

Feedback on the Review of the Health and Disability Commissioner Act and Code of Health and Disability Services Consumers' Rights

This is to declare my submission to the HDC for proposed changes to the Act and Code. I Sarah Brodrick declare this submission for the review of the Health and Disability Commissioner Act and Code of Health and Disability Services Consumer's Rights 2024. No Artificial Intelligence has been used in the writing of this submission, although I do make comments about (AI) at the end of this pdf document. My opinion and findings in this submission are based on my consumer perspective navigating the HDC Complaints Resolutions Process and reviewing the latest reporting from the HDC. My proposed recommendations are based on suggestions to provide better support to the Health and Disability Commissioner's Office and the Nationwide Health and Disability Advocacy.

I am highly concerned about the future viability of the HDC and long-term sustainability. There are some major problems that the HDC internally has and foreseeable challenges over the next financial year. The most pressing concern is that the infrastructural issues the HDC has will continue to negatively impact capacity and capability within the HDC, that will cause further internal pressures on staff and impact the service the HDC provides to both consumers and service providers. I also have concerns about decision making regarding financial management, funding allocation and adequately resourcing staffing numbers appropriately that reflects internal key performance indicators against external demands.

Post covid there have been major disruptions across our Public Healthcare system, including legislation and policies which include funding cuts and staff redundancies health & disability sector wide. The HDC needs to address the underlined issues and keep applying pressure to the Coalition Government for funding and more support.

This submission is also my response to the Provisional Findings Letter dated 17.05.2024 from the Ombudsman's Office in regards to an existing complaint against the HDC and the Complaints Resolutions Process. A final decision outcome is currently in the process of being finalised in regards to a formal complaint I made against the HDC to the Ombudsman in 2023. The complaint is relevant to this submission in the context that the issues I experienced within the HDC's Complaint Resolutions Process, form part of my suggestions for improvements as part of the current HDC Review of the ACT and Code. This has been a therapeutic experience, as I've been able to form a better understanding on my own behind the issues that the HDC are currently experiencing including the HDC Complaints Resolutions Process.

I hope that this submission will close my complaint in a mana enhancing way that will support the Health and Disability Commissioner and the Nationwide Health and Disability Advocacy with future improvements.

All the very best,

Ngā manaakitanga

Sarah Brodrick

Sarah Brodrick

Feedback on the Review of the Health and Disability Commissioner Act and Code of Health and Disability Services Consumers' Rights 1.1: Did we cover the main issues about supporting better and equitable complaints resolution? Sarah's response: No

IT Infrastructure/Capability

The HDC has the ability through the Complaints Resolutions Process to contribute to better health outcomes for all New Zealanders by resolving complaints in a mana enhancing way which seeks to build whanaungatanga through a people-centred resolution. An HDC proposal to upgrade HDC's digital systems to be in line with current Government expectations was unsuccessful. This is concerning because an external review of HDC's processes undertaken in 2022, identified significant barriers to increasing the Complaints Resolutions Process efficiency due to outdated IT infrastructure. The unsuccessful bid is problematic for the HDC because post Covid, the Complaint Resolution Process is not sufficiently resourced in terms of staffing, clinical input and IT capability to be able to meet the increased demand. I will provide further insight of the issues from the consumer perspective in my submission as to why it's simply not feasible to ignore the infrastructural needs of the HDC.

Increase in demand

The HDC's undertaking process change is due to an increase of 43% in complaint volumes over the last five years and an increase by 36% pre-COVID-19 numbers. A significant increase in the volume of complaints means that the HDC receives more complaints than the Complaints Resolutions can close, and this has led to an increase in open complaints. The latest HDC Annual report shows in 22/23 that an internal target of between 4-6% complaints open for no longer than 24 months was not achieved for both years. As of 30 June 2023, 2342 complaints were open files and 11.4% of the total, 267 complaints were still open after a year. The latest figures predict the next financial year will increase demand due to complaint volumes, kpi's each year post Covid and expenditure. The Coalition Government drives an expectation for the HDC to deliver better outcomes for less money, however this is more difficult if out-dated technology is behind existing inefficiencies. A responsible government would set expectations that are achievable for a public sector agency that supports the wellbeing of staff.

Reform/Policy

It's a consistent pattern for past governments to not properly invest into infrastructure, to withstand the demands of advancing technology, migration into our country as well as meeting the needs of New Zealanders. When there is a change of government with the repealing of policy and further monetary investment into new legislation, the New Zealand people suffer as our infrastructure fails to create the long-term stability that our country needs. At present the Coalition Government is addressing underlined issues with electricity supply and demand that associates high costs to businesses and consumers. IT Infrastructure requires a high supply of electricity, and I believe New Zealand is currently in an energy security crisis. I urge the Coalition Government to reform the electricity sector and address the inequities including inflated profits by power companies, to support the future investment and growth of our public sector agencies.

Financial Positioning

I urge the Minister of Health to power-up the HDC, by supporting a business case to seek capital funding to secure the IT Infrastructure needed. This will help the HDC to better manage the Complaints Resolutions Process with modernised IT capability, internal systems, reporting and to deliver better outcomes for consumers, service providers and communities across the motu. I don't believe the HDC is currently in a

financial position to be able to manage additional costs such as electricity bills that new IT Infrastructure would require without the reform of the energy sector, significant funding & future cost analysis. The HDC Statement of Performance Expectations outlines what the Health and Disability Commissioner is forecasted to achieve in 2024/25, how this will be assessed, the associated expenses and revenues generated. The HDC earlier this year started the process of finalising the operational budget for 2024/2025 financial year, with an unexpected fall in funding which factored in a letter of expectation received by the Minister of Health. The latest HDC annual report shows a 16.5% decrease in funding forecasted for the next financial year.

Accountability Measures for Funding & Resources

On the 30 May 2024 in Budget 2024, the HDC was informed of a 2.9 million reduction of crown funding. This is a significant amount of money to lose in Budget 24/25, considering the total crown funding for the financial year 22/23 was \$18,944,000. What's concerning is that the HDC spent 65% of the total budget on staff wages and salaries alone, with over 33 HDC staff are on salaries with a starting scale of 100k and upwards of over 300k and the HDC paid out over 2.5 million to the leadership team. Since 2022, the HDC has seen an increase of 2.8 million in employee payments. This is set to increase by a milion dollars in budget 24/25. I am concerned about the 16.5% decrease in crown funding and the impact of funding allocation to resources, including staffing that supports the Complaints Resolutions Process because of past expenditure behaviours by the HDC.

The HDC relies on two Clinical Navigators with heavy workloads, to provide support to consumers across the country, whilst triaging complaints and providing clinical input to Investigators, as well as flexibility to respond to the wider needs of the HDC. I question the sustainability and scalability of this role given the low number of Clinical Navigators recruited to support the HDC.

Clinical Navigator Role

- Reviewing complaints, clinical records, and other information in order to assist complaints resolution and investigation teams with the identification of clinical issues, and gaps in clinical information.
- Assisting to progress complaints relating to older people through suggesting and taking part in quality improvement activities.
- Working with providers if more information is required to resolve the complaint. Navigator (Aged Care) August 2022
- Working as part of the Aged Care team and in partnership with the Complaints Assessment team, Investigations team, Legal team and Clinical Advisor team.
- Facilitating interactions between consumers and providers if kanohi ki te kanohi (in person) meetings are requested.
- Developing and maintaining effective relationships with all HDC staff.
- Perform any other duties as needed by HDC

Clinical Navigator: Issues

- 20% of complaints are from our older population in regards to Aged Care
- A Clinical Navigator cannot be made by request from the Complainant
- There are only two Clinical Navigators employed full time and on a permanent basis for the entirety of the New Zealand population
- The existing role sits under the Aged Care Team, so is limited

- Navigators assist HDC staff to identify any concerning clinical aspects of complaints. For example, they are involved in the HDC ‘triage’ process to identify issues which may not be as clear to someone with limited or no clinical experience.”
- Navigators may reach out to a complainant when the HDC identifies that the consumer would benefit from talking to someone with the experience required to understand and discuss clinical issues, as opposed to a complaints assessor who may not have the requisite clinical experience

Complaint Resolutions Staffing Resource

The existing mechanism of the Complaints Resolutions Process reliance on Clinical Navigators to triage complaints and provide clinical input to complaints, because the investigator team doesn’t have the same capacity to be able to understand or interpret clinical information within complaints, could be a contributing factor to delays with response times, or complaints being dismissed, and sent back to service providers, or the Nationwide Health and Disability Advocacy to resolve directly with the consumer.

