

Briefing to the Incoming Minister



Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

29 November 2023

The Code of Rights



Key People



Morag McDowell, Health and Disability Commissioner

Appointed: September 2020

Morag took up the Commissioner role after serving nearly 13 years as a Coroner. She was formally a Crown Prosecutor, Director of Proceedings at HDC, and a Senior Legal Advisor at Crown Law.



Carolyn Cooper, Aged Care Commissioner/Deputy Commissioner

Appointed: March 2022

Carolyn brings a wealth of health sector leadership experience to the role. Her previous roles include General Manager for Canterbury DHB, Chief Operating Officer at Wairarapa and Hutt Valley DHBs, and Managing Director and Lead Nurse at Bupa NZ.



Rose Wall, Deputy Commissioner, Disability

Appointed: August 2013

Rose, who is a nurse by training, has been involved in the public health system for most of her career. This has given her a broad insight into service quality, government strategy, and the regulatory environment.



Deborah James, Deputy Commissioner, Complaints Resolution

Appointed: August 2021

Deborah brings significant public sector and community sector leadership skills to the role, including previous roles as the Head of Diversity and Inclusion at Auckland Council and Sector Manager at the Office of the Auditor General. Deborah is a former registered general and obstetric nurse.



Dr Vanessa Caldwell, Deputy Commissioner

Appointed: September 2021

Vanessa (Kāi Tahu, Te Rapuwai, Waitaha, Kati Māmoē) is a psychologist with extensive knowledge of the health system, and experience in supporting partnerships with Māori in a range of health sector roles. Most recently she was Clinical Executive for Mental Health and Addictions services at MidCentral DHB.



Ikimoke Tamaki-Takarei, Kaitohu Matamua Māori (Director, Māori)

Ikimoke (Waikato, Tainui) has extensive experience working across government agencies. Most recently he was the Director of Tikanga within the Māori Equity and Health Improvement Directorate at Waikato DHB. Ikimoke is the Deputy Chair of Te Whakaitenga o Waikato, the iwi governance group that manages iwi strategies and aspirations.

Agency snapshot

The Health and Disability Commissioner (HDC) has the unique role of promoting and protecting the rights of people using health and disability services as set out in the Code of Rights. This critical function ensures that consumers have a voice, holds providers to account where appropriate, and helps to preserve trust in the health and disability system. We use our insights and levers to improve the system. Importantly:

- We promote and protect peoples' rights through education, advocacy, and holding the system and providers accountable through the resolution of complaints.
- We are an independent Crown entity – independent from Government and service provision, enabling HDC to be an effective and impartial guardian of consumers' rights.
- In a no-fault system for treatment injury where HDC is the key independent avenue for people to formally raise their concerns about health and disability services, we provide a critical layer of accountability and independence. This ensures people's rights are protected and assists to maintain public trust in the system.
- Through the making and monitoring of recommendations we also hold the system to account to ensure quality and safety is improved (96% of our recommendations are complied with).
- HDC receives around 3,400 complaints a year – there is a wide breadth in complaints from more minor concerns through to complaints involving significant harm and public safety issues.
- Complaints to HDC have increased significantly in recent years – the volume of complaints is currently 36% above pre-COVID levels. HDC currently receives 300+ complaints a month.
- Most complaints are resolved using early resolution methods, such as referring the complaint for direct resolution between the complainant and provider (sometimes with the assistance of the National Advocacy Service). About 170 more serious complaints are investigated each year which may result in a provider being found in breach of the Code.
- HDC also has the power to undertake own motion investigations in the absence of a complaint. A recent example is our investigation into [cancer care delays in the Southern region](#).
- Our unique dataset is grounded in consumer and whānau experience and can highlight areas of emerging risk. We take a collaborative approach to amplify the consumer voice and address areas of systemic concern. We work closely with other agencies to ensure public safety issues are identified and addressed.
- An Aged Care Commissioner was established within HDC in 2021 to monitor and drive quality improvement in health and disability services for older people.
- HDC is currently undertaking a review of the HDC Act and Code of Rights and will be reporting our findings and recommendations to you in December 2024.

