A Review of

The Health and Disability Commissioner Act 1994

and the

Code of Health and Disability Services Consumers' Rights

Report to the Minister of Health

June 2004

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Te Toihau Hauora, Hauātanga

30 June 2004

The Honourable Annette King
Minister of Health
Parliament Buildings
WELLINGTON

Dear Minister

Background to review

The Health and Disability Commissioner Act has been in force since 1994 and the Code of Health and Disability Services Consumers' Rights since July 1996. The legislation requires the Commissioner to undertake reviews of both the Act and the Code, consider whether any amendments are necessary or desirable, and report the findings to the Minister. I decided to undertake these reviews simultaneously.

Consultation

In late 2003 I invited preliminary comments from representative persons and bodies with an interest in health and disability service matters to assist in the development of any recommendations for change to the legislation. In response to the comments received and my own experience of the Act and Code, I published a resource document for wider public consultation in February 2004. This provided discussion on key provisions in the Act and Code and highlighted the changes introduced by the Health and Disability Amendment Act 2003.

Copies of the consultation document were distributed to a wide range of representative consumer and provider groups and statutory agencies. A commentary about the review and a copy of the consultation document were posted on the HDC website. To assist with discussion of the issues and canvass widespread views on the legislation, I also embarked on a series of public meetings throughout New Zealand.

I have received 63 submissions as part of this review. Details of the consultation process and a list of those making submissions are included in the appendices to my report.

Report

Having reviewed the submissions, and further considered the Act and Code, I now submit my final report.

To contain the length of this report and avoid repetition I have concentrated on those matters that require further discussion as a result of submissions or my current experience of the legislation. Where no specific comment on a key provision was received, no further discussion occurs in this report, and my views on the matter remain as stated in the consultation document. Accordingly, this report needs to be read in conjunction with the consultation document.

I trust my report will assist in the ongoing review of the legislation.

Yours sincerely

Ron Paterson

Health and Disability Commissioner

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A. The Act

The following discussion summarises submissions and includes additional comment in response to submissions or as a result of my own experience of the legislation. While I have considered all matters raised in submissions, it is not possible in this summary to note each individual suggestion or comment. However, the submissions did indicate certain common themes, which have been addressed. Where no further discussion occurs in this report, my views remain as stated in the consultation document. Accordingly, this report needs to be read in conjunction with the consultation document. The numbering in this report corresponds with that in the consultation document.

1.0 Preliminary Provisions

1.2 Definitions: sections 2–4

Question 1 in the consultation document asked whether the definitions in the Act were adequate and appropriate. Twenty-seven submissions were received in response to this question, with 11 submissions endorsing the existing definitions and 16 submissions suggesting change.

1.2.1 New definitions

The majority of the submissions endorsed the new definitions of "authority" and "health practitioner" introduced by the Health and Disability Amendment Act 2003. However, some queried whether the new definitions were too legalistic and may be difficult for people to understand out of their historical context.

While I acknowledge that there may be some confusion with the new terminology during the transition period, I consider that the new definitions are essential to ensure consistency between the Health Practitioners Competence Assurance Act and the Health and Disability Commissioner Act.

1.2.2 "Health consumer", "Disability services consumer"

A number of submissions argued that the scope of the Act and Code should be extended to include other people besides the consumer. For example, the National Council, Schizophrenia Fellowship requested that the scope of the Act include family, whānau and next of kin who support consumers. Women's Health Action (WHA) noted that the definition of a disability services consumer makes no mention of procedures but, to qualify as a health consumer under the Act, a person must be subjected to a health care procedure. WHA argued that a "health consumer" should be defined as "any person who has contact with a health service or health care provider, irrespective of whether they are subjected to a procedure".

The rights in the Code are based on the direct relationship between a consumer, a provider, the delivery of health and disability professional services, and the rights that arise out of that relationship. Code rights do not automatically extend to support people and family members. Such an extension could breach the consumer's privacy and cause the consumer unwanted stress. In my view, extending the relationship beyond the consumer would also create onerous and complex obligations for the provider, which may detract from the quality of care provided to the consumer.

There are, however, certain situations where support people or family members do become involved in the consumer/provider relationship. First, Right 8 specifically entitles the consumer to have one or

more support persons present in most situations. Although the support person does not have any enforceable rights under the Code, this provision allows a consumer to waive his or her right to privacy in return for support.

Secondly, a consumer may have diminished capacity to give consent, because of age or impairment, and require a family member, caregiver or support person to give consent as his or her legal representative. In such cases, the legal representative is entitled to enforce the Code rights on behalf of the consumer.

Thirdly, it may be a requirement of professional standards or continuity of care for the provider to involve the consumer's caregiver(s) in the services provided to the consumer. For example, in the provision of mental health services, a failure to communicate appropriately with the consumer's caregivers about treatment may result in a breach of Right 4(2) or Right 4(5).

Finally, I note that while the rights and obligations in the Code are limited to the consumer–provider relationship, people who have contact with providers but do not fall within the definition of a "health consumer" are still entitled to make complaints about providers (eg, family or colleagues).

I consider that the direct relationship between a consumer and a provider must be preserved, and that the Code is sufficiently flexible to cover situations where other people are involved in the relationship at the consumer's request or through necessity. I therefore do not recommend any amendment to the definitions of "health consumer" and "disability services consumer".

1.2.3 "Health care provider", "Disability services provider"

A number of submissions argued that the scope of the Act was not clear when health care procedures were carried out in workplace or educational settings.

Section 3 defines a "health care provider" and lists categories of providers. Section 3(k) is a catch-all paragraph which defines a health care provider as "any other person who provides, or holds himself or herself or itself out as providing, health services to the public or to any section of the public, whether or not any charge is made for those services". I consider that the Act is clearly intended to apply to the provision of health services in a wide range of contexts, including workplace and educational settings.

"Health services", as defined in section 2, includes services to promote health and services to protect health. A "health care procedure" also includes health teaching. In most cases it is obvious whether a particular situation involves teaching.

One submission noted that disability services providers were often employed by the consumer, and queried whether that relationship had any impact on the enforceability of Code rights. My view is that a disability services consumer is entitled to enforce his or her Code rights regardless of whether a contract of employment is in place. If a contract of employment exists, the consumer may have an additional avenue of redress in the event that services are not of an appropriate standard.

1.2.4 After-death services

A small number of submissions argued that the Code should apply to representatives acting on behalf of deceased consumers. For example:

> "We would like to see an extension of the Act and Code of Rights to cover the rights of the family/next of kin of a dead person when using services relating to after-death care, e.g. funeral directors, hospitals and mortuaries. This is an important aspect of health services where rights need to be protected." (Palmerston North Women's Health Care Collective)

The definition of "health care procedure" specifically limits services to those carried out on or *in respect of any person*. The law distinguishes between living people (persons) and the deceased, and a medical procedure cannot be carried out on a "person" if death has occurred. A body after death is not, in law, a person.

In practice, however, the immediate family of the deceased have a legitimate interest in receiving appropriate after-death services, and providers of health and disability services have ethical obligations to treat the deceased appropriately. However, to stretch the definition of "health care procedure" to include actions taken in respect of a body after death would potentially bring the Code into conflict with the Human Tissue Act 1964. That Act provides for the removal and retention of parts from the bodies of health and disability services consumers following their death, and is currently being reviewed. In my view, it would be inappropriate for the Code to create a rival and potentially inconsistent scheme for regulating this area of health services. However, it is proposed to draw the submitters' concerns to the attention of the Minister of Health, so that they may be taken into account as part of the Human Tissue Act review.

1.2.5 Miscellaneous matters

One submission argued that the Act and Code should cover doctors who prepare reports for ACC. The Commissioner's complaints resolution role under the Act is restricted to matters relating to the quality of health delivery; it does not cover matters relating to the content of medical reports written by health practitioners. In my view, complaints about the *contents* of an assessment report, and complaints about purely paper-based reviews, are usually not within the scope of the Act. However, complaints relating to the *process* of an assessment generally fall within jurisdiction.

Under the Act a "health consumer" includes any person on or *in respect of whom* any health care procedure is carried out. Obviously the consumer is the person on the receiving end of the services, not the person paying the bill. "Health care procedure" is broadly defined and includes any health examination carried out on or *in respect of* any person by any health care provider. Thus, any assessment for a third party involving a face-to-face consultation with the patient is likely to fall within the definition of a "health care procedure", and the non-treating doctor will have a legal duty to comply with the Code during the assessment process. In particular, the doctor must conduct him- or herself in accordance with the Code (eg, treat the patient with respect and communicate effectively) and the assessment must be of an appropriate standard.

In practice, I rarely investigate complaints about non-treating doctors who have carried out an assessment at the request of a third party. Under section 37(1)(e) I have a discretion to take no action on a complaint where there is another adequate remedy or right of appeal. ACC clients have specific rights set out in the ACC Code of Claimants' Rights, and complaints relating to ACC assessors are generally referred to the Office of the ACC Complaints Investigator.

Finally, one submitter queried whether a "professionally recognised quality assurance programme" (Right 7(10)) would be defined in the Code. I consider that the plain language interpretation of these words is clear, and the phrase does not require further definition.

1.2.6 Recommendation

Having reviewed the submissions in respect of sections 2 and 3 of the Act, I do not recommend any amendments to the Act.

1.3 Purpose of the Act

Question 2 in the consultation document asked whether the purpose of the Act was appropriate. Twenty-two submissions were received in response to this question, with 17 submissions endorsing the existing definitions and only 5 submissions suggesting change.

A number of submissions responded to question 2 asking that the scope of the Act be extended or that the Commissioner's functions be enhanced. These submissions were considered as part of paragraphs 1.2 or 2.3 in this report.

CCS submitted that the complaints resolution function of the Act required a more strategic purpose:

> "Some issues e.g. non-consensual sterilization of disabled women, and withdrawal of life sustaining support need a more strategic approach. Suggest add to purpose … fair, simple, speedy, efficient and where necessary, strategic resolution …"

I acknowledge that sensitive complaints do require a very careful and well-planned approach but consider that a strategic approach is reflected in the overarching requirement that the Commissioner "promote and protect the rights" of consumers in resolving complaints.

1.3.1 Recommendation

Having reviewed the submissions in respect of section 6 of the Act, I do not recommend any amendments to the Act.

1.4 Reference to Treaty of Waitangi

Question 3 in the consultation document asked whether the Act should 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 Treaty). Twenty-four submissions were received in response to this question, with 10 submissions endorsing the status quo, and the majority (14 submissions) supporting change.

1.4.1 Treaty in the Act

The majority of submissions supported inclusion of an obligation for all persons exercising functions and powers under the Act to have regard to the principles of the Treaty of Waitangi. The following comments are representative of the reasons given in support of the amendment:

> "Our understanding is that although the Act does not currently have an explicit reference to the Treaty, the Office of the Health and Disability Commissioner (HDC) has endeavoured to ensure that the Treaty is not forgotten in the conduct and practices of the office. … By including a direct reference to the Treaty in the Act HDC reinforces and strengthens the commitment the Office has to the Treaty. The acceptability, credibility and integrity of the decisions that the Commissioner makes are increased by such a commitment." (The New Zealand AIDS Foundation)

Those who opposed reference to the Treaty tended to base their opposition on the fact that they did not want racial differences enshrined in legislation and that a single group of New Zealanders should not be singled out for special mention.

1.4.2 Treaty in the Code

Some of the submissions indicated support or opposition for the inclusion of a reference to the Treaty in the Code.

I do not recommend that the Code be amended to include a reference to the Treaty. The Treaty is an agreement between the Crown, or its representatives, and the tangata whenua of New Zealand. The Act creates obligations for the Commissioner, who is a Crown entity. The Code creates obligations for providers, who are, for the most part, not representatives of the Crown and, in my opinion, do not have responsibilities under the Treaty.

1.4.3 Recommendation

Having considered all of the submissions in response to question 3, I recommend that 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.

