

Response ID ANON-C5F6-7WQR-5

Submitted to About the Act and Code Review
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Your details

1 What is your name?

Name:
Erika Butters

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]

[REDACTED]

[REDACTED]

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[REDACTED]

[REDACTED]

[REDACTED]

Questions for organisations/groups

1 Name of your organisation or group (if applicable)

Organisation:
Volition Solutions Limited

2 Type of organisation/group (if applicable)

Organisation - type of organisation/group/ropū :
Other (please specify below)

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::

It is important that the Code be used as a way to socialise Supported Decision Making. This is captured in principle through the current Code, but could be strengthened in language and execution in a revised Code.

HDC has a role to play in being a hub or home for Supported Decision Making theory and practice in New Zealand.

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:

Yes.

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 agree with all of the proposed changes, and particularly want to emphasis my endorsement of changes to allow complaints to be made by supporting people on behalf of the person. This has historically been a recurring gripe for advocates.

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:

The KPIs for Advocates and for the Advocacy service need to be carefully reviewed also - currently there are benchmarks and targets for speed of resolution, processing and file closure, that can inadvertently result in compromised service and only partial resolution - resulting in a poor service. A review of how the advocacy service and complaints are reported on should also follow the review of the Act and the Code.

The Advocacy service should have a greater focus on disability - with consideration to having disability specific advocates who are in-situ, present and accessible in communities.

It is also important that advocacy support is available to make a complaint in the first place.

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:

This is not my area of expertise, but I agree with the issues identified.

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 agree with the suggestions recommended.

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:

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:

An additional issue is that in the "Health and Disability Commission" disability has always been the poor cousin to health. This is reflected in the statistics around the number of complaints received annually that relate to disability services. This is not because there aren't issues of concern with providers, but it is because the complaints process has been inaccessible.

There needs to be greater elevation of Disability across the Commission, in the Act and in the Code.

HDC also has a role to play in being a government home and proponent for Supported Decision Making. SDM should be explicitly included as a right in the Act - not just implicitly - and should introduce and socialise the language of Supported Decision Making, will and preference, and safeguards. The suggestions already lean towards this approach.

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 agree with all of the recommendations.

In addition to the suggestion for Right 7 (4)(c)(ii), it is important that Right 7 (4)(c)(i) also be revised to acknowledge that it may not be possible to determine whether the obtained the views / will and preference of the consumer would be consistent with the informed choice they would have made if they were "competent," particularly if that person has never been regarded as having decision making capacity due to a lifelong learning disability.

Their will and preference should still be considered - so that it does not default to an either or approach of either considering their views if they are consistent with what they would have been if competent (i) OR the views of other suitable persons (a best interests approach).

Regarding the ability to participate in low risk research - I do believe this is important so that data can be obtained to improve health and wellbeing of disabled people. I agree with the proposed threshold considerations for participation.

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:

Having disability specific advocates who are in-situ in the community and accessible for disabled people to connect with.

Having a greater education role with disabled consumers directly, not just the workforces of disability service providers.

Providing tools / templates for disability service providers to self-audit their services against the code.

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:

I think that there needs to be a focus on reducing wait lists - because currently some of the dissatisfaction will be with the process and not the decision. So working on improving the process (and wait times) could have a significant impact on reducing the number of potential appeals.

There also needs to be greater clarification between the differences of advocacy support as a response to a complaint, and an investigation as a response to a complaint, and what appeals relate to.

While it is important to have a right to appeal, this could blow out already untenable wait times.

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:

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:

Improve service delivery to reduce potential appeals

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:

Agree with the considerations. Particularly would be in favour of a 10 year review cycle if each review is purposeful and in depth. Some previous reviews have been tick box exercises with little real potential for change and impact. This review has been good.

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:

That the introduction of new technologies and AI be balanced for each use case with the clear benefits and efficiencies against the potential risk factors.

In other words - I do not think new technologies should be unduly restricted or withheld from implementation, but they need to have some testing, quality control and reporting methods attached.

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

Please add your response below:

It could be appropriate to include the need to consent for health and disability services to include the use of AI, and an explicit responsibility for service providers to provide information on the AI interventions that are offered.

Publishing and data protection

May we publish your submission?

Yes, you may publish my submission

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