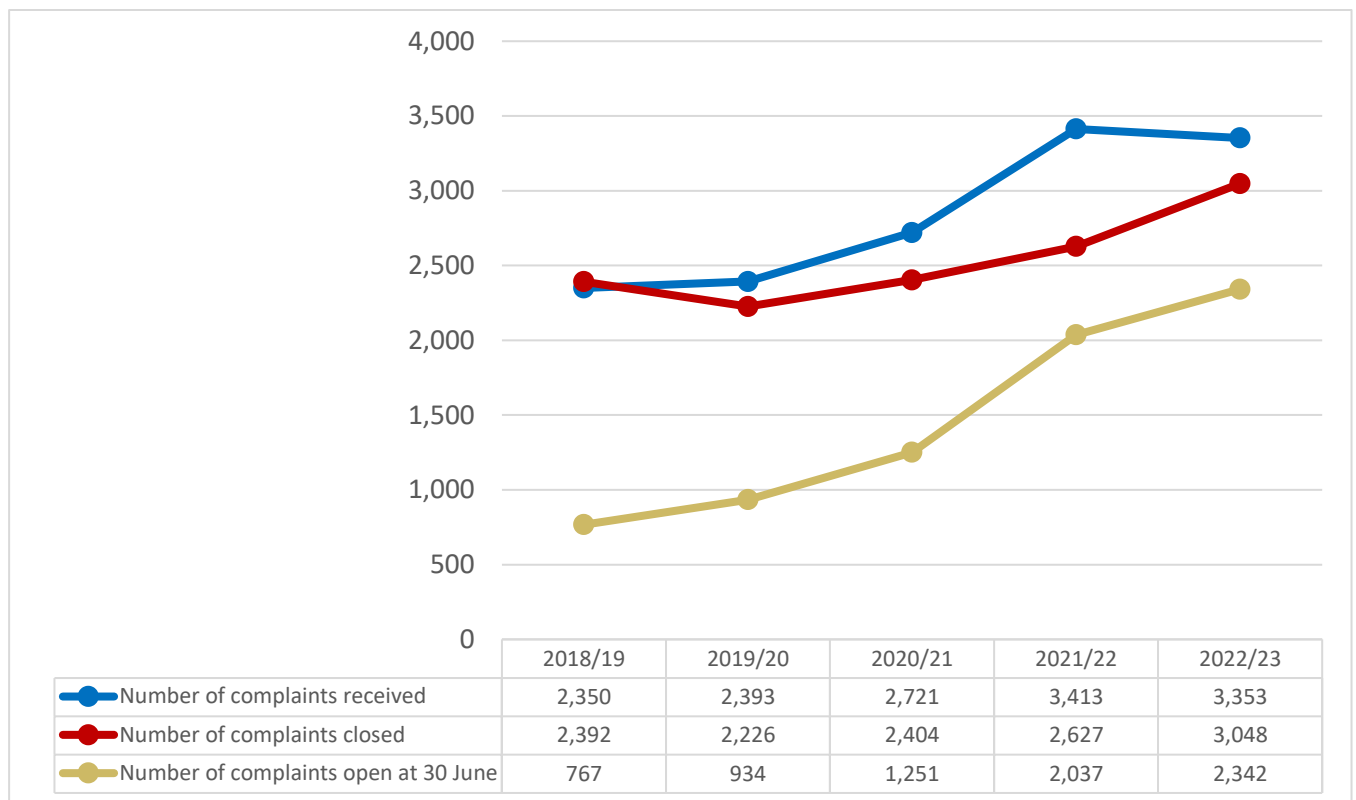
The role of the National Advocacy Service

- HDC, through its independent Director of Advocacy (DOA), is legislatively required to purchase advocacy services. The DOA contracts the Nationwide Health and Disability Advocacy Service to support people to resolve complaints directly with their providers and undertake community-level promotion of the Code of Rights, with a particular focus on empowering vulnerable/marginalised communities.
- Advocacy resolves around 2,900 complaints a year, with 100% of complaints resolved within nine months. Advocates undertake over 880 education sessions, and 3,300 scheduled visits and meetings to promote the Code across Aotearoa New Zealand each year.

HDC's current priorities

Responding sustainably to growing demand

Figure 1. Number of complaints received by HDC



Complaints to HDC have increased significantly in recent years. In 2021/22 HDC experienced an unprecedented and unexpected 25% increase in complaints. We received a similar number of complaints in 2022/23, with the volume of complaints currently sitting at 36% above pre-COVID levels. While initially this increase in volume could be attributed to the impacts of the pandemic, volumes continue to remain very high despite a significant reduction in complaints related to COVID-19. In the current year to date, HDC is receiving on average 300 complaints and 200 enquiries a month. The impacts of the pandemic have also resulted in an increase in novel issues which are complex and resource intensive to resolve.

This increase in volume has placed significant pressure on the time it takes HDC to resolve complaints and has led to a growing number of complaints under assessment. While we have worked to improve our efficiency as much as possible, including by closing a record number of complaints in 2022/23 (3,048 complaints were closed – a 16% increase on the previous year), there remains a gap between the number of complaints we receive and what we can conceivably close within current resources. We ended 2022/23 with 2,342 complaints under assessment, 11% of which were aged over two years.