- I propose the integration of staff with relevant healthcare experience across a diverse range of areas across the sector recruited as Investigators within the Complaint Resolutions Process, to help resolve complaints in a timelier manner. The diversity of health and disability issues across New Zealand, I believe requires the HDC to be powered-up with staff that have relevant experience from the health sector to be able to triage, investigate and make appropriate decisions based on the clinical correspondence which is included in complaints.

The HDC’s Investigator team would benefit from diverse expertise from the health sector that doesn’t detract from other resources, which could be best utilised elsewhere. By ensuring the Complaints Resolutions Process is adequately resourced, the HDC will be able to deliver better outcomes with the inclusion of a more people-centred approach. Healthcare professionals understand the issues that both consumers and service providers can experience, but also have strong interpersonal skills, and values such as empathy and compassion, that I believe are hugely important when responding to complaints and seeking mutual resolution.

Resourcing the Nationwide Health and Disability Advocacy

I am concerned that the 16.5% decrease in crown funding will further hinder the HDC with issues around staff resourcing to support the Nationwide Health and Disability Advocacy. The HDC must find efficiencies to drive better outcomes and one of the ways the HDC is achieving this is by utilising the Nationwide Health and Disability Advocacy to provide “early resolutions”.

Total Enquiries	24506	Total Complaints	6210	Closed Complaints	6028
Advocacy	21738	Advocacy	2857	Advocacy	2980
HDC	2768	HDC	3358	HDC	3048 16% increase

2022/2023 the Advocacy

- 1,314 advocacy education sessions in comparison to 38 HDC educational sessions
- 3,351 visits and meetings with community groups and service providers
- achieved high satisfaction rate, with 95% of consumers and 95% of providers satisfied or very satisfied with the complaints management processes

The Advocacy spend for the budget ending June 2023 was \$3,688,000 and although given a significantly less financial spend, outperformed the HDC in terms of the number of enquiries, educational sessions, visits and meetings against volumes of complaints, versus the closure of complaints against the quality of service from both consumers and service providers, as per the statistics provided in the HDC's latest annual report. The high-output from the Advocacy service shows that the team are delivering excellent outcomes for the allocated budget. However, I question the targets given to the NHDA around closing complaints, as I believe the threshold should be reduced.

Advocates do not have the same skillset or experience in closing complaints that the HDC does, their roles are limited in how much influence they have to close complaints, their roles are diverse which include driving educational outcomes, and the team rate of enquiries is significantly much higher. I would expect that there would be issues with the NHDA not being able to achieve internal targets set and propose the leadership team sets more reasonable targets for the NHDA which takes into consideration their current resourcing capability. Based on the above figures, and the staff numbers at the Advocacy Service of less than 30 staff, I am highly concerned about the internal pressures on the NHDA to increase capacity without the support of the Coalition Government.

It is simply unreasonable for the HDC leadership team to increase the work capacity of the NHDA because of the inefficiencies that the HDC's Complaint Resolution Process is producing without providing resource to support the additional work that will contribute to internal pressures in the future within the Nationwide Health and Disability Advocacy. The annual report states that the HDC are aware of the current lack of support within the NHDA and puts the onus on the government. This is simply not acceptable that the HDC leadership hasn't considered other options of resourcing the NHDA, as the HDC holds the NHDA contract. I urge the Minister of Health to please invest further in the Nationwide Health and Disability Advocacy, by increasing funds for the service, you will enable the NHDA to increase it's capacity to achieve more.

NHDA Greater Powers to deliver "Early Resolutions"

I propose a review of the Advocates role in regards to the HDC's Early Resolutions strategy, as I believe the Advocacy service needs greater powers, skill set training and better accountability measures to fully optimise the Nationwide Health and Disability Advocacy.

- Advocate role is not for the purpose of mediation or investigation
- Advocate role is not for the purpose of understanding or interpreting clinical information within complaints
- Advocate role doesn't have the same level of skills that the HDC Complaints Resolutions Process
- Limited staff numbers to provide support to the HDC

NHDA: Consumer Feedback

Despite the high satisfaction rate from the NHDA I question the mechanism used to collect consumer and service provider feedback. I propose an automated questionnaire which is more cost effective than money spent on recruiting a staff member independent from the NHDA to manually call thousands of consumers and service providers. As the consumer I was phoned but was unavailable to answer, so I was emailed directly instead to provide feedback about the service provided by the most recent Advocate, but the questions were very brief and limiting. I question the quality of the information being collected from consumers and service providers.

- NHDA can use monkey survey which has a free element, rather than paying a staff to invest many manual hours and efforts into calling people and service providers who may not be fully available to speak at the time.

- NHDA could target the ageing population and anyone who has disclosed specific requirements around communication for the NHDA to call directly.
- NHDA can easily populate multiple questionnaires, and send out to a diverse range of demographics, as well as retaining the responses of consumers and service providers to whom choose to provide feedback

Disability Sector/Accessibility issues

I'm concerned about the HDC's funding to support disability issues, which has been allocated to the reporting, measuring and monitoring of Tāngata Whaikaha.

- There is inequity within the Complaints Resolutions Process for Tāngata Whaikaha as there is no support. I propose Clinical Navigators are also considered to support Tāngata Whaikaha who would largely benefit from having health professionals who would be able to provide a more accessible service to complaints resolutions.
- HDC's approach with probing, monitoring and reporting would be more welcomed, with a balance of addressing the accessibility barriers that Tāngata Whaikaha experience within the Complaints Resolutions Process.
- HDC have an emphasis on delivering better health outcomes which includes the approach and support provided within the Complaints Resolutions Process
- HDC to ensure that the mechanisms being used for disabled people, take into consideration advice from the sector and also from differently-abled people ourselves, decisions made with us, not without us.

Can the HDC please include the total number of complaints about disability issues across all health and service providers, and not limit reporting just to disability support service providers. In 2022/23 the HDC received 101 complaints about disability support services providers, and the issues complained about were:

- Inadequate care and support provided
- Lack of access to services and funding
- Failure to communicate effectively with the consumer and their whānau
- Inadequate staffing levels or rostering concerns
- Delays in treatment
- Inadequate coordination of care 25% of complaints are disability related

Māori Resolution

The HDC has reported high numbers of discrimination, structural inequities and accessibility barriers in prioritising healthcare needs for Māori wāhine which is reflective in my personal experience since the Covid Pandemic, with my own healthcare. I've never received any support within the HDC Complaints Process which has responded to my complaints using a culturally appropriate mechanism such as incorporating people-centered tikanga practices, for example consultation within the resolution process that is mana enhancing. Moving forward I'll be more weary about sending complaints to the HDC.

There is a lack of engagement from Māori with the Health and Disability Commissioner's Office, and honesty I don't blame our people, as the HDC's Complaints Process doesn't provide an appropriate cultural response to meet the diverse needs and issues of Māori. There has been the introduction of support services for our people, however it's limiting and targeted to a selected few. Our people need better visibility and collaboration from non-Māori to work together to eliminate the barriers we have that diminishes our mana.

Comments made in the HDC June 2023 Annual Report

1. Inclusion of cultural advice early in the complaints assessment process

This is misleading in the context of my experience

2. Providing people with an option to receive cultural support/oversight with their complaint

This is misleading in the context of my experience

3. Implementation of a hui-ā-whānau option for Māori consumers and their whānau

I wasn't made aware of this service until I read the Review of the Act & Code of this option for Māori consumers.

