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

Background to the Auckland Women's Health Council

The AWHC was founded 36 years ago (July 1988) just before the release of *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters* (the Cartwright Report).[1] AWHC has a special interest in women's health, patient rights, informed consent and decision-making in health care, health consumer advocacy, the Code of Health and Disability Services Consumers' Rights, consumer voice and representation, and medical ethics.

AWHC has had a sustained interest in the HDC and the Code of Rights. We made submissions on the Health and Disability Commissioner Act 1994, then once the legislation was passed and the first Health and Disability Commissioner appointed, we made submissions and participated in consultation meetings that occurred during the development of the 'Code of Rights'. We have also made submissions on previous reviews (2004, 2009 and 2014) and other HDC public consultations, such as the 'Health and disability research involving adult participants who are unable to provide informed consent' consultation.

In addition: several of our founding members, were involved in the working groups set up following the release of the Cartwright Report; Lynda Williams, a former AWHVC co-ordinator was appointed as the first patient advocate at National Women's Hospital, fulfilling one of the key recommendations from the inquiry; and Judi Strid, the first AWHC co-ordinator, was later appointed Director of Advocacy.

Please note *that the author of this submission, Sue Claridge on behalf of the Auckland Women's Health Council, is also a Trustee of the Health Consumer Advocacy Alliance. She has also contributed to the writing of the HCAA submission. As many of the concerns and interests relating to the HDC and the review of the Act and Code are the same for both organisations, there are portions of both submissions that are very alike or identical.*

General Comments

Acknowledgement

The Auckland Women's Health Council (AWHC) would like to acknowledge the efforts that the Health and Disability Commissioner and her staff have made, to engage with stakeholders and health consumers since the beginning of 2023, in her statutory review of the Health and Disability Commissioner Act 1994, and the

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[1] Cartwright SR, 1988: *The Report of the Committee of Inquiry into Allegations of the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters*, Government Printing Office.

Code of Health and Disability Services Consumers' Rights. We appreciate having had the opportunity to provide early input into the review process in March 2023, and to participate in workshops in November 2023 and January 2024.

The AWHC also acknowledges the current economic climate and Government cost cutting across the public sector. We understand that the HDC has had its budget reduced, and that, considering year on year increases in the number of complaints lodged, a reduction in the budget must make it difficult to adequately investigate all complaints that merit investigation. As our health system sinks deeper into crisis, we can only expect that the annual burden of complaints will increase further.

We submit in the strongest possible terms that the recommendations from this review must protect consumers in the future, irrespective of the agenda and policies of the Government of the day.

Previous Reviews of the Act and Code

Notwithstanding the lack of public consultation for the 2019 review, former Commissioner Anthony Hill raised some concerning issues in that review. Commissioner Hill referred to past recommendations made in the 2009 and 2014 reviews and confirmed his continued support for four earlier recommendations. He stated:

> "These recommendations were supported by the then Minister of Health and the Ministry at the time, but have never been actioned."

These reviews of the Act and Code are a statutory requirement, and for two of the reviews (2009 and 2014) stakeholders and/or health consumers were asked for their feedback and input. It is concerning that, despite the recommendations that were made by those "at the coalface" of promoting the rights of all people in New Zealand who use health and disability services, the recommendations were not acted upon even in the face of support from the Minister and Ministry of Health.

That successive Governments have not acted on the recommendations in previous reviews shows a woeful lack of respect, not only for the Commissioner's review and recommendations, and the stakeholders and health consumers he/she has consulted, but for the legislation itself and the recommendations of the Cartwright Inquiry.

Regarding Commissioner Hill's 2019 review, his lack of consultation with stakeholders and health consumers may have been less about undervaluing their input and more about him not wanting to waste his and his staff's time, and the time and effort of submitters, given the complete failure of the Government of the day to act on the recommendations of previous reviews, including his own 2014 review.

Code of Consumer Expectations

We understand that the HDC was not one of the health entities required, under sections 59 and 60 of the Pae Ora (Healthy Futures) Act 2022, to act in accordance with, the Code of Expectations for health entities' engagement with consumers and whānau (Code of Expectations), because it would have required an amendment to the HDC Act.

However, this review of the HDC Act offers an ideal opportunity to amend the Act to require the HDC to "act in accordance with the code approved under section 59 when engaging with consumers and whānau" and "report annually on how it has given effect to the code."

We acknowledge the significant lengths that the current Commissioner has gone to engage with stakeholders and health consumers in this review, and recognise her willingness to meet with stakeholders and organisations with an interest in the HDC Act, Code of Rights and the work of the HDC, to discuss with them their concerns and views on the complaints process and other work of the HDC.

We are concerned that future Commissioners, and future Governments, may be less concerned with the importance of engaging with consumers and whānau, and the importance of the consumer voice in upholding and promoting the rights of health and disability services consumers. By enshrining in law the requirement of the HDC to act in accordance with the Code of Expectations, the HDC can future proof the commitment of the previous Government to health system reforms that would lead to a “people-centred system”, which cannot be achieved without authentic and ongoing engagement with health consumers.[2]

We believe that making recommendation in this review, that the HDC Act be altered to make the HDC one of the health entities required to act in accordance with the Code of Expectations, would be an act of good faith; one that honours the HDC’s stated purpose to promote the rights of all people in New Zealand who use health and disability services.

Topic 1: Supporting better and equitable complaint resolution

General Comments

The AWHC has been concerned about complaints resolution for some time, and issues with the “fair, simple, speedy, and efficient resolution” of complaints, particularly the balance between those ideals, and whether or not those outcomes are achieved for complainants.

In 2020 AWHC published an article in its April *Newsletter* entitled “Has the HDC Fulfilled Its Promise?”[3]. This article was written before the appointment of the current Commissioner, Morag McDowell, and as we have to some extent acknowledged in our opening comments to this submission, we are well aware of the significant efforts of the current Commissioner to improve the complaints process. We are also cognisant of the fact that the sheer volume of complaints received each year places a significant burden on the office of the HDC, and recent cost-cutting imposed by the Coalition Government will not be making it any easier to address any of the limitations and deficiencies in the fair, simple, speedy, and efficient resolution of complaints.

However, the article concluded that:

> “Given the evidence, it appears that the HDC’s resolution of complaints is neither fair, timely, or effective. In addition, there is scant evidence, if any, that there has been any change in the culture or system, or a shift in focus to the patient or consumer. As a result, the HDC is not fulfilling its “promise” to promote and protect the rights of consumers.”

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[2] Te Whatu Ora, 2022: *Te Pae Tata I Interim New Zealand Health Plan 2022*, Te Whatu Ora|Health New Zealand and Te Aka Whai Ora|Māori Health Authority, New Zealand Government, Wellington.

[3] We have appended the article to this submission as it encapsulates many of the concerns we still have.

We continue to harbour those concerns about the fair, timely and effective resolution of complaints. In addition, the year-on-year increase in the number of complaints speaks volumes about the ability of the HDC so far, to effect any change in the culture or system, or a shift in focus to the patient or consumer.

Again, we acknowledge that the current crisis in our health system imposes significant burdens that make culture change even harder to achieve, and that responsibility for the crisis can be largely placed at the feet of successive governments over the last three decades (notwithstanding the global burden of the pandemic and health workforce shortages), and not with the HDC.

Did we cover the main issues about supporting better and equitable complaints resolution?

In general, we believe that the consultation document has fairly set out the issues that detrimentally affect the complaints process. There are a few points that we would like to emphasise and/or comment on:

1. We believe that the Code of Rights is clear and simple and easy to understand for consumers and providers. However, many consumers may not be properly aware of their rights, even when they have a clear understanding that there may have been deficiencies in their care, that their rights have been infringed. They may struggle to articulate what specific rights have been infringed, and may not understand the importance of relating the inadequacies in their care or outright breaches of their rights, to the actual Code when making a complaint. We believe that it may be difficult for those who know and understand the Code of Rights and complaints process so well, to understand that some consumers may really struggle to understand how to make a complaint, or seek and obtain acknowledgement, accountability and redress for the negative experiences they have had.

   We strongly support the idea of clinical navigators to help people understand and navigate the complaints process and to be realistic about possible outcomes of the process.

2. Surveys of complainants (and providers) experiences of the complaints process are important. Such surveys used to be done and used to be regularly reported upon in the HDC annual reports (e.g. 2002 to 2006 annual reports), but it appears that the last satisfaction surveys of the complaints process were reported on in 2015 (excluding surveys of the advocacy service), and there is no indication that such surveys have been undertaken since. While it may be unpleasant to find that complainants are less than satisfied with their experience of the complaints process, if the HDC wishes to improve the consumer experience, such surveys are critical. Many health consumers are of the opinion that the HDC primarily protects providers, and the process is weighted in favour of providers. As a result, some consumers believe that lodging complaints is a waste of time.

3. One of the factors listed on the HDC website that is relevant to a no further action decision on a complaint is "the length of time that has passed since the incident being complained about occurred." We understand why this is a significant factor, but there needs to be much greater consideration of how this impacts the complainant, and the reasons why there may be a considerable delay between the incident being complained about and the lodging of a complaint.

   For some complainants, the harm caused to them, for example, medical injury or harm, or a health condition that is at the centre of the experience with a provider, takes time to recover from. Many complainants are left disabled or with physical disfunction, or lacking the energy, emotional or physical resilience and strength required to lodge a complaint. Some complainants may require further treatment and may not want to put that treatment at risk by lodging a complaint until their treatment is completed and they have recovered. They may not want to request their medical notes or other evidence needed to lodge a complaint until they have finished necessary treatment. These are all valid reasons for delay and several speak to the significant power imbalance between health consumer/patient and provider.

In other complaints, the awareness that there has been an infringement of rights, or breach of the Code, may not become apparent for some time after it actually happens. For example, a wrong diagnosis, or failure of a provider to follow-up on critical clinical evidence of a serious health condition that leads to catastrophic outcomes for the patient. A patient may die as a result, leaving whānau to lodge a complaint. However, in such a situation, dealing with a critically ill or dying whānau member, followed by grief, could delay the ability of the whānau to make a complaint. This delay does not lessen the gravity of what occurred or absolve a provider of the need to be accountable and face whatever action is appropriate for the severity of the breach.

Finally, prospective complainants may delay their complaint (or perhaps never make one) for fear of the impact it might have on a concomitant ACC claim for medical injury. We know of people who have delayed, or decided against lodging a complaint with the HDC for breaches of the code that have led to medical injury, for fear that such a complaint may negatively impact on the acceptance of a claim with ACC. ACC claims for medical injury can take up to nine months to determine, or longer if the claim is denied and then subject to review. It could easily be two years or more from the date of the incident or experience that would be the subject of a complaint, to the point where the potential complainant feels able to lodge a complaint with the HDC.

What do you think of our suggestions for supporting better and equitable complaints resolution, and what impacts could they have?

Amend purpose statement

We agree that there should be a shift away from the process and towards placing the consumer and their whānau at the centre of a complaint.

We agree that the Code should include concepts that are akin to upholding, or protecting and enhancing a person’s mana. However, care should be taken not to exclude New Zealanders not as familiar with te ao Māori, and migrants who may be even less familiar with te ao Māori and te reo, and ensure that they have a clear understanding of how the purpose of the HDC and complaints process applies to them.

The need for people to have the seriousness and impact of their experience and outcomes acknowledged and recognised must not be ignored, even if there is no eventual “punishment” for the provider(s) that are the subject of the complaint. This is important later in discussion of the “no further action” decision and the way that such a decision impacts on complainants.

