HDC Consultation Document

Summary Easy to Read Version

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

A Letter From the Commissioner

- The Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights are being looked at.
- I want your opinions please.
- We have written this booklet to help you tell us what you think.
- We have some questions for you.
- We think the Act and Code are generally working well.
- There are a few areas for possible change.
- There may need to be improvements to your rights when using disability services.
- There may need to be a right to access services written into the Code.
- There may need to be the right to health information privacy written into the Code.
- There may need to be changes to the structure of advocacy services.
- There may need to be more ways for reviewing HDC decisions.
- When I have heard what you think, I will write to the Minister of Health to suggest any changes to the Act and Code of Rights.
- Thank you for your help.

Yours sincerely

Ron Paterson
Health and Disability Commissioner
24 November 2008

Contents

Health and Disability Commissioner Act

- The Health and Disability Commissioner Act was passed by Parliament in 1994.
- The Act set up the office of the Health and Disability Commissioner (HDC).
- The Act talks about and protects your rights when you use health and disability services.
- The Act helps you fix any complaints if you think your rights have not been followed.
- We help you with the fair, simple, speedy, and efficient fixing of complaints.
- The Act set up the Code of Health and Disability Services Consumers' Rights.
- The Act set up a nationwide consumer advocacy service to help you know about your rights.
- The Act also has a Director of Proceedings who may take service providers to court if they have seriously broken the Code of Rights.
- The Act covers all providers of health and disability services - public or private, registered or unregistered.
- Everyone who uses health or disability services is protected by the Act, not just patients in hospitals or in doctors' surgeries.

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 lists ten rights.
- Each rights belongs to you as a consumer of health and disability services.
- Providers of services must respect your rights.

- **Your rights in the Code are:**
    - To be treated with respect
    - To be treated fairly
    - To dignity and independence
    - To care and support that suits you
    - To be told things in a way you understand
    - To be told about your health or disability
    - To make choices about your care and support
    - To a support person
    - To decide if you want to be part of training, teaching or research
    - To make a complaint

See Appendix 2 for more information about the Code.

Commissioner's role

The Commissioner's job is

- to promote respect for your rights as a consumer of health and disability services through education and publicity.

The Commissioner also

- helps to sort out your complaints when you think your rights have not been looked after.
- the Commissioner has several ways he can help you to sort out complaints about the quality of health care and disability services. These choices include:
    - referring the complaint to an appropriate agency or person;
    - referring the complaint to an advocate;
    - calling a mediation conference;
    - investigating the complaint; or
    - taking no action, if action is "unnecessary or inappropriate".

Advocacy service

- There is an advocacy service to support you if you wish to complain about health and disability services. Advocates act on your behalf.

- The Advocacy Service is independent of the Health and Disability Commissioner.

See Appendix 3 for more information about the advocacy service.

Director of Proceedings

- The Commissioner can pass on to the Director of Proceedings situations where providers have broken the Code.

- The Director of Proceedings must decide whether or not to start legal proceedings against the provider.

Appendix 4 contains more information about the role of the Director of Proceedings.

This Review in context

The Health and Disability Commissioner Act says the Commissioner has to look into the Act and the Code every five years to see if they need updating.

- After looking into the Act and the Code, the Commissioner has to tell the Minister of Health whether changes are necessary.
- This is the third review of the Act and Code.
- So far few changes have been made.
- Changes that have been introduced have made it easier to make complaints.
- As the Commissioner, I think the Act and Code are working well.
- So I think the time between checks of the Act and Code should be at least 10 years.

Question 1

- Should the Act and Code be looked into every 3-5 years?

- Would 10-yearly checks be often enough?

What is working well?

As the Commissioner, I think the Act and Code are working well.

- The Act and Code give you a helpful way to sort out complaints about health or disability service providers.
- Because the Commissioner works with you to sort out complaints, the lessons we learn can lead to safer and better quality health care and disability services.
- Research shows that when complaints are fixed, the safety and quality of services are improved.
- The public of New Zealand, service providers and you all respect the Code.
- The rights listed in the Code are protected by the laws of New Zealand.
- The Code is simple and easily understood, making it easy for you to use to take charge of your services.
- As the Commissioner, I do not think the Act or Code need any big changes.
- But I think there are some areas that need looking at, where some change may improve things.

What needs looking at?

Four issues need special talking about and feedback from you.

1. the need for an independent Disability Commissioner or some changes about your rights to disability services;
2. the benefits of including a right to access certain services and/or the right to health information privacy in the Code;
3. improvements to the advocacy services to make sure they work well and independently for you; and
4. the possibility of more ways of reviewing HDC's decisions.

These issues are briefly summarised below. The appendices have more details.

1. Your Rights and Disability services

- Parliament's Social Services Committee recently looked at the quality of care and service provision for people with disabilities.
- The Committee made several suggestions on how the quality of care and service provision for people with disabilities could be improved.
- The Committee suggested the appointment of an independent Disability Commissioner (possibly within HDC).
- It suggested widening the areas the Commissioner may examine (including access to disability services), and an independent way of checking funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.
- The Commissioner told Parliament that many complaints received about disability services cannot be looked into by the Commissioner under the Act as it is written now.
- Even more importantly, few complaints received by HDC are about disability service provision.
- It can be hard for people with disabilities to put in a complaint to HDC.
- People with disabilities are often cautious about complaining for fear of punishments and the lack of choice of disability support services.
- So HDC receives few complaints about disability service provision.
- The advocacy service, however, receives a large number of complaints about disability services.
- The advocacy service has a significant focus on working in the disability sector.
- Currently all rest homes and disability homes have at least one contact a year with a local health and disability advocate.
- Advocates assist you to make a complaint and often the "face-to-face" process works better to fix the complaints.
- Currently, the Act and Code cover only the quality of services that are delivered (not how services are accessed or funded).
- This causes problems, as often the way in which a disability service is funded or paid for leads to the poor quality service.
- Complaints that are about access to disability services or goods, even where quality of service issues are raised, are not things that HDC can look into.
- One of the greatest barriers to advocates assisting people with disabilities is the coverage of the Act and Code which makes it hard to take a big picture view in helping you.
- Possible options for widening HDC's role in disability services include:

  - linking a needs assessment to a legally enforceable right for you, so that when you seek disability services, you have a right to receive the services you have been assessed as needing, or
  - enabling the Commissioner to check decisions about funding for, or access to, disability support services.
- As the Commissioner, I would welcome your opinions about changing the Act to widen the Commissioner's powers around disability services.
- The appointment of an independent Disability Commissioner, possibly within HDC, was suggested by the Social Services Committee.
- HDC already has a successful model with four legal appointees as well as the Commissioner: two deputy Commissioners and the Director of Advocacy and the Director of Proceedings.
- Using a similar model, it would be possible to change the Act to add a Disability Commissioner.
- The Disability Commissioner could answer to either the Health and Disability Commissioner and/or the Minister for Disability Issues.
- Keeping the Disability Commissioner inside HDC means the close link between health and disability is kept. It is not uncommon for a complaint to include both health and disability service providers; one of the Deputy Commissioners already looks after investigations into disability services; and HDC has expertise in advocacy and complaints resolution.
- So the HDC is checking if there is sufficient support for a change in legislation to let HDC better serve you when you are using disability services.

Further information about these issues is contained in Appendix 5.

Question 2 - What changes to the Act or Code in relation to disability do you suggest and why?

