

Submitted to About the Act and Code Review  
Submitted on 2024-07-30 12:56:23

Your details

1 What is your name?

Name:  
[Redacted]

2 What is your email address?

Email:  
[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?

Select from the following options:  
Through my job

If you selected other, please specify below:

Questions for individuals

[Redacted]

[Redacted]

[Redacted]

[Redacted]

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[Redacted]

[Redacted]

[Redacted]

[Redacted]

Questions for organisations/groups

1 Name of your organisation or group (if applicable)

Organisation:

2 Type of organisation/group (if applicable)

Organisation - type of organisation/group/ropū :

Please feel free to provide any further detail below:

Share 'one big thing' or upload a file

5 Are you here to tell us your 'one big thing'?

Your one big thing::

6 Upload a file

File upload:  
No file uploaded

Not Answered

## Topic 1: Supporting better and equitable complaint resolution

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

Please add your response below:

I think you have covered the main issues in excellent detail.

As the advocacy service is able to facilitate a consumers concerns directly with the provider they are well placed to facilitate equitable resolution. There is a need for them to be resourced sufficiently to enhance the options available.

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

Please add your response below:

I think to be equitable for multiple ethnicity consideration needs to be given around how complaints can be received from whanau and groups who are aware of issues rather than just focusing on an individual with a complaint.

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

1.3 changes - supporting better and equitable complaint resolution:

When attempting to be more equitable and person centred there is a need for more time and resources. It is important to establish whether the government is prepared to support your vision to oversee the sector in this manner.

I think the idea of looking into protecting against retaliation is good, it is challenging to establish what that looks like in practice as often providers can give justifications for their actions.

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

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

Please add your response below:

I think incorporating Mana into the code is an excellent idea, it is a concept that is starting to be widely understood across the community and regularly is referred to when Māori consumers raise concerns.

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

Please add your response below:

I support the ideas and note that Māori engagement will increase with the provision of the director of Māori role. I think that Māori concepts and language in health are key to everyone receiving better care.

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

Please add your response below:

It may be worth considering how important meetings are for Māori consumers as there is a tendency for providers to decline meetings when there is a perceived lack of time.

## 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?

Please add your response below:

I think there is a very challenging aspect of disability to address - those in residential care who are unable to speak up for themselves. At times we have seen carers themselves wanting to speak up on behalf of those people when particular services don't have the best interests of residents at the centre of care. Often these consumers don't have family members to raise concerns for them or can't even physically speak. I don't claim to have answers, but it is on my mind that this is a key area to consider.

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?

Please add your response below:

I really like what you have written regarding research participation, I think that could make a significant difference for the sector. I have observed issues with providers disregarding a patient and talking directly to staff or family instead. I acknowledge that this is really hard to get right and may be around the need for education but also it may improve with new wording around decision making capacity.

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

Please add your response below:

There is another challenging area which again I don't have the answers to where people with disability have a particular view of what they would like and their guardian which may be family disagree. This can cause tension for organisations who wish to facilitate the person with disability to have as much autonomy in their life as possible. It is really outside your remit with the exception that the provider should be affirming the consumer's position where possible. The language that you have suggested using may well support providers who wish to put the consumers view first.

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

4.1 Have we covered the main issues about considering options for a right of appeal of HDC decisions?

Please add your response below:

This appears very thorough.

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

Please add your response below:

I think that if the option of making it easier to access the HRRT it would be important to reduce the time it takes to investigate complaints as there are impacts on the stress levels of our health and disability providers. It wouldn't be helpful to make the system more cumbersome for those navigating it.

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

Please add your response below:

The options you have outlined are good. It would be good to consider whether consumers would feel that the outcomes are improved by having these appeal options or whether it makes no difference to their outcome.

## Topic 5: Minor and technical improvements

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

Please add your response below:

I think they make good sense and should be actioned.

I've noted personally that the area that my rights have not been fully considered has been where students are involved. It seems that providers need clarity around this.

When there is retrospective research, my interpretation is that it would be a paper-based review process, if this is going to support our ability to understand health conditions and needs the ability to engage in this should definitely be considered. The code is designed to enable better care and reduce harm, personally I wouldn't have an issue with researchers accessing my health history if it was kept anonymous and appropriate parties were overseeing its use.

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

Please add your response below:

5.3 What are your main concerns about advancing technology and its impact on the rights of people accessing health and disability services?

Please add your response below:

I think the rights need to apply to any provider offering AI as a service and they should be responsible for putting in safeguards. It needs to be made clear to consumers when AI is being used and for them to be able to opt out.

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

Please add your response below:

Publishing and data protection

May we publish your submission?

Yes, but please remove my name/my organisation

Please note any part(s) of your submission you do not want published::

Reasons to withhold parts of your submission

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

No

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

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

Yes, you can contact me

Would you like to receive updates about the review?

I'd like to receive updates about the review