Clarify cultural responsiveness

We support clarification of Right 1(3) and the acknowledgement that cultural identity is not just based on ethnicity. It is important that providers are enabled to gain insight into their own biases and attitudes that can lead to discrimination and inequities in the treatment of consumers. We support any changes to the wording of the Code that would facilitate this.

Clarify the role of whānau

We support the changes proposed regarding whānau and other supporters of consumers. However, not all whānau/family members necessarily have the best interests of an individual at heart and may hold attitudes and beliefs that are not consistent with those of an individual and their needs.

Unfortunately, not all whānau/family are supportive of the health and wellbeing decisions an individual makes, and, sadly, in some cases the views and involvement of whānau/family in such decisions are unwelcome, disruptive and possibly even harmful, and may seek to take away the right of a competent individual to autonomy.

Care must be taken to ensure that the rights of the individual are not infringed in attempts to ensure that the often vital role of whānau is recognised.

Ensure gender inclusive language

We agree that there should be amendments made to the Code of Rights to specifically to include gender diversity in rights of dignity and respect; services that take into account the needs, values, and beliefs of gender diverse people; and freedom from discrimination, coercion and harassment, exploitation, etc.

New Zealand and international research has found that discrimination and a lack of respect and dignity in health care is a significant issue for the LGBTQI+ community, and that their mental and physical health suffers as a result. Many in the queer community suffer poor physical health, in part because they are reluctant to see doctors when they need to because of past experiences. Many gender diverse New Zealanders report being misgendered, or having their gender identity dismissed, questioned or disrespected, and their health concerns trivialised or misunderstood, by health care professionals. We believe that more explicit wording in Right 2 to prevent discrimination and improve the experiences of LGBTQI+ New Zealanders could be warranted.

Protect against retaliation

While it is appalling that complainants might be subject to retaliation, we believe that may happen and that complainants have legitimate fears of retaliation. Many people are fearful of making a complaint, no matter how justified a complaint may be, because of the repercussions for them in future health care. This would be especially significant for people in small centres where there are few choices available to them in terms of switching health care providers, or where economic circumstances leave them with few options. We support proposed changes to include a non-retaliation clause in Right 10, as it is clear from the behaviour of some health professionals and providers (see comments regarding informed consent) that if it is not spelled out in the Code, some seem unclear about their moral obligations.

Clarify provider complaints processes

We support clarification of provider complaints processes. However, many consumers feel intimidated by the significant power imbalance, particularly between doctors (GPs and specialists) and patients/health consumers, and are both fearful of the repercussions of laying a complaint, and don’t have confidence that a complaint to the provider will be taken seriously or acted upon in a fair and reasonable manner.

While no doubt there are many complaints to the HDC that could be better resolved directly between provider and the complainant, until there is a change in culture and attitude with the health system, it is likely that many consumers with good reason to complain will prefer to do so through an agency at “arm’s length” from the provider.

Strengthen the Advocacy Service

Strengthening the role of the Advocacy Service is particularly important with regard to our comments above about provider complaints processes. However, there is a view among many health consumers that the Advocacy Service is not really independent of the HDC, and is a means to “fob off” consumers with complaints and deter consumers from lodging complaints with the HDC. This view will need to be addressed if the Advocacy Service is to play a greater role in resolving complaints to the satisfaction of health consumers.

Greater transparency of the Advocacy Service, a programme to better educate consumers of the role and benefits of the service, and moves to further separate the service from the HDC may help change the perception that it lacks independence. In particular, having the Advocacy Service produce a separate, publicly available, annual report, rather than being included in the HDC annual report, would help it visibly maintain its independence.

Improve the language of complaint pathways in the Act

The “no further action” decision would have to be one of the most depressing and demoralising outcomes that is possible for a complainant. Irrespective of what has gone on in the preliminary assessment, those three words tell many complainants that whatever happened to them – sometimes serious harm and life-long disability – didn’t warrant an investigation and that the provider about whom they complained is not required to take responsibility, make amends, apologise or change their practice. For many complainants the message they get is that the system is heavily weighted in favour of the provider.

In 2013, Stuart McClennan, a researcher in biomedical ethics, wrote that the continuing low number of HDC investigations were a cause for concern.[4] He detailed the number of closed complaints versus the number of investigations every year from the year ended June 2001 to the year ended June 2012, with data from the HDC’s annual reports.

He found that investigations as a proportion of closed cases had declined from 40% in the year to June 2001, to 3% in the year to June 2012. In the AWHC article “Has the HDC Fulfilled Its Promise?” (appended) additional information from annual reports for 2013 to 2019 showed that the average over those years was just over 4.4%.

McClennan wrote that: “The low amount of investigations being carried out raises concerns that access to HDC investigations has become too restricted. The 2009 HDC satisfaction survey also found that one reason for complainants’ dissatisfaction with the HDC process was being denied an investigation.”

The situation has not improved; in the last four annual reports (2019/20 to 2022/23) it was reported that Investigations as a percentage of closed cases is between 4.5 and 6%. Between 30 and 40% of closed complaints over that period (an average of 915 per year) have been no further action (NFA) decisions; a further 7.5 to 10.5% are NFA decisions where there has been follow-up or educational comment.

It is clear that hundreds of complainants get no real closure and justifiably feel fobbed off and denied accountability or justice, particularly in those complaints with NFA decisions that have involved serious harm and death. In addition, some so-called ‘preliminary assessments’ that lead to NFA decisions take months or years, time comparable with an actual ‘investigation’.

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[4] McClennan S, 2013: Low yearly completion rate of HDC investigations is a cause for concern, *New Zealand Medical Journal,* 15 February 2013, Vol 126 No 1369

There needs to be an overhaul of the complaints process and the subsequent ‘resolution’ of a complaint that results in the current ‘no further action’ decision. This must not just be a change in the language used – a new placatory euphemism for ‘no further action’ – but must include far greater transparency in how the complaint was assessed, the rationale for the decision, and to ensure that complainants have a real resolution to their complaint.

The NFA decision in many cases appears to sacrifice ‘fair’ for ‘speedy’ resolution, and in many, the lengthy preliminary assessment sacrifices both ideals. Without an appeals process (see below) these complainants have been denied justice and closure, and our no-fault ACC system prevents consumers from seeking remedies through the court when they have been harmed by medical care and other services obtained from health and disability services providers.

Topic 2: Making the Act and the Code more effective for, and responsive to, the needs of Māori

General Comments

The Auckland Women’s Health Council is not a tangata whenua organisation and does not speak for or on behalf of Māori. However, we believe that the Act needs to be amended to reflect a greater acknowledgement of te ao Māori and te Tiriti, as is the case in much recent legislation, and health agency and Government documents, in particular the Pae Ora (Healthy Futures) Act 2022. We believe that the Act should honour and empower Te Tiriti o Waitangi. However, the AWHC is not in a position to comment on how that should be done.

We support moves to make the Act and the Code more effective for, and responsive to, the needs of Māori. We support moves that will, in some way, address the inequities and disparities in Māori health, access to affordable and culturally appropriate health care and disability services, and health outcomes, including upholding their rights as health and disability services consumers, and improving their experiences with, and outcomes from, the complaints process.

We believe that when our health system, including the HDC and complaints process, actively work to address inequities and disparities, and improve experiences and outcomes for Māori, there will be improved experiences and outcomes for all New Zealanders.

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?

Generally, the AWHC agree that the main issues regarding people with disabilities have been covered.

However, there should be greater recognition of learning impairments or disabilities, and people who have a hearing and/or vision impairment or who are Deaf, particularly regarding how information is provided both in terms of interaction with the HDC, but also with health and disability providers.

Health and disability and consumer rights information needs to be in appropriate and accessible formats. Perhaps the HDC should have an educational role with providers, and institutions that train the health and disability services workforce, to ensure that people with disabilities understand their rights – simply having a poster in a provider's waiting area, that sets out the Code of Rights, is insufficient for many people who have disabilities. Education on the unique issues people with disabilities face in learning about and understanding their rights under the Code, should be compulsory for the health and disability services workforce.

Similarly, many people with disabilities will need adequate provision of time with a health or disability services provider in order to ensure that the interaction complies with the Code of Rights. For example, for a Deaf person, when they are using a sign language interpreter, it's a three-way conversation between the patient, interpreter and health professional, which takes time.

The HDC, and health and disability service providers, must recognise the environmental and social factors that further disable people with impairments.

We also believe that the HDC should report to the Minister for Disability Issues. When the HDC Act was passed there was no Minister for Disability Issues. Given that more than 25% of the complaints received by the HDC are about care provided to tāngata whaikaha | disabled people, it seems entirely appropriate that HDC should report to the Minister for Disability Issues as well as to the Minster for Health.

What do you think of our suggestions for making the Act and the Code work better for tāngata whaikaha | disabled people, and what impacts could they have?

Strengthen disability functions in the Act

We agree with adding a legislated role focused on disability issues within the HDC. As mentioned above, we also believe that the HDC should report to the Minister for Disability Issues as well as the Minister for Health.

Update definitions relating to disability

We agree that definitions related to disability must be updated and should be consistent with the needs and views of people with impairments and the CRPD.

Strengthen references to accessibility

We agree with proposed changes to the Code to strengthen references to accessibility.

Strengthen and clarify the right to support to make decisions

We agree with proposed changes to the Code to strengthen and clarify the right to support to make decisions. We note that the HDC acknowledges "that supported decision making is a developing practice". In light of this being a "developing practice", we believe that the wording in the Code should be regularly reviewed, including consultation with people with disabilities, to ensure that it continues to reflect the views and needs of those New Zealanders.

In addition, education of providers and the health and disability services workforce on these changes, and what it means for their practice and upholding of consumers rights, is necessary.

Progress consideration of HDC's draft recommendations relating to unconsented research

We would like to express our disappointment that this important issue has been "buried" in the section on tāngata whaikaha | disabled people. It is sufficiently important that it merited a section/topic on its own. It is not an issue that concerns just people with disabilities, and can involve people who are temporarily unconscious or unable to consent. In the original 2017 consultation document it included case studies of acutely unwell ICU dialysis patients, patients with brain tumours, and cardiac arrest patients, none of whom would necessarily be considered to be people with disabilities.

Background

In May 2014, then AWHC co-ordinator, Lynda Williams, wrote a letter on behalf of the AWHC to Commissioner Anthony Hill, regarding research on incompetent or incapacitated patients who are unable to provide consent to participate in clinical trials.

It was Lynda's regular attendance at the Northern A Health and Disability Ethics Committee (HDEC) meetings that brought her attention to this issue. She wrote about it in the May 2014 AWHC *Newsletter* and the issue was picked up by the *New Zealand Herald* when reporter Martin Johnson received a copy of the AWHC *Newsletter*.

In her letter to Commissioner Hill, Lynda wrote:

> "We have become increasingly alarmed and are now extremely concerned at what has happened to patient rights in the current clinical trials environment. There are many clinical trials being undertaken which involve vulnerable patients, including infants, children, young adults with Down Syndrome, as well as unconscious patients."

This was the first of seven increasingly frustrated letters that were sent by the AWHC to Commissioner Hill expressing concern over the inclusion of patients unable to consent to participation in research, and the lack of action to address this. In responding to some of the letters, the HDC promised a consultation process would be commenced, in theory at the beginning of 2015.