2. Gaps in the Code

Right to access to services

- Missing from the Code is a right to access services; this is a problem especially for you if you have a disability.
- Everyone who uses health and disability services shares this problem.
- Section 20 of the Act looks only at the quality of service delivered and does not permit the Code to cover things like access to services.
- The Act does not worry about which services are to be paid for by the public of New Zealand.
- The Act talks about just the quality of services themselves.
- The Human Rights Commission has talked about this issue.
- The Human Rights Commission said 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.
- The Code already supports open decision-making about access to care (such as through government supervision of waiting times). However, in a rights framework like the Code which focuses on individual rights, it may be hard to include matters of access (in the context of limited resources and the competing rights of others to the same resources).
- As the Commissioner, I look forward to 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 changed to include a right to access publicly funded services? If so, what words should be used to state the right?

Health information privacy

- The Code does not cover the right to the confidentiality of, and access to, health information.
- The Code just looks at a patient's physical privacy (such as places for undressing that preserve the patient's privacy or the way a provider conducts a physical examination).
- The Code does not apply to privacy or confidentiality of health information.
- The Commissioner has no power over, and must pass on to the Privacy Commissioner, any complaint about a breach of confidentiality.
- A simple fix would be to change the Act and Code to delete the exclusion of information privacy, so that the right to have privacy in Right 1(2) also covers privacy of information.
- This change would permit HDC and the Privacy Commissioner to have joint powers over complaints relating to health information privacy.
- There is an example of joint powers for complaints alleging breach of "the right to be free from discrimination" (Right 2), which is shared with the Chief Human Rights Commissioner. When discrimination complaints are received, the two Commissioners are able to talk and decide on who most sensibly should look at the complaint.
- As the Commissioner, I think issues of the confidentiality of, and access to, health information are so much a part of 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 shared powers between HDC and the Privacy Commissioner.

This issue is explored further in Appendix 2.

Question 4 - Should the Act and/or the Code be changed to add health information privacy? If yes, what changes do you suggest and why?

3. Structure of advocacy services

- The Act provides for an independent advocacy service for health and disability consumers. This is looked after by a Director of Health and Disability Services Consumer Advocacy (the Director of Advocacy).
- The Director of Advocacy must work separately from the Commissioner, but reports to the Commissioner for the efficient, effective and economical management of his or her activities. This separation of the Director from the Commissioner was meant to protect the advocates' role in acting on the side of the consumer and the Commissioner's fairness when investigating and mediating complaints.
- The Director of Advocacy buys independent advocacy services for the Government. In 2006 a contract was let with one provider covering the whole country (National Advocacy Trust).
- There have been benefits with one provider of advocacy services nationwide. But some problems remain.
- Even-handed quality assurance across the country for advocacy services is an issue.
- There are inefficiencies in the way advocacy services are managed, as the Director does not handle the money spent on the services.
- Meeting the ethical standards expected of public servants is not absolutely protected.
- Experience of 12 years of contracting shows that quality, efficiency and good conduct may be better achieved in other ways.

The following options are put forward for consultation:

Option 1: Status quo - retaining the contracting model

- Within the present contracting model there are other possible variations, which have not been tried to date. For example, the Director of Advocacy could choose a preferred provider or providers for advocacy services so a regular tendering round would not be required.
- Another option that may be possible is for the Director to have agreements with individual advocates (rather than an organisation) to provide advocacy services.

Option 2: Advocates as HDC employees

- A second option would be for advocates to be HDC employees. This would be the same as for 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 this model, the Director of Advocacy would ensure the quality and consistency of service, and the wise use of resources.

Option 3: Independent Office of Advocacy with advocates as employees

- A third option would be to have an independent office of the Director of Advocacy, who would be able to employ advocates directly.
- This would have the same advantages as Option 2, but would give greater independence from the Commissioner. It would also give some separation from the Commissioner when dealing with 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. So this would be more complicated.

Refer to Appendix 3 for further explanation of this issue and the possible options for change.

Question 5 - Is the current contracting model for providing advocacy services appropriate?

If not, which of the two alternative options suggested do you agree with and why?

4. Review of HDC decisions?

- Some have suggested that providers should have a right of appeal from a Commissioner's opinion about a breach of the Code and/or a decision to publicly name a provider who has breached the Code.
- Anyone who thinks the process the Commissioner followed when looking into a complaint was unfair, or the opinion is unreasonable, may ask for a review at no cost by the Office of the Ombudsmen. Each year approximately 20 cases are reviewed by the Ombudsmen, but most are sorted out by making some things clearer.
- The Commissioner's opinions may be challenged in the High Court (to date without success).
- As the Commissioner I do not think a formal right of appeal under the Act is necessary. Appeals would slow down sorting out of complaints.
- A lot more is at stake for a provider found in breach of the Code if the Commissioner decides to publicly name that provider. The naming policy is on the website www.hdc.org.nz
- Individual providers are only named in very limited circumstances.
- As the Commissioner, I don't think there is a need for a further way to appeal a naming decision.
- But, I would welcome your thoughts about changing the Act about naming decisions.

Further discussion of this issue may be found in Appendix 1.

Question 6 - Do you suggest any changes to the Act about appeal rights or naming decisions?

Other possible amendments or changes

There are other areas where changes to the Act or Code may be helpful. These possible changes are raised in the Appendices, which discuss 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).
- Changing 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).
- Putting 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).
- Changing 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

As the Commissioner, I welcome your thoughts and feedback on these issues, and any other comments on how the Act and Code are working. I will use your feedback to feed into 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.

To make it easier to respond, this document and the appendices have been put into separate parts and questions are raised 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 writing your comments. A copy of this document is also available on the HDC website (www.hdc.org.nz).

You may wish to read 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 www.legislation.govt.nz. 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

Appendix 1 - Health and Disability Commissioner Act

Aims of the Act

- The Health and Disability Commissioner Act (the Act) gives a way for you to sort out complaints directly with the service provider, with the assistance of the advocacy service, or through the Commissioner's office.
- The Act also seeks to ensure the good behaviour of health and disability service providers, and protection of the public, by being an independent public watchdog.
- Education and more understanding of your rights, to support improvements in the overall quality of services, is also an aim of the Act.
- So, HDC focuses on three key aims - Resolution, Protection, and Learning.

Effect of the Act

- As understanding about the Act and Code grows, the positive effects of the Act are being seen. Most complaints are sorted out within six months, and only about 10% of complaints lead to a formal investigation. Advocacy continues to be a remarkably good way of resolution or fixing problems, with 88% of complaints received by the Advocacy Service partly or fully sorted out with advocacy support.
- Commissioner's decisions on complaints are often used by providers as a way for education and quality improvement. Key reports are sent out to appropriate agencies in the health and disability sector. Providers quickly agree to put in place Commissioner's recommendations.
- The New Zealand system corrects practitioners rather than punishes them. This is in line with modern understanding about error and the importance of a culture of learning to improve patient safety.
- Where a provider is found to have breached the Code, the Commissioner usually tells the provider to review its policies and practices, give the complainant a written apology, and give its staff with further education or training in a specific area.
- Complaints are sorted out in a fair, simple, speedy, and efficient way. Providers are more willing to accept they have made mistakes, apologise where appropriate, and take steps to fix the situation. The Commissioner continues to play an important role in quality improvement in the sector.

Recent statistics

- In the year ended 30 June 2008, the Commissioner received 1,292 complaints. The most common complaints were about services provided by GPs and public hospitals, reflecting the high level of contact these providers have with the general public. Complaints were sorted out using the full range of options written into the Act. 88% of complaints were sorted out 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). With approximately half of complaints (661) the Commissioner decided that no action was necessary because an educational approach was taken.
- 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 person who made the complaint 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.

- 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. A person must undergo a health care procedure to become a health consumer under the Act. The relationship between the "health care procedure" and "health services" definitions in the Act and Code is also not clear. 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 mean a broad range of disability services providers are covered by the Act and Code. However, if changes are made to the Act about the Commissioner's powers over disability services, or an independent disability commissioner is established, these definitions may also need improving. The definitions in the Act about 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.