4. We also made several recommendations to improve cultural safety. These focused on improving knowledge of tikanga and other important cultural practices, maximising use of existing cultural support channels for Māori and their whānau and strengthening culturally appropriate complaints resolution options offered by providers.

I was never provided with any appropriate complaints resolutions options

Recommendations:

- I propose a Complaint Resolutions Process with an equitable and appropriate cultural responsiveness to Māori.
- The recruitment of Māori into front-line roles to respond and resolve complaints within the HDC as we have the poorest of health outcomes.
- The recruitment of Māori into front-line roles to deliver education outcomes for our own people which can be communicated in a culturally appropriate way including the location options
- The recruitment of Māori excellence into HDC senior leadership positions
- I would like to see funding allocation with an increasing investment in HDC's options for complaint resolution including the Hui ā-whānau process led by tikanga and Hohou te rongo, using principles and values from Te Ao Māori, with a focus on delivering education and support.

Advocating for a Complaints Resolutions Process

Te Whare Tapa Whā

That considers the wellbeing of both staff, consumers and service providers: the four pillars

- taha wairua/spiritual wellbeing,
- taha hinengaro/mental and emotional wellbeing,
- taha tinana/physical wellbeing and
- taha whānau/family and social wellbeing. Our connection with the whenua/land forms the foundation.

Code of Consumer rights as core values as the foundation of the Complaints Resolutions Process for staff to live and breathe, when making decisions about complaints.

IT Infrastructure that holds the four pillars and all that is embedded into protecting the rights of New Zealander's and delivering better outcomes in a mana enhancing way.

Targets

The HDC has reported on page 63, 35% of the total volume of complaints were sent back to the consumer and service providers to resolve. However there's conflicting information provided in the report, as on page 28 of the report 35% 1219 complaints were closed with no further action required. A total of 636 complaints were sent back to the service provider. The HDC suggested that within the 35% total, the team would often refer complaints onto the Nationwide Health and Disability Advocacy, however this is confusing, because on page 28 it states in a separate column that 477 complaints were referred to the Advocacy Service.

HDC Target Actual Performance

Target	60% complaints closed with 3 months	80% complaints closed within 12 months	95% complaints closed within 24 months	No more than 4-6% complaints open are over 24 months
2022	71%	87%	96%	6.09% not achieved
2023	66.5%	74.9% not achieved	93.5% not achieved	11% 267 not achieved

HDC Complaints Resolution

I am concerned that the HDC is using a dismissive approach to close complaints with a core focus on meeting internal targets and key performance indicators, over the quality of service being provided to consumers and service providers. There has been a high number of open complaints over an extended period of time, with internal targets not being met over the last two years. There has also been a high number of closed complaints being dismissed, with a lack of transparency around accuracy of figures. Based on the lack of surveying information by the HDC to provide transparency around consumer and service provider satisfaction rates, I question the HDC's conduct because I have no doubt that the leadership team are very much aware of the disruptions which are being caused to both consumers and service providers.

Service Provider Impact

A decrease in crown funding with increased costs to the HDC negatively impacts both consumers and service providers with dismissing a high number of complaints back to consumers and service providers to resolve without any support. Post Covid there have been major disruptions across our healthcare sector and more recently funding cuts including staff resourcing. Strained working relationships between consumers and service providers causes toxicity on the wellbeing of complainants and staff. It is also time consuming for both parties, and if the service providers are not equipped with a dedicated staff member or department that oversees the administration of complaints, then there could be further time delays in resolution which doesn't deliver better health outcomes for New Zealanders.

Dismissive Approach

- the lack of engagement from staff
- lack of access to appropriate cultural response for Māori consumers to resolve complaints
- the lack of support for differently-abled consumers with complaints within the Customer Resolutions Process
- lack of information around the qualifying process of complaints and understanding the qualifying of complaints alongside decisions made by the HDC within the Complaints Resolutions Process

- Overlapping issues with ACC, regarding consumer complaints made against ACC health service providers.
- disclosing personal information about the consumer's complaint to the service provider including the decision outcome letter without first informing the consumer
- The confusion the HDC creates with closing complaints and referring complaints back to the service provider and/or the Nationwide Health and Disability Advocacy
- Confusion around complaints that provide examples of code of consumer breaches aligned to the code closed by the HDC
- information provided to the HDC to support complaints not thoroughly reviewed, or the refusal to retrieve information on behalf of the consumer with disabilities due to health capacity
- No right to appeal the decision and by another staff member
- Ignoring the distress of the consumer from the issues raised in the complaint by closing the complaint by referring the complaint back to the service provider
- Lack of HDC checks on the wellbeing of the consumer as part of the complaint investigation
- The negative effects to the wellbeing of the consumer, and disruptions to service providers because of the existing Complaints Resolutions Process

Examples of consumer service

As a result of the HDC's refusal to provide support in regards to my disability issues by retrieving information to support my complaint due to my health and capacity at the time, to send all of the correspondence to the HDC. The complaint was closed and sent back to the service provider and at the end of last year I experienced retaliation from senior management which caused distress. The complaint is now sitting with the Human Rights Commissioners Office.

“Upon review of your outstanding concerns, I do not consider further action on the part of this Office is warranted. HDC reviews each complaint individually and considers the most appropriate resolution in the circumstances. This means that where a consumer has multiple complaints with our Office, the outcomes may differ. In this instance, we did not consider a formal referral to the Advocacy Service was necessary, however, we noted your preference to meet with St John and considered you may wish to speak with the Advocacy Service on this point.”

Despite the referral from a nurse at Healthline who called 111 St Johns Ambulance I was refused transportation to hospital because ambulance staff thought the symptoms, I was experiencing was mental health related and ignored my concerns of reporting the respiratory issues as an Asthmatic and levels of physical pain. I did require medical intervention that day and was able to get access to the medication I needed. As a paying member of St Johns Ambulance, I found the service on that morning to be unacceptable. The HDC dismissed this complaint and did not support a formal referral to the Advocacy service was necessary. I thought the response from the HDC was not culturally responsive to the needs of Māori, as we have poorer respiratory health outcomes than any other ethnic group in New Zealand.

“I offer my apologies as we conveyed to you earlier that the survey was anonymous. This was incorrect: although the information remains confidential, the information gathered from this survey is used to help HDC resolve complaints in a way that is appropriate to the complainant's needs. The information from the survey may be used to determine whether or not it is appropriate for HDC to refer a complainant to an advocate to assist in the complaints process. The survey is of course optional and it does not affect the assessment of your complaint if you choose not to fill it out.”

I am not satisfied with this response in an explanation in regards to a complaint about surveying information sent to me. The HDC's funding allocation has solely been focused on monitoring consumers that identify as having disabilities, nor is there any current HDC role to support complainants with disability issues within the Complaints Resolutions Process. I believe the survey was sent to me, so that the HDC could validate my disabilities as the questions asked were around my capacity in terms of if I could dress or shower myself, my physical capacity and the level of my vision impairment.

The questions were the same as those asked in the recent census. The HDC survey was identifiable, so if I had consented to participating in the HDC survey they would be able to use this information for its own purposes, without me being fully aware to what extent. I believe that this information should be collected by healthcare and disability service providers or organisations that require this information for the purpose of determining assessment, treatment or support services for tangata whaikaha. I encourage the HDC to review its current position and consider the dignity of tangata whaikaha and their loved ones, as I believe the questions were intrusive. If the HDC wants to survey consumers I believe that its reasonable to request from the HDC to ask appropriate and relevant questions in regards to the Complaint Resolutions Process. Ask service questions first, before asking any personal information. I'd also like to see surveys created that are anonymous as an option, rather than identifiable.