Finally, in February 2017, the consultation process did commence, and submissions were sought on a discussion document, *Health and disability research involving adult participants who are unable to provide informed consent*, with submissions to be lodged by the end of April 2017. AWHC made a substantial submission.

Commissioner Hill eventually released a report in November 2019 in which he recommended changes. He mentioned this issue in his 2019 HDC Act review report to then Minister of Health, David Clark writing:

> "We propose to carry out further consultation regarding these proposed changes in due course."

As far as AWHC is aware, no further consultation was undertaken until this current review of the Act and Code, under Commissioner McDowell.

We believe that this serious issue regarding the rights of unconscious, incompetent and incapacitated patients, has only been considered by the HDC because of the persistence of Lynda Williams to have the issue properly addressed. It is of considerable concern to us that, ten years after we brought this issue to the attention of the HDC, the work to protect vulnerable New Zealanders from harm in a medical or health research context has still not been fully completed.

Further General Comment

It is clear that the law as it stands is sufficiently weak and uncertain as to allow "studies to proceed in relation to participants who are unable to consent if participation in the research is in their 'best interests' "[5] This implies that the researcher is able to make the decision as to what constitutes in the patients "best interests".

The AWHC does not believe that researchers are capable of making unbiased decisions that are truly in the best interests of the consumer or patient. In addition, it is the AWHC's view that the current Health and Disability Ethics Committees (HDECs) do not sufficiently prioritise the protection of research subjects.

Philosophically, the AWHC opposes involving anyone in medical experiments, including within the auspices of clinical trials, without their fully informed consent. However, we also understand the need for research that builds greater knowledge of certain conditions and improves treatment and services for groups affected by those conditions.

The AWHC believes that absolutely no incapacitated or incompetent adults should be enrolled for medical experiments, clinical trials or any sort of research, until there are sufficient protections and safeguards established in law that first and foremost protect their rights and interests, health and well-being. This would include an adequate ethical and legal framework, including specific definitions of terms such as "minimal risk/burden", "benefits", "best interests", and who constitutes an authorised legal representative.

We Need a Special Ethics Committee

In discussing our response to the consultation paper, the AWHC committee felt that the existing HDECs were not adequately qualified and robust enough, nor had the required focus, to make critical decisions on research involving such vulnerable groups of people; people who do not have the capacity to provide informed consent and cannot advocate on their own behalf.

The AWHC Comments on the Recommendations of the 2019 Report

1. That some health and disability research not currently permitted involving adults unable to consent should be allowed in order to build greater knowledge of certain conditions, treatment, and services, but only in limited circumstances and with robust safeguards.

   In theory we agree that certain research that builds greater knowledge of certain conditions, treatment, and services could be permitted, but cannot possibly agree in practice until the "limited circumstances" and "robust safeguards" are drawn up, discussed, reviewed and widely consulted upon including with stakeholders and the public.

3. That, subject to other safeguards being in place, health and disability research involving adults unable to consent should be permitted if it entails "no more than minimal foreseeable risk and no more than minimal foreseeable burden" to participants.

   These terms – "minimal foreseeable risk" and "minimal foreseeable burden" – are barely an improvement on "best interests". Who determines what is minimal? Minimal risk or burden to a doctor or researcher, or any given person, may be very different to what is seen as minimal by someone else, depending on their values, quality of life, desires for their future and any health conditions/co-morbidities or disabilities. With regard to "foreseeable", human beings have an innate inability to

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[5] HDC, 2017: HDC Consultation Document: *Health and disability research involving adult participants who are unable to provide informed consent.* Health & Disability Commissioner, Wellington, NZ.

accurately and clearly see the potential risks in very many activities, especially where new science and technology is concerned. Who determines what is "foreseeable"?

4. That additional safeguards to protect these very vulnerable groups of consumers should be introduced, including:
    a. A comprehensive set of principles with an appropriate regulatory framework to underpin the legal and ethical settings for health and disability research involving adults unable to consent (see Recommendation 5);
    b. A specialised ethics review and approval process and enhanced governance system in relation to health and disability research involving adults unable to consent (see Recommendation 6);
    c. Monitoring and evaluation of any changes to the legal and ethical framework, systems, and processes relating to health and disability research with adults unable to consent, with a particular focus on outcomes for participants.

    While we agree, in theory, that there must be a comprehensive set of principles within an appropriate regulatory framework, we cannot agree to this until this has been drafted and reviewed, and widely consulted upon including with stakeholders and the public.

    We agree that if any research is ever to include unconscious, incompetent and incapacitated patients unable to provide informed consent, there must be a **specialised ethics review** and approval process.

    We agree that if any research is ever to include unconscious, incompetent and incapacitated patients unable to provide informed consent, there must be very close monitoring and evaluation, with the outcomes for participants being of paramount importance.

5. That the principles referred to in Recommendation 4(a) cover both the approval of research studies by ethics committees, requiring updating of the National Ethics Advisory Committee (NEAC) guidelines and Standard Operating Procedures, and decisions about enrolling an individual in a study, requiring amendments to the Code.

    The principles that should be applied by ethics committees when determining whether to approve a study including adult participants who are unable to consent should include:
    a. Such research should be permitted only when the research question cannot be answered without involving adults unable to consent;
    b. Such research should be permitted only when the purpose of the research is to advance knowledge about the condition causing the participants' impairment or its treatment or relevant services;
    c. Such research should be scientifically robust, worthwhile (have social value), and aim to answer a genuine research question;
    d. Such research should involve no more than minimal foreseeable risk and no more than minimal foreseeable burden to participants;
    e. Where the provider is the decision-maker with regard to enrolment of participants, the management of any perceived or actual conflicts of interest arising from the researcher and the provider being the same person or closely aligned should be actively addressed in research protocols to the satisfaction of the ethics committee.

If any research is ever to include unconscious, incompetent and incapacitated patients unable to provide informed consent, we agree with principles (a), (b) and (c). We have already set out our concerns regarding "minimal foreseeable risk" and "minimal foreseeable burden" under recommendation 3 above. Regarding principle (e), we believe that the decision-maker regarding the enrolment of participants unable to provide informed consent should ***never*** have any role in the research. Decisions made about the involvement of unconscious, incompetent and incapacitated patients in research must be made at more than "arms-length" by independent persons with absolutely no connection to the proposed research. Managing "any perceived or actual conflicts of interest" is insufficient protection for vulnerable people.

6. Note that the amendments to the ethics review and approval processes and governance system referred to in Recommendation 4(b) include:
    a. That no health and disability research with adult participants who are unable to consent should take place unless the research has received the approval of an ethics committee;
    b. Amending pathways to enable all health and disability research studies involving adults unable to consent to be considered by an ethics committee;
    c. Clear guidance being developed about defining and assessing minimal foreseeable risk and minimal foreseeable burden;
    d. A specialist ethics committee being established with responsibility for reviewing all health and disability research involving adults unable to consent that would:
        i. Have the necessary expertise to evaluate risks and other considerations, and/or have the resources to commission its own peer review and risk assessment;
        ii. Be resourced to oversee auditing and follow-up of approved research studies;
        iii. Play a role in monitoring and oversight of approved research studies and the outcomes for participants.

All these amendments should refer to a ***specialist ethics committee*** as per point 6(d). Point 6(d) should be the first in these amendments. Also see our comments above under General Comments, regarding our view that the existing HDECs are not adequately qualified and robust enough, nor have the required focus, to make critical decisions on research involving such vulnerable groups of people; people who do not have the capacity to provide informed consent and cannot advocate on their own behalf.

If there is insufficient resourcing to adequately set up a specialist ethics committee, to undertake monitoring and evaluation or to oversee auditing and follow-up of approved research studies, there must be ***absolutely no permitted research*** involving unconscious, incompetent and incapacitated patients unable to provide informed consent.

7. That the principles that should be incorporated in the Code include:
    a. A consumer who is unable to give informed consent may only be enrolled in health and disability research that has been approved by an ethics committee;
    b. A consumer who is unable to give informed consent may be enrolled in health and disability research only if the research will involve no more than minimal foreseeable risk and no more than minimal foreseeable burden to that consumer;
    c. The consumer's known wishes should be taken into account as practicable;

d. Any indications of dissent by the consumer should be respected and responded to on an individual basis;

e. If the research participant regains capacity to consent, or some capacity to be supported in a decision, where practicable that consumer must, as soon as possible, be given the opportunity to give or decline informed consent to continued participation in the research, and/or to the use of data about that consumer that has already been collected;

f. The decision about enrolling such a consumer in an approved research study should be made by a person legally entitled to consent on behalf of the consumer, where possible;

g. Where there is no person legally entitled to consent on behalf of the consumer, the decision-maker about enrolling an individual should be the provider;

h. Where the provider is the decision-maker:

    i. Available suitable persons interested in the consumer's welfare must be consulted (as now required under Right 7(4)), and those suitable persons should have the right to veto participation in the research at any time for any reason;

    ii. If the consumer has no suitable person interested in his or her welfare to consult, he or she should not be enrolled in research;

    iii. If because of the nature of the research, there is no time to identify whether there are suitable persons who could be consulted or to consult them, the consumer may be enrolled in the research, but suitable persons must be consulted as soon as possible and have the right to veto further participation and to withdraw the data collected if practicable.

Recommendation 7(a) must be changed to read "A consumer who is unable to give informed consent may only be enrolled in health and disability research that has been approved by a **specialist ethics committee**.

Recommendation 7(b): as stated previously, we remain concerned about the terms "minimal foreseeable risk" and "minimal foreseeable burden".

The words "as practicable" should be removed from recommendation 7(c).

Recommendation 7(d): Any indications of dissent by the consumer ***must exclude*** them from the research.

Recommendation 7(e): remove the words "where practicable".

Recommendation 7(g): Where there is no person legally entitled to consent on behalf of the consumer, the decision-maker about enrolling an individual should be a provider ***with absolutely no connection to the proposed research.***

Recommendation 7(h): we agree with (i) and (ii) but point (iii) must be removed. If there is insufficient time to comply with (i) and (ii) the person must be excluded from the research.

Topic 4: Considering options for a right of appeal of HDC decisions

General Comments

In 2020 and 2021 we actively supported Renate Schütte's petition to Parliament requesting the right to appeal decisions made by the Health and Disability Commissioner, making written and oral submissions to the Health Select Committee. We continue to support the right for both complainants and providers to appeal HDC decisions and have appended our written submission.

Our main arguments in support of the right to appeal were:

1. Under the current legislation there is no mechanism by which decisions made by the Health and Disability Commissioner regarding complaints lodged by consumers/patients about adverse events and breaches of their rights, can be appealed or subject to independent review.

   This is not only highly unusual in New Zealand, as most if not all similar decision-making agencies offer the right of appeal and often multiple rights of appeal, but it denies consumers natural justice in the only forum available to them to seek accountability in the health and disability sector.

2. New Zealand's internationally highly regarded "no-fault" system prevents consumers from seeking remedies through the court when they have been harmed by medical care and other services obtained from health and disability services providers. Thus, the HDC is the only available option for consumers to seek accountability and resolution for complaints.

3. The overriding purpose of the *Health and Disability Commissioner Act 1994* (The Act) and the office of the HDC is to promote and protect the rights of consumers, and without the right to appeal decisions both the Act and the HDC fail to fulfil this purpose. The extraordinarily high number of 'no further action' decisions limits the transparency of the HDC process, negates the HDC's claims to be a consumer-centred system, and denies the vast majority of complainants natural justice or any ability to obtain real resolution of their complaints.

