

A Review of the

**Health and Disability
Commissioner Act 1994
and
Code of Health and Disability
Services Consumers' Rights**

**Report to the
Minister of Health**

June 2009



**HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA**

29 June 2009

The Honourable Tony Ryall
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 August 2008 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 November 2008. This provided discussion on key provisions in the Act and Code and proposed areas for change.

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, I also held some meetings throughout New Zealand with various interest groups.

I received 122 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 keep the report concise and avoid repetition, I have identified the key issues raised during the review and summarised the submissions made on each issue.

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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KEY ISSUES

This is the third review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights. In my view, the Act and Code are working well. However, I have identified three key issues that need to be addressed through an amendment to the Act and/or Code, summarised below.

I acknowledge the campaign by the Centre for Compassion in Healthcare to add to the Code a right to be treated with compassion. I do not support this change because it sits uneasily with a disability perspective (in a Code that belongs to disability and health consumers); the Code already permits denunciation of neglectful and callous conduct; and the laudable goal of compassionate health care is better promoted by ethics and training than by regulation.

Disability

The consultation confirmed that many stakeholders in the disability community support legislative change to strengthen the rights of disability services consumers. Submissions made a strong case for the Commissioner to be able to hold providers to account for failures to provide timely access to disability services that a disability services consumer has been assessed as needing. This would be a modest and achievable reform, circumscribed by the needs assessment process and clause 3 of the Code (the defence of "reasonable actions in the circumstances", including resource constraints). I consider that the Act and Code should be changed as follows:

- amend the definition in the Act of "disability services consumer" to ensure consistency with the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities;
- amend the definition in the Act of "disability services" to include needs assessment and service coordination services;
- amend Right 4(3) of the Code to give disability services consumers the right to timely access to disability services they have been assessed as needing following a needs assessment, and add a definition of "assessed as needing" to clause 4.

Advocacy services

Both the Director of Advocacy and I consider that the current contractual model for advocacy services is past its use-by date. Problems with the current model include the Director's inability to recruit or manage the performance of advocates, inefficient use of resources, and challenges in ensuring a consistent quality of service across the country. Most submissions supported change. I recommend the Act be amended to enable advocates to become employees of HDC, while retaining their independent functions.

Right to privacy

The most notable omission in the Code is that it does not cover the right to privacy of health information. Yet the right to privacy is integral to the quality of health and disability services and the rights of health and disability service consumers. Currently, consumers whose privacy complaint is an aspect of a service quality complaint must make separate complaints to the Privacy Commissioner and HDC. This is not consumer-friendly and adds unnecessary time and expense. I recommend amending the Act and Code to permit HDC to handle health information privacy aspects of complaints about service quality.

RECOMMENDATIONS FOR CHANGE

Summary of recommendations

I recommend that the Health and Disability Commissioner Act 1994 be amended as follows:

- Amend the definition of “disability services consumer” to ensure consistency with the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities;
- Amend the definition of “disability services” to include needs assessment and service coordination services;
- Amend the sections relating to the purchase of advocacy services to enable advocates to become employees of HDC;
- Amend section 20(1)(c)(i) to remove the restricted definition of the “matters of privacy” that can be included in the Code;
- Change the requirement to review the Act and Code to every 10 years;
- Insert a new section to allow information obtained during an investigation to be withheld, while the investigation is ongoing;
- Substitute the phrase “aggrieved person” with the phrase “the complainant (if any) or the aggrieved person (if not the complainant)”;
- Clarify the status of Deputy Commissioners pending reappointment;
- Amend the title of section 38 to better reflect its purpose;
- Increase the fine for an offence under the Act to \$10,000;
- Provide expert advisors contracted by HDC with the same degree of immunity enjoyed by employees under the Crown Entities Act;
- Clarify that the Director of Proceedings may take action only upon referral from the Commissioner;
- Enable the Director of Proceedings to require any person to provide information relating to a matter under consideration until a decision has been made to issue proceedings.

I recommend that the Code of Health and Disability Services Consumers’ Rights be amended as follows:

- Amend Right 4(3) to give disability services consumers the right to timely access to disability services they have been assessed as needing following a needs assessment;
- Add a definition of “assessed as needing” to clause 4 of the Code;
- Amend Right 1(2) to read: “Every consumer has the right to have services provided in a manner that respects the privacy of the individual”, and remove the definition of “privacy” in clause 4 of the Code;
- Amend Right 7(4) 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”;
- Amend Right 7(6)(c) by adding the words: “... or sedation that has a similar effect”.

Disability issues

The Social Services Committee has recently undertaken an inquiry into the quality of care and service provision for people with disabilities: *Inquiry into the quality of care and service provision for people with disabilities: Report of the Social Services Committee*, Forty-eighth Parliament (Russell Fairbrother, Chairperson, September 2008) (the Disability Inquiry). The Committee's report contains a number of recommendations on how the quality of care and service provision for people with disabilities could be improved, including the appointment of an independent Disability Commissioner (possibly within HDC), expansion of the areas the Commissioner may examine (including access to disability services), and an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.

During the Disability Inquiry, HDC highlighted certain areas of concern about the quality of disability services evident in the complaints we receive, and the fact that HDC is limited in what action it can take because many disability complaints are outside the Commissioner's jurisdiction. Furthermore, there are often significant hurdles for people with disabilities to overcome to submit a complaint to HDC. While the Act does allow consumers to make complaints verbally, disability services consumers are often reluctant to complain for fear of repercussions and given the limited range and number of disability support services. This results in HDC receiving few complaints about disability service provision. In contrast, the advocacy service receives a large number of complaints about disability services and has a significant focus on working in the disability sector.

A key limitation on complaints about disability services is that, currently, the Act and Code cover only the quality of services that are delivered (not how services are accessed or funded). This causes difficulties, as often the way a disability service is funded results in the poor quality service. Currently, complaints that technically relate to access to disability services, even where quality of service issues are raised, are not matters that HDC can look into. One of the greatest barriers to advocates assisting people with disabilities is the scope of jurisdiction, which makes it difficult to take a holistic approach to assisting the consumer.

The explanation that consumers and families often receive for reduction in support is that the funding has gone. Disabled consumers and their families find it difficult to obtain adequate information to allow them to understand the process for needs assessments, reviews and funding. There appears to be a lack of information and ongoing, meaningful dialogue with disabled consumers about rationing and prioritisation of resources.

Issues of access and funding relating to disability services

Currently, the Act and Code do not cover how services are accessed or funded. The Code is confined to covering the quality of service delivered. The Act does not specifically authorise the Code to cover issues of access to services (section 20).

Question 2 in the consultation document asked for suggested amendments to the Act and Code in relation to disability, and question 27 asked whether there should be any amendment to the Act in relation to the Commissioner's jurisdiction over disability services. In the Disability Inquiry, the Select Committee suggested that the areas a Disability Commissioner could examine be expanded "to include, for example, access to services and individual funding

issues”, and should be responsible for “considering disability issues in relation to health, education, social development, and housing, and promot[ing] the recognition that disability is a fact of life and not primarily a health matter” (Disability Inquiry, page 36).

The general theme of submissions was that the Act and Code should be amended to extend the Commissioner’s jurisdiction over disability services to consider issues of access and funding. Most submitters wanted the Commissioner to be able to review decisions made about funding for, or access to, disability services:

“Lack of access to services is a key concern for and detrimental to people with disabilities — it leads to a feeling of helplessness and loss of independence and self esteem.”

(NZ Federation of Business and Professional Women Inc)

“This is also a very important focus for people with significant and complex disabilities as their access to and funding of services relates to essential services such as assistance with the necessities of life.”

(Judi Strid, Director of Advocacy)

Possible options outlined in the consultation document for extending HDC’s jurisdiction in relation to access to disability services include:

- a right for disability services consumers to receive the services the consumer has been assessed as needing. This would effectively enable the Commissioner to review access decisions only once a needs assessment has been completed and approved;
- enabling the Commissioner to review any decision about access to disability services.

The Disability Inquiry recommended the establishment of “an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health”. Many submissions on the consultation document referred to extending the Commissioner’s jurisdiction to link needs assessments made by these organisations to a legally enforceable right so that disability consumers can receive the services they have been assessed as needing. Submitters commented:

“... [C]urrently, a person may have an assessment, their needs be identified, a service plan developed and provided with the possible result of no service provision to allow that person to lead a dignified and independent life.”

(Name withheld)

“Proper assessment of needs, service match to needs, and access to the services identified are integral to the quality of care for people with disabilities.”

(Age Concern New Zealand)

I consider that, given the Select Committee’s recommendation and the significant support expressed in submissions, there is a strong case for legislative change to enable the Commissioner to review decisions made about access to disability services. I recognise that concerns about funding and resource allocation decisions may be best addressed through the accountability of government and funders. I am alert to concerns about finite resources, where a provider has a duty under the Code to provide services. However, clause 3 of the Code enables the provider to raise the defence of resource constraints to explain why it has not been possible to provide a consumer with a specific service.

Section 20(2)(a) of the Act authorises the Code to provide for any matter relating to the rights of disability services consumers if the Commissioner considers that the matter is of “particular importance” to disability services consumers. This is a clear signal that Parliament contemplated broader rights in the disability area. It is clear that timely access to services a disability services consumer has been assessed as needing *is* an issue of particular importance to disability service consumers.

I recommend that the Code be amended to give disability services consumers the right to timely access to disability services they have been assessed as needing following a needs assessment. Specifically, I recommend inserting the following words to Right 4(3) of the Code: “Every consumer has the right to have services provided in a manner consistent with his or her needs *and, in relation to disability services consumers, to have services that the consumer has been assessed as needing provided in a timely manner.*” A definition of “assessed as needing” will need to be inserted in clause 4 of the Code, to ensure that the right applies only when a formal, recognised needs assessment has been undertaken. I also note that, as explained above, clause 3 of the Code provides a safeguard for providers who are unable to provide the services that a consumer has been assessed as needing in a timely manner because of resource constraints.

In addition, I consider that the following matters are also of particular importance for disability services consumers:

- effective communication and information from the provider about access decisions and the criteria for accessing services; and
- involvement in the decision-making process in relation to what services they are to receive.

To address these matters, I recommend that the definition of “disability services” in the Act be amended to clarify that disability services include needs assessment and service coordination services.

Definitions relating to disability services

Question 8 in the consultation document asked for comments on the appropriateness of the current definitions relating to disability services. A number of submissions argued that the definitions relating to disability services should be updated to correspond with the definitions used in the New Zealand Disability Strategy and the United Nations Convention on the Rights of People with Disabilities. The New Zealand Disability Strategy states:

“Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.”

The UN Convention on the Rights of People with Disabilities describes disability as:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The Strategy and the UN Convention are powerful documents that postdate the HDC legislation and reflect contemporary disability thinking.

I consider that the definitions in the Act should be updated to be consistent with these definitions. I recommend amending the definition of “disability services consumer” in the Act accordingly.

Disability Commissioner

Question 28 of the consultation document asked whether a Disability Commissioner with a dedicated focus on disability issues and services should be created within the Office of the Health and Disability Commissioner (“HDC”). The majority of submissions argued that a designated Disability Commissioner should be created within HDC. Two submissions suggested that there should be an independent Disability Commission within the Human Rights Commission, not HDC.

I do not support establishing a Commissioner for disability as a separate office. The benefits of establishing a dedicated Commissioner within HDC include that health and disability are closely linked, and it is not uncommon for a complaint to include both health and disability service providers; one of the Deputy Commissioners already has delegated responsibility for disability issues; and HDC has expertise in advocacy and complaints resolution for disability consumers.

Section 9(2) of the Act allows the Commissioner to delegate any power, duties or functions to a Deputy Commissioner. Recently, I designated one of the Deputy Commissioners as “Deputy Health and Disability Commissioner — Disability”, and delegated to her the powers, duties and functions of the Commissioner in respect of all disability service investigations.

I do not recommend any amendment to the Act to ensure a Deputy Commissioner with a focus on disability issues, given the Commissioner’s power to delegate that already exists under section 9(2).

Advocacy services

Currently, the Act provides for an independent advocacy service for health and disability services consumers, which is overseen and monitored by a Director of Health and Disability Services Consumer Advocacy (the Director of Advocacy). The Director of Advocacy is required to operate independently of the Commissioner, but is responsible to the Commissioner for the efficient, effective, and economical management of her activities. This structural independence of the Director from the Commissioner was intended to protect the advocates’ role in acting on the side of the consumer, and the Commissioner’s impartiality in handling complaints. By their very nature, advocates are not impartial but take the side of the consumer. In contrast, it is essential that the Commissioner remain impartial and independent of both consumers and providers when assessing and investigating complaints.

Following the first review of the Act in 1999, the Commissioner recommended that advocates become employees of the Commissioner but retain the obligation to act independently, in order to offer a more centralised service. Another decade of experience has confirmed that a change is needed to the structure of the advocacy service. The Director of Advocacy and I both consider it necessary to change the current statutory model to better ensure effective independent advocacy services for consumers. Issues with the current contractual model include quality assurance and ensuring a consistent standard of advocacy services nationwide. The Director has no role in recruitment or performance management of advocacy staff. There

are inefficiencies in the delivery of advocacy services — the Director has no direct control over the application of funds or service delivery, and must monitor the service through the contract.

Question 5 of the consultation document asked for submissions on the appropriateness of the current contracting model for advocacy services. Two alternative options from the status quo (Option 1) were suggested in the consultation document: under Option 2 advocates would become HDC employees. This resembles the current structure of the Director of Proceedings team. The Director of Proceedings is an independent statutory officer but an employee of the Commissioner, and leads a small team who are also employed by the Commissioner but report to the Director. The Director of Advocacy would have direct involvement in ensuring the quality and consistency of service, and the wise use of resources. The independent function of advocacy services would be protected by statute.

Option 3 suggested an independent office of the Director of Advocacy, who would be able to employ advocates directly. This would have the same advantages as Option 2, but would give greater perceived independence. This option would be more complex as it would likely require the Director of Advocacy to be appointed by the Governor-General, rather than by the Commissioner.

Forty-six submissions were made on this question with 32 submissions in favour of change, with an even split of 16 submissions in favour of each of the two options for change.

Submitters in favour of Option 2 argued this would be a better use of resources and could be based on the existing model (Proceedings) with direct involvement by the Director of Advocacy. This option:

“... increases consistency in training, delivery and advice. It ensures an adequate level of independence, as demonstrated by the current functioning of the Director of Proceedings.

To that end, the Director of Advocacy should govern recruitment, performance management and discipline of advocacy staff. The Director should be the hub for funding and direct coordination of the service. In the public interest, the advocates should be subject to the Public Service Code of Conduct and relevant policies of the Public Service Code. This model provides efficiencies and assurances to the public.”

(National Centre for Health and Law Ethics)

The National Centre for Health and Law Ethics cited the example of the Office of Clients’ Rights Advocacy in California. There, legal advocacy is delivered by Disability Rights California (“DRA”) through the state-wide Office of Clients’ Rights Advocacy. DRA employs legally trained Clients’ Rights Advocates to deliver independent advocacy, legal advice, and representation. These advocates are trained and supervised by DRA but located within the 24 community-based regional centres. Each regional centre offers assessment and coordination of health, disability, respite and education services for people with disabilities.

