

A Review of the

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

Report to the
Minister of Health
June 2014



HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

27 June 2014

The Honourable Tony Ryall
Minister of Health
Parliament Buildings
WELLINGTON

Dear Minister

Background to review

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

Consultation

In early December 2013 I published a document for public consultation. This outlined previous reviews, noted the proposed amendments that arose from the 2009 review that I continue to support, and welcomed thoughts and feedback on questions about the Act and the Code and their general operation.

Copies of the consultation document were sent to a wide range of representative consumer and provider groups, and statutory agencies. A copy of the consultation document was posted on the Health and Disability Commissioner website.

I received 44 submissions as part of this review. A list of those who made submissions, and a summary of those submissions, are included in the appendices to my report.

Report

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

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

Yours sincerely



Anthony Hill
Health and Disability Commissioner

TABLE OF CONTENTS

INTRODUCTION	1
RECOMMENDATIONS FOR CHANGE	3
Review of the Act and the Code.....	3
Increase the maximum fine for an offence.....	3
Definition of “aggrieved person”	4
Director of Proceedings – power to require information	4
ISSUES NOT REQUIRING CHANGE	5
The Act	5
Definition of “disability”.....	5
Referrals	5
Information during investigation.....	5
The Code	5
Access to disability services.....	5
Interpreters	6
Disclosing information about identity and qualifications	6
Nurse and pharmacist prescribing	6
Research	6
Situations requiring written consent.....	7
Provider compliance.....	7
Assisted Reproductive Technology.....	8
General operation of the Act and the Code	9
Jurisdiction	9
Collaboration between agencies.....	10
Naming.....	10
Privacy.....	10
Advocacy.....	11
Ethics Committees.....	11
Appeals.....	11
Investigations processes	11
APPENDIX A – LIST OF SUBMITTERS	13
APPENDIX B – SUMMARY OF SUBMISSIONS	15

INTRODUCTION

The Health and Disability Commissioner (HDC) was established under the Health and Disability Commissioner Act 1994 (the Act) to promote and protect the rights of consumers of health and disability services. The rights of consumers are set out in the Code of Health and Disability Services Consumers' Rights 1996 (the Code).

The legislation requires the Commissioner to periodically undertake reviews of both the Act and the Code, consider whether any amendments are necessary or desirable, and report the findings to the Minister. As has been the practice in previous years, I decided to undertake these reviews simultaneously.

Consultation process

Since the last review in 2009, and during the four years that I have been Commissioner up until I commenced this review, I had not become aware of any issues with the Act or the Code that might warrant particular focus in this review. At the time I began consultation on this review, a number of recommendations from the 2009 review were still on the legislative agenda. Accordingly, I decided to carry out a general consultation in which I confirmed my support for the amendments to the Act, agreed on by the Minister of Health after the 2009 review, and asked for thoughts and feedback on whether the Act and/or the Code should be amended in any other way. I published a consultation document in December 2013. Copies of that document were distributed to a wide range of representative consumer and provider groups, statutory agencies, and to the media, as well as being posted on the HDC website.

Submissions

I received 44 submissions on the current review. The submissions raised similar issues to those raised in previous reviews, confirming my view that the Act and the Code are operating well. I have not been persuaded by any submissions that any additional amendment to the Act or the Code is necessary at this point.

In the following section I outline my comments on the main issues raised; further detail of the submissions received is set out in Appendix B.

Recent amendments

I note that the Act has recently been amended as follows:

- Section 9 (Deputy Commissioners and Mental Health Commissioner) was amended by adding: “(1A) Part 2 of the Crown Entities Act 2004 (except section 46) applies to the appointment and removal of a Deputy Health and Disability Commissioner in the same manner as it applies to the appointment and removal of the Commissioner.”
- The heading of section 38 (Commissioner may decide to take no action on complaint) was amended by inserting “or no further action” after “action”.

- Section 47 (Director of Proceedings' right to participate in disciplinary and other proceedings) was amended by inserting, after "may", ", after referral from the Commissioner under section 45(2)(f),".

RECOMMENDATIONS FOR CHANGE

As outlined in the consultation document, I continue to support the following proposed amendments to the Act arising out of the 2009 review:

- To require review of the Act and the Code only every ten years with the option of an earlier review if desirable.
- To increase the maximum fine for an offence under the Act from \$3,000 to \$10,000.
- To substitute the phrase “aggrieved person” with the phrase “the complainant (if any) or the aggrieved person(s) (if not the complainant)”.
- To enable the Director of Proceedings to require any person to provide information relating to a matter under consideration, until a decision has been made to issue proceedings, subject to section 63 of the Act.

Review of the Act and the Code

As mentioned above, the Act requires a regular review of the Act and the Code to consider whether any changes are necessary or desirable (sections 18 and 21 of the Act). This is the fourth review of the Act and the Code.

Of the 13 submissions received on this issue, opinion was divided over whether change was needed.

I recommend that the Act be amended to require review of the Act and the Code every ten years. Given that, since the early days of the Act and the Code, the reviews have not resulted in significant change and are resource-intensive, I consider that it is unnecessary to require such a regular review. The legislation already allows the Commissioner to undertake a review at any time as necessary, and the proposed amendment retains that safeguard. I do not consider that a less regular review in any way diminishes the ability of the Commissioner to protect and promote the rights of consumers. In my view, the fact that submissions received on the current review did not raise any significant new issues supports the recommendation that such regular reviews are unnecessary.

Increase the maximum fine for an offence

Section 73 sets out the offences against the Act with the penalty being a fine not exceeding \$3,000.

Ten submitters commented on this amendment, with all but one agreeing that the maximum fine should be increased to \$10,000. I consider that increasing the fine to align with other offences such as those outlined in the Health Practitioners Competence Assurance Act 2003 would send a strong message to those who choose to obstruct the Commissioner’s process. Accordingly, I recommend that the Act be amended to increase the fine in section 73 to \$10,000.

Definition of “aggrieved person”

Sections 50 to 58 of the Act outline who is able to bring proceedings before the Human Rights Review Tribunal (the Tribunal), and therefore who can claim damages in that forum arising from a breach of the Code. Rather than referring to health or disability consumers, the term “aggrieved person” is used. The Court of Appeal in *Marks v Director of Health and Disability Proceedings* [2009] NZCA 151 held that the term “aggrieved person” in the Act is essentially limited to consumers who themselves have rights under the Code, apart from two additional classes of people who may fall within the definition of “aggrieved person”: fathers of babies in the course of pregnancy and the birth process, and executors/administrators of the estates of deceased consumers.

Recently, in *P v F* [2014] NZHC 456 the High Court considered a claim for damages from a father whose baby suffered oxygen deprivation as a result of birth complications and developed cerebral palsy. Justice Young considered the situation of an involved father to be quite different from that of a party representing a consumer’s estate or a party acting for a consumer who cannot act for themselves, and ruled that such fathers do not come within the definition of “aggrieved person”.

Bearing in mind this context, I remain in agreement with the proposed amendment to replace “aggrieved person” with “the complainant (if any) or the aggrieved person(s) (if not the complainant)”. In my view, the proposed change would promote accountability and quality improvement by allowing a potentially wider class of complainants to bring proceedings in the Tribunal. Ten submitters commented on this amendment with nine agreeing that “aggrieved person” should be defined in this way. Accordingly, I recommend that section 2 of the Act be amended to define “aggrieved person” as “the complainant (if any) or the aggrieved person(s) (if not the complainant)”.

Director of Proceedings – power to require information

I support the amendment proposed to give the Director of Proceedings the same power as the Commissioner under section 62 to require the provision of information, until a decision has been made under section 49 to issue any proceedings. I agree that there may be situations where the Director wishes to obtain additional information in order to inform the Director’s decision under section 49, regarding what (if any) action to take after a referral is received from the Commissioner.

Nine out of ten submissions on this issue supported the proposed amendment. I have considered the submission that such an amendment would undermine the right to silence and common law rights to decline to provide further information. However, on balance, I recommend that this amendment be made to the Act.