Sorting out complaints (Complaint resolution), promotion of respect for your rights, and making public statements and publishing reports on matters affecting the rights of health consumers are specific duties 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 duties of the Commissioner. The Health and Disability Commissioner is appointed by the Governor-General, on the advice of the Minister of Health for a term of up to five years which can be renewed.
- there has been talk about changing the name of the Office of the Health and Disability Commissioner to the "Health and Disability Commission". There is more reason for a change because there are now Deputy Commissioners.
- As the Commissioner, I welcome any comments or feedback on this.

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 advice 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.

- In August 2006 the Commissioner delegated some of the complaints to the Deputy Commissioners to sort out. The deputy commissioners can specialise.

- If a complaint concerns prison or disability services, allied health services, or a Maori health or disability service, or if you are M?ori, the Deputy Commissioner, Education and Corporate Services (Tania Thomas), has responsibility.

- Rest homes, dentistry, pharmacies/pharmacists, nurses, psychologists, ambulance care workers, and any other non-medical practitioners are the responsibility of the Deputy Commissioner, Complaints Resolution (Rae Lamb).

- The Commissioner looks after complaints about doctors, medical centres, district health board services, public hospitals, private surgical hospitals, and maternity services.

- Perhaps greater clarity is needed in the Act about the reappointment of Deputy Commissioners because it is unclear how to manage their positions while awaiting reappointment.

- As the commissioner, 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 agree with clarifying the status of Deputy Commissioners while waiting for possible reappointment?

1.4 Functions of the Commissioner - s 14(1)

Section 14(1) lists the duties of the Commissioner. It is important for the Commissioner to have broad duties so that the Act can be carried out.

1.4.1 Promotion and protection

- The Commissioner must promote, through education and publicity, respect for your rights, and to make public statements and publish reports about anything affecting the rights of health consumers (sections 14(c) and 14(d)). As an independent statutory agency, the Commissioner is in a good position to improve your interests and play a key role in shaping public policy debate.
- The Commissioner's education role is carried out by sorting out complaints and also by educating you, as a user of health and disability services about your rights under the Code and how to use your rights, and by making sure that providers are aware of their responsibilities under the Act. Education is also a key role of the nationwide advocacy service.
- The Commissioner puts investigation reports on the HDC website that talk about public safety issues, areas for improvement, and lessons to be learned.
- Case studies or reports of complaints that have been sorted out are also put on the website. Complaints are an important way to educate providers about the rights in the Code, and improve the quality of services. Providers are encouraged to view complaints as opportunities for learning and quality improvement.
- Lessons learned from individual cases are shared with relevant parts of the health and disability sector including relevant registration authorities, Colleges or professional groups, and major employers (such as District Health Boards), 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 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.
- 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, especially elderly and disabled people, and M?ori and Pacific peoples. Recent initiatives to educate the wider community include a Health TV advert about your rights shown in medical centre waiting rooms, and an email alert to consumer

  groups to additions to the HDC website. Recent cases are usually reported by newspapers within 24 hours of posting on the website.

  - Greater media coverage has led to more 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 (www.hdc.org.nz/opinions); 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 been checked 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 or learning impairments. 73% of HDC's promotional material meets better practice print accessibility standards, and improvements are continuing. The HDC website is a good way of giving information and education to a wide audience, with an average of 87,902 hits per month (2007/2008 year).
- The Commissioner runs consumer forums, to find out your views on the health and disability service sectors and on how HDC can improve the service it gives you. Forums usually include a specific consumer group. Feedback from you at the forums is used to improve HDC education and processes.
- The HDC Consumer Advisory Group was formed to give insight, advice and input into improving HDC's education and promotion services and improve HDC's complaints service.
- As part of improving 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).
- Providers are also educated through talks to hospitals, university classes, and provider groups and by regularly writing in publications put out by providers.
- Submissions on key policy documents and proposed legislation are another way that HDC uses to protect and promote your rights under the Code.
- 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 duties should be changed to improve 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

HDC is the first port of call for complaints about health and disability service providers. The change to the Act that confirms this was meant to reduce the confusion that can happen 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 also tells responsible authorities to forward complaints about the practice or conduct of a health practitioner to HDC.

1.4.3 Other roles?

- Some feel the Commissioner should have a wider role (for example, to monitor the implementation of recommendations from Commissions of Inquiry). HDC already has staff who follow up the Commissioner's recommendations, but more resources would be needed if more checking was to take place.

- As the Commissioner, I would welcome any thoughts on whether the HDC's role should be widened or the duties of the Commissioner changed.

Question 11 - Are the duties of the Commissioner appropriate? If not, what changes do you suggest and why?

1.5 Review of operation of the Act - s18

- Section 18 tells the Commissioner to look at the operation of the Act and report the findings to the Minister every five years.
- I am not aware of other consumer protection legislation (or any other legislation) that requires such regular reviews.
- I think the gap between these checks should be extended to at least 10 years.
- It has also been suggested that the checks of the Act and Code should be done by someone independent of the Commissioner. While there could be advantages in this, the Commissioner with intimate knowledge of the operation of the Act is the best person to check the Act and give advice to the Minister. The need for consultation and a publicly available report given to Parliament means there is independent checking of the Commissioner's work.

- The checks of the Act and Code take up a lot of time. They have so far made little change. If needed, consultation may take place on a specific proposed change, which happens with any law reform.
- I welcome further discussion and comment on this matter (see Question 1 above).

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, which can be obtained from HDC or downloaded from the website (www.hdc.org.nz).

1.6 Complaints

Under section 31(2) of the Act, any person may make a complaint saying 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 has very little power over complaints about conduct before 1 July 1996 when the Code came into force. In practice, the Commissioner has power over only serious cases about individual practitioners. Because so much time has gone by, the Commissioner may decide to take no action.

1.7 Options for resolving complaints

The choices the Commissioner has to sort out complaints 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 choices are because fixing a complaint need not always happen after a formal investigation under the Act. HDC sorts out complaints through the best choice to ensure the purpose of protecting and promoting your rights, and sorting out the complaint in a "fair, simple, speedy, and efficient" manner. When deciding what action to take the need to ensure public safety and proper accountability to protect you are the most important factors. 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, talking with the parties may be the best process, either directly or by way of advocacy or

mediation. A common first step in deciding what to do about a complaint, is to request that the provider talk directly to the complainant. The Commissioner encourages the parties to sort the complaint out between them. The Commissioner will then re-assess the complaint if this does not work, but there is often no benefit commencing an investigation if the provider has already apologised and/or taken steps to fix the situation. In some cases complainants prefer that no formal action is taken and that providers receive a simple reminder of their duties under the Code.

- However, in other cases an investigation is necessary. Sometimes a complaint can be sorted out only when the provider is made to see the effects of his or her actions. Formal action is taken to prevent the same events from happening again. Investigation takes time (up to six to nine months for a simple investigation, and a complex investigation can take 18 months). This is not always consistent with fair, simple, speedy and efficient sorting out of complaints in all cases. Nor is a formal investigation the best way when there is an ongoing relationship between the parties. Investigation is therefore kept for only a small number 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" showing up poor care, public safety issues and systems problems, and can also shake up internal complacency. HDC uses complaints that are resolved in a variety of ways as case studies to share the learnings.