Nationwide Health and Disability Advocacy Service issues

I am dissatisfied with the current level of service that the NHDA Advocates provide. Despite the advocacy outlining the services to support consumers via the website, I'd like better regulated standards implemented to ensure that Advocates are actively engaging with the consumer and not withholding important information that could be of the benefit to the consumer. I've had the help of 3 advocates since the pandemic and overall, the advocates do not proactively talk about the support they can provide to the consumer, our rights and options as per the website when making a complaint about the service provider. There is very minimal interaction outside of writing the complaint letter and sending email correspondence, unless I prompt the advocate for additional support which I've found to be tiring at times. I've edited and helped to write advocacy letters in which the most recent one was highly exhausting.

“Dear Ms Manion As you are aware the Health and Disability Commissioner (the Commissioner) referred Miss Sarah Brodrick to the Advocacy Service in the hope we may be able to resolve the complaint between the parties. I am writing to advise Miss Brodrick does not wish the advocacy service to assist her to resolve the concerns with your service.”

As part of a privacy request I was able to get access to my file with the Advocacy Service. An Advocate closed a complaint because I didn't approve of the letter she wanted to send on my behalf to a service provider. As a result of going through my own personal information stored with the Advocacy Service a report that was sent back to the HDC by the Advocate of my request for the HDC to facilitate the complaint, stated that I didn't engage in the advocacy process which is a lie. I prompted phone calls to the advocate and engaged in email correspondence which I have a papertrail of. Instead of the Advocate providing an honest account of what happened, she blamed me and in-turn the Geneva Healthcare Complaint in the end was closed by the HDC. I would like to propose a procedural change which includes the Advocacy Service, disclosing the report sent alongside any referral letter to the HDC, to be forwarded onto the consumer because I don't believe it's fair to provide a misleading opinion of a complainant. As the HDC then can form an incorrect position of a consumer, based on inaccurate information provided by the Advocacy Service, in which I believe happened to me.

People Centred Approach

In 2023 I made a formal complaint about the issues I've had navigating the HDC Complaints Resolution process and was invited to meet with the Health and Disability Commissioner Morag McDowell. My negative experience with describing the Complaint Resolutions Process, as a dismissive and transactional process, was validated as the HDC informed me of the team being aware that the Complaints Process isn't people centred. During a second meeting with the HDC Deputy Commissioner Rose Wall responsible for the Disability Portfolio, informed me that the complaints approach stems from difficult Complainants, who have been abusive towards HDC staff.

HDC's view on a People Centred Approach

This closed mindset from HDC Leadership fosters a very toxic environment, as I don't believe it's fair, equitable or reasonable for the HDC's dismissive approach within the Complaint Resolution Process to be targeted to all consumers. I believe that you can apply robust safeguards to protect the HDC staff from poor and abusive behaviours from people, whilst treating consumers aligned to the Code of Consumer Rights throughout the Complaints process.

Sarah's response: "Complaint processes could be more focused on people; and Obligations in the Code for culturally responsive practice could be clearer" The HDC needs the support of the Minister of Health and Coalition Government to power up a Complaint Resolution process that is people centred focus, because the issues are people focused. I propose a Complaints Resolution Process which reflects the cultural representation of the diversity across New Zealand and supports the wellbeing of HDC and NHDA staff members to meet the demands with complaint volumes. This can be achieved by replacing the out-dated IT infrastructure and upgrading internal systems, recruitment of staffing and better allocation of HDC resources.

Amend purpose statement

Sarah's response: I support the proposed option to improve the Act to broaden its purpose statement for the complaint resolution, and recommend further changes

- To clearly separate people centred practices and Te Ao Māori. To clearly define people centred practices in the context of actions taken by HDC staff, within the Complaint Resolution Process, and Te Ao Māori Concepts for example 'mana enhancing' to be values that underpin the output.
- by removing the word 'simple' and inserting the words "people-centred"
- by removing the word 'speedy' and replacing with the word "timely"
- or removing the word 'speedy' and incorporating the timeliness of the complaint resolution, as part of the word 'efficient'. The word efficient can reflect in the context of productivity including time.
- by inserting the words "mana enhancing"

Additional Comments) Since 2021 there has been an increase in the volume of HDC complaints by 40% with a future forecast of 16.5 crown funding. This has contributed to the HDC being less resourced, and significant delays within the Complaint Process to respond and resolve complaints, which has impacted negatively on the quality of service, outcomes and complainants. I recommend that the Purpose Statement reflects a Complaint Resolution in our existing social, economic and geopolitical climate, and is future forward with being aspirational.

b. Clarify cultural responsiveness

Sarah's response: I support the proposed amendments to Right 1 (3) and the proposal to seek sector guidance to clarify cultural responsiveness, and to clearly define what is meant by inclusiveness and setting expectations of cultural responsiveness that align with sector standards.

c. Clarify the role of whānau

Sarah's response: I support the proposed changes to the Code, to clarify the role of whānau in the consumer-provider relationship and to help providers provide for whānau participation appropriately.

- Changing the wording in Right 3 (Dignity and Independence) from 'independence' to 'autonomy' to recognise the interdependence people often have with whānau and support networks.
- Strengthening Right 8 (Support) to include the right to have whānau involved, even where they cannot be present physically.
- Clarifying Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer.

d. Ensure gender-inclusive language

Sarah's response: I support the proposed amendments to the Code to ensure it is gender inclusive, and propose sector guidance

e. Protect against retaliation

Sarah's response: I support changes to Right 10 to include a non-retaliation clause to protect consumers and to encourage people to feel safe when making complaints and raising concerns.

f. Clarify provider complaints processes

I support changes to Right 10 to set more explicit expectations for provider complaint processes, including promoting the right to complain.

- I propose changes to right 10 to simplify and set clearer expectations for provider complaint processes, including promoting the right to complain and effective promotion so that processes are accessible for tāngata whaiora.
- Restorative practice alongside Kaupapa Māori services where tāngata whaiora can feel safe to be heard, raise their concerns and resolve these directly with other service providers.

g. Strengthen the Advocacy Service

Sarah's response: I've made a list of recommendations under what Non-Legislative Changes can be made to strengthen the Complaints Resolutions Process, and I've included the Nationwide Health and Disability Advocacy Service, and below are some further comments to support the Advocacy Service.

I propose changes to:

1. Funding & Resourcing Allocation

I firstly want to acknowledge the leadership team and every staff member at the Advocacy Service. As a New Zealander I am truly proud of the achievements by the Nationwide Health and Disability Advocacy Service. I am impressed with the level of high output and contributions by everyone at the Advocacy Service to support both consumers and service providers. I am concerned about the level of support and funding you are currently receiving considering the significant numbers in communication from consumers and service providers. I believe that the Minister of Health and the Coalition Government should invest significantly into the funding for the NHDA contract, because of the share volumes of complaints, educational lessons and visits your team are delivering across the country. I am also concerned about the awareness of the HDC's Leadership team with the lack of support the NHDA has, and would like the HDC

to be more proactive in finding other ways outside of government funding as alternatives such as I have recommended in this submission with aligning strategic partnerships with other ministries and organisations.

2. HDC & NHDA Accountability Measures

I'd like the HDC and NHDA leadership teams to review the existing internal targets to ensure that the Advocacy targets are reasonable and look at dropping the threshold to consider staff resourcing and internal capacity. To avoid burn-out or the negative effects from increased workloads and internal pressures I believe the Coalition Government has a responsibility to ensure that the crown provides adequate and appropriate support. I'd like to urge the Minister of Health to have better accountability measures in place, to ensure that any funding approved for the Nationwide Health and Disability Advocacy by the HDC is fair and reasonable.

3. Procedural Changes to the HDC and NDHA

The HDC Complaints Resolution closes complaints by referring to the Nationwide Health and Disability Advocacy in the consumer decision outcome letters but does not always notify the NHDA of the HDC's decision. As a consumer I've found the referral system between both organisations to be highly confusing. I've experienced receiving a response of a referral from the HDC of my complaint being sent to the Advocacy Service, and then another form of response where the HDC only notifies the service provider in the decision outcome letter about the encouragement of using the Advocacy Service, but where no formal contact has been made. I've had a response letter from the HDC notify me with an decision outcome letter which has outlined that the HDC didn't believe that a referral to the Advocacy Service was appropriate. The HDC has one approach to complaints, and the NHDA applies different approaches by Advocates to complaints dependent on the location, which creates confusion. The perceived lack of cohesion between the HDC and the NDHA, contributes to negative effects for the consumer like me, with feeling often at times stressed by the service, with trying to understand the HDC's Internal Complaints Process & the way the NDHA responds to complaints.

