

Submitted to About the Act and Code Review
Submitted on 2024-08-11 03:46:05

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:

Social media

If you selected other, please specify below:

Questions for individuals

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[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::

It took me 6 years (10-16years) of thinking I was going mad and wanting to die before I finally got diagnosed and got any support. I went to so many Drs including hospital specialists and they just labeled me as having anxiety ignoring all my physical symptoms. In this time I lost out on any support I could have had to gain an education and at 16 my school said they couldn't support me staying on with M.E. So I was forced to leave. Drs including paediatric specialists need education on recognising and diagnosing M.E. Teachers also need education on recognising symptoms of M.E. in their students and how to support students with sensory sensitivities, brain fog, sleep disorders, physical exhaustion etc. We also need a lot more M.E. Specialists. Mine is so booked up it is difficult to get an appointment and she has reached capacity for new patients. A survey needs to be done to find out how many people including children and teenagers actually suffer from M.E. in New Zealand. Difficult as most sufferers like me probably get wrongly labelled as mentally ill. The figures for M.E. sufferers in N.Z. seem to be many years old. If people realised how many people suffer from M.E. and now long covid also and how many lives could be saved by just recognising it and treating sufferers and their carers with support and respect, maybe they would be more interested in educating themselves.

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:

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:

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:

Give children/ students a voice. Support by independent people educated about M.E. and other chronic illnesses within schools. Independent from Principal and staff - not employed by school

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:

More provision needs to be put in place for physical carers... if in whanau to be paid a carers allowance (my Mum is my full time unpaid carer) or to fund daily carers for those with M.E.

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:

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:

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:

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:

People with M.E. are often much more sensitive to medications and are more likely to experience more severe side effects, for this reason written consent and reduced doses and clear outline of risks should be required when prescribing treatments to M.E. Patients

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:

Health care should not be put in the hands of AI as every individual has different factors affecting their needs ...ie physical, mental, spiritual, social ... than cannot be assessed using algorithms

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

Please add your response below:

Increased rights to human and consistent care and assessment. (not a different Dr each time)

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