HDC CONSULTATION DOCUMENT

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

A resource for public consultation

November 2008

Cover photo – commemorating 20 years since the Cartwright Inquiry

The Spirit of Peace statue, situated in the grounds of the old National Women's Hospital, is the work of American sculptor Pierce Francis Connelly. The statue has become symbolic of the Cartwright Inquiry into the events at National Women's Hospital. HDC and the Code had its genesis in the Report of the Cartwright Inquiry (Cartwright S, *The report of the committee of inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital and into other related matters* Auckland, Government Printing Office, 1988).

(Photo by Rae Lamb)

Statement from the Commissioner

E ngā iwi, e ngā reo, e ngā karangatanga maha o ngā hau e whā, tēnei te mihi atu ki a koutou katoa.

This consultation document is the first phase of a review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights. The Health and Disability Commissioner is required to undertake a review of the legislation every five years. This is the third such review.

The document explains that the Act and Code are generally working well but highlights a few areas for possible change. Key issues for possible change include amendments in relation to disability services consumers' rights; inclusion of a right to access services and/or the right to health information privacy in the Code; changes to the structure of advocacy services; and whether further avenues are needed for reviewing HDC decisions.

I welcome your thoughts and feedback on these issues, and any other comments on how the Act and Code are working, to inform my report to the Minister.

I look forward to hearing your views.

Yours sincerely

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Ron Paterson Health and Disability Commissioner Te Toihau Hauora, Hauātanga

24 November 2008

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A brief introduction to the Act and Code

Health and Disability Commissioner Act

The Health and Disability Commissioner Act (the Act) was enacted on 20 October 1994, to "promote and protect the rights of health and disability services consumers and, to that end, to facilitate the resolution of complaints relating to infringements of those rights".¹

The Act established the office of the Health and Disability Commissioner (HDC) with the role of promoting and protecting the rights of health and disability services consumers, and facilitating the fair, simple, speedy, and efficient resolution of complaints; provided for the drafting of the Code of Health and Disability Services Consumers' Rights;² and set up a process for dealing with complaints about alleged breaches of those rights (including the establishment of a nationwide consumer advocacy service). The Act also provides for the appointment of the Director of Advocacy and the Director of Proceedings, both of whom are independent of the Commissioner.

The Act is broad ranging and covers all providers of health and disability services — public or private, registered or unregistered. Consumers are widely defined to cover all users of health or disability services, not simply patients in traditional hospital and community settings. The Act is deliberately consumer focused, recognising the imbalance of knowledge and power between consumers and providers.

See Appendix 1 for more information about how the Act operates in practice.

Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights (the Code) confers ten legally enforceable rights on all consumers of health and disability services, and places corresponding obligations on providers of those services. The Code became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act. The ten rights set out in the Code are:

- 1. the right to be treated with respect
- 2. the right to freedom from discrimination, coercion, harassment, and exploitation
- 3. the right to dignity and independence
- 4. the right to services of an appropriate standard
- 5. the right to effective communication
- 6. the right to be fully informed
- 7. the right to make an informed choice and give informed consent
- 8. the right to support
- 9. rights in respect of teaching or research
- 10. the right to complain.

¹ Section 6 of the Act.

² The Code is set out in the Schedule to the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

The Code rights are not absolute. It is a defence for providers to prove that they have taken "reasonable actions in the circumstances". Relevant circumstances include "the consumer's clinical circumstances and the provider's resource constraints".³ The Code does not override other legislation, and nothing in the Code requires providers to act in breach of a duty or obligation imposed by any enactment, or prevents a provider doing an act authorised by another enactment.

See Appendix 2 for more information about the Code.

Commissioner's role

The Commissioner's primary role is to promote respect for the rights of health consumers and disability services consumers, through education and publicity, and facilitate the resolution of complaints alleging a breach of those rights.⁴ Since the Health and Disability Commissioner Amendment Act 2003 (the HDC Amendment Act) came into effect in September 2004, HDC has had more options for facilitating the resolution of complaints about the quality of health care and disability services. These options include referring the complaint to an appropriate agency or person, referring the complaint, or taking no action, if action is "unnecessary or inappropriate".

Advocacy service

The Act provides for an independent advocacy for health and disability service consumers who wish to complain about an alleged breach of the Code. Advocates act on behalf of the consumer, and the service operates independently of the Commissioner. Advocates are required, among other things, to promote awareness of consumers' rights when using health and disability services, and to assist consumers who have concerns and want to make a complaint. The advocacy service reports to an independent Director of Advocacy. See Appendix 3 for more information about the advocacy service.

Director of Proceedings

Under the Act, the Director of Proceedings receives referrals from the Commissioner of providers found in breach of the Code, and must decide whether or not to institute proceedings against the provider. Although the Director may provide representation or assistance to complainants in any forum (eg, a court or tribunal), the primary focus is on disciplinary proceedings and proceedings before the Human Rights Review Tribunal. Appendix 4 contains more information about the role of the Director of Proceedings.

This Review in context

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.

³ Clause 3 of the Code.

⁴ See section 14(1) of the Act.

The first review of the Act and Code was undertaken by the inaugural Commissioner, Robyn Stent, in 1999. That review and the 2001 Cull Report on the Review of Processes Concerning Adverse Medical Events resulted in a number of changes to the Act as part of the "Health Practitioners Competence Assurance" legislative reforms. These changes are set out in the HDC Amendment Act, which came into force on 18 September 2004. The key amendments were improvements to the Commissioner's complaints resolution processes to enhance the Commissioner's power to deal with complaints appropriately, help reduce duplication of process, and enable early resolution of complaints. A number of interested groups also made submissions on Right 7(10) of the Code as part of the consultation undertaken during this review, which resulted in an amendment to the Code by Cabinet in 2004.

The second review was undertaken in 2004, before the "Health Practitioners Competence Assurance" legislative reforms had come into force. As the main concerns I had with the operation of the Act and the Code were about to be addressed by these changes, I concluded that further substantial amendment was not necessary or desirable at that stage. However, in my report to the Minister, I recommended that reviews of the Act and Code occur less frequently, that the Act reflect the Office's current practice of honouring Treaty principles, and that the Code be amended in relation to the "best interests" test for research involving consumers who are not competent to consent. These recommendations have not led to any amendment of the Act or Code.

It has now been four years since the "Health Practitioners Competence Assurance" legislative reforms came into force. The Health Practitioners Competence Assurance Act 2003 is currently under review. This review provides an opportunity to reflect on how the amendments have changed the operation of the Commissioner's office, and whether any further amendments are desirable. However, overall, I consider that the Act and Code are working well.

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 and 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. Therefore I consider that the interval between reviews should be extended to at least 10 years. I welcome your feedback and comments on this.

Question 1

Is it necessary to review the Act and Code every 3–5 years? Would 10-yearly reviews suffice?

What is working well?

In my view, and according to feedback from stakeholders, the Act and Code are working well. Particularly since the HDC Amendment Act, the Act and Code have provided a flexible mechanism for consumers to resolve complaints about health or disability service providers. They allow HDC to play a key role in linking dispute resolution with improvements in safety and quality of health care and disability services. Research on

the relationship between complaints and quality of care in New Zealand shows that "complaints offer a valuable portal for observing serious threats to patient safety and may facilitate efforts to improve quality".⁵ HDC's work is widely publicised resulting in a high level of awareness of consumer rights. The Act also allows HDC to act as a "public watchdog", sharing information with other agencies to ensure the safety of the public. Proper accountability of health and disability service providers is ensured through investigation and referral of providers to the Director of Proceedings or appropriate authorities.

The Code has earned widespread support from the public, patients, and providers. A key strength of the Code is that, in contrast to patients' charters elsewhere, the rights are legally enforceable. The Code is simple and easily understood, making it accessible to consumers as a tool for their empowerment.

Accordingly, I do not consider that the Act or Code require any substantial amendment. However, there are some areas that need looking at, where amendment may be beneficial.

What needs looking at?

Four issues merit specific discussion and feedback:

- 1. the desirability of an independent Disability Commissioner and/or changes in relation to disability services consumers' rights;
- 2. the benefits of including a right to access certain services and/or the right to health information privacy in the Code;
- 3. amendments to the structure of advocacy services to ensure effective independent advocacy services for consumers; and
- 4. the possibility of further avenues for reviewing HDC's decisions.

These issues are briefly summarised below, and the appendices contain more detailed discussion.

1. Disability services consumers' rights

The Social Services Committee has recently led an inquiry into the quality of care and service provision for people with disabilities (the Disability Inquiry).⁶ 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

⁵ Dr Marie Bismark, Troy Brennan, David Studdert, Peter Davis and Ron Paterson, "Relationship between complaints and quality of care in New Zealand: a descriptive analysis of complainants and non-complainants following adverse events" (2006) *Qual Saf Health Care* 15, 17–22.

⁶ 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), available at <u>www.parliament.nz/en-NZ/SC/Reports/</u> [Disability Inquiry Report].

independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.⁷

During the Disability Inquiry, we highlighted certain areas of concern about the quality of disability services as highlighted in complaints to the Office, and the fact that HDC is limited in what action can be taken because many complaints received about disability services are outside the Commissioner's jurisdiction.⁸ Furthermore, few complaints received by HDC are specifically about disability service provision. 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 consumers are often reluctant to complain for fear of repercussions and the limited range and number of disability support services.⁹ This may be a crucial reason for HDC receiving few complaints about disability service provision.

The advocacy service, however, receives a large number of complaints about disability services and has a significant focus on working in the disability sector. As the service has been expanded, the focus on disability has increased significantly. Currently all rest homes and disability homes have at least one contact a year with a local health and disability advocate. Advocates are required to assist consumers to make a complaint and often the advocacy "face-to-face" process is better suited to the resolution of complaints where relationships may need to be rebuilt.

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 in which a disability service is funded results in the poor quality service. Complaints that technically relate to access to disability services or goods, 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. Possible options for extending HDC's jurisdiction in relation to disability services consumers to receive the services the consumer has been assessed as needing, or enabling the Commissioner to review decisions about funding for, or access to, disability support services. I would welcome further discussion and feedback on whether the Act should be amended to extend the Commissioner's jurisdiction in relation to disability services.

The appointment of an independent Disability Commissioner, possibly within the office of the Health and Disability Commissioner, was suggested by the Social Services Committee. HDC already operates a successful model with four statutory appointees in addition to the Commissioner: two deputy Commissioners and the Director of Advocacy and the Director of Proceedings. Using a similar model, it would be possible to amend the Act to allow for a statutorily designated Disability Commissioner. Accountability and reporting lines within HDC would need to be considered (eg, would the Disability

⁷ Disability Inquiry Report, pages 36–37.

⁸ HDC's submission to the Disability Inquiry is available at <u>www.hdc.org.nz/publications/submissions</u>.

⁹ Examples of disability consumers' concerns about complaining can be found in HDC's submission, paras 91–96, available at <u>www.hdc.org.nz/publications/submissions</u>.

Commissioner be designated "Chief Commissioner"?; would the Disability Commissioner report to the Minister for Disability Issues?).

The benefits of establishing a 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 is already responsible for investigations into disability services; and HDC has expertise in advocacy and complaints resolution.

It is not clear that the issues identified above with the current system (eg, consumers being reluctant to complain) will necessarily be solved by a separate Disability Commission, particularly if there is still the same limited choice of services. There may be greater benefit in establishing a designated Disability Commissioner within HDC.

In light of these issues, HDC is canvassing the level of support for a change in legislation that will enable HDC to better serve consumers using disability services. Further exploration of these issues is contained in Appendix 5.

Question 2

What amendments to the Act or Code in relation to disability do you suggest and why?

2. Gaps in the Code

Right to access to services

While the exclusion from the Code of a right to access services is particularly detrimental for disability consumers, it also results in broader issues for all consumers of health and disability services. Section 20 addresses only the quality of service delivered and does not authorise the Code to cover issues of access to services. The Act is not concerned with which services are to be publicly funded, but only with the quality of services delivered.

As a preliminary comment to this review, the Human Rights Commission highlighted that access to publicly funded health services continues to be an issue for many New Zealanders and suggested that the Code should include a right to access health services (New Zealand Action Plan for Human Rights: Mana ki te Tangata, HRC, Wellington, 2005). In surveys, health emerges as a leading concern for New Zealanders, particularly the ability to access treatment, or timely treatment, when they or their family members need it.

To date, Parliament has taken the view that issues of access and funding should be addressed through political accountability. Courts have also expressed concerns about ruling on access entitlements and resource allocation decisions, as they lack knowledge of the competing claims to those resources. Some overseas codes or charters do include an access entitlement, but the right is not legally enforceable. The Code already supports a transparent and accountable process for decision-making regarding access to care (such as through centralised supervision of waiting times). However, in a rights framework like the Code which focuses on individual rights, it may be difficult to include matters of access (in the context of finite resources and the competing rights of others to the same resources). I welcome your comments on whether a right of access should be included in the Code. Appendix 2 explores this issue further.

Question 3

Should the Act and the Code be amended to include a right to access publicly funded services? If so, how would such a right be framed?

Health information privacy

Currently, the Code does not cover the right to the confidentiality of, and access to, 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 health information privacy. Although Right 1(2) of the Code states that every consumer has "the right to have his or her privacy respected", this right only covers privacy matters that do not give rise to a complaint under the Privacy Act 1993 or the Health Information Privacy Code (HIPC).

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 does not apply to privacy or confidentiality of health information. The Commissioner has no jurisdiction over, and must refer to the Privacy Commissioner, any complaint alleging breach of confidentiality.

Very occasionally, the Commissioner has taken action on complaints that are about a breach of information privacy, where the information privacy issue is only a minor aspect of the complaint and the other issues are covered by the Code. Although this a sensible approach (as it is in the parties' interests not to have the complaint split between agencies), it is not straightforward. It requires the breach to be framed as a breach of Right 4(2), "the right to have services provided that comply with legal, professional, ethical, and other relevant standards" (as the duty of confidentiality is both a legal duty under the Health Information Privacy Code and an ethical duty imposed on most health practitioners by professional codes of ethics). The current system also means that a health practitioner who breaches the core ethical duty of confidentiality may not be held accountable under the Code and, more importantly, by the Director of Proceedings' process before the Health Practitioners Disciplinary Tribunal.

A simple solution would be to amend the Act and Code to delete the exclusion of information privacy, so that the right to have privacy in Right 1(2) extends to privacy of information. This would allow for HDC and the Privacy Commissioner to have concurrent jurisdiction over complaints relating to health information privacy. The "concurrent jurisdiction" approach has been adopted for complaints alleging breach of "the right to be free from discrimination" (Right 2), where there is a concurrent jurisdiction with the Chief Human Rights Commissioner. In alleged discrimination cases, the two Commissioners are able to consult and decide on who most sensibly should decide the complaint. As a preliminary response to this review, the Privacy Commissioner queried the desirability of shared jurisdiction, but suggested that the HDC Code may benefit from amendment so that it "appropriately supplements privacy rights in the sector and fills gaps not well covered by the Privacy Act".

In my view, issues of the confidentiality of, and access to, health information are so integral to the rights of health and disability services consumers that they should be protected in the HDC Code. Complaints about breaches of health information privacy during the provision of a health or disability service fall naturally within HDC's role. I support an amendment to allow for limited concurrent jurisdiction between HDC and the Privacy Commissioner. This issue is explored further in Appendix 2.

Question 4

Should the Act and/or the Code be amended to include health information privacy? If so, what amendments do you suggest and why?

3. Structure of advocacy services

Currently, the Act provides for an independent advocacy service for health and disability 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 his or 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 when investigating and mediating 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 investigating complaints.

The Director of Advocacy has responsibility for negotiating and entering into agreements to purchase advocacy services, on behalf of the Crown. This is the contracting or purchaser–provider model which was fashionable in the New Zealand health sector in the 1990s. The definitions of "advocacy services agreement" and "advocacy services" in the Act mean that the Director must contract with independent advocacy service providers. This structure enables the advocates to be "partial" in their support of the consumer, and protects the impartiality of the Commissioner.

Initially advocacy services were provided by ten separate organisations, each covering a different region of New Zealand. From 1999 until 2006 there were three service providers, and following discussion and consultation in 2005, a tendering round in 2006 led to a contract with a sole provider covering the whole country (National Advocacy Trust). While there have been benefits with a sole provider of advocacy services nationwide (such as the creation of national leadership and support roles within the one service, and better access to a range of skills and expertise for consumers), some problems remain.

Issues with the current structure include:

• Quality assurance for advocacy services is an issue. The Director of Advocacy has no role in the recruitment, performance management or discipline of advocacy staff, or their terms and conditions of employment. This makes it difficult to ensure a consistent standard of advocacy services around the country.

- There are inefficiencies in the delivery of advocacy services, as the Director has no direct control over the application of funds or the service delivery.
- Meeting the ethical standards expected of public servants is not currently assured. While the Director is a public servant, and the advocacy services are purchased with public funds, the service is delivered by employees of a private organisation (who are not covered by Public Service Code of Conduct and other rules and policies established by the State Services Commission for the benefit of the public).

Whatever the theoretical advantages of a contracting model, experience of 12 years of contracting indicates that quality, efficiency and good conduct may be better achieved in other ways. Both the Commissioner and the Director of Advocacy consider it is time to review the current statutory model, to find a better way to ensure effective independent advocacy services for consumers.

The following options are put forward for consultation:

Option 1: Status quo — *retaining the contracting model*

Within the current contracting model there are other possible variations, which have not been implemented to date. For example, the Director of Advocacy could identify a preferred provider or providers for core advocacy services so a regular tendering round would not be required.¹⁰ This would provide certainty for a provider such as the National Advocacy Trust, and reduce the risk of challenges to tendering decisions. Another option that may be possible within the existing statutory framework is for the Director to have agreements with individual advocates (rather than an organisation) to provide advocacy services.¹¹

Option 2: Advocates as HDC employees

A second option would be for advocates to be HDC employees.¹² This would resemble the current structure of the Director of Proceedings, who 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. This model has worked well for the Proceedings team.