4. NHDA Consumer Feedback

Asking more specific questions in the consumer and service provider satisfaction surveys which are relevant to the service that an Advocate can provide. Asking questions relevant to the service which is stated on the Advocacy's website, if the Advocate has engaged in the process with the consumer. I believe that the Advocacy Service should send automated surveys.

5. NHDA Staff recruitment

Increase staff resourcing, which is reasonable, sustainable and supports the demands of the Advocacy Service

h. Improve the language of complaint pathways in the Act

Sarah's response: I support the HDC proposed changes with two slight changes.

- Changing 'no further action' to, for example, 'no investigative action' to be empowering and reflective of the work undertaken to assess and resolve the complaint
- Changing 'mediation conference' to, for example, 'facilitated resolution' to encourage broader forms of resolution such as restorative practice and processes led by tikanga.

Sarah's response: I'd recommend removing the word "empowering" as it's an overstretch for the HDC to use in the context that it's not considerate of the Complainant as there is nothing empowering about making a complaint and receiving a response to close their complaint with no further action.

- Changing 'no further action' to, for example, 'no investigative action' to be reflective of the work undertaken to assess and resolve the complaint

Sarah's response:

- I'd recommend removing the words "for example" and "encourage" to changing 'mediation conference' to 'facilitated resolution' to include broader forms of resolution such as restorative practice and processes led by tikanga.

Questions 1.2: What do you think of our suggestions for **supporting better and equitable complaint resolution**, and what impacts could they have?

Sarah's response: 1.2 I support the suggestions made for supporting better and equitable complaint resolution, however it doesn't go far enough. I urge the Minister of Health to provide more funding to the HDC to address the inequities, in particular the IT infrastructure, capability. I urge the HDC leadership to have targeted funding allocation which addresses the inequities for Tāngata Whaikaha and Tāngata Whaikaha Māori and increases funding to enable increased support which focuses on better health outcomes for both consumers and service providers.

The impacts of these proposed changes are:

- Improved complaint resolution processes can contribute to systemic changes by identifying and addressing recurring issues, leading to better practices and policies within New Zealand health and disability services.
- Investment of resources will better support the Nationwide Health and Disability Advocacy and the delivery of services to both providers and individuals to navigate the complaint process, ensuring they receive appropriate assistance

1.3: What other changes, both legislative and non-legislative, should we consider for **supporting better and equitable complaint resolution**?

Non-Legislative changes to consider for supporting better and equitable complaint resolution

Capital Funding

- Seek business sector advice in regards to IT Infrastructure/Digital systems.

Income Generation

- A surcharge for the HDC & NHDA delivering educational sessions to service providers as part of a complaint resolution outcome
- A donation option for service providers/events to contribute financially to the HDC/NHDA
- IT Infrastructure – business sponsorship, donations, discounted rates
- A donation option for consumers to pay a small fee. I'd pay \$5.00 to the NHDA for the support of an Advocate

HDC & NHDA Strategy

Educational Institutions

- To resolve funding issues around staffing resource, I propose that the HDC and the NHDA seek advice around the recruitment of students from New Zealand Education Institutions for work placement experience, to help temporarily fill the gaps in the HDC Complaints Resolutions Process, and the lack of resource the NHDA until further funding can be provided by the Coalition Government.

HDC & NHDA Strategy

Ministry of Social Development

- To resolve funding issues around staff resource I propose the HDC seek advice around utilising MSD job seekers/MSD Support Living Payment who are wanting to return to work.
- MSD has several financial supports including the training incentive allowance to help potential employees train and return to work.
- The HDC could look at a strategic partnership to recruit MSD job seekers for temporary work placements, based on their current skills and experience.

HDC Optimisation of Complaints Resolutions Process

Investigator position

- I propose that the HDC recruits' staff into Investigator roles with relevant experience within our health sector to empower, enhance and strengthen the existing Complaint Resolutions Process. This will provide better oversight and a more equitable process with having staff that can understand, interpret and make fair decisions regarding consumer complaints, and service provider recommendation

HDC Clinical Advisor

- Provide a Clinical Advisor role (HDC Internal) and a Clinical Navigator role (Complaints Resolutions).
- Revise the existing job description to a reasonable workload by providing two role.
- Allocate role of CN's to triage and qualify complaints to include Tāngata Whaikaha.
- Increase staff numbers to increase capacity and provide better support

Māori Support

- An equitable and appropriate cultural responsiveness to Māori.
- Measure reporting of every Māori complainant within the Complaints Resolutions Process. More engagement with Māori complainants/consumers.
- The recruitment of Māori into front-line roles to respond and resolve complaints within the HDC as we have the poorest of health outcomes.
- The recruitment of Māori into front-line roles for devolution of delivering educational outcomes.
- Further investment into the Hui ā-whānau process led by tikanga and Hohou te rongo, using principles and values from Te Ao Māori, with a focus on delivering education and support services through devolution and Kaupapa Māori approaches to deliver better outcomes.
- Increase staff numbers to increase the capacity to deliver Hui ā-whānau process led by tikanga and Hohou te rongo to support Māori

Disability Support

- Inclusion of Clinical Navigators also considered to support Tāngata Whaikaha as they would largely benefit from having health professionals who would be able to provide a more accessible and efficient service to complaints resolutions.
- Inclusion of HDC reporting numbers of consumers that have open complaints with disability issues that include all health and disability service providers, not just targeted reporting of disability support providers.
- Inclusion of HDC reporting numbers of consumers that self-identify as having a disability and what accessibility needs information provided to the HDC to support them during the Complaints Resolutions Process
- Seeking sector advice, including the inclusion of Tāngata Whaikaha in the decision-making process

HDC & NHDA Accountability Measures

- Accountability measures and targeted funding to hold the HDC to account, to ensure that the HDC gets the best value for every dollar spent against driving better outcomes
- Accountability measures for funding allocation to ensure that the front-line services of the HDC including staff recruitment, training, systems/policy and procedures for the purpose of delivering the services required within the Complaints Process, the Nationwide Health and Disability Advocacy are being optimised

Procedural Changes HDC & NHDA

- I propose a review of the procedures between the HDC and the NHDA to ensure there are clear guidelines between each organisation in regards to the referral of a complaint from the HDC to the NHDA and vice versa of a complaint referred from the NDHA to the HDC
- I propose for any consumers who disclose disability needs as part of sending a complaint to the HDC. In the instance the HDC refers an individual through to the Nationwide Health and Disability Advocacy that the HDC disclose any accessibility needs to support the consumer to the NHDA, so that the Advocate is able to adapt their communication to suit the complainant.

