WOMEN'S
HEALTH
Action

Submission on the Review of the HDC Act and Code

This is submission is made by Women's Health Action Trust

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Date due: 5 February 2014 Submissions can be made orally (via the HDC 0800 line: 0800 11 22 33), **emailed** to hdc@hdc.org.nz, made **electronically** by following this link, or **posted** to:
Health and Disability Commissioner

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We wish to appear in support of this submission.

Women’s Health Action Trust

Women’s Health Action (WHA), which was formed as a result of the Cartwright enquiry, is in its 30th year of operation and remains on the forefront of women’s health in Aotearoa New Zealand.

We are a non-government organisation that works with health professionals, policy makers and other not for profit organisations to influence and inform government policy and service delivery for women. We provide quality, evidence-based, consumer-focused information and advice to health consumers and organisations. We aim to ensure that health policy and service delivery meets the needs of diverse women and has equitable outcomes.

We have extensive networks in the public health and not-for-profit sector and provide information, analysis and advice to health providers, NGOs, DHBs, the Ministry of Health and other public agencies on women’s health in particular, gender and consumer issues. Women’s Health Action has a particular interest in safety and quality in health services and research. We regularly participate in discussions and debates around quality assurance systems and relevant legislative change.

Introduction

Women's Health Action was active in lobbying for the creation of the Office of the Health and Disability Commissioner and provided input into the Code of Health and Disability Consumer Rights. We are committed to the Office of Health and Disability Commissioner and its primary focus -the protection of consumers and the promotion of their rights within the health system.

WHA has made submissions to the previous reviews of the Health and Disability Commissioner Act with a particular focus on the rights of health consumers, advocacy and informed consent and ethics. We are pleased to have the opportunity to provide a submission on the current review of the Act.

Current review

Our response to the Commissioner's support of the following amendments arising from the 2009 review is as follows.

- **We do not support a review of the Act and Code only every ten years with the option of an earlier review if desirable.**

We suggest that the review period is not extended at this point and recommend that the Act is again reviewed in 5 years. In particular, we believe there is a need for regular review of the Act and Code particularly in this environment of rapidly changing health services and changes to information technology. We also think there is a need to consolidate the role of the Deputy Health and Disability Commissioner and Mental Health Commissioner and note that some reports have criticised HDC, and other agencies for a lack of cross-agency collaboration and communication with regard to timely and effective resolution of complaints about disability support services[1].

- **We note that previous reviews have asked substantially more questions of submitters around specific sections of the Act.**

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[1] 'Putting People First, Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services December 2013'

We have no comment for the other amendments described in the consultation document. However, in our submissions to the previous review (2009) we raised several issues and believe parts of the Act and Code still require amendment and would like to make the following additional comments:

Additional comments

The primary focus of this Act is to promote and protect consumer rights, and the primary role of the Commissioner(s) is to represent consumer interests in the health and disability sector.

- As we noted in previous submissions WHA believes the office of the HDC could be more often used as an advocate for classes of people and the public as a whole. Current examples where the HDC could lead debate include ethical issues with direct-to-consumer advertising and enlistment in clinical trials or informed consent processes around the use of medical devices such as surgical mesh.
- We believe there is an urgent need to improve the national system of Ethics Committees and Ethical Reviews which could fit more naturally under the jurisdiction of HDC rather than in the various other areas where they are currently located. Ethics committee's were set up after the Cartwright Inquiry to protect and promote the rights of the patients and consumers. Increasingly, they are being seen not as protectors of consumer rights but as obstacles to research. This tendency has increased with the changes to Right 7(10). Women's Health Action therefore continues to contend that a national system of ethics committees should be under the jurisdiction of the HDC. We continue to maintain there is a place for a Director of Ethics to oversee all human ethics committees with a focus on the rights of research participants and those involved in innovative and experimental procedures. We would like this review to consider the feasibility of this.
- We have some concerns about the under resourcing of the Advocacy Service particularly to ensure 'speedy, efficient, resolution of complaints at the lowest level' concept, and in the lack of more detailed analysis/reporting of the complaints. We also question whether there are more complaints that should be escalated to HDC office, either for noting for any trend development, or for higher level investigation because of their nature and/or complexity. For example, an increasing trend of sub-standard care in disability residential cares facilities.

We do not think the Code should be amended at this point but wish to make the following points:

- WHA believes that the key principles in the Code should be maintained and not diluted or compromised. The principles in the Code are an important protection for consumers at all times and in all situations, not just when they are easy and convenient for health researchers and practitioners to meet them.
- It is still our view that provider resource constraints do not excuse a breach of the Code.
- Consumers have a right to effective communication, to be fully informed and make informed choices and consent to treatment. We remain concerned re interpreter services and note the continued reliance on family members by some providers is particularly difficult for women in matters of sexual health or domestic or sexual violence in particular.
- Health and disability consumers' rights to make informed choices and give informed consent is covered by the code. Women's Health Action continues to be concerned that the underlying principles and meaning of the terms 'informed choice' and 'informed consent' are not well implemented by health policy makers and health professionals, with major implications for how informed choice is facilitated and informed consent/informed decline is obtained. A recent example includes the use of surgical meshes for gynaecological procedures.
- We are also very concerned that health interventions are increasingly being presented to consumers as "routine" with the offer that they can "opt-out". However, if the 'offer' to opt out is assumed – it is assumed that the consumer knows they have a right to do this but the offer is not explicitly made. This does not constitute informed choice and informed consent and it is WHA's opinion that this practice does not meet health practitioners' responsibilities under the code.
- We continue to believe the code of rights needs to be strengthened, not by changes to the code itself but in changes to how it is practised. We believe public education in this area needs to be lead by the HDC.
- Women's Health Action continues to be concerned about the decentralisation and fragmentation of ethics committees. We are also concerned that the culture of ethics committees is increasingly dominated by the interests or even "rights" of researchers and

academics to do research, over the interests of consumers and their rights under the code.

Concluding comments

In summary we continue to believe this Act and the Code have been important in improving relationships between health practioners, health providers and health consumers. However, evidence from our research and from the HDC reports themselves demonstrates we continue to need legislative protections and advocacy to ensure consumer rights.

Thank you again for the opportunity to comment.

We trust our comments are useful in your consideration. Please contact us if you need any further information.