Response ID ANON-C5F6-7WJF-J

Submitted to About the Act and Code Review Submitted on 2024-06-18 12:50:00

Your details

1	What	is	your	name?
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2 What is your email address?



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: Other (please specify)

If you selected other, please specify below: Yellow Brick Road

Questions for individuals



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:

No. You should extend SOME aspects of the Code rights to whanau caregivers. If we are supporting our loved ones as consumers, are we not also users of the service to some extent? For example, whanau caregivers should be treated with Respect / Mana and given Fair treatment / Manaakitanga. This is particularly important if you intend allowing for complaints to be made by support people on behalf of the consumer.

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:

Your suggestion for amending Right 10 (right to complain) to explicitly allow for support people to complain is a much-needed improvement. When young people suffering from significant mental distress receive inappropriate care they are not able to effectively complain themselves. They may not be aware of their rights or the level of care they have a right to expect. Complaining could also be a source of further distress. Allowing support people to complain on their behalf could improve the standard of care and support they are receiving and help to improve outcomes for others too.

- 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:

Under the section about clarifying the role of whanau, you talk about consent. This area needs further review in relation to young people. Many organisations now consider that youth services should continue until the age of 25. Your proposals do not really address how providers can enable appropriate whanau engagement and participation for this age group. While a young person suffering significant mental distress and suicide ideation may appear capable of making decisions, their decisions often further damage their wellbeing. This includes decisions around giving consent: they may need support when deciding on consent. What does this support look like? Who provides it? Wrap-around care that includes whanau engagement can often lead to better outcomes. Especially if the young person still resides at the family home. You acknowledge that there are problems currently with how whanau are involved - "we are hearing that how this works in practice is poorly understood". However, it is unclear how your proposals will actively resolve this issue for whanau supporting youth disabled through mental distress and/or harm from substance use. Changes need to be made that will pre-empt the need to raise a complaint and make a complaint unnecessary.

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

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

Please add your response below:

NO. Your definition of disability remains unclear. If it now includes "people with lived experience of mental distress and/or harm from substance abuse" why are mental health and addiction still treated differently? Also, the following statement needs review: "disability services include whanau carers where there is an employer/employee or contractual relationship for services". What about whanau carers of young people with a disability? Do whanau really need a contract when acting in the role of carers for dependent children?

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

Please add your response below:

Your proposals regarding support for decision-making need further work. A young person suffering from significant mental distress and suicide ideation may still be considered to have decision-making capacity. However, depending on their mental state or mood at any given time, the decisions they reach may cause them further harm. Your proposals do not explain how young people are supported to make the best choices about their care. Who should do this? What about whanau engagement where the young person still lives at home? Decisions can have a huge impact on family members - shouldn't they also be consulted? What about whanau carers who are affected by decisions in which they are not allowed to participate?

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

Please add your response below:

Allow for young people disabled by long-term mental distress or harm from substance use to have a whanau carer appointed as agent. This would bring the Act and Code in line and provide for consistency across all types of disability.

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:

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:

Yes, I agree with the proposal to introduce a statutory requirement for review of HDC decisions. The original decision-maker should have a right to be heard, but the process must include peer involvement or independent review.

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:

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:

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:

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?

No. do not contact me

Would you like to receive updates about the review?

I'd like to receive updates about the review, I'd like to receive updates from the HDC about this and other mahi