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Submitted to About the Act and Code Review Submitted on 2024-09-06 12:08:05

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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: Word of mouth
If you selected other, please specify below:
Questions for organisations/groups

1 Name of your organisation or group (if applicable)

Organisation:

Awhi Mai Stroke Trust

2 Type of organisation/group (if applicable)

Organisation - type of organisation/group/rop $\bar{\mathbf{u}}$:

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::

Somebody needs to be accountable to actively promote the Code of Rights with whanau when their loved one is admitted, either at a hospital or a hauora/health clinic. If Code of Rights promotion is somehow paid for, then I'm sure it can be measured and accounted for too.

- a) Most hospitals have Māori teams that support across all wards e.g. Te Aka Matua at Rotorua Hospital. Promotion could be a valuable awareness and confidence builder with the anxious whanau (and patient) and take some of the pressure off them.
- b) The more promotion, the better the info re Code of Rights gets out to whanau. Because Awhi Mai volunteers are with Māori & Pasifika stroke patients and whānau in the OPRS ward Rotorua Hospital at least two days a week, we can make the promotion part of our little contribution. The information brochures and posters are displayed and available everywhere but most whanau and patients just don't see them. Who can/will walk the whānau out and show/explain?

Waka eke noa = The education canoe can safely go through any storm (and funding helps too).

From where we sit, no-one is promoting, accountable AND educating Code of Rights. Something or someone has to do this kaupapa differently or the least informed (i.e. M & PI consumers) will remain CoR-less.

- a) The OPRS rehab ward has an information booklet explaining all the things that the patient and whanau should know while there, but guess what is missing? Yep, Code of Rights!! Awhi Mai has just discovered it and decided to revamp it and make our own booklet. CoR could/will have it's own page and we explain when we give out to every whanau we support in OPRS.
- b) There are other opportunities for us/Awhi Mai to engage with others:
- e.g. hauora doctors and general managers, We are organising our first hui at the end of this month on their marae. Be a great chance for both of us to learn about what each does and hopefully build trust for beneficiaries.
- I'm not sure whether we'll be ready for this one, but it would be great to show our new TE ARA KUITI booklet (i.e. what you need to know when you are in the OPRS/hospital) and go through it with the hui.
- we have monthly meetings with stroke survivors and whanau. Maybe CoR should/could be one of our Awhi Mai 2024/25 HINENGARO GOALS (i.e. learning goals)?
- and we have our biennial stroke conference. This could be a good opportunity to mahitahi, nohotahi, etc e.g. CoR, H&D, hauora.
- 6 Upload a file

File upload:

Review of Code of Rights 2024.docx was uploaded

This file is a submission

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:

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:

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:

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 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: 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: 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: 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: 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: 5.4 What changes, both legislative and non-legislative, should we consider to respond to advancing technology? Please add your response below: 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.:

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?

Review of the Health & Disability Code of Rights

Background

Awhi Mai Stroke Trust is made up of Māori, Pacifica and Tauiwi (i.e. Pakeha) stroke survivors and whānau members in the Bay of Plenty (i.e. groups in Tauranga, Rotorua and Whakatane). Our trust deed have the following goals:

- supporting Mäori Stroke survivors and their whänau;
- providing pastoral care for Mäori Stroke survivors and their whänau;
- inspiring Mäori Stroke survivors to reach their full potential; and
- working cooperatively with others in the Stroke/Hauora area.

Unfortunately, we have only just heard about the national HDC review but appreciate being invited to contribute.

Awhi Mai Stroke Trust was created in 2019 and within a few months we had our first Māori Stroke conference held across three marae in Ohinemutu, Rotorua. One of the issues raised at the hui was the lack of knowledge re patient and whānau rights and protections while receiving health care in the health providers throughout the Bay of Plenty region. The Code of Rights was quickly identified and that offers real protection while receiving care.

In February 2021, we had a three day wānanga at Otamarākau Marae, about half way on the coastline between Tauranga and Whakatane. The Code of Rights was a major part of the program including i) what are the rights? ii) Who are the Health & Disability Commission? and iii) what is a complaint and how do we do that? The great thing was that we had a whānau with a fresh complaint and Rose White, Deputy Commissioner of HCD attending. For those of us who knew nothing about the of Code of Rights displayed on the hospital walls and then to have this example complaint on our marae with all our cultural protections in place, it was incredible and an honour just to be there.