ISSUES NOT REQUIRING CHANGE

The Act

Definition of disability

The 2009 review recommended that disability be defined in section 2 of the Act, in a manner consistent with the definitions in the New Zealand Disability Strategy and the United Nations Convention on the Rights of People with Disabilities. Submissions on the current review reflected this recommendation, with reference once again made to the UN Convention. While it is not ideal that these two definitions are different, I do not consider that the current definition impairs HDC's ability to consider the concerns of disability services consumers. I note that the Minister of Health declined to amend this section following the 2009 review as it does not reflect a change in policy. The Ministry of Health noted that such 'stylistic' changes are undesirable as they imply that Parliament intended to substantively alter the meaning of the words defined, which is not the case, and may lead to uncertainty and increased litigation. After careful consideration, I too am not convinced that such an amendment to section 2 is necessary.

Referrals

Two submissions considered that all complaints about registered providers should be referred to the relevant registration authority. This was consulted on as part of the 2009 review and it was noted that HDC has a Memorandum of Understanding (MOU) with a number of registration authorities so that they are informed of complaints where appropriate. Since that time, I note that MOUs have been agreed with additional registration authorities. I consider that these continue to operate effectively, and do not recommend that any change be made to the Act in this respect.

Information during investigation

Two submissions considered that the Commissioner should have the power to withhold information during an investigation. Once again, this was a change that was recommended to the Minister of Health in 2009 and subsequently declined. I consider that the current investigative process is working well, and affords natural justice to both providers and consumers. I am not convinced that any change to the Act is necessary in this regard.

The Code

Access to disability services

In the 2009 review it was recommended that the Code be amended to give disability services consumers a legally enforceable right to receive the services they have been assessed as needing following a needs assessment. The issue of whether Right 4 should be extended to include a right of access to disability services was raised again in a number of submissions in the current review.

In response to the recommendations made in the 2009 review the Ministry of Health noted that Needs Assessment and Services Coordination (NASC) services are already covered by the Code. The Ministry considered that the proposed amendment could have the unintended consequence of bringing resource allocation decisions within HDC's jurisdiction. Notwithstanding the submission received from the Office of the Ombudsman in the current review, I agree with that analysis, and am wary of making any amendment that could have that effect. I also agree that services delivered by NASCs already often come within my jurisdiction.

Interpreters

A number of submissions considered that the qualification in Right 5(1) that there is a right to an interpreter only where "reasonably practicable" should be removed. I am not convinced that such a change is necessary. Clause 3 of the Code already allows providers to assert that they have taken reasonable actions in the circumstances, therefore a qualification of reasonableness would continue to apply even if those words were removed from Right 5(1).

Disclosing information about identity and qualifications

The Medical Council of New Zealand expressed concern in their submission that there is a lack of direction around when providers should disclose information to consumers about their identity and qualifications. Providers are currently required to provide such information when asked (Right 6(3)), but this information is not explicitly specified as information that a consumer would expect to receive under Right 6(1).

Providing this information when asked is a minimum requirement, and overall I support an environment of voluntary, positive and early disclosure of information. In my view, the sector should be moving towards greater transparency in regards to matters such as who is performing a procedure and information about a provider's level of experience. This is consistent with my wider conversation with the sector about the importance of transparency in a consumer-centred system.

I consider that an amendment to the Code would be inappropriate, as the information that should be provided will depend on the circumstances. I also note Right 6(2), which already provides a right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.

Nurse and pharmacist prescribing

The Medical Council also expressed concern about nurse and pharmacist prescribing, specifically submitting that Right 6(1) be amended to make it clear what information patients should be receiving in those circumstances. I consider that Right 6(2) already provides adequate safeguards to consumers in these situations, and do not consider that the Code requires amendment on this point.

Research

Currently Right 7(4) permits the participation of incompetent consumers in research only in very limited circumstances. As a prerequisite to that participation, services to be provided must be in the consumer's best interests. The submissions made during the 2009 review were

divided over whether Right 7(4) required amendment to widen this to include situations not known to be contrary to the consumer's best interests as long as there was also approval from an ethics committee. The 2009 review report recommended amending Right 7(4)(a) to read:

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

When I took office as Health and Disability Commissioner, the next step in progressing such a change would have been to prepare a draft Code and further consult on that draft. However, in my view, the safeguards in Right 7(4) are important to protect consumers' rights and, after careful consideration of the competing views about this issue, I was not convinced that Right 7(4) required amendment. Accordingly, I did not take those next steps.

In the current review, two submissions were received on this issue. One submission supported the amendment suggested in 2009, while the other did not. Subsequent to the consultation process on the current review, issues surrounding research involving incompetent consumers have come to light and the application of Right 7(4) has been debated, including in the media. Having again heard strong views both for and against the change, I remain unconvinced that there is a clear mandate for any amendment at this stage and particularly in the absence of a more fulsome public information and consultation process. I will continue to monitor this issue before deciding whether a separate and wider consultation process is warranted.

One submission was received that expressed concern that the Code does not apply to all health and disability research, such as non-therapeutic health and disability research carried out by people other than health care providers. In my view, the Code adequately covers health and disability research. Specifically, it covers all health research conducted by health care providers. In addition, any research that involves the provision of health or disability services will also be covered. I do not consider there is a significant gap that needs filling through amendment of the Act's and/or the Code's definitions relative to research.

Situations requiring written consent

Right 7(6) sets out situations where written consent is required. The 2009 review report recommended that Right 7(6)(c), which outlines that consent must be in writing when the consumer will be under general anaesthetic, be amended by adding the words "...or sedation that has a similar effect". However, I did not consider that such amendment was necessary at that time, and accordingly determined not to proceed with further consultation on a draft Code. This is not an issue that I see appearing in complaints. One submission was received on this issue in the current review, however, I am still not persuaded that an amendment to this right is necessary.

Provider compliance

Two submissions on Clause 3 considered that it could be expanded to include specific circumstances where a provider's reasonable actions will not breach the Code. The current

wording of the clause is very broad, and, as such, I do not consider that such an amendment is necessary.

Assisted Reproductive Technology

The Advisory Committee on Assisted Reproductive Technology (ACART) noted in their submission that some aspects of fertility services, and the parties involved, appear not to be caught within the definitions used in the Act and the Code. In particular, they noted that:

- some individuals who contribute to fertility treatment, but are not subject to a “health care procedure”, are not “consumers”;
- some fertility services, such as creating an embryo outside the body or storage of gametes and embryos, are not “health care procedures”; and
- an embryo created outside the body is not a “body part” or “bodily substance” under the Code.

I note that complaints concerning the use of assisted reproductive technology are not necessarily excluded from HDC’s jurisdiction. Rather, the Act specifically includes “fertility services” in its definition of “health services”. Accordingly, many users of assisted reproductive technology services do have rights under the Code, for example, donors receiving fertility counselling, people having gametes extracted, and women having an embryo implanted.

I recognise, however, that there are some limited circumstances involving the use of assisted reproductive technology which may not be captured by the provisions of the Act and the Code, and may fall outside of HDC’s jurisdiction. Exactly what these are will depend on the particular circumstances of the case concerned. However, I am not convinced that any such gaps are sufficiently problematic to warrant an amendment to the Act.

The Act and the Code, and HDC’s jurisdiction, should be seen in the context of the other organisations and regulations that also operate to ensure the quality of fertility services. The Human Assisted Reproductive Technology Act 2004 (HART Act) regulates assisted reproduction procedures, including the creation and storage of embryos, and provides protection for the people involved. It sets out a regime where certain assisted reproductive procedures are prohibited (for example, the creation of cloned embryos), certain ‘established procedures’ are permitted without ethical approval (for example, IVF) and others may only be carried out with ethical approval, in accordance with guidance issued by ACART. The Ethics Committee on Assisted Reproductive Technology (ECART) reviews, determines and monitors applications for assisted reproductive procedures and human reproductive research. According to ACART’s annual report (2012/13), as part of its role, ACART also monitors the application, and health outcomes, of assisted reproductive procedures and established procedures.