The Director of Advocacy supports Option 3 because she believes that is the best way to secure the independence of advocates and the Commissioner’s impartiality. The main argument put forward by Option 3 supporters concerned independence:

“Option 3 provides the clearest separation and accountability for the Office of Advocacy, ensuring both accountability and independence from the investigation role of the Commissioner.”

(NZ Council of Christian Social Services)

“It is agreed that [Option 3] provides some distance from the Commissioner when dealing with complaints about advocacy services. Even though a further layer of complexity is added if the Governor General appoints the Director of Advocacy, it would ensure separation and further proof of independence.”

(NZ Federation of Business and Professional Women Inc)

Obviously there is a distinction between the Director of Proceedings team, which is located in Wellington, and the advocates who are located in offices throughout the country. However, in practice, the Director of Advocacy will be responsible for the operation of the advocacy service under either Option 2 or 3, and managing this service through an independent office would not be very different to the situation where advocates are employees of HDC.

After careful consideration of the submissions, I recommend adopting Option 2. This option will help achieve a consistent quality of service, with appropriate accountability, while retaining independence from the Commissioner, without the additional cost and complexity of Option 3. It will also enable a reduction in unnecessary administration so that more resource can be directed into core services and actual service delivery. This recommendation will involve amendment to a number of sections in the Act, including the definitions of “advocacy services”, “advocacy services agreement”, and “advocate”, and Part III of the Act.

Review of the Act and Code

The Act requires the Commissioner to regularly undertake reviews of the Act and the Code to consider whether any changes are necessary or desirable, and report the findings to the Minister of Health (sections 18 and 21 of the Act). This is the third review of the Act and Code. To date these reviews have resulted in very little substantive change to the original Act and Code.

Question 1 of the consultation document asked whether it is necessary to review the Act and Code every 3–5 years and whether 10-yearly reviews would suffice. Fifty-nine submissions were received on this question and 28 submissions were in favour of 10-yearly reviews, 16 for 5-yearly reviews and 15 for the status quo.

I consider that the interval between reviews should be extended to at least 10 years. As noted by Professor Peter Skegg:

“In the early years of the Act and the Code, the provision for frequent review seemed to be, and indeed was, sensible. However, the Act and the Code are no longer in need of this frequent reexamination. In most respects they are now working very well indeed. This being the case, I recommend that the Act be amended so that a review is required (if at all) only after ten years have elapsed from the previous review. The Commissioner should, however, be left with the discretion to instigate an earlier review if the Commissioner considers that the circumstances warrant such a review.”

In my view, the requirement to conduct such regular reviews is unnecessary. The reviews are a time-consuming, resource-intensive exercise, and do not necessarily result in change. No other consumer protection legislation is subject to such regular reviews. The requirement seems to be a hangover of initial fears on the part of provider groups that their duties would prove too onerous. If a new problem emerges with the operation of the Act or Code (something that becomes less likely as the jurisdiction becomes well established over time), consultation may be undertaken on a specific proposed change, as for any law reform.

I recommend that the Act be amended to require review of the Act and Code every 10 years.

Definition of “aggrieved person”

The term “aggrieved person” is not defined in the Act. It has been the source of some litigation. In sections 50 to 58 of the Act, which deal with proceedings before the Human Rights Review Tribunal (the Tribunal), there is no reference to health or disability services consumer. Rather, the term “aggrieved person” is used.

In *Director of Proceedings v O’Neil* [2001] NZAR 59, the High Court interpreted “aggrieved person” as including non-consumers, when the Director claimed damages on behalf of both parents of the deceased baby, where only the mother had been a consumer of midwifery services. In accepting that the parents had a claim under s 57(1)(c) as they were “persons aggrieved”, the High Court noted, “There can be a clear distinction between a ‘person aggrieved’ and a person who has suffered personal injury” (para 20).

Question 26 of the consultation document asked if the term should be defined, and whether this definition should be limited to health and disability services consumers. Thirty-one submissions were made on this question with 22 submissions agreeing that the term “aggrieved person” should be defined. Within this group, 11 submissions commented that the term should be limited to health and disability services consumers, and 8 were against this limitation.

Since the consultation document was published, the Court of Appeal has held, in *Marks v Director of Health and Disability Proceedings* [2009] NZCA 151 (28 April 2009), that the term “aggrieved person” in the Act is essentially limited to consumers who have rights under the Code. In this case, the Director brought a claim in the Tribunal on behalf of the parents of a man who died of self-inflicted injuries, seeking a declaration of a breach of the Code by a consultant psychiatrist when providing health services to their son. The claim also sought damages of \$40,000 on account of humiliation, loss of dignity, and injury to feelings suffered by the parents. The central issue on appeal was whether the parents were aggrieved persons for the purposes of the Act.

In deciding that the parents were not “aggrieved persons” under the Act, the Court of Appeal commented:

“[W]e consider that there would be difficulties in defining which secondary victims can be aggrieved persons. Ms McDonald [for the Director] was not able to be more precise in her definition than proposing that it would be a question of fact in each case but that such victims must have a connection to the primary victim greater than the public at large ... We suspect this test would encompass too large a group and would also risk not being interpreted in the same manner by differently constituted tribunals. We also

consider that there would be issues in determining what causal link is required between the breach of the Code and the situation of the secondary victim and then in deciding on when that causal link is proved. Ensuring an appropriately close causal link between the breach of the Code and any damage suffered by secondary victims could risk narrowing the ambit of the HDC Act remedies for primary victims, contrary to the purpose of the Act... [T]here may also be conflicts between primary and secondary victims that are not resolved by the HDC Act.” (paragraph 61)

The Court did, however, note two caveats:

- i. Fathers of babies in the course of pregnancy and the birth process may be “*derivative consumers in their own right and thus aggrieved persons under the HDC Act*” (paragraph 61);
- ii. It would be “*unsatisfactory if breaches of the Code with regard to deceased consumers remained without remedy*” (paragraph 63). In those circumstances, executors or administrators would be claiming on behalf of the deceased consumer and not in their own right, and the Court appears to regard such claims as potentially open (paragraph 69).

The Court of Appeal has thus clarified the definition of the terms “aggrieved person” and “person alleged to be aggrieved” in the Act. With the exception of fathers in cases concerning maternity care, claims before the Tribunal under the Act may only be brought on behalf of consumers. However, there remains the question whether the purpose of the Act would be advanced by an expanded definition of “aggrieved person”. Claims before the Tribunal may support improved public safety through vindication of the rights in the Code, enhancing professional accountability, and preventing and deterring breaches of the Code. An important aspect of professional accountability is that, for unregistered providers, claims to the Tribunal act as a substitute for disciplinary proceedings.

I have considered two options for change to the definition of “aggrieved person” and access to the Tribunal. The first option is to define the term as all consumers of health and disability services, including those covered by the definition of “consumer” in the Code, ie, those who are “entitled to give consent on behalf of that consumer”. An amendment along these lines would appear sufficient to open the way for claims by parents and legal guardians in relation to the care their children receive, and also for claims by welfare guardians under the Protection of Personal and Property Rights Act 1988. However, this amendment would not allow claims by family members of adult consumers legally competent to make their own decisions.

The second option uses the Human Rights Act 1993 as a model, substituting the phrase “aggrieved persons” with the phrase “the complainant (if any) or the aggrieved person (if not the complainant)”, where it appears in relevant provisions from section 51 onwards, notably sections 51–54 and section 57. This option would leave the *Marks* definition of “aggrieved person” in force, but allow complainants who are not an aggrieved person access to the Tribunal and to awards of damages. It would also not be necessary to define in the legislation which complainants can bring claims.

After careful consideration of the options, I prefer option 2. It has not proved problematic in claims for breaches of human rights before the Tribunal (under the Human Rights Act 1993). I consider that some change to the legislation is required in light of the *Marks* decision, which makes access to the Tribunal overly restrictive. The proposed change would promote

accountability and quality improvement, and in my view would not lead to a flood of claims. I recommend amending the Act to adopt the changes suggested in option 2.

The Code

Right to privacy

Currently, the Code does not cover the right to confidentiality of, and access to, information collected during the provision of health and disability services (“health information”). These issues are integral to the rights of health and disability service consumers, yet HDC is restricted in how it can deal with complaints about privacy and confidentiality. Although Right 1(2) of the Code states that every consumer has “the right to have his or her privacy respected”, this right does not cover privacy matters that can be the subject of a complaint under the Privacy Act 1993 or the Health Information Privacy Code (see section 20(1)(c)(i)).

The Code is therefore restricted to protection of a patient’s physical privacy (such as facilities for undressing that preserve the patient’s privacy or the way a provider conducts a physical examination), and not information privacy. The Commissioner has no jurisdiction over, and must refer to the Privacy Commissioner, any complaint alleging breach of confidentiality (section 36). This means that a complaint alleging breaches of the Code but also alleging a breach of privacy of information must be split, so that the privacy aspect is referred to the Privacy Commissioner, which results in a duplication of process and detracts from seeing a complaint in its totality.

Question 4 of the consultation document asked whether the Act and Code should be amended to include health information privacy. Forty-seven submissions were received on this question; 33 supported change and 14 endorsed the status quo. Submissions supported the suggestion in the consultation document to amend section 20(1)(c)(i), deleting the exclusion of information privacy:

“The Council strongly supports the inclusion of a right to confidentiality and access to health information. The Council has noted that these matters have been referred to the Nursing Council and/or the Privacy Commissioner and is of the view that actions that may breach confidentiality or privacy should also amount to breaches of the Code. Not only will this allow the Commissioner to undertake an investigation into such breaches but will also [allow] low level resolution or disciplinary action to be taken where appropriate.”

(Nursing Council of New Zealand)

The Privacy Commissioner expressed concern about allowing HDC to consider matters of health information privacy, arguing that compressing the HIPC into one right in the Code would add confusion rather than clarity. She was also concerned about competing jurisdictions handling health information privacy issues. Other submissions argued that the Privacy Commission should be the sole agency to consider issues of privacy about health information:

“FWHC prefers to leave health information privacy under the jurisdiction of the Privacy Commissioner as relevant understanding and expertise has been developed within that Office.”

(Federation of Women’s Health Council Aotearoa)

I remain of the view that there is a strong case for change to remedy this notable omission in the Code of Consumers’ Rights. The right to privacy in relation to health information is

integral to the quality of health and disability services and the rights of health and disability service consumers. For present purposes, HDC is concerned with privacy only in the context of a consumer receiving health and disability services. In this context, a complaint raising privacy issues is often one aspect of a broader complaint about service quality. A “one-stop shop” approach, with HDC handling both the privacy and service quality issues, would be more convenient for complainants and would reduce unnecessary duplication of process, time, and expense.

I recommend amending the Act and Code to include health information privacy by amending the definition of “privacy” in clause 4 of the Code and section 20(1)(c)(i) of the Act to remove the references to the Privacy Act, and amending Right 1(2) of the Code to refer to the right to have services provided in a manner that respects the privacy of the individual.

Informed consent — Right 7(4)

In the previous review of the Code, I consulted on whether Right 7(4)(a) should be amended to state that services should not be “contrary to the best interests of the patient” because sometimes it is not yet known whether research is in the best interests of the consumer.

Right 7(4) is an important protection for a particularly vulnerable class of consumers — those who are not competent to give consent and no other person is available to give consent on their behalf. Right 7(4) has been very carefully worded to ensure that certain steps are taken before services can be provided in these circumstances.

The first requirement of Right 7(4) is for the provider to attempt to obtain informed consent from someone entitled to give consent on the consumer’s behalf. Examples of those entitled to consent on the consumer’s behalf include a parent giving consent on behalf of a child, or a welfare guardian appointed by the court with authority to make health decisions on behalf of the consumer (according to the definition of “consumer” in the Code). If no such person is available, the remaining steps in Right 7(4) must be followed before any service is provided.

Right 7(4)(a) then requires the proposed service to be in the best interests of the consumer. This includes a clinical assessment by the provider of the need for treatment. It also involves looking at the consumer’s needs, interests, and quality of life from a holistic viewpoint, as required by Right 4(4) of the Code. If it is not known whether the proposed research or any other service is in the best interests of the consumer, Right 7(4) is at present inapplicable.

Sometimes it is not known in advance whether research is in the best interests of the consumer. The current requirement of affirmatively showing that the proposed research is in the best interests of the consumer inevitably deprives consumers of the benefit of research that *may* prove to be beneficial and is known not to be harmful.

In the 2004 review, I recommended a specific provision relating to research on unconscious or incompetent patients with appropriate safeguards, rather than wholesale change to Right 7(4) to cover treatment of incompetent patients generally (not just research). The recommended amendment of Right 7(4)(a) was to add that, in the case of research, services may be provided when it is not known to be contrary to the best interests of the consumer and the research has received the support of an ethics committee.

Submissions were almost evenly split (7:8) on whether this right should be amended to allow research on unconscious or incompetent patients in limited circumstances. Submitters who agreed supported the proposed amendment to Right 7(4)(a) to allow research where it “is not

known to be contrary to the best interests of the consumer”. Submissions against the proposed amendment argued:

“We think that weakening Right 7(4)(a) will increase the vulnerability, and undermine the consumer rights, of an already vulnerable group of health consumers ...”
(Women’s Health Action Trust)

In making this recommendation, I was aware that these are a particularly vulnerable class of consumers, and care needs to be taken to ensure that general protection of them is not diluted. However, it must be noted that Rights 7(4)(b) and (c) impose additional safeguards, requiring that the provider also take reasonable steps to ascertain what the consumer would want if he or she were competent. Services may only be provided where they are consistent with the informed choice the consumer would make if competent. Where it is not possible to ascertain this information, the views of other “suitable persons” able to advise the provider must be taken into account. “Suitable persons” may include family, partners, friends or caregivers who have an interest in, and a relationship with, the consumer such that it makes them suitable advisors on the type of care they believe is in the consumer’s best interests.

Therefore, I recommend that Right 7(4)(a) of the Code 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.”

Written consent — Right 7(6)

Right 7(6) stipulates that where informed consent to a health care procedure is required it must be in writing if:

- a) the consumer is to participate in any research; or
- b) the procedure is experimental; or
- c) the consumer will be under a general anaesthetic; or
- d) there is a significant risk of adverse effects on the consumer.

One submission argued that the term:

“‘general anaesthetic’ is also problematic, as there are many situations with the use of sedation that would be equivalent.”
(Dr Colin McArthur, Clinical Director, Dept of Critical Care Medicine & Medical Advisor — Quality and Safety, Auckland DHB)

I agree that the term “general anaesthetic” requires clarification and I recommend amending Right 7(6)(c) to add the words “... or sedation that has a similar effect”.

Administrative amendments

Status of Deputy Commissioners pending reappointment

As a preliminary comment to this review, the Ministry of Health suggested that greater clarity is needed within the Act around reappointment of Deputy Commissioners because it is unclear how to manage their positions while awaiting reappointment.

Question 10 of the consultation document asked whether there was support for clarifying the status of Deputy Commissioners pending reappointment. Thirty-five submissions were made on this question and all supported a change to clarify the Deputy Commissioners’ status.