NHDA Consumer Feedback

- I propose a review in regards to the mechanism used to collect consumer and service provider feedback which includes automation, which is more cost effective and time efficient
- I propose the HDC provide reporting for the next financial year around service satisfaction of the Complaints Resolutions Process by surveying both consumers and service providers

NHDA Staff Recruitment

- I propose the HDC provides better support to the Nationwide Health and Disability Advocacy by increasing funding to power up the Nationwide Health and Disability Advocacy with the resources to better support the HDC
- I propose recruiting more staff, as at present the total number of Advocates is less than 30 people for the entirety of New Zealand's population which isn't reasonable or sustainable in the long-term for the NHDA, due to the increase in complaint volumes at the HDC.
- I propose an additional role to support the Early Resolutions Strategy, as I believe the Advocacy service needs to create another role with greater powers and better accountability measures to fully optimise the Nationwide Health and Disability Advocacy.
- If funding is an issue, the HDC to work alongside the Coalition Government to look at other strategic partnerships with other ministries or organisations to source staffing through work experience placements

HDC & NHDA Early Resolutions

- An Early Resolutions Process implemented into the Complaints Resolutions Process would help expedite matters and support the HDC to triage complaints better. Consider seeking advice from the Ombudsman about their “Early Resolutions Model” and other successful models. Engage with ACC Resolutions Services to look at other ways of driving better efficiencies.
- Seek sector advice around threshold on targets to ensure that staff resourcing and capability is factored into key performance indicators
- Qualifying process for the NHDA to support the team in identifying which complaints meet the threshold for early resolutions
- An Early Resolutions Process implemented into the Nationwide Health and Disability Service which gives NHDA staff greater influence and more engagement to help resolve issues, alongside the consumer and service provider.
- I propose another career pathway for “Advocates” looking for advancement within the NHDA to upskill and train within “Early Resolutions” by training and upskilling at the HDC creating a way for advocates to seek future employment at the HDC in the future.
- Crosstrain HDC staff to be able to upskill and train at the Advocacy Service to provide support to the NHDA if and where possible
- I propose two teams within the Advocacy Service, one role focused on early resolutions with more powers to influence decision making aligned to the HDC Complaints Resolutions Process, and other role focused on education and navigation of complaints

NHDA Review of Advocate role

- I propose changing the role name Advocate to “Navigator” as this would be a more suitable reflection of the services provided by the Nationwide Health and Disability Advocacy for New Zealanders during a complaint process with a Health Service Provider. The traditional role of an Advocate is more involved than what the NHDA provides and has more influence to advocate on behalf of someone to reach their desired goal.

Legislative changes to consider for supporting better and equitable complaint resolution

- I implore and urge the Minister of Health to please consider operational and legislative changes which could be made to further improve access to justice within the HDC’s Complaints Resolution Process

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

2.1: Did we cover the main issues about making the Act and Code more effective for, and responsive to, the needs of Māori?

Issues

Māori aren’t benefiting equitably from the Act and the Code.

Sarah’s response 2:1 I support the main issues about making the Act and Code more effective for, and responsive to, the needs of Māori including a recommendation to the HDC to engage with the sector and Māori. My main issue with the HDC is the lack of transparency about the issues, as the words “don’t reflect” and “largely” should be removed from the HDC’s proposed issues.

- Māori engagement with HDC and the Advocacy Service is less than expected given the experiences of, and outcomes for, Māori in the health and disability sector.

- Promotion of the Code is not reaching Māori communities. When it does, many feel that Code rights and complaint processes are not designed for them.
- Complaint processes and interpretation of rights often don't reflect te ao Māori values and tikanga.
- Te Tiriti | the Treaty and its practical application is also largely absent from the Act and the Code.

Additional Issue:

I am concerned about the negative impact of legislation such as the repealing of the Māori Health Authority, the reduction in funding to Māori organisations that deliver healthcare support services to communities across the motu and the Coalition Government's meaning behind devolution in removing co-governance from central government, which recognises the partnership between the Crown and Māori to address the enquiries of our people, and to strive for better health outcomes. Whilst I do support devolution at a community level, I am concerned about how Māori can achieve this when the Coalition Government has reduced, retracted and removed funding and opportunities for our people to thrive.

Sarah's response: I support the recent changes including:

Director Māori role in leadership, along with a small team, to make HDC more responsive to the needs of Māori, help providers to be more responsive, and raise awareness of HDC in Māori communities.

a. Incorporate tikanga into the Code

Sarah's response: I recommend further sector guidance in regards to incorporating Tikanga into the Code. I would recommend adding an additional right into the Code of Consumer Rights, instead of making an amendment, for example to change an existing Right 1 (Respect) that every consumer has the right to have their mana upheld.

b. Give practical effect to te Tiriti | the Treaty in the Act

Sarah's response: I support adding protections into the Act to give practical effect to Te Tiriti | the Treaty to ensure Te Ao Māori values and tikanga are applied with integrity. I support the suggested changes for the HDC Act and Code to explicitly give general effect to Te Tiriti o Waitangi in the Act's preamble and give specific effect to the principles, so that the articles can be interpreted and adapted in contemporary localised health and disability service contexts. I agree that both general and specific changes will support the Crown honour its obligations under Te Tiriti | The Treaty (p31).

2.2: What do you think about our suggestions for **making the Act and the Code effective for, and responsive to, the needs of Māori**, and what impacts could they have?

Sarah's response: 2.2 I support the HDC's suggestions for the Act to give practical effect to te Tiriti | the Treaty include amendments to provide for:

- Processes to ensure equitable Māori engagement and leadership in the operation of the Act and the Code. For example, requiring HDC to make and maintain effective links with iwi/Māori and engage with iwi/Māori when reviewing the Act and the Code, and in the development of Advocacy Service guidelines.
- Māori values and worldviews, overseen by Māori. For example, including the promotion and protection of tikanga in the functions of HDC and the appointment of a Deputy Commissioner Māori.

- Māori to benefit equitably from health and disability rights as Māori. For example, changing complaint processes to better align with tikanga.

The impacts of these proposed changes are: Tino rangatiratanga

2.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code effective for, and responsive to, the needs of Māori?**

The use of applying the Te Whare Tapa Whā Māori Health Model, when applying the HDC Code and Act to complaints from Māori: Complaint Process – Māori Resolution

As Māori I apply the Te Whare Tapa Whā the Māori health model based on the concepts of whānau (family), tinana (physical), hinengaro (mental) and wairua (spiritual) health.

- I'd like to see more funding allocation into the investment around education of the Te Whare Tapa Whā Māori Health Model in mainstream healthcare services, for health professionals and health and disability service providers. It's important that the HDC consider that when applying the HDC Act and Code within the Complaints Process for Māori Complainants like me, that a more people-centered approach within the HDC Complaints Resolutions is needed that is mana enhancing. There is no consultation process at all, and very minimal email correspondence between staff members.
- To seek a mutual resolution with Māori, the HDC must incorporate our cultural values, and as Māori we have the poorest health outcomes so when we raise issues, we look at the holistic overview of our health including those four pillars when reporting complaints. It's important for the HDC to consider the views of Māori in the Complaints Resolution because the existing approach isn't equitable to meet the needs of Māori.

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

Issues

- Since the Act and the Code were first developed, there have been shifts in understanding of the rights of tāngata whaikaha | disabled people and the provision of supports and services, including in relation to mental health and addiction. The Act and the Code can be strengthened to reflect a modern understanding of disability rights, including the rights of tāngata whai ora, and of service provision.
- HDC is also seeking feedback on an earlier review, which looked at whether adults unable to consent should be able to participate in research, and, if so, what safeguards should be in place.

Updating the Act and the Code to support tāngata whaikaha | disabled people would support the Government to uphold its commitments under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Updates to the Act and the Code would also contribute to better and more equitable outcomes for tāngata whaikaha | disabled people when they access health and disability services.

What we're doing already

Traditionally, HDC has had a Deputy Commissioner, Disability and a dedicated delegation for mental health and addiction complaints. Recently, HDC made changes to improve how we work for tāngata whaikaha | disabled people, including:

- Improving how we measure and report on disability issues;
- Monitoring the experience of tāngata whaikaha | disabled people in our complaints processes to improve accessibility and responsiveness;
- Responding to trends from complaints about disability support services and opioid substitution treatment; and
- Reviewing and updating our resources to ensure they are accessible, modern, and culturally appropriate.

Question 3.1: Did we cover the main issues about *making the Act and the Code work better for tāngata whaikaha | disabled people*? No

- Provide better accessibility for tāngata whaikaha and their disability needs within the complaint's resolutions process

The HDC is a bystander to the distress that tāngata whaikaha experiences rather than an Upstander in addressing the underlined issues within the Complaint Process, and the way the HDC investigates complaints. We need Upstanders not the HDC hovering and monitoring our distress whilst using approaches that are dismissive, not people-centred, accessible, or easy to understand.

