caution, or too many cases may go to the already overloaded HRRT.
    - Judges may not be familiar with many HDC cases. (as the various Judges were not familiar with my HR case, it felt like a lottery every time the HRC faced a judge/judges on my behalf). You will need to educate judges on the HDC as happened when the Intellectual Disability and Compulsory Care and Rehabilitation Act (IDCCRA) was introduced in 2003.

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

You need to consider if a right of appeal can lead to damages, and if so, who pays? If a provider appeals, and wins, will the HDC or HRC pay?? This was an issue in my HR legal case.

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?

Most of the minor and technical improvements, some consequential, seem sensible e.g.

b. an offence under the Act rises from $3000 to $10,000. We hope providers will think twice before offending, although this change will not be a deterrent to large providers. Should there be a scale of offence, based on the size of the provider?

d. Not sure I like the term ‘aggrieved person’ even if defined, Is there not a better term e.g. appellant. (‘Aggrieved’ sounds like ‘the other party’ in a divorce.)

d. Good to require information in some cases (grounds need to be clearly spelt out) and to withhold information where appropriate (f), so that lurid/ distressing and personal details do not end up on TV and people are not identifiable.

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

We are not familiar enough with the Act to comment at this time.

The Code:

https://www.hdc.org.nz/your-rights/about-the-code/the-code-summary/

Right 1: The right to be treated with respect.

Right 2: The right to freedom from discrimination, coercion, harassment, and exploitation.

Right 3: The right to dignity and independence.

Right 4: The right to services of an appropriate standard.

Right 5: The right to effective communication.

Right 6: The right to be fully informed.

Right 7: The right to make an informed choice and give informed consent.

Right 8: The right to support.

Right 9: Rights in respect of teaching or research.

Right 10: The right to complain.

Looking down the Code rights, from the point of view of someone receiving disability services (in my case, in a residential service, but others in our groups are living in the community), I find your review does not mention many rights important to us e.g.

Right 1: The right to be treated with respect
Right 2: The right to freedom from discrimination, coercion, harassment, and exploitation.
Right 3: The right to dignity and independence. (you do cover 'independence')
Right 4: The right to services of an appropriate standard.
Right 8: The right to support.

All of these are critical to our wellbeing. Your review of rights is largely legalistic, although supportive and fair legal frameworks are important. I hope many other comments are received from a consumer of services point of view.

Your recently released Review of HDC complaints on Residential Disability Support Services (released after the draft of this submission was written) shows all Code rights are important to disabled people living in group homes and many residential services - a pity there did not seem to be complaints from people funded by Whaikaha who were living in Aged Residential Care (ARC) as some of us do.

We need help to ensure our rights above are available to us, by training of consumers and Providers and their staff (see in our 'one big thing' above). Advocates help but there are not enough of them

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

You only seem to be referring to AI. This can both help and be a threat.

In our Groups, many of us are dependent on assistive and medical technology, e.g. my oxygen concentrator, Bi-Pap assisted breathing device, powered wheelchair, blind people need good access to adaptive computer technology – this could be linked to AI.

HDC needs to support our battles and rights to get assistive and medical equipment services of an acceptable standard via sufficient funding. This is a huge area. Be careful if a government agency (e.g. Whaikaha on behalf of Enable) takes you to appeal, they (government agencies) seem to find the huge money involved, even though Crown Law is not cheap.

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

See 5.3.

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)

☐ Yes, you may publish any part of my submission

☐x Yes, but please remove my name/my organisation/group's name x 3

☐ 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:

See below.

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.

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

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

I would like references in 4.2 to my personal court case Smith versus Air NZ withheld as this paragraph was mildly critical of the HRC when I know they did their very best under difficult circumstances and it cost a lot. It was written to illustrate a tangential point I making to the HDC, and I put it in brackets to show this.

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

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

Thank you

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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.