4. A robust complaints process that includes the right of both complainants and defendants to appeal decisions, including 'no further action' decisions, will contribute to improvements in culture and safety for both consumers and practitioners. A transparent, robust and thorough complaints system will be a catalyst for improving patient safety and ensuring that practitioners take responsibility for upholding patient rights.

5. The Auckland Women's Health Council submits, in the strongest possible terms, that a process for appealing HDC decisions or subjecting them to independent review, both those with a 'no further action' decision and those that undergo an investigation, is the only way to ensure a consumer-centred complaints system and to ensure that justice is served.

Did we cover the main issues about considering options for a right of appeal of HDC decisions?

We generally believe that the HDC has been reasonably thorough in their overview of the issues regarding the right to appeal, and we welcome the improvements the HDC has made to increase the transparency of the complaints process. However, the impact of no further action decisions, especially where there have been serious outcomes for complainants, including serious harm and life-long disability, affects many complainants every year and many of them are justifiably outraged by what they see as the complete lack of resolution of their complaint, or accountability for what they have experienced and suffered.

We understand that there is the potential for a right of appeal to open the 'flood gates' and in doing so potentially impact the already under-resourced office of the HDC, depending on the model adopted for the review process. However, the onus must be on the legislation that underpins the HDC, and the HDC complaints resolution process, to reduce the likelihood of high numbers of appeals. If the HDC fears an avalanche of appeals to their decisions, then it behoves the HDC and legislators to ensure the complaints process is not only fair and just but is seen and believed to be fair and just.

The HDC must be adequately resourced so that all complaints can be properly assessed and investigated, rather than the current situation where it seems that only the most appalling cases are investigated, and many valid complaints worthy of investigation are relegated to the NFA pile. The purpose of the HDC as set out in the Act demands that adequate funding must be made to enable the HDC to comply with the legislation that underpins it.

We understand that the HDC is probably doing the best it can with the resourcing it has. It is incumbent on the Government to ensure that the HDC is adequately funded to ensure that it can comply with its purpose, which is to deliver justice and resolution to those New Zealanders whose rights as consumers of health and disability services have been infringed.

The resources that would be required to implement an appeals process, and the negative impact on the HDC of a right to appeal, are unconscionable reasons to deny New Zealanders justice when their rights as consumers of health and disability services have been breached. Without the right to appeal, many complainants are denied justice and closure, and our no-fault ACC system prevents consumers from seeking remedies through the court when they have been harmed by medical care and other services obtained from health and disability services providers.

The current options – an internal HDC review of a closed file, lodging a complaint with the Ombudsmen, and seeking a judicial review in the High Court – do not provide anything approaching an appeals process:

- The internal review is essentially asking the same decision makers to make a different decision and is confined to cases where there is new evidence or there has been a procedural error, and cannot be compared to an independent review that AWHC submits is the only option that would satisfy the right to appeal HDC decisions.

- The Ombudsman can only consider procedural fairness, not whether or not the correct decision was arrived at, and therefore does not come close to being a proxy for the right of appeal.

- A judicial review is financially prohibitive for most complainants, and again, generally considers procedural fairness, not the actual decision, and is therefore not a proxy for the right of appeal.

It is disingenuous to suggest that complainants can take a matter to the Human Rights Review Tribunal, as that only applies to those cases that were subject to an investigation, not just a preliminary assessment, and in which there was a breach finding. For those complainants who get an NFA decision it is currently the end of the road for them.

The only valid option is to include the right of appeal in the HDC Act.

What do you think about our suggestions for considering options for a right of appeal of HDC decisions, and what impacts could they have?

Introduce a statutory requirement for review of HDC decisions

The AWHC submits that there must be a statutory right to appeal. The appeals process must be independent of the HDC to ensure that the complaint, evidence, complaints process and decision are viewed through fresh eyes. We do not agree that it could be part of the existing HDC processes. It is insufficient to just exclude the original decision-maker but still have a pseudo appeals process within the HDC.

The AWHC acknowledges the risk that there might be endless rounds of appeals on the same complaint, or that there may be vexatious complainants, or those completely without merit. The process for accepting applications for appeal must be robust in order to prevent such applications for appeal. However, the risk of endless or meritless appeals is insufficient reason to deny others access to a fair and just appeals process.

We provide a potential model for the hearing of appeals below.

Lower the threshold for access to the HRRT

This option provides absolutely nothing for those complaints – sometimes involving serious harm or death – that receive an NFA decision. We oppose this as an option instead of a proper right to appeal HDC decisions through an independent appeals process. Lowering the threshold for access to the HRRT is only acceptable as an additional measure for those decisions that have already undergone a full investigation by the HDC.

A Model for an Independent Appeals Process

The AWHC believes that an independent appeals process could be partially modelled on the Health and Disability Ethics Committees.

First, applications to have a decision go to appeal would have to be independently assessed, or triaged, before being passed on to an independent appeals body. There would need to be criteria for appeals applications. There should be a set of weighted criteria; for example, higher weighting would be given to complaints where serious injury, disability/disfunction or death was an outcome in the original complaint. Such weighted criteria would enable screening or scoring of complaints lodged for appeal.

The process must be transparent, and the criteria should be publicised; some sort of 'calculator' or flow chart for applicants may reduce the number of appeals that would not pass the initial screening. Those applicants that are rejected for appeal should be given an opportunity to discuss why their appeal application was rejected; this may prevent repeat or vexatious applications

The Independent Appeal Body

The AWHC envisages an appeals body – a panel or committee – of approximately eight people, including at least two consumer representatives with relevant knowledge of the health and disability sector, and lived experience. The panel would also include at least one member with a background in health/medical ethics, two or three health and disability services professionals with broad knowledge, and perhaps experienced people from the Advocacy Service with a thorough understanding of the Code of Rights, but who are not involved in HDC decisions.

The membership of the panel/committee may need to change on a regular basis depending on the complaints to be considered. There may need to be a pool of potential members that could be called upon.

The appeals body would meet on a regular basis, say every two months, but this would be dependent in part on the number of appeals. The evidence and paperwork for each "case" to be considered would be provided in advance to the members of the appeals body and each member would need to familiarise themselves with each case before an in-person or virtual meeting to discuss. The appellant would have the opportunity to speak with the appeals body to discuss their complaint and the reasons why they have appealed, why they believe the incorrect decision on their complaint was made.

Many complainants feel unheard in the current complaints process, and to have an opportunity to face the decision makers and plead their case is an important part of resolution for many complainants.

The appeals body would need to have powers to overturn the HDC decision and send the case back to the HDC for a full investigation or to modify the decision, or to instruct the HDC to engage in some other process with the appellant (e.g. mediation and perhaps a restorative justice style approach with both the HDC and the provider in the case of consumer appellants).

Alternatively, of course, the appeals body may determine that the HDC decision was fair and just and the correct decision, and reject the appeal.

Topic 5: Minor and technical improvements

What do you think about the issues and suggestions for minor and technical improvements, and what impacts could they have?

Revise the requirements for reviews of the Act and the Code

The AWHC are concerned – as mentioned previously – that the recommendations in previous reviews have been ignored by the Government of the day, and in the case of some recommendations in the 2009 and 2014 reviews, were supported by the then Minister of Health and the Ministry at the time yet were never actioned.

It seems pointless, and a ridiculous waste of time and resources for not only the HDC, but all the stakeholders and consumers that are consulted and provide their considered opinion on the Act and Code, to conduct reviews, provide recommendations only for those recommendations to be completely ignored. It is ludicrous that we are still considering and providing input on issues raised in previous reviews (as long as 15 years ago), and the recommendations for change that have had prior support of the previous Ministers of Health and the Ministry.

In the current consultation, AWHC alone has committed in excess of 50 hours to providing input on the review, including this submission. It is most unsatisfactory to think that this may be a complete waste of time owing to the lack of value placed on the content and recommendations of the HDC's final review report by the Minister of Health, the Government and the Ministry.

We are undecided about the desirability of extending the gap between reviews. We believe that there would be far less work in undertaking the review as currently required, if the Government took the review and its importance more seriously, and accepted and acted upon the recommendations of the HDC when his or her advice is provided.

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

We agree that the maximum fine should be increased. This was set in 1994, and since that time, inflation alone represents an increase of almost $3000 to $6000. We agree that there needs to be a greater deterrent to those who might refuse to comply with the Act, and should be brought into line with comparable offences under the Health Practitioners Competence Assurance Act.

Introduce a definition for 'aggrieved person'

We support the proposal to substitute the phrase 'aggrieved person' for the phrase 'the complainant (if any) or the aggrieved person(s) if not the complainant'.

Allow for substituted service

We support the proposal that Section 43(1) of the Act be amended to require that the HDC has made 'reasonable attempts to advise' specified persons of the results of an investigation. We also support substituted service when the HDC cannot find a person including giving them notice via registered post, or through their social media account/s. While we don't think the use of social media accounts is ideal, nor should this means of communication be used frequently or as a primary means of contact, we can see that in the event that all other efforts have failed it is an option to consider.

We do not wish to see the HDC waste precious resources on futile attempts to contact people who are not contactable. When standard methods fail, the most favourable alternative means should be employed.

Provide HDC with grounds to withhold information where appropriate

We support changes that would "level the playing field" for complainants. We agree that providers, with all their resources and the legal advice available to them, should not be able to use the Privacy Act and the Official Information Act 1982 to gain an advantage over complainants.

We agree that the HDC should have a similar ability to the Privacy Commissioner's office to withhold information during the course of an investigation, in order to safeguard the integrity of the complaint investigation process.

Expand the requirement for written consent for sedation that is equivalent to anaesthetic

We agree that there should be an expanded requirement for written consent in the case of other forms of sedation that are not currently covered in Right 7(6)(c), where any form of sedation has an impact on a person's ability to make or remember decisions.

Clarify the requirement for written consent where there is a high risk of serious adverse consequences

We are concerned that a provider's view of what constitutes "a significant risk of ***serious*** adverse consequences" may not be the same as a health consumer's view. Health consumers must be advised of all the risks and benefits of a proposed treatment or course of action, and only they can decide the level of risk that they consider appropriate to accept. What might be considered serious by one person in the context of their life, including quality of life, desires for their future and any health conditions/co-morbidities or disabilities, may be viewed very differently by another.

We believe that Right 7(6)(d) should remain "there is a significant risk of adverse effects on the consumer."

Clarify the Code's definition of teaching and research

Research over recent years has shown persistent breaches of patients' informed consent rights, particularly in teaching hospitals. These breaches continue in the face of the 2015 consensus statement on medical students and informed consent, prepared by the faculties of Medical and Health Science of the universities of Auckland and Otago, the chief medical officers of district health boards, the New Zealand Medical Students' Association, and the Medical Council of New Zealand. It ***is*** a statement ***clarifying*** expectations for informed consent in the training of medical students in New Zealand today. In other words, there is little room for ambiguity regarding the obligations on medical students and their medical supervisors in obtaining informed consent where students are present or taking part in providing care to a patient.

Despite the continued breaches of informed consent rights, we do not believe that there needs to be any clarification. It is hard to imagine that the Code could be made any clearer and simpler. In addition, the 2015 consensus statement sets out 18 principles pertaining to informed consent for the presence of a medical student during the care of patients, in some detail and with multiple examples.