In an employment model, 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 would remain a statutory requirement.

Option 3: Independent Office of Advocacy with advocates as employees

A third approach would be to have an independent office of the Director of Advocacy, who would be able to employ advocates directly.¹³ This would have the same advantages as Option 2, but would give greater perceived independence. It would also provide some distance from the Commissioner when dealing with

 $^{^{10}}$ See Appendix 3, 3.3.1 "Renewable contract arrangements with preferred providers".

¹¹ See Appendix 3, 3.3.1 "Contracts with individual advocates".

¹² See Appendix 3, 3.3.2.

¹³ See Appendix 3, 3.3.3.

complaints about advocacy services. Adopting this approach may require the Director of Advocacy to be appointed by the Governor-General, rather than by the Commissioner. This would add a further layer of complexity.

Refer to Appendix 3 for further exploration of this issue and the possible options for reform.

Question 5

Is the current contracting model for providing advocacy services appropriate? If not, which of the two alternative options identified do you support and why?

4. *Review of HDC decisions?*

As a preliminary comment to this review, certain provider groups have 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.

The possibility of appeal from a Commissioner's opinion was consulted on during the 2004 review of the Act. I remain of the view that the options of challenging the Commissioner's opinions through the Office of the Ombudsmen, or judicial review, are sufficient remedies. Anyone who is concerned that the process the Commissioner adopted in assessing a complaint or during the course of an investigation was unfair, or that the result is substantively unreasonable, may seek a review (free of charge) by the Office of the Ombudsmen. Each year approximately 20 cases are reviewed by the Ombudsmen, but most are resolved by clarifying procedural matters. The exercise of the Commissioner's power may be challenged by judicial review proceedings in the High Court (to date without success). I do not consider that a formal right of appeal under the Act is necessary. I believe that appeals would bog down the Commissioner's processes, which are required to be "fair, simple, speedy, and efficient", and would delay effective resolution of complaints.

Obviously, a lot more is at stake for a provider found in breach of the Code if the Commissioner decides to publicly name that provider. Some provider groups have submitted that naming decisions by HDC should only occur after the provider has had the opportunity to review the decision and correct any inaccuracies. Others have challenged the Commissioner's legal authority to name, despite the wording in section 59(1) of the Act that "[e]very investigation ... by the Commissioner may be conducted in public or private".

The naming policy (dated 1 July 2008) sets out the factors that are taken into account when making a decision to name a provider. The full naming policy is available on the HDC website.¹⁴ Each decision to name is considered on its merits, and taking into account all the circumstances, and the parties are given an opportunity to comment before the decision is finalised. Individual providers are only named in very limited circumstances. I do not consider it necessary to provide a further avenue to appeal a naming decision.

¹⁴ See <u>www.hdc.org.nz/files/hdc/Naming-Providers-in-Public-HDC-Reports.pdf.</u>

However, I would welcome your thoughts on whether the Act should be amended in relation to naming decisions. For example, should the Act include a specific section allowing the Commissioner to name providers found in breach of the Code, or give the Commissioner the power to suppress identifying information. Further discussion of this issue may be found in Appendix 1.¹⁵

Question 6

Do you suggest any amendment to the Act in relation to appeal rights or naming decisions?

Other possible amendments

There are other areas where amendment to the Act or Code may be beneficial. These possible amendments are raised in the Appendices, which canvass the provisions of the Act, the content of the Code, and the role of the Director of Advocacy and the Director of Proceedings. Possible amendments include:

- Renaming the Office of the Health and Disability Commissioner (HDC) as the "Health and Disability Commission" (see Appendix 1, 1.2).
- Providing greater clarity within the Act around reappointment of Deputy Commissioners (see Appendix 1, 1.3).
- Amending section 38 of the Act ("Commissioner may decide to take no action on a complaint") to better reflect its purpose (see Appendix 1, 1.7.4).
- Specifying that HDC may lawfully withhold information while an investigation is ongoing (see Appendix 1, 1.14).
- Placing independent health and disability ethics committees under the oversight of HDC (see Appendix 1, 1.12).
- Including a right to compassion in the Code (see Appendix 2, 2.3.1).
- Amending Right 7(4) of the Code to allow research to proceed where it is not known to be contrary to the best interests of the consumer and has received the support of an ethics committee (see Appendix 2, 2.3.3).
- Procedural amendments relating to the Director of Proceedings' functions (see Appendix 4).

Your feedback

I welcome your thoughts and feedback on these issues, and any other comments on how the Act and Code are working, to inform my report to the Minister. Please note that this document only contains an overview of the issues, and more information is contained in Appendices 1–5.

¹⁵ See 1.8.3 and 1.9.

To make it easier to respond, this document and the associated appendices have been structured into separate parts and questions are posed whenever an issue is identified. A full list of the questions is set out at the end of the document. You may wish to use this list as a guide when formulating your comments. A copy of this document is also available on the HDC website (www.hdc.org.nz).

You may wish to obtain background material to assist in making your comments. For example, copies of the Act (1994, No 88) and the HDC Amendment Act (2003, No 49) are available from Bennetts Bookshops. The Act and the HDC Amendment Act may be accessed at <u>www.legislation.govt.nz</u>. The Code is available from HDC. The HDC website includes copies of the Code, HDC annual reports, and opinions.

Meetings/hui will be held in Auckland, Wellington and Christchurch in February (depending on numbers).

Written submissions may be emailed to hdc@hdc.org.nz or posted to:

Review of the HDC Act and Code Health and Disability Commissioner P O Box 12299 WELLINGTON 6144

Submissions must reach HDC no later than 28 February 2009.

Confidentiality

The final report to the Minister will contain a list of submissions received and may refer to individual submissions. If you wish your submission, or any part of it, to be treated confidentially, please indicate this clearly. The Health and Disability Commissioner is subject to the Official Information Act 1982 and copies of submissions may therefore be released on request. Any request for withholding information on the grounds of confidentiality or any other reason will be determined in accordance with that Act.

Conclusion

Thank you for your contribution to this review process. I look forward to hearing your views.

APPENDIX 1 — HEALTH AND DISABILITY COMMISSIONER ACT

Aims of the Act

The Health and Disability Commissioner Act (the Act) provides a mechanism for consumers to resolve complaints directly with the service provider, with the assistance of the advocacy service, or through the Commissioner's office. It also seeks to ensure proper accountability of health and disability service providers, and protection of the public, by maintaining the role of an independent public watchdog. Education and an increased awareness of consumer rights, to support improvements in the overall quality of services, is also an aim of the Act. Thus, HDC focuses on three key aims, as expressed in our strategic mission:¹⁶ Resolution, Protection, and Learning.

Effect of the Act

As awareness of the Act and Code continues to increase, the positive effects of the Act are being seen. Consistent with the Act's focus on early resolution, most complaints are resolved within six months, and only about 10% of complaints lead to a formal investigation. Advocacy continues to be a remarkably effective means of resolution, with 88% of complaints received by the Advocacy Service partly or fully resolved with advocacy support.

Commissioner's decisions on complaints are often used by providers as a tool for education and quality improvement. Key reports are distributed to appropriate agencies in the health and disability sector. Specific recommendations for changes in a provider's practice are made, which are invariable complied with by providers (in the year ended 30 June 2008, 99% of recommendations were complied with).

The New Zealand system emphasises the rehabilitation of practitioners rather than punishment, and is consistent with modern understanding of the nature of error and the importance of a culture of learning to improve patient safety. The Act allows the Commissioner to find an organisation in breach of the Code, in recognition of the role that systems play in the delivery of health care and disability services. Where an organisation is found to have breached the Code, the three most common recommendations are that the organisation review its policies and/or practices in light of the Commissioner's report, provide the complainant with a written apology, and provide its staff with further education or training in a specific area.

While the steady volume of complaints from consumers continues,¹⁷ the greater flexibility in options for resolving complaints introduced by the HDC Amendment Act has ensured that complaints are resolved in a fair, simple, speedy, and efficient manner. Providers are demonstrating a greater willingness to acknowledge shortcomings, apologise where appropriate, and take steps to remedy the situation. The Commissioner continues to play an important role in quality improvement in the sector, advocating on behalf of consumers at a systemic level in policy and media debates, and influencing developments in the medico-legal and regulatory environments.

¹⁶ *Health and Disability Commissioner Strategic Plan 2006–2010* (available at www.hdc.org.nz).

¹⁷ Approximately 1,200 complaints each year.

Recent statistics

In the year ended 30 June 2008, the Commissioner received 1,292 complaints. The most common complaints concerned services provided by GPs and public hospitals,¹⁸ reflecting the high level of contact these providers have with the general public. Complaints were resolved using the full range of resolution options available under the Act. 88% of complaints were resolved within six months, and 96% were completed within a year.

Of the 1,292 complaints received, 100 resulted in investigations, with 59 resulting in a finding that a breach of the Code had occurred (60% of investigations). Approximately half of complaints (661) were closed under section 38(1) of the Act, meaning that the Commissioner decided that no action, or no further action, was necessary or appropriate (generally because an educational approach was taken).¹⁹

The Commissioner referred 180 complaints to the Nationwide Health and Disability Advocacy Service. Of these, 63 were formal referrals requiring a report back from the advocate, and in 117 cases the consumer was given information and contact details for the service and encouraged to use it.

Of the 59 matters where an investigation was conducted and a breach of the Code was found, 23 resulted in a provider being referred to the Director of Proceedings to consider further proceedings.

PRELIMINARY PROVISIONS OF THE ACT

Sections 1–7 of the Act set out some preliminary provisions dealing with such matters as definitions and the purpose of the Act.

1.1 Definitions

Section 2 sets out a series of definitions that are used to give a standard meaning to words or phrases that occur frequently in the Act such as "health consumer", "disability services consumer", "disability services" and "health services". "Health care provider" is defined in section 3. A good set of definitions is important for the effective operation of the Act. The definitions assist in interpreting and applying all other provisions in the Act, as well as those in the Code.

1.1.1 Health services

"Health services" are broadly defined in section 2 of the Act to include services to promote or protect health, or to prevent disease or ill-health; treatment, nursing, rehabilitative or diagnostic services; and services such as psychotherapy, counselling, contraception, fertility and sterilisation services. "Health consumer" is defined as including "any person on or in respect of whom any health care procedure is carried out". "Health care procedure" is defined as meaning any health treatment, examination, teaching, or research administered to or carried out in respect of any person by any health care provider; including the provision of health services.

¹⁸ Of 1,292 complaints received in the year ending 30 June 2008, 246 complaints concerned GPs and 462 complaints concerned public hospitals.

¹⁹ Section 38 decisions are discussed below at 1.7.4, "Decision to take no action".

The definition of a "health care provider" in section 3 of the Act is also very broad, and includes hospitals, health practitioners and "any other person who provides, or holds himself or herself or itself out as providing, health services to the public or to any section of the public, whether or not any charge is made for the services". Both registered and unregistered providers are covered by this definition, as are group and individual providers (public or private).

The use of "health care procedure" and "health services" in defining health care "consumer" and "provider" results in some interpretation difficulties. During the 2004 review of the Act, Women's Health Action noted that a person must be subjected to a health care procedure to qualify as a health consumer under the Act, and argued that a "health consumer" should not be limited to whether that person is are subjected to a procedure. Although the Act does define "health care procedure" very broadly, it encompasses a range of health services that would not generally be termed procedures in common usage. The relationship between the "health care procedure" and "health services" definitions in the Act and Code is also not clear, with "health services" being a subset of the "health care procedure" in the Act but "health care procedure" being a subset of "services" in the Code. It may be helpful to simplify these definitions.

Question 7

Do you suggest any change to the definitions in the Act relating to health services?

1.1.2 Disability services

The definition of "disability services consumers" (and the associated definitions of "disability services" and "disability services provider") in the Act are broad. Section 2 of the HDC Act provides the following definitions:

"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.

"Disability services provider" means any person who provides, or holds himself or herself out as providing, disability services.

"Disability services consumer" means any person with a disability that:

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

These definitions result in a relatively broad range of disability services providers being covered by the Act and Code. However, if changes are made to the Act in relation to the Commissioner's jurisdiction over disability services, or an independent disability commissioner is established, these definitions may also require amendment. The definitions in the Act relating to disability are discussed further below (see Appendix 5).

Question 8

Are the definitions in the Act relating to disability services appropriate? If not, what changes do you suggest?

1.2 Purpose of Act

Section 6 sets out the purpose of the Act:

The purpose of this Act is to promote and protect the rights of health consumers and disability services consumers, and, to that end, to facilitate the fair, simple, speedy and efficient resolution of complaints relating to infringements of those rights.

This purpose reflects HDC's three key areas of work: resolution of complaints; protection of individuals and the public; and learning from complaints to improve all health and disability services. HDC resolves complaints through the most appropriate process. Protection of the public is achieved by being alert to concerns that may indicate a risk of harm to others, and responding appropriately. Complaints are also used for educational purposes, to improve the quality of health care and disability services.

Complaint resolution, promotion of respect for consumers' rights, and making public statements and publishing reports on matters affecting the rights of health consumers are specific functions of the Commissioner under section 14 of the Act, and are discussed further below (section 1.4).

HEALTH AND DISABILITY COMMISSIONER - PART 1

Part I of the Act, sections 8 to 18, explains the status, appointment, qualifications, term and functions of the Commissioner. The Health and Disability Commissioner is appointed by the Governor-General, on the recommendation of the Minister of Health, to fulfil the Commissioner's functions for a term of up to five years (renewable). Section 8 of the Act provides that the Commissioner is a corporation sole and is a Crown entity (and the board) for the purposes of the Crown Entities Act 2004.²⁰

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". While there was no groundswell of support for this change at that time, there is now more reason for a change in light of the appointment of Deputy Commissioners. Use of the term "Health and Disability Commissioner" in a single piece of correspondence or a report, and referring variously to the legal entity (HDC or Office of the Health and Disability Commissioner) in contrast to the individual office-holder, is often clumsy. I welcome any comments or feedback on this.

²⁰ Crown entities are bodies established by law in which the Government has a controlling interest but that are legally separate from the Crown. The Crown Entities Act 2004 provides a consistent framework for the establishment, governance and operation of Crown entities.

Question 9

Do you agree that the Office of the Health and Disability Commissioner should be renamed the "Health and Disability Commission"?

1.3 Deputy Commissioners

The Act also allows for the appointment of one or more Deputy Commissioners by the Governor-General, on the recommendation of the Minister of Health (after consultation with the Commissioner). The Deputy Commissioners have powers, duties, and functions delegated by the Commissioner, and may exercise the Commissioner's functions during the absence of the Commissioner from duty.

From 1 August 2006, following changes to the Act as a result of the HDC Amendment Act, the Commissioner delegated some of the complaints resolution functions to the Deputy Commissioners.²¹ All new investigations notified after that date have been handled as set out below. The Commissioner or one of the two Deputy Commissioners then has overall responsibility for the assigned files. This has enabled the development of specialisation in the relevant areas and shares the overall load of final decision-making on investigations.

Under current delegations, if a complaint concerns prison or disability services, allied health services, or a Māori health or disability service, or if the consumer/complainant is Māori, the Deputy Commissioner, Education and Corporate Services (Tania Thomas), has jurisdiction. For matters involving rest homes, dentistry, pharmacies/pharmacists, nurses, psychologists, ambulance care workers, and any other non-medical practitioners, jurisdiction lies with the Deputy Commissioner, Complaints Resolution (Rae Lamb). The Commissioner is responsible for complaints concerning doctors, medical centres, district health board services, public hospitals, private surgical hospitals, and maternity services.

As a preliminary comment to this review, the Ministry of Health has 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. Possible mechanisms for resolving this may be:

- To amend sections 8 and 9 of the Act to make the Commissioner and Deputy Commissioners the board for the purposes of the Crown Entities Act 2004.²² The Commissioner would then be assigned the office as chairperson of the board for the purposes of the Crown Entities Act 2004. In this way, the Deputy Commissioners are members of the board, so Deputy Commissioners may remain in office until reappointed or a successor is appointed (pursuant to section 32(3) of the Crown Entities Act).
- To insert 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

²¹ Note that other delegations by the Commissioner are dealt with by sections 68–71 of the Act.

²² This is similar to the structure of the Human Rights Commission, which has the Chief Commissioner as chairperson of the board with up to seven other Commissioners as members of the board (see Human Rights Act 1993, section 8).

Deputy Commissioner in the same manner as it applies to the appointment and removal of a Commissioner."²³

I welcome your comments on whether the Act should be amended to provide greater clarity about the process for appointing Deputy Commissioners.

Question 10

Do you support clarifying the status of Deputy Commissioners pending possible reappointment?

1.4 Functions of the Commissioner — s 14(1)

Section 14(1) lists the general functions of the Commissioner. It is important for the Commissioner to have sufficiently broad functions to enable the purpose of the Act to be fulfilled.

1.4.1 Promotion and protection

The Commissioner is specifically required to promote, through education and publicity, respect for consumers' rights, and to make public statements and publish reports in relation to any matter affecting the rights of health consumers (sections 14(c) and 14(d)). As an independent statutory agency, the Commissioner is well placed to advance consumers' interests and play a key role in shaping public policy debate.

The Commissioner's education function is fulfilled not only by facilitating the resolution of complaints but also by educating health and disability services consumers about their rights under the Code and how to exercise their rights, and by ensuring that providers are aware of their responsibilities under the Act. Education is also a key role of the nationwide advocacy service, which provides direct education to consumers and providers. The following outlines the key education and publicity initiatives undertaken by the Commissioner's office.

Increasingly, the Commissioner has been using investigation reports on the HDC website to highlight public safety issues, areas for improvement, and lessons to be learned. Recently, the Commissioner has also been placing case studies or reports of complaints resolved through means other than investigation on the website. In this way complaints are an important way of educating providers about the rights in the Code, and ultimately improving the quality of services. Providers are encouraged to view complaints as opportunities for learning and quality improvement.

