

Act and Code Review – Supporting timely, people-centred resolution

Notes

Date / Time / Location	21 November 2023
Attendees	Tui Taurua (NAMHSCA and HDC's Consumer Advisory Group); Sue Claridge (AWHC and Health Consumer Advocacy Alliance); David Dunbar (Medical Council NZ); Louise Grant (Advocacy Service); Bronwen Scott (Advocacy Service); Edna Havea (Phd Candidate / lecturer and Te Tāhū Hauora Kōtuinga kiritaki); Sam Powell (Aged Care Association); Danae (InsideOUT); Tristram Ingham (Te Ao Mārama); Ann Buckley (HQSC); Alison Eddy (NZ College of Midwives); Martin Thomas (HQSC); Dianne Black (NAMHSCA); Rebekah Graham (PVINZ); Gabriel Lau (Royal Australasian College of Radiologists)
HDC Attendees	Catherine McCullough; Deborah James; Charmaine Pene; Vanessa Lin; Kylie Arihi; Jane Carpenter; Ikimoke Tamaki-Takerei

Introduction

Catherine welcomed everyone and thanked people for their time. Kylie opened with mihi and karakia.

As part whakawhaungatanga attendees were asked to share what was most important to them to improve complaints processes:

- Length and Māori voice
- Lack of right to appeal HDC decisions (important for both consumers and providers)
- Human-centric process that is visible and continuous for the consumer and practitioner and provider. Seamless journey that is safe for all participants
- For consumers to feel empowered and have a voice. Looking at how can we make a complaints process / raising concerns safer for consumers and providers. How can draw people into a process that is daunting, particularly consumers who are too afraid to have a voice and for providers
- Process that is accessible, have no fear, and engagement by providers to not feel like a victim and can engage with the resolution process.
- Keen to understand restorative processes and how can be used better
- Balance of safety and care of providers and the impact of adverse comments on providers
- Easier and less stressful for rainbow and takatāpui whānau
- Paradigm shift away from deficit and adversarial processes to learning opportunities and languaging
- Increase in clarity and accessibility for consumers to engage with the Code and know where and when to go to HDC compared to providers

- Mana-enhancing process for all – see downstream effect of losing members of profession because processes of complaints can be denigrating
- Would like to see improvement in communication and timing
- Need to improve learnings from complaints when things go wrong and embed across system
- Want to see complaints heard and feel respected even if complaints are declined
- Shift away from the burden on the individual to make formal complaints to a system. Explore other ways to explore complaints at a system level
- Challenges with bias in small cohort of oversight and the benefit of hindsight.

Principles of complaints resolution

Questions:

- Are the four principles for complaints resolution “fair, simple, speedy and efficient” still fit for purpose? Why / Why not?
- Should a requirement to ‘enhance mana’ be included as a principle for complaints resolution? Why / why not?
- Are there any other principles we should consider? Why?

- Like the four principles. Clear. But on reflection, are also transactional. Love making more person and whānau-centred through mana-enhancing. Would also like to see addition of learning opportunity. How can they influence systemic change.
- Simple and speedy important, but have to keep people at the centre, and don't want to compromise natural justice.
- How do you legislate for how people conduct themselves in a mana-enhancing way
- Four principles are important, but fair has often been sacrificed for speedy and efficient. Inherent power imbalance
- Complainant doesn't have the right of response to cross examine the provider – comes back to how articulate the complainant is to lay out the issue. Power imbalance. Another principle should be that complainants should have the right to respond to and cross-examine the response of the provider
- Agree list sounds transactional. Element of learning.
- Appreciate that mana not a zero-sum gain
- If list becomes longer than four could become muddled – maybe separate out human component and procedural aspects
- Fairness could be tightened in terms of learning
- Tautoko mana-enhancing and advocate of hohou te rongo and the review of adverse events policy
- Essence of the principles fine but the way that communicated and described not person-centred – speedy could be seen as rapid and without due care. Important that language is meaningful in and of itself
- Is very process focused – missing human element. Don't see **safety** in there. Culturally safe. Not just ethnicity. Holistic approach in process and reflect that whānau focused and about people. Definition of 'fair' is not fair.
- Safety supported as a necessary principle. Eg boundary violations.