Suggestions

We seek feedback on the following suggestions for the Act and the Code as they relate to tāngata whaikaha | disabled people. We also seek feedback on HDC's draft recommendations for unconsented research.

Sarah's response: I recommend seeking sector guidance to collect feedback from the Disability Sector directly in regards to unconsented research. I personally wouldn't support unconsented research as I'm not convinced at this stage that New Zealand would be able to deliver robust safeguards to protect our most vulnerable, given the fragility of our Public Healthcare system and New Zealand's infrastructure. I do not condone unconsented research going ahead, until we have better policies and legislations in place to support our tāngata whaikaha, disabled people.

Sarah's response: I support Clause A. to add a legislated role. I'd like to also include the Minister of Mental Health into the reporting requirement.

a. Strengthen disability functions

Adding a legislated role focused on disability issues could strengthen oversight of complaints from a disability perspective, enhance HDC's focus on the rights of tāngata whaikaha | disabled people and promote trust and engagement with HDC. This could include adding a reporting requirement to the Minister for Disability Issues as well as the Minister of Health.

Sarah's response: I support Clause B. with a recommendation that the HDC should change the definitions of 'disability services' and 'disability services provider' in the Act to reflect modern strengths-based concepts of disability, aligned with the CRPD.

b. Update definitions relating to disability

The definitions of ‘disability services’ and ‘disability services provider’ in the Act could be revised to reflect modern strengths-based concepts of disability, aligned with the CRPD.

Sarah’s response: I support the proposed changes to Clause C. with a recommendation that the HDC seek input from the sector to define accessibility.

c. Strengthen references to accessibility

We propose changes to the Code to explicitly reference accessibility in Right 5 (Effective Communication) and in Right 10 (Right to Complain). We also propose removing the words ‘reasonably practicable’ in Right 5 in relation to the right to a competent interpreter.

Sarah’s response: I support the proposed changes to Clause D

d. Strengthen and clarify the right to support to make decisions

We propose the following changes to clarify that a person should be supported to make decisions about their care to their fullest decision-making ability.

- Strengthen Right 5 (Effective Communication) in the Code to explicitly reference the right to support to understand information.
- Update the language in Right 7 (Informed Choice and Consent) relating to ‘competence’ and ‘incompetence’ to decision-making capacity to align with the Law Commission’s review of adult decision-making capacity law.
- Strengthen Right 7(3) to reference the right to support to make decisions.
- Update the language in Right 7(4) from consumer’s ‘views’, to ‘will and preferences’, to align with the language of the CRPD.
- Strengthen Right 7(4)(c)(ii) to make sure that the will and preferences of people who will never have legal decision-making capacity are taken into account.

Sarah’s response: Clause E. I do not support the consideration of draft recommendations relating to unconsented research. I strongly advise against the HDC using our most vulnerable to experiment with for the benefit to support greater knowledge of specific conditions and improve treatment and services for groups affected by those conditions.

e. Progress consideration of HDC’s draft recommendations relating to unconsented research

A review by HDC in 2019 recommended that some health and disability research that is not currently permitted should be allowed, in limited circumstances and with robust safeguards. The intent was to support greater knowledge of specific conditions and improve treatment and services for groups affected by those conditions. The next step for this review was to seek public feedback on HDC’s recommendations.

The test HDC recommended for research when people could not consent was that research could go ahead only if it posed ‘no more than minimal foreseeable risk and no more than minimal foreseeable burden’ on the consumer. Recommended safeguards included that suitable people who cared about the person could prevent their participation in the research; and that specialist ethics committees would oversee the research. We would like to know what you think of these recommendations.

You can read the full 2019 report at <https://tinyurl.com/unconsented-research>.

Questions 3.2: 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?

The impacts of these proposed changes are:

3.3: What other changes, legislative and non-legislative, should we consider for **making the Act and the Code work better for tāngata whaikaha | disabled people**?

- Adequate resources including funding allocation to support the Health and Disability Commissioner's changes to the Code and Act which impact the services and supports for disabled people in New Zealand
- Inclusive Policy Development such as the Accessibility Legislation which the previous Labour Led Government introduced better protectionisms for our New Zealand Disability Community.
- To strategically align with other ministries such as the Ministry of Social Development which has recently taken over providing funding allocation for Disability Support Services from Whaikaha, the Ministry for Disabled persons.

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

Issues

A petition to the Health Select Committee argued that there are limited options to challenge HDC decisions and that introducing a right to appeal HDC decisions would strengthen the promotion and protection of the rights of people accessing health and disability services. Considerations for assessing the value of an appeal include the potential costs and impacts of delay; the importance of reaching final resolution; and the expertise of the initial decision-maker.

Question 4.1: *Have we covered the main issues about **considering options for a right of appeal of HDC decisions**?*

Sarah Response: No

1. The impact of limited options to challenge HDC decisions which means the consumer's next option is to make a complaint against the HDC's Complaint Process to the HDC.
2. The lack of professionalism from the HDC in regards to the lack of professional written correspondence including providing a formal written response of my complaint dated 05.05.2023, which was sent through to the HDC's general email on 08.05.2023. As a consumer and complainant time was spent writing the complaint, and I do not understand why the same level of professional written correspondence isn't applied when a consumer makes a formal complaint against the HDC, to the HDC.
3. The impact of limited options to challenge the HDC decisions which means the consumers next option is to make a complaint against the HDC to the Ombudsman's Office.
4. The internal issues I've experienced within the Ombudsman's Office Complaint Resolutions Process
5. The Ombudsman's recommendations are not binding and there is no requirement for the HDC to implement the Ombudsman's recommendations. Judicial review isn't an accessible review mechanism because of the costs involved, creating further accessibility issues for New Zealander's who want to take matters to the High Court.

The Ombudsman's Office: issues with the review mechanism

As I've been dissatisfied with the lack of response in terms of formal written correspondence and outstanding queries, I had to lodge a formal complaint against the HDC with the Ombudsman. However this review mechanism has not provided a fair, equitable, efficient and timely resolution.

1. I am currently waiting for the final decision outcome of the Ombudsman regarding my complaint against the HDC in regards to my dissatisfaction with the Complaints Resolutions process and from the time my complaint with the Ombudsman has been submitted to the now, it has now been over 12 months. There are delays within the Ombudsman's complaints process, which contributes to overall delays in resolving complaints and accessing justice.
2. I was allocated an investigator who showed little interest in my complaint, wasn't considerate of my disability needs, whereby I felt that I needed to go above and beyond to self-advocate just to seek validation from the staff member of my disability issues through email correspondence and trying to explain through phone calls. I was proactive and tried to source all information under a privacy request from the HDC in which I was successful. However the response by the HDC was that I could only have temporary access to the files, so I wasn't able to print off and read through the correspondence. I did speak to the investigator about my concerns and I felt that there was very minimal effort.
3. I had to report an incident where the Investigator was very disrespectful towards me during a phone call. After speaking directly with the Investigator's direct report my concerns were ignored, and the Investigator continued to work on my complaint, whereby I believe there is a conflict of interest.
4. The provisional letter with the provisional opinion described a meeting that took place with the HDC Deputy Commissioner on the 21.07.2023 as a misunderstanding in regards to the purpose of the meeting which isn't accurate.
5. I waited months for the provisional opinion of the Ombudsman, and was given a short lead time of less than two weeks to respond back to their provisional findings, which was inconsiderate of my disability needs. Despite the Ombudsman's portrayal of the position of supporting disabled persons, I have not experienced that within the Complaint Process within this office.
6. I had to complain about the short lead time given to respond to the provisional findings letter to get an extension of 12 weeks to be able to have the same access to time, as the Ombudsman had in completing the investigation.
7. I reported a privacy breach as email correspondence which I had addressed to a specific staff member, wasn't sent to the staff member and instead the general enquiries team forwarded my email onto the investigator. Despite making a privacy complaint, I was emailed a letter which dismissed my privacy concerns.
8. The provisional letter excludes my accessibility needs which includes that I would prefer an online meeting with the allocation of an hour for an HDC staff member to review each complaint, and to have the ability to ask questions and seek understanding. Instead, the Investigator accepted a request from the HDC to email me and provide a short phone call to answer any

questions I may have. The Ombudsman and the HDC have decided an agreement that suits them, but have failed to include me into the conversation of what would be an appropriate form of communication and way of seeking resolution that meets my disability and cultural needs.