1.7.1 Decision to refer the complaint

- The Commissioner can refer complaints to statutory officers (the Chief Ombudsman, the Privacy Commissioner, the Chief Commissioner under the Human Rights Act), and to specified agencies or persons involved in the health and disability sectors, as appropriate. The specified agencies include ACC (if it seems that the consumer may receive compensation), relevant registration authorities (if it seems from the complaint that the ability of the health practitioner, or the correctness of his or her conduct, may be in doubt), the Director-General of Health (if it seems 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 public health and safety questions). Reports have to come back to the Commissioner about what action, if any, has been taken. The Commissioner may take further action if not satisfied with the reported outcome.
- The Act expects co-operation between the Commissioner and a number of agencies. While each complaint is looked at on its own merits, the referral of a complaint about an apparent breach of the Code to such agencies (other than the provider) is made at the same time as any action by the Commissioner on the matter. The Act also

allows the sharing of information more generally to other appropriate persons where this is called for in the public interest.

- The Commissioner has a broad duty to tell the appropriate authority about risks. The Commissioner must tell 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".
- The Commissioner must tell 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".
- Referral to an appropriate person or authority must also occur where the Commissioner thinks there is evidence of any significant breach of duty or misconduct by the provider, for example referral to the Police where a crime is suspected.
- Most referrals to other agencies relate to competence or professional conduct issues which must be checked by registration authorities (138 in the year ending 30 June 2008). In practice, any complaint that shows the skill of the health practitioner or the correctness of his or her conduct is cause for concern is given to the appropriate registration authority.

Question 12 - Do you think that the Act should be changed to make HDC pass on all complaints about registered health practitioners to the relevant registration authority?

1.7.2 Advocacy

Another way of sorting out complaints is by passing them to a health and disability consumer advocate "for the purpose of resolving the matter by agreement between the parties". Advocates must represent or assist complainants to try to sort out the complaint by agreement between the parties concerned. Unlike the Commissioner, advocates act on the side of the person who is complaining. 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. The advocate must report the results to the Commissioner.

Referral to an advocate is often a very successful way of sorting out a complaint. This assistance may include giving information about your rights, assisting you to get your questions answered, and have explanations given and actions taken (where appropriate). Taking action at an early stage and dealing directly with the provider (that is, sorting out the matter at a local level) takes less time than a formal investigation and is more likely to achieve an outcome you are satisfied with.

1.7.3 Mediation

- The Commissioner can call a mediation conference about anything that is being complained about or investigated, to try to sort out the matter by agreement between the parties. Anything discussed or disclosed during the mediation cannot be used in any future proceedings in a Court or Tribunal. If agreement is reached, the mediator will write up the agreement to be signed by each of the parties before leaving the mediation. If the complaint is not sorted out by mediation, the Commissioner after reading the mediator's report will decide what, if any, further action to take.

- The option of referring a complaint to mediation is there because some matters need a more formal approach than a referral to the provider or advocacy, but where an investigation is not necessary. Mediation tries to sort out the matter through the formal intervention of an impartial mediator. Mediation is an effective way of sorting out difficult and complex matters, or where the ongoing relationship between the parties must have a formal agreement about the future delivery of services; where there are a number of providers involved; or where the parties have tried without success to sort out the complaint.

- It is 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. The number of complaints sorted out through mediation over the past nine years has been disappointingly low, just 135.

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 thinks that any action is unnecessary. The Act tells the Commissioner to give the complainant and the provider reasons for a decision to take no action on a complaint.

- Things the Commissioner may think about when deciding to take no action include:

    - the complainant wishes no action to be taken;
    - the complaint is trivial or is not made in good faith; or
    - a "fix" or right of appeal already exists.

- Before a decision is made to take no further action on a complaint, a lot of information is gathered and carefully thought about, and preliminary expert medical advice is asked for if needed.

- In addition to the things listed above, other factors thought about include:

    - The matter has already been fully investigated by an independent agency (for example, a District Inspector or Coroner) and their suggestions have been put in place.

    - The matter has been fully looked into by the provider and the review has been thorough, has uncovered the relevant causes and problems, and fixes have been made (for example, an apology and carrying out the findings).

- The complaint is sorted out because HDC has found additional information and shared this with the parties concerned, or by taking an educational approach. An educational approach may involve an "education letter" to the provider(s) stating any issues and aspects of care needing to be looked at. 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 breach of the Code, or is outside HDC's powers (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.

- There is no apparent breach of the Code, or because matters are already being addressed through other appropriate processes or agencies.

- Most complaints sorted out when no action is taken are where HDC thinks an educational approach is better than an investigation. Before any decision is made, a lot of information is gathered, careful thought is made, and preliminary expert medical advice is asked for 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.

- 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.

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, is an investigation of the complaint. Balancing the objectives of "fair" and "speedy" is not always easy during an investigation. Parties and witnesses must be interviewed, patient records checked and, where the correct standard of care is in issue, independent expert medical advice is received. To be fair, providers and any other person adversely affected by the report must be allowed to comment before the report is finalised. Investigation is therefore a lengthy way to sort out a complaint.

- Investigations are generally used for only the most serious matters such as complaints of sexual wrongdoing and other behaviour involving major 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 lists the rules for doing an investigation.
- First, the Commissioner must write to the provider and complainant telling them about the investigation. The provider must be given the details of the complaint or the subject matter of the investigation, and the right to give a written response to the Commissioner within 15 working days. The provider is asked to reply.
- Where the investigation directly concerns a health practitioner, the Commissioner must promptly tell the relevant registration authority). 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 medical records in order to establish the facts. Information and documents may be asked for in writing and a person may be summoned to give oral evidence under oath.
- If the complaint is about standards of care, the Commissioner may request independent expert advice on the reasonableness of the conduct which led to the complaint.
- If things change during the process, the Commissioner can choose to take 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.
- Any person who is the subject of adverse comment in any report or recommendation has a reasonable chance to be heard; has a reasonable chance to reply in writing to that adverse comment; and may, if they require, have their response or a summary of it as decided by the Commissioner included in the report.
- The right to respond to adverse comment is a basic right in administrative law. This is to ensure a fair process and outcome for the parties. During an investigation of a complaint, a provider has a number of chances for input before the Commissioner forms a final opinion that a breach of the Code has occurred. 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.
- 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 remain fair without disadvantaging complainants, in a way that is still "speedy and efficient".

- It has been suggested that changes to the Act should include timelines and information provided to the professional under investigation.
- In my view, the Act is clear that investigations must be carried out 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 their time, which can delay HDC's process. The speediness of an investigation must be balanced against the requirements of 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 gives the Commissioner's choices about what to do after an investigation.

1.8.1 Reporting to other bodies

After an investigation, the Commissioner may tell the answer to the following:

- any authority or professional body;
- the Accident Compensation Corporation;
- the Minister of Health;
- or any other person that the Commissioner thinks is important.

1.8.2 Recommendations

If the Commissioner thinks a provider has breached the Code he or she will recommend either an apology, checking of practice, re-training, staff training, internal audit and systems review. The Commissioner may ask the person to say when the steps to fix things will be taken. If the steps are not taken within the agreed time, the Commissioner can tell the Minister of Health. People generally do the things the Commissioner asks them to do within the time requested.

1.8.3 Naming

  - For the first ten years after the Code of Consumers' Rights started in 1996, HDC's investigations did not name the health and disability providers who were looked into. The aim was to educate, and because providers were not named they worked with the Commissioner. By 2006, however, the Commissioner was worried that secrecy was working against public support for the complaint handling procedures. The Commissioner decided to name district health boards in Code breach decisions. In 2007, the Commissioner began naming other group providers and individual providers (in limited circumstances). This change brought about strong criticism from the sector.
  - In 2008 the Commissioner stopped naming providers, talked with the sector and thought about the naming policy. The new naming policy from July 2008 says:
- The Commissioner will continue to name DHBs and public hospitals in breach of the Code unless it would not be in the public interest or would unfairly go against your privacy interests or those of a provider.
- The Commissioner will name rest homes, residential facilities and private hospitals, medical centres, pharmacies and other group providers where their systems are in breach of the Code unless it would not be in the public interest or would unfairly go against your privacy interests or those of an individual provider.
- The Commissioner may decide to name individual providers in breach of the Code if:

  1. the behaviour of the provider completely ignores your rights or is a serious drop in the acceptable standard of care, and the provider is risking harm to the public; or
  2. the provider has refused to comply with the Commissioner's recommendations; or
  3. the provider has breached the Code in three episodes of care in the past five years where each breach was a moderate break from acceptable standards.