Key complaint and investigation reports are used as an educational tool for provider groups working in a similar area. Lessons learned from individual cases are shared with relevant parts of the health and disability sector. Anonymised copies of decisions are sent to relevant registration authorities, Colleges or professional groups, and major employers (such as District Health Boards). Other recipients of reports include coroners, the Accident Compensation Corporation, the Mental Health Commission, the Disabled Persons Assembly (NZ) Inc, and consumer groups (such as Women's Health Action, the

²³ This is similar to the Privacy Commissioner's structure (see Privacy Act 1993, section 15).

Federation of Women's Health Councils of Aotearoa and the Maternity Services Consumer Council). Six-monthly reports are sent to DHBs, to assist providers to identify opportunities for improvement in quality and safety. A close working relationship with the Quality Improvement Committee provides a mechanism for implementing HDC recommendations at a national level.²⁴

The lessons learned from complaints are increasingly being shared with the public, due to greater television, radio and print media coverage. Reaching the wider community is always a challenge, particularly groups such as elderly and disabled consumers, and Māori and Pacific peoples. Recent initiatives to educate the wider community include a Health TV advertisement with information about consumers' rights shown in medical centre waiting rooms, and an email alert that notifies consumer groups to items of interest being posted on the HDC website. Recent cases are usually reported by newspapers within 24 hours of posting on the website. A monthly column in *New Zealand Doctor* highlights recent cases to the general practice community. Greater media coverage has led to increased enquiries to HDC and the advocacy service from members of the public.

General information about the Code and the Commissioner's processes is available through:

- booklets explaining the rights in the Code and how to make a complaint;
- posters and booklets sent to providers for display in public areas;
- a plain language poster, brochure and guide about the Code and HDC processes (published in conjunction with IHC in 2002);
- a brochure on advance directives by mental health consumers produced in conjunction with the Mental Health Commission in April 2003;
- the HDC website which includes information on the Code, case notes of key decisions and full copies of key decisions (<u>www.hdc.org.nz/opinions</u>); and
- toll free numbers for both consumers and providers to make enquiries about HDC (0800 11 22 33) or the advocacy service (0800 555 050).

HDC pamphlets, posters, cards and information handouts have recently been assessed against better practice print accessibility standards, including accessibility to better meet the needs of people with partial sight, those who are blind, people who are Deaf, and people with intellectual and/or learning impairments. Currently, 73% of HDC's promotional material meets better practice print accessibility standards, and further work to ensure accessibility of educational material is being undertaken. The HDC website continues to be an effective way of providing information and education to a wide audience, with an average of 87,902 hits per month (2007/2008 year).

The Commissioner facilitates periodic consumer forums, to find out consumers' views on the health and disability service sectors and on how HDC can improve the service it delivers. Forums usually involve a specific consumer group, for example, older persons, consumers who use mental health services, consumers with an intellectual impairment, Māori health and disability services consumers, youth 15–25 years and Pacific Islands

²⁴ The Quality Improvement Committee is a statutory committee established under the New Zealand Public Health and Disability Act 2000, and is appointed by, and accountable to, the Minister of Health.

health and disability services consumers. Feedback from consumers at forums is used to develop educational initiatives and improve HDC processes.

The HDC Consumer Advisory Group was formed in 2003 to provide insight, advice and input into improving HDC's education and promotion services and increasing HDC's responsiveness to consumers via its complaints resolution processes. The Consumer Advisory Group has recently been extended to include two more disability advisors, two more health advisors and four new Pacific advisors. HDC's four iwi advisors are also part of the Group.

As part of promoting the importance of quality care, HDC and the Nationwide Health and Disability Advocacy Service have published a booklet in which 14 consumers tell their personal stories of what care looked like when it worked well: *The Art of Great Care* (2007).²⁵ By sharing what consumers report as quality care, HDC hopes to encourage providers to provide more consumer-centred, compassionate care (using a strengths-based approach to learning).

Providers are also educated through presentations to hospitals, university classes, and provider groups, by interactive case-based educational sessions, and by regular columns in provider publications. For example, in the 2007/2008 year, I presented at national meetings of general practice managers, palliative care workers, pain medicine specialists, intensive care specialists, emergency medicine providers, GPs and IPAs. Presentations and educational displays are also provided by health and disability advocates.

Submissions on key policy documents and proposed legislation are another avenue used by HDC to protect and promote consumers' rights under the Code.

The recent Social Services Select Committee Disability Inquiry highlights the experience of disability consumers in relation to the current advocacy and complaint processes. The options for strengthening HDC's role in promoting and protecting disability consumers are explored in Appendix 5. However, I would also welcome any thoughts or comments on whether the Commissioner's functions should be amended to improve the accessibility and responsiveness of HDC's services for particular consumer groups (such as people in prisons or other secure facilities, people with disabilities, or people of a particular cultural group).

1.4.2 One stop shop

The HDC Amendment Act inserted section 14(1)(da), which confirms HDC's function as the initial recipient of complaints about health and disability service providers. This amendment was intended to reduce the confusion that results when several agencies are involved in health care complaints and it is not clear whom to complain to or what the respective roles of the agencies are. The Health Practitioners Competence Assurance Act 2003 (HPCA Act) has an equivalent section (section 64), which requires that responsible authorities forward complaints "alleging that the practice or conduct of a health practitioner has affected a health consumer" to HDC.

²⁵ Available at <u>www.hdc.org.nz/files/hdc/Great-Care.pdf</u>.

1.4.3 Other roles?

As a preliminary comment to this review, the Ministry of Health recommended that the scope of the Commissioner's role should be consulted on to consider whether the Commissioner should have a wider role (for example, enabling independent monitoring of the implementation of recommendations arising out of Commissions of Inquiry). HDC already has staff tasked to follow up the Commissioner's recommendations, but additional resourcing would be necessary to enable a more extensive monitoring role.

I would welcome any thoughts on whether the HDC's role should be extended, or whether the functions of the Commissioner should be amended in some way.

Question 11

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

1.5 Review of operation of the Act — s 18

Section 18 requires the Commissioner to carry out a review of the operation of the Act and report the findings to the Minister. This is to occur at five-yearly intervals.

I am not aware of other consumer protection legislation (or any other legislation) that requires 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. I consider that the intervals between reviews should be extended to at least 10 years. I recommended this in my 2004 report, and the Ministry of Health and the Royal New Zealand College of General Practitioners (RNZCGP) have indicated support for this proposal.

As a preliminary comment to this review, RNZCGP suggested that consideration also be given to whether the review of the Act and Code should be undertaken by an independent body, rather than the Commissioner. I canvassed this issue in the 2004 review and concluded that, while there could be advantages in having an independent person review the operation of the Act, the Commissioner (as the person with the most intimate knowledge of the operation of the Act) is best placed to undertake the statutory review and provide advice in the first instance to the Minister. The requirement for consultation and a publicly available report (tabled in Parliament) enables independent scrutiny of the review. Furthermore, this is only the first step in a process of possible amendment to the Act — an opportunity for further public scrutiny of any proposed changes occurs as part of the legislative process.

The reviews are a time-consuming, resource-intensive exercise. They do not necessarily result in change (as shown by the lack of action on the recommendations from the 2004 Review). Furthermore, if a new problem emerges with the operation of the Act and 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 welcome further discussion and comment on this matter (see Question 1).

COMPLAINTS AND INVESTIGATIONS — PART IV

Part IV of the Act, sections 31 to 58, deals with the Commissioner's process for receiving, assessing, and investigating complaints under the Act. An overview of the Commissioner's processes is also set out in brochures,²⁶ which can be obtained from HDC or downloaded from the website (<u>www.hdc.org.nz</u>).

1.6 Complaints

Under section 31(2) of the Act, any person may make a complaint alleging that any action of a provider appears to be in breach of the Code. The complaint may be made orally or in writing, to the Commissioner or an advocate.

There is no time limit on making a complaint. However, the Commissioner's jurisdiction over complaints about conduct prior to 1 July 1996 (when the Code came into force) is very limited. Section 31(2) states that the complaint must allege that the conduct of the health practitioner,²⁷ (a) affected a health consumer; and (b) was, at the time that it was taken, a ground for bringing disciplinary proceedings against the health practitioner under a former health registration enactment; but (c) was not referred to the body that, under that enactment, had jurisdiction to consider it. Such complaints are considered by applying the duties or obligations that were binding at the time when the alleged incidents occurred.²⁸ In practice, this means that the Commissioner has jurisdiction over only relatively serious cases relating to individual practitioners. Even if jurisdiction exists, the Commissioner may decide to take no action in light of the time elapsed since the events complained of occurred.²⁹

1.7 Options for resolving complaints

Since the enactment of the HDC Amendment Act, the Commissioner has had more options for handling complaints, to facilitate resolution of complaints in the most appropriate way. Section 33 requires the Commissioner, on receipt of a complaint, to make a preliminary assessment of the complaint to decide what course of action is appropriate. The Commissioner's decision must be promptly notified to the complainant and provider (section 33(2)). The courses of action open to the Commissioner on receipt of the complaint are:

- referring the complaint to an agency or person in accordance with section 34 or section 36;
- referring the matter to an advocate for resolution;
- calling a mediation conference;
- investigating the complaint; or
- taking no action, if action is "unnecessary or inappropriate".

These options reflect that resolution of a complaint need not always occur through a formal investigation under the Act. HDC resolves complaints through the most

²⁶ Health and Disability Commissioner's Investigation Process — Guide for Providers and Health and Disability and Commissioner's Investigation Process — Guide for Consumers (April 2006).

 ²⁷ Defined in section 2(1) of the Act to mean a registered health professional and to include "a person who is receiving training or gaining experience under the supervision of a health practitioner".
²⁸ Health Practitioner Connectance Act 2003, action 217(4).

²⁸ Health Practitioners Competence Assurance Act 2003, section 217(4).

²⁹ Section 38(2) of the Act.

appropriate process, bearing in mind the purpose of protecting and promoting consumers' rights, and facilitating resolution in a "fair, simple, speedy, and efficient" manner (ie, focusing on resolution, protection and learning). When deciding what action to take under section 33, the need to ensure public safety and proper accountability to protect consumers, are primary considerations. Protection of the public is achieved by being alert to concerns that may indicate a risk of harm to others, and referring these complaints to the appropriate bodies or otherwise ensuring public safety.

If public safety and provider competence are not an issue, resolution between the parties may be the most appropriate response, either directly or by way of advocacy or mediation. A common first step in deciding what action to take on a complaint, is to request that the provider respond directly to the complainant. This is consistent with HDC's focus on local resolution, encouraging the parties to sort the complaint out between themselves. The Commissioner will then re-assess the complaint if this approach fails, but there is often no benefit commencing an investigation if the provider has already apologised and/or taken sufficient steps to remedy the situation. In some cases complainants prefer that no formal action be taken and that providers receive a simple reminder, in general terms, of their obligations under the Code.

However, in other cases an investigation is necessary. Sometimes appropriate resolution can only occur when the provider is held accountable for his or her actions, and formal action is taken to prevent the same events from recurring. Nonetheless, investigation is the most drawn-out form of complaint resolution (up to six to nine months for a simple investigation, while a complex investigation can take 18 months), and is not necessarily consistent with the statutory purpose of fair, simple, speedy and efficient resolution of complaints in all cases. Nor is it the most appropriate method where there is an ongoing relationship between the parties. Investigation is therefore reserved for only a small proportion of the most serious complaints.

Complaints are also seen as an opportunity to improve the quality of health care and disability services, by sharing learning throughout the sectors and the community. Complaints (even those that HDC does not investigate) offer vital "red flags" exposing poor care, public safety issues and systems problems, and can also provide an antidote to internal complacency. Increasingly, HDC is using complaints that are resolved in a variety of ways as case studies to share the learning from complaints.

1.7.1 Decision to refer the complaint

Sections 33–36 enable the Commissioner to refer complaints to statutory officers (the Chief Ombudsman, the Privacy Commissioner, the Chief Commissioner under the Human Rights Act),³⁰ and to specified agencies or persons involved in the health and disability sectors, as appropriate.³¹ The specified agencies include ACC (if it appears that the consumer may be entitled to compensation), relevant registration authorities (if it appears from the complaint that the competence of the health practitioner, or the appropriateness of his or her conduct, may be in doubt), the Director-General of Health (if it appears that there are systems failures or the practices of the provider may harm the health and safety of the public) and/or the provider (if the complaint does not raise

³⁰ Section 40.

³¹ Section 34.

public health and safety questions). Such referrals are accompanied by reporting requirements back to the Commissioner³² on what action, if any, it has taken in relation to the matter. The Commissioner may take further action if not satisfied with the reported outcome.³³

The Act anticipates co-operation between the Commissioner and a number of agencies. While each complaint is assessed on its own merits, the referral of a complaint about an apparent breach of the Code to such agencies (other than the provider) is usually concurrent with, rather than instead of, any action by the Commissioner on the matter because of the respective roles and purposes of the various agencies. The Act also allows the sharing of information more generally to other appropriate (but unspecified) persons where this is called for in the public interest.³⁴ Section 59(4) gives the Commissioner wide discretion to refer a matter to an appropriate person or authority at any time.

Section 39(1) imposes a broad obligation on the Commissioner to notify risks to the appropriate authority. The Commissioner is required to notify the appropriate registration authority if he or she has "reason to believe that the practice of a health practitioner may pose a risk of harm to the public". This reporting obligation focuses on the potential risk of harm to the public, and is not limited to the issues of competence.³⁵ The Commissioner is required to notify the Director-General of Health if there is "reason to believe that failures or inadequacies in the systems or practices of a health care provider or a disability provider are harming or likely to harm the health or safety of members of the public" (section 39(2)). Referral to an appropriate person or authority is also mandatory where the Commissioner considers there is evidence of any significant breach of duty or misconduct by the provider (section 39(3)), for example referral to the Police where a crime is suspected.

Most referrals to other agencies relate to competence or professional conduct issues requiring review by registration authorities (138 in the year ending 30 June 2008). Registration authorities have a distinct and important role in protecting the health and safety of members of the public by ensuring health practitioners are competent and fit to practise their professions. They are the appropriate agencies to consider referrals from the Commissioner about the competence and fitness of practitioners, and to follow up those concerns with a review of the practitioner, where appropriate. The Act currently gives the Commissioner a discretion to notify the relevant health professional body of HDC's decision on a complaint that is resolved by means other than investigation. In practice, any complaint that provides evidence that the competence of the health practitioner or the appropriateness of his or her conduct is cause for concern is notified to the appropriate registration authority.

³² Section 35.

³³ Sections 33(3) and 34(5).

³⁴ Section 59(4).

³⁵ Unlike section 34(2) of the HPCA Act, which requires the Commissioner and the Director of Proceedings to notify the appropriate registration authority if they have "reason to believe that a health practitioner may pose a risk of harm to the public by practising below the required standard of competence", the requirement is to notify concerns with the practice of a health practitioner generally.

The Ministry of Health is currently undertaking a review of the Health Practitioners Competence Assurance Act 2003 (HPCA Act), the legislation under which registration authorities operate. One of the responses to the Ministry's survey on the operation of the HPCA earlier this year suggested that all complaints about registered health practitioners received by HDC should be referred to the relevant registration authority, to enable the authorities to discern possible patterns that may indicate competence issues.³⁶ HDC would not be precluded from taking further action itself.

Question 12

Do you think that the Act should be amended to require HDC to refer all complaints about registered health practitioners to the relevant registration authority?

1.7.2 Advocacy

Referral to a health and disability consumer advocate "for the purpose of resolving the matter by agreement between the parties" is a further complaint-handling option.³⁷ Advocates are required to represent or assist complainants to endeavour to resolve the complaint by agreement between the parties concerned.³⁸ Unlike the Commissioner, advocates act in a partial role (as advocates for the complainant). When communication is the main issue, where there are ongoing relationships to maintain, where consumers need immediate help, or where organising a face-to-face meeting seems sensible, using an advocate is often the best option.

For referrals made under section 37 of the Act, the advocate must (a) use his or her best endeavours to resolve the complaint by agreement between the parties concerned; and (b) report the results of those endeavours to the Commissioner.³⁹

Referral to an advocate is often a very successful way of resolving a complaint. Advocates use a consumer-centred empowerment model that involves standing alongside the consumer and assisting in the manner the consumer identifies as being most helpful. This assistance may include providing information about consumer rights, assisting consumers to get their questions answered, and have explanations provided and actions taken (where appropriate). Taking action at an early stage and dealing directly with the provider (that is, resolving the matter at a local level) takes less time than a formal investigation and is more likely to achieve an outcome consumers are satisfied with.

1.7.3 Mediation

Section 61 enables the Commissioner to call a mediation conference in respect of any matter that is the subject of a complaint, or an investigation, for the purpose of

³⁶ Analysis of Responses to Ministry of Health Survey Document — Review of the Health Practitioners Competence Assurance Act 2003: Identification of issues and proposed solutions (Ministry of Health, Wellington, 2008) — available at <u>http://www.moh.govt.nz/hpca</u>.

³⁷ Section 37(1). The majority of complaints to the advocacy service are made directly to advocates, with only a small number being referred by HDC.

³⁸ Section 30(h).

³⁹ This is an additional requirement to advocates' general function of referring complaints to the Commissioner if unable to resolve (section 30(3)).

endeavouring to resolve the matter by agreement between the parties. Any information, statement, or admission made or disclosed in the course of mediation cannot be used in any future proceedings before a Court or Tribunal.⁴⁰ If a resolution is reached, the mediator will draw up an agreement to be signed by each of the parties before leaving the mediation. If the complaint is not resolved by mediation, on receipt of the mediator's report, the Commissioner will decide what, if any, further action to take.

The option of referring a complaint to mediation recognises that some matters warrant a more formal approach than a referral to the provider or advocacy, but where an investigation is unnecessary. Mediation involves attempting to resolve the matter through the formal intervention of an impartial mediator. Mediation is an effective way of resolving difficult and complex matters, or where the ongoing relationship between the parties requires a formalised agreement as to the future delivery of services; where there are a number of providers involved; or where the parties have unsuccessfully attempted to resolve the complaint.