In January 2020, in response to reports of breaches of patients' rights in the teaching context at North Shore Hospital, the Waitematā DHB was reported by RNZ to have said that national guidance on informed consent was required, saying that lack of consistent national guidance is partly at fault.[6]

For the WDHB to say that there needs to be consistent national guidance and to imply that there is some confusion is disingenuous. By this stage the Consensus Statement signed by all DHBs was five years old.

In the same RNZ report, Dr Curtis Walker, chair of the Medical Council, says "I wouldn't suggest there's a problem so much as an ongoing conversation as to how much [informed consent] is enough and how much might be too much, and certainly also how much is practical in any given clinical situation."

How is it possible to have "too much" informed consent? Informed consent is not the same as "too much" drugs, or in the same box as overdiagnosis and over treatment. There is no such thing as too much informed consent.

The problem is not the lack of clarity but the ongoing attitude of many in the medical profession that the rules simply do not apply to them; the more senior they are the more prevalent the attitude seems to be.

For researchers, and teaching hospitals and their staff, to suggest that the rights around teaching, research and informed consent are insufficiently clear, shows an appalling degree of wilful ignorance. It is unbelievable that any medical or health researcher in Aoteroa New Zealand, in the years since the Cartwright Inquiry could possibly not have a sufficiently clear understanding of their obligations to participants in medical and health research particularly around informed consent.

If there are professionals or institutions/providers that have a role in teaching or research that are not able to understand what constitutes teaching or research, and/or do not understand their obligations regarding informed consent and other aspects of the Code of Rights, we suggest that they should seriously reconsider their careers. If they lack the capability to understand these things as they are already clearly set out in the Code of Rights, they should not be teaching medical students or taking any role in research.

We do not believe that clarity is lacking. Rather, we would like to see:

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[6] Pennington P, 2020: Waitematā DHB seeks national guidance on consent for procedures, *Radio New Zealand*, 27 January 2020 accessed at https://www.rnz.co.nz/news/national/408217/waitemata-dhb-seeks-national-guidance-on-consent-for-procedures

- some legislative means to enforce informed consent rights, beyond the complaints process;
- greater penalties for those who breach the Code of Rights in this way; and
- greater protection for those who blow the whistle on health professionals who fail to comply.

Many health consumers are not aware of their rights and/or are too vulnerable to speak up, particularly when their care occurs in a teaching hospital. That consumers may not be aware of their rights is no justification for continued breaches by medical staff and institutions, whose claims that there needs to be more clarification is an insult to the intelligence of those who work to uphold the rights of consumers.

Appendix One

Has the HDC Fulfilled Its Promise

By Sue Claridge

“The purpose of the Health and Disability Commissioner is to promote and protect the rights of consumers as set out in the Code of Health and Disability Services Consumers’ Rights. This includes resolving complaints in a fair, timely, and effective way.”

~ HDC Website[1]

The passing of the Health and Disability Commissioner Act 1994 and establishment of the role of Health and Disability Commissioner (HDC) was a direct response to the recommendations of the Cartwright Inquiry. Dame Silvia Cartwright recommended that the Human Rights Commission Act 1977 should be amended to provide for a statement of patients’ rights and the appointment of a Health Commissioner, whose role would include negotiation and mediation of complaints and grievances by patients, and heightening the health professionals’ understanding of patients’ rights.[2]

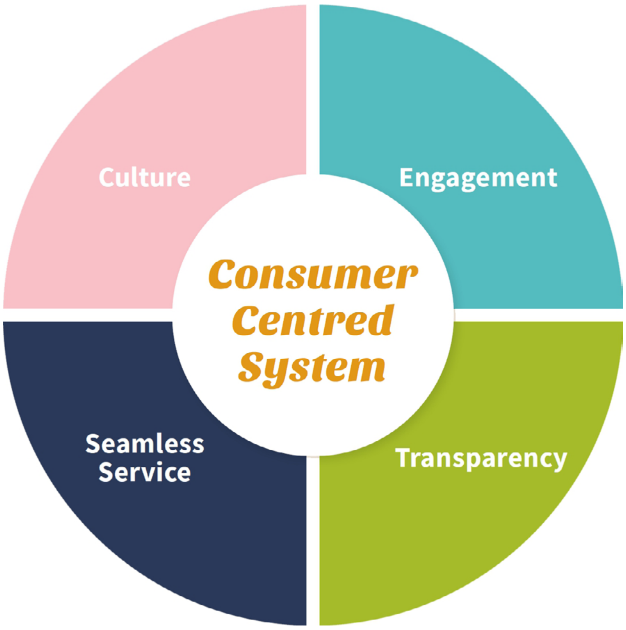
The establishment of the HDC and the implementation of The Code of Health and Disability Services Consumers’ Rights (The Code), made law in 1996 by regulations, gave New Zealanders the impression that the sort of harm caused by Herbert Green and the “unfortunate experiment” and its cover-up would never happen again; that patients’ rights were protected; and there was a clear means for investigation and remedy through The Code and the HDC.

It was an entirely reasonable expectation. The Act and Code and the HDC were a promise to the New Zealand people that health and disability services providers would be held to account; that there would be fairness and justice applied in doing so. The Act promised “fair, simple, speedy, and efficient resolution of complaints”.[3]

Twenty-five years on from passing of the Act, appointment of the first Commissioner, and implementation of the Code, has the HDC fulfilled its promise?

Many complainants describe protracted investigations of their complaints that take years to achieve resolution, while thousands of others lodge complaints only to find that their “cases” are closed without so much as an interview or follow-up. There is no right of appeal if your case is closed without further investigation or if you are unhappy with a decision, and under a no-fault system there is virtually no other way in which to obtain accountability for harms caused in health and disability services, no suing of health professionals for negligence or incompetence.

The 2019 HDC Annual Report[4] includes a graphic (see below) on its second page that has a Consumer Centred System at its core, surrounded by the ideals of culture, engagement, transparency and seamless service.



It’s not clear whether this refers to the HDC and the way in which it works, or our health system. Either way, it is aspirational, because this is certainly not what we have in either of them.

Few Complaints are Actually Investigated

The HDC was set up to protect the rights of New Zealanders in the health system; it is the only agency to which people can turn when something has gone wrong.

In his foreword to his 2019 Annual Report[4], Commissioner Anthony Hill talks of “closing” complaints. This would suggest to many readers that there has been resolution of these complaints, that there is some sort of closure or outcome for complainants, but the reality is very different. In the vast majority of complaints, the HDC’s decision is to take ‘no further action’ on the complaint after receipt and preliminary inquiry into it. Between 2014 and 2017 the HDC decided to take no further action

Health and Disability Commissioner Act 1994[3]

An Act to promote and protect the rights of health consumers and disability services consumers, and, in particular,—

(a) to secure the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights; and

(b) to provide for the appointment of a Health and Disability Commissioner to investigate complaints against persons or bodies who provide health care or disability services; and to define the Commissioner's functions and powers; and

(c) to provide for the establishment of a Health and Disability Services Consumer Advocacy Service; and

(d) to provide for the promulgation of a Code of Health and Disability Services Consumers' Rights; and

(e) to provide for matters incidental thereto

in 55% of complaints received, approximately 1,072 of the approximately 2,000 complaints received per annum.[5]

Law professor, Jo Manning, told *North & South* that the fact that only about 4% of complaints lead to a formal investigation "attests to heavy emphasis on simple, speedy and efficient resolution. It is open to question whether this has been at the expense of fairness and whether the pendulum has swung too far in denying complainants access to the process given that they have no alternative avenue for resolution."[6]

Others have noted the decline in investigations undertaken. In 2011, in an article in *Medical Law Review*, Prof. Peter Skegg wrote that investigations "declined markedly after the HDC Amendment Act 2003 came into force, and continues to decline."[7]

Prof Jo Manning

HDC Anthony Hill

In 2015, Stuart McClennan, a researcher in biomedical ethics, wrote that the continuing low number of HDC investigations were a cause for concern.[8] He detailed the number of closed complaints versus the number of investigations every year from the year ended June 2001 to the year ended June 2012, with data from the HDC's annual reports.[4, 9]

Bringing Stuart McLennan's data to up to date, we see that the trend has not improved (see Table 1).

Table 1 Relative number of investigations as a proportion of complaints closed.

Year Ended 30 June	Complaints closed	Investigations closed	Investigations as a proportion of closed cases
2001	1338	538	40%
2002	1299	234	18%
2003	1338	345	26%
2004	1162	178	15%
2005	1158	172	15%
2006	1110	116	10%
2007	1273	89	7%
2008	1295	100	8%
2009	1378	112	8%
2010	1524	51	3%
2011	1355	27	2%
2012	1380	44	3%
2013	1551	60	4%
2014	1901	115	6%
2015	1910	100	5%
2016	2007	80	4%
2017	2015	80	4%
2018	2315	102	4%
2019	2392	102	4%

Source: McLennan (2015)[8]; HDC (2019)[4] and various other HDC annual reports[9].

Stuart McClennan wrote that: "The low amount of investigations being carried out raises concerns that access to HDC investigations has become too restricted. The 2009 HDC satisfaction survey also found that one reason for complainants' dissatisfaction with the HDC process was being denied an investigation."[8]

He concluded that, while formal investigation not always be the most appropriate way to handle a complaint, the current amount of investigations being conducted was concerning and required further examination.

Four years on nothing has changed.

Even if all of the increase in complaints lodged could be regarded as not meriting further investigation, investigated complaints as a proportion of closed cases has dropped significantly from 40% in 2001 to under 5% in 2019.

In her *New Zealand Law Review* article, Jo Manning says that "Once made, a complainant loses control over the handling of their complaint… The Commissioner's choice of complaint resolution option is discretionary, with no relevant criteria attached, albeit subject to the Act's purposes."[5]

Most complainants who receive a 'no further action' decision are stuck with it. Unless the complainant is able to produce new and compelling information or evidence, the HDC is very unlikely to revisit their assessment.[5]

Complainants Feel the HDC is Weighted in Favour of Health Professionals

In an investigative article for *North & South*, journalist Donna Chisholm spoke to families who felt let down by the HDC and the complaints process. Kaya Miller died from a metabolic brain disorder after his diagnosis was delayed when an opthamologist — who believed that eight-year old Kaya was making up his symptoms, including near blindness — did not refer him to a neurologist urgently. A more timely response by the ophthamologist could have saved Kaya. His mother, Vicky Gibson, lodged a complaint with the HDC, but it closed Kaya's case without further action or investigation; she says that "it feels absolutely that [the system is] in favour of doctors and you are constantly up against it."[6]

Delays in Complaint Resolution

The "wheels" of the HDC turn very slowly.

"Resolution times for both preliminary assessments and investigations can be lengthy, typically involving two to three years,"[5] writes Jo Manning, which is as long as, if not longer than a civil action in our courts.[5]

A *Sunday* (TV1, Sunday 19 April 2020) investigation into the workings of the HDC complaints process found that it may take years of families doing their own research to uncover what has happened to loved ones injured in the medical system, leaving "kiwi families adrift in a system that is meant to be protecting them."

In one case, a family has spent years working out for themselves what went wrong in the case of their premature, brain damaged daughter's death. Andrea Donaldson, herself a health professional and PhD in Biochemistry and Forensic Science, undertook effectively a forensic examination of her own medical records to work out what went wrong when she gave birth to their daughter. What do those without this sort of training and skills and financial wherewithal do when something goes wrong? The Waikato DHB made a 'Clayton's' apology, saying "sorry for your loss", but there has not accepted responsibility.