Given the support for this change, I suggest a structure similar to that of the Privacy Commissioner. I recommend amending the Act by inserting a subsection in section 9 of the Act stating: *“Part 2 of the Crown Entities Act 2004, except section 46, applies to the appointment and removal of a Deputy Commissioner in the same manner as it applies to the appointment and removal of a Commissioner.”*

Decision to “take no action” — section 38

The Act enables the Commissioner, after a preliminary assessment of a complaint, to decide to take no action “if the Commissioner considers that, having regard to all the circumstances of the case, any action or further action is unnecessary or inappropriate” (section 38(1)). Under section 38(4), the Act requires that the Commissioner give the complainant and the provider reasons for a decision to take no action on a complaint. Matters that the Commissioner may take into account in determining whether to take any action are specified in section 38(2), for example that the consumer wishes no action to be taken, the complaint is trivial or is not made in good faith, or an adequate remedy or right of appeal already exists.

In practice, before a decision is made to take no further action on a complaint, considerable information is gathered and assessed, and preliminary expert clinical advice may be obtained. Most complaints closed under this section of the Act are where HDC considers an educational approach is more appropriate than an investigation. HDC frequently elicits an apology and ensures follow-up action by the provider(s). Section 38 is also used because matters are already being addressed through other appropriate processes or agencies.

Question 13 of the consultation document asked whether section 38 should be revised to better reflect its purpose. Thirty-six submissions were made on this question, with 26 in favour of an amendment. Of those in favour, six submissions suggested amendment to the title of section 38. Submissions agreed:

“... [T]he current terminology used in section 38 of the Act regarding the Commissioner deciding ‘to take no action on a complaint’ is a misnomer. It may be better defined as ‘taking no further action’ as the decision is always made following a preliminary assessment by the Commissioner, with or without further investigations.”

(Capital & Coast District Health Board)

In my view, the heading “Commissioner may decide to take no action on a complaint” is misleading, given that invariably this decision is taken after significant information gathering and assessment. I recommend amending the title of section 38 accordingly.

Withholding information obtained during investigations

Currently, HDC is subject to the requirements of the Privacy Act 1993 and the Official Information Act 1982 (the OIA). This means that HDC is required to undertake an assessment of every request for information held by the Office to assess whether release of that information is required. This is a complex and time-consuming task. Releasing information during the early stages of an investigation tends to favour providers (and their lawyers), who have greater familiarity with HDC’s processes during an investigation and may seek tactical advantages.

Question 19 of the consultation document asked whether the Act should be amended to allow information obtained during an investigation to be withheld, while the investigation is ongoing. The majority of submissions were in favour of the amendment (33 out of 41

submissions). The Privacy Commissioner submitted that HDC should have a similar ability to the Privacy Commissioner's office to withhold information obtained during the course of an investigation while the investigation is ongoing, as this is an important safeguard for the integrity of a complaint investigation process.

In my view, the Act should be amended to allow information obtained during an investigation to be withheld, while the investigation is ongoing, to allow speedy and efficient investigations. This issue was canvassed during the 1999 review, when the Commissioner recommended that a new section should be inserted into the Act allowing HDC to maintain secrecy in relation to material gathered during an investigation (but retaining the discretion to release material where this is necessary to give proper effect to the Act). As noted above, the Privacy Commissioner, as an equivalent statutory body, has a similar provision. Section 55(e) of the Privacy Act 1993 states that the right to request access to personal information does not apply in respect of "Information contained in any correspondence or communication that has taken place between the office of the Commissioner and any agency and that relates to any investigation conducted by the Commissioner under this Act, other than information that came into existence before the commencement of that investigation." Including such a provision in the Act would not jeopardise the fairness of the investigation. All relevant information would continue to be released to the appropriate parties when the Commissioner makes a provisional decision, to fulfil natural justice requirements.

I recommend that a new section be inserted into the Act to allow information obtained during an investigation to be withheld, while the investigation is ongoing.

Offences — section 73

Section 73 provides that: "Every person commits an offence against this Act and is liable on summary conviction to a fine not exceeding \$3,000 who,

- (a) Without reasonable excuse, obstructs, hinders, or resists the Commissioner or any other person in the exercise of their powers under this Act;
- (b) Without reasonable excuse, refuses or fails to comply with any lawful requirement of the Commissioner or any other person under this Act;
- (c) Makes any statement or gives any information to the Commissioner or any other person exercising powers under this Act, knowing that the statement or information is false or misleading; or
- (d) Represents directly or indirectly that he or she holds any authority under this Act when he or she does not hold that authority."

Question 16 of the consultation document requested views on whether the level of fines should be increased from \$3,000 to \$10,000. Forty-four submissions were received, with 33 in support of increasing the fines.

In my view, the \$3,000 maximum fine is very modest for the offences covered and provides little discouragement for those who choose to obstruct the Commissioner's process. I support an amendment to increase the fine for an offence under the Act to \$10,000. This is consistent with the Health Practitioners Competence Assurance Act 2003 (section 172, \$10,000 fine for knowingly making a false or misleading declaration or representation, or producing a false, misleading or not genuine document to a registration authority or the Health Practitioners Disciplinary Tribunal) and other consumer protection legislation (Fair Trading Act 1986,

section 40, \$10,000 fine for not complying with a notice requiring information or supplying false or misleading information to the Commerce Commission).

Immunity for independent expert advisors

Sections 120 to 126 of the Crown Entities Act 2004 provide some immunity from civil liability in respect of “excluded” acts or omissions by “members, office holders or employees” of statutory entities that are “in good faith and in performance or intended performance of the entity’s functions”. Before the enactment of the Crown Entities Act, independent expert advisors engaged in connection with the work of the Commissioner were protected by section 65(2)(a) of the Act. However, as independent advisors are not “members, office holders or employees”, the protections in the Crown Entities Act are not available to them.

Question 18 of the consultation document asked if the Act should be amended to provide independent expert advisors contracted by HDC with the same degree of immunity enjoyed by “members, office holders or employees” under the Crown Entities Act. Thirty-nine submissions were made on this question and 31 submissions supported such an amendment.

I noted in the consultation document that the risk of independent advisors being legally challenged is extremely slight. However, I consider that the Act should be amended to provide expert advisors contracted by HDC the same degree of immunity enjoyed by “members, office holders or employees” under the Crown Entities Act. Accordingly, I recommend amending section 65(1) to include “any person engaged in connection with the work of the Commissioner”.

Director of Proceedings

Action upon referral — section 47

As a preliminary comment to this review, the Director of Proceedings pointed out that section 14(1)(f) of the Act does not specify that the Commissioner must have undertaken an investigation before referring a provider to the Director of Proceedings. The Director of Proceedings has recommended amendment to sections 47 and 14(1) of the Act to make it clear that any powers or functions of the Director arise only on referral from the Commissioner after undertaking an investigation (ie, referral pursuant to section 45(2)(f)).

From time to time a complainant has approached the Director for assistance or representation where there has been no referral by the Commissioner. Because section 47 appears before section 49, it is not surprising that there has been an expectation that it may operate without a referral. However, the Director has declined to be involved in any such proceedings, on the basis that a referral from the Commissioner is required before the Director can exercise any of the powers and functions under section 49 of the Act. It is clear from the later provisions of the Act that there must be an investigation prior to referral.

Question 21 of the consultation document asked if submitters agreed that section 47 should be amended to clarify that the Director of Proceedings may take action only upon referral from the Commissioner. Thirty-four submissions were made and 30 submissions agreed with the proposed amendment. I recommend that section 47 be amended to clarify that the Director of Proceedings may take action only upon referral from the Commissioner.

Same power as Commissioner to require information

During the period from referral to the Director of Proceedings until a charge or statement of claim is filed, there is no power under the Act, or under any other Act, to compel the production of information. Section 62 provides the Commissioner with the power to require

information (that may be relevant to the subject-matter of the investigation), and summon a person to examination under oath. The Director of Proceedings has no power to do this. The referral to the Director takes place once the investigation has been completed and, because the Director's powers and functions are exercised independently, the Commissioner is no longer involved in the matter. Once a charge has been laid, the tribunals may subpoena information on the application of a party. However, sometimes the Director may wish to obtain additional information to decide, under section 49, what (if any) action to take in the first place. In particular, the Director may consider a specific piece of information highly relevant in deciding whether to lay a disciplinary charge against a provider.

Question 22 of the consultation document asked whether the Director of Proceedings should have the same power as the Commissioner under section 62 to require the provision of information, until a decision has been made under section 49 to issue any proceedings. Thirty submissions were made on this question and 26 submissions agreed with the proposed amendment.

I recommend that section 49 be amended to include additional powers for the Director of Proceedings to require information relating to a matter under consideration until a decision has been made to issue proceedings.

ISSUES NOT REQUIRING CHANGE

The Act

Definitions of health services

Many diverse submissions were made on changes to the definitions in the Act relating to health services. Several submissions asked for the definitions to be simplified and clarified. Others requested no changes to the definitions. In my view, there is no strong argument for any change to these definitions at this stage.

Health and Disability Commission

During the 2004 review of the Act, there was discussion of whether the Office of the Health and Disability Commissioner should be renamed the “Health and Disability Commission”. Use of the term “Health and Disability Commissioner” in a single piece of correspondence or a report, and referring variously to the legal entity (Office of the Health and Disability Commissioner) in contrast to the individual office-holder, is often clumsy.

An overwhelming majority of submitters supported this change: of 48 submissions, 44 were in support of a change of name to the “Health and Disability Commission”. Despite this, I am concerned about the practicalities and cost implications of this change. Therefore I do not recommend any change to the legislation.

Commissioner’s functions

While several submissions supported broadening the Commissioner’s functions, many believed that the Commissioner’s current functions set out in the Act are appropriate. None of the submissions made to broaden the functions convinced me that any change to the Act is necessary.

Requirement to refer all complaints to the relevant registration authority

Submissions for and against whether the Commissioner should be required to refer all complaints about registered health practitioners to the relevant registration authority were evenly split (23 submitted yes, 21 said no). In my view, the current referral system is appropriate. My office has Memoranda of Understanding with a number of registration authorities and these authorities are informed of complaints in appropriate cases. I recommend that no change be made to the Act on this issue.

Right of appeal

As a preliminary comment to the review, some provider groups suggested that providers should have a right of appeal from a Commissioner’s opinion regarding a breach of the Code and/or a decision to name a provider found in breach. Most submissions argued that a formal right of appeal should not be added to the Act because the current ability to seek a review by the Ombudsmen or bring a judicial review is adequate. I agree and recommend that no appeal right be added to the Act.

Naming of providers

Some submissions argued that the Act should be amended to allow the Commissioner to name providers found in breach of the Code. However, more submissions were received opposing such an amendment. HDC’s naming policy sets out the factors that are taken into account

when making a decision to name a provider. The parties are given an opportunity to comment before the decision is finalised. In my view, HDC's current naming policy is working well and I do not consider it necessary to provide a further avenue to appeal a naming decision.

Only a very small number of submitters supported an amendment to allow the Commissioner to suppress identifying information during an investigation and afterwards when no breach has been found. I do not consider a change is needed on this issue.

Ethics committees

Most submissions argued that ethics committees should not come under the oversight of HDC owing to concerns about the compromise of HDC's independence. Two submitters felt that the rights of participants were being compromised and should be protected by HDC. Other submitters argued that a separate Director of Ethics within HDC would address the concern about independence. The Ministry of Health has advised that it is currently reviewing all aspects relating to ethics committees. I recommend that no amendment be made in relation to ethics committees at this stage.

Complainants commenting on Commissioner's provisional opinion

Submissions were evenly split about giving complainants the opportunity to comment on the Commissioner's provisional opinion (19:19). The speediness of an investigation must be balanced against the requirements of natural justice and fairness to providers under investigation. I agree with the point made in one submission that releasing the Commissioner's provisional opinion could risk early release to the media. Provisional opinions sometimes change substantially before the final finding. I am not convinced by submissions that a change to the Act is necessary on this issue.

Timeframes for investigations

Very few submissions were received on whether the Act should prescribe timeframes for the Commissioner's investigations (3 were in favour of a timeframe, 5 against). HDC takes its responsibility to undertake investigations in a "speedy and efficient" manner very seriously. The majority of investigations are completed within 12 months (with a handful taking 18–23 months). I consider it unnecessary to prescribe a timeframe for investigations in the Act, and recommend that no change be made.

Limitation period

For some years now the Law Commission has been reviewing and consulting on reform of the Limitation Act 1950, which limits the time within which claims may be brought in court following an event that gives rise to a claim. During the consultation process, the Director of Proceedings recommended that the Act be amended to provide for a period of limitation in relation to Human Rights Review Tribunal proceedings, with the limitation period running from the time the Commissioner finds that the Code has been breached. This is on the basis that no one has the right to bring proceedings until there has been a breach finding, which contrasts with any other litigant who can bring a claim in a court as soon as the damage arises. The majority of submissions on this issue agreed that any limitation period under the Limitation Act should start to run from the date on which the Commissioner finds a breach of the Code (29 submissions received with 26 in support of the proposed amendment).

Since this consultation, a Limitation Bill has been introduced into the House (on 2 June 2009). Given that the Limitation Bill is currently progressing through the legislative process, and

does not specify a limitation period for claims made in proceedings in the Human Rights Review Tribunal, I do not suggest any specific amendment at this time.

The Code

Right to access publicly funded services

The Act is not concerned with which services are to be funded by public funds, but with the quality of services that are delivered. Section 20 addresses only the quality of service delivered and does not authorise the Code to cover access to health services.

A right to access health services was considered during the consultation on the original Code, and in the two subsequent reviews. Despite submissions in support of this right, neither report on the reviews recommended amending the Act and Code to include a right of access to services.

Question 3 in the consultation document asked whether the Act and/or the Code should be amended to include a right to access publicly funded services. Fifty-one submissions were received in response to this question, with 15 submissions endorsing the status quo and 36 submissions supporting a right to access publicly funded services.

Submissions in support centred on the issue of equity of access for all consumers:

“FWHC supports national equity of access to publicly funded services so that patients have similar access regardless of where they live, their socio-economic or cultural status, or any other perceived barriers, including disability.”

(Federation of Women’s Health Councils Aotearoa)

A few submitters suggested that the right be restricted to the right to access services in a “timely manner”, or “the right to access timely and appropriate services”. One submission suggested an amendment based on Scottish public service reforms, “the right to access convenient and appropriate public services” (Public Health South).

I acknowledge that access and funding issues are not readily justiciable. Submissions against this change raised the same concern:

“Decisions regarding access involve complex resource allocation issues which should generally be left to the government, rather than enforced through the Code of Rights.”

(NZ Private Surgical Hospitals Assoc Inc)

However, clause 3 of the Code would enable providers to mount a defence as to why it has not been possible to meet a particular consumer’s right to access a particular service. In the consultation document, I suggested the possibility of some form of limited right to access services, without opening the door fully to entitlements to access to services generally.

After careful consideration of the submissions made, in my view the Code should not be extended to include a limited right to access publicly funded services. In contrast to the limited right to timely access to disability services discussed above (page 3), a right to access publicly funded health services would be open-ended and would inevitably draw the Commissioner into rationing and prioritisation issues which properly live with government and funders.

Compassion

The Centre for Compassion in Healthcare (the Centre) submitted that the Code should be amended to include a “right to be treated with compassion”. The Centre noted the link between compassion and patient safety, the emotional impact of the health care experience, and the importance of having standards in law that align with the core values of health care. In the United Kingdom, the new NHS Constitution includes “compassion” as a core value of the NHS (but not a right, in contrast to “respect” and “dignity”). The quality of compassionate caring shown by every nurse in the NHS is to be measured by patient feedback (see <http://news.bbc.co.uk/1/hi/health/7460720.stm>).

