CHAPTER 29

The role of the Health and Disability Commissioner and the Code of Rights

Anthony Hill *has been New Zealand's Health and Disability Commissioner since July 2010.*

Cite this as Hill A 2013. The role of the Health and Disability Commissioner and the Code of Rights. Chapter 29 in St George IM (ed.). Cole's medical practice in New Zealand, 12th edition. Medical Council of New Zealand, Wellington.

The role of the Health and Disability Commissioner (the Commissioner) is to:

- promote and protect the rights of consumers who use health and disability services; and
- facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringement of those rights.

As a consequence of the Crown Entities Reform Act 2012, the advocacy and monitoring functions in the mental health and addictions sector were transferred to the Health and Disability Commissioner.

The Commissioner enforces the *Code of Health and Disability Services Consumers' Rights* (the Code). The Code confers legal rights on those who use health and disability services in New Zealand (consumers) and places corresponding responsibilities on providers of those services.

HDC supports the successful expression of a consumer centred system. Culture is critical — the "the way we do things around here" should successfully engage the whole team caring for the consumer. Consumer centred care involves sharing information and understanding, engagement between provider and consumer, quality and continuity of care, a supportive and transparent environment — all of which are underpinned by respect for the consumer and their values and preferences, and the role of the consumer's family.

The Commissioner aims to achieve resolution, as well as safety and quality improvement through continuous learning, and protection of the public. A key aspect of successful resolution involves ensuring that the provider, the organisation, and the system identify what went wrong and successfully learn from it, and that the system is strengthened as a result.

The Code of Rights

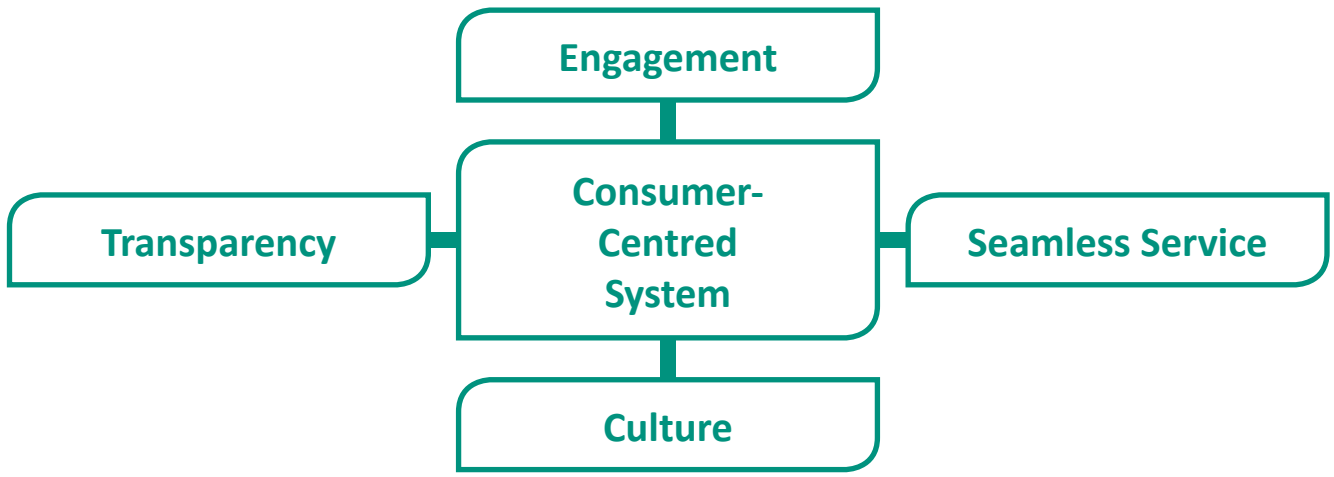
The Code became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act 1994 (the HDC Act).

Application of the Code is very wide and includes public and private services, paid and unpaid services, hospitals, and individuals. The Code covers all registered health professionals, such as doctors, nurses, and dentists, and can also cover other providers such as naturopaths, caregivers, and even people who care for family members with a disability.

The Commissioner can consider systems issues as well as individual actions.

The rights set out in the Code are not comprehensive. For example, the right to patient confidentiality is affirmed in separate privacy legislation (see chapter 13 on medical records), and the Code does not extend to funding decisions or confer entitlement to any particular service. The Code does not override duties or obligations established in other legislation.

