



**National Council of
Women of New Zealand**

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Wahine O Aotearoa

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**Submission to the Health and Disability Commissioner on the
Review of The Health and Disability Commissioner Act and Code of Health
and Disability Services Consumers' Rights**

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 42 nationally organised societies. It has 33 branches throughout the country attended by representatives of those societies and some 150 other societies. 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.

Members of the Health Standing Committee, Branch members and other interested parties were asked for their input into this document. The following is a summary of their comments.

General Comments

This is a well set out document which is clear and used language that was easy to understand. However, there was more than one version of the document available. This made it more difficult for the convenor to collate responses.

Some respondents have made the comment that this review and a simultaneous review of the Health Practitioners Competence Assurance Act should help to ensure seamless coverage and delivery of service.

It was noted that in relation to complaints in the secondary care setting, e.g. hospitals, there are people such as Patient Complaints/Patient Affairs Officers. In the experience of one respondent, these people are firmly on the side of the staff and do not even begin to conduct a fair inquiry into consumer complaints, e.g. at one hospital, the nurse who was given the job of dealing with complaints was a very close friend of the doctor who headed the Complaints Committee. They blocked virtually every inquiry. In contrast, another respondent reported that at another tertiary Hospital the patient advocate system has clear procedures, conducts thorough investigations and reports back independently to all parties. It is to be hoped that by having an independent advocacy service all complaints will be properly and fairly addressed.

Respondents were encouraged to know that reports of breaches are "being used as a tool for education and quality improvement."

NCWNZ believes that it is vital that accountability is explicitly stated and transparent. Services must be adequately funded, but NCWNZ recognise that there is a balancing act between the level of funding, appropriate use of time and the accountability of the Commissioner.

It is important that both the Director of Proceedings and the Director of Advocacy are able to make working decisions independently of the Commissioner. The question has been raised as to





whether this system works in practice, i.e. Chinese Walls. NCWNZ believes that consumers need to be reassured that decisions are made independently.

Specific Comments

1. Are the definitions in the Act adequate and appropriate? If not, what changes do you suggest?

NCWNZ agrees that the definitions in the Act are adequate and appropriate.

Comment was made that there is a risk of the definitions being very confusing especially to those who have not had an opportunity to study the background of the Act e.g. health consumers, family/whanau and supporters. The term 'Health Practitioner' may not be as well understood as 'Registered Health Professional'. The unregistered providers add another confusion despite the fact that they are still under the jurisdiction of the Commissioner. It is vital that the definitions are comprehensive, easily understood and are consistent with other relevant legislation, regulations and codes of practice.

2. Is the purpose of the Act appropriate?

The purpose of the Act appears appropriate and does not need to be changed. It encapsulates the functions of protection, mediation, advocacy and resolution. NCWNZ supports the concepts of "resolution not retribution" and "learning not lynching". These are reflected in the educative role of the Commissioner's Office.

3. Should the Act be amended to include an obligation that all persons exercising functions and powers under it have regard to the principles of the Treaty of Waitangi?

The majority of respondents did not think that the Act needed to be amended. Some clearly held strong views on this issue. A commonly held view was that all races and ethnic groups should be treated in the same way. A corollary of this is that no group, e.g. Maori, should be singled out for 'special' treatment under the Act.

Comments made by those who oppose any amendment included:

- "The principals of partnership, protection and participation are more than adequate."
- "Equal care for everyone regardless of race should be the norm."
- "There are plenty of people of other races and ethnic groups other than Maori and all should have equal care as New Zealanders."
- "There is already sufficient regard to the principles of the Treaty of Waitangi as demonstrated by training, education and guidelines in place."
- "Amendment of the Act could cause extra debate and therefore prolong investigations."
- "Perhaps because of the smaller Maori population in our area, everyone is treated the same, and we do not feel that Treaty of Waitangi principles need to be included. Other ethnic communities, Island, Indian, etc all have their own beliefs and values and should all be covered by the same regulations."
- "Treaty issues appear to be addressed by the Commissioner already. Thus formal inclusion of the Treaty of Waitangi in the document is not necessary."

Comment was also made that the formal inclusion of Treaty obligations would not of itself result in an improvement of the quality of services for Maori. The question was asked, "Is there evidence of Maori suffering undue harm that isn't remedied?" It was conceded that, "As a political manoeuvre Treaty of Waitangi obligations should be included in the document."