The Centre suggested amending Right 1(1) of the Code to read: “Every consumer has the right to be treated with compassion and respect”, and adding a clause to Right 1 to read: “Every consumer has the right to have services provided with compassion, including a prompt and humane response to distress, pain and suffering.”

The majority of submissions on the proposal were in favour of this amendment (44:19). In addition, Dr Robin Youngson on behalf of the Centre attached a petition with 529 electronic signatories in support of adding the right to be treated with compassion to the Code. The Centre submitted:

“Compassion is defined as ‘the humane quality of understanding suffering in others and wanting to do something about it’.”

We believe that caring and compassion are core values that motivate health professionals but our institutions and professions have evolved in ways that limit the expression of compassion. While the majority of health consumers are satisfied with their care, the increasingly technical nature of healthcare means that some consumers have experiences of healthcare that can feel thoughtless or uncaring and that fail to recognise or attend to distress and suffering. We need to restore the balance between clinical treatment and compassionate caring.”

(Centre for Compassion in Healthcare)

The Centre’s argument for adding the right to be treated with compassion is based on the belief that the current Code does not encompass such a right. In the Centre’s view, the words “respect” and “dignity and independence” do not adequately express the meaning and purpose of compassion, which needs to be explicitly stated as a right.

Most submissions in favour of this amendment suggested that Right 1(1) be amended to state that “Every consumer has the right to be treated with compassion and respect”. Many submissions echoed the Centre’s concern that the current wording of the Code does not encompass compassion:

“Committee members argued that compassion has a meaning distinct from dignity and respect, as it relates particularly to the humane understanding and relief of suffering in people who are very vulnerable. While there are undoubtedly many deeply compassionate health professionals, sometimes our systems of care allow consumers to suffer unnecessarily through neglect of basic human needs. Adding a right to be treated with compassion will strengthen the ability of the Health and Disability Commissioner to address institutional neglect of consumers’ basic needs.”

(Quality Improvement Committee)

The main arguments put forward for not adding a right to compassion to the Code were that the current wording in Right 1 already covers “compassion”, and that any right that requires a certain “emotion” will be unenforceable. For example:

“NZNO does not support including the right to compassion in the Code because it is unenforceable (legislation can direct actions but not emotions) and the concept is already less contentiously embraced in the Code’s first right...”

(NZ Nurses Organisation)

In response, the Centre argues that the test of the Code is in the “breach”, and lack of compassion is usually obvious because an ordinary person would judge that the consumer has suffered unnecessarily. Compassionate care can also be judged by the experience of the consumer and his or her family, the experience of loving kindness, and the relief of pain, suffering and fear.

Opponents submitted that it would be very difficult for the Commissioner to measure an emotion or feeling of compassion and to assess whether a provider is actually feeling compassion. For example, a submission suggested that the Centre is seeking an emotional response, which will hopefully lead to positive actions such as kindness and relief of pain:

“What the Centre is actually concerned about then, is not so much certain actions, but about certain characteristics, or virtues, of health practitioners ...

The rights in the Code are, of course, legally enforceable. You cannot legally require someone to have a certain kind of emotional response or engagement. This is a capacity one has developed, or has not. One must wonder about the practicalities of governing such a right for the Commissioner’s Office.”

(Stuart McLennan)

On 11 June 2009, I held a national meeting to consult further with 20 key stakeholders and people who made substantive submissions on this issue. Everyone present agreed that compassion is an important virtue in health care, and many shared a sense that it is often absent, especially in hospital settings. Proponents argued that the Code is a “living document”, that in the 21st century an ethic of “care” complements the earlier emphasis on autonomy, and that the proposed right would invoke the symbolic force of the law to change attitudes and behaviours.

However, meeting participants also recognised that the use of compassion in relation to disability services is inappropriate. Disability service consumers do not want to be thought of as suffering and needing to have something done “to” them. DPA New Zealand made a powerful submission explaining this concern:

“ ... [W]e are talking about the rights of 800,000 people who may use disability support services.

DPA opposes the addition of compassion to the HDC Code of rights, although we do support the practice of compassion by healthcare professionals towards all of those they encounter in their work — we think compassion is a compelling virtue, and of great value in health practice. But ... the use of compassion in relation to disability services is inappropriate. ...

[T]he harm of adding the right to be treated with compassion is that it reframes disability support in a medical model because the only reason to show compassion to another human being is when you think that they are suffering needlessly. This then requires the service provider to reframe their thinking about disabled people as suffering which is a very old-fashioned view. ...

DPA would strongly oppose such an [amendment] and urges the Commissioner to consider/suggest alternative (non-code) ways to emphasise compassion.”

I am persuaded by the view that adding the proposed right would undermine the confidence of disability services consumers in the Code because “treatment” with “compassion” reflects a model of care that is inappropriate in a disability context. I appreciate the concern about the absence of compassion in health settings, and I am supportive of moves to encourage compassion in health care. However, I do not believe that legislation is the most effective way to promote a virtue, and I have some misgivings about the enforceability of a *legal* duty to be compassionate. Furthermore, the Code is already broad enough to denounce neglectful and callous conduct (see, eg, case 05HDC11908, 22 March 2007).

In my view, the laudable goal of compassionate health care is better promoted by ethics and training than by regulation. To the extent that the law can play a role, my preference is to focus on a provider’s duty of care under Right 4 of the Code. Where professional ethical statements include a duty to act compassionately, Right 4(2) gives consumers the right to compliance with that “ethical standard”.

There is also scope for development of Right 4(3) (a consumer’s right to have services provided in a manner consistent with his or her needs) and Right 4(4) (a consumer’s right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer). The clause 4 definition of “optimise the quality of life” — “to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances” — is flexible enough to cover the prompt and humane response to distress, pain and suffering.

For these reasons, I do not recommend that a right to be treated with compassion be added to the Code.

Right to effective communication — Right 5

Many submissions on Right 5 of the Code supported a national interpreting and translation service being made available through HDC. While I support a national interpreting service, the Commissioner’s office and the Director of Advocacy do not have funding to support such a service, and it would in any event need to extend beyond health and disability services (eg, to cover social services and education). Such a broad service is beyond the scope of HDC. I do, however, support a national approach to interpreting and translating services to ensure that the right to effective communication (and informed consent) can be exercised. I recommend that no change be made to the Code to provide a national interpreting and translation service.

Written consent — Right 7(6)

A small number of submissions were received commenting on Right 7(6), and most supported a review of the requirements for written consent under the Code. The issue raised was that the Code seems to require written consent for the prescription of medicine. This has not proved problematic in practice over the past 13 years. In my view, a commonsense approach must be

taken to interpreting the Code, and I do not consider that any amendment should be made to the Code in relation to this aspect of written consent.

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

Several submissions were made arguing for the reversal of the 2003 amendment of Right 7(10). However, the same number of submissions supported the right as it is currently worded, as it has allowed valuable research. Given that, in practice, the exemptions from the informed consent requirements under Right 7(10) apply in very limited circumstances, I recommend that no change be made to Right 7(10).

APPENDIX A — CONSULTATION PROCESS

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

Consultation process

In August 2008, 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 a document for consultation. The consultation document contained discussion of a wide range of issues. 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 ninety-nine copies of the consultation document were posted and sent electronically. 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 approximately 2,500 hits during the consultation period (November 2008–February 2009).

One hundred and twenty-two submissions were received in response to the consultation document. The submissions were then considered and analysed. An analysis of the responses is included in Appendix C.

In the consultation document, we proposed holding public meetings if people were interested. However, due to a lack of interest in such meetings, we did not hold public meetings. However, in response to requests, we did hold two forums in Auckland in January and February 2009 focusing on the possible changes in relation to disability consumers' rights, at the request of Auckland Disability Law and Deaf Aotearoa New Zealand. In addition we held a meeting with submitters on the proposed right to be treated with compassion in June 2009. Feedback on the Act and Code and proposed changes was obtained during these meetings.

APPENDIX B — LIST OF SUBMISSIONS

	Submission No.
A W Beasley	49
Age Concern New Zealand	41
AIDS Epidemiology Group, University of Otago	22
Ann Bain	47
Annie Price	25
Auckland Deaf Christian Fellowship	98
Auckland Disability Law	117
Auckland Disability Providers Network Inc	106
Auckland Women's Health Council	64
Australian and New Zealand College of Anaesthetists, NZ National Committee	88
Bay of Plenty DHB	36
Brain Injury Association of Auckland	79
Cancer Society Tissue Bank, Christchurch	1
Canterbury DHB Consumer Advisors	62
Canterbury Mental Health Consumers Network	89
Capital & Coast DHB	112
Carol McCord	11
Catherine Gibson	8
CCS Disability Action	59
Centre for Compassion in Healthcare	68
Complex Carers Group	51
David Loving-Molloy	29
Deaf Aotearoa New Zealand	75
Disabilities Resource Centre Trust	103
Disability Information Waitakere Network	70
Dr Colin McArthur	97
Dr Elizabeth Harding	61
Dr Evan Mason	13
Dr Nigel Millar	3
Edel Felix	10
Equity for Illness	21
Family Planning	101
Federation of Women's Health Councils Aotearoa	91
Gail Lyons	26
Gary Watts	12
Geoff Cardwell	50
Health Research Council of New Zealand	120
HealthCare Providers New Zealand	24
Helen Capel, Suzanne Paul and Graham Foster	92
Helen Morrin	99

Hine Potaka	18
Human Rights Commission	113
IHC	84
Jacqueline Raynes	28
Jacque Kerslake	31
Jane Cunningham	27
Jenny Miles	19
Jill Lamb	17
Judi Strid, Director of Advocacy	116
Julie Hermes	6
Kathy Torpie	4
Katrina Fowler	2
Katrina Strickett	63
Kites Trust	85
Leo Hobbs	7
Lorna Dyll	100
Manawanui Ariki Charitable Trust, Generation 9	95
Margaret O'Sullivan	9
Marion Partington	23
Maternity Services Consumer Council	87
Medical Council of New Zealand	58
Mental Health Commission	57
Mental Health Foundation of New Zealand and Mental Health Advocacy Coalition	67
Ministry of Health	119
Muscular Dystrophy Association of New Zealand Inc	78
Name withheld	107
Name withheld	71
Name withheld	96
National Advocacy Service Managers Group	104
National Centre for Health Law and Ethics	74
National Council of Women of New Zealand	53
Nationwide Advocacy Trust	60
New Zealand Association of Optometrists Inc	105
New Zealand College of Midwives	81
New Zealand Council of Christian Social Services	108
New Zealand Federation of Business and Professional Women Inc	33
New Zealand Medical Association	40
New Zealand Nurses Organisation	55
New Zealand Organisation for Rare Disorders	32
New Zealand Private Surgical Hospitals Association Inc	43
New Zealand Psychologists Board	46
New Zealand Sterile Services Association	35
Nigel Dunlop	20

Nursing Council of New Zealand	122
NZRDA and New Zealand Medical Professionals Ltd	82
Osteopathic Council of New Zealand	80
Otago and Southland DHB	114
P S Survivors Inc	44
Palmerston North Women's Health Collective	52
Peter Kimble	5
Pharmac	102
Pharmaceutical Society of New Zealand Inc	93
Pharmacy Council of New Zealand	90
Privacy Commissioner	42
Professor George Salmond	14
Professor Grant Gillett	16
Professor Peter Skegg	69
Public Health South	115
Quality Improvement Committee (QIC)	48
Rachel Coppage	30
Rescare New Zealand Inc	94
Robert Finlay	37
Royal Australasian College of Physicians	109
Royal Australasian College of Surgeons	110
Royal Australian and New Zealand College of Psychiatrists	86
Royal New Zealand Foundation for the Blind	38
Royal New Zealand Plunket Society	65
Rural Women New Zealand	66
Sacha Dylan	118
Sarah Hunter	45
Stuart McLennan ¹	56
Taranaki DHB	54
Te Puni Kōkiri	73
Te Roopu Taurima O Manukau Trust	39
The New Zealand Committee of Pathologists, RCPA	72
The Royal New Zealand College of General Practitioners	111
Tina Smith	15
Wairarapa DHB	77
Waitaki District Council, Positive Ageing Working Party	34
Wakefield Health Limited	121
Wilson Home Trust	76
Women's Health Action Trust	83

¹ Stuart McLennan is employed by HDC but submitted in his personal capacity.

APPENDIX C — ANALYSIS OF SUBMISSIONS

Questions referred to in this analysis relate to the questions posed in the consultation document for the Review of the Act and Code (November 2008), which is available at www.hdc.org.nz.

Review of the Act: question 1

Many submitters commented on the length of time that should elapse between reviews of the Act and Code. Most agreed with the Commissioner that every 10 years would be sufficient,¹ with some suggesting giving the Commissioner the discretion to review earlier if necessary.² Submitters did not provide reasons for wanting to retain the three- to five-yearly review; however, two submitters commented that the changing nature of the health sector meant that 10 years was too long between reviews.³ Some submitters suggested the review be undertaken occasionally by an independent person.⁴

Disability issues: questions 2, 8, 27 and 28

Suggested amendments to the Act/Code in relation to disability: question 2 Suggested amendments to the Act relating to the Commissioner's jurisdiction over disability services: question 27

The general theme of submissions was that the Act and Code should be amended to extend the Commissioner's jurisdiction over disability services to consider issues of access and funding. Most submitters wanted the Commissioner to be able to review decisions made about funding for, or access to, disability services. In addition, many referred to extending jurisdiction to link a needs assessment to a legally enforceable right so that disability consumers can receive the services they have been assessed as needing.⁵ Some submitters commented on improving access to the complaints process for consumers with disabilities.⁶ Some also asked that the recommendations from the Select Committee Disability Inquiry be implemented, expanding the areas the Commissioner may examine and consider including access and funding, and education, social development and housing.⁷ One submitter referred to the UN Convention on the Rights of Persons with Disabilities and argued that the Act should be strengthened to reflect this Convention to promote, protect and ensure the full and free enjoyment of all rights and freedoms of persons with disabilities.⁸ Another submitter suggested that HDC develop and monitor national standards in relation to disability.⁹

¹ 28 in favour of 10-yearly reviews, 15 for the status quo and 16 for 5-yearly reviews.

² NZ Sterile Services Association #35, Professor P Skegg, Faculty of Law, Otago University #69.

³ Federation of Women's Health Councils Aotearoa #91, Name withheld #107.

⁴ Bay of Plenty DHB #36, The National Advocacy Trust #60, Name withheld #96, Nationwide Advocacy Service Managers Group #104.

⁵ NZ Federation of Business and Professional Women Inc #33, Age Concern NZ #41, NZ Nurses Organisation #55, Canterbury DHB Consumer Advisors #62, Women's Health Action Trust #83, NZ Association of Optometrists #105.

⁶ NZ Federation of Business and Professional Women Inc #33, Mental Health Commission #57, Canterbury DHB Consumer Advisors #62, Family Planning #101, Public Health South #115, Sacha Dylan, Disability Strategist #118.

⁷ NZ Federation of Business and Professional Women Inc #33, CCS Disability Action #59, Canterbury DHB Consumer Advisors #62, Disability Information Waitakere Network #70, Deaf Aotearoa New Zealand #75, Auckland Disability Law, Auckland University #117.