The HART Act also requires providers of assisted reproductive technology services to be accredited. It is complemented by the New Zealand Standard – Fertility Services (NZS 8181:2007) which defines the quality and safety requirements for the provision of fertility services in New Zealand.

All health practitioners involved in providing assisted reproductive technology services are also subject to the requirements of their relevant regulatory authority pursuant to the Health Practitioners Competence Assurance Act 2003. This may include an assessment of a practitioner's competence, conduct, or fitness to practise, and the imposition of various restrictions, as required.

In addition, and as acknowledged in ACART's submission, there are common law remedies available to users of assisted reproduction services. While those processes and remedies may differ from those applicable in HDC's jurisdiction, I do not consider the common law remedies to be inappropriate. This is partly because of the specific contractual basis for the provision of many of the services that fall outside of the coverage of the Code (such as embryo storage).

General operation of the Act and the Code

Most submitters considered that the Act and the Code are operating well. However, there were a number of general comments on the operation of the Act and the Code, some of which I comment on below. Other comments are noted in Appendix B –“Analysis of Submissions”.

Jurisdiction

Submissions were made about groups of consumers that submitters consider fall outside the jurisdiction of the Act and the Code, in particular, consumers accessing assisted reproductive treatments, consumers being examined by an ACC contracted health professional, and consumers who have not yet received a service.

Each complaint received by HDC is considered individually, including as to the issue of jurisdiction. I consider that my jurisdiction is already sufficiently broad, and I am not persuaded that there are groups who fall outside my jurisdiction who should be offered the protections of the Code. Accordingly, I do not consider that there is a strong argument for any widening of my jurisdiction.

For completeness, I note that it is not correct to say that all complaints concerning examination services provided by ACC contracted health professionals fall outside of HDC's jurisdiction. For example, HDC has considered, and will continue to consider, where appropriate, issues relating to the manner, examination or diagnoses made by such providers. However, the reality is that, in many of those cases, the outcome that the complainant is seeking can more appropriately be achieved through the ACC review process. Section 38(2)(e) of the Act specifically allows me to take other such processes into account in making the decision to take no further action on a complaint.

I am currently in discussions with ACC with a view to developing an MOU as to our agencies' respective roles.

Collaboration between agencies

Three submissions commented on the issue of cross-agency collaboration, suggesting that better collaboration could occur.

HDC already works closely with a number of other agencies with responsibilities for quality and safety including: professional bodies, the Human Rights Commission, the Mental Health Foundation, the Office of Disability Issues, the Office of the Chief Coroner, the Ministry of Health, the Health Quality and Safety Commission New Zealand (HQSC), and ACC.

HDC is part of a quality forum and an information sharing forum also involving HQSC, ACC and the Ministry of Health. Together, issues of common interest are discussed and progressed. Recently, the four agencies have signed an MOU that formalises this relationship. In addition, HDC has developed close working relationships with other agencies whose jurisdictions may see them investigating similar issues to HDC. In many cases, HDC has implemented MOUs to formalise these interactions in order to ensure appropriate collaboration and information sharing, and to decrease any unnecessary duplication between agencies.

I do not consider that any amendment to the Act is necessary on this issue.

Naming

Two submissions were received recommending that all providers found in breach of the Code should be named. I acknowledge that this issue has been the subject of some public debate over the last few years.

HDC's naming policy sets out the factors that are taken into account when deciding whether an individual provider should be named. As articulated in that policy, there are circumstances in which naming of individual providers is appropriate, and even necessary. On occasion, public safety requires that the public be put on notice of the risk posed by a particular provider. However, those situations are few and far between. In the vast majority of cases, public safety is better achieved through other means, such as imposing targeted recommendations for change, and following up compliance with those recommendations. Sometimes accountability, independent of public safety considerations, may mean serious consideration should be given to naming an individual provider. However, as for naming for public safety reasons, this will usually only be appropriate following a proper, measured, and robust process involving rigorous analysis of the facts and competing interests at issue.

I believe that the naming policy balances the interests well and do not consider that routine naming of providers found in breach of the Code would be appropriate at this time.

Privacy

Only a handful of submissions commented on health information privacy and those submissions were divided on whether privacy should be dealt with by HDC. One of the recommendations in the 2009 review was to amend the Act and the Code to include the right to privacy in relation to health information. This was not accepted by the Minister. The Ministry noted that creating an overlapping jurisdiction between HDC and the Privacy

Commissioner could lead to inconsistency in the application of the law, and confusion for the public about the two roles. I consider that the current system with the Privacy Commissioner considering matters relating to privacy and access of health information works well, and I am not persuaded that the Act or the Code require amendment in this area.

Advocacy

The 2009 review recommended amending the Act so that advocates become employees of HDC, while retaining the independent function of advocacy services.

While I received some submissions on this issue, I consider that the current model is working well and preserves the independence of the National Advocacy Trust as a service provider. The issues relating to quality assurance and consistency of service standards that were raised in the 2009 review report are, in my view, appropriately addressed through standard contract management mechanisms. Accordingly, I do not recommend any amendment be made.

Ethics Committees

Two submissions suggested that ethics committees should come under the oversight of HDC. I do not consider that this would be appropriate given the independence of HDC and the need to consider complaints regarding research which may have been approved by an ethics committee. I also note that since the 2009 review, the operation of ethics committees in New Zealand has been reviewed and substantially amended, and greater involvement of HDC was not the direction chosen. I do not recommend that any amendment be made in relation to the oversight of ethics committees.

Appeals

The issue of including a right of appeal in the Act was raised by a few submitters pursuant to the current review. At present, parties may seek a review of my decisions by the Ombudsman and may bring judicial review proceedings in the High Court. In the context of those reviews, I am not convinced that a statutory right of appeal is necessary.

Investigations processes

Several submissions were made regarding the length of time taken to complete investigations. One submission was made about the transparency of the investigation process.

In every case, HDC must strike the appropriate balance between speed, efficiency, simplicity, and fairness. That balance is the most difficult to achieve when conducting complex formal investigations, the outcomes of which are highly significant for all involved. I cannot, and must not, compromise the quality and fairness of an investigation simply to expedite an outcome.

I am mindful of the need to progress matters as expeditiously as possible, while ensuring high quality decisions and compliance with natural justice for all parties involved. Complaints have increased significantly in the last four years (27% projected to June 2014), with output also increasing during that period (37% projected to June 2014). At the same time as this significant increase in output, the organisation is materially meeting its timeliness targets.

APPENDIX A – LIST OF SUBMITTERS

1. New Zealand Orthopaedic Association
2. The Office of the Children’s Commissioner
3. Council of Medical Colleges
4. The Royal Australasian College of Physicians
5. Federation of Women’s Health Councils
6. Medical Protection Society
7. Health Quality and Safety Commission New Zealand
8. NZ Organisation for Rare Disorders
9. Dental Council
10. Office of Ethnic Affairs
11. Human Rights Commission
12. Interpreting New Zealand
13. Elaine Henderson
14. Medical Council of New Zealand
15. Auckland Women’s Health Council
16. Pharmacy Council of New Zealand
17. ProCare
18. New Zealand Society of Anaesthetists
19. New Zealand Medical Association
20. Women’s Health Action Trust
21. National Ethics Advisory Committee
22. Ministry of Health – submissions by staff do not necessarily represent the Ministry’s views.
23. ACC
24. New Zealand Nurses Organisation
25. Advisory Committee on Assisted Reproductive Technology
26. Waikato District Health Board
27. Nurse Executives of New Zealand Inc
28. Health Professional Legal Services Ltd
29. Southern Cross Hospitals – submissions by staff do not necessarily represent Southern Cross Hospitals’ views.
30. Association of Blind Citizens of New Zealand Inc
31. Name withheld
32. Name withheld
33. Name withheld
34. Name withheld
35. Name withheld
36. Name withheld
37. Name withheld
38. Name withheld
39. Dr Ross Wilson, Paediatrician, Capital and Coast District Health Board
40. State Services Commission
41. New Zealand Law Society

42. Office of the Ombudsman
43. Advocates and Representatives Group to ACC
44. Mr Bryce Whiting

APPENDIX B – SUMMARY OF SUBMISSIONS

Recommendations arising out of the 2009 review

The consultation document informed submitters that the following amendments, arising out of the 2009 review, have the continued support of the Commissioner and that comments on these points was not necessary. Nevertheless, a number of comments were received.