Nor are the rights absolute. It is a defence for a provider to show that he or she took "reasonable actions in the circumstances to give effect to the rights, and comply with the duties in [the] Code". "The circumstances" are defined to include the consumer's clinical circumstances, the provider's resource constraints, and any other relevant circumstances.



In summary, there are ten rights.

1. Consumers should always be treated with respect.
2. No one should discriminate against consumers, pressure them into anything, or take advantage of them.
3. Services should help consumers to live dignified, independent lives.
4. Consumers should be treated with reasonable care and skill and receive well coordinated services.
5. Service providers should listen to consumers and give them information in a way they can understand and that makes them comfortable to ask questions if they don't understand. This may require the services of an interpreter.
6. Consumers should have any treatment explained to them, including benefits, risks, alternatives, and costs, and have any questions answered honestly. They must receive information that a reasonable consumer, in that consumer's circumstances, would expect, and information needed to receive to give informed consent.
7. Consumers can make their own decisions about treatment, and are free to change their mind.
8. Consumers can have a support person with them at most times.
9. The Code rights apply if consumers are asked to take part in research or teaching.
10. Consumers have a right to make a complaint and have it taken seriously.

All doctors should be familiar with the Code, and should take action to inform consumers about the rights in the Code. Copies of the Code, as well as other educational materials, can be obtained from the Commissioner's website (www.hdc.org.nz) or by phoning 0800 11 22 33.

Complaints resolution

Any person (including the consumer, a family member, or even another provider) may complain to the Commissioner alleging that any action of a provider is or appears to be in breach of the Code. Complaints made to an advocate that remain unresolved after advocacy assistance must be referred to the Commissioner. If the Medical Council receives a complaint about patient care, it must refer the complaint to the Commissioner in the first instance.

The Commissioner is responsible for ensuring that each complaint about health care and disability services providers is dealt with appropriately.

On receipt of a complaint, the Commissioner is required to make a preliminary assessment of the complaint to decide what course of action, if any, is appropriate. The Commissioner may, among other things:

- refer the complaint to another agency or person, including a regulatory authority such as the Medical Council, ACC, the Director General of Health, or the person who provided the services about which the consumer has complained
- refer the complaint to an advocate
- call a mediation conference
- formally investigate the complaint
- take no action on the complaint.

The HDC Act supports resolution of complaints at the lowest appropriate level.

In the 2011/2012 financial year, around 65 percent of the complaints HDC received were about doctors. Recurring themes in those complaints were failures to get the basics right, such as:

- reading the notes
- asking the questions
- talking to the patient
- listening to the patient and the patient's family
- ensuring continuity of care
- taking responsibility.

No further action

At any time after completing a preliminary assessment of a complaint, the Commissioner may, at his discretion, decide to take no action on a complaint if he considers that any action is unnecessary or inappropriate. This may occur when, for example:

- the length of time that has elapsed between the incident and the making of the complaint is such that an investigation is no longer practicable or desirable
- the subject matter of the complaint is trivial
- the complaint is frivolous or vexatious

- the consumer does not want action to be taken
- there is an adequate remedy which it would be reasonable for the complainant to exercise
- the matter has been fully investigated and reviewed, any recommendations of the review have been implemented, and an HDC investigation is unlikely to shed further light on the matter.

In some circumstances, the Commissioner may decide to take no further action but will make recommendations for improvement to systems and practices. The Commissioner will then follow up the recommendations to ensure any changes are appropriately implemented. In cases where the wider health sector may benefit from the learnings revealed by the assessment of complaint, the Commissioner may publish an anonymised case note on the HDC website.

Case study

Parents complained about the care provided to their eight year old son when he died following an anaphylactic reaction to nuts. In particular, they were concerned with the quality of information provided by a paediatrician about his nut allergy, resulting reactions, and links between asthma and nut allergy. They were also concerned about the lack of planned follow up or review when their son was discharged from paediatric overview.

The parents were concerned that their son's general practitioner did not adequately review or update the management of their son's nut allergies, or take the allergy into account when considering treatment for asthma.

The parents also complained that the health authorities did not provide national standards or consistent national delivery of advice and treatment on food allergies. They were concerned about the availability of immunology services and direct links between paediatricians and immunologists. The parents considered that advice on when to prescribe and administer adrenaline autoinjectors was unclear and inconsistent across the country.