- If paradigmatic change of how complaints are seen is that there needs to be a change in language and expectation. Eg raising / reporting issues
- Feedback rather than complaints would change the wairua
- Where is it that all in it together and shows Te Tiriti? Mana Motuhake – how do we get to determine ourselves in this process. Manaaki – how is everyone in the process looked after, including staff. Missing those types of concepts in this kōrero. Legislation is words and not the process.

Right to complain (Right 10)

Questions:

- What is your experience of how well provider complaint processes (as set out in the Code) are working?
- What options should we consider to improve provider complaint processes?

- Within advocacy service having a clear understanding that should they go directly to provider will be dealt with in faith. That Advocacy is taken seriously by the provider when dealing with the consumer's issue(s).
- Maintain consumer's feeling that they will be respected when going to a provider. How do we encourage them to have faith in the provider/process.
- Risk of retaliation to the consumer. E.g limited number of providers for the consumer.
- Consumer experience their complaint has been put on their medical records, and labeled "difficult", and could follow them to another provider.
- Need to explicitly prevent provider retaliation. Some providers deny the person the right to give permission or informed consent. Retaliation can take a wide variety of form.
- Yes to less prescriptive and more principled based.
- Some consumers are traumatised when taking a complaint. Some expectations for consumer when raising a complaint will be different - so principle based rather prescriptive.
- Professionals / provider have a duty of care. Who is taking responsibility for providing duty of care for the consumer who is going through a complaint process. This should be spelt out.
- The process is not transparent / user friendly and puts the complainer at a disadvantage.
- (Provider) Duty of care is to ensure complainants have an empowering experience and not disempowered and its not a tick off process.
- Provider induction needs to include the 'complaint' process face to face and not just hand out a brochure or show a poster. Face to face korero is much more available to the consumer and it stays with them and is whanau focussed. It is friendlier.
- What is retaliation? And who monitors, what do you do if a breach? Still doesn't deal with power imbalance. Right not to do something is more difficult to enforce. Should be able to complain

- How do we support people to make complaints. Having a navigator to rebalance power.
- Group think and different paradigm - sense here that don't trust the provider to think differently to the individual who makes the complaint - complaints process (and assessors) is biomedical. Involvement of the complainant in determining who are 'experts' - i.e. who would be good to be an assessor of the process. Who's voice is to be valued here. Eg disability rights. Assessors may be thinking from a medical rather than a multidisciplinary approach. Especially if a systems issue, determinants of health, policy, UNCRPD, consideration of tikanga etc.
- Real need to consider right for protection against retaliation. Have felt unsupported by HDC when retaliation has occurred.
- While Code says that a person should not be adversely affected by making a complaint, does not happen in practice
- Not just in the Code, but in the approach, raising support
- Making a complaint is a lonely process and needs to be done in different ways around the individual's needs. Feeling supported all through the process. Dejected when turned down, but if someone touches base then can be supported
- Navigation can extend to providers - need to support and understand how will unfold
- Yes, should be protection against retaliation. Needs to be very clear and very explicit provision. Needs to spell out what retaliation looks like and what you can do if that happens. Sometimes there is an implied threat - needs to be clear that this is just as bad.
- How do we define retaliation?
- Sometimes ending therapeutic relationship is in the best interests of all
- There is no screening for clearly vindictive claims
- What can we do to protect everyone's mana
- When people make a complaint - often there is a lot of information / but the key issue is just one part of it but they include a lot of their own experience and it can be very damaging for the provider
- There isn't an alternative process for a consumer to just vent and relay their experience
- When providers are reading the complaint letter - there is a significant personal impact on the individual provider
- Have we lost a bit of balance?
- Providers are also vulnerable and want to correct what has happened / learn from complaints
- Preference is for consumers to go to providers with their concerns first. But reality is that people often won't
- Can HDC have a more restorative process - have kaumatua supporting both sides in a process. Swap stories about how each side is feeling. Finding a way forward for all parties.
- Would hate to see more time added for the consumer. Need to keep the system moving
- Keep timeframes in Right10
- What processes do we have for supporting people when we aren't taking action on their complaint?
- The hui a whanau process should be available to all consumers