As a result of the HDC Amendment Act, section 33(1) allows the Commissioner to call a mediation conference at any time after a complaint has been received (not just during an investigation). While this has the benefit of more flexibility, in not having to commence an investigation before mediation is available, it continues to be a major challenge to get the parties to agree to mediation. HDC's "public watchdog" responsibility also means that we must be wary of serious failures being covered up by a confidential mediation process (which is essentially "behind closed doors"), and so are selective in what matters are referred to mediation. As a result, the number of complaints resolved through mediation over the past nine years has been disappointingly low: 14 (2000), 20 (2001), 28 (2002), 23 (2003), 10 (2004), 8 (2005), 11 (2006), 14 (2007), 7 (2008).⁴¹

1.7.4 Decision to "take no action"

The Commissioner may, after a preliminary assessment of a complaint, 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)). This is a significantly wider power than was in the original Act, which could only be exercised during an investigation.

The Act requires that the Commissioner give the complainant and the provider reasons for a decision to take no action on a complaint.⁴² Matters that the Commissioner may take into account in determining whether to take any action are specified in section 38(2) of the Act, for example 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.

Before a decision is made to take no further action on a complaint, considerable information is typically gathered and carefully assessed, and preliminary expert clinical

⁴⁰ Section 61(5).

 ⁴¹ Health and Disability Commissioner Annual Reports (available on the HDC website: <u>www.hdc.org.nz</u>).
⁴² Section 28(4)

⁴² Section 38(4).

advice is sought when needed. As well as the matters specified in section 38(2), other relevant considerations in deciding whether to take no action on a matter may be:

- The matter has already been fully investigated by an independent agency (for example, a District Inspector or Coroner) and the recommendations of the independent review have been implemented.
- The matter has been fully investigated by the provider and the review has been thorough, has uncovered the relevant causes/problems, and appropriate remedial action has been taken (for example, an apology and implementation of recommendations).
- The complaint is satisfactorily resolved as a result of HDC gathering additional information and sharing this with the parties concerned, or by taking an educational approach. An educational approach may involve an "education letter" to the provider(s) highlighting any issues and aspects of care needing review. A request for an apology or some other follow-up action may be recommended (which is then followed up in the same way as recommendations arising from investigations).
- The information gathered indicates that there has been no apparent breach of the Code, or is otherwise outside HDC's jurisdiction (for example, it concerns access to, or funding for, services).
- Other official proceedings (such as a criminal prosecution, a Family Court process, or a coroner's inquest) relating to the matter complained about are under way.

Most complaints closed under this section of the Act are where HDC considers an educational approach is more appropriate than an investigation. Before any decision is made, considerable information is generally gathered, careful assessment is undertaken, and preliminary expert clinical advice is sought when needed. "Education letters" may be sent to providers highlighting any issues and aspects of care needing review. An apology or other follow-up action is frequently requested. Section 38 is also used to close complaints when no further action is required because there is no apparent breach of the Code, or because matters are already being addressed through other appropriate processes or agencies.

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 a lot of information gathering and assessment has been undertaken. I also consider that the list of matters set out in section 38(2) could better reflect the range of considerations required before deciding to take no further action.

Question 13

Should section 38 of the Act be revised to better reflect its purpose?

1.7.5 Investigation

The final option for the Commissioner, following preliminary assessment of a complaint, is a decision to investigate the complaint. Balancing the objectives of "fair" and "speedy" is not always easy during an investigation as parties and witnesses must be interviewed, patient records reviewed and, where the appropriate standard of care is in issue, independent expert clinical advice is obtained. As a matter of natural justice, providers and any other person adversely affected by the report must be given an opportunity to comment before the report is finalised. Investigation is therefore a lengthy way to resolve a complaint.

In recent years, investigations have increasingly been used for only the most serious matters such as allegations of sexual impropriety and other behaviour involving significant breaches of ethical and professional boundaries, and major lapses in standards of care. Public safety concerns, the need for accountability, and the potential for the findings to lead to significant improvement in health and disability services, are other reasons for a formal investigation.

The Act sets out the procedural requirements when undertaking an investigation.

- On commencement of an investigation, the Commissioner must give written notice to the provider and complainant (or any other person "alleged to be aggrieved") of the intention to investigate.⁴³ The provider must be notified of details of the complaint or the subject matter of the investigation, and the right to submit a written response to the Commissioner within 15 working days.⁴⁴ This notification is generally achieved by sending the provider a copy of the complaint, and the terms of reference for the investigation, and asking the provider to provide a response.
- Where the investigation directly concerns a health practitioner, the Commissioner must promptly notify the "appropriate authority" (that is, the relevant registration authority).⁴⁵ At this point, HDC also requests any relevant information from the authority.
- During an investigation, HDC gathers information from the parties and witnesses, and relevant clinical records in order to establish the facts. The Commissioner is empowered to gather any information, and make such enquiries, as he or she thinks fit.⁴⁶ The provision of relevant information and the production of documents may be required by written notice, and a person may be summoned to give oral evidence under oath.⁴⁷
- If the complaint concerns standards of care, the Commissioner may request independent expert advice on the reasonableness of the conduct giving rise to the complaint.

⁴³ Section 41(1).

⁴⁴ Section 41(1)(b).

⁴⁵ Section 42(1).

⁴⁶ Sections 59(1), 59(2) and 59(3).

⁴⁷ Section 62.

• If circumstances change during the process, the Commissioner retains the option of taking no further action on a complaint. The parties may also be referred to mediation at any stage of an investigation. In practice this occurs only if the complaint does not raise issues of exploitation or public safety.

Section 67 ensures that any person who is the subject of adverse comment in any report or recommendation has a reasonable opportunity to be heard; has a reasonable opportunity to make a written statement in response to that adverse comment; and may, if they require, have their response or a summary of it (whichever the Commissioner considers appropriate) included in or appended to the report or recommendation.

The right to respond to adverse comment is a fundamental right in administrative law. Its purpose is to ensure a fair process and outcome for the parties. During an investigation of a complaint, a provider has a number of opportunities for input before the Commissioner forms a final opinion that a breach of the Code has occurred. As a minimum, this includes the opportunity at the start of the investigation to respond to the complaint (as required by section 41(b)), as well as the opportunity to respond to any adverse comment in the provisional opinion. Accordingly, before the Commissioner finalises an opinion on whether the complaint gives rise to a breach of the Code, a provisional opinion is sent to the provider (in the case of a provisional breach finding or adverse comment) or the complainant (in the event of a provisional no breach finding). Occasionally, a copy of the full provisional opinion is sent to the complainant, but this depends on the circumstances and the complexity of the case. At provisional opinion stage, a summary of the information gathered during the investigation is sent to all parties for comment. Once any response has been considered, the opinion is finalised and a final written report is sent to the parties.⁴⁸

A concern raised by some complainants whose complaint has been investigated by the Commissioner is that, in cases where there is a proposed adverse comment about a provider, only the provider gets to see and comment on the provisional opinion — even though the complainant has a strong interest in the outcome. I would welcome any comments on how to satisfy natural justice requirements without disadvantaging complainants, in a way that is still "speedy and efficient".

By way of preliminary comment, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) National Committee suggested that the review of the Act should address timelines and information provided to the professional under investigation. Similarly, the New Zealand Private Surgical Hospitals Association (NZPSHA) suggested that the Act should provide deadlines or indication of a reasonable time within which HDC should complete an investigation.

In my view, the Act is clear that investigations must be undertaken in a "speedy and efficient" manner. HDC takes this responsibility seriously and the majority of investigations are completed within 12 months (with a handful taking 18–23 months). It is a fact of life that consumers, providers and expert advisors have other demands on

⁴⁸ Section 43 requires the Commissioner to inform the complainant, any person alleged to be aggrieved (if he or she is not the complainant), the provider, and the appropriate authority (if the investigation concerns a health practitioner) of the results of the investigation and any further action that the Commissioner proposes to take.

their time, which can delay HDC's process. The speediness of an investigation must be balanced against the requirements of natural justice and fairness to providers under investigation.

Question 14

Do you consider it is necessary or desirable to amend the provisions of the Act governing the Commissioner's investigations? For example, by giving complainants the opportunity to comment on the Commissioner's provisional opinion even if it contains adverse comment about the provider(s), or by setting prescribed timeframes?

If, at the end of an investigation, the Commissioner is of the opinion that there has been a breach of the Code, there are a number of options available. These options are discussed in the next section.

1.8 Procedures after investigation

Section 45 of the Act sets out the Commissioner's options after an investigation where the Commissioner is of the opinion that a provider was in breach of the Code (or in the case of an action of a health practitioner before 1 July 1996, was a ground for bringing disciplinary proceedings against the health practitioner under a former health registration enactment).

1.8.1 Reporting to other bodies

After concluding an investigation, the Commissioner may report the opinion to all or any of the following: any authority or professional body;⁴⁹ the Accident Compensation Corporation;⁵⁰ the Minister of Health;⁵¹ or any other person that the Commissioner considers appropriate.⁵²

1.8.2 Recommendations

An opinion finding that a provider has breached the Code will usually include recommendations ranging from an apology, review of practice, re-training, staff training, internal audit and systems review.⁵³ Section 46(1) states that, where the Commissioner has made such a recommendation, the Commissioner may request that person notify the Commissioner of the steps that the person proposes to take to give effect to that recommendation, within a specified timeframe. If, within a reasonable timeframe, the Commissioner has not received advice that the recommendation has been carried out, the Commissioner may "make such comments on the matter as the Commissioner thinks fit" and may report the matter to the Minister.⁵⁴

This provision has been interpreted to give the Commissioner an implied power to publicly name a non-compliant provider if a recommendation is not met. However, in

⁴⁹ Section 45(2)(b)(i).

⁵⁰ Section 45(2)(b)(ii).

⁵¹ Section 45(2)(c).

⁵² Section 45(2)(b)(iii).

⁵³ Sections 45(2)(a) and 45(2)(b) provide that the Commissioner may make "any recommendations as the Commissioner thinks fit".

⁵⁴ Section 46(2).

practice, the process for following up on recommendations generally results in timely compliance. In the 2007/2008 year, 99% of recommendations were complied with. The three providers who failed to act on HDC's recommendations were referred to their registration boards.

1.8.3 Naming

For the first decade after the Code of Consumers' Rights came into force (on 1 July 1996), HDC published investigation reports without naming the health and disability providers involved. The focus was on educating the sector, and a policy of name suppression ensured maximum provider cooperation with those processes.

By 2006, however, the Commissioner was concerned that this level of secrecy was undermining public confidence in the health professions and complaint handling procedures. Consumers were being denied information that could influence their choice of practitioner or facility, and there was a growing public desire for openness. The Commissioner decided to name district health boards in Code breach opinions on the basis that they should be publicly accountable for the quality of care they fund or provide.

In 2007, the policy was extended to include other group providers and individual providers (in limited circumstances). The policy prompted a strong response from the sector, particularly in relation to HDC naming group providers such as rest homes, private hospitals, residential care facilities, medical centres and pharmacies. In light of these concerns, the Commissioner put the policy on hold (no providers having been named in the interim), consulted the sector and reviewed the naming policy in 2008.

The naming policy dated 1 July 2008 sets out the policy developed as a result of that consultation. In summary, the policy states:

- The Commissioner will continue to name DHBs and public hospitals found in breach of the Code unless it would not be in the public interest or would unfairly compromise the privacy interests of an individual provider or a consumer.
- The Commissioner will name rest homes, residential facilities and private hospitals, medical centres, pharmacies and other group providers where their systems are found to be in breach of the Code unless it would not be in the public interest or would unfairly compromise the privacy interests of an individual provider or a consumer.
- The Commissioner may decide to name individual providers found in breach of the Code if:
 - 1. the conduct of the provider demonstrates a flagrant disregard for the rights of the consumer or a severe departure from an acceptable standard of care, such that the provider poses a risk of harm to the public; or
 - 2. the provider has refused to comply with the Commissioner's recommendations; or
 - 3. the provider has been found in breach of the Code in relation to three episodes of care within the past five years where each breach involved an (at least) moderate departure from appropriate standards.

Each decision to name is considered on its merits, and the parties are given an opportunity to comment before it is finalised. This recognises that both the provider(s) and the consumer can be affected by naming. The full policy on naming, including the factors that are taken into account, is set out on the HDC website.⁵⁵

As a preliminary comment to this review, the NZPSHA submitted that naming decisions by HDC should result in providers having an opportunity to review the decision and correct any inaccuracies prior to naming (and there is no reason to distinguish between individual and group providers). Other provider groups have challenged the Commissioner's legal authority to name, despite the wording in section 59(1) of the Act that every investigation by the Commissioner "may be conducted in public or private". Concerns have also been expressed that HDC is subject to the Official Information Act 1982, and therefore may be required to release identifying information.

In light of these concerns, I would welcome your thoughts on the following:

- whether the Act should be amended to include a specific section allowing the Commissioner to name providers found in breach of the Code.
- whether the Act should be amended to give the Commissioner the power to suppress identifying information relating to (a) parties not found in breach, and (b) parties found in breach, before all processes have been concluded.

Question 15

Do you suggest any amendment to the Act in relation to the Commissioner naming providers found in breach of the Code?

1.8.4 Referral of providers to the Director of Proceedings

One of the options available to the Commissioner at the end of an investigation is to refer a provider to the Director of Proceedings for the purpose of deciding whether to institute proceedings against the provider (section 45(2)(f)). The provisions of the Act relating to the Director of Proceedings are discussed below in Appendix 4.

1.9 Right of appeal

As a preliminary comment to this review, the Australian and New Zealand College of Anaesthetists and Bay of Plenty DHB have suggested that providers should have a right of appeal from a Commissioner's decision. This issue was consulted on during the 2004 review of the Act. I remain of the view that the options of challenging the Commissioner's opinions through the Office of the Ombudsmen, or judicial review, are sufficient remedies.

Anyone who is concerned that the process the Commissioner adopted in assessing a complaint or during the course of an investigation was unfair, or that the result is substantively unreasonable, may seek a review (free of charge) by the Office of the

⁵⁵ See <u>www.hdc.org.nz/files/hdc/Naming-Providers-in-Public-HDC-Reports.pdf.</u>

Ombudsmen. Each year approximately 20 cases are reviewed by the Ombudsmen, but most are resolved by clarifying procedural matters, without the need for any formal recommendation. The exercise of the Commissioner's power may be challenged by judicial review proceedings in the High Court (to date without success).

In my view, no formal right of appeal under the Act is necessary, in light of the requirement that the Commissioner's complaint resolution processes are "fair, simple, speedy, and efficient" and the existence of remedies through judicial review or the Ombudsmen.

MISCELLANEOUS PROVISIONS — PART V

Sections 59 to 82 of the Act cover various miscellaneous matters relating to complaints and procedure, the calling of mediation conferences, protections and privileges, delegations, vicarious liability, offences, etc. Although placed in a part of the Act entitled "Miscellaneous", these provisions are essential to the Act's effective operation.

1.10 Procedure

Section 59 contains a number of important provisions enabling the Commissioner to regulate procedures as he or she thinks fit. This flexibility is essential if the Commissioner is to achieve the Act's stated purpose of "fair, simple, speedy, and efficient resolution of complaints". In summary, section 59 provides as follows:

- investigations may be in public or in private (s 59(1))
- the Commissioner may hear or obtain information from such persons as he or she thinks fit (s 59(2)(a))
- the Commissioner may make such enquiries as he or she thinks fit (s 59(2)(b))
- it shall not be necessary for the Commissioner to hold any hearing (s 59(2)(c))
- subject to the right to respond to a complaint and to adverse comment, no person shall be entitled as of right to be heard by the Commissioner (s 59(3))
- if it is in the public interest to do so, the Commissioner may refer matters to the appropriate person or authority (s 59(4))
- subject to the provisions of the Act, the Commissioner and every advocate may regulate their procedure as they think fit (s 59(5)).

1.11 Offences

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."

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, which is consistent with the High Court's approach,⁵⁶ the Health Practitioners Competence Assurance Act,⁵⁷ and other consumer protection legislation.⁵⁸

Question 16

Do you agree that the fine for an offence under the Act should be increased? If so, do you agree that the maximum fine should be \$10,000?

1.12 Ethics committees

During the 2004 review, Women's Health Action, Auckland Women's Health Council, and Maternity Services Consumer Council all argued that a national system of ethics committees should fall within the scope of the Act. These organisations have again raised this issue as a preliminary comment to this review, and have raised concerns about "the decentralisation and fragmentation of ethics committees", and that the culture of ethics committees is "increasingly dominated by the interests or even 'rights' of researchers and academics to do research, over the interests of consumers and their rights under the code". Women's Health Action believes:

"the national system of Ethics Committees and Ethical review fits more naturally under the jurisdiction of the HDC than the various other areas where they are currently located. We believe that there is a place for a Director of Ethics which encompasses all human ethics committees, not just the regional ones, as the focus should be on the rights of research participants and those involved in innovative and experimental procedures."

As stated in my 2004 report to the Minister, this review of the Act and Code is not the proper place to make recommendations on the system for ethical review of health and disability research in New Zealand. I have an open mind about the possibility of ethics committees falling within the statutory oversight of the Health and Disability Commissioner, although a consultation process would be required to canvass the views of the sector and to discuss how such a relationship would work in practice. A range of issues such as independence (eg, under an independent Director of Ethics within HDC), funding and conflict of interest provisions (in the event of a complaint to the Commissioner about research approved by an ethics committee) would need to be resolved. Many of the research protocols reviewed by ethics committees raise questions of health information and the secondary use of data for research, matters that currently

See Martin v Director of Proceedings (High Court Auckland, CIV-2006-404-005706, 2 July 2008, Courtney J). Dr Martin was found guilty of professional misconduct by the Health Practitioners Disciplinary Tribunal for altering clinical notes and intentionally misleading the Commissioner about that fact during the course of the HDC investigation. The High Court reduced the fine from \$10,000 to \$7,000, noting that Dr Martin's conduct "cannot be regarded as the most serious conduct of its type" (para 117).