An external review in 2022 identified significant barriers to increasing the efficiency of complaints process due to our outdated IT infrastructure (including use of Lotus Notes). A recent funding proposal to upgrade our digital systems was unsuccessful, and we will continue to engage with Government in respect of this and look for areas where we can achieve further efficiencies wherever possible.

HDC is working to improve our process further to be more timely and people-centred, including focusing on early resolution where possible. For example, we have introduced fast-track processes for appropriate complaints and introduced clinical navigator roles to assist people in understanding their care and the clinical information provided. We have also re-configured our triage process to focus on early resolution where appropriate and prioritise HDC resource to those complaints that need it most. While these changes have delivered positive results, delivering process change in the context of a growing number of complaints, outdated electronic systems and current resource constraints is challenging.

Enhancing our contribution to equitable health outcomes

Diversity of age, gender, ethnicity, gender identity, sexual orientation, ability, religion and culture are all factors that contribute to people's experience of the health and disability sector. HDC provides an important platform for the consumer voice to be heard and equity issues to be raised and addressed. We also have a role in holding the sector accountable for providing culturally safe care where appropriate.

HDC has a focus on becoming a culturally safe organisation, and with the support of our Kaitohu Mātāmua Māori | Director Māori we have been working to improve the cultural capability of HDC, introduce a te ao Māori approach to resolution, and better respond to complaints with a cultural dimension. In 2022/23 68 complaints were referred to our Kaitohu Mātāmua Māori | Director Māori, and currently demand outstrips the capacity of our small cultural team, making it difficult for them to provide timely cultural input. HDC is exploring further investment in cultural support to ensure our process is culturally appropriate and to support providers to improve their cultural response to complaints.

Our Kaitohu Mātāmua Māori | Director Māori also supports effective engagement with Māori communities, working to increase understanding of the Code and avenues for complaint. He also works with providers to support a cultural approach to complaints resolution. Such work has been correlated with a small increase in complaints to HDC from Māori.

HDC has a critical role to play in improving quality of care provided to disabled people and ensuring their rights are upheld. Currently around 25-30% of complaints to HDC relate to care provided to disabled people. There are areas of the disability community who are under-represented in complaints, including those in residential care, Pacific peoples and tāngata whaikaha Māori.

Working with disabled people to support improved quality of care, increase awareness of their rights under the Code and reduce barriers for engagement with HDC is a key focus for us. In 2022/23 we began work on developing a monitoring framework to assess the performance of the sector in regard to upholding the rights of disabled people.

System monitoring and impact

HDC closely monitors the trends that emerge across complaints, and aims to take a timely, collaborative approach to raising issues of systemic concern. HDC works with sector leaders and other agencies (including regulatory authorities), who have a role in quality and safety to share intelligence, ensure that timely action is taken on public safety concerns, and, where appropriate, take a multi-agency approach to areas of shared concern. HDC has recently had a focus on developing relationships with entities in the system, including Te Whatu Ora | Health New Zealand and Whaikaha | Ministry of Disabled People to ensure that issues are raised and responded to.

In addition, the Aged Care Commissioner has a mandate to monitor and work to address quality and safety issues in the aged care and wider health and disability sector. She works closely with the sector

and relevant agencies to assist in ensuring that a collective approach is taken to improve care for older people and their whānau.

HDC's accountability function also plays an important role in improving the quality and safety of services. Accountability is an important aspect of a learning system and assists to ensure that risk is appropriately escalated, public safety is protected, recurrent behaviour and systemic issues are addressed, change occurs, people's resolution needs are met and public trust in the system is maintained. Through the making and monitoring of recommendations HDC also holds the system to account to ensure that learning and change occurs.

Reviewing the HDC Act and Code of Rights

HDC has a statutory obligation to undertake regular reviews of the HDC Act and the Code of Rights to consider whether any changes are necessary or desirable. We are currently undertaking a review of the HDC Act and Code of Rights and will be reporting our findings and recommendations to you in December 2024.

This review is a significant opportunity to ensure that the Act and Code remain fit for purpose and continue to be effective mechanisms for the protection and promotion of the rights of all consumers of health and disability services. We are also mindful that there have been significant shifts in the landscape since the last time changes were made to the HDC Act or Code of Rights. This includes the reform of the health and disability system; increasing pressure on the system; evolving social demographics and norms; evolving models of care; and changing expectations in relation to rights and complaints resolution.