⁸ Nationwide Advocacy Service Managers Group #104.

⁹ Public Health South #115.

There were a few submitters who argued that the Commissioner’s jurisdiction should not be amended or extended to consider access or funding issues.¹⁰ Submitters also proposed that the Commissioner should be able to consider the issue of disparity of funding between those disabled through an accident (ACC) and those disabled through disease (Ministry of Health).¹¹

Comments on the appropriateness of definitions relating to disability services and suggested changes: question 8

Regarding the definitions relating to disability services, several submitters commented that these will require amendment if an independent disability commissioner is established. Some submitters requested amendments to the definitions to update them to correspond with various other definitions used by Statistics NZ,¹² the Human Rights Act,¹³ the NZ Disability Strategy, and the UN Convention.¹⁴ Submitters also commented that the definitions should not specify the length of time a person is disabled,¹⁵ and should cover sporadic and temporary impairment requiring intermittent support (as with mental illness).¹⁶ One submitter suggested that the definitions be clarified so that consumer organisations carrying out advocacy and other information services are not disability service providers.¹⁷

Disability Commissioner with a dedicated focus on disability issues created within HDC: question 28

The vast majority of submitters on this issue agreed that a designated Disability Commissioner should be created within HDC (39:6). Two submitters agreed that there should be a separate Disability Commissioner but within the Human Rights Commission, not HDC.¹⁸ Some submitters argued that this Disability Commissioner should report to the Minister for Disability Issues and have adequate funding.¹⁹ Another submitter suggested that regional committees should be set up to assist the Disability Commissioner and report back to the Commissioner.²⁰

A right to access publicly funded services: question 3

Many submitters argued that the Act and Code should be amended to include a right to access publicly funded services (36:15). The right to access is a major issue for consumers with disabilities.²¹ A few submitters suggested that the right be restricted to the right to access services in a “timely manner”,²² or “the right to access timely and appropriate services”.²³ Some submitters proposed amendments linking the right to access to assessment of needs — for example:

¹⁰ NZ Association of Optometrists #105, The Royal Australasian College of Surgeons #110, Ministry of Health #119.

¹¹ Equity for Illness #21, NZ Federation of Business and Professional Women Inc #33, National Council of Women #53, NZ Nurses Organisation #55.

¹² Royal NZ Plunket Society #65.

¹³ Women’s Health Trust #83, Auckland Disability Law #117.

¹⁴ Deaf Aotearoa NZ #75, Name withheld #96, Auckland Disability Law #117, Sacha Dylan, Disability Strategist #118.

¹⁵ Muscular Dystrophy Assoc #78.

¹⁶ Mental Health Foundation & Mental Health Advocacy Coalition #67, Kites Trust #85.

¹⁷ Nationwide Advocacy Service Managers Group #104.

¹⁸ CCS Disability Action #59, Women’s Health Action Trust #83.

¹⁹ CCS Disability Action #59, The National Advocacy Trust #60, Federation of Women’s Health Councils Aotearoa #91, Sacha Dylan, Disability Strategist #118.

²⁰ Gary Watts, Sigjaws #12.

²¹ Auckland Disability Law, #117.

²² NZ Federation of Business and Professional Women Inc #33, Mental Health Foundation of NZ & the Mental Health Advocacy Coalition #67, Name withheld #96.

²³ NZ Nurses Organisation #55.

“Right to receive publicly funded services

(1) Every consumer has the right to receive services identified to meet his or her needs that can reasonably be delivered through the publicly funded system. If the services are not locally available the consumer has the right to information about:

- (a) where these services are available*
- (b) the processes and costs involved in accessing these services from outside the local area*
- (c) private local options.”²⁴*

Another suggestion was to include a limited right to access, as there is a need to assess patients fairly and assign appropriate priority when resources are limited.²⁵ An interesting amendment was suggested based on Scottish health reforms, “the right to access convenient and appropriate public services”.²⁶ Clause 3 would provide a workable and effective safeguard in the application of a right to access services.²⁷

The major argument against providing a right to access in the Act and Code is that this is a function of government and HDC should not be involved in resource allocation issues.²⁸ Concern was also expressed that consumers would be likely to have unrealistic expectations as to services being provided, and that the focus would shift from the quality of care. An alternative amendment was suggested to expand the Commissioner’s functions to give the Commissioner the ability to comment on and make recommendations about access.²⁹

Health information privacy: question 4

Many submitters agreed that the Act and Code should be amended to include health information privacy (33:14). Four submitters requested a limited concurrent jurisdiction with the Privacy Commissioner³⁰ and three submitted that the Commissioner should only consider this information when it is connected to other aspects of a complaint.³¹ Amendments suggested were in agreement with the Commissioner’s proposal to amend section 20(1)(c)(i), deleting the exclusion of information privacy so that the right to privacy in Right 1(2) extends to privacy of information.

The main concerns about including health information privacy surrounded the issue of double jeopardy: submitters were concerned that a privacy issue could be dealt with more than once. The Privacy Commissioner³² was strongly opposed to the amendment suggested by the Commissioner. The Privacy Commissioner argued that compressing the Health Information Privacy Code (“HIPC”) into one right in the Code would add confusion rather than clarity. She was also concerned about two jurisdictions developing concerning health information privacy. The Privacy Commissioner suggested several areas where there is potential to amend the Act and Code to specify more closely what aspects of privacy are covered and to address issues of unethical disclosures that do not fall under the HIPC. In particular, she suggested amending the Act and Code to:

²⁴ Age Concern NZ, #41.

²⁵ Dr Colin McArthur, Dept Critical Care Medicine, Auckland City Hospital #97.

²⁶ Public Health South #115.

²⁷ Judi Strid, Director of Advocacy, HDC #116.

²⁸ Eg, NZ Private Surgical Hospitals Assoc Inc #43, Ministry of Health #119.

²⁹ Medical Council of NZ, #58, Nursing Council of NZ #122.

³⁰ NZ Sterile Services Assoc #35, Age Concern NZ #41, Royal NZ Plunket Society #65, Man wanui Ariki Charitable Trust, Generation 9 #95.

³¹ The National Advocacy Trust #60, The Royal Australasian College of Physicians #109, Nationwide Advocacy Service Managers Group #104.

³² #42.

- allow HDC to consider breaches of confidentiality even where that breach may not raise an issue under the HIPC. For example, the balance between a practitioner’s discretion to disclose information under the HIPC and the ethical obligation to a patient;
- clarify controls on the handling of bodily parts and substances regardless of associated personal information;
- clarify standards to be imposed on providers that would not be imposed under the Privacy Act, for example, the obligation for soundproof consulting environments;
- clarify standards or rights focused upon intrusion into solitude; and
- clarify dignity, ethical and disclosure issues where there is no identifiable patient information, for example, the recent case of a nurse filming brain surgery operations and putting them on her Facebook page.

The appropriateness of the current contracting model for advocacy services: question 5

Most submissions on the question whether the current contracting model for advocacy services is appropriate were in favour of a change from the status quo (32:14) but evenly split between the two alternative options proposed: both Option 2 and 3 had 16 submitters in favour.

The National Advocacy Trust³³ was very much in favour of retaining the current contracting model. The Trust submitted that a new structure could compromise the Commissioner’s present impartiality. The current model enables advocates to be partial in their support of consumers and to protect HDC’s impartiality. Any issues of consistency can be addressed through a single contract management arrangement with the Director of Advocacy. The current model also protects the sustainability of the service to consumers in the medium term without the risk of reduction in funding through competing priorities in HDC’s budget process. Other submitters made suggestions about improving the current model with independent audits, standardised training and changes to its operation and Code of Practice. The Ministry of Health submitted that there was no compelling evidence that the current contracting model cannot address problems related to the suitability or performance of advocates.³⁴

Submitters in favour of Option 2 (advocates to be employees of HDC) argued that this option would be a better use of resources and could be based on the existing model (Proceedings) with direct involvement by the Director of Advocacy. One submitter gave the example of the Office of Clients’ Rights Advocacy in California.³⁵

Option 3 supporters argued that this option (independent Office of Advocacy with advocates as employees) would provide an independent office with distance from the Commissioner. Judi Strid, Director of Advocacy,³⁶ argued that the current contracting model achieves independence but it is not providing a quality consumer-centred service. The Director has no role in the recruitment or assessment of advocates. There is also confusion about whether advocates are providing a service for the National Advocacy Trust or the Director of Advocacy. Option 3 is the best option to establish a separate office for the Director who can directly employ the advocates and have separate arrangements regarding salaries and travel. She pointed out that the shift from private to public “ownership” will rely on the goodwill of the Trust to allow its property to go with the advocates or a significant amount of funding will

³³ #60.

³⁴ #119.

³⁵ National Centre for Health Law and Ethics, AUT University #74. Legal advocacy is delivered by Disability Rights California (“DRA”) through the state-wide Office of Clients’ Rights Advocacy. DRA employs legally trained Clients’ Rights Advocates to deliver independent legal advice, advocacy and representation. These advocates are trained and supervised by DRA but located within the 24 community-based regional centres. Each regional centre offers assessment and coordination of health, disability, respite and education services for people with disabilities.

³⁶ #116.

be required to purchase these resources. Submitters also highlighted that this option would require funding independent of HDC.

In addition, several submitters suggested that advocates should be skilled in dealing with disability issues or that a specific section of advocacy services should be dedicated to disability.³⁷

Amendments to the Code: question 20

General

A few submitters requested that all of the Code rights referred to in the consultation document be amended.³⁸ Some also submitted that there should be no amendments to any of the rights in the Code.³⁹ In addition, some general comments were made by submitters on the Code, and suggested amendments included:

- examine the Code to remove inconsistencies, for example, Right 4 and 7 are capable of being in conflict as the treatment a consumer desires (Right 7) may not be good treatment (Right 4);⁴⁰
- publish the Code with a commentary to help clarify and explain its application. In particular, a commentary which explains Right 7(7) in relation to patients under a compulsory treatment order would be very useful;⁴¹
- all the rights in the Code need to reflect the principles of the New Zealand Sign Language Act 2006;⁴²
- references to a consumer's cultural rights need to consider this in terms of not just ethnicity but deaf culture;⁴³
- add a new provision that prevents the Commissioner from suggesting, supporting or introducing changes to the Code without widespread consultation;⁴⁴
- remove "clause 3" elements found in various rights and place all those provisions in clause 3. Clause 3 should be the only place that describes where providers are unable to meet their duties. Add a sentence to clause 3: "If a provider cannot meet one of these rights they will explain why."⁴⁵

Should the Code include the right to compassion?

The majority of submitters who commented on the proposal that a right to compassion be added to the Code were in favour of this amendment (44:19). In addition, Dr Robin Youngson on behalf of the Centre for Compassion in Healthcare ("the Centre")⁴⁶ attached a petition with 529 electronic signatories in support of adding compassion to the Code. The Centre's argument for adding the right to compassion is based on the belief that the current Code does not encompass such a right. In the Centre's view, the words "respect" and "dignity and independence" do not adequately express the meaning and purpose of compassion, which needs to be explicitly stated as a right. Compassion is defined as "humane quality of understanding suffering in others and wanting to do something about it". Compassion and caring are core values that motivate health professionals; however, institutions and professions

³⁷ NZ Nurses Organisation #55, Mental Health Commission #57, CCS Disability Action #59, Name withheld #71, IHC #84, Rescare NZ Inc #94, Nationwide Advocacy Service Managers Group #104.

³⁸ Jacqui Kerslake #31, NZ Sterile Services Assoc #35, Helen Capel, Suzanne Paul & Graham Foster #92.

³⁹ Bay of Plenty DHB #36, Ann Bain #47, Royal Australasian College of Physicians #109, Ministry of Health #119.

⁴⁰ A W Beasley #49.

⁴¹ Medical Council of NZ #58.

⁴² Deaf Aotearoa NZ #75.

⁴³ Deaf Aotearoa NZ #75.

⁴⁴ Auckland Women's Health Council #64.

⁴⁵ The National Advocacy Trust #60, Judi Strid, HDC #116, Nationwide Advocacy Service Managers Group #104.

⁴⁶ #68.

are evolving in ways that limit the expression of compassion. The balance needs to be restored between clinical treatment and compassionate care. International support for compassionate health care is growing with the UK announcing plans to measure the quality of compassionate caring of all nurses based on patient feedback.

Most submitters in favour of this amendment suggested that Right 1(1) state: “Right 1(1) Every consumer has the right to be treated with compassion and respect.” Some suggested adding a clause to Right 1: “Every consumer has the right to have services provided with compassion, including a prompt and humane response to distress, pain and suffering.”

The Quality Improvement Committee argued that adding a right to be treated with compassion will strengthen the Commissioner’s ability to address institutional neglect of a consumer’s basic needs.⁴⁷ When a consumer has been injured it is not enough simply to demonstrate respect and follow due process. A deeper level of caring is required to recognise the suffering caused and to allow healing to occur. Compassion has a meaning distinct from dignity and respect as it relates particularly to the humane understanding and relief of suffering in people who are very vulnerable.

The main arguments put forward for not adding a right to compassion to the Code were that the current wording in Right 1 covers “compassion” and any right that requires a certain “emotion” will be unenforceable. It would be very difficult for the Commissioner to measure an emotion or feeling of “compassion” and to assess whether a provider is actually feeling “compassion”. In addition, in relation to some health providers, showing compassion may not actually be in the best interests of the consumer.⁴⁸

In response, the Centre argued that the test of the Code is in the “breach” and lack of compassion is usually obvious because an ordinary person would judge that the consumer has suffered unnecessarily. Compassionate care can also be judged by the experience of the consumer and his or her family, in their experience of loving, kindness, and the relief of pain, suffering and fear.

Stuart McLennan⁴⁹ made an interesting argument against including the right to compassion. He states that Dr Youngson and the Centre are seeking an emotional response, which will hopefully lead to positive actions such as kindness and relief of pain. He believes the Centre is actually concerned with the characteristics and virtues of health professionals, which will not be altered by adding a right into the Code. An emotional response cannot be legally required. Training and the working conditions of health professionals need to be improved to restore compassion as a virtue of health professionals. This cannot be achieved through the Code.

In a late submission, DPA New Zealand argued that the use of the word “compassion” in relation to disability services would be inappropriate. While supportive of the practice of compassion by healthcare professionals, DPA opposed the addition of compassion to the Code because of the risk that a right to be treated with compassion would reframe disability support into a medical model, by suggesting that disability services consumers are suffering. It would be inappropriate for disability service providers to reframe their thinking about disabled people as suffering, as New Zealand has moved away from this old-fashioned view. The concept of compassion would not add any value to disability services that are just enabling people to get on with their life. DPA suggested that a right to be treated with compassion has the potential to further distance disability services consumers from having their rights met.

⁴⁷ #48.

⁴⁸ For example, midwives; see NZ College of Midwives #81.

⁴⁹ #56.