⁵⁷ See 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).

⁵⁸ See 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).

fall within the jurisdiction of the Privacy Commissioner rather than the Health and Disability Commissioner.

Question 17

Do you consider that ethics committees should be under the oversight of HDC?

1.13 Indemnity of expert advisors

Until the enactment of the Crown Entities Act 2004 (on 25 January 2005), section 65(2)(a) of the Act provided:

"No proceedings, civil or criminal, shall lie against any person to whom this section applies [namely the Commissioner, every advocate, every person engaged or employed in connection with the work of the Commissioner] for anything he or she may do or report or say in the course of the exercise or intended exercise of his or her duties under this Act, unless it is shown that he or she has acted in bad faith."

As independent expert advisors are engaged in connection with the work of the Commissioner, this section provided immunity against civil or criminal proceedings in relation to anything they said or did in that role, provided that they had not acted in bad faith. Sections 120 to 126 of the Crown Entities Act provide that there is 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". However, as independent advisors are not "members, office holders or employees", the protections in the Crown Entities Act are not available to independent advisors.

The risk of independent advisors being legally challenged is extremely slight,⁵⁹ as concerns about expert advice are most likely to be raised in the context of challenging the Commissioner's decision rather than an action directly against the independent advisor. However, I consider that the HDC Act should be amended to include expert advisors contracted by HDC in the definition of "members, office holders or employees" under the Crown Entities Act so that advisors are offered a similar level of protection.

Question 18

Do you consider that 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?

1.14 Protection of information

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

⁵⁹ It will generally not be possible to bring an action for defamation against an independent advisor for advice to the Commissioner, as section 65(4) of the HDC Act provides that "[a]nything said or any information supplied or any document or thing produced by any person in the course of any inquiry by or proceedings before the Commissioner or an advocate under this Act shall be privileged in the same manner as if the inquiry or proceedings were proceedings in a Court".

assessment of every request for information held by the Office to assess whether release of that information is required, which is a complex and time-consuming task. Releasing information during the early stages of an investigation also gives rise to the risk of tainting the evidence. All relevant information is released to the appropriate parties when the Commissioner makes a provisional decision.

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 and free and frank communications. This issue was explored 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). The Privacy Commissioner, as an equivalent statutory body, has a similar provision.⁶⁰ Including such a provision in the Act would not jeopardise the fairness of the investigation, but would prevent parties using information requests as a delaying tactic.

Question 19

Should the Act be amended to allow information obtained during an investigation to be withheld, while the investigation is ongoing?

⁶⁰ 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."

APPENDIX 2 — CODE OF HEALTH AND DISABILITY SERVICES CONSUMERS' RIGHTS

2.1 Overview

Sections 19–23 cover the preparation, content, review and notification of the Code of Health and Disability Services Consumers' Rights (the Code).

Section 20 of the Act governs the content of the Code. The Code came into force on 1 July 1996. It sets out the rights and responsibilities of health and disability consumers within a clear and accessible framework. One of the Code's real strengths is that it allows the Commissioner to refer to external sources for guidance on appropriate standards within different professions, and for different modalities of treatment. This ensures that the Code remains dynamic and responsive to change within the health and disability sectors.

The Code consists of six clauses:

Clause 1 confers the rights contained in the Code on consumers and establishes the duties and obligations of providers to comply with the Code. It also requires providers to inform consumers of their rights and enable them to exercise those rights.

Clause 2 details the rights that are available to all health and disability services consumers, including those involved in teaching and research. Each right imposes a corresponding legal duty on all health and disability service providers. The ten Rights are as follows:

- Right 1: the right to be treated with respect
- Right 2: the right to freedom from discrimination, coercion, harassment, and exploitation
- Right 3: the right to dignity and independence
- Right 4: the right to services of an appropriate standard
- Right 5: the right to effective communication
- Right 6: the right to be fully informed
- Right 7: the right to make an informed choice and give informed consent
- Right 8: the right to support
- Right 9: rights in respect of teaching or research
- Right 10: the right to complain.

Under Clause 3 of the Code, a provider will not be in breach of the Code if he or she has taken "reasonable actions in the circumstances" to give effect to a consumer's rights. This takes into account factors such as the consumer's clinical circumstances and the provider's resource constraints. Proof of actual harm to the consumer is not necessary for the Commissioner to find a provider in breach of one of the rights.

Clause 4 sets out the definitions of certain words used in the Code.

Clause 5 notes that, in meeting the requirements of the Code, no provider is required to breach any other New Zealand law, nor does the Code prevent a provider from doing an act authorised by such a law.

Clause 6 ensures that all existing rights outside of the Code still apply.

Overall, the provisions in the Code have worked very satisfactorily and there is little need for amendment. As understanding of the Code has increased, so too has its general acceptance. However, a few matters continue to raise issues for both consumers and providers. These matters are explored below.

2.2 Review of the Code — ss 21–23

Section 21 provides that the Commissioner shall complete a review of the Code and make recommendations to the Minister at intervals of not more than three years. Given the level of resources necessary to conduct such a review and the time required for legislative reform, I recommend that the timing of reviews be amended from no more than three years, to intervals of no more than 10 years, as is also recommended for reviews of the Act (currently required every five years). See Question 1.

As a preliminary comment to this review, the Maternity Services Consumer Council has also suggested that a new provision should be inserted in the Act to prevent HDC "suggesting, supporting or introducing" changes to the Code without first consulting with consumers. I agree that any changes to the Act or Code should only be made after consulting with health and disability service consumers. However, HDC has no ability to amend the Act or Code, and any proposed amendments must go through the legislative amendment process, which requires that appropriate consultation has been undertaken.

2.3 Amendment of existing rights?

2.3.1 Right to compassion?

As a preliminary comment to this review, the Compassion in Healthcare $Trust^{61}$ has suggested that the Code should be amended to include a "right to be treated with compassion". The Compassion in Healthcare Trust believes that the rights in the Code "do not adequately express the core value at the heart of healthcare, which is the humane quality of understanding suffering and wishing to relieve it — expressed as compassion". In support of the addition of a right to compassion to the Code, the Trust points to the link between compassion and patient safety, the emotional impact of the healthcare experience, and the importance of having standards in law that align with the core values of healthcare.⁶²

In my view, the right to be treated with respect (Right 1), the right for every consumer "to have services provided in a manner that respects the dignity and independence of the individual" (Right 3), and the right to services that comply with ethical and professional standards, already encompass the elements of a right to compassion. HDC Opinions have on occasion recognised this.⁶³

However, I welcome your thoughts and comments on whether the Code should be amended to include a right to compassion and, if so, whether this should be added to Right 1 or expressed as a separate right.

⁶¹ See <u>www.compassioninhealthcare.org</u>.

⁶² In the United Kingdom, the Secretary of State for Health has declared that "compassion" will be a core value of the NHS and that the quality of compassionate caring shown by every nurse in the NHS will be measured by patient feedback (see http://news.bbc.co.uk/1/hi/health/7460720.stm).

⁶³ See Capital and Coast District Health Board Case 05HDC11908 (22 March 2007), p 106, finding that Mr A "was not treated with compassion, nor accorded the basic dignity and respect that is the right of every patient", in breach of Right 1(1).

2.3.2 Effective communication — Right 5

Right 5(1) provides that "every consumer has the right to effective communication in a form, language and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter."

Right 5(1) explicitly states that the right to a competent interpreter applies "where necessary and reasonably practicable". Right 5(1) is also subject to clause 3, which states that the provider is not in breach of the Code if the provider has taken reasonable actions in the circumstances to give effect to comply with the duties in this Code. In day-to-day situations, many providers avoid language difficulties by asking consumers to bring a friend or family member to assist with communication. This may not, however, be appropriate, depending on the nature of the consultation.

From time to time, providers ask about the extent to which Right 5(1) requires them to provide an interpreter to assist consumers. However, very few complaints are received that raise issues of language difficulties between providers and consumers. As a preliminary comment to this review, Women's Health Action, Auckland Women's Health Council, and the Maternity Services Consumer Council have suggested that a national interpreting and translating service should be made available through the Commissioner's office. This submission was also raised during the previous review of the Code. In my report to the Minister, I noted that the Commissioner's Office and the Director of Advocacy do not have funding to support a national translation service. There is also currently no provision in the Act for the Commissioner to provide a national interpreting and translating service. However, the Director of Advocacy has been working collaboratively with Ethnic Affairs and the Office for Disability Issues to develop a national whole of government approach to interpreting and translation.

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

In the previous review of the Code, I consulted on whether:

- the Code should give more guidance on the treatment of incompetent consumers, particularly the extent to which coercion may be used to provide treatment and prevent harm;
- 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.⁶⁴ 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 that 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.⁶⁵ If it is not known whether the proposed research or any other service is in the best interests of the consumer, it cannot lawfully be carried out (although, in some circumstances, it may be justified by the common law of necessity).

However, 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 of the Act and Code, Auckland DHB suggested amending Right 7(4)(a) to state that services should be "not contrary to the best interests of the patient". Changing the test to "not contrary to the best interests of the consumer" would weaken a safeguard put in place by Right 7(4)(a) to protect this vulnerable class of consumers. HDC did not support the amendment in this form but recommended a cautious approach, with further consultation. HDC did, however, support 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:

"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 support of an ethics committee."

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. As a preliminary comment to this review, the Australian and NZ College of Anaesthetists and the Ministry of Health expressed support for the change recommended in my 2004 report to the Minister. I welcome your comments and feedback on whether Right 7(4) of the Code should be amended.

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

⁶⁴ The definition of "consumer" in clause 4 includes, for the purposes of Rights 5, 6, 7(1), 7(7), 7(10), and 10, a person entitled to give consent on behalf of that consumer.

⁶⁵ Right 4(4) provides "Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer." The phrase "optimises the quality of life" is defined in Clause 4 of the Code to mean "to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances".

that it makes them suitable advisors on the type of care they believe is in the consumer's best interests. This is a matter of the provider taking into account the views of "suitable persons" in deciding whether treatment is in the consumer's best interests (rather than seeking informed consent, as the procedure set out in Right 7(4) is based on the premise that no one who is legally entitled to consent is available).

2.3.4 Written consent — Right 7(6)

Right 7(6) requires 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 general anaesthetic; or d) there is a significant risk of adverse effects on the consumer.

The definitions of "health care procedure" and "health services" in section 2 of the Act and clause 4 of the Code are rather circular. Taking a broad interpretation of the Act and Code, it seems that the prescription of medication is both a "health service" and a "health care procedure" (since the latter phrase is defined to include "any provision of health services to any person by any health care provider"). Therefore Right 7(6)(d) of the Code requires providers to obtain written consent to the prescription of medication that will expose the patient to a significant risk of adverse effects. It has been suggested that complying with this requirement is very complicated and onerous in everyday practice.

In light of these issues, it may be timely to review when written consent should be required under the Code.

2.3.5 *Right to refuse treatment and the Mental Health Act — Right 7(7)*

Right 7(7) states that every consumer has the right to refuse services and to withdraw consent to services. A District Inspector has recently queried whether Right 7(7) should be amended to clarify the situation of consumers under compulsory treatment orders pursuant to the Mental Health (Compulsory Assessment and Treatment) Act 1992.

The right "to refuse to undergo any medical treatment" is also protected under the New Zealand Bill of Rights Act 1990 (section 11). However, while the legal rights of a patient to withdraw and refuse treatment are well established in New Zealand, a consumer's right to refuse or withdraw consent to services can be overridden in certain circumstances, notably under the Mental Health (Compulsory Assessment and Treatment) Act 1992. Clause 5 of the Code recognises that the rights in the Code are not absolute in stating that nothing in the Code "requires a provider to act in breach of any duty or obligation imposed by any enactment or prevents a provider doing an act authorised by any enactment".

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

Right 7(10) provides that any bodily substances or body parts removed or obtained in the course of a health care procedure may not be stored, preserved or used otherwise than:

- (a) with the informed consent of the consumer; or
- (b) for the purpose of research that has received the approval of an ethics committee; or

(c) for the purpose of a professionally recognised quality assurance programme or an external audit or evaluation of services that is undertaken to assure or improve the quality of services.

Cabinet approved this amendment of Right 7(10) in 2003.⁶⁶ This was a controversial change. HDC supported the amendment because of evidence that the Right 7(10) requirement for informed consent had, in some cases, hindered valuable public research, and audit and evaluation activities. The consumer's consent is still needed to the actual procedure, such as the taking of the body part or substance. The intent of the amendment was not to remove the need for consent, which is still be required in the vast majority of cases, but to allow for ethics committee approval as a back-up or exception when consent is problematic, and to permit certain activities conducted for the purpose of improving the quality of health and disability services.

As a preliminary comment to this review, Women's Health Action, Auckland Women's Health Council, and the Maternity Services Consumer Council have suggested that there is a need to reverse the change made to Right 7(10). They consider that consumers should always be asked to give consent to the use of their body parts and substances.

In practice, the exemptions from the informed consent requirements under Right 7(10) only apply in very limited circumstances. Ethics committees considering a research proposal are required to weigh the public interest in allowing for an exception from the requirement for informed consent against the very strong ethical principle of protecting individual autonomy. Consumers also continue to benefit from the protection of the other rights in the Code. For example, Right 7(9) provides every consumer with the right to make a decision about the return or disposal of any body parts of bodily substances removed in the course of a health care procedure. Providers must comply with Right 1(3) and take into account the needs, values, and beliefs of different cultural, religious, social and ethnic groups, including the needs, values and beliefs of Māori. Anyone involved in research, audit or evaluation activities is bound by the requirements of the Health Information Privacy Code 1994 (the HIPC).⁶⁷

During the 2004 review of the Code, one submitter queried whether a "professionally recognised quality assurance programme" (Right 7(10)) would be defined in the Code. Recently, I have become aware of some confusion in the sector over whether this means that providers have to comply with a certain quality assurance programme. As a preliminary comment to this review, the Ministry of Health suggested that the concerns about how Right 7(10) is interpreted may be allayed by capturing expectations of how it would be interpreted (similar to the commentary to the Health Information Privacy Code), to provide providers, researchers and ethics committees with further guidance.

I welcome any comments on whether the Act or Code needs amending to revisit the rights and duties under Right 7(10) of the Code.

⁶⁶ CAB Min (03) 40/8, 8 December 2003. Right 7(10) previously provided: "Any body parts or bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer."

⁶⁷ The HIPC states that any information obtained in carrying out these activities must not be published in a form that could reasonably be expected to identify an individual (Rule 11(2)(c)(ii)).

Question 20

Do you think any of the above Code rights should be amended?

2.4 A right to access to health services?

Section 20 addresses only the quality of service delivered and does not authorise the Code to cover issues of access to 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. The issue of whether the Act should be amended to cover access decisions for disability services is discussed below (in Appendix 5). Therefore this section focuses on the possibility of the Act and Code including a general right in relation to access that would include access to health services.

As a preliminary comment to this review, the Human Rights Commission highlighted that access to publicly funded health services continues to be an issue for many New Zealanders and suggested that the Code should include a right to access health services (New Zealand Action Plan for Human Rights: Mana ki te Tangata, HRC, Wellington, 2005). In surveys, health emerges as a leading concern for New Zealanders.⁶⁸ Their concern is apparently less about the quality of services, than about their ability to access treatment or timely treatment when they or their family members need it.

During the consultation on the original Code, there was support for including a right to access.⁶⁹ However, the inaugural Commissioner interpreted the Act as not authorising the Code to include rights relating to access to services.⁷⁰ Thus, no right of access to publicly funded treatment or to timely treatment (for example, within a specific timeframe) was included in the Code when passed. Despite submitters in both reviews of the Code supporting change, neither Commissioner has been persuaded since to recommend amending the Act and Code to include a right of access to services or to particular services free of charge.⁷¹

It is contentious whether access and funding issues are justiciable. Clinical judgements about who to prioritise for treatment are generally beyond the expertise of a judge (or Commissioner), who is not well placed to make orders that one individual receive a

⁶⁸ For example, health ranked as voters' top concern in the run-up to the national election of 2005: see "Informed Choice: Analysing the real issues to help voters in the run-up to the election," *New Zealand Herald*, July 25, 2005, at A5, available at <u>www.nzherald.co.nz</u>.

⁶⁹ Some politicians did want access included in the Code. See, for example, Dianne Yates MP Parliamentary Debates (Hansard), vol 543, 27 September 1994, p 3758.

⁷⁰ See R Stent, A proposed draft Code of Rights for consumers of health and disability services: A resource for public consultation (HDC, July 1995), pp 8 & 25.

⁷¹ See R Stent, A review of the Health and Disability Commissioner Act and Code of Rights for consumers of health and disability services: Report to the Minister of Health October 1999 (HDC, 1999), pp 13–15. A majority of submitters to the 2004 review considered the Code should guarantee a right to access services where services were already funded; see R Paterson, A review of the Health and Disability Commissioner Act and the Code of Rights for consumers of health and disability services: Report to the Minister of Health June 2004 (HDC, 2004), p 21. No recommendation was made to amend the Act or Code to create a new right of access in the 2004 Review; see pp 20–2.

treatment without knowledge of the competing claims.⁷² Resource allocation decisions with consequences for the utilisation of scarce resources are best addressed through political accountability. It can also be difficult to work in matters of access in a rights framework like the Code, since it makes little sense to talk about one individual's right of access to health services, in the context of finite resources and the competing rights of others to the same resources.⁷³ 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. One possibility would be to include some form of limited right to access services, without opening the door fully to entitlements to access to services generally.

