Auckland Women's
Health Council

A voice for women's health

Morag McDowell
Rose Wall
Office of the Health and Disability Commissioner
PO Box 11934,
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13 March 2023

Regarding the early input into the HDC Act and Code of Rights Review

Tēnā kōrua Morag and Rose,

The Auckland Women's Health Council appreciates the opportunity to provide early input into your review of the HDC Act and Code of Rights.

As you may be aware, AWHC has had a sustained interest in the HDC and the Code of Rights. We made submissions on the Health and Disability Commissioner Act 1994, then once the legislation was passed and the first Health and Disability Commissioner appointed, we made submissions and participated in consultation meetings that occurred during the development of the 'Code of Rights'. We have also made submissions on previous reviews and other HDC topics when public/stakeholder feedback has been invited.

There are a number of issues that we believe should be considered in your review, as we set out in brief below. There are two major concerns that have arisen in the last few years; one that was discussed in Anthony Hill's review in 2019, and one that has been raised since then:

1. The 'recruitment' of incompetent/unconscious patients unable to provide consent in medical/health research. After a number of communications from our then Co-ordinator, Lynda Williams, to Anthony Hill, the former HDC issued a public consultation document on this issue, on which we made a submission in 2017. Mr Hill released a report in 2019 in which he recommended changes, and mentioned this in his 2019 HDC Act review report to then Minister of Health, David Clark. As far as we are aware, nothing further has been done about recruiting incompetent/unconscious patients for medical/health research. We believe that it is important that the Act and the Code does more to protect some of our most vulnerable citizens from medical exploitation.
2. In 2020 and 2021 we actively supported Renate Schütte's petition to Parliament requesting the right to appeal decisions made by the Health and Disability Commissioner, making written and oral submissions to the Health Select Committee. The Health Select Committee's recommendation was that this issue was best suited to consideration in the regular review of the HDC Act. We absolutely support the right for both complainants and providers to appeal HDC decisions and refer you to our written submission in support of Ms Schütte's petition on our website.

Other issues we believe should be considered as part of your review:

3. The delays and extraordinary amount of time it takes for decisions to be made, especially for complainants who ultimately receive a no further action decision. These delays fail to fulfil the promise set out on the HDC website to resolve "complaints in a fair, timely, and effective way."
4. That so few complaints are formally investigated and so many complainants receive no further action decisions, even when there have been serious consequences for a patient, and the fact that there is no

recourse for such complainants to have their complaint reviewed, as there is no appeals process. Between 2001 and 2019, investigated complaints as a proportion of closed cases dropped significantly from 40% in 2001 to under 5% in 2019.

5. The HDC Act needs to be amended to reflect a greater acknowledgement of te ao Māori and te Tiriti, as is the case in much recent legislation and health agency and Government documents, in particular the Pae Ora (Healthy Futures) Act 2022.
6. Research over recent years has shown persistent breaches of patients' informed consent rights, particularly in teaching hospitals. These breaches continue in the face of the 2015 consensus statement on medical students and informed consent, prepared by both the medical schools, CMOs of the district health boards and the Medical Council. These continued breaches of informed consent rights are a huge concern (see AWHC August 2022 Newsletter, pp10-15). We would like to see some legislative means to enforce informed consent rights, beyond the complaints process, as many health consumers are not aware of their rights and/or are too vulnerable to speak up, particularly when their care occurs in a teaching hospital. That consumers may not be aware of their rights is no justification for continued breaches by medical staff and institutions.
7. Amendment to the Code of Rights to specifically to include gender diversity in rights of dignity and respect; services that take into account the needs, values, and beliefs of gender diverse people; and freedom from discrimination, coercion and harassment, exploitation, etc. Gender diversity was a barely recognised issue when the Code of Rights was written. However, New Zealand and international research has found that discrimination and a lack of respect and dignity in health care is a significant issue for gender diverse people, and that their mental and physical health suffers as a result. Many in the queer community suffer poor physical health, in part because they are reluctant to see doctors when they need to because of past experiences. Many gender diverse New Zealanders report being misgendered, or having their gender identity dismissed, questioned or disrespected, and their health concerns trivialised or misunderstood, by health care professionals.
8. The need for information sharing on harm from medicines/drugs, medical devices and medical procedures between HDC, ACC and Medsafe (or the new Therapeutic Products Regulator when the Therapeutic Products Bill is passed into law). A number of OIAs AWHC have lodged with HDC, ACC and Medsafe over the last few years regarding treatment injury, has shown that these agencies are completely siloed and none of them appear to share information (anonymised or otherwise), so there is no comprehensive understanding of the level of treatment injury.

The above points are just a very brief outline of our concerns, and we look forward to having an opportunity to provide a more comprehensive submission on these at a later date, together with feedback we might be able to make on any other issues that are raised in the process of your review of the Act and the Code of Rights.

Ngā mihi nui

Susan K Claridge

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For the Executive Committee
Auckland Women's Health Council