

# 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 <u>https://review.hdc.org.nz</u> 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?

2. What is your email address?

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

- $\Box$  I am submitting as an individual
- x I am submitting on behalf of an organisation or group

4. How did you hear about this consultation? (please select)			
☐ HDC website x Through my job	<ul><li>☐ News media</li><li>☐ Word of mouth</li></ul>	<ul> <li>□ Social media</li> <li>□ Other (please specify</li> </ul>	□ Internet v below)



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)

What is your gender?

How old are you?

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



#### Do you identify as having a disability?

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

What is the name of your organisation or group?

IHC

### What type of organisation/group is it?

x Consumer organisation/group (please specify below)

- □ Iwi/ Māori organisation/group (please specify below)
- x Health and/or disability services provider (please specify below)
- □ Central Government
- □ Local Government
- □ University/Academic
- $\Box$  Other (please specify below )

Please feel free to provide any further detail:\_



#### 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'?

The discussion paper reveals that over 25 percent of complaints received by the Health and Disability Commissioner (HDC) come from disabled people. IHC believes this is just the tip of the iceberg when it comes to concerns about disability service providers.

In our direct work with people who have intellectual disabilities, we frequently encounter complaints about basic issues in residential care. These often stem from repeated instances where individuals are denied the ability to make simple decisions about their own lives.

Real-life examples include situations where intellectually disabled people have been prevented from:

- Rearranging their bedroom furniture,
- Attending the funerals of loved ones,
- Having a front door key,
- Choosing when to go to bed.

Many of these instances go unreported, but as they accumulate, they significantly diminish the quality of life.

IHC believes that more outreach is needed within residential care homes to ensure that intellectually disabled people can easily lodge complaints and have these low-level issues addressed.



#### **Topic 1: Supporting better and equitable complaint resolution**

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

No response.

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



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



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**?



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?

No response.

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?



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?

Answer on page 4.



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?

IHC supports the following measures:

- The establishment of a legislated role dedicated to disability issues.
- Regular ministerial reporting to the Minister for Disability Issues.
- Explicit provisions to ensure people receive the support they need to understand information. The specific accessibility needs of intellectually disabled individuals are often overlooked. These needs include sufficient time to process information, materials that match the appropriate level of complexity, and content tailored to the individual's literacy level.

IHC generally endorses initiatives aimed at increasing the participation of intellectually disabled individuals, especially those deemed unable to consent, in low-risk research. Additionally, we advocate for the inclusion of a requirement that specialist ethics committees include representation from individuals with lived experience of disability. Importantly, this representative should have personal experience with cognitive disabilities or illnesses and a deep understanding of the unique challenges faced by those considered to lack the capacity to make decisions about their lives.

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**? Answer on page 4.



## 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**?



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?

No response.

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



### **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? No response.



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

No response.

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



No response.

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

No response.

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)

- x Yes, you may publish any part of my submission
- □ Yes, but please remove my name/my organisation/group's name
- $\Box$  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:

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.

□ 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:

## 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

 $\Box$  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

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

#### Thank you

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 <u>https://review.hdc.org.nz</u> for updates or to contact us if you have any questions. We can be reached at <u>review@hdc.org.nz</u>.