Some overseas Codes or Charters do include an access entitlement, although in practice they are not legally enforceable.⁷⁴ There is no evidence that including a right to access services would result in a high number of complaints about access to services.⁷⁵ However, the New Zealand approach of separating access from quality and safety in the Code, and requiring transparency (such as through centralised supervision of waiting times),⁷⁶ may well be preferable. The Code does support a transparent and accountable process for decision-making regarding access to care, and the Commissioner can still utilise the Code to advance patients' interests in relation to access issues, as the following case illustrates:

Opinion 04HDC13909 (4 April 2006)

In this case, the Code was invoked to clarify the relative roles and responsibilities of specialists, general practitioners and district health boards in prioritising patients accessing elective services. The case concerned a patient who waited 22 months for a First Specialist Assessment (FSA) in the public system, after being told that he was urgent and would be seen within several months.

 ⁷² See *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507 (CA), p 517 (Donaldson LJ), p 519 (Balcombe LJ); see also *R v Cambridge District Health Authority ex parte B* [1995] 1
WLR 898 (CA), p 906. See also *R (on the application of Pfizer Ltd) v Secretary of State for Health* (2002) 70 BMLR 219.

 ⁷³ See Soobramoney v Minister of Health (KwaZulu-Natal) (1998) 1 SA 765 (CC), para 54. See J Herring, Medical Law and Ethics (Oxford: Oxford University Press, 2006), p 19. See also Re J (A Minor) [1991] 4 All ER 614; R v Cambridge District Health Authority, ex parte B [1995] 1 WLR 898, 906 (CA), LJ Bingham MR).

⁷⁴ See the Australian Commission on Safety and Quality in Healthcare (ACSQH), *Australian Charter of Healthcare Rights* (July 2008), available at <u>www.safetyandquality.org</u>. See also the draft NHS Constitution, which includes a right to access local NHS services, stated to be enforceable ultimately by judicial review, and only an unenforceable Pledge "to provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution" (Department of Health, *A Handbook to the NHS Constitution* (2008), pp 7 & 10). The South African Constitution, section 27(1) provides: "Everyone has the right to access to health care services." However that guarantee is immediately qualified by a statement that the right can be limited by scarce resources: "The State must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights." See also, J Manning & R Paterson, "'Prioritization': Rationing Health Care in New Zealand" (2005) 33 JLME 681.

⁷⁵ See, for example, Health Care Complaints Commission (HCCC) Annual Reports (<u>www.nsw.gov.au</u>), which report that complaints about access amount to less than 10% of complaints to the HCCC.

⁷⁶ See the Ministry of Health's quarterly audit of waiting times for elective services at all DHBs, the results of which are tied to funding; see <u>www.moh.govt.nz/moh</u>.

HDC found that the specialist owed a duty of care to the unseen patient. When assessing a patient for the purpose of prioritising him for treatment, and when assigning a priority to the patient, a doctor exercises clinical skill and judgement and is held to the standard of care in Right 4(1). In addition, patients are entitled to be provided with accurate information about how long they may have to wait (under Right 6).

HDC also held that a DHB must appropriately manage its waiting lists. It has the primary responsibility for ensuring that patients and GPs are given clarity about when a patient can expect to be seen for a FSA and, if booked, when treatment will be provided. The DHB had a duty to advise patients and GPs that either the patient would be seen for FSA within six months or that the service is unable to do so, and about the option of seeking private assessment and treatment. The patient had received no explanation for the delay or about his options. A DHB cannot simply leave matters to the specialist, knowing that timeframes are not being met. The DHB was held in breach of Right 4(1), as well as the duty of co-operation to ensure quality and continuity of care under Right 4(5).

I welcome your comments on whether a right of access should be included in the Code and, if so, whether it should be limited (for example, a right to access publicly funded services in a timely manner) — see Question 3.

2.5 Health information privacy

Right 1(2) of the Code states that every consumer has "the right to have his or her privacy respected". This right only covers privacy issues "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" (section 20(1)(c) of the Act and clause 4 of the Code).⁷⁷ In effect, this means that the right to privacy in Right 1 of the Code excludes any matters that may give rise to a complaint under the Privacy Act or the Health Information Privacy Code (HIPC).⁷⁸

The Health Commissioner Bill originally provided that the Code must contain a right to privacy and confidentiality of personal information,⁷⁹ but that provision was amended in the final Act to state that the Code could only contain rights relating to matters of privacy that were not covered by the Privacy Act.⁸⁰ Thus, from the outset the Code was expressly prohibited from containing any rights relating to information privacy, which was already regulated by the Privacy Act, passed the year before the HDC Act.

The Code is thus restricted to protection of a patient's physical privacy (such as facilities for undressing that preserve the patient's privacy or the manner in which a provider

 ⁷⁷ Part 7 of the Privacy Act 1993 addresses the public register of private information; Part 8 covers complaints of interference with privacy; and Part 10 deals with information matching. The Privacy Commissioner has a right to issue codes under section 46 of the Privacy Act 1993.

⁷⁸ A breach of the HIPC is, pursuant to section 53 of the Privacy Act 1993, a breach of an information privacy principle under Part 8 of that Act. The HIPC governs the collection, holding, use and disclosure by health agencies of personal information relating to health.

⁷⁹ The second reading of the Bill provided for the Code to cover the right for privacy and confidentiality of personal information; see Parliamentary Debates (Hansard), vol 543, 27 September 1994, p 3736.

⁸⁰ See section 20(1)(c) of the Act.

conducts a physical examination of a patient),⁸¹ and does not apply to privacy or confidentiality of health information. The Commissioner has no jurisdiction over and is obliged to refer a complaint alleging breach of confidentiality (or the relevant part of it) to the Privacy Commissioner as a matter more properly within the scope of her functions (section 36).

Very occasionally, the Commissioner has taken action in relation to what are, in substance, complaints of breach of information privacy. It has been suggested that a complaint may be retained by the Commissioner for resolution where "the information privacy principle is only a minor aspect of the complaint and the other issues are covered by the Code".⁸² Although a sensible approach (as it is surely in the parties' interests not to have the complaint split between agencies), it is not straightforward as a matter of law. In some circumstances, a breach of the duty of confidentiality can amount to a breach of Right 4(2), "the right to have services provided that comply with legal, professional, ethical, and other relevant standards". This is possible because the duty of confidentiality is both a legal duty under the Health Information Privacy Code and an ethical duty imposed on most health practitioners by professional codes of ethics. The following case is an example of the overlap.

Opinion 01HDC03691 (17 May 2002)

This case concerned a GP (Dr A) who failed to advise her female patient that her test result disclosed that she had contracted gonorrhoea, instead telling her only that she had a "bacterial infection". Dr A's partner in the practice (Dr B) treated the woman's husband, who had disclosed to Dr B that he had contracted gonorrhoea on an overseas trip, did not want his wife to know, but wanted her tested and if necessary treated. When the woman later discovered the true nature of her condition, she asked Dr A if it was likely that she had contracted it from her husband. Dr A replied that it was possible her husband had been unfaithful, but that the condition could also be contracted through contact with a contaminated toilet seat.

The Commissioner found that Dr A breached Rights 4(2) and 6(1)(a) of the Code in not fully informing the woman that she had gonorrhoea and its likely cause, and breached Right 6(3) in misleading her that her husband could have caught gonorrhoea from a toilet seat. It was noted that Rule 11 of the Health Information Privacy Code would not have authorised Dr A to reveal her husband's gonorrhoea status to her patient.

In respect of Dr B, the Commissioner found him in breach of Right 4(2) of the Code for his handling of the confidential information about the husband's gonorrhoea status. It was noted that Rule 11(2)(d) of the Health Information Privacy Code would not have justified Dr B in revealing to the woman her risk of exposure to gonorrhoea from her husband without first attempting to counsel him and persuade him to make the disclosure himself. The finding in respect of Dr B is more problematic than that relating to Dr A (which fell squarely within Right 6 of the Code), since the decision that Dr B had inappropriately disclosed the husband's gonorrhoea status to Dr A involved the proper handling of Mr A's health information and was therefore strictly an issue for the Privacy Commissioner.

⁸¹ See, for example, *Director of Health and Disability Proceedings v DG* [2005] NZHRRT 3 (25 February 2005), and *Director of Health and Disability Proceedings v DG* [2005] NZHRRT 2 (25 February 2005).

 ⁸² See P Skegg & R Paterson, *Medical Law in New Zealand* (Thomson Brookers, 2006), para 2.6.2 note 62.

Others issues with the current system include:

- HDC may have jurisdiction on the basis that confidentiality and compliance with the HIPC are standards that providers must comply with under Right 4(2). However, this seems an artificial means of circumventing the narrow definition of privacy in Right 1(2) to determine the breach of the Code.
- 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 a different agency (the Privacy Commissioner). This can detract from seeing a complaint in its totality.
- Health practitioners who breach the duty of confidentiality, a core ethical duty, cannot be held accountable under the Code and in particular by the Director of Proceedings' process before the Health Practitioners Disciplinary Tribunal.

In my view, the provision in the Act excluding information privacy from being included in the Code has prevented the preferable and more flexible approach adopted for complaints alleging breach of "the right to be free from discrimination" in Right 2. There is a concurrent jurisdiction with the Chief Human Rights Commissioner in respect of these, meaning that the two Commissioners can then consult and decide on who most sensibly should decide the complaint.

A simple solution would be to amend section 20(1)(c)(i) of the Act (and clause 4 of the Code) to delete the exclusion of information privacy, so that the right to have privacy respected in Right 1(2) would extend to privacy of information. This would allow for concurrent jurisdictions over complaints relating to health information privacy, and a referral power between HDC and the Privacy Commissioner in appropriate cases (as there is for discrimination with the Human Rights Commission). Such a system works effectively between the HDC and the Human Rights Commission under Right 2 of the Code. It would remove the need to divide a consumer's complaint where part of the complaint involves an alleged breach of information privacy or where the provider's conduct in relation to privacy is evidence of an unprofessional attitude generally. The rare exceptions to patient confidentiality currently recognised by the general law, as well as others that might develop in accordance with societal change, could be accommodated within the "reasonable actions" defence (clause 3 of the Code).

As a preliminary response to this review, the Privacy Commissioner queried the desirability of shared jurisdiction, but suggested that the HDC Code may benefit from amendment so that it "appropriately supplements privacy rights in the sector and fills gaps not well covered by the Privacy Act". For example, the Privacy Commissioner suggested further controls on the handling of body parts or substances; specific standards relating to physical privacy, including intrusion into solitude; and noted the need to capture dignity, ethical and disclosure issues where there is no identifiable patient information.

The Australian Law Reform Commission's recent review of privacy laws resulted in a number of recommendations about health privacy, including a proposal that the Privacy Commissioner delegate the power to handle complaints under the Privacy Act to state and territory health complaint authorities.⁸³ The New Zealand Law Commission is currently undertaking a review of privacy values, technology change, and international trends, and their implications for New Zealand law.⁸⁴ In the report on stage one of this review, the Law Commission stated that the central issue for health information is "to achieve a proper balance between keeping personal health information confidential and getting the right information to the right person, at the time when it is needed" (page 23, para 76). The Commission noted that the delivery of health care raises complex questions about how to reconcile privacy and confidentiality with the need to share information for the benefit of the patient, or for the benefit of the wider society (page 204, para 8.78). While members of the health professions are under stern ethical duties of patient confidentiality to protect the information about the patient they have collected, they need to be able to communicate that information between themselves (page 205, para 8.79). The Commission concluded that it was their initial impression that it "may be worth considering designing a purpose-built health information statute that lays down a clear framework as to the following issues": who may gather personal health information; who may use it, for what purposes, and under what conditions; how the information may be communicated within the health system, and subject to what protections; how the information may be held, and by whom; and how information may be used by health researchers (page 208).

In my view, issues of the confidentiality of, and access to, health information are so integral to the rights of health and disability services consumers that they should be protected in the Code. I consider that it would be a rational and sensible extension.

I welcome further discussion or feedback on this matter — see Question 4.

⁸³ Australian Law Reform Commission, *For Your Information: Australian Privacy Law and Practice* (May 2008) volume 3, chapter 60, pages 2013–2041 (para 60.54).

⁸⁴ See Privacy: concepts and issues: review of the law of privacy: stage 1 (NZLC SP19, Law Commission, Wellington, 2008). This report is also available on the Internet at the Law Commission's website: <u>www.lawcom.govt.nz</u>.

APPENDIX 3 — HEALTH AND DISABILITY SERVICES CONSUMER ADVOCACY SERVICE

3.1 Overview

Part III of the Act provides for an independent advocacy service for health and disability services consumers who wish to complain about an alleged breach of the Code of Health and Disability Services Consumers' Rights. Consumer advocacy has proved to be a very successful means of resolving complaints that appear to raise no issues of exploitation or public safety. Complaints suitable for advocacy assistance may include:

- complaints involving communication issues, including being given relevant information;
- complaints involving the attitude of the provider (eg, lack of courtesy and rudeness);
- complaints involving issues where the dignity and/or independence of a consumer have not been respected;
- situations where there is an ongoing relationship between the parties and it is important that a good relationship is maintained (eg, ongoing care situations);
- complaints involving lack of co-operation among providers;
- complaints involving misunderstandings brought about through a lack of understanding around cultural and social issues;
- complaints involving a minor lapse in the provider's standard of care;
- complaints about events that occurred prior to 1 July 1996.

Consumers can access local advocates, who assist them to clarify the issues giving rise to a complaint and the options for resolving the complaint. Consumers are then supported by advocates in raising the complaint with the provider in an effective manner, usually through a meeting or correspondence. This process allows consumers to assert their concerns in a way that increases their confidence and allows them to achieve direct and early resolution of their complaint.

From the provider's point of view, the advocacy process allows the provider an opportunity to understand the issues behind a complaint and to respond in an environment that is less formal and stressful than having the complaint investigated by the Commissioner.

Sections 24 to 30 of the Act set out how advocacy services are to operate. In particular, they deal with the appointment and functions of the Director of Advocacy, the establishment and operation of the advocacy services and the functions of advocates.

3.2 Structure of advocacy services

The Act provides for the Commissioner to appoint a Director of Health and Disability Services Consumer Advocacy. The Director of Advocacy is responsible to the Commissioner for the efficient, effective, and economical management of his or her activities.⁸⁵ The functions of the Director of Advocacy are set out in section 25 as being:

⁸⁵ Section 24(3).

- (a) To administer advocacy services agreements;
- (b) To promote, by education and publicity, advocacy services;
- (c) To oversee the training of advocates; and
- (d) To monitor the operation of advocacy services, and to report to the Minister from time to time on the results of that monitoring.

In addition the Minister approves guidelines for the operation of advocacy services. These guidelines are issued by the Commissioner.⁸⁶

The structural independence of the Director from the Commissioner was introduced into the legislation both to protect the advocates' role in acting on the side of the consumer and the Commissioner's impartiality when investigating and mediating complaints. Concern had been expressed in the developmental stages of the legislation that the Commissioner's position might be compromised if advocates operated directly under the Commissioner's control. 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 investigating complaints. The decision was therefore made to place advocacy services under the control of an independent Director.

The Act enables the provision of independent advocacy services to health and disability services consumers through agreements entered into by the Director of Advocacy on behalf of the Crown. This is the contracting or purchaser–provider split which was fashionable in the New Zealand health sector in the 1990s. The definitions of "advocacy services agreement" and "advocacy services" in the Act mean that the Director must contract with independent advocacy service providers. This structure enables the advocates to be "partial" in their support of the consumer, and protect the impartiality of the Commissioner.

An advocacy organisation may exist and provide services independently of HDC. While those services may be delivered in any manner, an "advocacy services agreement" under the Act is a contract to provide advocacy services, and it is negotiated and entered into on behalf of the Crown. The Director of Advocacy has the responsibility for that negotiation.⁸⁷ The terms and conditions must require not only economical, but also efficient and effective management, and the service must operate in accordance with the advocacy guidelines.

Initially advocacy services were provided by ten separate organisations, each covering a different region of New Zealand. From 1999 until 2006 there were three service providers, and following discussion and consultation in 2005, a tendering round in 2006 led to a contract with a sole provider who covers the whole country (National Advocacy Trust).

The advantages of having advocacy services provided by one organisation have been:

- creation of national leadership and support roles within the one service;
- better access to a range of skills and expertise for consumers;

⁸⁶ Sections 28 and 29.

⁸⁷ Section 27.

- consistency of human resource policies and salaries nationwide; and
- in theory, consistency of service across the country is more achievable.

3.3 Does the current structure of advocacy services best serve the purposes of the Act?

While there have been benefits with a sole provider of core health and disability advocacy services nationwide, there remain problems with the current contracting structure. Accordingly, the Director of Advocacy has explored other structures and now wishes to consult on those.

In the first review of the Act in 1999, it was recommended that advocates become employees of the Commissioner, but with the obligation to act independently, in order to offer a more centralised service. While some submissions supported the proposal, particularly if it would streamline the service and promote consistency of high quality advocacy services, some thought that the Director should employ the advocates (rather than the Commissioner). There were also some concerns that the community focus of services would be eroded and that the roles of advocates and the Commissioner in respect of receiving and resolving complaints could become further blurred. The recommendation was not pursued.

In the intervening nine years, there have continued to be challenges with the contractual model for advocacy services. The service has become centralised and streamlined by the recent shift to a contract with one national advocacy provider, so the questions now are whether a contract mechanism is the best way to achieve independence and whether the advocacy service should be provided publicly or privately. It is therefore time to reconsider the current contracting model, to consider how best to ensure effective independent advocacy services for consumers. The following options are put forward for consultation:

3.3.1 Option 1: Status quo — retaining the contracting model

Current arrangement

The contracting model does allow the maintenance of the independent function of advocates, who support consumers, separate from the Commissioner's varied functions, which include the impartial investigation of complaints. It also allows the Director of Advocacy to enter into contracts for specialist advocacy services (eg, for a particular consumer group) as well as the core health and disability advocacy service. However, under the current structure it is difficult for the Director of Advocacy to meet the statutory requirements, and in practice the accountability arrangements are problematic. Some examples of the problems include:

- Quality assurance for advocacy services. The Director of Advocacy has no role in the recruitment, performance management or discipline of advocacy staff or their terms and conditions of employment. This has made it difficult to ensure a consistent standard of advocacy services around the country.
- Meeting the ethical standards expected of public servants. While the Director of Advocacy is a public servant and the advocacy services are purchased with public funds, the service is delivered by employees of a private organisation, who are not covered by Public Service Code of Conduct and other rules and policies established by the State Services Commission for the benefit of the

public. The Director is also unable to delegate his or her responsibilities to an experienced advocacy manager.⁸⁸

- Loss of control of public funds once transferred to the contracted advocacy service provider. An incompetent or unethical provider of advocacy services could apply funds wrongly, and intervention via a claim for breach of contract may not be timely enough to preserve all funds. The service and resources are accumulated by the private organisation, rather than retained by the public service.
- Unnecessary layers in the management and administration of service delivery, resulting in inefficiencies.