Right to effective communication — Right 5

The majority of submitters commenting on Right 5 supported a national interpreting and translation service being made available through HDC to ensure no barriers exist for a consumer to exercise rights under the Code.⁵⁰ Many also requested an amendment to Right 5 to expressly provide the right to a qualified interpreter, rather than a competent interpreter.⁵¹ Some concern was expressed about funding for any interpreting and translation service: a few submitters stated that the service should not be at the provider's cost and questioned the feasibility of funding such a service.⁵² Other submitters requested a publicly funded interpreter service available nationally,⁵³ with one submitter arguing that this service should be established under the direction of HDC as an urgent priority.⁵⁴ More specifically, one submitter argued that the Act and Code should require qualified NZ Sign Language interpreters for all levels of communication, all information about the Act and Code should be translated into NZ Sign Language, and advocates should be fluent in NZ Sign Language.⁵⁵

On the other hand, submissions were made that no national translation service is needed,⁵⁶ and a health service provider should not have to provide an interpreter as there is also a responsibility on the consumer to achieve understanding from a reasonable explanation.⁵⁷

Right to be fully informed — Right 6

Following on from their submission regarding clause 3, the National Advocacy Trust,⁵⁸ Judi Strid,⁵⁹ and the Nationwide Advocacy Service Managers Group⁶⁰ suggested the amendment of Rights 6(1) and (2) by removing the word “reasonable”, which qualifies “consumer”.

Right to make an informed choice and give informed consent — Right 7

One submitter suggested that the term “informed consent” should be used only where entry to a research project is involved. Otherwise, where treatment is based on the consumer seeking treatment, the term should be amended to read “informed request”.⁶¹

Providing services where consumer not competent to give informed consent — Right 7(4)

Submitters were evenly split on whether this right should be amended to allow research on unconscious or incompetent patients in limited circumstances. Submitters who agreed supported the proposed amendment to Right 7(4)(a) to allow research where it “is not known to be contrary to the best interests of the consumer”.⁶² One submitter went so far as to argue that providers should be required to give treatment if in the best interests of the patient, but if there is any doubt as to the best interests, then treatment may be provided if “not contrary to the best interests of the patient”.⁶³

⁵⁰ Auckland Women's Health Council #64, Rural Women NZ #66, Deaf Aotearoa #75, NZ College of Midwives #81, Women's Health Action Trust #83, Maternity Services Council #87, Pharmacy Council of NZ #90, Judi Strid, HDC #116.

⁵¹ Rachel Coppage #30, The National Advocacy Trust #60, Deaf Aotearoa #75, Maternity Services Consumer Council #87, Judi Strid, HDC #116, Nationwide Advocacy Service Managers Group #104.

⁵² Federation of Women's Health Councils Aotearoa #91, Pharmaceutical Society of NZ Inc #93.

⁵³ NZ College of Midwives #81, Maternity Services Consumer Council #87.

⁵⁴ Women's Health Action Trust #83.

⁵⁵ Rachel Coppage #30.

⁵⁶ Dr Evan Mason #13.

⁵⁷ NZ Association of Optometrists #105.

⁵⁸ #60.

⁵⁹ #116.

⁶⁰ #104.

⁶¹ AW Beasley #49.

⁶² NZ Nurses Organisation #55, Medical Council of NZ #58, Canterbury DHB Consumer Advisors #62, Manwanui Ariki Charitable Trust, Generation 9 #95, Dr Colin McArthur, Dept of Critical Care Medicine, Auckland City Hospital #97, NZ Association of Optometrists #105.

⁶³ Dr Evan Mason #13.

Several submitters strongly disagreed with any amendment to Right 7(4).⁶⁴ A few considered more debate is needed.⁶⁵ One submitter asked that any amendment be closely linked to provisions 11, 12 and 13 of the Declaration of Helsinki.⁶⁶

The Medical Council commented that it occasionally receives complaints from the public that they have not been consulted about the treatment of incompetent family members, or that their wishes have been inappropriately ignored.⁶⁷ Right 7(4)(c)(ii) does not actually require providers to seek out the views of family members or to do so with respect. Despite these concerns, the Council urged caution in further amending this right to include a requirement of respect or compassion when seeking the views of “suitable persons”.

Written consent — Right 7(6)

Only a few submitters commented on this right, and most supported a review of the requirements for written consent under the Code (8:3).⁶⁸ Three submitters agreed a review is needed because the Code seems to require written consent for the prescription of medicine.⁶⁹ Complying with this requirement will be complicated and costly, particularly for consumers on long-term medication.⁷⁰ Another submitter stated that a commonsense approach must be taken to interpreting the Code, and the issue relating to prescribing medicine ignores the fact that the provision of medical care is a series of events and consent to one aspect of care naturally flows on to other interventions.⁷¹

One submitter disagreed stating that it is very reasonable to require written consent for a prescription if it will expose the patient to significant risk of adverse effects.⁷² One submitter commented that “any research” in Right 7(6)(a) should be amended as a lot of observational research is undertaken using existing information in an aggregated and non-identifiable manner.⁷³ Ethics committees approve such research without requiring individual written consent. In addition, the term “general anaesthetic” should also be reviewed as in many situations the use of sedation creates the same effect. Another submitter was concerned about the prescription and administration of medicines which are used for purposes other than those for which they are licensed, and supported written consent being required in those circumstances as this poses a risk to consumers of which they may not be fully informed.⁷⁴ One submitter suggested upgrading the form that gives the consumer’s authorisation for a procedure (written informed consent) so that it more clearly sets out the realities of the provision of treatment.⁷⁵

⁶⁴ Auckland Women’s Health Council #64, Women’s Health Action Trust #83, Royal Australian and NZ College of Psychiatrists #86, Maternity Services Consumer Council #87, Federation of Women’s Health Councils Aotearoa #91, Capital & Coast DHB #112, Human Rights Commission #113.

⁶⁵ Dr Elizabeth Harding, GP #61, Royal Australian and NZ College of Psychiatrists #86, The Royal NZ College of General Practitioners #111.

⁶⁶ The Royal NZ College of General Practitioners #111.

⁶⁷ Medical Council of NZ #58.

⁶⁸ For a review NZ Private Surgical Hospitals Assoc Inc #43, NZ Nurses Organisation #55, Medical Council of NZ #58, NZ College of Midwives #81, Royal Australian and NZ College of Psychiatrists #86, Auckland City Hospital #97, NZ Assoc of Optometrists #105, The Royal NZ College of General Practitioners #111; against a review Women’s Health Action Trust #83, Maternity Services Consumer Council #87, Federation of Women’s Health Councils Aotearoa #91.

⁶⁹ Medical Council of NZ #58, NZ Assoc of Optometrists #105, The Royal Australasian College of Surgeons #110.

⁷⁰ The Royal Australasian College of Surgeons #110.

⁷¹ The Royal NZ College of General Practitioners #111.

⁷² Women’s Health Action Trust #83.

⁷³ Dr Colin McArthur, Dept of Critical Care Medicine, Auckland City Hospital #97.

⁷⁴ NZ College of Midwives #81.

⁷⁵ AW Beasley #49.

Right to refuse services and withdraw consent to services — Right 7(7)

Two submitters argued that this right should be amended to clarify that the right to refuse medical treatment does not apply to people under a compulsory treatment order.⁷⁶ One submitter suggested that no amendment was necessary as clause 5 covered the issue.⁷⁷ Another suggested that any amendment be deferred until a review of the Mental Health (Compulsory Assessment and Treatment) Act has been carried out (currently being planned).⁷⁸

Right to express a preference as to who will provide services — Right 7(8)

The National Advocacy Trust,⁷⁹ Judi Strid,⁸⁰ and the Nationwide Advocacy Service Managers Group⁸¹ suggested the amendment of Right 7(8) deleting the words “where practicable” in accordance with their position on clause 3 above.

Right to make a decision about the return or disposal of body parts or substances — Right 7(9)

One submitter suggested that the right to the return of body tissues should be limited to “significant” amounts of tissue.⁸²

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

Several submitters argued strongly for the 2003 amendment to be reversed because consent should always be obtained for any storage of body parts or substances.⁸³ Te Puni Kōkiri⁸⁴ agreed and also argued for the amendment to be reversed because:

- research should only be approved for the purpose for which the body part or substance was initially obtained, and must not be used for another purpose;
- the removal of any body parts or substances with informed consent needs to remain explicitly within Right 7(10) and should only be used for the purpose for which the body storage and preservation of body parts or substances should comply with Māori cultural practices;
- an exemption for audit should be constrained to audit activities that relate to the purpose for which the body part or substance was obtained.

However, the same number of submitters supported the right as it is currently worded,⁸⁵ as it has allowed valuable research such as monitoring HIV infections among populations at potential risk,⁸⁶ and research on extremely rare disease and chronological comparisons of disease pathology.⁸⁷

In addition, the Privacy Commissioner submitted that this right be amended to be more closely aligned to Rule 11(2) of the Health Information Privacy Code.⁸⁸ Rule 11(2) requires agencies

⁷⁶ Mental Health Foundation of NZ & the Mental Health Advocacy Coalition #67, Kites Trust #85.

⁷⁷ Federation of Women’s Health Councils Aotearoa #91.

⁷⁸ Otago and Southland DHB #113.

⁷⁹ #60.

⁸⁰ #116.

⁸¹ #104.

⁸² Dr Evan Mason, #13.

⁸³ Palmerston North Women’s Health Collective #52, Auckland Women’s Health Council #64, Te Puni Kōkiri #73, NZ College of Midwives #81, Women’s Health Action Trust #83, Maternity Services Consumer Council #87, Federation of Women’s Health Councils Aotearoa #91.

⁸⁴ #73.

⁸⁵ Bridget Robinson, Cancer Society Tissue Bank #1, AIDS Epidemiology Group, University of Otago #22, NZ Organisation for Rare Disorders #32, NZ Nurses Organisation #55, Royal College of Pathologists of Australasia #72, Dr Colin McArthur, Dept of Critical Care Medicine, Auckland City Hospital #97, Helen Morrin, Cancer Society Tissue Bank #99.

⁸⁶ AIDS Epidemiology Group, University of Otago #22.

⁸⁷ Helen Morrin, Cancer Society Tissue Bank #99.

⁸⁸ #42.

seeking to disclose health information to first believe on reasonable grounds that obtaining authorisation for the disclosure from the individual concerned is either not desirable or not practicable. The Privacy Commissioner submits that Right 7(10) be amended by adding the phrase “where it is not desirable or practicable to obtain the informed consent of the consumer” at the beginning of Rights 7(10)(b) and (c).

Another amendment was suggested to clarify that storage of body parts or substances is permitted under the Code even if informed consent has not been obtained for that storage.⁸⁹ Currently, Right 7(10) prevents the storage of medical and genetic information relevant to patient care and investigation of inherited disease, unless informed consent is first obtained. Right 7(10), it was suggested, should be amended to state that in the absence of instructions from the consumer there should be no compulsion on the provider to discard the body part or substance.

Right to support — Right 8

The National Advocacy Trust,⁹⁰ Judi Strid,⁹¹ and the Nationwide Advocacy Service Managers Group⁹² suggested the amendment of Right 8 deleting “except where safety may be compromised or another consumer’s rights may be unreasonably infringed” in accordance with their position on clause 3 above.

Right to complain — Right 10

The National Advocacy Trust,⁹³ Judi Strid,⁹⁴ and the Nationwide Advocacy Service Managers Group⁹⁵ suggested the amendment of Right 10(8) by deleting “As soon as practicable after a provider decides whether or not it accepts that a complaint is justified”, so the provision begins “The provider must inform the consumer of...”, in accordance with their position on clause 3 above.

Commissioner’s jurisdiction: questions 7, 11, 12 and 14

Suggested changes to definitions of health services: question 7

There were many diverse submissions on changes to the definitions in the Act relating to health services. However, a few trends emerged. Several submitters asked for the definitions to be simplified and clarified. A group of submitters asked that the definitions and the Code be amended to apply to “population health initiatives”⁹⁶ and the Ministry of Health⁹⁷ to encompass vaccination programmes, for example. Several suggested a broader definition of “health consumer” not limited to when a “health care procedure” is carried out.⁹⁸ Some submitters requested no changes to the definitions be made.⁹⁹ Other changes were suggested such as: “health services” should extend to after death services;¹⁰⁰ the definition of “health

⁸⁹ NZ Medical Association, #40, Dr A BM Tie, Board of Censors Representative for NZ, The Royal College of Pathologists of Australasia #72.

⁹⁰ #60.

⁹¹ #116.

⁹² #104.

⁹³ #60.

⁹⁴ #116.

⁹⁵ #104.

⁹⁶ Judi Strid, HDC #116, Nationwide Advocacy Service Managers Group #104.

⁹⁷ Auckland Women’s Health Council #64, Auckland Women’s Health Council #66, Women’s Health Action Trust #83, #87.

⁹⁸ Dr Evan Mason #13, Palmerston North Women’s Health Collective #52, Women’s Health Action Trust #83, Federation of Women’s Health Councils Aotearoa #91, Nationwide Advocacy Service Managers Group #104.

⁹⁹ Bay of Plenty DHB #36, Age Concern #41, Wairarapa DHB #77, Muscular Dystrophy Association of NZ #78, NZ College of Midwives #81, Royal Australian and NZ College of Psychiatrists #86, Pharmacy Council of NZ #90, Pharmaceutical Society of NZ Inc #93, Rescare NZ Inc #94, Otago and Southland DHB #114.

¹⁰⁰ Palmerston North Women’s Health Collective #52.

services” should be clarified;¹⁰¹ and the definition of “health consumer” should be amended to refer to health care “service” rather than “procedure” as the use of “procedure” is confusing given its different clinical and legal meaning.¹⁰²

Are the Commissioner’s functions appropriate: question 11

A number of submitters believe that the Commissioner’s functions are appropriate.¹⁰³ Some submitters commented that the accessibility and responsiveness of HDC’s services could be improved for those in secure facilities or with mental health issues,¹⁰⁴ and consumers with disabilities.¹⁰⁵ Several other submitters supported broadening the Commissioner’s functions in specific areas:

- Independent monitoring of the implementation of recommendations arising out of Commissions of Inquiry¹⁰⁶ and recommendations in general.¹⁰⁷ This may require some specialist expertise to assess implementation, and specific funding;¹⁰⁸
- Initiating a specific consultation process with Māori as to how HDC and legislation could be improved. All functions need to be reviewed from a Treaty of Waitangi and Māori perspective to include:
 - (a) recognition of the Treaty of Waitangi in all roles, functions and activities of HDC;
 - (b) creation of a Māori Health and Disability Commissioner;
 - (c) recognition of the Treaty of Waitangi in the Code, with the Code widened to focus on the concept of whānau consistent with He Korowai Oranga, and government strategy to advance and lead improvements in Māori health and well-being;
 - (d) establishment of a national independent Māori advocacy and human rights service to inform Māori individually and collectively of their rights;
 - (e) provision or reallocation of funding to create clearly visible full Māori engagement and participation in all HDC’s activities;
 - (f) definition of clear goals, objectives and outcomes to be achieved and reported on annually, to improve Māori access to quality, delivery and effective services which achieve and visibly contribute positive outcomes to Māori;
 - (g) consideration of Māori views on privacy before any changes are made to access or exchange of information;
 - (h) development of a framework to address and remove inequalities in health for Māori;
 - (i) establishment of links with other health organisations globally;
 - (j) ensuring that all publications are bi-cultural.¹⁰⁹
- Highlighting more strongly in the Act the independent nature of the Commissioner’s role under section 14(2)(a).¹¹⁰

¹⁰¹ For example, is Pharmac covered? Pharmac #102.

¹⁰² Dr Evan Mason #13.

