

18 February 2009

S09.02

**Submission to the Health and Disability Commissioner;
Review of the Health and Disability Commissioner Act 1994 and the Code of Health and
Disability Services Consumer's Rights HDC consultation document.**

Introduction

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 46 nationally organised societies and national members. It has 28 branches spread throughout the country to which women some 150 societies are affiliated. The Council's function is to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ has a longstanding history of encouraging the promotion of social and health issues, particularly as they affect women.

NCWNZ has contributed in many ways to health and disability issues and wishes to convey thanks for this opportunity for consultation.

Members of the Health Standing Committee and branch members were asked for their input into this document. The timing over Christmas and New Year holidays meant that many members were on holiday and so the breadth of consultation was not as wide as usual. However the following is a summary of comments made.

General comments:

Opinion was divided equally on the review period. Some think that with the current economic climate it is important to minimize unnecessary and costly spending and extend the review period to 10 years. However others think that with advances in medicine and the complexity of ethical issues which are arising the review should be continue to be every 3-5 years.

It is thought that an independent Disability Commissioner could develop specialized knowledge across the disability sector ensuring depth and breadth in enquiries and be proactive on behalf of people with disabilities. In general NCWNZ considers it should remain within the Health and Disability Commission.

NCWNZ considers that if there are areas that are not being addressed because they are not included in the Act or the Code then these must be rectified. This gives additional justification to a Disability Commissioner role. It is recommended that the areas the Commissioner can examine be expanded including access to services, funding decisions and decisions made by Needs Assessment and Service Co-ordinators. It is felt that an Act with loopholes in unjust and ineffective.

There is some debate however about a legally enforceable complaints service. Some members think that individual issues should be left with political accountability and that there needs to be

limitations on a complaints process. Others beg the question “how can one have rights and not be able to access them?” NCWNZ does agree, however, that more generic issues should be addressed such as service delivery and funding. The rights of indigenous people need to be taken into account.

Privacy from the media is seen to be important and disabled people have the right to access information about themselves. Generally it is felt that the Health Commissioner should be able to investigate alleged breaches of privacy.

An Independent Office of Advocacy with advocates as employees is deemed to be the best option to maintain a nationwide standard of consistency accountability and professionalism.

The vast majority agreed with renaming the Office of the Health and Disability Commissioner to Health and Disability Commission and providing greater clarity around the re-appointment of the Deputy Commissioners.

The reasons for Amending section 39 of the Act; that the Commissioner may decide not to take any action on a complaint needs to be specific especially for reporting back to the complainant.

NCWNZ agrees with the Commission being able to withhold information during an investigation to enable speedy investigation of a complaint.

Placing an independent Health and Disability Ethics Committees under the oversight of the HDC is not generally accepted by NCWNZ. Most members think that the Ethics Committee needs to retain its independence especially with regards making decisions about research.

Including a right to compassion in the Code generated some discussion. Most members believe it is already included in the Code but further training is necessary. Some asked what constitutes compassion in each case and also asked if compassion is really available on demand. Not everything can be legislated.

NCWNZ agrees that research may proceed so long as it has the approval of the Ethics Committee (which is why the Ethics Committee should remain independent) and it is not known to be contrary to the interests of the consumer. Some think that a collective “good” could override individual interests.

Member’s comments expressed a great deal of concern that there is no reporting of the findings of previous reviews to the Minister of Disability Issues. Those with greater levels of disability are less inclined to complain because of total reliance on the primary caregiver. It is felt by some members that in reality little has been done to improve the services for those consumers with disabilities particularly those domiciled in their own homes.

It is also a concern that those who receive ACC payments and services are better resourced than those whose disability is brought about by deteriorating health. It is always a struggle for these people to gain access to assistance and adequate resources.

There is also concern expressed about the lack of appropriate services for people of ethnic cultures, particularly migrants, and that this may be a contributing factor to some migrants opening up home care and health service businesses with little or no knowledge of the need for compliance to governing legislation.

In conclusion NCWNZ welcomes the opportunity to be able to speak to this discussion document and holds to the premise that there should be no discrimination against people with disabilities.

NCWNZ looks forward to seeing the final document.

Elizabeth Bang
National President

Sheryll FitzPatrick
Convener, Health Standing Committee