Response ID ANON-C5F6-7W24-8

Submitted to About the Act and Code Review Submitted on 2024-07-31 16:38:18

Your details

1 What is your name?

Name:

2 What is your email address?

Email:

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

I am submitting on behalf of an organisation/group

4 How did you hear about this consultation?

Select from the following options: Through my job

If you selected other, please specify below: From HDC

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 : Health and/or disability services provider (please specify below)

Please feel free to provide any further detail below:

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:

Whilst the document highlights areas of development, one notable omission is a lack of accountability of timeframes for resolution. We think the act and the proposed changes need a review period specified to specify accountability e.g are the proposed changes effective or not reviewed every 24 months.

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:

We agree that the consumers / clients and/or their whānau should be encouraged to approach the providers directly to support early complaint resolution.

Below are some considerations specific to the timeframes provided by the HDC for providers to:

- 1) Investigate concerns,
- 2) Implement corrective actions and
- 3) Measure effectiveness of the actions.

Currently, for a Provider Referral, Formal Referral to Advocacy and a Request for Information from the HDC, we are provided with different timeframes but the same complaints process is followed within the business regardless of whether it was a complex complaint or a straightforward complaint from

the HDC.

Hui ā-whānau and hohou te rongo options are a forward way of thinking and would be a good way for providers to connect with clients - something to consider here is when it would be most appropriate to.

Currently, when we are asked to meet with consumers, it is either at the start of the process to understand their concerns further or at the end, to discuss our findings and provide our response letter. In any case, this would require consideration of resources and allocated time to plan with meeting the schedules of consumers and staff members.

With regards to the Advocacy Service, our experience is that we often have to wait a long time to hear back regarding FRAs. This may take between 8 to 12 weeks until we hear back from the allocated advocate. This timeframe is too long, yet crucial towards an early complaint resolution process.

In the past, we have been asked to not make contact with the consumer, before the Advocacy Service makes contact, to deal with the complaint. We feel that the current process does not align with the expectations of a speedy and efficient resolution process. We suggest that whilst the advocates await to contact the consumer, the provider should also be asked to work towards a resolution directly and to update the advocate on any progress / resolution that might occur during that timeframe. Within the 8 to 12 weeks, the complaint may get resolved directly with the provider.

- 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 wording in the act needs to define the terms "fair, simple, speedy and efficient resolution" The wording referred to is too broad and open ended. Defining these terms in the context of the act will provide clarity for anyone wanting to interpret and reduces ambiguity.

In regard to the application of the Code to children and young people, and people whose decision-making capacity is affected. We refer specifically to young people 16 years or older with capacity to make decisions, can say yes or no to medical treatment just like adults can (Care of Children Act 2004):

- The age figure needs to be considered an increase from 16 years to 18 years. Increasing the age to 18 years may support mental maturity when providing consent to any medical or surgical treatment or procedure. The information that will support the young person's decision making should be communicated in a form, language and manner that enables the person to understand it.
- At 16 years of age, we believe there should be a requirement that parents/caregivers and the young person concerned sign off collectively on any medical treatment, providing it is in the best interest of the young person.
- If no one is available to provide consent, we agree that the provider may provide services where it is in the consumer's best interests, and other conditions in Right 7(4) (Right to make an informed choice and give informed consent) have been satisfied.
- There needs to be an option to allow the young person's extended family e.g parents brother, uncle, mum, etc. (particularly for Māori and Pasifika) who qualify under the best interests for the young person in being able to be engaged in consultation on what is best for the young person.

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:

It would be good to understand what the process looks like and how the Māori community would benefit from having the new Māori leadership role and team, with clarity around what "responsive to the needs of Māori" looks like in practice.

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:

We believe that having te reo Māori translation of the Code would assist in responding to the needs of Māori. It is important that the Act and Code of Rights use simple language so that it is easy for people to understand and interpret. It should be accessible to people with the lowest levels of literacy. Another consideration is an access to an easy read.

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 would also be good to see how the Act and Code is responsive to the needs of the Pacific community alongside our other diverse ethnicities here in New Zealand. It would be good to understand how HDC will utilise the role of the Māori Director and what benefits this will bring to the process.