In my view, an express Treaty reference of this nature ("have regard to") should not cause legal difficulties, but would signal the Commissioner's commitment to have regard to the Treaty principles of partnership, protection and participation in exercising functions and powers under the Act. The Commissioner is already required (by section 7 of the Health and Disability Commissioner Act) to take into account the specific objective "to reduce health disparities by improving health outcomes for Māori …" (section 22(1)(e), New Zealand Public Health and Disability Act 2000) and the New Zealand health strategy and the New Zealand disability strategy, both of which acknowledge "the special relationship between the Crown and Māori under the Treaty of Waitangi". It is therefore arguable that the Commissioner is already subject to an implied obligation to have regard to the principles of the Treaty.

However, the feedback I have received indicates that some Māori feel the Commissioner's Office would be more accessible if the Treaty were specifically recognised in the Act. An amendment may therefore enhance confidence in the role of the Commissioner and encourage Māori participation in the statutory complaints processes. This in turn may assist in improving the quality of services for Māori and, over time, contribute to better health outcomes for Māori.

2.0 Part I: Health and Disability Commissioner

2.1 Health and Disability Commissioner – section 8

2.1.1 Commissioner or Commission

One submission queried whether the Office should be renamed the Health and Disability Commission. I agree that this would be a sensible change, as it is often clumsy to use the term "Health and Disability Commissioner" in a single piece of correspondence or a report, to refer variously to the legal entity (as Commission or Office of the Health and Disability Commission) and the individual person who is the Health and Disability Commissioner. However, there has been no groundswell of support for this change and it appears that the majority of consumers respond to the concept of an identifiable Commissioner, maintaining a personal overview of complaints concerning health and disability services. It may be appropriate to review this issue in the future if there is more than one Commissioner appointed, as in the case of the Human Rights Commission.

2.1.2 Full capacity

Section 8 describes the role of the Commissioner and states that he or she will be "a natural person of full age and capacity". As part of its submission, CCS raised an issue with respect to the wording of section 8:

> "The language in legislation to be of 'full capacity' is no longer appropriate. It is specifically targeted at disabled people, whose experience may be an asset, rather than a liability, in doing the job of Commissioner."

In my view, the wording in section 8 would not prevent a disabled person from performing the role of Commissioner, provided he or she has the appropriate skills and knowledge required for the role (ie, professional capacity).

2.2 Deputy Commissioners: section 9

The majority of submissions indicated support for the changes to section 9, which will provide for the appointment of more than one Deputy Commissioner. However, a number of submitters were concerned about the selection and appointment process for this role. For example:

> "The RACS supports the amendment that will allow the appointment of more than one Deputy Commissioner, particularly if this will help to speed up the complaints process. However, if these Deputies carry the same delegated powers of the Commissioner we assume that they will operate under the same constraints and that the same rights of appeal and consultation will exist for complainants and practitioners. The appointment of the deputies should be overseen by the same body that appoints the Commissioner." (Royal Australasian College of Surgeons)

I can confirm that Deputy Commissioners are subject to the same constraints and obligations as the Commissioner and are appointed by the Governor-General on the recommendation of the Minister of Health.

2.3 Functions of the Commissioner: section 14(1)

Question 4 in the consultation document asked whether the functions of the Commissioner were appropriate. Thirty-two submissions were received in response to this question. Some of the submissions initially presented as a request for change but, upon analysis, it became apparent that the requested outcome could be achieved under existing wording in the Act or Code. Other submissions indicated support for existing provisions but were coupled with a request that the provisions be applied differently or given more status by the Commissioner. These submissions have been categorised as being in support of the existing definitions. Accordingly, 22 submissions supported the existing provisions and 10 submissions suggested change.

2.3.1 Promote and Protect

Whilst many submissions discussed the Commissioner's role in general terms, three aspects of the Commissioner's function elicited the most comment — advocating publicly on behalf of consumers, consumer education and provider education.

Advocating on behalf of consumers

A common theme in the submissions seeking amendment to the Act or operational change, was a request for the Commissioner to speak out publicly on behalf of groups of consumers. For example:

> "In relation to the functions of the Commissioner, the HFNZ strongly supports a stronger advocacy role on behalf of consumer groups collectively affected by decisions or actions and/or lack of due care by health providers. For example, in the case of the many New Zealanders affected by 'bad blood' and the infection by the Hepatitis C virus, a role of the Commissioner should be to advocate for these people to obtain free adequate health care and compensation for all those affected. There are thousands of people in New Zealand affected with HCV and no one is helping them obtain health care to the standard of world's best practice." (Haemophilia Foundation of New Zealand)

DPA submitted that in terms of public advocacy, the Commissioner should advocate with, rather than on behalf of, disabled consumers, who are the authoritative experts in relation to their own needs.

Women's Health Action acknowledged that the Commissioner carries out part of the public advocacy role by making submissions on key policy documents, but commented that this aspect of the Commissioner's role should be more visible to the public by posting submissions on the HDC website.

I agree that public advocacy is a very important aspect of the Commissioner's role under section 14(1)(c). As I discussed in the consultation paper, this aspect of the Commissioner's function is currently fulfilled by making comments of interest to the media and by making submissions on key policy documents and legislation. Placing policy submissions made by the Commissioner on the HDC website is a good idea, and will be followed up. However, I do not consider that section 14(1)(c) requires amendment.

Dispute resolution

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists suggested that the Act should enable the Commissioner to take up a public role in mediating between providers:

> "We wonder whether there is an added function for the Commissioner in terms of dispute resolution between professional individuals or between professional groups. While the Act should be focused on consumers and patients, there are public policy interests and indeed part of Right 4 refers to co-operation between professionals. There are times where that co-operation reaches an impasse and the Commissioner might well have a role, even if it is to refer parties to mediation. It is something that regulatory bodies have been unwilling to tackle."

This is an interesting idea. Although the Commissioner does not have jurisdiction to handle complaints that do not involve patient care, disputes between health professionals and groups can adversely affect quality of care. In my view, this is a possible area for Commissioner involvement as part of the broader patient advocacy role, but does not require a specific law change.

Education for disabled consumers

A significant number of the submissions commented on the need for certain groups of consumers to receive targeted education, particularly disability services consumers. The following comment is representative of many of the submissions on this point:

> "Most of our members don't know about their rights and therefore can't access them. We note that the Commissioner has a role in consumer education. Although there is a plain language booklet, most of our members do not read and we think that much more must be done to help our members, such as the production of special videos featuring scenarios that are common in the lives of people with an intellectual disability. We would like to see an extra clause added to Section 14 (1): 'to give priority to education that is accessible to vulnerable groups in the community'. (People First New Zealand Inc)

I agree that more vulnerable groups of consumers have a particular need for targeted education in a form that is accessible. HDC is currently implementing a number of initiatives to respond to the increased educational needs of disability services consumers. In particular:

- HDC will provide a New Zealand sign language interpreter at all of its public presentations and seminars from 2004
- An 0800 free fax number will be available for public use and will, in particular, improve accessibility to HDC by people who have speaking difficulties
- HDC is currently working with IHC to produce easy-read posters to provide information to intellectually disabled consumers in an appropriate format
- HDC will be revising and reprinting all easy-read pamphlets over the next two years. These were produced in consultation nationally with consumers, providers and caregivers of people with intellectual disabilities.
- HDC has developed a joint disability contact database with information from Advocacy Services, the Office for Disability Issues, and the Human Rights Commission.
- HDC has joined the "Mainstream" programme, which is a supported employment programme for people with disabilities.

Implementing the New Zealand Disability Strategy

The Government has recently developed and launched the New Zealand Disability Strategy. The aim of the Strategy is to guide Government action to promote a more inclusive society for disabled people. More information on the New Zealand Disability Strategy is available on the Office for Disability Issues website (www.odi.govt.nz).

HDC is in the process of drafting its implementation plan for the New Zealand Disability Strategy. The proposed responses to the 15 objectives set out in the strategy include:

Objective 1: Encourage and educate for a non-disabling society

- Developing a database of people with disabilities who are available to provide training to HDC staff, and reviewing all HDC promotional material to ensure it is in an appropriate format to meet the needs of disabled consumers and disability service providers

Objective 2: Ensure rights for disabled people

- Working with disabled consumers to develop specific education plans for use by HDC with disabled consumers, disability service providers and health care providers

Objective 4: Provide opportunities in employment and economic development for disabled people

- Identifying the range of work options available for disabled persons in working alongside HDC or within HDC by ensuring an accessible and flexible workplace.

Objective 5: Foster leadership by disabled people

- Modelling the inclusion of disabled people in leadership roles within HDC and supporting leadership/mentoring programmes for disabled people within HDC.

Objective 6: Foster an aware and responsive public service

- Providing services that treat disabled people with dignity and respect and providing information in formats that are accessible by disabled people.

Objective 7: Create long-term support systems centred on the individual

- Training HDC staff in cultural awareness surrounding disability.

Objective 10: Collect and use relevant information about disabled people and disability issues

- Reviewing customer satisfaction surveys and systems for recording statistical data about disabled people and disability issues.

Objective 11: Promote participation of disabled Māori

- Establishing and formalising consultation processes for obtaining comment on HDC services from Māori who are disabled and from Māori disability service providers.

Objective 12: Promote participation of disabled Pacific peoples

- Establishing and formalising consultation processes for obtaining comment on HDC services from Pacific peoples who are disabled, and from Pacific peoples disability service providers.

Objective 13: Enable disabled children and youth to lead full and active lives

- Establishing a process for HDC to seek advice from disabled people on disability and health issues for children and youth.

Objective 14: Promote participation of disabled women in order to improve their quality of life

- Including the perspective of disabled women in the development of all HDC service strategies.

Objective 15: Value families, whānau and people providing ongoing support

- Improving the accessibility of HDC education to those who support disabled consumers.

While the HDC implementation plan is currently still in its draft stage, it is hoped that many of these initiatives will be operational within the next two years.

Education for mental health consumers

The Mental Health Commission submitted that consumers should receive more education on how the Code is applied by the Commissioner and, in particular, how resource constraints may be taken into account in considering whether or not a provider has breached the Code.

While it is difficult to give general guidance on how resource constraints are taken into account in assessing complaints under the Code, many education sessions do make valuable use of case studies. I acknowledge that this is an area where consumers could benefit from further education.

Provider education

A number of submissions commented on the fact that providers also require targeted education on how best to provide services to groups of consumers, eg intellectually disabled consumers, and that this education should be formulated in conjunction with consumer groups.

I agree that the input from consumer groups is particularly important in this area and, as noted above, education plans for both health and disability services providers on the specific needs of disabled consumers are being developed by HDC in conjunction with disabled consumers.

Other submissions supported the concept of educating all providers at tertiary level:

> "Provider education appears to be an important step in promotion and protection of the public. It would be useful if provider education at the tertiary level be promoted to all health practitioners rather than specifically medical students." (NZ Speech-Language Therapy Association)

2.3.2 Recommendation

I do not consider that the functions of the Commissioner as described in section 14 need any change. Section 14(1)(c) is drafted in very broad terms and a law change is not needed to promote targeted

education to groups of vulnerable consumers. Provider education is also the focus of continuous review and improvement. I do not, therefore, recommend any amendment to section 14 of the Act.

2.4 Interface with District Inspectors

The consultation document discussed the interface between the Commissioner and District Inspectors appointed under the Mental Health (Compulsory Assessment and Treatment) Act 1992. The discussion referred to my own view that the existing statutory provisions (eg, section 59(4)), which allow referral to another body, are sufficient to govern the relationship with District Inspectors. Furthermore, the obligation to consult with the Director of Mental Health, contained in section 14(2) of the Act, is sufficiently broad to accommodate issues concerning the interface with District Inspectors.