The average time for the HDC to deal with maternity complaints is more than two years, but they have been investigating Andrea Donaldson's complaint for more than three years. She is still waiting for the HDC report, while ACC has already completed theirs.

Anthony Hill, told *Sunday*: "in my view three years is too long, and I do I regret that, I think it is unacceptable." But there are few signs that anything is changing to improve the process for New Zealanders.

Tim Lawn spoke to *Sunday* about his daughter's brain damage as a result of her mishandled birth and their complaint to HDC. He said: "you just lose a lot of hope throughout the whole process." His family's complaint took seven and a half years to resolve, including a two and a half year HDC investigation. Despite a damning report by the HDC that found 14 breaches in the maternity care provided, the Lawn family faced a further five-year fight for compensation and acceptance of responsibility by the DHB.

Jo Manning told *North & South* that the HDC quickly "resolves" cases by taking no further action, and that when investigations are undertaken, it "publishes less information on resolution times than it did before and key dates are no longer included it its reports."[6]

"The last two tactics are surely intended to shield the office from criticism for delays,"[6] she says.

Effecting Change?

It would not be unreasonable to expect that, over time, if the HDC was effective, the relative proportion of complaints (i.e. per capita or relative to the number of interactions with health and disability service providers) would decrease.

Commissioner Hill told *North & South* that "consumers say to us that they don't want this to happen to anyone else. They want the system to improve."[6] He claimed that the way in which the complaints system operates brings change in the health system that improves performance.

In truth, empirical evidence supporting a correlation between the work of complaints bodies and improvements in the safety and quality of health care is weak. But, taking Hill at his word — that HDC brings change that improves provider performance — if he is correct, one might perhaps expect to see no increase in or, at the very least, a slowing in the rate of increase in complaint numbers over time, given that complaint entities around the world are all experiencing increases in complaint volumes. However, the reality is far removed from this. Not only have complaint numbers increased year-on-year, but the rate of increase has accelerated each year, with an "an unprecedented 28% increase in the number of complaints received" between 2016 and 2019.[4]

In an analysis of complaints presented in a session at the HDC Conference in November 2017,[10] the presenters revealed that those at increased risk of complaints were:

- male*,
- general practitioners,
- vocationally registered, and
- had been in practice for 21-30 years.

Australian research, highly likely to be reproducible here, has found complaints clustered heavily among a small group of doctors. Approximately 3% of practicing doctors accounted for half of all complaints. The greater the number of prior complaints doctors had experienced, the greater their short-term risk of further complaints.[11]

No Right of Appeal – A Denial of Natural Justice

If your ACC claim is denied, you can appeal.† If you are convicted of a criminal offence, you can appeal. If an Employment Relations Authority decision goes against you, you can challenge it through the Employment Court. If you lodge a complaint with the HDC and the HDC takes no further action, refuses to investigate, or the investigation does not uphold your complaint or the resolution is unsatisfactory you can, well, do nothing. There is no right of appeal and there is no ability in New Zealand to take a medical negligence action for damages.[5]

Jo Manning writes:

> "…the governing legislation does not provide an appeal or review mechanism, … it gives the Commissioner broad, largely unreviewable powers to control the fate of complaints. The HDC complaints process is the only available option for aggrieved patients and their families to have their grievances substantively addressed; there is no alternative means of doing so. The HDC complaints process is virtually the "only game in town" for complainants. Yet they cannot access it as of right, nor can either party seek to correct decisions they consider wrong or unjust."[5]

The lack of right to appeal is equally applied – health and disability service providers also have no avenue to appeal a decision that goes against them.[5]

Jo Manning says that the only option if you are dissatisfied with the HDC's response is to "seek an internal review, a prohibitively expensive judicial review or make a complaint to the Ombudsman."[6] However, with the Ombudsman or a judicial review, only procedural unfairness and errors of law will be considered, not the merits or fairness of the decision itself.[6]

Even then, the most the Ombudsman can do is refer the complaint back to the Commissioner, enabling him to reconfirm his original decision.[5]

In comparing the generous rights of appeal on ACC decisions with the striking "lack of any opportunity for external review or appeal from adverse HDC decisions", Jo Manning says that the difference between the two is indefensible.[5]

One of Jo Manning's significant concerns is that if there are high levels of dissatisfied complainants, there is the risk that they will boycott the complaints regime.[5] Thus, providers who breach patient rights are never held to account and their shortcomings are never brought to light. In such an environment, Commissioner Hill's claim that the complaints system will bring change in the health system and improve performance is no longer valid.

Among a number of remedies to the current situation, Jo Manning advocates for an external review or appeal process, saying that while "the finality of the process is consistent with the simple, speedy, and efficient aim of the legislation… [it] compromises the ability to achieve fair outcomes too much."[5]

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* Even when correcting for the number of males in practice versus females, male providers were far more likely to be the subject of a complaint to the HDC than female providers. Approximately 75% of complaints were about male doctors while they make up only about 60% of doctors in the workforce.

† In fact, there are multiple levels of appeal against ACC decisions all the way to the High Court and Court of Appeal.[5]

Surgical Mesh and the HDC Response

Surgical mesh arguably represents the most serious medical injury crisis New Zealand has experienced in the last twenty or more years. Yet, the HDC, who should have been there to protect, and advocate for the vulnerable patients harmed by mesh procedures, has been remarkably absent from attempts to address, repair and ameliorate the damage.

According to the report on the surgical mesh restorative justice process held in 2019, there were only 45 complaints to the HDC relating to surgical mesh in the four years to June 2019.[12]

In her Bachelor of Laws Honours Dissertation, Jade du Preez found that, "Despite articles and submissions indicating mesh-related complaints to the HDC, a website search of HDC decisions concerned with problems from the use of mesh yielded only 3 results, and all of these were in relation to hernia repair."[13]

In August 2018 a Medsafe report found that more than 1000 people have reported issues with surgical mesh.[14] ACC received over 1018 treatment injury claims between 2005 and June 2018, of which 771 claims were accepted. Hernia repair accounted for 271 accepted claims and pelvic organ prolapse and/or stress urinary incontinence repair accounted for 453 accepted claims.[15]

So, why have so many of the hundreds of women devastatingly damaged by pelvic mesh devices failed to complain and why were only three of the 45 complaints upheld — all of them relating to hernia repair?

In her research, Jade du Preez found that mesh injured New Zealanders were frustrated in their attempts to complain via the HDC process.[13]

The report on the surgical mesh restorative justice process further detailed the mesh patients' frustration and disillusionment with the HDC process:

The HDC was frequently described as "not upholding my rights". Participants stated there was "no point" in pursuing the HDC process as the mesh community knows "they don't do anything".[12]

The report said that patients who had experienced an HDC investigation found it deeply distressing, and those who had complained that their right to make an informed choice and give informed consent had been breached were told, 'I had informed consent because I signed the form.'"[12]

Many wanted "the HDC to step up, encourage people to make complaints and actually act on them in the patient's interest".[12]

Mesh Down Under co-founder, Charlotte Korte, has been appalled by the HDC response to the restorative justice process and the request that they participate.[16] The HDC claimed that the decision not to participate was in order to remain completely impartial. The HDC was the only agency who chose not to attend a listening circle (ACC, the Royal Australasian College of Surgeons, Royal Australia & New Zealand College of Obstetricians and Gynaecologists, Royal New Zealand College of General Practitioners and the Medical Council all attended). This supposed impartiality is seen as a frequent excuse for a lack of engagement.

Charlotte Korte says that the HDC chose to only 'promote the visibility' of their advocacy service, a service that people are unwilling to use because of their cynicism towards the organisation. She reiterates the restorative justice report, saying that "the majority see laying a complaint as waste of time, and a fruitless exercise. Those that have complained have found the process extremely distressing, because in many cases the ineffective complaints process leads to patients having to do their own investigation. The mistrust of this organisation's ability to uphold patients' rights is clearly evident."[14]

How is it possible to reconcile the stated purpose and duty of the HDC — to promote and protect the rights of consumers — with the HDC's incredible "hands off" approach to dealing with the devastation wrought by surgical mesh?

Commissioner Anthony Hill did respond to the criticism levelled at his office and the complaints process, saying "HDC will take on the feedback we have heard in the report about our complaints process", but then went on to promote the National Advocacy Service, without addressing the distress and frustration that patients experienced with the complaints process.[17] Nor did he address the HDC's refusal to participate in the Listening Circles in which other agencies participated.

Conclusion

Given the evidence, it appears that the HDC's resolution of complaints is neither fair, timely, or effective. In addition, there is scant evidence, if any, that there has been any change in the culture or system, or a shift in focus to the patient or consumer. As a result, the HDC is not fulfilling its "promise" to promote and protect the rights of consumers.

The AWHC has previously expressed its concerns in several fora, and including directly to the Minister of Health, about the inadequacy of the HDC in fulfilling its purpose to protect consumers and respond appropriately and in a timely manner when their rights have been breached.

After ten years as Commissioner, with a second term in the position (which was to end in July 2018) and an extension to his tenure, Anthony Hill will leave the role this year.[18]

We have expressed to the Minister of Health our hope that the new Commissioner will bring fresh insights and different expertise and experience to the role. After periods (since 2000) during which male appointees have occupied the role, we also hope serious consideration will be given to appointing a woman. We have no insight into the current process of recruiting and appointing the new Commissioner, and at the time of writing, the global Covid-19 pandemic will no doubt have forced this process down the list of the Minister's priorities. However, given the ongoing importance of the role, we hope that it will be publicly advertised, and that a thorough search will be conducted to ensure a strong field.

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AWHC Annual General Meeting

The Auckland's Women's Health Council AGM was held under Covid-19 alert level 3 conditions via Zoom, on Wednesday 29th of April 2020. With the exception of Trish Fraser, who has stepped down from the Executive Committee (see page 3 this edition), all existing members returned to the Committe. The AWHC 2019 Annual Report will soon be available on the AWHC website.

Appendix Two

Auckland Women's Health Council

Submission of the Auckland Women's Health Council on the petition of Renate Schütte (Petition no 2017/535; presented 22 June 2020) on the right to appeal decisions made by the Health and Disability Commissioner

Executive Summary

1. The Auckland Women's Health Council (AWHC) supports the request of Renate Schütte (Petition no 2017/535; presented 22 June 2020):

   "*That the House of Representatives amend the Health and Disability Commissioner Act 1994 to give complainants, and those that are the subject of complaints, the right to appeal decisions made by the Health and Disability Commissioner*."

2. Under the current legislation there is no mechanism by which decisions made by the Health and Disability Commissioner (HDC) regarding complaints lodged by consumers/patients about adverse events and breaches of their rights, can be appealed or subject to independent review.

   This is not only highly unusual in New Zealand, as most if not all similar decision-making agencies offer the right of appeal and often multiple rights of appeal, but it denies consumers natural justice in the only forum available to them to seek accountability in the health and disability sector.

3. New Zealand's internationally highly regarded "no-fault" system prevents consumers from seeking remedies through the court when they have been harmed by medical care and other services obtained from health and disability services providers. Thus, the HDC is the only available option for consumers to seek accountability and resolution for complaints.