- Each decision to name is thought about with care and the parties are given an chance to comment before it is finalised. This is because both the provider(s) and the consumer can be affected by naming. The full policy on naming with reasons is on the HDC website.
- Some providers have challenged the Commissioner's legal authority to name. Others have said that HDC is subject to the Official Information Act 1982, and therefore may be required to release naming information.
- As the Commissioner, I would welcome your thoughts on the following:
    - ▪ Should the Act be changed to let the Commissioner name providers in breach of the Code?

- Should the Act be changed to give the Commissioner the power to not tell anyone the names of providers if no breach has happened or until all processes have been completed?

Question 15 - Do you suggest any change to the Act about the Commissioner naming providers found in breach of the Code?

1.8.4 Referral of providers to the Director of Proceedings

The Commissioner can, after an investigation, refer a provider to the Director of Proceedings who can decide to start proceedings against the provider. The provisions of the Act relating to the Director of Proceedings are discussed below in Appendix 4.

1.9 Right of appeal

- Some have suggested that providers should have a right of appeal from a Commissioner's decision. This issue has been consulted on previously. I believe that the choices of challenging the Commissioner's decisions through the Office of the Ombudsmen, or judicial review, are enough protection.
- Anyone who thinks the Commissioner's process or decision was unfair, or that the result is unreasonable, may seek a review at no charge by the Office of the Ombudsmen. Each year about 20 cases are checked by the Ombudsmen, but most are sorted out 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 and so far no judicial review has been successful.
- I think no formal right of appeal under the Act is necessary, because the Commissioner's complaint fixing processes are "fair, simple, speedy, and efficient" and the checking procedures are already in the Act.

Miscellaneous Provisions - Part V

Sections 59 to 82 of the Act cover various things about complaints and procedure, the calling of mediation conferences, protections and privileges, delegations, vicarious liability, offences, and so on. Although put in a part of the Act called "Miscellaneous", these provisions are essential to the Act's effective working.

1.9 Procedure

Section 59 has a number of important provisions letting the Commissioner control procedures as he or she thinks is right. This flexibility is essential if the Commissioner is to carry out the Act's purpose of "fair, simple, speedy, and efficient resolution of complaints". In summary, section 59 says:

- investigations may be in public or in private
- the Commissioner may listen to or get information from anyone the Commissioner chooses
- the Commissioner may ask any questions that the Commissioner feels are necessary
- the Commissioner does not have to hold a formal hearing
- no one shall have the right to be heard by the Commissioner except when replying to criticism from the Commissioner
- if it is in the public interest to do so, the Commissioner may pass on matters to the appropriate person or authority
- subject to the provisions of the Act, the Commissioner and every advocate may control how they do things in the way they think is best.

1.10 Offences

Section 73 says that: Every person who is found guilty of committing an offence against this Act will have to pay a fine of up to $3,000.

The offences are:

(a) Without good reason stops the Commissioner or any other person from using their powers under the Act
(b) Without good reason disobeys any lawful instruction from the Commissioner or any other person under this Act;
(c) Makes any statement or gives any information to the Commissioner or any other person using the powers under this Act, knowing that the statement or information is incorrect or misleading; or
(d) Pretends that he or she has powers under this Act when he or she does not have any such powers.

As the Commissioner I think the $3,000 maximum fine is very small for the offences covered. The fine is not big enough to stop people from getting in the way of the Commissioner's work. I support an increase to the fine for an offence under the Act to $10,000. This is in line with the High Court's approach, the Health Practitioners Competence Assurance Act, and other consumer protection legislation.

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?

1.11 Ethics committees

- Some women's health groups have suggested that a national system of ethics committees should be part of the Act. Ethics committees are locally based. Some think they are on the side of the researchers instead of looking after consumers and their rights under the Code. Perhaps there should be a Director of Ethics at HDC to look after all human ethics committees, not just the regional ones, looking after the rights of research participants and those involved in innovative and experimental procedures.

- As I said in my 2004 report to the Minister, I don't think this checking of the Act and the Code is the right place to think about the system for ethical checking of health and disability research in New Zealand. I have an open mind about ethics committees coming under the Health and Disability Commissioner. A consultation process would be necessary to hear the views of the sector and to discuss how the change would work in practice. A range of issues would need to be sorted out. Many of the research protocols looked after by ethics committees raise questions of health information and the secondary use of data for research, matters that are looked after by 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?

1.12 Indemnity (immunity) of expert advisors

- Section 65(2)(a) of the Act says that no proceedings, civil or criminal, can be taken out against any staff member of HDC for anything he or she may do or report or say while working for the Commissioner under this Act, unless he or she has acted in bad faith. This also covered independent expert advisors. Sections 120 to 126 of the Crown Entities Act extends this protection from prosecution further. But independent advisors are not covered by this additional protection.
- The risk of independent advisors being legally challenged is extremely slight. However, I think the HDC Act should be changed to include expert advisors contracted by HDC.

Question 18 - Do you consider that the Act should be changed to give independent expert advisors contracted by HDC the same amount of protection as under the Crown Entities Act?

1.13 Protection of information

- HDC has to follow the rules of the Privacy Act 1993 and the Official Information Act 1982 (the OIA). HDC has to decide about every request for information held by the Office to assess whether release of that information is necessary. This 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.

- I think the Act should be changed to stop information being given out during an investigation. In 1999 the Commissioner said a new section should be added to the Act allowing HDC to maintain secrecy about material gathered during an investigation, retaining the discretion to release material where this is necessary to carry out the Act. The Privacy Commissioner has a similar rule. This change would not risk the fairness of the investigation, but would prevent parties using information requests as a delaying tactic.

Question 19 - Should the Act be changed to let information gathered during an investigation to be kept inside HDC, while the investigation is ongoing?

Appendix 2 - Code of Health and Disability Services

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 sets out what should be in the Code. The Code started on 1 July 1996. It sets out the rights and duties of health and disability consumers within a clear and accessible framework. The Commissioner can look at external sources for guidance on appropriate standards in different professions, and for different types of treatment. This ensures that the Code remains up to date in the health and disability sectors.
- The Code has six clauses:
    - Clause 1 ensures the rights written in the Code belong to consumers and establishes the duties of providers to comply with the Code. It also tells providers to tell consumers about their rights and help them to use those rights.
    - Clause 2 lists the rights of all health and disability services consumers, including those taking part in teaching and research. Each right has a legal duty forced on all health and disability service providers. The ten Rights are:
        - Right 1: the right to be treated with respect
        - Right 2: To be treated fairly
        - Right 3: To dignity and independence
        - Right 4: To care and support that suits you
        - Right 5: To be told things in a way you understand
        - Right 6: To be told about your health or disability
        - Right 7: To make choices about your care and support
        - Right 8: To support
        - Right 9: To decide if you want to be part of training, teaching or research
        - Right 10: To make a complaint

- Under Clause 3 of the Code, a provider will not have broken the Code if he or she has taken reasonable steps to ensure a consumer's rights. This looks at the consumer's medical situation and the provider's resource constraints. Proof of actual harm to the consumer is not necessary for the Commissioner to decide a provider has broken one of the rights.
- Clause 4 defines certain words used in the Code.
- Clause 5 says that, in carrying out the rules in the Code, no provider is told to break any other New Zealand law, nor does the Code stop a provider from doing an act permitted by such a law.
- Clause 6 ensures that all existing rights outside of the Code still apply.
- Overall, the Code has worked very well and there is little need for change. As understanding of the Code has increased, so too has its 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 of the Act says the Commissioner shall check the Code and suggest any changes to the Minister every three years. Because of the amount of time and high cost of this, I think the timing of checks of the Code should be every 10 years, as is also my thinking about checks of the Act - See Question 1.
- HDC itself cannot change the Act or Code. Any suggestions for change must go through the Parliament and therefore there will be appropriate consultation.