In response to the consultation document, the Ministry of Health commented:

> "The Ministry agrees with your view that the Act does not need to be amended to specifically deal with District Inspectors (page 20). The development of robust procedural protocols between your office and District Inspectors, appointed under the Mental Health (Compulsory Assessment and Treatment) Act and the Intellectual Disability (Compulsory Care and Rehabilitation) Act, will be an ongoing matter." (Deputy Director-General, Sector Policy, Ministry of Health (Dr Gillian Durham))

2.5 Director of Proceedings

Question 5 in the consultation document asked whether the Director of Proceedings should be able to negotiate funding directly with the Minister of Health. Seventeen submissions were received in response to this question, with 6 submissions endorsing the status quo and the majority (11 submissions) suggesting change.

2.5.1 Independent funding

Submissions in favour of keeping the funds with the Commissioner included the following:

> "… As the Director is responsible to the Commissioner for efficient, effective and economical management, NZAO considers that the Director of Proceeding's budget should be allocated by the Commissioner." (New Zealand Association of Optometrists)

> "Funding for the implementation of the Health and Disability Commissioner Act 1994 is provided by Parliament through an appropriation. This funding is given to the Health and Disability Commissioner to allocate, as he or she considers appropriate, in order to implement the Act. In the Ministry's view, the Commissioner is in the best position to determine the appropriate allocation of funding." (Deputy Director-General, Sector Policy, Ministry of Health (Dr Gillian Durham))

Some submissions indicated support for an amendment in principle but queried what impact the change might have on the Commissioner's ability to negotiate funding:

> "FPA supports ability of the Director of Proceedings to directly negotiate funding with the Ministry of Health as this may provide a better separation of roles. However, if this was to occur there would need to be an assessment of the effect this had on the functionality of the Office of the Health and Disability Commissioner in order to ensure the separation improved the functionality of the Office, rather than leading to decreased communication or decreased regard for the Office, or decreased budget for resolution, etc." (Family Planning Association)

The majority of submissions supported the Director of Proceedings being able to negotiate separate funding on the basis that it would enhance independence. For example:

> "The Act obviously considers that the Director of Proceedings needs to be independent of the Commissioner. There is no doubt that control over finances carries the risk of compromising that independence and impartiality. For this reason the RACS would support the Director being able to negotiate annual budgets directly with the Ministry." (Royal Australasian College of Surgeons)

2.5.2 Recommendation

Having considered all of the submissions in response to question 5, I am not convinced that separate funding arrangements are necessary or practicable. The Director, like the Commissioner's complaints assessment and investigation teams (and indeed all publicly funded health and disability services providers), will always face resource constraints, but over the past eight years there has been sufficient flexibility to allow shifts in funding to accommodate the ebb and flow of workload in the respective divisions of the Commissioner's Office. If a need arises for significantly increased funding for Proceedings, the Commissioner and the Director of Proceedings can jointly submit the case to the Minister and Ministry officials. There will always be a strong public policy case for a properly funded Director of Proceedings to ensure accountability in appropriate cases.

The Minister of Health and the Commissioner would face justified public criticism if disciplinary proceedings could not be brought because of funding constraints. However, in my view, this is not currently (or in the foreseeable future) a problem and the Commissioner is best placed to assess the overall needs of the various divisions, including Proceedings, within the Commissioner's Office.

2.6 Delegation by Director of Proceedings

Question 6 in the consultation document asked whether the Director of Proceedings should be able to delegate powers, duties and functions under the Act. This question drew a larger response, with 22 submissions received. Again, the majority (19 submissions) supported amendment and only 3 submissions were in favour of maintaining the status quo.

Many felt that allowing the Director of Proceedings to delegate powers, duties and functions would increase administrative efficiency. Support for the amendment was, however, often conditional on the Act specifying that the delegate would have the appropriate skills and knowledge to be able to carry out the role.

> "The intent of this concern is recognised and NZNO supports changes that will improve the timeliness of complaints. NZNO's concern is to ensure that any delegation of powers must be appropriate to the level of skill expertise and accountability as decided by the Director of Proceedings. If changes are made to extend powers of delegation there needs to be an assurance that delegation is at the appropriate level of skill, knowledge and accountability." (New Zealand Nurses Organisation)

Those who were opposed to the concept of delegation submitted:

> "… In my view it is more important to have cases thoroughly and personally reviewed even if it means a delay." (Carolyn Hodson and Annette Waring)

Having considered all of the submissions in response to question 6 and after further discussion with the Director of Proceedings, I do not consider that the Act requires amendment at this point. I do, however, recommend that the Director continue to monitor the need for delegation so that this issue can receive further consideration when the Act is next reviewed.

2.7 Review of the Act: section 18

Question 7 in the consultation document asked whether it is necessary to retain a provision to review the Act every five years. This question prompted a large number of responses, with 31 submissions received. Support was evenly divided, with 16 submissions in favour of change and 15 preferring the status quo.

2.7.1 Regular reviews

Those in favour of maintaining section 18 in its current form argued that the medico-legal landscape was dynamic and regular review of the Act was required to ensure that the Act was keeping pace with changes. The Royal Australasian College of Surgeons noted that the "reviews are, in effect, the opportunity for the consumers of the Commissioner's service to provide comment".

Even where there was support for change, the majority of submissions were in favour of keeping the reviews but extending the intervening periods, such as every 10 years. For example:

> "Although reviewing the Act may be expensive and time consuming, changes have already been made in the first 10 years of this legislation due to the review process. Because of the nature of this legislation regular review is necessary and the NZAO considers it important that a formal process with appropriate consultation occur regularly. This is especially so with the imminent changes associated with the HPCA Act.
>
> We would, however, make a distinction between the Act and the Code. It is our view that the Code requires more frequent review than the Act. A five yearly review of the Code could combine with a ten yearly review of the Act, for example. In essence we are suggesting that the review period for the Act should equate with every second review of the Code." (New Zealand Association of Optometrists)

2.7.2 Review of HDC Act with HPCA Act

Others submissions agreed that the Act would need to be reviewed in line with the HPCA Act, and one submission suggested that the Act undergo a review in three years' time when the HPCA Act is reviewed. Women's Health Action suggested that the next review would be a good opportunity to evaluate the success of the amendments brought about by the HDC Amendment Act 2003 and the HPCA Act:

> "As a general comment, we would like the next review to be able to assess the impending changes that will occur under the HPCA so this review should make provision for the collection of appropriate baseline information and data for audit and evaluation. Particular attention should be given to the views, experiences and satisfaction ratings of consumers in these processes and options. This is particularly important where there is a decision to take no action."

I agree that it would be useful to review the efficacy of the changes brought about by the HDC Amendment Act 2003 and will endeavour to collect statistical data for that purpose.

2.7.3 Independent review

A small number of submissions expressed a preference for reviews of the Act to be conducted by an independent, external reviewer, rather than by the Commissioner. A comment was also made that the current focus of the reviews on legislative reform does meet the need for review by consumers and consumer advocacy groups.

I accept that there could be advantages in having an independent person review the operation of the Act. This model is adopted in some parts of Australia (eg, Western Australia) but can be time-consuming and problematic if the reviewers are unfamiliar with the work of the Commissioner. I consider that the Commissioner, as the person with the most intimate knowledge of the operation of the Act, is best placed to undertake the statutory review and provide advice in the first instance to the Minister. The requirement for consultation and a publicly available report (tabled in Parliament) enables independent scrutiny of the review. Furthermore, this is only the first step in a process of possible amendment to the Act — an opportunity for further public scrutiny of any proposed changes occurs as part of the legislative process.

The need for review of the Commissioner's internal procedures is accepted. It is current practice to solicit and review feedback from complainants and providers involved in the Commissioner's processes. Feedback is considered as part of the continuous quality review of the Office. Amendment to the Act is not necessary for review and change to internal procedures.

2.7.4 Recommendation

Having considered all of the submissions in response to question 7, and for the reasons set out in the consultation document, I recommend that section 18 be amended to require 10-yearly reviews of the Act.

3.0 Part II: Code of Health and Disability Services Consumers' Rights

3.2 Content of the Code – section 20

3.2.1 Responsibilities of consumers

Question 8 in the consultation document asked whether the Act and/or the Code should be amended to include reference to the responsibilities of consumers. Again, this was a popular topic with 32 submissions received, some focusing solely on this issue. Eighteen submissions endorsed the status quo and 14 submissions supported change.

Not surprisingly, most comment on the need for change came from providers. The main themes were the difficulty in divorcing rights from responsibilities, and the view that inclusion of rights and responsibilities would assist in fostering greater partnership between consumers and providers. The following are illustrative of the concerns raised:

> "… Ambulance services consider that there is a case to strengthen the obligations of consumers. There is a growing tendency for ambulance services to be the subject of intimidation and threatening behaviours and actions. There have been a number of recent assaults on ambulance crews who have been responding to an emergency." (Ambulance New Zealand)

> "The matter of rights and responsibilities of consumers and patients does need to be visited. While there is provision in the Code for that, and the decisions of the Commissioner have not given rise for concern, any future Commissioner might well take a different approach. It would do no harm, and in our view do nothing to adversely affect 'power imbalances' to have a statement about responsibilities of patients, for example, to tell the truth and to supply the health professionals with appropriate information." (Royal Australian and New Zealand College of Obstetricians and Gynaecologists)

One submission suggested an alternative to including a reference to consumers' responsibilities:

> "ADHB submits that the Code should expressly state that abusive, threatening, or uncooperative behaviour, of an unreasonable nature or extent, is justification for a provider refusing to provide services. Such a provision would answer ethical obligations to treat. Alternatively the clause 3 defence should be expressly extended to incorporate 'patient behaviour' as an acceptable ground for failing to comply with the Code." (Auckland District Health Board)

Many of the submissions opposed to amendment felt that a reference to consumer responsibilities would detract from the Code's emphasis on consumer rights:

> "The MSCC remains strongly opposed to the Act or the Code being amended to include reference to the responsibilities of consumers. The previous Commissioner summed it up well in her report to the Minister dated October 1999 when she wrote that the 'inherent vulnerability' of consumers reflects reality as I see it time and again. Few people who are sick, or have a disability, are able to deal on truly equal terms with their service provider. The Code's emphasis on rights continues to be needed to empower consumers, to encourage their participation and feedback and, ultimately, to improve the quality of health and disability services in New Zealand." (Maternity Services Consumer Council)

Some submissions were also opposed to the concept of providers developing internal codes of consumer responsibilities:

> "The AWHC is strongly opposed to the Act or the Code being amended to include reference to the responsibilities of consumers. The Council also opposes the implied suggestion on page 23 of the consultation document that organisational providers (such as hospitals) or Colleges publish internal codes of consumer responsibilities. There are serious implications to the HDC being seen to be encouraging the production of other codes for consumers including:
>
> - If such codes of consumer responsibilities are produced it is essential that consumers are informed of the difference between such codes which have no legal backing and the HDC Code of Consumers' Rights which is enshrined in legislation
> - Who will have oversight of such codes to ensure that they do not attempt to override or contradict the HDC Code of Consumers' Rights?
> - The focus on consumer responsibilities shifts the balance of power even further in favour of health practitioners" (Auckland Women's Health Council)

Having considered all of the submissions on this issue, I am not persuaded that the Act or the Code needs to refer specifically to consumer responsibilities. Consumers clearly do have responsibilities — the question is whether it is necessary to codify them. In my view, the clause 3 defence that a provider took "reasonable actions in the circumstances" is adequate to take into account the fact that a consumer knowingly withheld relevant information at a consultation, failed (after giving informed consent) to comply with an agreed treatment plan, was uncooperative or abusive, or did not act fairly or honestly in making a complaint.

I do, however, maintain that providers are entitled to publish internal guidelines setting out consumer responsibilities to clarify behavioural expectations of consumers (eg, zero tolerance of abuse towards staff).

3.2.2 Access to services

Question 9 in the consultation document asked whether the Act and/or the Code should be amended to include a right to access publicly funded services. Thirty-one submissions were received in response to this question, with 10 submissions endorsing the status quo and 21 submissions suggesting change.