4. The overriding purpose of the *Health and Disability Commissioner Act 1994* (The Act) and the office of the HDC is to promote and protect the rights of consumers, and without the right to appeal decisions both the Act and the HDC fail to fulfil this purpose. The extraordinarily high number of 'no further action' decisions limits the transparency of the HDC process, negates the HDC's claims to be a consumer-centred system, and denies the vast majority of complainants natural justice or any ability to obtain real resolution of their complaints.

5. A robust complaints process that includes the right of both complainants and defendants to appeal decisions, including 'no further action' decisions, will contribute to improvements in culture and safety for both consumers and practitioners. A transparent, robust and thorough complaints system will be a catalyst for improving patient safety and ensuring that practitioners take responsibility for upholding patient rights.

6. The Auckland Women's Health Council submits, in the strongest possible terms, that a process for appealing HDC decisions or subjecting them to independent review, both those with a 'no further action' decision and those that undergo an investigation, is the only way to ensure a consumer-centred complaints system and to ensure that justice is served.

Background to the Auckland Women's Health Council

The AWHC was founded 33 years ago (July 1988) just before the release of *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters* (the Cartwright Report).[1] AWHC has a special interest in patient rights, informed consent and decision-making in health care, health consumer advocacy, the Code of Health and Disability Services Consumers' Rights (Code of Rights), the National Cervical Screening Programme, and medical ethics – issues that were highlighted during the inquiry into the treatment of cervical cancer at National Women's Hospital in 1987-88 and in the recommendations contained in the Cartwright Report.

Subsequent to the Cartwright Inquiry, the AWHC played a significant role in assisting with the establishment of the National Cervical Screening Programme and in monitoring the implementation of many of the other recommendations contained in the Cartwright Report. One of our founding members, Lynda Williams, was involved in several of the working groups set up following the release of the Cartwright Report and was appointed as the first patient advocate at National Women's Hospital, fulfilling one of the key recommendations from the inquiry. Subsequently, AWHC made submissions on the Health and Disability Commissioner Act 1994, then once the legislation was passed and the first Health and Disability Commissioner appointed, we made submissions and participated in consultation meetings that occurred during the development of the Code of Rights.

The AWHC has had a long and sustained interest in the recommendations of the Cartwright Report, the establishment and function of the office of the HDC and the introduction of the Code of Rights. Over the last three decades we have been active in advocating for upholding patient/consumer rights, including making formal submissions on a wide range of health topics, such as the legislation and regulations governing various health and disability services, and in consumer representation roles relating to health and disability services.

Since the establishment of the Office of the HDC, AWHC has made substantial submissions in the reviews of the Health and Disability Commissioner Act 1994 and Code of Rights in 2004, 2009 and 2014, and had regular correspondence with the HDC on a variety of issues. In addition, over several years the AWHC lobbied for and made a very substantial submission on the HDC consultation on health and disability research involving adult participants who are unable to provide informed consent.

In numerous submissions to and about the HDC, AWHC has expressed its belief that the HDC needed to "refocus on the rights of consumers, rather than the needs of health practitioners and medical researchers."

The Need to Provide for an Appeals Process

1. Background

The passing of the Health and Disability Commissioner Act 1994 and establishment of the role of Health and Disability Commissioner (HDC) was a direct response to the recommendations of the Cartwright Inquiry.

Judge Silvia Cartwright identified gaps in the accountability mechanisms of health professionals "in a jurisdiction where the financial accountability of the medical profession has been distorted by no-fault Accident Compensation legislation".[1, 2] She recommended that the Human Rights Commission Act 1977 should be amended to provide for a statement of patients' rights and the appointment of a Health Commissioner, whose role would include negotiation and mediation of complaints and grievances by patients, and heightening the health professionals' understanding of patients' rights.[1]

The Act exists to promote and protect the rights of health consumers and disability services consumers, and, in particular, to secure the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights.[3]

The establishment of the HDC and the implementation of The Code, gave New Zealanders the impression that the sort of harm caused by Herbert Green and the "unfortunate experiment" and its cover-up would never happen again; that patients' rights were protected; and there was a clear means for investigation and remedy through the Code of Rights and the HDC.

2. The Right to Appeal Decisions

The right to appeal decisions is widespread not just in the judicial and criminal arena but in other public authorities both in New Zealand and internationally. The right to appeal decisions on a wide range of matters is seen as an important process in the application of fairness and natural justice.

The notion of appeal refers to the right of both a complainant/prosecuting authority and defendant to have the chance to appeal the judgement of a decision-maker under the premise that the decision-maker has made an error; the appeal plays the role of the instrument that corrects the errors that might have been made in the original judgement.[4]

The Human Rights Commission (HRC) states that "Adjudicative procedures provided by the State should be fair. The overarching objective of the rule of law and the right to justice is that fair outcomes are realised by everyone encountering the judicial process."[5]

The right to justice is recognised under the Universal Declaration on Human Rights, and includes the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.[5] The HRC goes on to state that "the notion that decision-makers, including judges, should abide by the principles of natural justice is a common law principle."[5]

The AWHC strongly believes that the absence of any right of appeal undermines the rights of New Zealanders to the fair resolution of complaints against providers of health and disability services, and denies natural justice. The Act and Code of Rights and the HDC were a promise to the New Zealand people that health and disability services providers would be held to account; that there would be fairness and justice applied in doing so.

The HRC states that "Equality and fairness are not just about having laws and processes that appear to treat everyone equally or in the same way … Equality and fairness are also about what happens in practice in everyday life."

AWHC believes it is both incongruous and inconsistent that other New Zealand decision-making agencies – any tribunal or other public authority that has the power to make a determination in respect of that person's rights – allow the right of appeal, yet there is no such right under the Health and Disability Commissioner Act. This is a particularly unjust omission in light of our no-fault system and the inability of aggrieved parties to take civil action against providers who have breached their rights.

3. The HDC Versus Other Public Authority Determinations

If an ACC claim is denied, there are multiple options to appeal all the way to the High Court and Court of Appeal. If a person is convicted of a criminal offence, he/she can appeal again through the High Court and Court of Appeal. If an Employment Relations Authority decision goes against someone, they can challenge it through the Employment Court. However, if a consumer or their representative lodges a complaint with the HDC and the HDC takes no further action, refuses to investigate, or the investigation does not uphold the complaint, or the resolution is unsatisfactory to either the complainant or the defendant, there are no other options; there is no right of appeal and there is no ability for a complainant in New Zealand to take a medical negligence action for damages.[2]

Three complaint processes were established in the 1990s – the HDC, the Privacy Commissioner and the Human Rights Commission.

"All are based on the same broad template, which created a complaints regime with access to the HRRT [Human Rights Review Tribunal]. Victims of discrimination and an interference with privacy who make complaints are much better served in terms of access to justice than HDC complainants and consumers."[2]

With the HDC complaints process "…the governing legislation does not provide an appeal or review mechanism, … it gives the Commissioner broad, largely unreviewable powers to control the fate of complaints. The HDC complaints process is the only available option for aggrieved patients and their families to have their grievances substantively addressed; there is no alternative means of doing so. The HDC complaints process is virtually the "only game in town" for complainants. Yet they cannot access it as of right, nor can either party seek to correct decisions they consider wrong or unjust."[2]

The lack of right to appeal is equally applied – health and disability service providers also have no avenue to appeal a decision that goes against them. With no right of appeal there is no opportunity for the vast majority of complainants or defendants to correct errors of fact made in the determination of the outcome of the complaint by the HDC.

Complainants to the HDC have limited opportunity to present their case compared with judicial proceedings: they cannot present their case in person, cannot call witnesses or cross-examine opposing witnesses, and conclusions are reached on papers without the Commissioner being able to assess a witness's reliability or credibility.[2, 6]

Yet, despite these significant limitations, complainants have no right to appeal.

The only option if a complainant is dissatisfied with the HDC's response is to "seek an internal review, a prohibitively expensive judicial review or make a complaint to the Ombudsman."[7] However, with the Ombudsman or a judicial review, only procedural unfairness and errors of law will be considered, not the merits or fairness of the decision itself.[7]

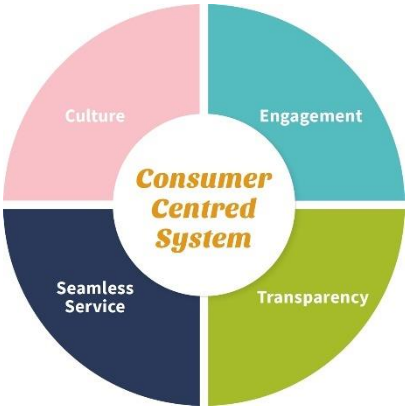
Even then, the most the Ombudsman can do is refer the complaint back to the Commissioner, enabling him to reconfirm his original decision.[2]

In comparing the generous rights of appeal on ACC decisions with the striking "lack of *any* opportunity for external review or appeal from adverse HDC decisions", Prof Joanna Manning says in her *New Zealand Law Review* article that the difference between the two is indefensible;[2] sentiments with which AWHC entirely agrees.

Under New Zealand's no-fault system there is virtually no other way in which to obtain accountability for harms caused in the provision of health and disability services, no suing of health professionals for negligence or incompetence, or other breaches of their rights.

4. A Consumer-Centred System?

The HDC Annual report includes a graphic that has a Consumer Centred System at its core, surrounded by the ideals of culture, engagement, transparency and seamless service (see illustration on page 5[8]). Without the right to appeal the HDC is neither consumer-centred nor transparent.



A transparent and consumer-centred system must be fair and just. A fair system is described by Manning as one that "has a high likelihood of reaching substantively accurate and just results on the merits; and it does so through a process that treats the parties fairly and is accepted by them as such."[2]

Without an appeals process that would allow the correction of errors in the process of making a determination or decision, that system cannot be described as fair. Without fairness the system cannot be described as consumer centred or transparent.

In the vast majority of complaints, the HDC's decision is to take 'no further action' (NFA) on the complaint after receipt and preliminary inquiry into it – currently only about 4% of complaints lead to a formal investigation, and without any right to appeal this is the "end of the road" for complainants. AWHC believes that the emphasis on efficient resolution of complaints has been at the expense of fairness and justice and denies complainants access to a fair and just process given that they have no alternative avenue for resolution or accountability.

In her *New Zealand Law Review* article, Manning says that "Once made, a complainant loses control over the handling of their complaint… The Commissioner's choice of complaint resolution option is discretionary, with no relevant criteria attached, albeit subject to the Act's purposes."[2] Many consumers who have suffered serious harms in the provision of health and medical services, and who have lodged complaints with the HDC do not believe they have been dealt with fairly.

In an investigative article for *North & South*, journalist Donna Chisholm spoke to families who felt let down by the HDC and the complaints process. One complainant said that "it feels absolutely that [the system is] in favour of doctors and you are constantly up against it."[7]

Surgical mesh arguably represents the most serious medical injury crisis New Zealand has experienced in the last twenty or more years. Despite over 1018 ACC treatment injury claims between 2005 and June 2018,[9] according to the report on the surgical mesh restorative justice process held in 2019, there were only 45 complaints to the HDC relating to surgical mesh in the four years to June 2019.[10]

In her 2018 research, Jade du Preez found that mesh injured New Zealanders were frustrated in their attempts to complain via the HDC process.[11] The report on the surgical mesh restorative justice process further detailed the mesh patients' frustration and disillusionment with the HDC process. The HDC was frequently described as "not upholding my rights". Participants stated there was "no point" in pursuing the HDC process as the mesh community knows "they don't do anything". The report said that patients who had experienced an HDC investigation found it deeply distressing.[10]

It is clear that there is high level of dissatisfaction among complainants to the HDC. In the early 2000s the HDC Annual Reports contained information on the results of satisfaction surveys. Between 2002 and 2009 when relatively detailed data was provided, between 38% and 61% were dissatisfied or very dissatisfied with their view being heard in a fair and unbiased way.[13] In contrast, providers expressed much higher levels of satisfaction.[13]

In 2003 and 2004 when this question was reported, 51% and 59% respectively said they would not want to deal with HDC in the future.