Sarah's response: I support the proposed changes in 4.1 Clause for the Act to challenge HDC decisions. Although the HDC has reviewed and improved the 'closed file review'/internal review process to clarify its decision-making guidance relating to taking no further action and notifying an investigation, I would describe the HDC Complaint process from my own personal experience to be transactional and highly dismissive, with no people-centered focused.

Sarah's response: I support the proposed changes in 4.1 Clause a) and highly recommend this change

a. Introduce a statutory requirement for review of HDC decisions

Currently, HDC can undertake internal reviews of decisions if requested. The Act could be amended to require such reviews. This option could include a requirement that the original decision-maker is not part of the review or that there is peer involvement. Another variation of this option could be for an entirely independent review panel or body.

Sarah's response: I support the proposed changes in 4.1 Clause b

b. Lower the threshold for access to the HRRT

The HRRT considers breaches of rights concerning the Privacy Act 2020 and the Human Rights Act 1993 in addition to our Act. The threshold for accessing the HRRT is highest under our Act, which requires a breach decision by HDC to be made following an investigation.

The threshold could be lowered to the equivalent level of the Privacy Act, which generally requires a complaint to be investigated, or reduced further to the equivalent level as the Human Rights Act, which requires only that a complaint be made to the Human Rights Commissioner. Different thresholds would require different levels of resourcing for the HRRT.

Questions 4.2: What do you think about our suggestions for **considering options for a right of appeal of HDC decisions**, and what impact could they have?

Sarah's response: I support the suggestions for considering options for a right of appeal of HDC decisions because I believe that there are systematic and systemic issues which need to be addressed urgently.

The impacts of these proposed changes are: a more fair and equitable Complaints Resolution Process.

4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

Non-Legislative changes to consider for a right of appeal of HDC decisions

Although I support the changes, the HDC only has the power to issue recommendations and opinions which can't be appealed, so my only other issue is how will the change of this right of appeal of HDC decisions sit in the current statutory framework that you have.

Legislative changes to consider for a right of appeal of HDC decisions

I'd like legislative change so that the HDC can apply the new changes with the right of appeal

j. Respond to advancing technology

We also want to hear your views on how the rights of people accessing health and disability services can be promoted and protected in the context of advancing technology, including artificial intelligence and related changes to service provision. By focusing on these areas, the integration of AI and other advanced technologies into health and disability services can be managed in a way that upholds and enhances the rights of all individuals.

Questions 5.3: *What are your main concerns about **advancing technology** and its impact on the rights of people accessing health and disability services?*

- In the context of the Health and Disability Commissioner I'd like to use the existing situation with the expense of the IT Infrastructure needed to support the existing needs of the HDC and future needs. The HDC has provided a proposal to meet the needs of the government, whilst resolving the existing inefficiencies, however this has been declined. I have concerns around the viability of our public agencies in modern times with the lack of investment by past and existing governments in advancing technologies including IT Infrastructure.
- The expense of advancing technology to taxpayers, and the fragility within New Zealand's infrastructure to be able to keep up with globalisation and the rest of the world. New Zealand is more at risk to natural disasters, as we are more remote in comparison to other countries and different parts of the world.
- AI technologies require a significant supply of electricity to maintain its IT capability. At present we have had business closures because of a national energy crises which has contribute to high electric bills for both businesses and consumers, due to issues with supply across our country and inflated profits by power companies. If New Zealand was to consider incorporating AI into healthcare this would be at an expense that the government considers.
- If New Zealand does introduce AI technology to replace the decision making of clinicians or integrated into our healthcare system into the future, we would need to resolve our existing electricity issues, as well as have strong and robust measures to protect us from global outages, hackers and other potential security risks.
- The advancement of technology replaces manual labour and people's jobs which I believe for a small country like New Zealand isn't good

1. Data Security and Protection

What security measures would protect the privacy of sensitive patient information from breaches and misuse. Ensuring that systems including AI for example comply with data protection laws and standards relevant to New Zealand Legislation.

2. Regulations and Ethical Standards

The use of (AI) artificial intelligence in New Zealand healthcare services would require robust ethical guidelines and regulations to ensure privacy, consent, and equitable treatment for patients. This includes data protection and ethical use of AI tools.

3. Regulatory Oversight

The New Zealand Government would need to invest funding and resource to regulatory bodies to ensure organisations are equipped to monitor the impacts in the advancement of technology such as (AI) artificial intelligence, including trials, efficacy and research development. To address any issues that consumers and health and disability services may experience. This includes updating regulations as technology evolves and advances to protect patient rights effectively.

4. Transparency and Accountability

As technology evolves, we need to ensure transparency when integrating systems such as AI into the assessment, treatment and support of patient's health outcomes. Health and disability service providers would need to be transparent with communicating effectively the impact of new technology, the protection of their data, and patient consent. How do we hold health and disability service providers accountable for patient outcomes, if using systems such as AI.

5. Inclusivity with AI Tools, System & Design

AI could potentially disadvantage people with disabilities if the technology doesn't meet the needs of our disability community. Designing AI systems and tools would require input from a diverse range of users including those with disabilities to ensure that differently-abled people are not inadvertently excluded or disadvantaged, when health service providers integrate modern and new technologies in the future.

Question 5.4: What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

Legislative changes to consider with responding to advancing technology

1. Legislation & Policy Changes

Amend legislation to ensure that new technologies and platforms for example are accessible to people with disabilities, including enforcing standards for digital accessibility.

2. Data Protection Laws

Update data protection regulations to address the unique challenges posed by advanced technologies such as AI, including stricter rules on data privacy, consent, and security.

3. Intellectual Property Rights

Adjust intellectual property laws to address issues related to evolving technology, for example AI-generated content and inventions, balancing innovation with public access and fairness.

4. Consumer Rights & Code of Consumer Rights

Introduce or update laws to protect consumer rights in the context of private and public healthcare services including if new technology such as AI automated decisions for the healthcare of the patient, including the right to be treated aligned to the Code of Consumer Rights

5. Healthcare Regulations

The Minister of Health to revise healthcare regulations with Te Whatu Ora New Zealand and other healthcare sector providers, to address the integration of new technology such as AI including medical diagnostics, treatment, and patient management, ensuring safety, efficacy, and equitable access that meets the needs of the diversity of people.

6. Ethical Standards

Develop and enforce laws that establish ethical standards for the development and deployment of advancing technologies such as AI here in New Zealand- including transparency, accountability, and fairness requirements. This also includes trials, efficacy and research development.

Non-Legislative changes to consider with responding to advancing technology

5

1. Education and Public Awareness

If the New Zealand Healthcare System uses AI in the future to support patient healthcare services for example to replace clinician patient contact for delivery healthcare services and recommendations, that the New Zealand Government and the Minister of Health will ensure that there is public awareness, consultation and scrutiny of the emerging technologies benefits, outlining the potential risks in educating individuals to make informed decisions and advocate for their rights.

2. Training and Skill Development

Provide ongoing education and training for healthcare professionals in the relevant sector and service providers on the use of new technologies. Provide training and resources for professionals in relevant fields to adapt to new technologies, ensuring they can effectively integrate and manage these advancements.

3. Patient Awareness, Empowerment and Education

Empowering patients through education about their rights in the context of new technologies and AI. This includes understanding how to make informed choices and advocating for themselves within the healthcare system.

4. Feedback Mechanisms

Establishing channels for patients and service users to provide feedback on their experiences with new technology such as AI-driven services. This feedback can be used to improve technology and address any issues of bias or discrimination.