¹⁰³ NZ Sterile Services Assoc #35, Age Concern NZ #41, NZ Private Surgical Hospitals Association Inc #43, Taranaki DHB #54, Clinical Board, Wairarapa DHB #77, NZ College of Midwives #81, Royal Australian and NZ College of Psychiatrists #86, Pharmacy Council of NZ #90, Family Planning #101, Disabilities Resource Centre Trust #103, NZ Association of Optometrists #105, The Royal NZ College of General Practitioners #111, Otago and Southland DHB #114, Ministry of Health #119.

¹⁰⁴ Mental Health Commission #57, Kites Trust #85.

¹⁰⁵ NZ Federation of Business and Professional Women Inc #33, Mental Health Commission #57, Canterbury DHB Consumer Advisors #62, Family Planning #101, Public Health South #115, Sacha Dylan, Disability Strategist #118.

¹⁰⁶ Te Roopu Taurima O Manukau Trust #39, Palmerston North Women’s Health Collective #52, Canterbury DHB Consumer Advisors #62, Federation of Women’s Health Councils Aotearoa #91, Manawanui Ariki Charitable Trust, Generation 9 #95.

¹⁰⁷ NZ Nurses Organisation #55.

¹⁰⁸ The Royal NZ College of General Practitioners #111.

¹⁰⁹ Dr Lorna Dyall, Senior Lecturer, Te Kupenga Hauora Māori, University of Auckland #100.

¹¹⁰ The Royal Australasian College of Physicians #109.

- Allowing the Commissioner to carry out general enquiries (similar to that in section 5(2)(h) of the Human Rights Act) and issue more extensive guidelines than those under section 14(1)(h).¹¹¹
- Extending the quality improvement, learning and monitoring role of HDC. HDC is well placed to become the National Reporting and Learning Centre which is needed to complete the implementation of the QIC National Incident Management.¹¹²

Requiring HDC to refer all complaints about registered health practitioners to the relevant registration authority: question 12

Submitters who commented on whether the Commissioner should be required to refer all complaints about a registered practitioner to a registration authority were evenly split: 23 submitted yes,¹¹³ 21 said no.¹¹⁴ One submitter suggested that the Commissioner should have discretion regarding referral.¹¹⁵ Two submitters in favour of referral argued that this would allow the relevant authority to track trends and patterns of complaints.¹¹⁶ Of those who argued for referral, two stated that this should happen only after a complaint is investigated,¹¹⁷ and one stated that referral should occur only if a complaint is upheld.¹¹⁸ Arguments against referral focused on the waste of time and resources if all complaints were referred. Referral should only be made where the competence of the practitioner or the appropriateness of his or her conduct is cause for concern.¹¹⁹ The Medical Council of NZ¹²⁰ argued that the current memorandum of understanding between it and the Commissioner was working well and HDC should consider developing similar memorandums with other regulatory boards.

Provisions governing the Commissioner's investigations — complainants having the opportunity to comment on the Commissioner's provisional opinion: question 14

Submitters were evenly split about giving complainants the opportunity to comment on the Commissioner's provisional opinion (19 against giving this opportunity, 19 in favour). Those who argued against this amendment stated that this would unfairly prejudice the provider, and that reports often change substantially before the final finding.¹²¹ One submitter commented

¹¹¹ Human Rights Commission #113.

¹¹² Judi Strid, Director of Advocacy, HDC #116, Nationwide Advocacy Service Managers Group #104.

¹¹³ Dr Evan Mason #13, Jacquie Kerslake #31, NZ Sterile Service Assoc #35, Age Concern NZ #41, NZ Psychologists Board #46, Complex Carers Group #51, Palmerston North Women's Health Collective #52, Mental Health Commission #57, Auckland Women's Health Council #64, Royal NZ Plunket Society #65, Rural Women NZ #66, Assoc Prof Kate Diesfeld, National Centre for Health Law and Ethics, AUT University #74, Women's Health Action Trust #83, Kites Trust #85, Maternity Services Consumer Council #87, Federation of Women's Health Councils Aotearoa #91, Helen Capel, Suzanne Paul and Graham Foster #92, Rescare NZ Inc #94, Manawanui Ariki Charitable Trust, Generation 9 #95, Auckland Deaf Christian Fellowship #98, Disabilities Resource Centre Trust #103, Name withheld #107, The Royal NZ College of General Practitioners #111, Public Health South #115.

¹¹⁴ Dr Nigel Millar, Chief Medical Officer Canterbury DHB #3, Bay of Plenty DHB #36, Ann Bain #47, Taranaki DHB #54, NZ Nurses Organisation #55, Medical Council of NZ #58, The National Advocacy Trust #60, Dr Elizabeth Harding #61, Mental Health Foundation of NZ and the Mental Health Advocacy Coalition #67, Clinical Board, Wairarapa DHB #77, NZ College of Midwives #81, Royal Australian and NZ College of Psychiatrists #86, Pharmacy Council of NZ #90, Pharmaceutical Society of NZ Inc #93, Dr Colin McArthur, Dept of Critical Care Medicine Auckland City Hospital #97, Family Planning #101, NZ Assoc of Optometrists #105, The Royal Australasian College Of Surgeons #110, Otago & Southland DHB #114, Ministry of Health #119, Nationwide Advocacy Service Managers Group #104.

¹¹⁵ Canterbury DHB Consumer Advisors #62.

¹¹⁶ NZ Psychologists Board #46, The Royal NZ College of General Practitioners #111.

¹¹⁷ Auckland Women's Health Council #64, Maternity Services Consumer Council #87.

¹¹⁸ Mental Health Commission #57.

¹¹⁹ Pharmaceutical Society of NZ Inc #93.

¹²⁰ #58.

¹²¹ Dr Nigel Millar, Chief Medical Officer Canterbury DHB #3, Bay of Plenty DHB #36, NZ Medical Association #40, NZ Private Surgical Hospitals Assoc Inc #43, Taranaki DHB #54, Dr Elizabeth Harding #61, Rural Women NZ #66, Clinical Board, Wairarapa DHB #77, NZ College of Midwives #81, Royal Australian and

that this would cause delays and risk release to the media.¹²² Most submitters in favour of the amendment did not give reasons for this support, although two submitters argued that the complainant should be provided with the same information as the provider.¹²³

Should timeframes for investigations be prescribed?

Submitters were evenly split regarding the setting of prescribed timeframes for the Commissioner's investigations (3 in favour of a timeframe,¹²⁴ 5 against¹²⁵). Three submitters made comments about expert opinions: two suggested that the HDC should require more than one expert opinion except with straightforward issues,¹²⁶ and the other suggested that the Commissioner be able to release his expert opinion to the provider under investigation upon receipt and before the provisional report so the provider can engage its own expert in a timely fashion.¹²⁷

Addition of an appeal right: question 6

Many submitters (26:10) agreed that a formal right of appeal should not be added to the Act, because the current review provisions are adequate.¹²⁸ Of those submitters in favour of an appeal right,¹²⁹ three submitters suggested there should be a right of appeal for naming decisions,¹³⁰ and another suggested an internal review process undertaken by an independent person.¹³¹

Clarification of the Commissioner's ability to name providers found in breach of the Code: questions 6 and 15

More submitters disagreed with an amendment to name all providers in breach of the Code (29:22) than those who wanted the Act amended to allow naming. Some submitters only wanted providers named where there was a serious breach.¹³² One submitter suggested the Act be amended to require HDC to formulate and regularly review a naming policy and to empower HDC to name accordingly.¹³³ A submitter reiterated a concern previously expressed

NZ College of Psychiatrists #86, Pharmacy Council of NZ #90, Pharmaceutical Society of NZ #93, Dr Colin McArthur, Dept of Critical Care Medicine, Auckland City Hospital #97, Disabilities Resource Centre Trust #103, NZ Assoc of Optometrists #105, The Royal Australasian College Of Surgeons #110, The Royal NZ College of General Practitioners #111, Otago & Southland DHB #114, Ministry of Health #119.

¹²² Pharmaceutical Society of NZ #93.

¹²³ Ann Bain #47, NZ Nurses Organisation #55.

¹²⁴ Rescare NZ Inc #94, Manawanui Ariki Charitable Trust, Generation 9 #95, NZ Association of Optometrists #105.

¹²⁵ NZ Nurses Organisation #55, The National Advocacy Trust #60, Women's Health Action Trust #83, Federation of Women's Health Councils Aotearoa #91, Nationwide Advocacy Service Managers Group #104.

¹²⁶ AW Beasley #49, Australian and NZ College of Anaesthetists #88.

¹²⁷ NZ Medical Professionals Ltd & NZ Resident Doctors Assoc #82.

¹²⁸ Jacquie Kerslake #31, Age Concern NZ #41, Complex Carers Group #51, Palmerston North Women's Health Collective #52, NZ Nurses Organisation #55, Mental Health Commission #57, The National Advocacy Trust #60, Auckland Women's Health Council #64, Royal NZ Plunket Society #65, Mental Health Foundation of NZ and the Mental Health Advocacy Coalition #67, Muscular Dystrophy Association of NZ Inc #78, NZ College of Midwives #81, Women's Health Action Trust #83, Royal Australian and NZ College of Psychiatrists #86, Maternity Services Consumer Council #87, Pharmacy Council of NZ #90, Federation of Women's Health Councils Aotearoa #91, Pharmaceutical Society of NZ #93, Manawanui Ariki Charitable Trust, Generation 9 #95, Name withheld #96, Disabilities Resource Centre Trust #103, The Royal Australasian College of Surgeons #110, The Royal NZ College of General Practitioners #111, Human Rights Commission #113, Ministry of Health #119, Nursing Council of NZ #122, Nationwide Advocacy Service Managers Group #104.

¹²⁹ Dr Evan Mason #13, Bay of Plenty DHB #36, NZ Private Surgical Hospitals Assoc Inc #43, Clinical Board, Wairarapa DHB #77, Australian and NZ College of Anaesthetists #88, Canterbury Mental Health Consumers Network #89, Helen Capel, Suzanne Paul, & Graham Foster #92, NZ Association of Optometrists #105, NZ Council of Christian Services #108, Otago & Southland DHB #114.

¹³⁰ Bay of Plenty DHB #36, NZ Council of Christian Services #10, Otago and Southland DHB #114.

¹³¹ Medical Council of NZ #58.

¹³² Assoc Prof Kate Diesfeld, National Centre for Health Law and Ethics, AUT University #74, IHC #84

¹³³ Age Concern Ltd #41.

in a submission regarding the Commissioner's naming policy that the Commissioner will name providers who refuse to comply with recommendations when at times these recommendations are contrary to internationally agreed practice standards.¹³⁴ Another submitter asked that where a District Health Board is named, an individual should also be named to avoid the rest of the department being implied in the particular case.¹³⁵

Only a few submitters commented on whether the Act should be amended to give the Commissioner power to suppress identifying information before all processes have been concluded, and most were in favour of amending the Act to give the Commissioner this power to suppress information (6:1).¹³⁶ Wakefield Health Limited¹³⁷ asked the Commissioner to consider an amendment giving the Commissioner the power to suppress identifying information in appropriate circumstances so that the media cannot name a provider who is not in breach and the Commissioner has not named. The National Advocacy Trust¹³⁸ also asked that the Commissioner be given the ability to suppress identifying information where there is no breach. A similar submission was made in relation to question 11 concerning the Commissioner's jurisdiction: the NZ College of Midwives¹³⁹ raised concerns about the media coverage of issues and suggested that the Commissioner should have the right to veto information published in the media about cases under HDC investigation to support a fair investigation process. One submitter asked that either the Act be amended or HDC policy be altered to allow the name suppression of experts because experts are becoming reluctant to give advice owing to criticism from their peers.¹⁴⁰

Ethics committees under the oversight of HDC: question 17

Many submitters argued that ethics committees should not be under the oversight of the HDC (27:15). Submitters stated that having ethics committees under HDC's oversight would compromise HDC's independence.¹⁴¹ One submitter was concerned about the shift in priorities of ethics committees to facilitate research and the public good ahead of the protection of research participants, and that this could result in conflicts of interest for HDC.¹⁴² The Health Research Council was opposed to ethics committees coming under the oversight of HDC,¹⁴³ and stated that it has a good and effective working relationship with the two types of research committees operating in New Zealand which should be preserved. Both these committees provide annual reports and are accredited by the Health Research Council Ethics Committee. Any concerns about fragmentation and decentralisation are addressed by the current process of accreditation and oversight of these committees. Other ethics committees do exist in New Zealand and there have been suggestions that New Zealand should pursue a single system for research involving human participants. This might address concerns about fragmentation and decentralisation; however, its development would be a very big task and it is not clear that this system would fall within the scope of HDC.

¹³⁴ NZ College of Midwives #81.

¹³⁵ Otago and Southland DHB #114.

¹³⁶ In favour of the amendment: Auckland Women's Health Council #64, Wairapa DHB #77, Women's Health Action Trust #83, Maternity Services Consumer Council #87, Federation of Women's Health Councils Aotearoa #91, NZ Association of Optometrists #105; against: Canterbury DHB Consumer Advisors #62.

¹³⁷ #121.

¹³⁸ #60.

¹³⁹ #81.

¹⁴⁰ Australian and NZ College of Anaesthetists #88.

¹⁴¹ Gary Watts, Sigjaws #12, Federation of Women's Health Councils Aotearoa #91, Dr Colin McArthur, Dept of Critical Care Medicine, Auckland City Hospital #97, The Royal NZ College of General Practitioners #111.

¹⁴² Federation of Women's Health Councils Aotearoa #91.

¹⁴³ #120.

One submitter suggested that HDC should retain the ability to receive complaints from research participants about their participation and to comment on or sanction unethical research that breaches the Code.¹⁴⁴

In support of an amendment to bring ethics committees under the oversight of HDC, Judi Strid argued that these committees are compromised under the authority of the Ministry of Health as the Ministry is also a provider of research.¹⁴⁵ The strong focus on rights of participants has been lost as the focus has shifted more to expediting the approval of research applications. Right 9 provides a clear link to the rights of research participants.¹⁴⁶ A Director of Ethics Committees would ensure an independent separation between the committees and the Commissioner in the event of a complaint about how the committees operate.¹⁴⁷ The Health Research Council currently provides the mechanism for reviewing the decisions of ethics committees only when the researcher requests this. The Council should continue this role with the right to request a second opinion extending to include consumers as well as researchers.¹⁴⁸

Some submitters suggested that this issue requires a review of its own and more debate.¹⁴⁹ The Ministry of Health advised that it is currently reviewing all aspects relating to ethics committees.¹⁵⁰ One submitter suggested that ethics committees should come under HDC's oversight when they concern the activities of unregistered practitioners, but the oversight of HDC seems unnecessary for registered practitioners.¹⁵¹

Withholding information obtained during an investigation: question 19

Many submitters agreed that the Commissioner should have the power to withhold information while an investigation is ongoing (33:8). Most of these submitters did not give reasons for this view. The Privacy Commissioner submitted that HDC should have a similar ability to the Privacy Commission to withhold information obtained during the course of an investigation while the investigation is ongoing as this is an important safeguard for the integrity of a complaint investigation process.¹⁵²

One argument against withholding information during an investigation was that as a starting point, information should be available, with exceptions only to ensure a fair and speedy process.¹⁵³ Another submitter¹⁵⁴ stated that it is not sufficient to argue that producing the information is complex and time-consuming; HDC should not be treated any differently to other organisations subject to the Official Information Act; releasing information at an early stage allows all the parties to have a meaningful opportunity to state their case; deferring the release of information until the delivery of the Commissioner's provisional report would be contrary to fundamental principles of fairness and natural justice and could undermine public confidence in the process; and the special provision that relates to the Privacy Commissioner is quite different — the Privacy Commissioner may receive information that has been withheld from the complainant and to release this prior to a decision would defeat the purpose of the review.