Within the current contracting model there are other possible variations, which have not been implemented to date. The Director of Advocacy supports consultation on these proposals:

Renewable contract arrangements with preferred providers

In negotiating and entering into core advocacy service agreements to date, the Director of Advocacy has operated a tendering round and assessed proposals. As noted above, the last round resulted in a single contract for services with the Nationwide Advocacy Trust.

This option would have the Director identifying a preferred provider(s) for core advocacy services, so a regular tendering round would not be required. This would provide certainty for a provider such as the National Advocacy Trust and reduce the risk of challenges to tendering decisions.

Because of the specialist nature of the core advocacy service there are not other contestable providers ready to provide even a comparable service. This reality was clearly revealed during the last tendering round, where significant set-up expenditure would have been required for any new providers to take on such a role.

This approach, however, would have the same limitations of a contracting relationship. This could also be problematic if a future Director wanted to take a different contracting approach, as this would be contrary to the expectations of the preferred provider/s.

Contracts with individual advocates

While it has never occurred, it is possible within the existing statutory framework for the Director of Advocacy to contract on behalf of the Crown with individual advocates to provide advocacy services. Each contract would be an individual "contract for services". The advocate would be an independent contractor. This is different from an employee, who has a "contract of services". Consideration would need to be given to the responsibility under the contract for hire of office space and products, IT, telephones and so on.

⁸⁸ Section 68(5) only allows the Director of Advocacy, with the prior approval of the Commissioner, to delegate to any person holding office under the Commissioner.

3.3.2 Option 2: Advocates as HDC employees

One option would be for advocates to be HDC employees. This would resemble the current structure of the Director of Proceedings, who leads a small proceedings team. Like the Director of Advocacy, the Director of Proceedings is an employee of the Commissioner and is an independent statutory officer, responsible to the Commissioner for the "efficient, effective, and economical management" of his or her activities, but not responsible to the Commissioner in exercising the powers, duties and functions of the role (section 15). Recruitment and management of the staff is undertaken by the Director of Proceedings, with appointment of staff approved by the Commissioner, as employer. The current proceedings team operates independently within the Wellington office of the Commissioner. All the team's corporate support services such as payroll, IT, telephone, photocopiers and stationery are provided by HDC. The Director of Proceedings reports that this system has worked well.

Features of this model would be that the Director of Advocacy would have direct involvement in ensuring the quality and consistency of service, particularly in relation to recruitment and management of personnel, and the wise use of resources.

An amendment to section 25 ("Functions of Director of Advocacy") to include the recruitment and management of staff as statutory functions of the Director would rectify the position by making those tasks independent of the Commissioner, subject to the statutory accountability for the efficient, effective and economic management of advocacy. Although the Commissioner could legitimately have input into the employment of advocacy personnel, he or she would not be able to interfere in the recruitment and management of staff. The current contracting provisions in the Act would be repealed.

It might be argued that, as the advocates would be employees of the Commissioner, there is potential that the independent function of advocacy would be compromised. However, in practice, this has not been an issue for the Director of Proceedings. HDC has provided corporate support services to the Director of Proceedings and her team (all of whom are employed by HDC) but the Director manages their workload independently of the Commissioner.

This option may be seen to combine a simple way of ensuring a consistent quality of service, with appropriate accountability (albeit for independent functions).

3.3.3 Option 3: Independent Office of Advocacy with advocates as employees

A third approach is based on the model of the Office of the Human Rights Proceedings (OHRP) under the Human Rights Act (section 20). The Director of Human Rights Proceedings is appointed by the Governor-General and heads the OHRP. The Director employs staff directly (Schedule 2) and the legislation specifies that they are to "help him or her to exercise or perform the functions, powers, and duties of the Director under this Act". Although part of the Human Rights Commission, the Director of Human Rights Proceedings and his or her staff are required to act independently from the Commission. While not a Crown Entity, certain provisions of the Crown Entities Act apply to the Director of Human Rights Proceedings.

Like the existing arrangements between the independent Directors and the Health and Disability Commissioner, the Director for Human Rights Proceedings is responsible to the Chief Human Rights Commissioner for the efficient, effective and economical management of his activities. Adopting a similar arrangement for the Director of Advocacy would have the same advantages as Option 2, while maintaining the independence of the advocates from the Commissioner. In addition it would provide some distance from the Commissioner in the case of a complaint about advocacy services.

Adopting this approach may necessitate a change to the way the Director of Advocacy is appointed (to appointment by the Governor-General). Whereas the Commissioner and Deputy Commissioners are appointed by the Governor-General, the two independent Directors are currently appointed and employed by the Commissioner (section 24). Consideration would then need to be given to whether the Director of Proceedings should be appointed in the same manner. This could involve a lengthy official process and would add further complexity to the governance arrangements for the Office of the Health and Disability Commissioner.

3.3.4 Role of National Advocacy Trust

Pursuing either option 2 or 3 poses important questions about the future of the existing National Advocacy Trust which was created specifically for the purpose of providing the advocacy service for the Director. The current contract between the Director of Advocacy and the National Advocacy Trust expires on 30 June 2011. The Trust members have shown a strong commitment and dedication to the advocacy service and have a long history and knowledge of the service. They must clearly share the credit for the success of the service and the high regard with which it is held. In addition, as the current employer of the advocacy personnel, it is important that the Trust has an active role in any transition of the service to a different arrangement.

Community input is a valuable way to keep the advocacy service relevant and on track. This could be achieved by a national advisory group with links to the community generally, and with input from specific communities such as Māori, Pacific peoples and rural communities. The experience and knowledge of the existing national trust members makes them well placed to continue in a community advisory and liaison role rather than an employment and governance one.

I welcome your thoughts on whether the current contracting model for providing advocacy services is appropriate. If not, which of the two alternative options identified above do you support and why? See Question 5.

APPENDIX 4 — DIRECTOR OF PROCEEDINGS

4.1 Role of the Director of Proceedings

One of the options available to the Commissioner at the end of an investigation is to refer a provider to the Director of Proceedings (the Director), an independent statutory officer appointed under section 15 of the Act. Upon receiving a referral from the Commissioner, the Director must decide whether to institute proceedings against the provider. Although the Director may provide representation or assistance to complainants in any forum (eg, a court, tribunal, inquiry), the primary focus is on proceedings in the Health Practitioners Disciplinary Tribunal or the Human Rights Review Tribunal, and sometimes both.

The Health Practitioners Disciplinary Tribunal hears charges of professional misconduct against registered health practitioners. This includes medical practitioners, nurses, midwives, dentists, chiropractors and pharmacists.

Where the health provider is not a registered health practitioner, the Director may file proceedings before the Human Rights Review Tribunal. Non-registered health practitioners include providers such as counsellors, massage therapists and acupuncturists. Action may also be taken against bodies such as rest homes and District Health Boards as well as against a registered health professional (whether or not disciplinary proceedings are also brought). Unlike the Health Practitioners Disciplinary Tribunal, the Human Rights Review Tribunal has the power to order the provider to pay compensation to the aggrieved person. However, because of the limitations imposed by ACC legislation, compensatory damages are available only in limited circumstances.

Under section 44 the Commissioner may not refer a provider to the Director unless the provider has been given an opportunity to comment on the proposed referral, and the Commissioner is required to have regard to any comments from the provider, as well as the wishes of the complainant/consumer and the public interest.

Where the Commissioner has found a breach of the Code but does not refer the matter to the Director, or where the Director decides not to institute proceedings before the Human Rights Review Tribunal, an aggrieved person may personally bring proceedings. This does not apply to disciplinary proceedings, which may be issued only by the Director or a professional conduct committee appointed by a registration authority.

4.1.1 Referral to the Director of Proceedings

As a preliminary comment to this review, the Director of Proceedings pointed out that section 14(1)(f) does not specify that the Commissioner must have undertaken an investigation before referring a provider to the Director of Proceedings.⁸⁹ It is suggested that the Act should be amended to clarify that the Commissioner can only refer a provider to the Director of Proceedings *after* undertaking an investigation (ie, referral pursuant to section 45(2)(f)).

⁸⁹ Section 14(1)(f) states: "To refer 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 or alleged breach."

4.1.2 Action by Director of Proceedings without referral

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, but 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. This decision has been based on interpretation of the relationship between sections 47 and 49. A number of factors support this interpretation, including the fact that the powers of the Director are contained in Part IV of Act, which is entitled "Complaints and Investigations", and are under the sub-heading "Investigations by the Commissioner"; there is no express "function" in section 49 conferring upon the Director a power to take any of the actions contemplated by section 51 makes no reference to the aggrieved person's ability to seek representation from the Director.

In addition, it is clear that there is no power to provide representation or issue proceedings in the Human Rights Review Tribunal pursuant to section 47. It is apparent that the use of the word "tribunal" does not refer to the Human Rights Review Tribunal. This is because wherever the word "tribunal" appears in section 47, it has a lower case "t". Pursuant to section 2 of the Act, "Tribunal" with a capital "T" refers to the Human Rights Review Tribunal, and in sections 50 to 57, the Human Rights Review Tribunal when referred to as "the Tribunal" always has a capital "T".

This gives rise to the question whether, in fact, the public should be able to make a direct approach to the Director of Proceedings. One of the Commissioner's functions under section 14(1)(f) of the Act is to "refer complaints, or investigations on the Commissioner's own initiative, to the Director of Proceedings". On first reading, it appears to be saying that the Commissioner may refer a complaint without an investigation taking place. Yet the basis of referral to the Director is set out in sections 44 and 45. The referral takes place after an investigation, and there must be consultation before the matter may be referred. Clearly, the distinction in section 14(1)(f) is between a "complaint" and a Commissioner-initiated investigation where there has been no complaint. In either case, it is clear from the later provisions of the Act that there must be an investigation prior to referral.

The practical difficulty with other interpretations (ie, that the Commissioner may refer a complaint without investigation, or that the public may make a direct approach to the Director of Proceedings) is that it would preclude the entire complaints and investigations process, under which the Commissioner has a considerable range of options. In contrast, the Director has no power to investigate, mediate, or refer the complaint to the provider or any other body, and has insufficient resources to do so. If complainants were able to submit complaints directly to the Director, the Commissioner's role under this part of the Act would be duplicated, but not the range of powers.

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 after investigation.

Question 21

Do you agree that section 47 should be amended to clarify that the Director of Proceedings may take action only upon referral from the Commissioner?

4.1.3 Ability to obtain further 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. Because the Director's powers and functions are independent, the Commissioner and his staff are no longer involved in the matter. Once a charge has been laid, the tribunals may subpoena information on the application of a party, but sometimes this information is important in the consideration, under section 49, of whether to take action in the first place. Therefore, 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 HDC Act, or under any other act, to compel the production of information.

The need for further information may arise in several circumstances. The Director, in undertaking an independent review of the investigation, may consider a certain piece of information highly relevant in deciding whether to lay a disciplinary charge against a provider. The Commissioner may not have needed it in order to form an opinion that the Code has been breached, but it may have more significance in satisfying the Health Practitioners Disciplinary Tribunal that there has been conduct that amounts to professional misconduct and warrants a disciplinary sanction. The focus of the Commissioner's investigation is not on preparation for litigation.

Sometimes further information is obtained that puts certain other issues into a different light. An allegation found by the Commissioner not to be proven may later appear more capable of proof, yet there are limitations on the Director of Proceedings' ability to explore it further.⁹⁰

The Director of Proceedings considers that it would be useful if he or she were given the same investigative powers as the Commissioner for the period from referral until a decision has been made under section 49 to issue any proceedings. Sometimes the Director decides to lay a charge in the Health Practitioners Disciplinary Tribunal and puts on hold the decision regarding Human Rights Review Tribunal proceedings. It is recommended that any ability to require information would end at the time of the first decision under section 49. The additional powers could be included in section 49.

Question 22

Should the Director of Proceedings have the same powers as the Commissioner under section 62 until a decision has been made pursuant to section 49 to issue proceedings?

⁹⁰ If the Director of Proceedings is considering pursuing a matter that was not the subject of a breach finding by the Commissioner, the Director must observe the rules of natural justice and allow the provider an opportunity to respond.

4.2 Human Rights Review Tribunal proceedings — ss 50–58

4.2.1 Direct action in the Human Rights Review Tribunal

Section 51, enacted by the HDC Amendment Act, has given aggrieved persons greater access to the Human Rights Review Tribunal, by enabling a claim to be made where the Commissioner has formed an opinion that the consumer's rights have been breached but has not referred the provider to the Director of Proceedings, or where a referral is made but the Director does not issue proceedings in the Human Rights Review Tribunal.⁹¹

This proposal was strongly opposed by many health practitioner groups in submissions and through the media. Some legal commentators feared it would result in a surge of litigation. This has not been the case. To date, few matters have been taken to the Human Rights Review Tribunal by a complainant, rather than the Director.

Because the Act requires the Human Rights Review Tribunal to have regard to the findings and penalty imposed in disciplinary proceedings,⁹² the Director of Proceedings may decide to issue a disciplinary charge against a registered practitioner, but put on hold the decision regarding Human Rights Review Tribunal proceedings, pending the outcome of the disciplinary charge. It is also possible that the Director could delay for other reasons. Where the Director has not yet made a decision about proceedings, it is not clear under the current Act, at what point it could be shown that the Director has "failed" to bring proceedings. The Director of Proceedings has raised this question because delay on the part of the Director could have adverse consequences for the claimant under the Limitation Act, the details of which are discussed below.

Question 23

Should the Director of Proceedings have to make a decision to issue Human Rights Review Tribunal proceedings within a certain timeframe, after which point the Director might be deemed to have "failed" to bring proceedings?

On occasion, the Director has issued Human Rights Review Tribunal proceedings, then re-evaluated and decided to withdraw. The aggrieved person cannot then bring proceedings. Yet if the Director of Proceedings had made a decision declining to issue proceedings in the first place, the aggrieved person would have been able to make his or her own claim. In reality, the decision to withdraw is usually based on prospects of success, and the Director's desire to minimise any costs awards against the Commissioner should the claim not succeed. Such a decision is made in consultation with the aggrieved person, and so the likelihood of a claim then being brought is slim.

Question 24

Should an aggrieved person be able to bring proceedings where the Director of Proceedings has decided to withdraw a claim, or reverses an initial decision to issue proceedings?

⁹¹ Section 51.

⁹² Section 54(5).

4.2.2 Limitation periods for bringing proceedings

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. The effect of the current limitation legislation is that, in cases of bodily injury, a court proceeding must be brought within two years from the date on which the claimant became aware of the damage and, in all other cases, six years. Because the earliest point at which aggrieved persons can access the Human Rights Review Tribunal is once an HDC investigation has been completed, the aggrieved person (who has been through the investigation) is disadvantaged compared with a prospective litigant in another jurisdiction, who effectively has an "entitlement date" from the time the acts or omissions occurred, with a limitation period commencing then. At this stage it is expected that any amendment to the Limitation Act will continue to contain rules of general application, and special limitation rules contained in specific Acts will continue to prevail.

The Director of Proceedings has 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. This contrasts with any other litigant who can bring a claim in a court as soon as the damage arises.

Question 25

Should the Act be amended 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? If so, how long should the Director of Proceedings or individual person have to bring a claim once the Commissioner has found a breach?

4.2.3 Aggrieved person

The term "aggrieved person" is not defined in the Act. It has been the source of some litigation. Prior to amendment by the HDC Amendment Act 2003, the words first appeared in section 49, where, in deciding whether to issue proceedings, the Director of Proceedings was obliged to:

"have regard to the wishes of the complainant (if any) and the aggrieved person (if not the complainant) in relation to that matter".

Since amendment to the Act, that function has now shifted to the Commissioner. The term now first appears in section 43(2) where the Commissioner must advise relevant persons of the outcome of an investigation. Relevant persons include any complainant and "any person alleged to be aggrieved (if not the complainant)". "Aggrieved person" no longer appears in section 49, but it continues to be used from section 50(4) of the Act onwards in relation to proceedings before the Tribunal. Where proceedings are commenced by the Director:

"... neither the complainant (if any) nor the aggrieved person (if not the complainant) shall be an original party to, or unless the Tribunal otherwise orders, join or be joined in, any such proceedings".

In sections 50 to 58 of the Act, which deal with proceedings before the Human Rights Review Tribunal, there is no reference to health or disability services consumer. This contrasts with the terminology earlier in the Act. Rather, the term "aggrieved person" is used. Section 52(2) prevents claims for damages (other than punitive damages) arising out of personal injury. Such damages are barred when claimed by "any person" who has suffered "personal injury". In this context, the words "aggrieved person" or "consumer" are not used.

Hansard's Parliamentary debates do not assist in interpretation of the words "aggrieved person" in the HDC Act or the Human Rights Commission Act 1977, which preceded the Human Rights Act, where the term "aggrieved person" is used.

In *Director of Proceedings v O'Neil*,⁹³ the High Court interpreted "aggrieved person" as including non-consumers, where the Director claimed, not on behalf of the deceased baby but on behalf of both parents, where 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."⁹⁴ In *Harrild v Director of Proceedings*,⁹⁵ the Court of Appeal left open the question whether the father, in a case of negligent obstetric care, could claim damages as an aggrieved person.