The issue of "right to access" was interpreted in a number of ways. Some felt that the Commissioner had a role to play in lobbying for the allocation of resources to ensure consumers had guaranteed access to certain services. However, the majority argued that the Code should guarantee consumers a right to access where services were already funded. The Mental Health Commission aptly identified the distinction:

> "There are perhaps two types of access issue that could be considered:
>
> a) the right to have a service established or funded, which could be considered a political decision, and
> b) the right to access services already established. The Commission refers to the latter issue when referring to access concerns. We have, for example, identified circumstances where access to some government subsidised psychiatric medications were available in some health districts and not others. Such issues of equity may need further attention."

A right to access services was supported by some provider groups, such as the Royal Australasian College of Surgeons, on the basis that a delay or denial of services can increase health risks for the consumer and clinical problems for the provider.

Opponents of a right of access considered that it would detract from the complaints resolution focus in the Act. For example:

> "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." (The National Council of Women of New Zealand)

Others commented that while it would be the ideal, it is simply not realistic to guarantee access to services in today's political climate:

> "FWHC does not support inclusion of a right to access publicly funded services, nor of including references to timely referrals. FWHC acknowledges there is a very gray area around a lack of timely referrals and inappropriate/poor quality or incorrect assessments that is of increasing concern to consumers. The crossover from clinical decision making and management decisions about access thresholds is a shifting domain that is unlikely to be clarified or enhanced by codifying the matter. We absolutely agree it would be an ideal situation to have consumer assurance through reference to a Code of Rights with regard to timely access to publicly funded services. However, we suggest that these issues can't be enforced in the current climate where relevant resources are simply not available." (Federation of Women's Health Councils)

I agree that it is neither practical nor appropriate, in an environment of limited resources, for the Commissioner to seek to enforce a right of access to publicly funded services. Nor do I believe any Government would confer such a role on an independent Commissioner.

This does not mean, however, that the Commissioner can play no role with respect to funding issues. The general functions under section 14 already allow the Commissioner to make public statements or suggestions on any matter affecting the rights of health and disability services consumers, including funding matters. My own practice has been to use this power with discretion, being mindful that a call for more resources in one area will inevitably result in a reduction of resources in another.

Many of the submissions on this issue felt that the Code should guarantee *timely* access to publicly funded services. The basis for this argument is that where a service has been approved for funding, the

provider should not delay in providing it. In some cases, the Code can already support a right to timely access to services. For example, the timeliness of a provider's actions can be investigated as a quality of care issue, under Right 4(1), and services must be provided in a manner that minimises the potential for harm, under Right 4(4). However, resource constraints inevitably impact on the time within which services can reasonably be provided, and can be taken into account under clause 3 of the Code. Overall, I do not recommend amendment to the Act to create a new right to access publicly funded services.

3.3 Review of the Code: section 21

Question 10 in the consultation document asked whether it is necessary to retain a provision to review the Code every three years. Thirty-five submissions were received in response to this question, with 10 submissions endorsing the status quo and 25 submissions suggesting change.

3.3.1 Review of the Code

The majority of submissions agreed that it is important to review the Code more frequently than the Act, and most were of the view that five-yearly reviews would be adequate.

Those in favour of retaining the three-yearly reviews felt that regular review was necessary to ensure the Code was keeping pace with the changing needs of consumers.

3.3.2 Public consultation on amendments to the Code

A number of submissions expressed disappointment that Right 7(10) had been amended without widespread public consultation, and argued that the Act should be amended to prevent the Commissioner from amending the Code in this manner.

The Act does, in fact, require the Commissioner to canvass a wide range of views when reviewing the Code. Section 23 requires the Commissioner to consult with a number of people in carrying out a review of the Code, including the Ombudsmen, the Human Rights Commission, the Race Relations Conciliator, the Privacy Commissioner, the Commissioner for Children, the Director of Mental Health, and representatives of health services consumers, disability services consumers, health care providers and disability services providers.

The recent amendment to Right 7(10) was made under sections 74 and 75 of the Act. In such cases the Governor-General may, by Order in Council, make regulations to amend the Code without a recommendation from the Commissioner and without wide public consultation.

The Minister of Health has recently published a section 75(1) notice explaining the amendment to Right 7(10). The notice appears at p 41 of this document.

3.3.3 Recommendation

Having considered all of the submissions in response to question 10, I recommend that section 21 be amended to require five-yearly reviews of the Code. The Code impacts directly on consumers and providers throughout New Zealand but, in my view, five-yearly reviews will allow sufficiently regular opportunities to review the operational effectiveness of the Code. The Commissioner retains the option under section 21 of carrying out reviews more frequently if necessary.

I do not recommend any amendment to section 23, which requires the Commissioner to consult widely when carrying out reviews of the Code.

4.0 Part III: Health and Disability Services Consumer Advocacy Service

4.2 The Director of Advocacy

Question 11 in the consultation document asked whether the Director of Advocacy should be able to negotiate funding directly with the Minister of Health. Twenty-one submissions were received in response to this question, with 7 submissions endorsing the status quo and the remaining 14 submissions suggesting change.

4.2.1 Independent funding

Submissions in favour of keeping the funds with the Commissioner reiterated the arguments reported in paragraph 2.5 above — that the Director was part of the Commissioner's staff and responsible to the Commissioner for the economical management of services.

The Chief Ombudsman commented that separate funding for both the Director of Advocacy and the Director of Proceedings would not necessarily ensure their independence:

> "Although the Act requires the Directors to act independently in the performance of their functions, and although they are not responsible to you in this respect, they are nevertheless appointed by you and form part of your staff pursuant to clause 2 of Schedule 2 of the Act. Your employer relationship with the Directors could be seen as detracting from their independence, in that it could be perceived to influence the manner in which they discharge their functions, notwithstanding that the statute requires them to act independently in this regard.
>
> You may wish to consider whether the Commerce Act 1986 provides a model that could be adapted for the purposes of the Health and Disability Commissioner Act, to avoid any perception of the Directors' independence being compromised by the nature of their position."

A number of submissions in favour of separate funding wanted to protect advocacy funds from being reallocated to other parts of HDC. For example:

> "The future of the … Advocacy Service is dependent upon the Director's ability to influence the Commissioner's financial priorities in favour of Advocacy. This was evident in 1999 when the then Commissioner determined the activities within the Commissioner's office warranted a larger portion of the available funding this resulting in a $600,000 reduction in the funding available for the National Advocacy Service.
>
> Our trustees have made a concerted effort to minimise the impact upon consumers following the reduction in funding. We believe we have maintained the standard of service despite having to reduce the number of full time equivalents." (Advocacy Network Services Trust)

4.2.2 Recommendation

Having considered all of the submissions in response to question 11, I am not convinced that separate funding arrangements are necessary or practicable. The Director, like the Commissioner's complaints assessment and investigation teams (and indeed all publicly funded health and disability services

providers), will always face resource constraints, but in the past eight years there has been sufficient flexibility to allow shifts in funding to accommodate the ebb and flow of workload in the respective divisions of the Commissioner's Office. If a need arises for significantly increased funding for Advocacy, the Commissioner and the Director of Advocacy can jointly submit the case to the Minister and Ministry officials. There will always be a strong public policy case for a properly funded Director of Advocacy to ensure accountability in appropriate cases.

4.3 Structure of advocacy services

Question 12 in the consultation document asked whether the current structure for advocacy services was appropriate. Twenty-one submissions were received in response to this question, with 9 submissions endorsing the status quo and the remaining 12 submissions suggesting change.

4.3.1 Regional advocacy services

The majority of the submissions in support of the status quo argued that the existing structure works well and the recommendations arising out of the 2003 review of advocacy will further enhance the consistency and accountability of advocacy services.

4.3.2 National advocacy service

Those in favour of amendment to the Act felt that consistency would be enhanced if advocacy services were restructured under a national advocacy service. The following comments from Women's Health Action are representative of many of the submissions on this issue:

> "Women's Health Action has opposed the funder/provider split for advocacy since its inception and this position has not changed. We would prefer a national system with advocates employed by the Director of Advocacy with a discrete budget and its own service contract.
>
> We believe this would bring substantial advantages in consistency and accountability and open up useful training and support opportunities. The present arrangement means there is no national system for providers of advocacy services who contest the contracting round — a situation we believe is most inappropriate. The review of the advocacy service has highlighted the difficulties that arise when three different service providers are contracted.
>
> Suggestions in the discussion paper are making the most of a currently existing bad situation. The model we have suggested would retain the advantages and remove the barriers. It would also remove layers of administration (trusts and managers) and better use scarce resources in achieving the service goals outlined in the changes."

Another common theme in the submissions was the need for an advocacy service that specifically targeted the needs of disabled consumers. This is discussed further in paragraph 4.4 — functions of advocates.

DPA submitted that a separate advocacy service was required to enable access by disabled consumers to a number of different services:

> "A separate individual advocacy service for disabled people needs to be established and resourced. A broader disability advocacy service would impact on services funded by the Ministries of Social Development, Education, Health, Transport, ACC, Justice, and others, and appropriate funding mechanisms would need investigation."

4.3.3 Recommendation

Having reviewed the submissions in response to this issue, I do not support change to the structure of advocacy services at this point. Advocacy services have recently undergone a comprehensive review. I consider it preferable to allow time for the findings from the review to be implemented and assessed before any major changes are made. I would, however, recommend that the structure of advocacy services receive careful consideration when the Act next comes under review. I therefore do not recommend any changes to this part of the Act.

4.4 Functions of advocates

Question 13 in the consultation document asked whether the functions of the advocates are appropriate. This question prompted a large number of responses, with 31 submissions received. Support was evenly divided, with 14 submissions in favour of change and 17 preferring the status quo.

4.4.1 Support for existing functions

A number of submissions supported the current empowerment model of advocacy and the belief that a more conciliatory approach achieves better outcomes for the consumer. For example:

> "I believe that the way in which advocates currently function is appropriate. It is important that we as advocates develop and maintain good working relationships with providers whilst maintaining the 'on the side of the consumer' approach. A professional respect towards providers is very important in resolution of complaints and in ensuring that future consumer outcomes are not jeopardised by the actions of confrontational advocates. In my education sessions with providers, a respect for both services and their functions is delivered, received, understood, appreciated, and upheld." (Elizabeth Love)

> "We support the Commissioner's view that 'a more conciliatory approach' is not inconsistent with supporting consumers, in fact our experience has shown that an advocate who takes an aggressive approach is less likely to achieve resolution for their consumer. Eight years of practice has shown that this approach is likely to result in a complaint about the advocate and a provider refusing to accept participation in the low level resolution process when approached again." (Advocacy Network Services Trust)

4.4.2 Case for change

Submissions were received from both consumers and providers requesting a change in advocacy approach. A common theme amongst consumers was that the advocates were too conciliatory and/or lacked the skills to carry out a conciliatory model of advocacy effectively. For example:

> "Given FWHC's concerns around variable quality of advocacy services, FWHC is not confident that all advocates are sufficiently skilled to take on the more conciliatory work that is proposed. Concern is also raised around the advocates' ability to maintain a healthy independence from the providers with whom they are often in frequent contact. There needs to be quality assurance built into processes that also involves feedback from consumers." (Federation of Women's Health Councils Aotearoa)

Some providers commented that while some advocates were "first class facilitators", others were aggressive and "displayed outspoken hostility".

I agree that empowerment advocacy and resolving disputes through conciliation do require specialised skills, and that there will always be a need for training and upskilling in the provision of advocacy

services. As I stated in the consultation document, however, the findings from the November 2002 review confirm that advocacy services are heading in the right direction.

Advocacy services are moving towards advocacy practice based on competencies, which will be reflected in a Code of Practice for advocates. This will formalise what constitutes best practice and should be an effective way to achieve greater consistency.