Review the Act and the Code only every ten years with the option of an earlier review if desirable

Of those submitters that commented upon this amendment, opinion was divided.¹

Those that disagreed with the proposed amendment provided a range of reasons as to why they disagreed. One submitter raised concern that consumer groups do not have the same influence in getting changes introduced outside of the review process as health care professionals do, and therefore should not be required to wait for ten years before being provided with an opportunity to have their concerns addressed.² Two submitters commented that, in conjunction with this review's more general format, a ten-yearly process will decrease public interaction and understanding of the Act and the Code.³ One also commented that the current period reflects the statutory intent of protecting and promoting the rights of consumers by allowing the Code to develop a flexible and relevant framework.⁴ Two submitters commented that New Zealand's health sector can change significantly over time, with one noting changes to information technology, and that as a result there is a need for regular review of the Act and the Code.⁵

Submitters who agreed with the amendment generally made no further comments. However, it was noted that change takes time to occur and be evaluated, and a ten-yearly review would enable the Act to stay current while allowing longitudinal review of decision making.⁶ Another submitter also noted that, given it takes roughly five years to implement any review recommendations through legislation, a ten-yearly review is appropriate.⁷ Both of these submitters also noted that an interim review, if required, is sensible.

In the 2009 review, most submitters agreed with the Commissioner that a review every ten years would be sufficient.

¹ 7 against the amendment, 6 in favour, and 1 anonymous submitter (#33) who commented that it is the nature of the review, rather than how often it is conducted, that is important.

² Auckland Women's Health Council #15, where particular issue was taken with the introduced change to Right 7(10) outside of the review process.

³ New Zealand Nurses Organisation #24, and the Advocates and Representatives Group to ACC #43.

⁴ New Zealand Law Society #41.

⁵ Women's Health Action Trust #20, and The Royal Australasian College of Physicians #4.

⁶ New Zealand Orthopaedic Association #1.

⁷ Office of the Children's Commissioner #2.

Increase the maximum fine for an offence under the Act from \$3,000 to \$10,000

All but one⁸ who commented on this amendment agreed with the proposed change. The submitter who disagreed considered that such occasions where alleged offences under the Act have been raised are rare, and that an alleged offence is itself a sufficient deterrent.⁹ Of those that agreed,¹⁰ one considered that \$3,000 is a negligible amount for the potential extent of offences that may occur under the Act, and that increasing the fine to align with offences under the Health Practitioners Competence Assurance Act would send a stronger message to providers.¹¹ Another agreed that bringing the fine in line with maximum fines for other registered practitioner groups allowed for delineation between the gravity of any decision, which is especially important for public confidence in decisions.¹²

Substitute the phrase “aggrieved person” with the phrase “the complainant (if any) or the aggrieved person(s) (if not the complainant)”

The majority¹³ of those who submitted on this proposed amendment agreed with the change. Two submissions¹⁴ noted that the restrictive interpretation of “aggrieved person” by the Court of Appeal in the *Marks v Director of Health and Disability Proceedings* [2009] NZCA 151 decision has limited the rights of complainants to be awarded damages by the Human Rights Review Tribunal, and to bring their own proceedings before the Tribunal if the Director of Proceedings (DP) declines to do so, or if the Commissioner does not refer a provider to the DP following an investigation and breach finding. For reasons of access to justice and accountability, they support the proposed amended definition.

The Medical Protection Society,¹⁵ who also referred to the *Marks* decision, disagreed. They noted that the proposed wording is already used in section 50(4) of the Act, and there is no need to widen the definition in sections 51–54 and 57. They stated that the Court of Appeal ruled upon this point in *Marks* to cover only consumers under the Code except in limited circumstances. They also noted that section 51 has the words “whether personally or by any person authorised to act on his or her behalf”, and that considering the wording already used in the Act and the Court of Appeal’s commentary in *Marks*, the definition of “aggrieved person” is unambiguous as well as sufficiently wide in its coverage.

Enable the Director of Proceedings to require any person to provide information relating to a matter under consideration, until a decision has been made to issue proceedings, subject to section 63 of the Act

All but one¹⁶ submission on this issue agreed with the proposed amendment.¹⁷ The Royal Australasian College of Physicians commented that in order for the Director to make an

⁸ Medical Protection Society #6.

⁹ Ibid.

¹⁰ 10 submissions.

¹¹ The Royal Australasian College of Physicians #4.

¹² New Zealand Orthopaedic Association #1.

¹³ 9:1.

¹⁴ Office of the Ombudsman #42, and New Zealand Law Society #41.

¹⁵ #6.

¹⁶ Medical Protection Society #6.

¹⁷ 9:1.

informed, apposite and objective decision more information may be required on a specific aspect of an investigation. They did however suggest that during this process, employees of the provider should be supported to comply with all information requests, and should be protected from undue scrutiny. They also suggested that the amendment have a provision that requires the anonymity of informants to be upheld in all reasonable circumstances.¹⁸

The Medical Protection Society disagreed,¹⁹ and was of the opinion that by the time the Director comes to consider a matter it already will have been fully investigated by HDC, and that by this point an adverse opinion has already been formed regarding the conduct or matter in question. At this point the provider should have the right to remain silent or not provide a statement or information, applying the laws and procedure of criminal law to disciplinary proceedings, as set out in *Gurusinghe v Preliminary Proceedings Committee of the Medical Council of New Zealand* [1989] 1 NZLR 139. They stated that common law rights are significantly undermined if providers are not given a right to decline to provide further information.

Changes to the Code

Right 1

Right to compassion

Auckland Women's Health Council²⁰ considered that, as the Code currently stands, Rights 1 and 3 do not cover the right to be treated with compassion. Thus, they suggested that Right 1 should include a right to compassion, with an additional Right 1(4) added, stating "every consumer has the right to services provided with compassion, including a prompt and humane response to distress, pain and suffering". The right to compassion was consulted on as part of the 2009 review, and the majority of submitters who commented on it were in favour of an amendment adding this right, however, amendment was not recommended.

Inclusion of health information privacy

One submitter²¹ noted that Right 1(2) should include health information privacy (with an equivalent Act amendment at section 20(1)(c)(i)). They considered that complaints about a breach of health information privacy would be more appropriately dealt with by HDC than by referral to the Privacy Commissioner.

Right 4

A number of submissions commented on amending Right 4 to include access to services. While one was more general in its approach, suggesting that an overall right to treatment would be appropriate,²² the majority of these submissions focused on extending Right 4 to include a right to access for certain disability services, as proposed in the 2009 review.

¹⁸ The Royal Australasian College of Physicians #4

¹⁹ #6

²⁰ #15

²¹ Pharmacy Council of New Zealand #16

²² Mr Bryce Whiting #44

The submission from the Office of the Ombudsman²³ in particular was supportive of this amendment. They noted that section 20(2)(a) of the Act authorises the Code to cover matters of “particular importance” to disability services consumers and that timely access to services a disability services consumer needs is an issue of particular importance to disability services consumers. They stated that, as Ombudsmen, their role is as an independent monitoring mechanism (IMM) under Article 33 of the United Nations Convention on the Rights of Persons with Disabilities. Signatories to the Disabilities Convention are to promote, protect and ensure the full and equal engagement of all human rights and fundamental freedoms by all persons with disabilities. They noted an appreciation for the nervousness about making any changes to the Code which could have the unintended consequence of extending complaints to cover resource allocation decisions. However, they also consider that the proposed amendment is carefully constrained, relating only to timely access to services a disability services consumer has been assessed as needing. In their view the change would be consistent with the human rights approach underpinning the Code and the Disabilities Convention, and would be a significant step towards the vision set out in “Making Disability Rights Real”, the 2012 report of the IMM in New Zealand, of which their Office is part.