- Should there be an opportunity throughout the entire process for hui a whanau to be included
- Current process is very narrow/procedures - assessment→ complaint Y/N
- Consumer experience (particularly women), get frightened when approaching a provider about a concern e.g., medical injury with a particular medical advice and procedure, adverse event. They can be advised, its in their head, they are fobbed off, its mental health and its their problem (not the provider). This traumatises the consumer. And the idea for them to resolve the issue with the provider. But they would back off from this. So it should be an idea but not required for them to go to the provider.
- Advocacy service will provide support to consumer and where the complainant's concern has been minimised or notes made about them they can go to an advocate to resolve.
- Advocacy isn't always able to resolve the issue but will work with the consumer in writing a complaint and identifying the issues (usually listed). Provider must respond.
- Safeguards; structure provided by advocacy.
- How can you complain to the very people that have wronged you. What would help, they should have someone neutral, to lodge the complaint with the provider. They feel disempowered / discriminate and already on the backfoot.
- Sensitive case - need to be aware of process, be able to have information to provide safety
- No - shouldn't be required. But recognising that attempting resolution is likely to be a better outcome but may not be a realistic process for people
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- No, don't think there should be a requirement to go to providers first. Most people have tried to resolve things without making a formal complaint. Just lengthens process. Very disheartening for people
- Should have easier process for lodging a complaint
- People often think they've made a complaint because they've had a conversation with an employee of the service - but then there is no record of it
- Lack of clarity around what a formal complaint looks like
- Just having a conversation with a support worker is not a formal complaint
- Very unfair to expect this of consumers
- People need to be assigned an advocate to support them to know where they can take their complaint and distill their complaint to issues that can be addressed
- Should have a central point of contact across the whole system
- Hard no for trans and gender diverse community - having that as a requirement is not feasible
- Very personal and intimate situation
- Would be a barrier for consumers if they were required to lodge a complaint first with providers
- Greater clarity about process overall is needed.

Advocacy services

Questions:

- What is your experience of how well the advocacy service is working for people and providers to resolve complaints?
- What do you think are the most important changes that could be made to strengthen advocacy services? Why?

- PVI - Most have never heard of Advocacy Service before. A lot parents don't know that they are entitled to access this service
- Aged Care - aware of Advocacy service. Often direction of HDC to utilise Advocacy service
- Many people are not aware of Advocacy Service.
- Parents/other whanau member making complaint on behalf of child
- Midwifery - mixed level of knowledge of Advocacy Service. The way the service is understood - some people don't want the same thing to happen to other people. The way the service is described is quite important. Many complaints HDC receives might be better managed by Advocacy Service. Public perception might have a different view of Advocacy and what they do.
- HDC will sometimes refer matters into Midwifery resolution process. We need to socialise these processes more and make them more accessible to people. HDC full investigation is long and time consuming /within a legal framework / not satisfactory outcome for consumer or provider - as it does not result in an outcome where people feel validated.
- Would be good to see what people understand about the Advocacy Service.
- HQSC - Advocacy can be more whanau centric and whanau accommodating.
- Māori don't have a lot of trust in the process. Many Māori when things are not going good- vote with feet and walk away
- I have had a personal experience in making a complaint and did not feel supported in the process. First contact by provider with patient to talk about the complaint process and advise on who can advocate for them.
- People would want to make the complaint in person (face to face) rather in writing. Wanting someone to listen but not react to emotions
- Some people who have a negative experience (or less than satisfactory) with HDC, rightly or wrongly the person feels that the advocacy service is not independent. And don't have confidence of independence in the process. They see the advocacy service as part of HDC and under its umbrella. Compounded by HDC decision such as NFA, or lack of outcome.
- Its a view through word of mouth, that advocacy services is 'just part of HDC'.
- Get providers through their lawyers delaying the process
- How well do providers understand the role of the advocates so that they know how can best work together - socialise the advocacy service with providers.
- Have had good experiences with advocacy, an ideal opportunity to strengthen advocacy service to address some of the issues raise - re-thinking how use advocacy services a good opportunity