2.3 Amendment of existing rights?

2.3.1 Right to compassion?

- The Compassion in Healthcare Trust thinks that the Code should be amended to include a "right to be treated with compassion". The Compassion in Healthcare Trust thinks that the rights in the Code do not talk strongly enough about the core value at the heart of healthcare, which is the humane quality of understanding suffering and wishing to relieve it - and their word for this is compassion. 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.
- As the Commissioner, I think 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 cover the right to compassion. HDC reports have sometimes mentioned this.

- 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.

2.3.2 Effective communication - Right 5

- Right 5(1) says you have the right to effective communication in a form, language and manner that lets you understand the information being given to you. This includes the right to a competent interpreter where reasonable and practical. This right is also affected by clause 3 in the Code, which says that the provider has not broken the Code if the provider has taken reasonable actions to obey the rules of the Code. In practice many providers get around language problems by asking you to bring a friend or family member to assist with communication. This is not always ideal, depending on the nature of the consultation.
- Sometimes providers ask about whether they must provide an interpreter to assist you. Very few complaints are about language problems between providers and consumers. Some women's health groups 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. I have previously advised the Minister that the Commissioner's Office and the Director of Advocacy do not have funding for a national translation service. There is no rule in the Act to tell the Commissioner to provide a national interpreting and translating service.
- However, the Director of Advocacy, Ethnic Affairs and the Office for Disability Issues are discussing 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)

I have previously asked if:

- 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 changed to say that services should not be against to the best interests of the patient because sometimes it is not yet known if research is in the best interests of the consumer.

- Right 7(4) is an important protection for a particularly vulnerable group of consumers - those who are not able to say if they agree with the treatment and no one else is present to agree with the treatment 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 situations.
- The first instruction in Right 7(4) is for the provider to try to get agreement from someone allowed to agree on the consumer's behalf. Examples include a parent agreeing to treatment on behalf of a child or a welfare guardian appointed by the court allowed to make health decisions on behalf of the consumer. If no one is present, the remaining steps in Right 7(4) must be followed before any treatment or service is provided.
- Right 7(4)(a) then says that the proposed service has to be in the best interests of the consumer. This includes a medical assessment by the provider of the need for treatment. The provider must think about the consumer's needs, interests and quality of life in total. 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 sometimes it may be right to give the treatment because of necessity.
- Sometimes it is not known in advance whether research is in the best interests of the consumer. For this reason, sometimes consumers may miss out on treatment even if it is not harmful.
- HDC has previously suggested a change about research on unconscious or incompetent patients with appropriate safeguards. The suggested change 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."
- I welcome your comments and feedback on whether Right 7(4) of the Code should be changed.
- *Please note that Rights 7(4)(b) and (c) have additional safeguards, which make the provider take reasonable steps to find out what the consumer would want if he or she were competent. Where it is not possible to find out this information, the views of other "suitable persons" able to advise the provider must be asked for and thought about. "Suitable persons" may include family, partners, friends or caregivers who have an interest in, and a relationship with, the consumer.*

2.3.4 Written consent - Right 7(6)

- Right 7(6) says that where agreement is needed to a health care procedure, it must be in writing if a) the consumer is to take part in any research; or b) the procedure is experimental; or c) the consumer will be under general anaesthetic; or d) there is a significant chance of bad 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 very broad. It covers the prescription of medication. Right 7(6)(d) of the Code tells providers to get

written agreement to the prescription of medication that will expose the patient to a significant chance of bad effects. It is very hard to comply with this in everyday practice.

- Now may be the right time to check when written agreement is needed 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 question has been raised if Right 7(7) should be changed to sort out the situation of consumers under compulsory treatment orders issued under 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).
- Even though 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 says that nothing in the Code allows a provider to break any other New Zealand law.

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

- Right 7(10) says that any bodily substances or body parts removed or obtained during a health care procedure may not be stored, preserved or used except:

  (a) with the informed consent of the consumer; or

  (b) for the purpose of research agreed to by an ethics committee; or

  (c) for the purpose of a quality assurance programme or an external audit or evaluation of services.

- The consumer's agreement is still needed to the actual procedure, such as the taking of the body part or substance. This allows for ethics committee approval as a back-up or exception when it is hard to get agreement and to permit certain activities conducted for the purpose of improving the quality of health and disability services.
- There are concerns about how Right 7(10) is understood in practice. It has been suggested the Commissioner explain how this section would be interpreted in a commentary 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.

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 talks about only the quality of service delivered and does not permit the Code to cover issues of access to services. The Act is not about 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 changed 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.
- The Human Rights Commission has said 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. 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.
- There has been support for including a right to access. No right of access to publicly funded treatment or to treatment given within a certain time limit was included in the Code when passed.
- It is contentious whether access and funding issues can be argued about in a court of law. Medical 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 treatment without knowledge of the competing claims. Decisions about prioritizing resources are best dealt with by politicians. 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. There is no evidence that including a right to access services would result in a high number of complaints about access to services. However, the New Zealand approach of separating access from quality and safety in the Code, and insisting on openness (such as through centralised supervision of waiting times), may well be better. The Code calls for an open process for

deciding access to care, and the Commissioner can still use the Code on behalf of patients about access issues.

- 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 says that every consumer has "the right to have his or her privacy respected". However, the right to privacy in Right 1 of the Code leaves out anything that may lead to a complaint under the Privacy Act or the Health Information Privacy Code (HIPC). The Code is 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 conducts a physical examination of a patient), and does not apply to privacy or confidentiality of health information.
- The Commissioner has no power over and is obliged to refer a complaint about breaking confidentiality to the Privacy Commissioner.
- Very occasionally, the Commissioner has taken action about complaints of breaking information privacy. This has been handled by the Commissioner where the information privacy principle is only a small part of the complaint and the other issues are covered by the Code. Two agencies do not have to handle the same case, a sensible approach. However it is not straightforward as a matter of law.
- As the Commissioner I think the rule in the Act which stops information privacy from being included in the Code has prevented the better and more flexible approach adopted for complaints about the right to be free from discrimination in Right 2. Both the Health and Disability Commissioner and the Chief Human Rights Commissioner share powers over these complaints. The two Commissioners can consult and decide on who most sensibly should decide the complaint.
- A simple solution would be to change 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 joint powers over complaints about health information privacy, and a referral power between HDC and the Privacy Commissioner in appropriate cases.
- The Privacy Commissioner has questioned the wisdom of shared powers. Instead perhaps the HDC Code could be changed to plug gaps in privacy rights in the sector. For example, the Privacy Commissioner suggested further controls on the handling of body parts or substances; specific standards about physical privacy, including intrusion into solitude; and noted the need to protect dignity, ethical and disclosure issues where there is no identifiable patient information.
- The New Zealand Law Commission is checking privacy values, technology change, and international trends, and their implications for New Zealand

law. In the report on stage one of this review, the Law Commission stated that the central issue for health information is to keep a balance between keeping personal health information confidential and getting the right information to the right person, at the time when it is needed.