4.4.3 Specialised advocacy

The Mental Health Commission and the Royal New Zealand Foundation for the Blind highlighted the need for specialised advocates to support disempowered groups of consumers. A number of submissions also highlighted the increased need for advocacy by intellectually disabled consumers. For example:

> "The intellectually disabled lack the ability to speak out for themselves and they lack a recognised advocate to speak on their behalf so the need for quality services and reliable auditing and control is crucial to protect this vulnerable group of consumers …
>
> Personal Advocacy Trust staff get involved with all sorts of smaller issues for advocacy but advocates also get involved with numbers of larger issues such as abuse of money and personal abuse (sexual or verbal etc). Often the advocate is the one who picks up that monies or possessions are going missing, health issues are not being attended to, vocational/day activities are not appropriate or relationships are becoming intolerable." (Personal Advocacy Trust)

From my perspective, advocacy services maintain well-established relationships with disability consumer groups. I am aware that a significant proportion of the advocacy workload is devoted to education and complaints resolution with disability consumers. The fact that fewer complaints about disability services are referred to the Commissioner in part reflects the valuable work by advocates "at the coal face" with disability services consumers.

The Director of Advocacy has provided me with the following case study as an illustration of the valuable support that an advocate can provide:

> Mr Y is severely physically disabled by cerebral palsy; his speech is slow and unclear, and writing ability almost non-existent; however, he has no intellectual impairment.
>
> Mr Y was scheduled for major surgery, which he cancelled the day before as he felt he had insufficient information about the procedure and his post-operative care both in the hospital and upon discharge. He discussed his concerns with a provider who referred him to advocacy.
>
> The advocate spent an hour and a half at Mr Y's home discussing the advocacy process and clarifying his concerns. With Mr Y's consent a letter was sent directly to the specialist outlining exactly what the consumer's concerns were including questions about whether:
>
> — the surgery would be performed by the specialist himself
>
> — a different surgical approach could be taken
>
> — the consumer would have the opportunity to meet with the anaesthetist pre-op to discuss anaesthetic options
>
> — the plan for post-operative care had been tailored to meet Mr Y's needs taking into account his disability
>
> While awaiting a response from the specialist the advocate contacted the hospital to check that Mr Y remained on the surgical waiting list despite his cancelling the surgery. The advocate also contacted the

local assessment agency to determine Mr Y's entitlement to home support services. Both agencies responded positively and their responses were relayed to Mr Y, allaying some of his apprehension.

The specialist wrote back advising that the surgery should be performed without undue delay. He had made an urgent referral to the anaesthetist requesting Mr Y be assessed and provided with the opportunity to discuss his concerns relating to anaesthesia. The specialist offered a date for a meeting between himself, Mr Y and the advocate to discuss the actual surgery and post-operative care.

Mr Y took up the offer of the meeting and the advocate attended as his support to ensure that Mr Y was able to communicate his concerns and receive sufficient information to enable him to make an informed choice about proceeding.

At the end of the meeting Mr Y advised the specialist and the advocate he felt very satisfied with the information given and gave the specialist the "go ahead" to schedule a date for the surgery.

Mr Y has since contacted the advocate advising the surgery and post-operative period were uneventful, with his needs being met every step of the way.

Despite the very good relationship that currently exists between advocacy services and disability consumers, I acknowledge that there is room for improvement. The Director of Advocacy is currently undertaking a number of important initiatives to further develop the links between advocacy and the disability community. For example:

- Each advocacy service has advocates who have completed "Train the Trainer" training and are available free to disability services consumers and their support persons to offer training in self-advocacy, which can assist in the resolution of day-to-day issues.
- Advocates network and maintain contact with all disability service providers in their areas, informing them of their service. Some complex carer groups, who are generally family caregivers, are more difficult to contact, so advocates use radio community notices and notices in community papers to advertise their services.
- The Director of Advocacy writes articles for *New Dialogue* and *Without Limits*, both disability magazines.
- The Director of Advocacy is developing a project for providing advocacy services to disability services consumers in conjunction with Ripple Trust, which provides Disability Empowerment, Advocacy and Support (DEAS) services including mentoring and peer support, support for disabled refugees and new settlers, disability awareness training and advice.
- Advocacy services work closely with other specialised advocates in the community, such as People First, Citizen Advocacy, and consumer advocacy groups set up by the Royal New Zealand Foundation for the Blind.

Building Capacity in Advocacy

The Director of Advocacy is also actively involved in a new initiative for providing specialised advocacy services for disability services consumers – Building Capacity in Advocacy. A group of interested parties (HDC, the Office for Disability Issues, CCS, and Workbridge) have come together to support, financially and in other ways, efforts by disabled people to advocate for improved service delivery.

Once this initiative is operational, it is hoped that the service can be a "first resort" advocacy service, run by disabled people for disabled people. The purpose will be to:

- resolve issues of service provision locally and at an early stage;
- influence the development of services and systems so that they better meet the needs of disabled people; and
- enable people with disabilities to take leadership roles in their community.

I support the Director of Advocacy in taking these initiatives, which will result in enhanced advocacy services for disability services consumers.

4.4.4 Recommendation

I do not consider that an amendment to section 30 is necessary, but the feedback during the review will be very useful to the advocacy services as they continue to evaluate and improve their services.

5.0 Part IV: Investigation of Complaints

Question 14 in the consultation document asked whether any further changes to Part IV (Complaints and Investigations) were necessary or desirable at this stage. Twenty-three submissions were received in response to this question, with 11 submissions endorsing the status quo and 12 submissions suggesting change.

5.2 Complaints resolution procedures

Oral complaints

Personal Advocacy Trust submitted that the need to submit a written complaint was seen as a barrier by many intellectually disabled consumers, and a simplified complaints process was requested.

I acknowledge that there are additional hurdles that an intellectually disabled consumer must overcome to submit a complaint, including the need for support in bringing the complaint and to distance oneself from full-time providers. The Act allows consumers to make complaints orally. Oral complaints can be made by telephone to the 0800 number, by visiting the HDC offices in Auckland or Wellington, or by speaking to an advocate.

Right of appeal

A small number of submissions argued that the Act should provide a right of appeal from a Commissioner's opinion, for both consumers and providers.

As noted in the consultation document, the ability to seek a review by the Office of the Ombudsmen or to bring judicial review proceedings in the High Court, together with the Act's purpose of "fair, simple, speedy, and efficient" resolution of complaints, suggests that the Act does not need to provide for a right of appeal.

Limitation period for closed files

The Royal Australasian College of Surgeons submitted that a limitation period should be placed on the Commissioner's ability to review or re-open cases once they have been closed on the basis that "it is unfair for health practitioners to live under the shadow of finalised cases being reviewable many years later".

This is a legitimate concern. There is obviously an important public interest in finality of legal processes (such as complaints adjudication). However, there is also a public interest in justice. Case law in Ombudsmen-type jurisdictions suggests that there is an implied power to re-open investigations in very limited circumstances. Each case must be decided on its own merits, taking into account the reasons

for the proposed reconsideration, the impact on the parties, the length of time since the events giving rise to the complaint, any detrimental reliance on the original report, and the overall justice of the situation. An important consideration is certainly the length of time that has elapsed since the events giving rise to the complaint took place, as this impacts on people's ability to accurately recall facts, and creates considerable stress for the provider.

I do not consider that a statutory bar on the ability to re-open cases is warranted. The discretion is currently exercised only in rare cases, and in practice invoked by providers as well as consumers.

5.3 Key changes to Part IV

The majority of submissions indicated support for the changes introduced by the HDC Amendment Act 2003. A number of submitters commented that the changes would allow the Commissioner more flexibility and increase efficiency in the Commissioner's processes.

Referring complaints to providers

A number of providers welcomed the changes that would see suitable complaints referred back to them for investigation or mediation. However, some consumer groups asked what protections would be put in place for consumers when matters were referred back to providers. For example:

> "The Foundation supports increasing the number of options available to deal with complaints, in particular referring the matter to the provider for resolution. We are interested to know if the Commissioner will be providing protocols for facilitating this process. Will the Commissioner also offer advice or develop policy templates on how providers should investigate complaints?" (The Royal New Zealand Foundation for the Blind)

Although a number of group providers have already established processes for investigating complaints, I do intend to give providers general education and guidance on the requirements of the Act. The Act also allows the Commissioner to consult with providers as to the most appropriate means of dealing with complaints on a case-by-case basis.

As discussed in the consultation paper, the Commissioner retains independent oversight of the complaint, as the provider is required to report back to the Commissioner on any action taken. If the Commissioner is not satisfied with that response, he or she can take further action.

Reporting public safety risks

The New Zealand Nurses Organisation raised concerns about the threshold for reporting public safety risks under new section 39 of the Act:

> "NZNO has concerns about the low threshold in the HPCA for reporting. NZNO submitted that the threshold should have been changed to a risk of 'serious' harm. All health care provision is subject to risk and there needs to be some guidance as to what this provision means to avoid the submitting of vexatious and inappropriate reports."

I do not accept that a high (risk of "serious" harm) threshold should be met before the Commissioner is required to report a public safety risk. There will need to be a proper evidential basis before the mandatory duty is triggered. The Commissioner also retains the right to take no action on frivolous or vexatious complaints (new section 38).

5.4 Referral of providers to the Director of Proceedings: sections 47–49

The Royal Australasian College of Surgeons expressed concern that the Director of Proceedings will no longer offer providers an opportunity to be heard before deciding what action to take:

> "While we realise that this step will now be required of the Commissioner instead, the role of the Director of Proceedings is meant to be independent of the Commissioner. Therefore the opinion of the Commissioner in relation to the provider's views should not necessarily be the opinion of the Director of Proceedings. Unless the Director of Proceedings can access provider comment directly, the only information received is filtered through the Commissioner. We do not believe this supports the independence of the Director from the Commissioner."

Although the Director of Proceedings and the Commissioner operate independently, the reality is that they deal with the same information when deciding what action to take. If the Commissioner decides to refer a matter to the Director of Proceedings, the Director receives a full copy of all the information that was available to the Commissioner, including any statements from the provider under the new section 44. The Director of Proceedings will not, therefore, need to rely on filtered information, and will be able to review all of the materials and form an independent decision whether to prosecute.

5.5 Direct action in the Human Rights Review Tribunal: section 51

A number of consumers commented favourably on new section 51, which will allow consumers to take direct action in the Human Rights Review Tribunal where the Commissioner has formed the view that the actions giving rise to the complaint are in breach of the Code. By contrast, a number of providers voiced their opposition to this amendment.

Access to the Human Rights Review Tribunal will still be more restrictive for health and disability services consumers than for privacy or human rights matters, as no breach finding is required as a prerequisite to complainants taking their own proceedings in those jurisdictions. I consider that the fears of monetary penalties are unfounded — the accident compensation bar prevents the awarding of compensatory damages, and the threshold for the award of punitive damages is very difficult to meet.

Recommendation

Having reviewed the submissions received in response to question 14, I do not recommend any amendments to Part IV of the Act.

6.0 Part V: Miscellaneous Provisions

Question 15 in the consultation document asked whether the Act should be amended or whether the existing provisions and the changes that will come into effect under the HDC Amendment Act were satisfactory. Only 17 submissions were received in response to this question, with 9 submissions endorsing the status quo and 8 submissions suggesting change.

A number of the submissions requesting change in response to this question reiterated submissions that were discussed in other areas. Others made general comments about the Commissioner's functions

and processes. For example, the Family Planning Association commented that a provider should be able to talk to an investigation officer during the investigation process in order to respond to any adverse comment. In practice the investigation process does involve contact by staff (often by telephone) with both consumers and providers, to allow each person to tell his or her side of the story and to test factual accounts where they conflict.

Ethics committees

Women's Health Action Trust, Auckland Women's Health Council, and Maternity Services Consumer Council all argued that a national system of ethics committees with a Director of Ethics should fall within the scope of the Act:

> "We believe that the national system of Ethics Committees and Ethical review fits more naturally under the jurisdiction of the HDC than the various other areas where they are currently located.
>
> We believe that there is a place for a Director of Ethics which encompasses all human ethics committees, not just the regional ones, as the focus should be 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." (Women's Health Action Trust)

The system for ethical review of health and disability research has recently been reviewed by the National Ethics Advisory Committee[1] following the recommendations of the Report of the Ministerial Inquiry into the under-reporting of Cervical Smear Abnormalities in the Gisborne Region (2001).The Minister of Health has decided that a reduced number of regional ethics committees and a new national ethics committee will be established under section 11 of the New Zealand Public Health and Disability Act 2000, with the Terms of Reference and annual reports of the Committees tabled in Parliament.