By 2010 satisfaction results were being reported only every second year and with only combined complainant and provider responses (highly irrelevant and deceptive given the gulf between the satisfaction levels expressed by complainants and providers), and by 2016 no satisfaction survey data about the complaints process was being reported at all.*

Given the lack of reporting, the increasing number of complaints being closed with NFA decisions, and so few complaints leading to an investigation, it is easy to come to the conclusion that satisfaction with the handling of complaints is at an all-time low.

Manning draws an obvious conclusion: "It is suggested that the access to justice barriers identified herein may well offer some explanation for this dissatisfaction."[2]

While the right to appeal HDC decisions may not address all the concerns of those disappointed by the complaints process and the decisions made, at least there would be greater fairness in the process and an opportunity to have the decisions on their complaints reconsidered as would be the case if their application for ACC cover for treatment injury had been declined.

No Appeal and No Further Action

The extraordinary increase in NFA decisions makes the right of appeal all the more crucial.

In his foreword to his 2019 Annual Report[8], Commissioner Anthony Hill wrote of "closing" complaints, suggesting resolution of complaints; that there is some sort of closure or outcome for complainants. However, the reality is very different. Between 2014 and 2017 the HDC decided to take no further action in 55% of complaints received, approximately 1,072 of the approximately 2,000 complaints received per annum.[7]

In 2011, in an article in *Medical Law Review*, Prof. Peter Skegg wrote that investigations "declined markedly after the HDC Amendment Act 2003 came into force, and continues to decline."[6]

In 2015, Stuart McClennan, a researcher in biomedical ethics, wrote that the continuing low number of HDC investigations were a cause for concern.[12] He detailed the number of closed complaints versus the number of investigations every year from the year ended June 2001 to the year ended June 2012, with data from the HDC's annual reports. AWHC has reviewed the figures provided in recent HDC Annual Reports adding that data to Stuart McLennan's to bring it up to date and we see that the trend has not improved (see table and graph on page 7).

Stuart McClennan wrote that: "The low amount of investigations being carried out raises concerns that access to HDC investigations has become too restricted. The 2009 HDC satisfaction survey also found that one reason for complainants' dissatisfaction with the HDC process was being denied an investigation."[12]

He concluded that, while formal investigation was not always the most appropriate way to handle a complaint, the current number of investigations being conducted was concerning and required further examination. Even if all of the increase in complaints lodged could be regarded as not meriting further investigation, investigated complaints as a proportion of closed cases has dropped significantly from 40% in 2001 to 6% in 2020 while the number of complaints has only doubled.

AWHC believes that the right of appeal would go some way to addressing complainants concerns about NFA decisions.

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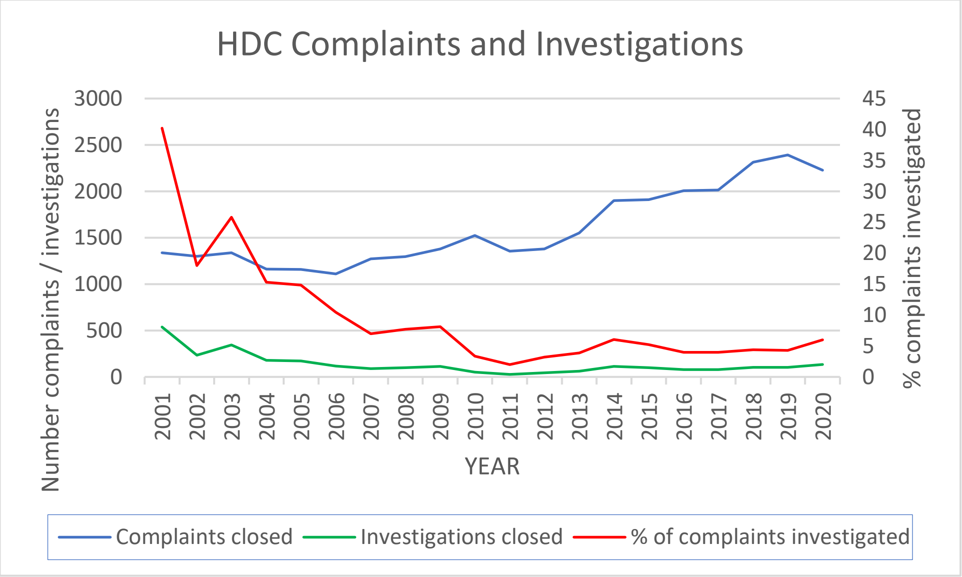
* Satisfaction data on the advocacy service is still reported.

Relative number of HDC investigations as a proportion of complaints closed.

Year Ended 30 June	Complaints closed	Investigations closed	Investigations as a proportion of closed cases
2001	1338	538	40%
2002	1299	234	18%
2003	1338	345	26%
2004	1162	178	15%
2005	1158	172	15%
2006	1110	116	10%
2007	1273	89	7%
2008	1295	100	8%
2009	1378	112	8%
2010	1524	51	3%
2011	1355	27	2%
2012	1380	44	3%
2013	1551	60	4%
2014	1901	115	6%
2015	1910	100	5%
2016	2007	80	4%
2017	2015	80	4%
2018	2315	102	4%
2019	2392	102	4%
2020	2226	133	6%

Source: McLennan (2015)[12]; and various HDC annual reports[13]



The importance of this lies in the fact that, for those whose complaints progress to an investigation, and for which a breach finding is made, a complainant may take their case to the Human Rights Review Tribunal (HRRT) or the Health Practitioners Disciplinary Tribunal (HPDT).[2, 6, 14]

However, the decision to take no further action deprives complainants of the ability to bring proceedings before the HRRT or the HPDT.[14]

Most complainants who receive an NFA decision are stuck with it. Unless the complainant is able to produce new and compelling information or evidence, the HDC is very unlikely to revisit their assessment.

Bizarrely, although there is no right to directly appeal decisions of the HDC, for the very few complainants who get an investigation, and in which a breach of the Code of Rights is found, if those complainants proceed to the HRRT and are still dissatisfied with the outcome there, they have further rights of appeal to the High Court and the Court of Appeal."[2]

Since 2007, in many cases the evidence suggests that whether or not complaints get an NFA decision or progress to an investigation is somewhat of a lottery and not necessarily based on the seriousness of the harms suffered. Complainants simply have no recourse for further action if they 'draw the short straw' and receive an NFA decision. AWHC contends that this is grossly insufficient to protect and promote the rights of consumers.

The Handling of Health Complaints in International Jurisdictions

It is difficult to systematically review and compare the health care complaints processes in other jurisdictions, not least because of New Zealand's no-fault system compared with the ability for aggrieved consumers/patients in many other countries to resort to litigation to obtain resolution.

For example, in Australia, "where a number of states have complaints entities like the HDC, with similar broad powers to take no action on complaints... complainants always have the option of suing the practitioner or hospital in the courts instead of or as well as pursuing their complaint."[2]

In 2008, the National Audit Office in the UK commissioned a report on *Handling Complaints in Health and Social Care* in nine countries, including New Zealand, with the purpose of informing improvements in the handling of such complaints in England.[15]

Only two of the countries considered – New Zealand and Denmark – have no-fault compensation for medical harm/injury, and therefore consumers have no ability to take civil proceedings in order to obtain remedies or resolution to their complaint. Neither country allows for appeals in the complaints system. This contrasts with the other seven countries. While the complaints systems in Northern Ireland, Scotland, Wales, Australia, Canada, Germany, and The Netherlands are all quite variable, all appear to permit both some or multiple levels of appeal or independent review of decisions handed down by the complaints authority as well as seeking resolution through the court system.[15]

Effecting Change

Then Commissioner Anthony Hill told *North & South* in a 2019 article on the HDC that "consumers say to us that they don't want this to happen to anyone else. They want the system to improve."[7] He claimed that the way in which the complaints system operates brings change in the health system that improves performance.

Bismark *et al.*, wrote that the HDC "strives to use complaints as a catalyst for improving patient safety."[16]

Empirical evidence supporting a correlation between the work of complaints bodies and improvements in the safety and quality of health care is weak. But, taking Hill at his word – that the HDC brings change that improves provider performance — if he is correct, one might perhaps expect to see no increase in or, at the very least, a slowing in the rate of increase in complaint numbers over time. However, the reality is far removed from this. Not only have complaint numbers increased year-on-year, but the rate of increase has accelerated each year, with an "an unprecedented 28% increase in the number of complaints received" between 2016 and 2019.[8]

A significant concern is that if there are high levels of dissatisfied complainants, there is the risk that they will boycott the complaints regime altogether.[2] Thus, providers who breach patient rights are never held to account and their shortcomings are never brought to light. In such an environment, Commissioner Hill's claim that the complaints system will bring change in the health system and improve performance is no longer valid.

Conclusion

The HDC is the only practical means by which consumers/patients who have been harmed in some way by health and disability service providers can seek accountability for what has happened to them.

The legal rights of consumers are set out in the Code of Rights and the "overriding purpose of the Health and Disability Commissioner Act 1994 is 'to promote and protect the rights of health consumers and disability services consumers'".[3]

With the current extraordinary level of NFA decisions and a lack of right of appeal, the HDC almost completely fails to 'promote and protect the rights of health consumers and disability services consumers'. Thus, The Act is not fit for purpose, as it is the legislation itself that imposes the greatest barrier to fairness and justice – the lack of right to appeal.

The vast majority of complainants do not have their complaints investigated and breach findings are rarely made. As a consequence, there is no cultural shift in the overall practice of providers or in the relationship between providers and consumers.

While the right of appeal will not fix all the limitations and failings of the HDC it will go some way towards better promoting and protecting the rights of consumers, and importantly offer them a real opportunity to achieve accountability, justice and resolution.

In her written submission to the Health Select Committee, Sarah Turner, Deputy Director-General of the Ministry of Health, says the HDC "intends to include a focus on this matter in its next review of the Act as this will enable consideration of both operational and legislative options". The inference is that, as far as the Ministry of Health is concerned, considering the issue of the right to appeal HDC decisions can wait until that review in 2024. Such a delay in addressing the inconsistency and lack of fairness in this legislation will deny a further 9000[*] or more New Zealanders the justice that they seek.

The overriding purpose of The Act is to achieve fair, simple, speedy, and efficient resolution of complaints. While simple, speedy, and efficient are admirable and important aims, in the absence of any other means of obtaining accountability for harms caused, the single most important aspect of the HDC's complaints process

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[*] based on complaints numbers in recent years.

must be fairness to complainants. Without any avenue of appeal, promotion and protection of consumer rights, fairness, justice and resolution of complaints, is simply unachievable.

Therefore, the Health and Disability Commissioner Act 1994 must be amended, as soon as possible, to allow for the right to appeal decisions, both for complaints that result in a 'no further action' decision and those that are investigated. Only a robust appeals or independent review process will ensure fairness and justice, and fulfil the HDC's obligation to protect and promote consumer rights.

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