- As the Commissioner I believe that issues of the confidentiality of, and access to, health information are so basic to the rights of health and disability services consumers that they should be protected in the Code. I welcome further discussion or feedback on this matter - see Question 4.

Appendix 3 - Health and Disability Services Consumer

Appendix 3 - Health and Disability Services Consumer Advocacy Service

3.1 Overview

- Part III of the Act sets up an independent advocacy service for health and disability services consumers who wish to complain about a break of the Code of Health and Disability Services Consumers' Rights. The HDC has learned that consumer advocacy is a very successful way of fixing complaints that are not about exploitation or public safety. Complaints suitable for advocacy assistance may include:
    - complaints about communication issues, including being given information;
    - complaints about the attitude of the provider for instance a lack of courtesy and rudeness;
    - complaints about issues where the dignity 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 about lack of co-operation among providers;
    - complaints about misunderstandings of cultural and social issues;
    - complaints about a minor drop in the provider's standard of care;
    - complaints about events that occurred prior to 1 July 1996.
- As a consumer you can access local advocates, who assist you to sort out the issues that led you to complain. The options for fixing the complaint are also talked through. You are then supported by advocates in taking the complaint to the provider in an effective way, usually in a meeting or in writing. This process allows you to raise your concerns in a way that increases your confidence and lets you sort out the complaint quickly.
- The advocacy process gives the provider a chance to understand the issues behind a complaint. The provider can answer the complaint in a place that is less formal and less 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 duties of the Director of Advocacy, the setting up and operation of the advocacy services and the duties of advocates.

3.2 Structure of advocacy services

- The Act permits the Commissioner to appoint a Director of Health and Disability Services Consumer Advocacy. The Director of Advocacy is in charge of the efficient, effective, and economical management of his or her activities. The duties of the Director of Advocacy are set out in section 25 as being:

  (a) To administer advocacy services agreements;

  (b) To promote, by education and publicity, advocacy services;

  (c) To look after the training of advocates; and

  (d) To monitor the operation of advocacy services, and to tell the Minister about the monitoring from time to time.

- In addition the Minister approves guidelines for the working of advocacy services. These guidelines are put out by the Commissioner.
- The independence of the Director from the Commissioner was put into the Act both to protect the advocates' role in acting on the side of the consumer and the Commissioner's evenhandedness when looking into and mediating complaints. Advocates are not impartial but take the side of the consumer. In contrast, it is essential that the Commissioner remain impartial or evenhanded 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 permits the independent advocacy services to health and disability services consumers through agreements with the Director of Advocacy acting 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 Director must contract with independent advocacy service providers. This structure permits the advocates to be on the side of the consumer in their support of the consumer, and it protects the impartiality of the Commissioner.
- An advocacy organisation may exist and provide services independently of HDC. An "advocacy services agreement" under the Act is a contract to provide advocacy services, and it is sorted out on behalf of the Crown. The Director of Advocacy does the negotiating of the agreement. The terms and conditions include economical, efficient and effective management, and the service must follow 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. After 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;
    - 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?

There have been benefits with a sole provider of core health and disability advocacy services nationwide. But problems remain with the current contracting structure. The Director of Advocacy has looked into other structures and now wishes to consult on those. 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 keep the independent work of advocates, who support consumers, separate from the Commissioner's varied roles, which include the impartial investigation of complaints. It also lets the Director of Advocacy contract for specialist advocacy services for example for a particular consumer group as well as the core health and disability advocacy service. However, it is hard for the Director of Advocacy to keep to the legal rules, and in practice there are problems with accountability. 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 hard to keep the same standard of advocacy services around the country.

    - Meeting the ethical standards expected of public servants. The Director of Advocacy is a public servant and the advocacy services are purchased with public funds. But the service is run by employees of a private organisation, who are not covered by the Public Service Code of Conduct and other rules and policies set up by the State Services Commission for the benefit of the public. The Director is not permitted to delegate his or her duties to an experienced advocacy manager.

  - Loss of control of public funds once transferred to the contracted advocacy service provider. A bad provider of advocacy services could use funds wrongly. Sorting this out by showing there has been a break in the contract may not happen quickly enough to stop any waste of the public funds.

  - 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 tried to date. The Director of Advocacy supports consultation on these proposals:

Renewable contract arrangements with preferred providers

- In sorting out core advocacy service agreements, the Director of Advocacy has called for tenders and assessed the proposals. As noted above, the last round resulted in a single contract for services with the Nationwide Advocacy Trust.

- This option would let the Director choose a preferred provider(s) for core advocacy services. A regular tendering round would not be necessary. 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 no other competing providers ready to provide even a comparable service. This was shown during the last tendering round, where significant set-up costs would have been necessary for any new providers to take on such a role.

- But this approach would have the same problems as a contracting relationship. It would also be hard 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

It is possible within the present rules 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". This has not been done so far. Consideration would need to be given to the tasks under the contract for hire of office space and products, IT, telephones and so on.

3.3.2 Option 2: Advocates as HDC employees

One option would be for advocates to be HDC employees. This would be like 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 legal officer. He is answerable to the Commissioner for the "efficient, effective, and economical management" of his or her activities, but not answerable to the Commissioner in carrying out the powers, duties and functions of the role (section 15). Recruitment and management of the staff is led 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 says that this system has worked well.

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

A change to section 25 ("Functions of Director of Advocacy") to include the recruitment and management of staff as legal roles of the Director would fix the position by making those tasks independent of the Commissioner, subject to the legal accountability for the efficient, effective and economic management of advocacy. The Commissioner would not be able to interfere in the recruitment and management of staff. The current contracting provisions in the Act would be repealed.

Some might say that, as the advocates would be employees of the Commissioner, it is possible that the independent function of advocacy would be put at risk. But 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 proper protections of independent functions.

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

A third option 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. They are to help him or her to carry out 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 must act independently from the Commission. 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 give some separation from the Commissioner in the case of a complaint about advocacy services.

Choosing this option may mean 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

If either option 2 or 3 is chosen, there are important questions about the future of the existing National Advocacy Trust. This was set up to provide the advocacy service for the Director. The current contract between the Director of Advocacy and the National Advocacy Trust ends 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 M?ori, 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.

As the Commissioner, 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

Appendix 4 - Director of Proceedings

4.1 Role of the Director of Proceedings

- One of the options the Commissioner can choose at the end of an investigation is to refer a provider to the Director of Proceedings. The Director of Proceedings is an independent legal officer appointed under section 15 of the Act. When the Director receives a referral from the Commissioner, he or she must decide whether to begin proceedings against the provider. Although the Director may give assistance to complainants in any forum for example 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 organisations 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 can tell the provider to pay compensation to the complainant. But because of the limitations imposed by ACC legislation, compensation money is possible only in a few situations.
- Under section 44 the Commissioner may not refer a provider to the Director unless the provider has been given a chance to comment on the proposed referral. The Commissioner must think about any comments from the provider, as well as the wishes of the complainant/consumer and the public interest.
- Where the Commissioner decides that the Code has been broken but does not refer the matter to the Director, or where the Director decides not to start proceedings before the Human Rights Review Tribunal, an complainant 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

The Director of Proceedings has pointed out that section 14(1)(f) does not say that the Commissioner must have first carried out an investigation before referring a provider to the Director of Proceedings. It is suggested that the Act should be changed to make clear that the Commissioner can only refer a provider to the

Director of Proceedings after carrying out an investigation (that is, referral pursuant to section 45(2)(f)).