The proposed terms of reference for the new ethics committees are currently being developed in consultation with Chairs, members and administrators of regional ethics committees, and other key stakeholders. Concerns have been raised about the independence of the new committees. In my view these concerns need to be addressed — but this review of the Act and Code is not the proper place to make recommendations on the system for ethical review of health and disability research in New Zealand. I have an open mind about the possibility of ethics committees falling within the statutory oversight of the Health and Disability Commissioner, although a consultation process would be required to canvass the views of the sector and to discuss how such a relationship would work in practice.

A range of issues such as independence (eg, under an independent Director of Ethics within HDC), funding and conflict of interest provisions (in the event of a complaint to the Commissioner about research approved by an ethics committee) would need to be resolved. Many of the research protocols reviewed by ethics committees raise questions of health information and the secondary use of data for research, matters that currently fall within the jurisdiction of the Privacy Commissioner, rather than the Health and Disability Commissioner.

Recommendation

Having reviewed the submissions received in response to question 15, I do not recommend any further amendments to the Act at this stage.

1 National Ethics Advisory Committee, *Review of the Current Processes for Ethical Review of Health and Disability Research in New Zealand*, Wellington: Ministry of Health, 2003.

7.0 Review of the Code

7.1 Overview

Question 16 in the consultation document asked whether the Code should be amended or whether the existing rights were satisfactory. Twenty-six submissions were received in response to this question, with 9 submissions endorsing the status quo and 15 submissions suggesting change. Again, a number of the submissions requesting change in response to this question reiterated comments that have been discussed in other areas.

Professional standards

The Haemophilia Foundation of New Zealand requested that professional standards — referred to in Right 4(2) — be set in conjunction with health providers, the Ministry of Health, and consumer groups.

Professional standards are usually set by the relevant authority or representative body in consultation with its members and key stakeholders. Others are set by Standards New Zealand. The Commissioner does not have jurisdiction over how standards are set but often comments or makes submissions on the content of professional standards, as part of the functions under section 14.

Right 7(6)

Dr Rosemary de Luca submitted that more education is required concerning the need for informed consent in writing if there is a significant risk of adverse effects on the consumer (Right 7(6)(d)). Her research has indicated that medical and nursing staff often interpret this risk differently and that organisations usually err on the side of caution to avoid exposure to liability.

I am aware that some providers require written consent beyond the situations outlined in Right 7(6) as a matter of internal administrative convenience. Obviously, the requirements for informed consent are more complex than a one-off action to authorise a medical intervention, and informed consent is more than just a signature at the bottom of the form. Rather it is a process that is embodied in three essential elements under the Code — effective communication (Right 5), disclosure of adequate information (Right 6), and (subject to certain exceptions) a voluntary decision by a competent consumer (Right 7).

Exercising Right 7(9)

Another submission queried how consumers choosing to exercise their rights under Right 7(9) would know that their body parts or substances had been destroyed.

Right 7(9) states that "every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure".

In my view, providers should develop systems to ensure that such requests are clearly noted on specimens, and that the consumer receives written confirmation of the disposal.

Right 10 complaints

One submission queried whether a complaint made under Right 10 which is noted on a patient's file may have an adverse effect on the care that patient receives. This is an interesting point to raise, particularly when more complaints are likely to be resolved directly by providers once the HDC Amendment Act 2003 comes into effect.

Right 10 of the Code deals with complaints made directly to providers. Right 10(5) states that "every provider must comply with all the other relevant rights in this Code when dealing with complaints". Depending on the situation, other relevant rights may include Right 1 (respect and privacy) and Right 5(2) (providing an environment where both consumer and provider can communicate openly, honestly and effectively).

When a consumer makes a complaint directly to a provider, the provider should therefore respect the consumer's privacy by keeping the complaint confidential, and provide an environment where both parties can discuss the complaint honestly and effectively. In accordance with the Code, I consider that consumers should not be adversely affected by making a complaint under Right 10.

Code of Family Rights

The Schizophrenia Foundation of New Zealand submitted that the key principles from the SFNZ Code of Family Rights should be included in the Code. SFNZ describes the code as "a guide to the level of mental health service provision that is acceptable for ensuring families and caregivers are empowered to provide the best support they are able for their family member".

While I support the intent of the SFNZ Code of Rights as a guide, I do not agree that its key principles need to be specifically incorporated in the Code of Health and Disability Services Consumers' Rights.

The involvement of family and caregivers is integral to the provision of health services for mental health consumers. In September 1997 the Privacy Commissioner and the Mental Health Commission published guidance notes for agencies in the mental health sector. The guidance notes clarify that health agencies can pass on necessary information about the care of a consumer to caregivers or other people who should be aware of certain aspects of care. However, if the consumer requests that the information be kept confidential, the information should not be disclosed unless there is a compelling reason to do so. The Privacy Act provides that information can be disclosed without authorisation if it is "necessary to prevent or lessen a serious and imminent threat to … the life or health of the individual concerned" (Information Privacy Principle 10, Privacy Act 1993).

The Mental Health (Compulsory Assessment and Treatment) Act 1992 was amended in 2000 to take into account the involvement of family members. Section 5 states that persons exercising powers under the Act must exercise the power:

(a) with proper recognition of the importance and significance to the person of the person's ties with his or her family, whānau, hapū, iwi, and family group; and
(b) with proper recognition of the contribution those ties make to the person's well-being; and
(c) with proper respect for the person's cultural and ethnic identity, language, and religious or ethical beliefs.

In 2001 the National Mental Health Sector Standards were updated. Standard 10 requires that "family, whānau are involved in the planning, implementation and evaluation of the mental health service".

Right 4(2) of the Code states that every consumer has the right to have services provided in accordance with legal, professional, ethical, and other relevant standards. Providers in the mental health sector must therefore consider the 1997 guidelines and the National Mental Health Sector Standards (professional standards) and (in compulsory assessment and treatment) section 5 (legal standard) when providing services to mental health consumers.

In conclusion, I consider that the requirement to comply with legal, professional and ethical standards under Right 4(2) of the Code is capable of incorporating by reference the key principles in the SFNZ Code of Family Rights.

7.2 Effective communication: Right 5

Question 17 in the consultation document asked whether the right to an interpreter under the Code should be enhanced in any way or whether the current provision in Right 5(1) is satisfactory. Twenty-four submissions were received in response to question 17, with 10 supporting the status quo and 14 requesting change.

The submissions supporting the status quo came predominantly from providers who felt that Right 5(1) was sufficiently flexible to allow a common-sense approach.

Right 8 — the right to have a support person present — can be a helpful way of enabling effective communication. The Federation of Women's Health Councils Aotearoa submitted that providers should encourage consumers to make more use of Right 8. Other submissions commented that it was often inappropriate to use friends and families as support persons because of the emotional stress this can cause the consumer. I agree that the involvement of friends and family may sometimes be inappropriate and can impact on the consumer's privacy. However, Right 8 is probably underutilised by consumers who are unaware of their right to support.

Two submissions commented on the fact that, with the increasing number of immigrant providers in New Zealand, it is sometimes difficult for consumers to understand a provider's accent, and that providers should have to supply information in writing or other more accessible means. Right 6(4) states that "every consumer has the right to receive, on request, a written summary of information provided". This should address any concerns about receiving oral information from providers.

Interpreters

A number of submissions argued that the Code should provide for, either specifically or by reference, a consumer's right to use New Zealand Sign Language. For example, CCS suggested that "interpretation" should be defined broadly to include "plain language, New Zealand Sign, Braille, large print, electronic, etc" and DPA argued that the Code should be amended to bring it into line with the New Zealand Sign Language Bill.

The Deaf Association of New Zealand supported consumer access to qualified NZSL interpreters but raised the issue of competency standards, suggesting that the Commissioner set up a mechanism for registering interpreters under a professional body. The New Zealand Nurses Organisation was also in favour of national standards or guidelines for interpreters.

The New Zealand Sign Language Bill establishes NZSL as the third official language of New Zealand. In that respect, when the Bill is enacted, members of the public will be entitled to use NZSL in court proceedings and in dealings with government agencies. The Bill does not prescribe competency standards for NZSL interpreters but the explanatory note confirms that this may occur at a later stage:

> "At this stage it is not proposed that there be an extensive certification system as to the competency of NZSL interpreters as there are existing competency standards that do not need to be incorporated into regulations. However, the Bill does contain a regulation-making power that would enable competency standards to be prescribed at a later stage, if this were to be considered desirable. Further work is being done to assess mechanisms for implementing standards and to prepare any administrative matters, such as forms for legal proceedings."

I do not consider that Right 5 requires amendment to specifically define an "interpreter", as the natural meaning of that word extends to all languages, including NZSL. It is apparent that if Parliament intends to set up a professional body for regulating NZSL interpreters, this will occur under the New Zealand Sign Language legislation, rather than under the HDC Act.

Accessible formats

In a similar theme, some submissions noted that effective communication in Right 5 often requires information to be provided in more accessible formats. For example, the Royal New Zealand Foundation for the Blind submitted:

> "While we acknowledge that the right is broad enough to cover other formats, if it is considered appropriate to mention interpreters, the right should also stipulate accessible formats. As in previous submissions, we recommend enhancing this right with the following wording:
>
> 'Every consumer has the right to communication in a form and manner that best enables the consumer to access the information independently and to understand the information provided. Where needed and where practicable, this includes the right to an interpreter and written materials in formats other than standard print.'"

I consider that the existing obligation in Right 5(1), to provide information in a "form, language, and manner that enables the consumer to understand the information provided", includes an obligation to provide information in accessible formats, where this is necessary and reasonably practicable.

As with all Code rights, Right 5 must, however, be read in the context of clause 3 of the Code, which states that a provider is not in breach of the Code if the provider has taken reasonable actions in the circumstances to give effect to the Code. Whether a provider has taken reasonable steps to meet the obligation in Right 5(1) will therefore depend on the particular circumstances of each case.

Interpretation and translation service

The consultation document recorded the preliminary comment from Women's Health Action suggesting the establishment of a national translation and interpretation service, and a number of submissions were received in support of this suggestion. Some felt that the service should be provided through HDC, and others thought it more appropriate that it be provided through advocacy services.

The Family Planning Association of New Zealand suggested that HDC join the language line interpreter service that is currently being piloted by the Office of Ethnic Affairs (www.ethnicaffairs.govt.nz):

> "The Office of Ethnic Affairs is currently running a pilot language line interpreter service. Currently services are provided to 6 participating agencies, including the Police. We understand the Ministry of Health has not signed up to be a part of this pilot but that there has been some talk of Health joining at some stage in the future as the language line expands it capacity.
>
> The pilot currently offers 35 different languages and is adding another 2 very shortly, with interpreters located in New Zealand and Australia. Note that
>
> - an interpreter's gender can be specified by the consumer
> - the interpreter will only use first names, supporting confidentiality for consumers
> - interpreters are bound in their contracts to decline and refer to another interpreter if they know the consumer or have a conflict of interest
> - the contracted service that provides the interpreters have a code of ethics specified in their contract
> - the contracted service undertakes police checks on the interpreters employed by their service."

A significant, and increasing, proportion of the community do not speak English or have a limited ability to use English when receiving health and disability services. However, the Commissioner's Office and the Director of Advocacy do not currently have funding to support a national translation service.

The translation service operating under the Office of Ethnic Affairs is a 12-month pilot scheme, which will be reviewed with a report to Parliament in November 2004. I will be interested to see the results of that review and whether the service can be extended to the health sector. I do not recommend any amendment to Right 5 in the interim but will maintain a close interest in this area.