Similarly, the Human Rights Commission²⁴ also considered that while they accept that problems may arise if an unqualified right to access services were to be introduced, some of the difficulties might be resolved if the right was qualified by a reference which reflects a human rights approach and involves an obligation to balance the individual’s right to a particular service, giving priority needs to those who are most vulnerable.

Another submission²⁵ also supported a change to Right 4(3) that would give disability services consumers the right to timely access to disability services that they have been assessed as needing following a needs assessment.

Access to disability services was consulted on in the 2009 review.

Right 5

Ten submissions commented on Right 5, which gives consumers the right to a competent interpreter where necessary and reasonably practicable. The general theme of these submissions was that the qualification of being “reasonably practicable” should be removed. Three submissions²⁶ noted that the Code is already qualified by Clause 3 which refers to “reasonable actions in the circumstances”. One submitter²⁷ considered that the effect of the qualification in Right 5 therefore is to imply that it is more acceptable to not comply with the right to a competent interpreter than any of the other rights, while another²⁸ thought that the effect of both qualifications was to make “reasonably practicable” redundant.

These submissions also stated that there are a number of interpretation services now available, and that since the inception of the Code the availability of interpreters has changed

²³ #42

²⁴ #11.

²⁵ New Zealand Law Society #41.

²⁶ Interpreting New Zealand #12, New Zealand Medical Association #19, and Anonymous – online #31.

²⁷ Anonymous – online #31.

²⁸ Interpreting New Zealand #12.

dramatically. Three submitters²⁹ noted that the Office of Ethnic Affairs offers a Language Line, a professional telephone interpreting service in 44 languages, with one noting that most District Health Boards around the country are already signed up to this service. They also commented that most health service providers are also offering face to face interpreting where available. It was suggested that wording that reflects this reality should be used in the Code, as they consider that it is now entirely reasonable for a consumer with English as a second language to be offered professional interpreting. The Pharmacy Council noted that they would support the introduction of a national interpreting and translation service to further enhance and ensure effective communication.³⁰

One submission³¹ also considered that for consumers with limited or no English, Rights 6 and 7 are impossible to adhere to effectively without an interpreter. Similarly, another³² noted that informed choice and consent are key components of the Code and considered that it is unacceptable to exclude those who do not understand or speak much English. They also noted that the use of family members or friends to assist with communication is very unsatisfactory and can be particularly inappropriate for women. Another two submissions³³ stated that it can be difficult to comply with Right 7 in the absence of a professional interpreter.

On a separate note, the Association of Blind Citizens of New Zealand considered that Right 5(1) should recognise the right and need for consumers (if they so choose), to independently read and/or access information communicated to them. While they considered that this may be intended by "...effective communication in a form, language and manner that enables the consumer to understand the information provided...", they considered that it should be expanded to specifically recognise the diversity of communication needs, for example by adding the words "alternate format including but not limited to large print, audio, Braille, easy read and sign language...".³⁴ Similarly, another submitter³⁵ considered that there will be a significant number of consumers for whom delivery of information verbally is only partially effective, and that the right should be re-worded to refer to the use of visuals, or communication experts.

Finally, one submitter³⁶ considered that, with reference to Right 5, the Code should specifically state that health professionals are responsible for ensuring they communicate clearly and checking that consumers have understood the information given.

Right 6

The Medical Council of New Zealand³⁷ made an extensive submission on Right 6. They noted that the Right separates information that patients should always receive (Right 6(1)) from information they should receive if they request it (Right 6(3)), and they considered that

²⁹ Office of Ethnic Affairs #10, New Zealand Medical Association #19, and Anonymous – online #31.

³⁰ #16.

³¹ Interpreting New Zealand #12.

³² Auckland Women's Health Council #15.

³³ Anonymous, online #31 and #35.

³⁴ #30.

³⁵ Southern Cross Hospitals – various anonymous providers #29.

³⁶ Health Quality and Safety Commission New Zealand #7.

³⁷ #14.

it seems unusual that information about the “identity and qualifications” of the provider are under Right 6(3). The submission made reference to a number of parties who have raised concerns about whether students, house surgeons, and the new physician assistant profession should be informing patients about their level of training, prior to being asked. While they noted the requirements of Right 6(1)(d) and Right 6(2), they considered that there is still a lack of direction to health care providers about what information to provide to patients about themselves and their role in providing the patient with care.

The Medical Council also raised concerns about nurse and pharmacist prescribing, in particular who holds overall responsibility for consumer care, how information about care is being shared, and who to contact if a consumer has concerns or questions. They considered that Right 4(5) and Right 6(2) might deal with some, but not all, aspects of the concerns raised. They suggested that Right 6(1) could be amended to make it clear that patients should always receive information about: who has overall responsibility for their care; what the various roles of the team in providing care may be; and how those involved in their treatment will work as a team to ensure continuity of care.

Other comments made around Right 6 included: whether there is a need to consider how technology may impact consumers receiving information, for example through the ‘new and evolving’ patient portals³⁸ whether consumers should receive written materials on procedure³⁹ and whether information provided by pharmacies should be more comprehensive, specifically, whether the original information leaflet, that is often left out when dispensing bulk medication, should be provided to consumers.⁴⁰

Finally, one submission⁴¹ considered that Right 6(3) should be amended to read “the identity, registration and qualifications of the provider...”, and that Right 6(4) should be reworded so that the consumer is entitled to actual copies of the documents, not just a written summary.

Right 7

Interpreters

Three submissions⁴² on Right 7 considered that where a consumer has limited English language proficiency, a competent interpreter is likely to be required, and that the Code should be amended to reflect that.

Preference of provider

The Medical Council⁴³ was concerned that Right 7(8) provides patients with a tool to see a certain provider, and there is no ability of a doctor to resist except where impracticality prevents it, even where that preference may be undesirable because of an inappropriate emotional attachment, discrimination on basis of race, sexuality or sex, or where another provider could provide the same service more cheaply and effectively. They noted their concern that patients may use the clause to insist that a highly qualified practitioner provide

³⁸ Health Quality and Safety Commission New Zealand #7

³⁹ Anonymous – online #37.

⁴⁰ Anonymous – online #34.

⁴¹ Bryce Whiting #44.

⁴² Interpreting New Zealand #12, New Zealand Medical Association #19, and Anonymous – online #31.

⁴³ #14.

them with services, where it may be practicable but highly inefficient as those services could be more cheaply and effectively provided by someone else, and that this in turn could result in a loss of training opportunity.

Sedation

Two submissions considered the use of sedation in respect to Right 7. The New Zealand Law Society⁴⁴ submitted that Right 7(4) and Right 7(6)(c) should be amended. The New Zealand Society of Anaesthetists⁴⁵ submitted that Right 7(6) should be expanded to include sedation, general, and regional anaesthesia, as all modalities have potential risks and benefits. They also submitted that the Code should clearly describe the responsibility that a health care facility or institution is under to support the health practitioners in the informed consent process for consumers.

Consent on behalf of another

One submission⁴⁶ extensively considered Right 7, in the context of advanced care planning, and giving consent on behalf of another generally.

The submitter suggested that “or person entitled to give consent on behalf of that consumer” should be included in the text of Right 7(1) (and other relevant rights such as Right 7(7) and Right 7(10)) rather than in the definition of “consumer” in Clause 4. The submitter considered that providers, unfamiliar with referring to definitions, appear to overlook the fact that 7(1) includes a “person entitled to give consent on behalf of that consumer”.

The submitter also considered that, in Right 7(2), “reasonable grounds for believing that the consumer is not competent” is not adequate if there is a person entitled to give consent on behalf of that consumer and that person is available. In particular, the submitter noted that with our large elderly population, the consent is likely to be a “significant matter relating to the donor’s personal care and welfare” (section 98(6) Protection of Personal and Property Rights Act 1988 (PPPR Act)). The submitter expressed concern that many practitioners do not seem to be aware of the PPPR (Enduring Power of Attorney Forms) Regulations 2008, for example, Form 5: health practitioner’s certificate of mental incapacity for enduring power of attorney in relation to personal care and welfare.