The Commissioner obtained a response from the paediatrician and general practitioner concerned. He then requested preliminary expert advice from an expert general practitioner and an expert general paediatrician, both of whom advised that the care provided was appropriate and reasonable in the circumstances.

Overall, the Commissioner was satisfied with the clinical decisions made, and the care provided by the general practitioner and the paediatrician. However, the Commissioner suggested to the general practitioner and the paediatrician that they reflect on the expert paediatrician's comment that the boy's long term conditions, including his nut allergy, should have been under ongoing review. He recommended that the general practitioner and paediatrician keep abreast of ongoing developments in this field, including the issue of health professionals working more closely together, with families, to ensure quality and continuity of services, and cooperative monitoring of long term conditions.

The Commissioner published a case study on the HDC website for educational purposes, and brought the case to the attention of the Royal New Zealand College of Practitioners, the Paediatric Society, Coronial Services, the New Zealand Clinical Immunology and Allergy Group, the Ministry of Health, Pharmac, the National Health Board, and the Health Quality and Safety Commission.

This case can be accessed in full at http://www.hdc.org.nz/media/192449/10hdc00458casenote.pdf

Provider resolution

Often the quickest and most satisfactory way of dealing with complaints is for the consumer to deal directly with the provider. A health or disability service provider who respects, listens to, and involves the consumer (and family and whānau where appropriate) is more likely to deliver a better service and be able to resolve any concerns at an early stage. The Code requires providers to have a complaints procedure, and sets out minimum requirements for keeping consumers informed about the progress of their complaint. Consumers are entitled to the assistance of a support person or an independent advocate when making a complaint.

The Commissioner may refer a complaint to the provider for resolution if the complaint does not raise public safety issues and can be appropriately resolved by the provider. In some cases, the provider may not have been aware of the complaint and may be well motivated to resolve the complaint directly with the consumer. All referrals to a provider are accompanied by reporting requirements back to the Commissioner. This enables the Commissioner to review the outcome of referrals to ensure the matter is adequately resolved, any compliance issues are addressed, and independent oversight is maintained. The Commissioner may take further action if not satisfied with the reported outcome.

Case study

The Commissioner received a complaint relating to a woman's care over a year or more by providers from many disciplines, all in one District Health Board. The woman complained of her "year of hell". She acknowledged that taken in isolation the matters she complained of could appear trivial, but in total they had had a serious effect on her health. After discussion with the District Health Board's chief executive officer, and with the woman's agreement, the complaint was referred to the District Health Board. The District Health Board looked into the complaint, met with the patient, and achieved a speedy resolution which satisfied her. She reported the positive outcome to the Commissioner before the District Health Board had reported back.

Advocacy

Free independent advocacy services are available throughout New Zealand. Advocates promote awareness of the Code and HDC Act, providing free education sessions to consumers and providers. They assist consumers to resolve complaints at an early stage and encourage self advocacy as well as providing more support as needed.

Advocates do not make decisions on whether there has been a breach of the Code. Rather, their role is to give consumers information about their rights, and to support them to make decisions and take action to attempt to resolve the complaint. Most complaints that advocates handle are received directly rather than via the Commissioner, but in some cases the Commissioner may decide that a complaint made to his office should be referred to an advocate to enable the parties to resolve the matter. The majority of complaints referred to advocacy are successfully resolved, often by face to face meetings with providers. Advocates must report back to the Commissioner with the results of a referral to advocacy, and may also report on any matter concerning the rights of consumers that they consider should be brought to the Commissioner's attention.

The nationwide health and disability service is provided by an independent national advocacy trust through a contractual arrangement with the Director of Advocacy. The advocacy service can be contacted by freephone on 0800 555 050, free fax on 0800 2787 7678 or at advocacy@hdc.org.nz.

Case study

Mrs D was provided with verbal and written information about advocacy and the Code after relaying the following information: on a number of occasions she and her doctor had discussed the probability that she would need to start an antihypertensive. At a consultation her blood pressure was noted, yet again, to be high, and the doctor advised that it was now time to start the treatment. They again discussed her reluctance to commence the treatment, but she agreed to do so. Mrs D was told the name of the medication being prescribed and she asked about possible side effects. The doctor told her she would know if she experienced any and she should return if she did. Mrs D then requested the same information from the dispensing pharmacist, who advised that it is not the pharmacy's normal practice to provide such information about the medication.