7.3 Providing services when the consumer is not competent to give informed consent: Right 7(4)

Question 18 in the consultation document asked whether the provision of services to consumers unable to consent under Right 7(4) of the Code should be modified. Nineteen submissions were received in relation to this question, with the majority (12 submissions) supporting the status quo and 7 submissions requesting change.

The submissions supporting the status quo were largely from consumers and consumer groups who felt that the existing wording established important protections for those consumers who are unable to give informed consent.

A number of disability groups commented that the definition of an "incompetent" consumer needed clarification in the Code as it can be a devaluing way to describe a person. CCS also commented that:

> "often family or welfare guardians with little understanding or experience of living with a disability or disability issues are not good judges of best interest. Values advocates, independent disability professionals, need to support people to consent or not to consent to key decisions. Some of these decisions need to go through legal process."

While I acknowledge that the colloquial meaning of "incompetent" can be disrespectful to disability consumers, the Code uses "competence" in its legal sense, which focuses on an individual's ability to give informed consent. Given that the term is used only in the context of the rights relating to informed consent, I do not consider that the legal meaning of "competence" needs to be defined further in the Code.

Advance directives

The Deaf Association of New Zealand and the Mental Health Commission submitted that Right 7 requires amendment in relation to advance directives. The Deaf Association argued that Right 7 is currently reliant on oral or written directives and there should be greater access to directives by the hearing impaired. The Mental Health Commission submitted:

> "The Commission believes advance directives should be given greater weighting within the Code, perhaps it could be incorporated into Right 7(4) stating that:
>
> > Advance directives should be referred to if one is available, and if not, decisions should be in the best interests of the consumer.
> >
> > Reasonable steps should be taken to ascertain the views of the consumer by reference to an advance directive, if one is available …"

Right 7(5) authorises the use of advance directives. Clause 4 of the Code defines "advance directives" to mean "a written or oral directive". In my view, consumers would be well advised to record their advance directive in writing to minimise any evidential problems that may later arise. I agree that advance directives should certainly be taken into account by a provider under Right 7(4)(b) but do not recommend any changes to the wording in the Code.

Best interests

Auckland District Health Board submitted that Right 7(4), as it is currently worded, hinders research involving consumers who are not competent to consent:

> "… The … requirement of being 'in the best interests of the consumer' fails when, on the basis of Right 9, it is attempted to be applied to participation in *research*. There are many aspects of patient care where the preferred treatment or investigation is unknown, and yet it is important that these questions be answered by undertaking quality scientific research. As a result, many patients readily agree to participation in such studies to further medical knowledge. Unfortunately, some of these important questions can only be answered by undertaking studies involving incompetent patients, as the condition in question only occurs where the patient is rendered temporarily incompetent by virtue of illness, injury or treatment. This applies to most research in emergency medicine and intensive care.
>
> This conflict has been noted by a number of research ethics committees and although such studies have been approved as ethical, this apparent illegality has been a difficulty. To remove conflict, it must be made clear that the standard for participation in research is not that it is in the best interests of the consumer, but rather that it is *not contrary* to the best interest of the consumer. This could be done by a change to Right 7(4)(a) itself, but this would lower the standard for the provision of any treatment to incompetent consumers, as you noted in the public consultation document.
>
> …
>
> There are, however, 2 possible alternative approaches. The first is to add a subsection to Right 7(4)(a) to indicate that in the setting of research, participation must not be contrary to the best interests of the consumer. This still would detract from Right 7(4) which is well structured for the provision of treatment.
>
> A better option would be to add such a section to Right 9 (Rights in Respect of Teaching or Research) so that it would read:
>
> '1. The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.
>
> 2. However, where a consumer is not competent to make an informed choice and the research has been approved by an accredited ethics committee, research services may be provided if they are not known to be contrary to the best interests of the consumer.'"

An amendment to allow research "not contrary to the best interests of the consumer" is supported by the New Zealand Optometrists Association, the Royal New Zealand College of General Practitioners, and the New Zealand National Committee of the Joint Faculty of Intensive Care Medicine.

Right 7(4) applies only in situations where there is no legal guardian available to consent on behalf of the consumer. In a number of situations involving proposed research on incompetent patients, a legal guardian will be available to give or refuse consent to research. Some consumers may, while competent, have made an advance directive giving consent to research in the event of incompetence at some point in the future. However, I accept that in the majority of cases (eg, for adult incompetent patients) there will be no legal representative and no advance directive authorising research not known to be contrary to their best interests. Such consumers are then deprived of the potential benefit of such research. I recommend that Right 7(4)(a) be amended to read:

> "It is in the best interests of the consumer or, in the case of research, is not known to be contrary to the best interests of the consumer and has received the approval of an ethics committee."

Given the controversy surrounding the recent amendment to Right 7(10), I recommend further consultation in the event that the Minister approves change to the Code in line with this recommendation.

7.4 Consent to the storage, preservation or use of body parts or bodily substances: Right 7(10)

The recent amendment to Right 7(10) proved to be controversial in submissions. As discussed in paragraph 3.3.2 above, this amendment was made under section 75 of the Act and came into effect on 10 June 2004.

A total of 14 submissions were received in response to the issues raised by Right 7(10). Four submissions supported the amendment and 10 disagreed with either the legislative process or the practical effects of the amendment.

Support for the amendment

In support of the amendment, the National Ethics Advisory Committee submitted:

> "The amended Right 7(10) in effect strengthens consumer entitlements, especially under the Code's Right 4: the right to services of an appropriate standard. It does so by facilitating research, quality assurance, audit, and evaluation of a sort that is integral to the quality improvement of health and disability support services. Exemption (b) quite properly builds in the safeguard of ethics committee review. Such review is primarily focused on the protection of research participants. Exemption (c) is needed too, because in its unamended form, Right 7(10) causes difficulties also for audit related activities. Due to their generally low risk and their central role in improving the quality of service provision, these activities typically do not require ethics committee review (see *Operational Standard for Ethics Committees*, 4.1)."

Support was also received from Dr Charlotte Paul, Associate Professor of Epidemiology, University of Otago:

> "This amendment will allow the conduct of unlinked anonymous monitoring of HIV prevalence in sentinel populations. Regular monitoring is important to track the movement of the HIV epidemic in different groups in the population, to allow timely response. This has been impeded since the introduction of the Code in 1996."

However, some support was conditional upon the amended Right 7(10) being applied strictly:

> "WCEC is very much aware of the potential benefits that could arise from using historical samples of body parts and bodily substances obtained in the course of a health procedure to advance public good research. We also recognise the limitations of the current Code in regard to utilising these samples unless informed consent is given for specified additional use by the consumer from whom the samples were first obtained.
>
> WCEC therefore supports the terms of the proposed amendment to Right 7(10).
>
> However, we wish to emphasise that this support is conditional upon the following:
>
> - That clause (b) must be strictly adhered to. Use of historical human body samples for research purposes where it may no longer be practical to seek informed consent should always be on a case by case basis and with the approval of an ethics committee.

- That external audits, and their results, undertaken as per the terms of clause (c) should be publicly notified to consumers.

A suitable consent form covering future uses could get around the need for REC approval. If we made that clear, it might encourage the use of better consent forms. Clearly currently historical samples will not have this but in the future, this generic consent could stand for all the purposes stated. It would also have the beneficial effect of streamlining research activities." (West Coast Ethics Committee)

Objections to the amendment

A number of submissions expressed strong objection to the legislative process that led to the amendment of Right 7(10). For example:

"The NZAF is concerned the cabinet process that occurred to amend the Code did not involve public consultation. We understand that the change has already been completed.

Our submission is that there are significant issues raised by presuming consent to participate in research. Whether the safeguards in place are outweighed by the value of the research is a question that should be answered by the public." (New Zealand Aids Foundation)

Some consumer groups felt they had not had an opportunity to debate the proposed changes, and were aggrieved at the ease with which the Code can be changed. In the future, I recommend that further review occur if a Minister proposes change to the Code, irrespective of whether it follows a review and Commissioner recommendation.

Some submitters felt that the absolute nature of the informed consent provisions should have been retained:

"We feel very strongly that Right 7(10) should be retained as an absolute requirement of informed consent. It is totally reasonable for consumers to expect informed consent to be absolute in regard to any storage, preservation or use of body parts or bodily substances. …

This may be an inconvenience for public health researchers but needs to be accepted as a requirement. Audit/evaluation needs should be included as a usual part of informed consent processes when this is an issue. It doesn't have to be seen as a reason to undermine the absolute nature of informed consent requirements." (Palmerston North Women's Health Collective)

The Director of Advocacy (Judi Strid) considered how the new Right 7(10) may work in practice and offered practical suggestions for ensuring that the requirement for informed consent was not eroded:

"The problem with the wording that is causing agitation is that researchers will have the choice of seeking informed consent OR ethics committee approval OR opting to call their initiative an audit. The concern is that researchers could see ethics committees as an easier option than seeking informed consent from patients/participants and could argue that they don't need to seek consent because they have another option.

Equally problematic is the lack of any agreed definition of what constitutes an audit and the lack of agreement that there may be ethical issues associated with an audit.

Although I am aware the intent is to facilitate a more rational approach to this matter, there have already been situations where researchers have attempted to circumvent the consent process by calling a study an audit. This is compounded by the view that if something is an audit it doesn't require ethical review and scrutiny.

> Ethics committees also take the view that it is better to deal with informed consent at the start and sort these matters out up front than try to do the 'damage control' later in the piece. For example, the application form for ethical approval specifically asks whether data, other information (tapes/videos etc) or tissue/body fluids will be kept for other possible research purposes in the future. Although future studies would require separate ethical approval in their own right any indication of this results in the researchers having to spell out their intentions in the information sheet and also to include specific consent provisions in the consent form that gives participants options. …
>
> It needs to be made clear that the intent of the change to Right 7(10) is not to remove the requirement to obtain consent, but to allow for a backup/exception via ethics committees where consent is problematic."

I agree with this conclusion. A number of submitters were under the misapprehension that the amendment to Right 7(10) would allow researchers *carte blanche* to avoid the need for informed consent in proposed research.

My view is that informed consent for the use of body parts or bodily substances in research will still be required in the vast majority of cases, and research proposals will need to address the question of consent by research participants. In exceptional cases, where the proposal seeks to avoid the need for individual consent, the ethics committee will need to carefully assess the proposed research and the validity of the stated reasons for dispensing with individual consent.

Some submitters who disagreed with the changes felt that the scope of the amendment had not gone far enough. For example, a submission from Dr Andrew Tie highlighted difficulties faced by pathologists:

> "Storage of tissues, fluids and other samples from patients is in the interests of the care of that patient both at the time of receipt, processing and reporting, and in the future. New reagents, antibodies, information and technology can be applied to stored samples, which may become available well after the date of original diagnosis, and this information may have therapeutic importance, as for example in Her-2-neu testing for breast cancer. A requirement to discard such material also removes the possibility of such things as retrospective genetic testing for family members with a suspected inherited disease such as hereditary non-polyposis colon cancer (HNPCC), if the relative has died. There should always be the possibility of reviewing stored material, and where appropriate, applying new tests and techniques."

Dr Tie's submission was supported by the Royal College of Pathologists of Australasia:

> "The proposed amendments to Right 7(10) do not allow for the routine storage of clinical material according to best practice guidelines. Recommendations regarding retention of material have been developed by the National Pathology Accreditation Advisory Council (NPAAC) of Australia. These guidelines were produced for pathology laboratories in Australia and determine the *minimum* standards considered acceptable for good laboratory practice in relation to holding of records and diagnostic material … These requirements are developed because it is in the best interests of the patient and are endorsed by NZ laboratories for this reason, not just to satisfy external audit requirements. …
>
> If the proposed amendment to Right 7(10) does not cover routine specimen retention, then all pathology laboratories will potentially be found in breach of the Code."