4.1.2 Action by Director of Proceedings without referral

- From time to time a complainant has gone to the Director for assistance where there has been no referral by the Commissioner. Because section 47 appears before section 49, it is not surprising that some may think the Director can act without a referral. The Director has declined to be involved in any such proceedings, on the basis that a referral from the Commissioner is necessary before the Director can use any of the powers and functions under section 49 of the Act.
- So the question has been raised whether the public should be able to make a direct approach to the Director of Proceedings. The practical problem with the Commissioner referring a complaint without investigation, or with the public going directly 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 straight to the Director, the Commissioner's role would be duplicated, but not the range of powers.
- The Director of Proceedings thinks a change should be made to sections 47 and 14(1) of the Act to make it clear that any powers or functions of the Director occur only after a referral following an investigation.

Question 21 - Do you agree that section 47 should be amended to make it clear that the Director of Proceedings may take action only after a referral from the Commissioner?

4.1.3 Ability to obtain further information

- Section 62 lets the Commissioner collect information that may be necessary for the investigation. He can summon a person to speak 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 no longer work on the case. 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 force the giving of information.
- The need for further information may come from a number of things. The Director, in doing an independent check of the investigation, may think a certain piece of information is very important in deciding whether to lay a

disciplinary charge against a provider. The Commissioner may not have needed it in order to form his view that the Code has been broken. but the information may have more importance to the Health Practitioners Disciplinary Tribunal. New information may show there has been behaviour or actions that is professional misconduct and there should be a disciplinary sanction.

- Sometimes further information puts other issues into a different light. An complaint not proven by the Commissioner may later appear more capable of proof, but there are restrictions on the Director of Proceedings' ability to check it further.
- The Director of Proceedings thinks he or she should be 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. 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?

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 complainants greater access to the Human Rights Review Tribunal. A claim to the Tribunal can be made where the Commissioner has formed an opinion that the consumer's rights have been broken but he has not referred the provider to the Director of Proceedings. A claim can also be made to the Tribunal where a referral is made but the Director does not issue proceedings in the Human Rights Review Tribunal.
- This change to the Act was strongly opposed by many health practitioner groups in submissions and through the media. Some legal commentators feared it would lead to an increase in legal cases. 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 tells the Human Rights Review Tribunal to think about the findings and penalty imposed in disciplinary proceedings, 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 bad 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 complainant cannot then bring proceedings. Yet if the Director of Proceedings had made a decision not to issue proceedings in the first place, the complainant 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 awards of costs against the Commissioner should the claim not succeed. Such a decision is made in discussion with the complainant, and so the likelihood of a claim then being brought is slim.

Question 24 - Should a complainant be able to bring proceedings where the Director of Proceedings has decided to withdraw a claim, or changes his mind about a decision to issue proceedings?

4.2.2 Limitation periods for bringing proceedings

- For some years now the Law Commission has been looking into 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 current law says, 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 complainants can go to the Human Rights Review Tribunal is once an HDC investigation has been completed, the complainant is worse off than someone working under different laws. Others have an entitlement date from the time the acts or omissions occurred, with a limitation period commencing then. It is thought that any change to the Limitation Act will have rules of general application; special limitation rules contained in specific Acts will stay in place.
- The Director of Proceedings thinks that the Act should be changed to add a period of limitation for Human Rights Review Tribunal proceedings, with the limitation period running from the time the Commissioner finds that the Code has been broken. This is on the basis that no one can start proceedings until there has been a finding that the Code has been broken. This contrasts with any other complainant who can bring a claim in a court as soon as the damage arises.

Question 25 - Should the Act be changed to say 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 legal dispute in court.
- The Director of Proceedings thinks that definition of this term would be useful in deciding whether or not to start 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?

Appendix 5 - Disability Services Consumers' Rights

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) raised a number of issues about how disability services consumers' rights are protected. So HDC is checking how much support there is for a change to the Act so that HDC can 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. The report makes several suggestions about how the quality of care and service provision for people with disabilities could be improved. Looking at advocacy and complaint processes, the Committee has said to the Government that it:

- Look into the appointment of an independent disability commissioner, possibly in the office of the Health and Disability Commissioner. Any law change should also expand the areas the commissioner may examine to include, for example, access to services and individual funding issues. The commissioner should be in charge of thinking about disability issues about health, education, social development, and housing, and promote the recognition that disability is a fact of life and not primarily a health matter.

- Change the law to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities. This should allow 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.

- Set up an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.

- Instruct 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, we talked about certain areas of concern about the quality of disability services that had come up in complaints to the Office. We explained that HDC is limited in what action can be taken because many complaints received about disability services are outside the Commissioner's duties. Few complaints received by HDC are specifically about disability service provision.

- The most common reason for complaints about disability services being outside HDC's role is that the concerns relate to access or funding of services (rather than the quality of the service provided). Others don't fit because they do not involve a health or disability service. For HDC to look into a complaint under the Act and Code, there must be a disability services consumer, a disability services provider, a disability service, and an apparent break in 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.
- 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 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.

5.3 Extension of jurisdiction?

- The issues identified by the Disability Inquiry suggest that it is necessary to look into whether disability service consumers would benefit from widening HDC's role about disability. A separate issue is whether 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 look into be widened "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 promoting the recognition that disability is a fact of life and not primarily a health matter".
- 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 allow the Code to cover issues of access to services (section 20). While it may be outside the Act and Code 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 under s 20(2)(a) of the Act.
- The Act does not define "disability", but merely refers to a "person with a disability". As the Commissioner, I note that there are different ways to define a disability guided by either the "medical model" or "social model". 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 comment on seriousness or length of time the person is disabled (section 20(1)(h)). It may be time to look at the definitions under the Act relating to disability (see above, Appendix 1, 1.1 "Definitions").

- The suggestion to widen a Disability Commissioner's role to look into disability issues about education, social development, and housing would need much more change 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 our role but is done because it is no one else's problem, and to provide a holistic approach for consumers where aspects of their complaint are within our role. Although it would be better for consumers to have this practice agreed to in the Act and Code, 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 suggested a change in law "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."
- Possible options for widening HDC's role about access to disability services include:
  - A right for disability services consumers to receive the services the consumer has been assessed as needing. This would allow the Commissioner to review access decisions only once a needs assessment has been completed and approved.
  - Allowing the Commissioner to review any decision about access to disability services.
  - I would welcome further discussion and feedback on whether the Act should be changed to widen the Commissioner's role about disability services.

Question 27 - Do you suggest any change to the Act about the Commissioner's role over disability services?

5.4 Accessibility of complaints process

- There are often extra hurdles that disabled consumers must get over to put in a complaint. This can include 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 important issue is the limited range and number of disability support services. This means that consumers are often reluctant to complain 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). This may be a key 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 meant better access to advocacy for vulnerable consumers, particularly those who find it hard 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. This allows 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 because 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 make more frequent visits with extra 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 whänau. Some of these educational initiatives are outlined above. 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".
- 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.
- 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 sets up legal 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 change the Act to allow for an independent and dedicated Disability Commissioner.

- As the Commissioner, I do not think 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. It is not uncommon for a complaint to include both health and disability service providers; one of the Deputy Commissioners is already looking after complaints about disability services; and HDC has skill in advocacy and complaints fixing for disability consumers.
- As well, 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 work with another organisation, it would be better for advocates to deal with a Disability Commissioner within HDC.
- Setting up an independent Disability Commission, if other arrangements have not made major change in six years (as recommended by the Social Services Committee), is a possibility. CCS Disability Action has supported 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 wide roles may be problematic, given the number of organisations that already deal with areas of the disability sector, for example:
    - the Human Rights Commission about discrimination;
    - the Children's Commissioner about children with disabilities;
    - the Families Commission for families who care for family members with disabilities;
    - the Office for Disability Issues which promotes the work of the New Zealand Disability Strategy, monitors actions to enable the participation and inclusion of disabled people in society, provides a focus on disability issues in government, leads cross-sector policy, and provides support to the Minister for Disability Issues; and
    - DHBs who meet 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?