- Previous advocate used to present to staff orientation. Consumer rights not compulsory training in hospital. Not just rights, but how to respond when rights are breached. This might prevent issues before they start. NB Health and Disability Standards require some training (audited against) - role for greater education / embedding and reinforcing - could the Act be strengthened in this regard?
- Advocacy service includes networking and engaging with communities and providers.
- Alternative dispute resolution HPPCA reforms
- Peer support resources to grow a greater diversity of peer support frameworks that can grow advocacy capability within marginalised communities and use advocacy services as training the trainers within diverse groups, to support breaking down the barriers and whakamā that goes with needing to rely on professionals to support - is a framing thing. In Māori and disability communities would rely more on whānau. Being able to funnel resources
- Formal data sharing between quality agencies - is that being used effectively? EG if a complainant went to a provider, does that translate as an adequate resolution of complaints / shared record.

- Go into the community and advise them - this will empower the community concerned. And not just wait for the community to receive the information from the provider. How do we get the information to the community, so they are fully aware?
- Advocacy services give presentations to the community and to health providers. Anybody can request advice/information on how to resolve issues with health provider. How do we identify and who do we need to go to and put ourselves (advocacy services) out more? The problem is if groups don't know we exist.
- Lived experience - there is a sense they are alone so when going to advocacy connecting with someone who has been the same situation or is of the same culture and are talking to someone who understands their context. Feeling not alone that they are not the only person going through this.
- How can we get the word out about advocacy services. Other community groups/agencies could promote more on media platforms e.g. website.
- When support by advocacy is offered, follow up would be important. You're feeling isolated and alone, the advocacy can endeavor to link the person to a support group. Be great to get to more groups but constrained by numbers of advocates (reach / time).
- Advocate means (for nationwide advocacy services) is walking alongside and being supportive of the process, making it timely and how the person is doing.
- Does the term advocacy need strengthening to enable people to engage with the service. Health literacy is an advantage and if you don't have it (or the privilege) how do you get through this and how do you get support.
- Advocates have contacts with providers and can provide immediate support but only works if the person knows to reach out. Should have advocacy number showing.
- Funding - with increased funding comes increased coverage and increased communication that the service exists for everybody
- AgedCare - with growing vulnerability and cognitive impairment - having better working understanding of these factors. Developing better relationships and what Advocacy can offer. Building knowledge around their service.

- Are there currently people with lived experience who can provide culturally responsive service?
- Skills and expertise need to be responsive no matter who is accessing it.
- Rainbow whanau - just won't engage / not worth the hassle / would rather just walk away / barriers to access
- The options for strengthening service in the paper - making sure that needs of Maori are met is essential to meet Te Tiriti obligations
- Need to look at promotional mahi and what that looks like. WE need to prove that we can be trusted and welcoming. That consumers will be safe when they come to us. Need to do better in marketing. HDC/Advocacy needs to be more visible / better PR. Nobody wants to come to HDC/Advocacy at the moment.
- Something has to be done so that people feel like they can come to us.
- When you start looking at pieces of legislation - we are not looking at it and specifically add Rainbow community. Everyone should already be included. Shifting perspective of whole framework.
- How is Advocacy integrated into the system - hasn't been offered to anyone am aware of. Seems like a parallel process rather than being offered off the bat. How well is it resourced, how well is it responding to tāngata whaikaha Māori / tāngata whaiora May need some or a lot of support and if haven't started with Advocacy then won't have that support. And can feel like haven't had resolution if haven't had advocacy support from the beginning.

HDC decision-making processes

Questions

- *What is your experience of how well HDC's complaints resolution processes support timely and people-centred resolution?*
- *What legislative and non-legislative changes do you think are most important to support timely, people-centred complaints resolution? What impact (positive and negative) do you think these changes would have?*

- Personal experience was that the process wasn't people centred and felt double traumatised by the process. The HDC report when it came out, it felt judgmental. E.g. the complainant is a snr lecturer (and RN) but was described as a big Pacific person (this person was pregnant). This experience was traumatising. Motivated complainant to take this experience and turn it into a learning experience for the sector focussing on Pacific peoples experiences (through PHD study). Need people to understand what the complainant is going through. Why would you have a male for example talking to a woman who has lost their baby? It wasn't human centred, it didn't give relief. Wants to make it a safe journey and empowering for the person (complainant).
- Processes: face to face always has value over written process (e.g letters, reports).
- HDC process is paper based. You don't get a sense through written words and can trivialise and demean the experience(s) of the complainant.