So..... we are only Māori stroke survivors, but we do have some skills, experiences, and a little bit of value to contribute to this review. Here are our whakaaro (i.e. thoughts and views) that were gathered at our Rotorua July Hui on Friday 26/7/24. The people involved belong to iwi from Te Arawa, Mataatua, Tauranga Moana, Tuwharetoa ki Kawerau, and Tokelau. These are our responses.

HDC CODE OF RIGHTS in English

• The Ten Rights = Respect, Fair Treatment, Dignity and Independence, Proper Standards, Communication, Information, It's Your Decision, Support, Teaching and Research, Complaints.

Positive Responses

- We basically agree to the 10 rights and to the definitions displayed underneath. All are how patients and whānau should be treated and cared for.
- We are pleased to see the English and Māori posters side by side through all health settings. That helps each side to explain the other for the consumer reading.

Things to Improve on

- The word AMUAMU in the Māori text/poster for COMPLAINT is too soft and not serious enough. If the patient or whānau disagree with the work or decisions of health staff this IS A SERIOUS MATTER and should be treated as such by staff. Most whānau lack confidence simply because they don't know about the Code of Rights and most will not cause a fuss and just quietly leave as soon as they can. The disappointment from our Trust perspective is that nothing has been changed or improved and that the next patient and whānau will enter the same unhealthy setting.
- Who is promoting the Code of Rights to the whānau and patients entering the health environment? Most of our members did not see the posters and/or the significance of what is offered within. THIS IS A HUGE FAILURE to our members!!

TE TOIHAU HAUORA, HAUĀTANGA (Te Reo Text)

• **Ngā Tika Tekau** = Mana, Manaakitanga, Tū Te Rangatiratanga Mana Motuhake, Tautikanga, Whakawhitiwhitingawhakaaro, Whakamōhio, Whakaritenga Mōu Ake, Tautoko, Ako Me Te Rangahau, Amuamu

Ngā Pāinga

- He rawe te kite i te nuinga o Ngā Tika Matua, e whakaatu ana i ngā tikanga me ngā mahi papai te kite i ngā wāhi Hauora, i nga kaimahi e mahi ana.
- He rawe te kite anō i ngā whakaahua e rua e tohu ana ki te reo o Tauiwi, ki te Reo Māori hoki. E iri tahi ana, e tautoko tahi ana hoki.

Ngā Hē

- ko te tika whakamutunga ko AMUAMU. He ōpaki rawa ki a mātou. Te nuinga o ngā Tūroro me ngā whānau i te nuinga o te wā, ka kite i ngā hē o Ngā Tika o ngā kaimahi, ka huri atu, ka kore e whakatika. Engari, ki te tū mai te whānau ki mua i te kaimahi Hauora me te kii 'kua hē tō mahi' he mea nui tērā. Nareira ki a mātou ko WHAKAHĒ kē te ingoa tika mō tēnei āhua. He māro tēnei kupu pea ki ētahi, engari ki a mātou ehara tēnei i tē kēmu. Ka pā mai ēnei mate kikino ki a tātou a ka tae atu ki te hōhipera me te wāhi Hauora, me whakapono tātou i Ngā Tika hei tiaki, hei arahi tātou katoa ahakoa turoro me te whānau, ahakoa kaimahi Hauora.
- Ki te kore te turoro me te whānau e WHAKAHĒ ana i ngā kaimahi o te Wāhi Hauora, ka ora tonu tēnei pēhitanga ki te whānau hou e uru mai ana i te Ao Hauora. Nāreira he tikanga, he whakapono mā te katoa i te Wāhi Hauora.

WHAKAMUTUNGA

Catherine, team and HDC, thank you for inviting us to contribute to the COR review. The posters and Code of Rights are basically good, it is just hidden amongst everything else when trauma hits the home and the whānau and unfortunately continues in the health sector. We'll be interested to see where this all goes.

Rukingi Haupapa Chair, Awhi Mai Stroke Trust