The submitter was also concerned that the lack of decision making capacity for the purpose of Right 7(3) is often assumed too early.

With regard to Right 7(5), the submitter considered that the definition of “advance directive” in Clause 4 of the Code is very broad. It was suggested that the definition of “advance directive” and Right 7(5) should be carefully reviewed and possibly amended. She noted that the category of advance directive that is of most concern is an anticipatory refusal of consent to services. She was concerned that generally, consumers (and providers) do not know what “in accordance with common law” means, and that they are also not aware of the requirement for validity of an advance directive which determines its legal status.

⁴⁴ #41.

⁴⁵ #18.

⁴⁶ Elaine Henderson #13.

Finally, regarding Right 7(7), the submission noted that “consumer” includes a person entitled to give consent on behalf of that consumer, a consumer has the right to refuse services and to withdraw consent to services but there are certain matters that an attorney or welfare guardian cannot decide on (sections 18 and 98(4) PPPR Act). In addition, it was noted that there may be other limitations imposed by the donor in an enduring power of attorney in relation to personal care and welfare.

Prior amendments

The Auckland Women’s Health Council⁴⁷ submitted that the change made to Right 7(10) should be reversed, so that it reads “no body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, accessed for research purposes, or used otherwise without the informed consent of the consumer”. They stated that the need for this is due to an increasing amount of research and number of clinical trials that are now being undertaken on body parts and tissue samples without the knowledge or consent of the consumer. The Council consider that environment has changed dramatically in the last five to ten years to the extent that those in the clinical trials and pharmaceutical industry are now able to make large amounts of money from research on tissue samples that are being accessed and used without the knowledge or consent of patients.

The submitter also considered Right 7(4), and noted they did not support the amendment recommended in the 2009 review. They also considered that Right 7(6) should remain as it is, and noted they would not support any attempt to reduce the need for written consent.

Right 9

The New Zealand Law Society⁴⁸ considered that the extent to which the Code protects the interests of research participants is unclear because “health research” and “disability research” are not defined in the Code or the Act. The Code does not apply to all health and disability research, such as observational research, or non-therapeutic health and disability research carried out by people other than healthcare practitioners. They submitted that an expanded definition of “health and disability research” should include research regardless of whether or not it has been reviewed by an ethics committee.

Right 10

One submission⁴⁹ was received about Right 10, which noted that the complaints process can be very stressful to providers. The submitter considered that the right to complain should continue to reflect an ability to raise concerns, but that it should also be grounded in a quality improvement process, where all the steps adopt a constructive approach which supports both parties.

⁴⁷ #15.

⁴⁸ #41.

⁴⁹ ProCare #17.

Clause 3

Three submissions were received on Clause 3.

The Association of Blind Citizens of New Zealand⁵⁰ considered that resource constraints are used too often as a reason for not meeting needs, for example, the information needs of consumers. They considered that this means that while the onus is on the provider to prove that it took reasonable actions, consumers and blind people specifically, may be disadvantaged while that process runs its course.

The Medical Council⁵¹ noted that Clause 3 allows the Commissioner to find that a doctor did not breach the Code if they took reasonable actions in the circumstances. They considered that this could be expanded to also include “the consumer’s choices”, “system errors” and “the actions of other providers”.

Waikato District Health Board⁵² commented that this section could be expanded to provide more detail on the limitation of a consumer’s right to demand a specific therapy, investigation, or other professional service from a provider. They also commented that such an addition could include the provider’s duty to arrange access to a second opinion if the provider and the consumer cannot agree on a treatment plan.

Clause 4

Aside from the changes to definitions that have been suggested throughout this analysis in conjunction with other suggested amendments, a few submitters commented directly on Clause 4.

In particular, ACART⁵³ made a submission about changing the definitions of consumer, health care procedure, and bodily part or bodily substance. They submitted that the current definition of “consumer” does not appear to take into account other parties who contribute to fertility treatment, but who are not the subjects of a health care procedure. For example: a gamete donor whose gametes have been stored, sometimes long term, before being used in a fertility procedure; and embryo donors who have had fertility treatment in the past and have stored surplus embryos, but do not require a health care procedure in order to donate (except for counselling requirements at the time of donation). They also noted that the definition in the Code is inconsistent with that in the Fertility Services Standard, where the definition of a consumer is “a user or participant in the service, including client, patient, gamete or embryo donor. Where appropriate this may include the family/whanau or other representatives.” They stated that the definition of “health care procedure” does not extend to some fertility treatment processes, such as the creation of an embryo in a laboratory, or the storage of gametes or embryos.

They also submitted that there is no definition of “body part” or “bodily substance” for the purposes of Rights 7(9) and 7(10). They consider that an embryo, once created, is unlikely to

⁵⁰ #30.

⁵¹ #14.

⁵² #26.

⁵³ #25.

be interpreted as meeting the definition of being a “body part” or “bodily substance” of a consumer for the purposes of Rights 7(9) and 7(10), on the basis that a separate, new entity has been created that is not the body part or substance of one consumer. They submit that excluding embryos from these definitions appears to create a significant gap that does not take into account the separation in time and space between the creation of an in vitro embryo and the transfer of the embryo to the uterus of a recipient woman. They noted that while many embryos used are fresh, around a third of embryos used in treatment have been stored and then thawed before being used.

On a separate note, two further suggestions were made directly about the Clause 4 definitions, with one submitter⁵⁴ suggesting a new definition could be added about shared decision making, and another⁵⁵ considering that it would be beneficial to have a more in-depth description of alternate formats of communication for the purpose of Right 5.

Changes to the Act

Those that submitted on changing the Act did so with reference to both current sections, and with suggestions for new sections to be added. While a range of suggestions were made, there was little crossover between submitters on which aspects of the Act require amendment.

Existing Sections

Section 2 – Interpretation

The 2009 review asked a number of questions relating to disability, including the appropriateness of the definitions relating to disability services.

In the present review, two submitters⁵⁶ considered that disability should be defined within the Act. One⁵⁷ suggested that this definition should reflect the social model of disability, which emphasises the limitations of a disabling environment which prevents those with disabilities living life in the way most others take for granted, rather than focusing on action impairment. They noted that this definition is reflected in the United Nations Convention on the Rights of Persons with Disabilities, and is promoted by the World Health Organisation. Both submissions suggested that the definition of “disability services consumer” should be amended to ensure consistency with the above Convention.

One⁵⁸ submitted that the definition of “disability services” should be extended to include access and funding of services, rather than simply rehabilitative and technical needs; while the other noted that “disability services” should include needs assessment and service coordination services.

⁵⁴ Health Quality and Safety Commission New Zealand #7.

⁵⁵ Association of Blind Citizens of New Zealand #30.

⁵⁶ Disability Rights Commissioner, Human Rights Commission #11, New Zealand Law Society #41.

⁵⁷ Disability Rights Commissioner, Human Rights Commission #11.

⁵⁸ Ibid.

Section 20(1)(c) – Access to services (disability)

As discussed under the Right 4 submissions, two submitters⁵⁹ raised the issue of access to services. As discussed, this was extensively consulted on in the 2009 review, in both a general context and in relation to disability services.

One submission⁶⁰ noted that if it were considered appropriate to limit the proposal to include access to services to disability services only, then this change could be made by regulation pursuant to section 20(2)(a), which could amend section 20(1)(c) to include a further subsection (iv) which could read “... access to services taking into account competing needs and recognising the requirements of more vulnerable groups”.

Section 34 – Referrals

The 2009 review consulted on whether HDC should be required to refer all complaints about registered health practitioners to the relevant registration authority.

In the present review, two submissions⁶¹ considered that all complaints about health practitioners should be notified to the responsible authority.

The Dental Council⁶² noted that if the Commissioner decides to take no further action on a complaint, pursuant to section 38, unless there has been a referral to the responsible authority under section 34, then that will be the end of the matter. The submitter was concerned that information gathered in the preliminary assessment by HDC may still indicate that the provider may need some help in a specific area, however without a referral, the responsible authority will be unable to help. They suggested that an amendment to the referral section of the Act, or alternatively a change in policy and process, could address this concern. The Dental Council further submitted that referral of a complaint should not preclude HDC from taking further action; that referrals should be clear as to whether or not any formal investigation had taken place and whether the responsible authority was expected to investigate the practitioner and/or the complaint.