In my view, the claimed difficulties of Right 7(10) in relation to storage are overstated. Where a pathology laboratory stores body parts or bodily substances in the interests of patient care (at the time of receipt, processing and reporting, and in the future), and the patient has not requested (in accordance with Right 7(9)) that the specimen be returned or disposed of, the storage is a "reasonable action in the circumstances" (permitted by clause 3(1) of the Code) on the part of the laboratory. To my knowledge,

the Commissioner has never received a complaint about storage, and for the reasons stated I do not believe that there is a breach of the Code in such circumstances.

I do not accept Dr Tie's submission that the Code is "in conflict with accreditation requirements and the best interests of the majority of patients" or that the amended provisions "interfere with normal medical practice" or are "inappropriate and impl[y] distrust". Events in England and New Zealand have made it very clear that patients want to retain control over future use of their body parts and bodily substances. The new Right 7(10) seeks to ensure a better balance between respect for individual autonomy and support for approved research and appropriate audit and quality assurance activities. I do not believe that the current consent provision in relation to storage is ethically unsound or unworkable in practice.

Minister's section 75 Notice

In accordance with section 75 of the Act, on 27 May 2004 the Minister of Health tabled the following statement in Parliament to explain the amendment to Right 7(10):

> "The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Amendment Regulations 2004 have been made in the absence of a formal recommendation by the Health and Disability Commissioner. The reasons for this are:
>
> - The need to respond to immediate concerns about the practicability of Right 7(10). The requirement to obtain informed consent for all possible future uses of body parts or bodily substances, which are obtained in the course of a health care procedure, is not always reasonably practicable for researchers and pathologists and has, in some cases, hindered valuable health research of significant public benefit. The provision has also hindered ongoing audit and monitoring activities, which might improve the safety and quality of health and disability services. This latter concern was reinforced by the findings of the Gisborne Cervical Screening Inquiry, which concluded that informed consent provisions were impeding the ongoing evaluation of the Cervical Screening Programme.
>
> - Although not part of a formal recommendation by the Health and Disability Commissioner as part of a review of the Code under section 22 of the Health and Disability Commissioner Act 1994, the proposed change was supported by the Health and Disability Commissioner, and considered to be a preferable approach, given the need for a timely resolution to the problem posed by Right 7(10). The Health and Disability Commissioner's formal review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights was released in February 2004 and submissions closed on 30 April 2004. That review notes the Health and Disability Commissioner's support for the amendment to Right 7(10) of the Code.
>
> - Considerable consultation had already been undertaken with consumers and the health and disability sector by the former Health and Disability Commissioner on problems with Right 7(10), as part of a review of the Code in 1999.
>
> - Given the proposed timeframes for the Health and Disability Commissioner's formal review, the most efficient mechanism to achieve a change was considered to be a recommended change outside of a formal review of the Code of Health and Disability Services Consumers' Rights under section 22 of the Health and Disability Commissioner Act."

Appendix A
Consultation Process

Statutory requirements

Section 18 of the Health and Disability Commissioner Act governs the procedure for review of the Act. Unlike the provision governing review of the Code, there is no specific requirement for consultation, apart from the general requirement to consult in section 14(2).

Section 22 (incorporated by section 21(3)) and section 23 of the Act set out the consultation requirements for review of the Code. These are the same requirements as existed for preparation of the initial draft Code. Consultation involved:

- an invitation for general submissions from persons and bodies with an interest in health and disability service matters, including relevant statutory agencies, to assist in the development of the report to the Minister (section 23);
- publication of the availability of the Commissioner's proposed report and consultation on the report before it is submitted to the Minister (section 22).

As the reviews of the Act and Code were conducted simultaneously, the same (more extensive) consultation process was undertaken for both.

Consultation process

In November 2003, invitations were sent out to representative persons and organisations with an interest in health and disability service matters, including consumers, providers and statutory agencies, seeking preliminary comments on the review.

Based on the responses and my own experience of the operation of the Act and Code, I prepared my report for consultation. The consultation document contained discussion of a wide range of issues, including the changes that are imminent under the HDC Amendment Act 2003. A number of key provisions were highlighted for consideration and, where appropriate, I provided my preliminary views on where the Act and Code would benefit from amendment.

Submissions were invited once again from interested organisations and individuals, as well as from the public at large. Two hundred and eighty-four copies of the consultation document were posted out. Release of the consultation document coincided with national and local media releases announcing the reviews. The HDC free phone 0800 number was available for those wishing to request information or to make an oral submission. The consultation document was also posted on the HDC website and received 1,908 hits during March and April 2004.

Sixty-three submissions were received in response to the consultation document. The submissions were then considered and analysed. A statistical analysis of the responses is included in Appendix C.

In addition to the invitation for submissions, feedback on the Act and Code and proposed changes was obtained during a series of meetings (the details of which are set out below). Public meetings were held throughout the country and were advertised beforehand by public notice and local media releases. Māori and Pacific Island Focus Group meetings were also held.

Public meetings

Date	Area	Venue
15 March	Rotorua	Kingsgate Hotel
15 March	Hamilton	Le Grand Hotel
18 March	Wellington	Archives New Zealand
30 March	Auckland	Wesley Community Centre
1 April	Christchurch	Holiday Inn
2 April	Dunedin	The Dunedin Centre

Māori focus groups

Date	Area	Venue
18 March	Wellington	Human Rights Commission
22 March	Auckland	Otara Community House

Pacific Peoples focus groups

Date	Area	Venue
18 March	Wellington	Human Rights Commission
22 March	Auckland	Otara Community House

Appendix B
List of Submissions

Advocacy Network Services
Advocacy Services South Island
Ambulance New Zealand
Auckland District Health Board
Auckland Women's Health Council
Australian and New Zealand College of Anaesthetists
Mrs M R Burrows
CCS
Deaf Association of New Zealand (Inc)
Dental Council of New Zealand
DPA (New Zealand) Inc
Federation of Women's Health Councils Aotearoa
Haemophilia Foundation of New Zealand
Mrs Carolyn Hodson
Hawke's Bay District Health Board

Human Rights Commission
Ms Elizabeth Love
Dr Rosemary de Luca
Manawatu Supporting Families
Maternity Services Consumer Council
Ms Kathryn McIlraith
Medical Council of New Zealand
Mental Health Commission
Ministry of Health, Deputy Director-General, Māori Health
Ministry of Health, Deputy Director-General, Sector Policy
National Council, Schizophrenia Fellowship
National Council of Women of New Zealand
National Ethics Advisory Committee
New Zealand AIDS Foundation
New Zealand Association of Optometrists
New Zealand Chiropractors Association
New Zealand Family Planning Association
New Zealand Medical Association
New Zealand National Committee of the Faculty of Intensive Care Medicine
New Zealand Nurses Organisation
New Zealand Psychologists Board
New Zealand Organisation for Rare Disorders
New Zealand Speech-Language Therapy Association
Nursing Council of New Zealand
Ms Lorraine McQuigg
Office of the Ombudsmen
Palmerston North Women's Health Collective
Dr Charlotte Paul
Personal Advocacy Trust
Patients Rights Advocacy Group
People First New Zealand
Mr Scott Read
Ms Anne Russell
Ms Judi Strid, Director of Advocacy
Taranaki District Health Board
The Order of St John
The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
The Royal Australasian College of Surgeons
The Royal College of Pathologists of Australasia
The Royal New Zealand College of General Practitioners
The Royal New Zealand Foundation for the Blind

Ms Tania Thomas, Deputy Commissioner
Dr Andrew Tie
Waikato District Health Board
Ms Annette Waring
Wellington Mental Health Consumers Union
West Coast Ethics Committee
Women's Health Action Trust

Appendix C
General Analysis of Submissions

The consultation document included the following 18 questions to prompt discussion:

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

Question 2: Is the purpose of the Act appropriate? If not, what changes do you suggest?

Question 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?

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

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

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

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

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

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

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

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

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

Question 13: Are the functions of the advocates appropriate? If not, what amendments do you suggest and why?

Question 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?

Question 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?

Question 16: Should the Code be amended or are the existing rights satisfactory?

Question 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?

Question 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?

A total of 63 submissions were received in response to the consultation document. Not all these submissions responded in detail to the questions highlighted for discussion in the consultation document. Of those submissions that did respond, the following table analyses the submissions (1–63) in terms of questions 1–18 to ascertain the level of support for maintaining the existing provisions (M) or for amending the Act or the Code (C). A question mark (?) indicates a query about how a provision will work in practice. In relation to the Right 7(10) column, M indicates support for the new wording of Right 7(10) and C indicates a request for change.

Qns	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	7(10)
1																?			
2																			M
3	C															?			
4				C															
5										C	C	M	M						
6												?							C
7				M									M	C					
8	C	C	C	C	M	M	M	M	C	M	M	C	C	C	C	C	C	?	C
9					?						?								
10	C																		
11																	M	C	
12														M	M	M			
13	C	C	M	C			M	M	C	M	C		C	C	C	C			
14		M		C	C	C		C		C		C	C	C					
15	C	C	C	M	C	C	C	M	C	C	C	C	C	M	M	M	M	M	C
16																			C
17											C	M	M						
18	C			M				C	C	C					C	C			
19			C	C									C						
20								C											
21											C	M	M						
22														M	M	M			
23								C											
24							C		C										
25				M	C	C	M	C	C	C			M	C	C	C			
26			C	M			C	M	C	M			C	?			C	C	
27				C			C		C	C			C						

Qns	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	7(10)
28	M	M	M	M	–	C	C	–	M	C	–	M	M	M	M	M	–	M	
29	C			M			C		–										
30							C	C	M	C						C	C	C	
31	C	M	M	C	M	M	M	M	C	M	M	C	C	C	–	C	C	–	
32	C	C	C	C			M	M	C	M		C	C	C	C	C	C	M	
33	M	M				C	C	C	C	C	M		M	C	M		M		
34	C		C	M				M	C								C		C
35							M	C		M						C			
36							C			C									
37	M	M	M	M	C	C	C	M	M	C	C	C	M	M	M	M	M	M	
38								C											
39	M	M	C	M	C	C	M	M	C	M	C	C	C	–	C	C	C	M	C
40	C															C			
41																			M
42	C	M	C	M	C	C	M	M	C	C	C	C	–	M	C	–	C	M	C
43	M	M	–	M	M	C	M	C	M	C	M	C	M	M	–	C	M	M	
44																			C
45			C			C	C	M	C	C									
46	M	M	C	M	C	C	C	C	M	C	C	M	M	M	M	M	M	M	
47																			M
48			C						M										C
49			M	M	M			M	M	C	M	M	M						
50	M	M	C	M	C	C	M	M	C	M	C	C	C	–	C	C	C	M	C
51	M	M	M	M	M	C	C	C	M	C	M	M	M	–		M	M	C	
52				M			M		C	C			M	M			C		
53	C	C	M	C	C	C	M	M	C	M	C	C	C	M	C	C	C	C	
54	C	M	C	M		C	M	M	C	C	C		C	C	C	M	C	M	
55	C	M	M	C	M	M	M	M	C	M	M	C	C	C	–	C	C	–	
56	M	M				C	C	C	C	C		M	M	C	M	C	M	C	
57	C	M	M	M		C		C	M	C			M	C		C	M	C	
58	M	M	C	M	C	C	M	M	–	C	C	M	M	M	M	C	C	M	
59	M	M	M	M		C	C	M	M	C			M			M	M	M	
60																			
61					C		C			C	C								M
62																			
63																			

Appendix D
Recommendations for Amendment

Having reviewed the Health and Disability Commissioner Act 1994, I consider the following amendments to the Act to be necessary or desirable:

1. That 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.
2. That section 18 be amended to require 10-yearly reviews of the Act.
3. That section 21 be amended to require five-yearly reviews of the Code.
4. That Right 7(4)(a) be amended to read:

"It is in the best interests of the consumer or, in the case of research, is not known to be contrary to the best interests of the consumer and has received the approval of an ethics committee."