Mrs D was very disturbed about not being able to get the information and contacted the local advocate to find out her rights. As a result of her concerns and discussions with the advocate, Mrs D decided to seek a second opinion from a specialist, and contacted her general practitioner's nurse to organise a referral letter. Within the hour her doctor had telephoned her, having recognised her distress, and asked to meet with her later the same day. Mrs D's advocate offered to support her, but Mrs D felt able to proceed alone.

She reported back to the advocate that the meeting had gone well and she had received the information she required. The doctor apologised for the distress caused and assured her that he would support her in obtaining a second opinion.

Other advocacy case studies can be found online at http://advocacy.hdc.org.nz

Mediation

The Commissioner may call a mediation conference at any stage. Mediation is often a very effective way of resolving complaints, and provides an opportunity for the parties to agree to a fair outcome with minimum delay and cost.

The parties meet across the table, with or without support persons, to discuss their concerns. Although the parties may have a lawyer present, this is not necessary. An impartial mediator assists the parties to define the issues in dispute, explore options for resolution of the complaint, and find their own solutions to the dispute. All statements made during mediation are confidential and, if a deed of settlement is signed, it is a full and final settlement of the issue.

If a complaint is not resolved by mediation, the Commissioner will decide what, if any, further action to take.

Case study

Mr E was admitted to a hospital Emergency Department after injuring himself in a car accident that morning. On assessment, his main complaint was abdominal and back pain. Xrays of his back and neck showed no fractures, and he was discharged around 5pm. Mr E's condition deteriorated and he was readmitted to the Emergency Department at 10pm with pain in the kidney region and symptoms of shock. He was reassessed and discharged home with pain relief and treatment for a urinary tract infection. Four days later he deteriorated markedly, with disorientation, increased abdominal and back pain, and weakening of his legs. He was admitted to Intensive Care and received treatment for a contusion of the small bowel. Mr E continued to complain of intermittent back pain, but another Xray showed no fracture. However, a further Xray and CT imaging taken a few days later indicated a fractured spine. Mr E experienced increasing heaviness in his legs and subsequently developed paraplegia.

This serious complaint concerned the standard of care Mr E received at the hospital. The primary issue was the failure of hospital medical staff to diagnose the fracture, which left Mr E paralysed. The complaint also concerned pain management, nursing care, and communication.

The Commissioner commenced an investigation and, after reviewing the hospital's response, referred the matter for expert orthopaedic advice. The advisor considered that, overall, the care Mr E received was satisfactory. Mr E's fracture was not displaced at the time of initial Xray investigation and was therefore hidden from view. The advisor stated that this was an exceptionally complex case, and that Mr E had received good management and well documented, compassionate care.

In light of the expert clinical advice, and the unresolved communication concerns, the matter was considered appropriate for mediation. As Mr E's family was Māori, the Commissioner engaged a Māori mediator with knowledge of cultural issues. The family and the District Health Board were provided with a copy of the expert advice prior to the mediation conference, to guide them in their discussions.

The mediation conference resulted in a successful outcome. This included a written apology by the Board to Mr E and his whānau, as well as the instigation of a process to restore his mana. In its letter of apology, the Board commented that the mediation was a learning experience for all involved, and that the knowledge gained would be applied for the benefit of all patients.

Investigations

Some complaints, for example those involving allegations of serious professional misconduct, sexual impropriety, complex systems issues, or public safety issues, are not appropriate for low level resolution and proceed to a formal investigation. The Commissioner may commence an investigation in response to a complaint or on the Commissioner's own initiative.

The investigation process is independent and impartial. Providers are informed of the investigation, given a copy of the letter of complaint, and asked to respond to the complaint. The provider's response is very important in informing the Commissioner's understanding of what occurred, and his opinion as to whether there has been a breach of the Code.

Registration authorities, such as the Medical Council, are notified of any investigation.

Where the appropriate standard of care is in issue, expert independent clinical advice is obtained to assist the Commissioner to form an opinion. Relevant professional groups, such as the Royal New Zealand College of General Practitioners, nominate expert advisers, and the advisers are named in the Commissioner's reports.

The HDC Act gives the Commissioner wide powers to gather relevant information. This includes the ability to summon witnesses, to take evidence under oath, and to require the production of relevant documents. It is an offence to obstruct or hinder the Commissioner or any other person in the exercise of their powers under the HDC Act, or to give false or misleading information.