Section 40 – Process of investigation

The transparency of the investigation process was commented on by one submitter,⁶³ who noted that section 40 gives no information on how an investigation is conducted. Similarly, under section 15, the Commissioner may appoint a Director of Proceedings, but there is no detail as to how the Director will conduct their investigation. The submitter was concerned that the role and standing of the investigating team is not defined, and that there is no description of appropriate support and advocacy that a health care provider is entitled to during an investigation. They considered that the Act should contain a description of the potential roles of HDC representatives and delineate the support that a health professional should obtain for the purposes of an investigation.

⁵⁹ Disability Rights Commissioner, Human Rights Commission #11, and Office of the Ombudsman #42.

⁶⁰ Disability Rights Commissioner, Human Rights Commission #11.

⁶¹ Dental Council #9, and Federation of Women’s Health Councils #5.

⁶² #9.

⁶³ Ibid.

Section 42 – No disciplinary action by authority during investigation

The Medical Protection Society⁶⁴ expressed concern that although section 42 prevents registration authorities, once notified, from taking any disciplinary action for any subject matter under investigation by HDC, in practice, authorities will often undertake an investigation into the same conduct, under the guise of another action. The submitter noted the stress that this puts on an investigated provider. While they accepted that there are times where the harm is so serious that there will be a risk to the public, short of that they considered there ought to be no further action whatsoever pending HDC's determination or response. It was proposed that section 42(2) of the Act be expanded to not only limit further action to "no disciplinary action", but also to incorporate any further action or investigation except for a case falling within the area of serious misconduct as above.

Section 65(1) – Expert advisor immunity

The lack of immunity afforded to expert advisors was noted by one submitter⁶⁵ who considered that immunity such as that provided under the Crown Entities Act 2004 should be extended to expert advisors to HDC. They noted that this would allow expert advisors to be afforded the same immunity from prosecution (criminal or civil) as Pharmacy Council agents under section 119 of the Health Practitioners Competence Assurance Act.

New Sections

Information during investigation

Two submitters⁶⁶ considered that the Commissioner should have the power to withhold information obtained during an investigation, while the investigation is ongoing. This was consulted on as a part of the 2009 review.

One submission⁶⁷ noted that all such information should be released at the time a provisional decision is made, and natural justice would still be served by comments being called for at that time. They also noted that releasing documents throughout an investigation may hinder the investigative process.

Naming

It was recommended by two submitters⁶⁸ that the Act be amended to include a section that would allow the Commissioner to name all providers found in breach of the Code. One of the submitters⁶⁹ considered that the threat of naming may provide an incentive to create a climate of safety for patients to make complaints and have these resolved at a local level.

⁶⁴ #6.

⁶⁵ Pharmacy Council of New Zealand #16.

⁶⁶ Auckland Women's Health Council #15, and Pharmacy Council of New Zealand #16.

⁶⁷ Pharmacy Council of New Zealand #16.

⁶⁸ Auckland Women's Health Council #15, Federation of Women's Health Councils #5.

⁶⁹ Federation of Women's Health Councils #5.

Changes without consultation

One submission⁷⁰ considered that a new section should be introduced that would prevent the Commissioner suggesting, supporting or introducing changes to the Code without widespread consultation.

Operation of the Act and the Code – General

While many submitters commented that the Act and the Code are, on the whole, operating effectively, a number of general comments were also received.

Application of the Code

One submitter⁷¹ raised concerns that the Act and the Code were being applied inconsistently by providers, noting that it is important that the expectations of consumers regarding the obligations and duties of providers are met by all providers and health professionals in the sector.

Access

While access to services is discussed above in relation to Right 4, with the focus on disability services, another submission made a more general operational comment. The Medical Council of New Zealand⁷² noted that some patients may not be entitled to receive health services, such as uninsured or non-citizens. However, they consider that these people should still be able to access acute services if they need them to prevent harm, but there is a lack of clarity when they request non-acute services. They note that to some degree this is a funding and access issue, but is also often an issue of patient rights and provider responsibilities. What rights does a patient have when requesting a service they are not entitled to? What responsibilities does the provider have in responding to such requests? The Council expressed the view that there needs to be a conversation around the expectations that should apply.

Jurisdiction

Several submissions made comments about jurisdiction, with respect to a number of different classes of consumers.

ACART submitted⁷³ that the Commissioner provides an accessible and free complaints service that contrasts with the costs that may be associated with other legal avenues, such as common law remedies. The functions and roles of the respective advisory committee (ACART) and ethics committee (ECART) do not involve statutory functions in respect of oversight of the outcome of individual fertility services to those consumers accessing assisted reproductive procedures or of addressing any complaints that may arise against providers. They recommend that HDC consider how all aspects of fertility procedures might fall under the protection of the Code.

⁷⁰ Ibid.

⁷¹ National Ethics Advisory Committee #21

⁷² #14

⁷³ #25

The Association of Blind Citizens of New Zealand⁷⁴ commented that the Code is silent on the processes and procedures that must be followed before someone is identified as being a “consumer” and their entitlement to those services is acknowledged. They submitted that the Code appears not to address the rights of those who are declined a service as they are not yet consumers. They recommended that the Code be amended to address this group of people.

The Advocates and Representatives Group to ACC⁷⁵ submitted that section 31 be amended to widen the jurisdiction for consumer complaints regarding non-treating doctors. They noted that ACC often requires injured claimants to see or have their medical records examined by a third party medical specialist, whose decision can have a significant implication on treatment outcomes for claimants. They stated that, in their experience, medical specialists contracted to ACC often offer medical opinions about diagnosis which they are either not competent to provide and/or which are outside their scope of practice, and also offer advice about medical treatment and management which ACC considers should be followed. They suggest that the Act be amended to allow such complaints from claimants, about their treatment, to be considered by HDC.

The New Zealand Law Society⁷⁶ made a similar submission, noting that they have been alerted to difficulties experienced by some ACC claimants (who are examined by medical specialists engaged by ACC, for the purpose of reports prepared for ACC) in having a complaint considered by HDC.

Collaboration between agencies

A number of submissions⁷⁷ raised the issue of cross-agency collaboration.

General

One submitter⁷⁸ noted that there are a host of agencies with responsibilities for supporting activities aimed at improving both quality and safety in the health sector. They stated that, on occasion, more than one agency will be reviewing or investigating the same provider and that working together would be beneficial regarding information gathering and identification of corrective measures that could be employed. Furthermore, they considered that there is occasionally a situation of competing statutory powers relating to investigations (citing the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003) and how investigations should progress without prejudice to each other (in comparison to section 42, regarding authorities). The submitter suggested that there could be a specific duty in the Act requiring the Commissioner to collaborate with other agencies, to an appropriate extent.

Another submission⁷⁹ suggested that more communication is needed between government departments, HDC, Medsafe, ACC, Medical Colleges, and DHBs. They considered that reporting needs a more cohesive approach, with information about adverse events shared between departments, and that this information should be made available to the public.

⁷⁴ #30.

⁷⁵ #43.

⁷⁶ #41.

⁷⁷ Federation of Women’s Health Councils #5, Ministry of Health (internal staff feedback) #22, and ACC #23.

⁷⁸ Ministry of Health (internal staff feedback) #22.

⁷⁹ Anonymous, online #37.

Another submission⁸⁰ also considered that there is a lack of cross-agency collaboration and suggested that legislative change could be considered to enable this, although protocols and processes could also be put in place to achieve this.

ACC

It was commented by ACC⁸¹ that sometimes it is not clear whether ACC or HDC should be responsible for the investigation of complaints under the two agencies' respective Codes. They stated that development of an MOU between the agencies is being considered.

