

Submitted to About the Act and Code Review
Submitted on 2024-08-11 17:57:31

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]

Share 'one big thing' or upload a file

5 Are you here to tell us your 'one big thing'?

Your one big thing::

My submission is on behalf of my [REDACTED] son who was diagnosed with Myalgic Encephalomyelitis (Chronic Fatigue Syndrome) [REDACTED]

I do not believe his rights under the code have been upheld due to a lack of education about the condition in the health system which results in inadequate medical care. A diagnosis of MECFS means you are treated like a pariah by the health system instead of a severely unwell patient deserving of treatment. Sadly, this disdain includes children.

My son's "care" has been intermittent, inadequate and, at times, inappropriate. I even had one doctor give me a brochure for The Switch - a programme that uses NeuroLinguistic training to stop false illness beliefs.

I can't help but wonder if my son had received more comprehensive & appropriate care from his Paediatricians early on, he may have been able to make a recovery instead of becoming more debilitated. It is perplexing that NZ paediatricians can diagnose a child with MECFS and then not treat them according to current international best practice guidelines which are easily accessible.

Instead, my son was given referrals to a psychologist and a physiotherapist who provided a programme of High Intensity Interval Training. At subsequent appointments, the underlying message was that he should be trying harder and that getting back to school was more important than feeling better. He is now categorised as having Severe MECFS, [REDACTED] and has developed more symptoms. He could potentially progress to very severe & develop life-threatening malnutrition, a fact that doctors here are oblivious to. He feels he is not believed by doctors & is now reluctant to engage with medical professionals.

If there were specialists in NZ who kept up with the latest evidence & best practice in treating patients with ME/CFS he would likely have a better quality of life.

At this point in time my son's future looks very bleak.

I would like there to be urgent attention given to educating doctors on the appropriate care for ME/CFS & stop harmful treatment.

6 Upload a file

File upload:
No file uploaded

Not Answered

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:

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:

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::

Age of my son and reference to the year of diagnosis

Reasons to withhold parts of your submission

Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.:
Yes

I think these parts of my submission should be withheld, for these reasons: :

Age of my son & year of diagnosis - as these are likely to identify him to those who have or are currently treating him.

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