Some respondents disagreed with some or all of the above views and thought the Act should be amended to include an obligation to have regard for the Treaty of Waitangi. While the present commission may give full consideration to the Treaty obligation, who is going to say that the commission will not change and we may face needless stress and turmoil, etc. in 50 years or less.

It was suggested that there is a need to recognise Maori as a diverse group and this makes it difficult to circumscribe needs. Knowledge of Maori language for Commission staff may be appropriate but it should be recognised that most Maori do not speak te reo.

It was noted that most health provider organisations have a specific reference to Treaty obligations in their policies. Extending this requirement to the Act would seem to be logical.

4. Are the functions of the Commissioner appropriate? If not, what amendments do you suggest and why?

The functions of the Commissioner are appropriate and very extensive and if the Health and Disability Commissioner Amendment Act were to expand the Commissioners functions it would seem to create a very heavy workload. Adequate staffing levels would be a consideration.

The "one stop shop" would seem appropriate and a means to reduce confusion because of the number of agencies involved in the past.

Several respondents have noted that 'respect' from professionals at all levels is not always evident to the consumer. It must be remembered that respect is important to each of us and it is gratifying to see that the Commissioner is required to uphold and promote this (section 14 (1) (c)).

5. Should the Director of Proceedings be able to negotiate funding directly with the Ministry of Health?

Respondents were evenly divided on this issue. It was suggested by some that as the Commissioner appoints the Director of Proceedings to his staff, the Commissioner should therefore have oversight of all incoming funding. However, others supported the concept of the Director of Proceedings being able to negotiate funding directly with the Ministry of Health. They believed that this would ensure more independence for the Director of Proceedings. The comment was made that there must be adequate funding through the Ministry otherwise the whole system could be severely compromised.

Regardless of the method of negotiating funding, an adequate working budget must be prepared for the Director. It is important to know how much is available for carrying out the functions of the office and not to overspend the budget e.g. Tainui and the Prison Consultation.

6. Should the Director of Proceedings be able to delegate powers, duties and functions under the Act?

NCWNZ agrees that the Director of Proceedings should be able to delegate duties and functions, but not necessarily powers. Respondents felt that this would be particularly useful in:

- Enhancing administrative efficiency
- Coping with any backlog of cases, and
- Dealing with issues of conflict of interest.

Comment was made that there is a lot of stress for all involved if there is a significant delay in a complaint being investigated. Steps taken to minimise delays would be seen as very positive.



7. Is it necessary to retain a provision to review the Act every five years? If not, what interval do you suggest?

The majority of respondents suggested that a review occur every 10 years or as needed, rather than every 5 years.

Comment was made about the time and resources involved in a review process and the fact that the Commissioner can report directly to the Minister. It is important that there is dialogue with the Minister where gaps or anomalies are identified in legislation. This might lead to a review. However, concern was expressed that a situation could arise where the Minister for political reasons did not want a review to occur. In the event of the Commissioner seeking a review there should be some onus on the Minister to respond.

8. Should the Act and/or Code be amended to include reference to the responsibilities of consumers? If so, what amendments do you suggest and why?

Opinions were evenly split on whether it was desirable to include reference to consumer responsibilities in the Act or Code. Those opposed to inclusion of consumer responsibilities made the following comments:

- “Consumers are often sick/vulnerable people and their families may be equally vulnerable.”
- “Consumers are often at risk of exploitation especially with poorly paid and trained caregivers.”
- “The Code should not be diluted in favour of providers.”
- “Most complaints to the Commissioner are made in good faith and after a lot of painful consideration.”
- “Unnecessary to include consumer responsibilities with section 37 (1) (c) in place.”
- “Complaints are seldom vexatious, frivolous or not made in good faith.”
- “The Commissioner’s views on the responsibilities of consumers are fair and reasonable.”

In particular, one respondent group stated that it would not support the Code including a section on patient responsibilities as this may create unrealistic expectations of some patients. It is their belief that many of the suggested inclusions e.g. share all relevant information, be fair and truthful, are based on rapport and mutual respect. It is not possible or realistic to legislate for openness or truthfulness, as being forthcoming with some medical information can run counter to deeply held cultural beliefs. To function well in today’s world, it is their belief the Western medical model must have regard for such cultural and language barriers if it is to empower and heal the clients it serves.