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:

It would be good for the HDC to explain the intended outcome of the opioid substitution treatment analysis and how will this improve access and application of the HDC for disabled people.

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:

We strongly agree with adding a requirement to report to the Minister for Disability Issues could strengthen HDC's ability to promote and protect the rights of tangata whaikaha | disabled people using health and disability services.

Relating to Section D - supported decision making (SDM)

We would like to see the SDM process made more robust and less of a guide. This then needs to be applicable in a legal sense (not just to give people a choice of what they would like to do / choose to do). The SDM framework needs to transcend industries including court proceedings and financial institutions. It was re-worked during COVID to vaccinate people, but banks are still unwilling to engage with people who need a SDM process.

Updating the language in Right 7(4) from consumers' 'views' to 'will and preferences' in alignment with the language of the CRPD will be a good change. The key will be ensuring that the guidance or methodology is consistent and can be applied in a broader sense in mainstream interactions.

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:

The code needs to be applicable beyond the scope of healthcare or disability support provision. The guidance and accountability need to stretch beyond healthcare / support provision to address legal, financial and day to day mainstream barriers of a person with a disability.

The code of rights should include the right to access services that people are eligible for. This would specifically address the Needs Assessment Service Coordination (NASC) process, which can often be subjective and inconsistent. Additionally, this would expand the coverage of the HDC Advocacy service to include access to services.

Legislative changes for Consideration:

Inclusion of the Right to Access Eligible Services

Amendment Proposal: Explicitly include the right for people to access all Health and Disability services they are eligible for.

Rationale: This ensures that tangata whaikaha are not unjustly denied services due to subjective interpretations or administrative barriers.

Expansion of HDC Advocacy Services

Amendment Proposal: Extend the scope of HDC Advocacy services to include support for accessing eligible services.

Rationale: Currently, the HDC Advocacy service does not cover issues related to access to services, leaving tangata whalkaha without crucial support in navigating and securing the services they need.

Non-Legislative Changes for Consideration:

Training and Capacity Building for NASC Assessors

Initiative Proposal: Implement comprehensive training programs for NASC assessors to ensure they understand the diverse needs of tangata whalkaha in line with EGL Principles and can make objective, informed decisions.

Rationale: Consistent and informed assessments will reduce subjectivity and improve service allocation and Enable Good Lives for tangata whaikaha.

Enhanced Support for Service Navigation

Initiative Proposal: Provide additional resources and support for tangata whalkaha to navigate the service system, including dedicated service navigators and improved information dissemination.

Rationale: Many tāngata whaikaha face challenges in understanding and accessing the services they are eligible for. Enhanced support will empower them to secure the necessary services.

Community Feedback and Continuous Improvement

Initiative Proposal: Establish mechanisms for ongoing community feedback and continuous improvement of the NASC process and related services.

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:

Rationale behind increasing fines, doubting its effectiveness in improving service experiences and suggesting that higher fines may not lead to better outcomes for affected individuals

We understand there is no current template for the appeal process. HDC should develop an appeal template for providers or complainant to provide accurate information and explanation.

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:

Both the original decision maker and the Complaints Assessor should not be involved in the Closed File Review.

This suggests a generally smooth process with HDC but acknowledges the importance of maintaining the option to appeal.

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:

Enrolment of third party (Independent of HDC) should be considered. There is a need for independence in validating the review process, suggesting that this would prevent prolonged cases and ensure a balanced approach to HDC 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:

Suggestion g – We agree with HDC's proposal to expand the requirement for written consent for sedation that is equivalent to anaesthetic. Health professionals are required to seek written consent from any person who requires sedation, and this should be sought from the person receiving the treatment, Welfare Guardian and/or activated Enduring Power of Attorney.

Suggestion h – We propose that HDC provide a clear definition of what constitutes as a significant risk of serious adverse effects. It would be good to have the definition or criteria aligned with the definition as outlined from the Quality, Health and Safety Commission.

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

Please add your response below:

A suggestion to shorten the acknowledgment period than the current five days to provide quicker reassurance to complainants by the HDC. This waiting period can exacerbate the emotional impact for the consumer.

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:

Make accommodation within the code to accommodate the use of technological advancements to supplement supported decision making.

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.:

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?