The Director of Proceedings has successfully argued before the Human Rights Review Tribunal that the term includes, but is not limited to, a health or disability services consumer and should not be interpreted in an unduly restrictive manner.⁹⁶ In response to concerns that this would open the floodgates on litigation, the Tribunal observed:

[56] In this case, the Director will have the burden of establishing that there is a sufficient connection between the alleged breach of the Code and the harm (to use a general word encompassing all of the different losses contemplated by s.57) suffered by the parents so as to justify a finding that the parents were aggrieved by the breach.

[57] There are no hard and fast rules, but obviously the more distant the relationship between someone who has suffered at the hands of a health care provider and the person claiming to be aggrieved, then the more difficult it will be to establish a grievance which will justify an award of damages.

The Director of Proceedings has suggested that definition of this term would be useful in deciding whether or not to institute proceedings in the Human Rights Review Tribunal.

Question 26

Should the term "aggrieved person" be defined? Should it be limited to health or disability services consumers?

⁹³ [2001] NZAR 59.

⁹⁴ Ibid, para 20.

⁹⁵ [2003] 3 NZLR 289.

⁹⁶ Director of Proceedings v Marks [2005] NZHRRT 37 (23 December 2005). The Tribunal's decision was the subject of an unsuccessful application for judicial review in the High Court, Marks v Director of Health and Disability Proceedings [2008] NZAR 168 and an appeal will be heard by the Court of Appeal in February 2009.

APPENDIX 5 — DISABILITY SERVICES CONSUMERS' RIGHTS

The recent Social Services Select Committee "Inquiry into the quality of care and service provision for people with disabilities" (the Disability Inquiry) highlighted a number of issues relating to how disability services consumers' rights are protected. In light of this, HDC is canvassing the level of support for a change in legislation that will enable HDC to better serve people with disabilities — see Question 2 above.

5.1 Select Committee report

The Social Services Select Committee (the Select Committee) has recently reported on the Disability Inquiry.⁹⁷ The report contains a number of recommendations for how the quality of care and service provision for people with disabilities could be improved. In relation to advocacy and complaint processes, the Committee has recommended to the Government that it:⁹⁸

- Investigate the appointment of an independent disability commissioner, possibly within the office of the Health and Disability Commissioner. Any required legislation should also expand the areas the commissioner may examine to include, for example, access to services and individual funding issues. The commissioner should be responsible for considering disability issues in relation to health, education, social development, and housing, and promote the recognition that disability is a fact of life and not primarily a health matter.
- Implement legislative change to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities. This should enable the independent disability commissioner to oversee access to disability services.
- Make it possible for complaints about disability support to be lodged verbally, to improve access for people with disabilities.
- Establish an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.
- Require the disability commissioner to establish a process for checking that his or her recommendations have been acted upon.

5.2 HDC's perspective

In HDC's submission to the Select Committee,⁹⁹ we highlighted certain areas of concern about the quality of disability services as highlighted in complaints to the Office, and the fact that HDC is limited in what action can be taken because many complaints received

⁹⁷ 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), available at <u>www.parliament.nz/en-NZ/SC/Reports/</u> [Disability Inquiry Report].

⁹⁸ Disability Inquiry Report, pages 36–37.

⁹⁹ Available at <u>www.hdc.org.nz/publications/submissions</u>.

about disability services are outside the Commissioner's jurisdiction.¹⁰⁰ Furthermore, few complaints received by HDC are specifically about disability service provision.

The most common reason for complaints about disability services being outside HDC's jurisdiction is that the concerns relate to access or funding of services (rather than the quality of the service provided). Others are outside of jurisdiction because they do not involve a health or disability service. In order for HDC to have jurisdiction to consider a complaint in accordance with the Act and Code, there must be a disability services consumer, a disability services provider, a disability service, and an apparent breach of the Code. Definitions of all of these terms are found in sections 2 and 3 of the Act. It is worth noting that the definitions of "disability services providers" and "disability services consumers" in the Act are relatively broad and inclusive.

Here is an example of how disability services are funded or decisions about access to goods or services result in poor quality services.

A mother of an adult woman living in a residential home was concerned that she had been told by the service provider and an auditor that her daughter would no longer be able to come and stay with her at weekends, despite the fact that her daughter enjoyed doing so. The reason given was that having her daughter home would affect the provider's "bed-night" funding levels and therefore she would only be able to have her daughter at home for a total of 21 days per year.

This example illustrates that the way a service is funded can conflict with the needs of individual consumers (potentially in breach of Right 4(3) of the Code, the right to have services provided in a manner consistent with his or her needs). Consumers also report that time pressures sometimes mean that providers/carers do not provide services that respect the consumer's independence, as required by Right 3 of the Code, but instead do tasks themselves rather than take the time to help the consumer be more independent or retain his or her independence.

However, if the reason for the services being provided in a manner that is inconsistent with the consumer's needs is that the funding requires the service to be provided in that way, the provider will often have taken reasonable actions in the circumstances in light of their resource constraints (meaning that they have not acted in breach of the Code; see clause 3 of the Code). In these circumstances, there is no apparent breach of the Code and therefore the Commissioner has no jurisdiction to take action.

The explanation that consumers and families often receive for reductions in support is that the funding has gone. Disabled consumers and their families often find it difficult obtaining adequate information to allow them to understand the process for needs assessments, reviews and funding. There appears to be a lack of information and

¹⁰⁰ From January 2000–August 2006, the Office of the Health and Disability Commissioner received 192 complaints about disability services, 34% of which were outside jurisdiction. Other decisions made on complaints were: no further action being taken on the complaint (23%); referral to Advocacy (13.5%); Resolution, other than Advocacy — usually by provider response (11%); referral to another agency (5%); investigation (2%).

ongoing, meaningful dialogue with disabled consumers about rationing and prioritisation of resources. The advocacy service often assists consumers concerned about the lack of information and explanation when changes are made to disability services.

Here is an example of a complaint that technically relates to access to services or goods for a disabled consumer, but also raises quality of service issues:

A father of a disability consumer approached HDC completely frustrated by his experience of moving from one District Health Board (DHB) area to another. His adult son, whom he cares for at home, uses a wheelchair, has physical and intellectual disabilities, is incontinent of urine and faeces, and has communication difficulties. Prior to leaving his home town he communicated with the new DHB to organise a supply of incontinence pants. The father was specific about the size and absorbency required (large with thick absorbency), yet it took six months to get the correct pants. This was also an infection control issue.

The father felt that if he had been provided with information on the process for applying for incontinence pants across DHB boundaries, he would have been saved a great deal of expense, time and energy. He also found it difficult to understand why the system in the second DHB area was so cumbersome, when applying for incontinence pants had been a straightforward process with the previous DHB. He wanted to know why there was not a standard process for all DHBs.

5.3 Extension of jurisdiction?

The issues identified by the Disability Inquiry suggest that it is necessary to explore whether disability service consumers would benefit from extending HDC's jurisdiction in relation to disability. A separate issue is whether the responsibility for handling complaints about disability services should remain with HDC, or whether a separate Commissioner (or other agency) should take over.

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".¹⁰¹

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). However, while it may be *ultra vires* to include an access right for consumers generally, such a right in respect of disability services consumers (who commonly experience acute difficulties accessing disability services) may be able to be included in the Code pursuant to s 20(2)(a) of the Act.

Interestingly, the Act does not define "disability", but merely refers to a "person with a disability". I note that there are differing opinions regarding how a disability should be

¹⁰¹ Disability Inquiry Report, page 36.

defined, influenced by the "medical model" and "social model".¹⁰² The definition of "disability services consumer" is somewhat restrictive in who it covers. For a person to fall within the definition of "disability services consumer" under the Act, the disability must reduce his or her ability to function independently *and* mean that he or she is likely to need support for an indefinite period. Therefore someone with a temporary disability (such as a broken leg) does not fall within the definition of "disability services consumer". This is more restrictive than the definition in the Human Rights Act 1993, which does not include any severity or temporal restrictions (section 20(1)(h)). Given the focus on how concerns about disability services are dealt with, it may be timely to review the definitions under the Act relating to disability (see above, Appendix 1, 1.1 "Definitions").

The suggestion to extend a Disability Commissioner's jurisdiction to consider disability issues in relation to education, social development, and housing would involve a much greater modification to HDC's role. In our submission to the Inquiry, we pointed out that a significant amount of the disability work carried out by advocacy is actually outside jurisdiction but is done because it is no one else's responsibility, and to provide a holistic approach for consumers where aspects of their complaint are within jurisdiction. Although it would be beneficial for consumers to have this existing practice validated, advocacy services are currently not funded for this broader scope of work, which cannot be systematically carried out at the expense of core advocacy services.

The Select Committee also recommended legislative change "to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities. This should enable an independent Disability Commissioner to oversee access to disability services."¹⁰³

Possible options 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.

I would welcome further discussion and feedback on whether the Act should be amended to extend the Commissioner's jurisdiction in relation to disability services.

¹⁰² New Zealand Disability Strategy: Making a world of difference (Ministry of Health, April 2001), page 7. The New Zealand Disability Strategy states that 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". However, the Disability Strategy recognises that individuals have impairments (physical, sensory, neurological, psychiatric, intellectual or other impairments), and that disability relates to the interaction between the person with the impairment and the environment. The Human Rights Act 1993 definition of "disability" includes "physical disability or impairment" or "any other loss or abnormality of psychological, physiological, or anatomical structure or function" (section 20(1)(h)).

¹⁰³ Disability Inquiry Report, page 36.

Question 27

Do you suggest any amendment of the Act in relation to the Commissioner's jurisdiction over disability services?

5.4 Accessibility of complaints process

There are often additional hurdles that disabled consumers must overcome to submit a complaint, including the need for support in bringing the complaint and to distance oneself from full-time service providers. However, the Act does allow consumers to make complaints verbally. Oral complaints can be made by telephone to the 0800 number, by visiting the HDC offices in Auckland or Wellington, or by communicating with an advocate. The more significant issue is the limited range and number of disability support services, which means that consumers are often reluctant to complaint fearing that they will face repercussions for complaining (such as having to move to an even less desirable service provider or losing the service altogether).¹⁰⁴ This may be a crucial reason for HDC receiving few complaints about disability service provision.

Advocacy offers the best solution for many consumers in this situation. The recent increase in funding for the advocacy service has enabled better access to advocacy for vulnerable consumers, particularly those who find it difficult to contact an advocate or make a complaint themselves. The advocacy process also includes a focus on rebuilding relationships, which is important for consumers in residential facilities and for those for whom there is only one specialist in their region. Advocates now regularly visit all disability homes and facilities (including rest homes), allowing consumers to form an ongoing trusting relationship with someone who is independent and who can raise issues on their behalf. However, more advocates are needed if the service is to be more proactive about assisting disability consumers, particularly in light of the number of consumers with limited ability to speak up for themselves, many of whom are totally reliant on others for all their daily needs. Currently advocates make at least one contact every 12 months with every disability facility, and could achieve more frequent visits with additional resourcing.

The Commissioner's Office has undertaken a number of initiatives in recent years to make the Code more accessible to people living with a disability, and their whānau. Some of these educational initiatives are outlined above.¹⁰⁵ Another programme is the "Speaking Up" Workshop, which reaches out to consumers in the disability sector to ensure they have the skills and confidence to take action under the Code when necessary. As well as working with participants to identify problems and explore possible solutions in the context of the Code, facilitators explore ways of raising issues in a non-confrontational manner, and provide the opportunity for participants to practise these skills during the session. Information about the Health and Disability Commissioner has been provided to the general community via local newspapers and through advocacy education sessions, presentations and displays. Groups with a special focus have also been targeted through material in specific publications. In the case of the disability community, this is achieved through the publication "Without Limits".

¹⁰⁴ Examples of disability consumers' concerns about complaining can be found in HDC's submission to the Disability Inquiry, paras 91–96, available at <u>www.hdc.org.nz/publications/submissions</u>.

 $^{^{105}}$ See Appendix 1, 1.4.1.

I welcome any feedback or comments on how the Act could be amended to make HDC and the advocacy service even more accessible to people living with a disability.

5.5 Independent Commissioner?

The Select Committee recommended the appointment of an independent Disability Commissioner, possibly within the office of the Health and Disability Commissioner.¹⁰⁶

HDC already operates a successful model with independent Commissioners — the Health and Disability Commissioner and two Deputy Commissioners (one of whom has delegated responsibility for disability issues). The Act also establishes statutory roles that are independent of the Commissioner (the Director of Advocacy and the Director of Proceedings). Using a similar model, it would be possible to amend the Act to allow for an independent and dedicated Disability Commissioner. I do not consider, however, that a Commissioner for disability should be established 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 is already responsible for opinions about disability services; and HDC has expertise in advocacy and complaints resolution for disability consumers.

In addition, the health and disability advocacy service operating under the Act is available nationwide, has a long history of assisting disabled people, and could do even more in the disability area by increasing the number of advocates. Although the advocacy service could interface with another entity, it would be more straightforward for advocates to deal with a Disability Commissioner *within* HDC.

Establishing an independent Disability Commission, if other arrangements have not achieved significant change within six years (as recommended by the Social Services Committee),¹⁰⁷ is a possibility. As a preliminary comment to this review, CCS Disability Action expressed support for the Select Committee's recommendation that a separate Disability Commission be set up. CCS Disability Action submitted that this Disability Commissioner should not sit within HDC because the role needs to have a human rights and social model focus. It was suggested that a Disability Commissioner should have a structure similar to the Children's Commissioner, that its powers and functions should include investigation powers, and monitoring of the United Nations Convention on the Rights of Disabled People, the New Zealand Disability Strategy, and any organisation put in place as a result of the Select Committee report (such as the proposed "new lead agency").

An independent Disability Commission with extensive jurisdiction may be problematic, however, given the number of organisations that already deal with areas of the disability sector, for example, the Human Rights Commission (in relation to discrimination), the Children's Commissioner (in relation to children with disabilities), the Families Commission (for families who care for family members with disabilities), the Office for Disability Issues (responsible for promoting the implementation of the New Zealand Disability Strategy, monitoring actions to enable the participation and inclusion of disabled people in society, providing a focus on disability issues in government, leading

¹⁰⁶ Disability Inquiry Report, page 36.

¹⁰⁷ Disability Inquiry Report, page 15.

cross-sector policy, and providing support to the Minister for Disability Issues), and DHBs (responsible for meeting the health and disability support needs of their population, with Disability Support Advisory Committees to advise the board on issues facing people with disabilities and how these can best be managed by the DHB). The Ministry of Health also has a role in the planning and funding of some disability services.

It is not clear that the issues identified above with the current system (eg, consumers being reluctant to complain) will necessarily be solved by a separate Disability Commission, particularly if there is still the same limited choice of services. There may be greater benefit in establishing a designated Disability Commissioner within HDC.

Question 28

Do you think a Disability Commissioner with a dedicated focus on disability issues and services should be created within HDC?

LIST OF KEY QUESTIONS

- 1. Is it necessary to review the Act and Code every 3–5 years? Would 10-yearly reviews suffice?
- 2. What amendments to the Act or Code in relation to disability do you suggest and why?
- 3. Should the Act and the Code be amended to include a right to access publicly funded services? If so, how would such a right be framed?
- 4. Should the Act and/or the Code be amended to include health information privacy? If so, what amendments do you suggest and why?
- 5. Is the current contracting model for providing advocacy services appropriate? If not, which of the two alternative options identified do you support and why?
- 6. Do you suggest any amendment to the Act in relation to appeal rights or naming decisions?
- 7. Do you suggest any change to the definitions in the Act relating to health services?
- 8. Are the definitions in the Act relating to disability services appropriate? If not, what changes do you suggest?
- 9. Do you agree that the Office of the Health and Disability Commissioner should be renamed the "Health and Disability Commission"?
- 10. Do you support clarifying the status of Deputy Commissioners pending possible reappointment?
- 11. Are the functions of the Commissioner appropriate? If not, what amendments do you suggest and why?
- 12. Do you think that the Act should be amended to require HDC to refer all complaints about registered health practitioners to the relevant registration authority?
- 13. Should section 38 of the Act be revised to better reflect its purpose?
- 14. Do you consider it is necessary or desirable to amend the provisions of the Act governing the Commissioner's investigations? For example, by giving complainants the opportunity to comment on the Commissioner's provisional opinion even if it contains adverse comment about the provider(s), or by setting prescribed timeframes?
- 15. Do you suggest any amendment to the Act in relation to the Commissioner naming providers found in breach of the Code?
- 16. Do you agree that the fine for an offence under the Act should be increased? If so, do you agree that the maximum fine should be \$10,000?
- 17. Do you consider that ethics committees should be under the oversight of HDC?
- 18. Do you consider that 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?
- 19. Should the Act be amended to allow information obtained during an investigation to be withheld, while the investigation is ongoing?
- 20. Do you think any of the Code rights should be amended?

- 21. Do you agree that section 47 should be amended to clarify that the Director of Proceedings may take action only upon referral from the Commissioner?
- 22. Should the Director of Proceedings have the same powers as the Commissioner under section 62 until a decision has been made pursuant to section 49 to issue proceedings?
- 23. Should the Director of Proceedings have to make a decision to issue Human Rights Review Tribunal proceedings within a certain timeframe, after which point the Director might be deemed to have "failed" to bring proceedings?
- 24. Should an aggrieved person be able to bring proceedings where the Director of Proceedings has decided to withdraw a claim, or reverses an initial decision to issue proceedings?
- 25. Should the Act be amended 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? If so, how long should the Director of Proceedings or individual person have to bring a claim once the Commissioner has found a breach?
- 26. Should the term "aggrieved person" be defined? Should it be limited to health or disability services consumers?
- 27. Do you suggest any amendment of the Act in relation to the Commissioner's jurisdiction over disability services?
- 28. Do you think a Disability Commissioner with a dedicated focus on disability issues and services should be created within HDC?