Another respondent commented that hospitals, for example, already have advocacy personnel to cover complaints about access to appropriate services. Therefore, there could be an overlap of personnel. Consumers would be expected to have a very good cause for making a complaint to the Commissioner. Some felt that presently the consumer responsibilities as stated are weak. They believed that patients should cooperate by fulfilling the doctor’s guidelines e.g. taking medication as instructed.

9. Should the Act and/or Code be amended to include a right to access publicly funded services? If so, what do you suggest and why?

Some respondents agreed that the Act and/or the Code should not be amended to include a right to access publicly funded services. It was thought that this was firmly in the political arena and would detract from the Commissioner’s role. Although the issue of access is one of political



accountability the question arises as to whether there should be a 'watch dog'. There was some frustration expressed that the issue of access seems to be increasingly fraught with delays and problems. However, some commented that issues of access and funding were peripheral to the main thrust of the Act and Code, i.e. complaints resolution.

Others were of the opinion that issues of timely access are an integral part of the quality of services delivered and therefore should be included in the Act. Clearly, access to publicly funded services is desirable, but until there is adequate Government funding, it cannot be a 'right'.

Currently, the health system is financially under resourced, with too few specialised staff in some specialties, which limits timely access. In light of limited resources and equipment, controlled specialised medication, in some cases older buildings, it is hard to imagine how the points outlined in 1.4 could be implemented.

One respondent group agreed that, for the most part, access issues are too wide to be addressed by the Act or Code, e.g. waiting lists, unavailability of health professionals in some locations. There will however, be instances that must be considered where lack of access is due to avoidable circumstances, e.g. clerical errors that result in overdue or misdirected notifications. While these would typically be covered under the service contracts with the funder, an amendment addressing these types of access issues is recommended. A reasoned approach must be used to distinguish between the latter and the former.

10. Is it necessary to review the Code every three years? If not, what interval do you suggest?

NCWNZ suggests that the Code be reviewed every 5 years. Respondents expressed some concern about the effects of changes to the Code that might follow a review if the frequency of review was 3 years.

11. Should the Director of Advocacy be able to negotiate funding directly with the Ministry of Health?

Respondents were evenly split on this issue. Some felt that it should not be necessary for the Director of Advocacy to negotiate funding directly from the Ministry of Health. Others felt that direct funding negotiation with the Ministry was appropriate and would help maintain the independence of the office.

12. Is the current structure for advocacy services appropriate? If not, what amendments do you suggest and why?

There was general agreement that the current structure for advocacy services was adequate.

It was suggested that national performance standards be established. Training and operational policies also need to be standardised. This encourages clear communication and professionalism. We are a small country with a very mobile population and fragmentation of services and standards causes ongoing problems. Some members felt strongly that there was still room for community input in the regions.

Comment was made that it is important to audit the advocacy service and that centralising the service would enhance quality management of the 3 regional contracted services.

Other respondents believed that the changes as stated, following the outcome of the 2003 review, should be implemented rather than centralising the service, thus enhancing shared vision and accountability, enhancing communication, enhancing best practice, develop the role



of senior advocate, develop a system for assessing specialist skills, undertake specific recruiting. This would serve to minimise reporting layers and avoid conflicts of interest.

Some respondents believe that advocates should be publicly funded and that they should be independent i.e. not closely identified with any specific health services provider. They must not, however, be funded directly by health boards as this may create the perception that they may be subject to 'employer' instruction or influence.

13. Are the functions of the advocates adequate? If not, what amendments do you suggest and why?

Respondents agreed that the functions of the advocates are adequate. However, it was suggested there is a need for assessing specialist skills and undertaking specific recruiting of advocates as they have a demanding and complex role to play if they are to remain impartial in terms of blame or confrontation and remain objective and empathetic.

Comment was also made that the Advocate must maintain a level of 'confidentiality' so that the client and/or the organisation concerned is not put at risk/stress.

In general, respondents thought it desirable to have advisers, interpreters, and advocates readily available in health care settings.

14. Do you agree that further changes to Part IV (Complaints and Investigations) are not necessary or desirable at this stage? If not, what amendments do you suggest and why?