Most investigations end in a written report from the Commissioner to the parties. Before forming a final opinion, the Commissioner sends a provisional report to the parties. If any adverse comment is made about a person, that person is given an opportunity to respond to the adverse comment before the Commissioner's report is published. The Commissioner considers responses to the provisional report, and sometimes seeks further expert advice, before issuing a final report. The reports are usually published in an anonymised form on the HDC website.

An investigation can be a lengthy process, depending on the complexity of the issues under consideration and the number of people involved.

Relationships with other organisations

Complaints may be referred to other agencies or persons involved in the health and disability sector. For example, a complaint of a breach of patient confidentiality will be referred to the Privacy Commissioner, and a complaint of discrimination will usually be referred to the Human Rights Commission. Concerns about the conduct or competence of a registered health practitioner will usually be referred to the appropriate registration authority, such as the Medical Council.

Working with other agencies is an important part of promoting and protecting the rights of consumers. Where necessary, the Commissioner shares information with a number of other agencies and persons, so that relevant information can be analysed and acted on to identify public safety concerns, and so that duplication can be minimised.

The Commissioner has wide discretion to refer a matter to an appropriate person or authority. For example, the Commissioner may contact ACC if it appears that the consumer may be entitled to compensation for a personal injury, and concerns about inappropriate prescribing may be referred to Medsafe.

The Commissioner must inform the appropriate authority or person if he becomes aware that the practice or systems of a health care provider may pose a risk of harm to the public.

Options where there is a breach of the Code

Where an investigation reveals a breach of the Code, the Commissioner has a number of options. Usually, the Commissioner's final report makes recommendations to improve systems or practices, and help ensure that a situation similar to that which led to the breach of the Code does not recur. For example, the Commissioner may recommend that the provider offer the consumer a written apology, review his or her practice in the light of the Commissioner's report, undertake further education, or implement appropriate systems to prevent a recurrence. The Commissioner cannot order compensation, but occasionally may recommend that a provider refund money paid for substandard services.

The Commissioner's opinion is reported to the relevant registration authority and, in the case of a doctor, the Medical Council may be asked to consider the need for a competence review. Copies of the report may also be sent to the Minister of Health, funders, or any other appropriate agency, to enable them to take further action if necessary.

Reports with significant educational value are distributed to the appropriate colleges and posted on the Commissioner's website (www.hdc.org.nz) in an anonymised form. The Commissioner is empowered to name individual providers publicly. While he will usually name group providers such as a DHB or a rest home, he only names individual providers in exceptional circumstances (eg, where the provider poses a risk of harm to the public). The Commissioner's naming policy can be accessed at www.hdc.org.nz.

The Commissioner uses individual complaints to promote wider systemic improvements. For example, in the cases below, the Commissioner investigated complaints involving deficiencies in the coordination of care (including handover) and supervision.

Case study

A woman complained about the care provided to her 79 year old father, who had Parkinson's disease, by a public hospital. The man was referred to the hospital's emergency department with acute pain in his left leg and a cold, blue left foot. He was diagnosed with impending ischaemia and admitted to hospital.

The man was initially under the care of a general surgeon. The hospital's vascular surgeon was on leave at the time the man was admitted. The vascular surgeon's registrar gave the general surgeon ambiguous information about the vascular surgeon's return, which led to a delay of ten days before the man was seen by the vascular surgeon.

Eight days later, the vascular surgeon performed a bypass of the aneurysm behind the man's knee.

Over the next few days, the man's condition deteriorated. The vascular surgeon again went on leave, and did not handover care of the man to the on call consultant, relying instead on the registrar. The registrar and a house surgeon reviewed the man, whose foot was pale, cool and his pulses faint. The registrar did not take further action or contact the on call consultant.

Five days after surgery the man was reviewed by the on call surgeon, who concluded that the bypass graft was blocked. The man was transferred to a larger DHB, where acute ischaemia following an acute thrombosis of the graft was diagnosed. Removing the clot did not improve the condition of the man's foot and he underwent an above knee amputation. The family told the Commissioner that despite raising concerns on several occasions, they were reassured that "it should be alright".

The Commissioner found that the general surgeon should have checked the roster to determine exactly when the vascular surgeon was back from leave. The delay of ten days to see a vascular surgeon was unacceptable. The general surgeon breached Right 4(1) of the Code (the right to have services provided with reasonable care and skill).