One submission⁸² considered that the Act needs amendment in order to be more consumer centred and more integrated with overlapping Acts, noting the Coroners Act and Accident Compensation Act. They considered that it is “utter nonsense” that only HDC can declare a service as “substandard” for the purpose of the Act when the ACC also make determinations of substandard care based on expert advice, and providers themselves will often admit substandard care. They suggested that if a service is determined “substandard” by either ACC, the Coroner, or the provider then this should be adopted by HDC. Such an approach would greatly reduce the time taken and stress involved in multiple jurisdictions for victims and their families.

Disability

One submitter⁸³ noted that there have been reports⁸⁴ criticising the lack of cross-agency collaboration and communication with regard to timely and effective resolution of complaints about disability support services.

Privacy

A few submitters⁸⁵ commented on the issue of health information privacy, which was consulted on in 2009.

The New Zealand Law Society⁸⁶ recommended that Right 1(2) be amended to read “every consumer has the right to have services provided in a manner that respects the privacy of the individual”, and that the definition of privacy be removed from Clause 4 of the Code.

One submitter⁸⁷ commented that information privacy issues should remain with the Privacy Commissioner. However, another⁸⁸ considered that health information privacy should be considered under the Act and the Code. Another submission⁸⁹ considered that it would be appropriate for privacy issues to be investigated by HDC when such issues are inextricably part of a complaint under investigation. However, they noted that such decisions should be

⁸⁰ Federation of Women's Health Councils #5.

⁸¹ #23.

⁸² Anonymous, online #32.

⁸³ Women's Health Action Trust #20.

⁸⁴ The submission noted the report “Putting People First, Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services December 2013”.

⁸⁵ Federation of Women's Health Councils #5, Pharmacy Council of New Zealand #16, and The Royal Australasian College of Physicians #4.

⁸⁶ #41.

⁸⁷ Federation of Women's Health Councils #5.

⁸⁸ Pharmacy Council of New Zealand #16.

⁸⁹ The Royal Australasian College of Physicians #4.

made in collaboration with the Privacy Commissioner, and in line with best practice protocols.

Advocacy

Two submitters⁹⁰ commented on the current model of advocacy services.

One⁹¹ considered that the current model is inappropriate, and noted that they support the introduction of an independent Office of the Director of Advocacy that could employ advocates directly. They stated that having advocates independent of the Commissioner is essential, and that the public should perceive that the advocacy service and advocates themselves are independent. In line with this, they suggested that it would be appropriate that the advocacy service have its own budget, rather than being linked to the services provided by HDC.

The other submitter⁹² also had concerns about the way that the advocacy service is resourced, noting the policy of resolving complaints at the lowest level. The submission also questioned whether more complaints should be referred to HDC from advocacy, either for noting any trend development or for higher level investigation due to their nature and/or complexity.

The model for advocacy services was consulted on as part of the 2009 review.

Ethics Committees

Two submitters⁹³ commented upon the national system of ethics committees, both suggesting they would fit better under the jurisdiction of HDC, with one⁹⁴ suggesting that there is a place for a Director of Ethics to oversee all ethics committees. Both submissions considered that the interests of research participants are no longer the focus of ethics committees, and that the interests of researchers are now central to the ethical committee review process.

The national oversight of ethics committees was consulted on in the 2009 review.

Appeals

Three submitters commented upon the current lack of a statutory right to appeal, which was part of the consultation in the 2009 review. One⁹⁵ noted that the majority of crown entities and government agencies allow a right of appeal, and that HDC may wish to investigate how such a procedure may be incorporated into existing processes. The other two⁹⁶ considered that it is against the principles of natural justice that there is no right of appeal.

⁹⁰ Auckland Women's Health Council #15, and Women's Health Action Trust #20.

⁹¹ Auckland Women's Health Council #15.

⁹² Women's Health Action Trust #20.

⁹³ Auckland Women's Health Council #15, and Women's Health Action Trust #20.

⁹⁴ Women's Health Action Trust #20.

⁹⁵ The Royal Australasian College of Physicians #4.

⁹⁶ Anonymous, online #32, and Southern Cross Hospitals – various providers #29.

Referral

It was noted in one submission⁹⁷ that referral to the Health Practitioners Disciplinary Tribunal is becoming more routine.⁹⁸ The submitter considered that the majority of providers referred to the Medical Council are found to be competent, and yet a significant amount of resources are spent on these investigations. They considered that the adversarial environment does not foster or encourage medical practitioners to openly disclose potential errors in episodes of care, and is concerned that this may lead to a very defensive method of medical practice.

Another submission considered that there should be a review of the Commissioner's discretion to investigate under section 40 of the Act, to avoid undue restriction of access to the HRRT.⁹⁹

Commissioner's discretion to take no action

One submitter¹⁰⁰ expressed concern that HDC has changed its attitude to what is considered a "major breach", and considered that some investigated complaints appear to be low level in nature.

Disability

One submitter¹⁰¹ noted that, while a Deputy Commissioner for Disability was first appointed in 2009, they consider that there is a need to consolidate and further strengthen this position in leading changes for disabled people.

Preliminary assessment

One submission¹⁰² considered that alternative dispute resolution pathways should be more prominent in preliminary assessment, as covered by section 33(1)(a)(i) of the Act, to assist in the resolution of low level complaints.

Expert advisors

One submission¹⁰³ noted that the Act does not describe a process or have established criteria for the selection of expert advisors. They commented that professional bodies could assist in the process. They further suggested that a panel of medical experts could be established to represent a broad range of practice in their field, including subspecialty work, and that this panel could be reviewed by the group of professional bodies periodically.

Response to complaints

The New Zealand Law Society¹⁰⁴ submitted that they consider there are problems with the interpretation of section 67, which may have a bearing upon the way the complaints process is conducted with health professionals facing complaints. They consider that any

⁹⁷ New Zealand Society of Anaesthetists #18.

⁹⁸ It was subsequently clarified with this submitter that the reference to the Health Practitioners Disciplinary Tribunal should have been to the Medical Council.

⁹⁹ New Zealand Law Society #41.

¹⁰⁰ New Zealand Society of Anaesthetists #18.

¹⁰¹ Federation of Women's Health Councils #5.

¹⁰² New Zealand Society of Anaesthetists #18.

¹⁰³ New Zealand Society of Anaesthetists #18.

¹⁰⁴ #41.

recommendation that a practitioner apologise, review aspects of their practice, make specific changes to their practice, or undergo further training, constitutes an adverse comment. They also stated that referral to registration bodies has occurred in the context of decisions to take no further action, and that implicit criticism of this sort should be disclosed to the practitioner for response.

Length of Investigations

Eight submitters commented on investigations timeframes. All of these submissions considered that investigations could be completed in a more timely manner.

Two submitters¹⁰⁵ suggested that the Act should state a reasonable timeframe for complaint investigation. Two submitters¹⁰⁶ commented on the timeframes given to providers when responding to a complaint. One submission¹⁰⁷ commented that in their operational experience, providers were being given shorter timeframes to respond to the initial complaint, consider expert opinions, and consider and respond to adverse comments. However, they considered that the timeframe of the investigation did not appear to be correspondingly timely, noting long periods of time elapsing between each step. They stated that this imbalance results in poor or incomplete information being considered by the Commissioner, as all the relevant facts may not be clear. Similarly, another two submissions¹⁰⁸ noted that while providers have timeframes for responses, as prescribed by Right 10, there are no corresponding timeframes placed upon HDC.

Finally, one submitter¹⁰⁹ commented that it would be worth considering, as part of the review, whether there are any legislative barriers which create impediments to the timeliness of the conduct of investigations, and whether these could be addressed while still maintaining the necessary natural justice obligations.

The 2009 review also questioned whether timeframes for investigations should be prescribed.

¹⁰⁵ New Zealand Society of Anaesthetists #18, New Zealand Law Society #41.

¹⁰⁶ New Zealand Nurses Organisation #24, and Health Professional Legal Services Ltd #28.

¹⁰⁷ New Zealand Nurses Organisation #24.

¹⁰⁸ Health Professional Legal Services Ltd #28, and Southern Cross Hospitals Ltd – various providers #29.

¹⁰⁹ Ministry of Health (internal staff feedback) #22.