HDC Code of Rights Review Feedback

Topic 1

1(b) Clarify cultural responsiveness

Cultural responsiveness should also include the values and beliefs of members of faith groups and communities.

1(c) Clarify the role of whanau

Bullet point no 3 "Clarifying Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer

Agree, however this needs to be *with the consent* of the consumer.

1(e) Protect against retaliation.

I don't disagree that it is important to protect against retaliation. However, the threat of retaliation can be covert/unspoken. It is also very subjective. How will this be determined and monitored ongoing? What is the process for the consumer if retaliation does occur? How can HDC protect the consumer when they have no legal right to act *within* the organisation where the retaliation is occurring? HDC processes already slow. By the time HDC is aware the consumer will already have suffered the consequences of their complaint.

1(g) Improve advocacy service

I think the current empowerment-self-advocacy model should be revised. People need more advocacy support in today's complex health context. Rather than requiring permission to go beyond supporting self-advocacy (Drage, J (2012) New Zealand's National Health and Disability Advocacy Service: A successful model of advocacy) I believe there should be a *secondary level of advocacy* that consumers can access if they are unable to advocate for themselves effectively. As the surgical mesh tragedy has shown, people who have been significantly harmed in the process of healthcare often need more than support to self-advocate. Fatigue, pain, stigma and steep authority gradients between consumers and medical practitioners prevent consumers from making complaints. Many simply cannot effectively self-advocate.

1(h) Improve language of complaint pathways.

The Code needs to be better aligned with National Adverse Event Policy and He maungarongo ki ngā iwi: Envisioning a restorative health system in Aotearoa New Zealand framework and use language like “review” instead of “investigate” and so on. Less punitive language and more Restorative Just Culture.

Topic 2

2(a) Incorporate tikanga into the Code

What about Pasifica and other cultures who may have different concepts? I strongly believe incorporating tikanga and language of a single culture into the Code in effect *creates a barrier* for other cultures to understand and be able to identify when their rights have been breached.

Agree with the statement that every consumer should have their mana upheld.

2(b) Give practical effect to te Tiriti o Waitangi/The Treaty of Waitangi in the Act

Article 1: I don’t believe we need a specifically Māori Commissioner.

The treaty is a bi-cultural partnership in the context of an increasingly multi-cultural society. *There needs to be a balance between upholding the treaty but also ensuring that consumers of other cultures see themselves represented in the Code.*

Article 2: The Ritenga declaration protected the religious freedom of all, not just Māori.

“E mea ana te Kawana, ko nga whakapono katoa, o Ingarani, o nga Weterania, o Roma, me te ritenga Māori hoki, e tiakina ngātahitia e ia” – translation: “The Govenor says the several faiths [beliefs] of England, of the Weslyans, of Rome, and also of the Māori custom or usage, shall be alike protected by him. (p 155, Bible and Treaty: Missionaries among the Māori – a new perspective, Keith Newman, 2010).

Topic 4

Right to appeal HDC decisions

4(a) Agree.

All cases where the practitioner was protected over the consumer (such as the Sally Walker case) should be open to appeal. *The harmed person must be the priority.* They are the one who must live with the life-changing consequences.

4(b) Agree the Code should have the same threshold as other acts for referral to the HRRT.

Topic 5

(b) increase the maximum fine for an offence under the Act from $3000 to $10 000.

This would require HDC to actually use it. In the last few years I did an OIA where HDC responded that the $3k fine had never been used. Is HDC actually going to use the fine if it is $10k? Will this include a fine for retaliation?

Appendix 2

Right 1(3) on page 57 of the consultation document. In the document it is proposed that the words "different cultural, religious, social and ethnic groups…" be removed, in favour of "culture, language, identity, values and beliefs"

This *weakens* the right in terms of its understanding and interpretation by consumers and providers in relation to consumers' right to have their spiritual needs met while receiving health care. The word "beliefs" does not adequately cover the concept of spirituality (which does not always involve beliefs), nor does it acknowledge faith traditions. While these may be closely inter-related with culture, identity and values, I believe that they should be made explicit in this right.

While there are other Acts such as the Bill of Rights (1990), or the Human Rights Act (1993) that mention religious beliefs, these themselves are out of date in this respect. These Acts are not specific to healthcare as the Code is. Spiritual harm is now recognised in the National Adverse Events Policy 2023 and as such I believe that the revised wording of this section of the Code should read, "culture, language, identity, values, spiritual and other beliefs" or similar.

Right 1(3) is one of the few pieces of legislation that healthcare chaplains can refer to that allows them to advocate effectively for consumer spiritual care in a secular health system.

Right 5

'competent' interpreter – I don't think this comes across correctly. Consumers need more than a competent v incompetent interpreter. They actually need someone who can not only competently interpret words but culture as well…which means they need not just to be competent but a culturally appropriate interpreter for the given context.

This links in to epistemic injustice – where one's testimony/lived experience is not believed/valued/acted on appropriately (Read Fricker, M (2007) Epistemic Injustice: Power and the Ethics of Knowing).

Also:

Definitions of health practitioner should include healthcare chaplains who are there to provide spiritual care (as one of the walls of the Te Whare Tapa Wha whare).