The Commissioner found that the registrar should have taken more care in informing the general surgeon about the vascular surgeon's return from leave. He also found that the registrar failed to recognise that the man's condition was deteriorating and seek appropriate specialist advice from the on call consultant. The registrar also failed to document all his examinations and findings. The registrar breached Right 4(1) of the Code.

The vascular surgeon failed to adequately handover the man's care to the on call consultant when he went on leave. No specific instructions were left in the clinical records to cover his absence, particularly in the event of the man's deterioration. The vascular surgeon breached Right 4(5) of the Code (the right to cooperation among providers to ensure quality and continuity of care).

The Commissioner made adverse comment about the DHB. The medical record demonstrated that the nurses and the medical officer were concerned about the man's deterioration, however, there was a lack of action at the stage when the registrar's management should have been questioned and when concerns about the care being provided should have been raised and escalated to the on call consultant. The Commissioner emphasised that DHBs and senior practitioners need to encourage a culture where it is acceptable and commonplace for questions to be asked, to and from any point in the hierarchy, at any time.

Case study

A woman complained about the services provided to her husband by DHB1. The man consulted a respiratory physician at DHB2, who arranged for tests, including an exercise tolerance test (ETT), which showed the man had significant coronary artery disease that required urgent attention. The respiratory physician telephoned DHB1, then faxed a referral and the ETT results to DHB1. The respiratory physician did not detail the ETT results in the referral letter but mentioned in the letter that the results were accompanying the letter.

The referral was triaged by a cardiologist at DHB1. He told HDC the ETT results were "too faint to read" and that he did not follow up a legible copy. He triaged the man's priority as "semiurgent" but later advised HDC that if he had seen the ETT results he would have assessed the man's priority as "urgent". Appointment dates were assigned in accordance with the "semiurgent" priority but, sadly, the man died of a heart attack before the first of those appointments.

The Commissioner found that a system, designed to ensure that patients who require either immediate hospitalisation or an urgent assessment are assessed in a timely way, failed to deliver.

DHB1 was found in breach of Right 4(1) of the Code because staff did not obtain sufficient information to determine whether it was necessary to refer the respiratory physician's call to the on call registrar or consultant, did not seek a legible copy of the ETT results, and did not appropriately acknowledge the referral. It also failed to communicate effectively with DHB2 and breached Right 4(5). DHB1 also failed to provide the man with adequate information about his referral and breached Right 6(1)(c).

Adverse comment was made about the cardiologist's failure to ensure that a legible copy of the ETT results were obtained and reviewed. The Commissioner also criticised DHB2 for its failure to ensure the referral was received and actioned.

Proceedings

Following a finding of a breach of the Code, the Commissioner may refer a provider to the independent Director of Proceedings, to decide whether legal proceedings will be issued against that provider. Before referring a provider, the Commissioner must give the provider an opportunity to comment on the proposed referral. The Commissioner must also have regard to the wishes of the consumer and complainant and the public interest (including any public health or safety issues).

The Director of Proceedings may take proceedings before the Human Rights Review Tribunal and/or the Health Practitioners Disciplinary Tribunal, or may decide to take no further action. An aggrieved person may themselves bring proceedings before the Human Rights Review Tribunal where the Commissioner, having found a breach of the Code, decides not to refer the matter to the Director of Proceedings, or where the Director of Proceedings decides not to take proceedings.

The functions of the Health Practitioners Disciplinary Tribunal are outlined in chapter 30.

The Human Rights Review Tribunal

Where proceedings are brought before the Human Rights Review Tribunal, the Tribunal has the power to award a number of remedies, including:

- a declaration that the provider's action is in breach of the Code
- an order restraining the provider from continuing or repeating the breach
- an order that the provider perform any specified acts with a view to redressing any loss or damage suffered by the consumer as a result of the breach
- damages of up to $200,000 (including damages awarded in respect of loss suffered, expenses reasonably incurred, humiliation, loss of dignity, injury to the feelings of the consumer, and punitive damages for any action that was in flagrant disregard of the consumer's rights), and
- any other relief the Tribunal thinks fit.

An important limitation is that where a person has suffered personal injury covered by the Injury Prevention, Rehabilitation, and Compensation Act 2001, no damages other than punitive damages (where the provider's action was in flagrant disregard of the consumer's rights) may be awarded.

Conclusion

The Commissioner promotes resolution of individual complaints and systemic improvements in health and disability services. The Commissioner's focus is on a consumer centred system, and HDC aims to achieve such a system through resolution, protection and learning.