NCWNZ agree that further changes to Complaints and Investigations are not necessary at this stage. It is suggested that where changes are proposed they should be trialled for a reasonable period time before being put in to operation nationally. With respect to the concern of timeliness raised previously by the NCWNZ it would seem that a number of issues including workload and complexity of matters referred could have a significant impact on the speed of resolution.

Respondents agreed strongly that where complaints are referred by the Commissioner to the provider, the provider in turn must report back (p33). It was also agreed that the Commissioner be required to notify the responsible authority or professional body, not just have the direction to do so (Section 42 (1) of the Act).

Some respondents expressed concern that there may be delays caused by the present hierarchical structure. However, others accepted that the present structure was necessary to ensure the independence of decision making processes from the investigative process.

NCWNZ is pleased to note that an aggrieved person can still bring proceedings before the Human Rights Review Tribunal where the Commissioner or the Director of Proceedings decline to take further action.

15. Should the Act be amended or, taken as a whole, are the existing provisions and the changes that will come into effect under the HDC Amendment Act 2003 satisfactory?

NCWNZ agrees that there is no need for further amendment to the Act. It appears to be operating appropriately and will be significantly improved by the reforms under the Health and Disabilities Commissioner Amendment Act 2003.

It was noted that the mediation conference is a creative option when advocacy is not able to assist with resolution.

**16. Should the Code be amended or are the existing rights satisfactory?**

Respondents were unanimous that the existing rights were satisfactory. It was suggested that all providers be required to display a Code of Consumers' Rights or make available copies of the same to all clients.

It was noted (Right 4) that provision of appropriate levels of service are often hindered by a lack of funding.

The right to effective communication (Right 5) needs to state how this right is to be supported. In cases of limited or non-existent English language skills, consumers must be made aware of how to access culturally appropriate and trained healthcare interpreters.

Respondents suggested there was room for improvement with regard to the right to be fully informed (Right 6). This is particularly so if the consumer is unable to comprehend and needs or requests the assistance of a support person. The support person needs to be able to access all relevant information. The excuse that it would breach the Privacy Act in these cases is not appropriate.

It is most important that a consumer who is not able to state their case because of their illness or disability has a support person to speak for them (Rights 7 & 8). Sometimes it is not appropriate that the support person be a family member. However, whoever takes on this role needs to be fully cognisant of the circumstances. Complaints need to be dealt with as expediently as possible and the process simplified as much as possible.

Access of care needs monitoring especially the delivery of services, suitability of carers and their training and accountability of work practices. Consumers have the right to be safe and able to stay in their own environment free from hassles and exploitation.

It is pleasing to see that Clause 3 of the Code includes factors such as the consumer's clinical circumstances and the provider's resource constraints.

17. Should the right to an interpreter under the Code be enhanced in any way, or is the current provision in Right 5 (1) satisfactory?

Respondents were evenly divided on this issue. Some felt that the current situation was satisfactory and there was no need for any enhancement.

However, others suggested there was some need for enhancement. For example, there are instances of people with conversational English who have very limited understanding of medical terminology. Further, they may not have the English language skills required to adequately or accurately describe their symptoms or medical condition. They may not always ask for translators because they may not think that there will be problems in comprehension. Another reason is that in our health systems we have many practitioners themselves with English as a second language whose accents pose a problem to those of yet another ethnicity.

There needs to be some flexibility about the health practitioner's duty to always provide an interpreter. Some respondents commented that the Commissioner's Office should not provide an interpreter service. Most communities have a network of voluntary interpreters available. It was also noted that it may not always be appropriate to use family members as interpreters.



18. Should the right to provide services to incompetent consumers under Right 7(4) of the Code be modified in any way? If so what amendments do you suggest and why?

The majority of respondents did not feel the Code needed to be modified. They commented that Right 7(4) was carefully worded. Some disagreed with the suggestions of the Auckland District Health Board, in particular, the suggested change to Right 7(4)(a).

The safety of other people also needs to be considered, as well as the right of the consumer for services optimising quality of life, e.g. a psychotic patient may wish to live in the community but this may put family members/carers at risk. In such circumstances common sense as well as the comfort and well being of the consumer should be considered, perhaps by a team of health professionals when there is an absence of suitable persons from whom to obtain informed consent.

NCWNZ thanks you for this opportunity to make comment and we look forward to viewing the final document.

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