- There is inconsistency for serious complaints with decisions (of HDC). The process does take too long.
- A perception that the HDC is more likely to accept the provider's version over the complaint. And is exacerbated by the inability for the complainant to respond to the provider's response.
- Is there ability in the current system/process for HDC to check in with the complainant to make sure they are okay?
- (Kylie noted the hui a whānau process recently adopted within HDC - enabling connection with the consumer)
- It doesn't matter what the complainant has gone through but if they are looked after and their questions have been answered (this is better).

- Had some good experiences of the advocacy service and support whānau
- Timeliness and people-centric not necessarily the same thing
- An observation is that is invisibility in the initial stages of investigation. Initial inquiry and decision not visible - when does the clock start ticking. Includes how the HDC and medical council interact
- Experience of supporting people through the process is that may have addressed the nuts and bolts issue of the complaint but haven't really addressed the systemic issues behind that. The nature of the complaint process is about specific errors directed at a particular clinician or service rather than systemic. Eg acts of omission where noone provides service, or practice that has become normalised. Unfair to peg on one.
- Only 5 trilingual sign interpreters in country. What are the changes of someone getting access to the service / communication they need. Address issue not solve the problem

- Provider perspective - timeliness is a big issue. Very difficult on whanau and providers. Some have dated back 3.5/4 years ago. Prolonged trauma for everyone. Anything we can do to improve that - whether it is mediation/advocacy - it is not helpful at the moment for anyone. Acknowledge that there are a lot of reasons for this - but strongly advocate for better communication during the process for each party.
- Cleansweep of the whole process and start again. Just feels that we are regurgitating a system that is already there. Many Māori do not like the process. It takes years. What are we going to do about it? Legislation does not move very fast.
- Multiple forms of investigation - Coroners/Acc/HDC/Internal investigations/Mortality and morbidity reviews. People are often traumatised by going through multiple processes - they all work in siloes and feels like it prolongs things. Everyone comes from their own perspective - needs a more cohesive system / single point of contact? People get caught up in going round and round in circles. Not productive - and very resource intensive. Each process can find a slightly different outcome. Different views - things can hang off the expert opinion - sometimes these are inconsistent. Every process has a slightly different focus.

- A factor in HDC decision on no further action (NFA) or when making a decision is the 'time' from when the incident/issue occurred. Example. Had a complaint about a provider (included ACC) about reconstruction surgery. But was exhausted, and 3.5

years of lack of physical function and didn't have the emotional resilience and head space to make a complaint at the time nor did the person want to put at risk the medical treatment they were receiving by making a complaint during this.. 2nd example of whānau member who passed and the person's whānau realised something occurred to their whānau member that resulted in them wanting to complain but this was over a year (so time had passed). The process needs to be cognizant of this.

- Face to face engagement in legislation.
- Some people realise retrospectively they should of made a complaint at the time or shortly after but for various reason's make the complaint down the track.
- Confusion over the term complaint resolution. May not be resolved. Perhaps some thought is needed around the title.
- No-further action - always actions that can be done. Not people-centred language. Related to that is jurisdictional boundaries. Can be a human rights issue and then drop. If took an interdependent approach / no-wrong door approach could run parallel or join
- As a rule would be useful for HDC to find ways to work together with other agencies in a more seamless way. Somewhat binary. Potential to review. Gives impression that agency not interested, when just waiting.
- Greater opportunity to address complaints at a local level. Perhaps people are bypassing providers. Embedding a more restorative approach within providers could support this.
- Accessibility is important with complaints management. Especially in rural areas where no internet or computer access. Support idea that arbitrated locally - continuum of where can escalate complaint. Should have consistency across advocacy for supporting direct to provider complaints. Advocacy supported resolution is much more people-centred, whereas the process at other levels are much to paper-centric
- Timeliness and people-centric can be enabled by enabling and empowering consumer with good information to understand the process
- Assume maximal wrap-around support is the starting position. Notification approach with assumption that need an advocate to help frame and form and decide whether could be made locally or needs to be escalated and that support stays through that process. A lot of people don't want to make a formal complaint but want something on record. May be Te Tāhū Hauora notification processes.
- At the moment - the only family member that can do something on behalf of someone else needs to have legal standing to do so. Can exclude whanau. It's not always the parent / depending on family might be the older sibling etc. There is no current process that recognises that it could be any family member that is speaking on behalf of a loved.
- No process for just letting HDC know - you have to make a formal complaint.
- Needs to have a process that is not so over the top formal
- Process is really onerous and takes years
- Legislation - changing can be a long process. HDC process all feels too hard at the moment.