¹⁴⁴ Family Planning #101.

¹⁴⁵ #116.

¹⁴⁶ Judi Strid, HDC #116, Nationwide Advocacy Service Managers Group #104.

¹⁴⁷ Auckland Women's Health Council #64, and Maternity Services Consumer Council #87 agreed that an independent Director of Ethics should be established within HDC.

¹⁴⁸ #116.

¹⁴⁹ NZ College of Midwives #81, Disabilities Resource Centre Trust #103, The Royal Australasian College of Physicians #109, Ministry of Health #119.

¹⁵⁰ #119.

¹⁵¹ Rural Women of NZ #66.

¹⁵² #42.

¹⁵³ Nationwide Advocacy Service Managers Group #104.

¹⁵⁴ NZ Medical Professionals Ltd & NZ Resident Doctors' Association #82.

One submitter stated that the Privacy Act gives sufficient protection,¹⁵⁵ while another argued that the Act provides sufficient remedies to address any deliberate delays.¹⁵⁶

Limitation period from the date the Commissioner finds a breach: question 25

The majority of submitters on this issue agreed with an amendment to state that any limitation period under the Limitation Act should start to run from the date on which the Commissioner finds a breach of the Code (26:3). Various time periods were suggested from 12 weeks to the period under the Limitation Act. A few submitters gave general support to amending the Act to be compatible with other legislation. Submitters did not give reasons for their views.

Administrative questions

QUESTION NUMBER	YES	NO	ALTERNATIVE
Question 9: change the name to the Health and Disability Commission?	44	4	Change to “Health and Disability (Consumers) Commission”
Question 10: clarify the status of Deputy Commissioners pending reappointment?	35		
Question 13: revise s38 to better reflect its purpose?	26 just amend title: 6	8	Specify reasons for deciding on no action: 1 Provide that must use expert opinion in prelim assessment: 1
Question 16: increase the level of fines to \$10,000?	33 excess of \$10,000: 1 review every 3–5 years: 1	7	\$3,000 for individuals, \$10,000 for companies: 1 \$10,000 for individuals, \$30,000 for companies: 1 \$100,000:1 Compatible with similar legislation:1
Question 18: provide independent expert advisors with immunity as under the Crown Entities Act?	31	8	

¹⁵⁵ Dr Evan Mason #13.

¹⁵⁶ National Advocacy Trust #60.

	YES	NO	ALTERNATIVE
Question 21: clarify s47 that Dir of Proceedings may take action only upon referral from the Commissioner?	30	3	Consumer able to make direct approach:1
Question 22: should Dir of Proceedings have the same power as the Commissioner under s62?	26	4	
Question 23: should the Dir of Proceedings have to make a decision to issue Human Rights Tribunal proceedings within a certain timeframe?	27	5	
Question 24: should an aggrieved person be able to bring proceedings when the Dir of Proceedings withdraws a claim/reverses a decision to issue proceedings?	21 Costs should be awarded against the person if unsuccessful: 1	10	Right of appeal of Director of Proceeding's decision: 1
Question 26: Should the term "aggrieved person" be defined?	22 Limit to health & disability consumers: 11 Do not limit to health & disability consumers: 8	9	

APPENDIX D — DRAFTING FOR RECOMMENDED CHANGES TO THE ACT AND CODE

Introduction

For the sake of clarity and to assist understanding of my recommendations, I have set out suggested drafting for the recommended changes in the context of the existing provisions of the Act and Code.

To indicate suggested changes, I have placed deleted text in italics and square brackets. Where I have inserted new text into an existing provision, or drafted a new provision, the new text is underlined.

Health and Disability Commissioner Act 1994

Preliminary provisions

2. **Interpretation** — In this Act, unless the context otherwise requires,—

(1) “Advocacy services” means the services provided by advocates; [*provision of health and disability services consumer advocates*;] and also includes the provision of such administrative services as may be necessary to enable those advocates to exercise and perform their functions and powers:

[“*Advocacy services agreement*” means an agreement under which the Crown agrees to provide money to a person in return for the person providing, or arranging for the provision of, advocacy services:]

“Advocate” means a health and disability services consumer advocate [*provided pursuant to an advocacy services agreement*] designated under section 27 of this Act:

“Aggrieved person” means the complainant (if any) or the aggrieved person (if not the complainant);

“Disability services” includes goods, services, and facilities—

- (a) Provided to people with disabilities for their care or support or to promote their independence; or
- (b) Provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of the independence of such people and includes needs assessment and service coordination services:

“Disability services consumer” includes any person with a long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers hinders their full and effective participation in society on an equal basis with others. [*means any person with a disability that—*

- (a) *Reduces that person’s ability to function independently; and*
- (b) *Means that the person is likely to need support for an indefinite period.*]

Part I — Health and Disability Commissioner

9. Deputy Commissioners—

...

- (4) Part 2 of the Crown Entities Act 2004, except section 46, applies to the appointment and removal of a Deputy Commissioner in the same manner as it applies to the appointment and removal of a Commissioner.

14. Functions of Commissioner—

- (1) The functions of the Commissioner are as follows:

...

- (f) To refer a provider whose action was the subject matter of an investigation [complaints or investigations on the Commissioner's own initiative,] to the Director of Proceedings for the purpose of deciding whether or not any further action should be taken in respect of any such breach, in accordance with section 45(f) of this Act. [or alleged breach]:

...

18. Review of operation of Act—

- (1) As soon as practicable after the expiry of the period of 3 years beginning on the commencement of this Part of this Act, and then at intervals of not more than 10 [5] years, the Commissioner shall—

- (a) Review the operation of this Act since—
- (i) The date of the commencement of this Part of this Act (in the case of the first review carried out under this paragraph); or
 - (ii) The date of the last review carried out under this paragraph (in the case of every subsequent review); and
- (b) Consider whether any amendments to this Act are necessary or desirable; and
- (c) Report the Commissioner's findings to the Minister.

...

Part II — Code of Health and Disability Services Consumers' Rights

20. Content of Code—

- (1) A Code of Health and Disability Services Consumers' Rights prescribed by regulations made under section 74(1) of this Act shall contain provisions relating to the following matters:

...

- (c) The rights of health consumers and disability services consumers, and the duties and obligations of health care providers and disability services providers, as they relate to—
- (i) The duties of health care providers and disability services providers in relation to matters of privacy [(Matters of privacy other than matters that may be the subject of a complaint under Part 7 or Part 8 of the Privacy Act 1993 or matters to which Part 10 of that Act relates)]:
 - (ii) Health teaching and health research:

- (iii) The provision of services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups:

...

21. Review of Code—

- (1) The Commissioner shall from time to time, as often as is necessary to ensure that a complete review of the Code is carried out at intervals of not more than 10 [3] years, review the Code and make recommendations to the Minister on what changes (if any) the Commissioner considers should be made to the Code.

...

Part III — Health and Disability Services Consumer Advocacy Service

25. Functions of Director of Advocacy—

The functions of the Director of Advocacy are as follows:

- (a) *[To administer advocacy services agreements:]*
(b) To promote, by education and publicity, advocacy services:
(c) To oversee the employment, management and training of advocates:
(d) To *[monitor the operation of advocacy services, and to]* report to the Commissioner *[Minister]* from time to time on the performance of the advocacy service. *[results of that monitoring.]*

26. Advocates *[Advocacy services]* to operate independently—

Subject to this Act, advocates *[advocacy services]* shall operate independently of the Commissioner, the Ministry, purchasers, health care providers, and disability services providers.

27. *[Purchase of c]* Consumer advocacy services—

- (1) For the purposes of this Act the Commissioner may from time to time, and on the recommendation of the Director of Advocacy, designate one or more employees as advocates. *[Subject to this Act, the Director of Advocacy shall from time to time, in the name and on behalf of the Crown,—*
(a) *Negotiate and enter into advocacy services agreements containing such terms and conditions as may be agreed; and*
(b) *Monitor the performance of each advocacy services agreement.]*
- (2) Every person designated under subsection (1) shall carry out the functions of advocates under section 30, subject to the direction of the Director of Advocacy. *[Every advocacy services agreement shall impose on the person that agrees to provide, or arrange for the provision of, advocacy services pursuant to the agreement the duty to ensure that any guidelines for the time being in force pursuant to section 28 of this Act are followed in the provision of those services.]*
- (3) Every advocate must follow the guidelines for the time being in force pursuant to section 28. *[Nothing in this section limits—*
(a) *Any other enactment; or*
(b) *Any powers that the Minister or the Crown has under any enactment or rule of law.]*

28. Guidelines for operation of advocacy services—

- (1) The Commissioner may from time to time, and shall if directed to do so by the Minister, issue guidelines relating to [*the operation of*] advocacy services.

...

30. Functions of advocates—

An advocate shall have the following functions:

...

[(j) To report regularly to the Director of Advocacy on the operation of advocacy services in the area served by the advocate:]

...

Part IV — Investigation of complaints

38. Commissioner may decide to take no further action on complaint—

- (1) At any time after completing a preliminary assessment of a complaint (whether or not the Commissioner is investigating, or continuing to investigate, the complaint himself or herself), the Commissioner may, at his or her discretion, decide to take no action or, as the case may require, no further action on the complaint if the Commissioner considers that, having regard to all the circumstances of the case, any action or further action is unnecessary or inappropriate.

...

47. Director of Proceedings' right to participate in disciplinary and other proceedings—

- (1) The Director of Proceedings may, following a referral from the Commissioner pursuant to section 45 (2)(f)—
- (a) Provide assistance (whether financial or otherwise) to any complainant in any proceedings before any authority or tribunal:
 - (b) Provide representation (either in person or by counsel)—
 - (i) For any complainant in any proceedings before an authority or a tribunal, in any case where the complainant, or any person acting on the complainant's behalf, is permitted, by or under the rules of procedure governing those proceedings, to appear and be heard in those proceedings:
 - (ii) For any party in any proceedings in any Court in relation to any proceedings that are or have been before an authority or a tribunal:
 - (iii) For any party in any proceedings before any Court, tribunal, authority, Royal Commission, commission of inquiry, board of inquiry, Court of Inquiry, or committee of inquiry, in any case where those proceedings in any way relate to or arise from any matter that was or is the subject-matter of any investigation by the Commissioner under this Part of this Act:
 - (c) Appear and be heard, either in person or by counsel, in any proceedings of a kind described in subparagraph (ii) or subparagraph (iii) of paragraph (b) of this subsection, whether or not the Director of Proceedings is a party to those proceedings:

- (d) In the Director of Proceedings' own right, take such proceedings as the Director of Proceedings thinks fit before any Court or other tribunal in respect of any matter that in any way relates to or arises from any matter that was or is the subject-matter of any investigation by the Commissioner under this Part of this Act.

...

49. Functions of Director of Proceedings—

- (1) The functions of the Director of Proceedings under this Part of this Act are—
- (a) To decide, on referral from the Commissioner pursuant to section 45(2)(f) of this Act,—
- (i) Whether to institute proceedings under section 50 of this Act, or disciplinary proceedings, or both, against a person against whom a complaint has been made under this Part of this Act or in respect of whom an investigation has been conducted under this Part of this Act; and
- (ii) Whether to take any of the actions contemplated by section 47 of this Act; [*and*]
- (b) If the Director of Proceedings decides that such proceedings should be instituted or, as the case may be, that any such action should be taken, to institute the proceedings or, as the case may be, to take the action.
- (2) The Director may, until a decision is made under subsection (1) of this section, by notice in writing, require any person who in the Director's opinion is able to give information relating to any matter under consideration by the Director to furnish such information, and to produce such documents or things in the possession or under the control of that person, as in the opinion of the Director are relevant to making a decision under subsection (1).

Part V — Miscellaneous provisions

62A. Commissioner may withhold information requested during an investigation—

During an investigation under section 40 of this Act, the Commissioner may withhold any information requested when that information is contained in any correspondence or communication that has taken place between the office of the Commissioner and any agency and that relates to the investigation being undertaken, other than information that came into existence before the commencement of that investigation.

65. Proceedings privileged—

- (1) Sections 120 to 126 and section 135 of the Crown Entities Act 2004 apply to [*an advocate,*] any person engaged in connection with the work of the Commissioner, with any necessary modifications, as if the [*advocate*] person engaged in connection with the work of the Commissioner were an office holder.
- (2) Subject to subsection (3) of this section,—
- (a) [*Repealed*]
- (b) none of the Commissioner, an office holder, [*or*] nor any employee of the Commissioner, [*nor any advocate*] is required to give evidence in any Court, or in

any proceedings of a judicial nature, in respect of anything coming to his or her knowledge in the exercise of his or her functions.

...

73. Offences

Every person commits an offence against this Act and is liable on summary conviction to a fine not exceeding \$10,000 [*\$3,000*] who,—

- (a) Without reasonable excuse, obstructs, hinders, or resists the Commissioner or any other person in the exercise of their powers under this Act:
- (b) Without reasonable excuse, refuses or fails to comply with any lawful requirement of the Commissioner or any other person under this Act:
- (c) Makes any statement or gives any information to the Commissioner or any other person exercising powers under this Act, knowing that the statement or information is false or misleading:
- (d) Represents directly or indirectly that he or she holds any authority under this Act when he or she does not hold that authority.

The Code of Health and Disability Services Consumers' Rights

Any amendment of the Code must be made by way of an amendment pursuant to section 74(1) of the Health and Disability Commissioner Act 1994.

Right 1 — Right to be treated with respect

RIGHT 1 Right to be Treated with Respect

...

- (2) Every consumer has the right to have services provided in a manner that respects the privacy of the individual. [*his or her privacy respected.*]

...

Right 4 — Right to services of an appropriate standard

RIGHT 4 Right to Services of an Appropriate Standard

...

- (3) Every consumer has the right to have services provided in a manner consistent with his or her needs and, in relation to disability services consumers, to have services that the consumer has been assessed as needing provided in a timely manner.

...

Right 7 — Right to make an informed choice and give informed consent

RIGHT 7

Right to Make an Informed Choice and Give Informed Consent

...

- (4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where —
- (a) 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; [It is in the best interests of the consumer;] and
 - (b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - (c) Either, —
 - i. If the consumer’s views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - ii. If the consumer’s views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

...

- (6) Where informed consent to a health care procedure is required, it must be in writing if —
- (a) The consumer is to participate in any research; or
 - (b) The procedure is experimental; or
 - (c) The consumer will be under general anaesthetic or sedation that has a similar effect; or
 - (d) There is a significant risk of adverse effects on the consumer.

...

Clause 4 — Definitions

In this Code,

“Assessed as needing” means a formal needs assessment using a recognised process and criteria:

*[“**Privacy**” means all matters of privacy in respect of the consumer, other than matters of privacy that may be the subject of a complaint under Part VII or Part VIII of the Privacy Act 1993 or matters to which Part X of that Act relates]:*

...

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