- Setting expectations at the beginning about what could happen. How much time at HDC is spent preparing whanau about how long/how complicated the process might be?
- Natural justice applies to both provider and complainant
- Consumers need a lot of support to go through the process - it is very draining and needs to be looked at very carefully.
- Using people centred language - expand application of mediation conference. Feels like replacing it with facilitated resolution/conciliation is just changing language/tinkering - not meaningful change/tweaks around the edges / not actually changing the substance of the process. This is not a fundamental shift.
- Introducing provider/consumer surveys - one of the problems with this is people will rate the service really highly but it will not have anything to do with whether the service is any good. There is value in these - but would recommend caution as it depends what the person's bar is.
- Māori whanau will often rate a service very highly even though comparatively they have received a poor service

Additional reflections on complaint resolution processes

- HDC provider and consumer feedback surveys. They dropped off in 2016. *An experience survey has been introduced that asks questions to support quality improvement, including communication*
- When go through HDC website, there is no definition of complaint – could set out for lay people to understand

Options for a right of appeal of HDC decisions

Questions:

- Do you think the current pathways to challenge an HDC decision are adequate? Why? / Why not?
- What options to challenge should we consider?

- Position set out clearly in the submission of the Cartwright Collective. Believe need the right to appeal. Is a matter of natural justice. Understand difficulties and
- Not in favour of the courts because people who don't have financial ability / resources will not
 - Support Internal review, but would need an independent body who was not involved in the original complaint
 - ACC no fault system means that consumers seeking remedy can't get it. This a robust reason why need appeal.
 - An appeals process would not just be for complainants, but for providers
 - Not in favour of the HHRT just being about just investigations because there are no further action decisions that, certainly in the past, have been seen to be unfair where serious harm has been done to a consumer, in some cases, involving death or long term disability. If to lower the threshold then should include NFA

- I strongly agree that appeals should not be a court based approach as it will be inequitably available and resource intensive. It could include an independent assessment of the finding which includes legal, professional and consumer advocacy perspectives
- If complaint is declined needs to be for a good reason. Needs to be a process for review or appeal. Not everyone puts down all the information necessary in a complaint. Was an issue with staffing at the time, but not revisited.
- In experience of Court appeals process, tend to refer back to decision-maker. Merit in considering a robust internal review process with timeframes and criteria, with an independent person identifying grounds and redirecting to HDC or having potential to make decisions themselves.
- Should be an internal audit process over decisions to see if met objectives and whether things that can be improved. First review should be internal and then other opportunities for escalation to Ombudsman, HRRT. Don't like linking to court processes. Either the Code has been breached or not.
- Internal review processes would need to have an independent consumer advocate and independent supporter to be part of that review who knows nothing about the complaint and process that has been through who can bring a set of fresh eyes and consider whether the decision was fair.
- Processes are hard enough if educated, know the system, can stand up for themselves.
- Consumer voice in a review process important – eg consumer advisory group to support/review process. Will need to think about privacy.
- Offer of mediation could be used to help support maintaining the relationship and also allowing the perspective of the provider
- For those who have been 'successful' – what is the outcome for people? Can still be traumatic for people
- Kaiāwhina navigation service walking alongside consumers and whānau through any of the process, whether directly with provider, with HDC, and could include a review and/or appeal process.