This is a substantive, resource intensive project particularly in making our consultation process accessible. The review is focussed on four priority issues identified during the scoping phase (January –June 2023) in consultation with key stakeholders:

1. Supporting better and equitable resolution for all communities
2. Making the Act and Code effective for, and responsive to, Māori
3. Making the Act and Code work better for disabled people
4. Considering the options for a right of appeal for HDC decisions

As well as the four priority areas above, the review is considering minor and technical amendments to ensure the Act and Code are fit for purpose in the current context.

We will be consulting publicly from March to July 2024 and are focussed on ensuring our engagement is accessible and wide-reaching.

What are complaints telling us about the system?

How HDC can support the Minister

HDC has a unique lens on the health and disability system. Our intelligence is grounded in the consumer experience and can provide insight on emerging risk and the issues people care about most. Therefore, we are well placed to monitor and escalate insights and risks to you relating to the impacts of the current reforms and environmental pressures on people and their whānau.

HDC has an important role to play in supporting Mānatu Hauora | Ministry of Health, Te Tahū Hauora | HQSC and other agencies to undertake their monitoring roles and improve quality and safety of the system. Our role and functions, particularly in respect of amplifying the consumer voice and supporting a learning culture, also support the Government to meet their commitments under Pae Ora (Healthy Futures) Act and the New Zealand Health Strategy.

We use the insights gained from complaints to influence legislation, policies, and practice. We regularly provide information to Government, Mānatu Hauora | Ministry of Health, Te Whatu Ora | Health New Zealand, Te Tahū Hauora | HQSC and other relevant agencies on systemic issues we see and how current safeguards can be strengthened to better protect consumers' rights.

Systemic issues in complaints

New Zealand has a high-functioning and well-regarded health and disability system, of which we can be justifiably proud. HDC has also been impressed by the commitment and resilience of the health and disability workforce over recent years. However, the system is under unprecedented pressure – there are significant workforce shortages, long delays for many services, continuing geographical inequities, inadequate and aging infrastructure, fragmentation between services, barriers to access and entrenched inequities in access and outcomes, particularly for Māori, Pacific and disabled people.

Notwithstanding the current pressure the system is under, the Code of Rights remains of central importance in this context, and it is critical that we continue to guard against complacency or tolerance of delay, and the potential for patient harm.

Below are some of the systemic issues that HDC is currently focused on:

Inequitable health outcomes

A number of our complaints point to people's concerns about discriminatory attitudes and approaches, and failures by people and services to act in a culturally safe way, including a lack of knowledge or respect for important cultural practices and a lack of cultural support options. Complaints also highlight the significant impact that a failure by providers to engage people and their whānau appropriately in their care can have on their understanding of the care provided and on health outcomes.

Complaints also highlight the difficulties experienced by disabled people in the health system. This includes poor knowledge or understanding of disability among health providers, health environments not adequately supporting people with disabilities, poor information sharing between health and social services, delays in diagnosis impacting on access to social supports and a lack of accessible

communication and information being available to support people's understanding of their options and the care provided. It is positive that disabled people have been recognised as a priority population by Pae Ora (Healthy Futures) Act. However, greater investment in services to support disabled people will be required to achieve equity of access.

Importance of strong quality and clinical governance frameworks as the system continues to reform

HDC has held concerns about the apparent lack of a clear permanent national clinical governance system, including national clinical risk management and transparent escalation pathways. Such pathways are particularly important in the context of current workforce pressures and significant delays in care.

HDC has been engaging with Te Whatu Ora | Health New Zealand regarding our concerns in this area. While we acknowledge the recent progress made, it will be important that permanent, effective pathways for risk escalation are implemented as soon as possible, and that health professionals at the front line know of those pathways. As we recently commented in respect of our investigation into cancer care delays: an effective accountability and performance framework where patients are the focus and patient safety concerns are signalled, acted upon and evaluated is a vital component of quality and risk management.

Specialist care delays

Many of the complaints HDC is currently receiving highlight the physical and psychological impacts on people of current delays in, and barriers in access to, specialist and emergency care, with many people reporting significant progression of symptoms or disease while on a waitlist.

Delays in cancer care

HDC holds significant concerns about current pressures on cancer care services, particularly in respect of radiation oncology and current surgical delays impacting on cancer management. We have received reports of people developing metastatic disease while on the waitlist for surgical management and both consumers and providers continue to raise concerns directly with HDC about these issues.

Complaints to HDC reflect long waits for radiation oncology treatment in some areas of the country, and there are currently significant constraints on the radiation oncology workforce nationally. While we acknowledge that addressing the workforce issues in this area is complex and will take time, long waits for cancer treatment can cause considerable life-limiting and psychological harm and it is critical that these services be prioritised.

We have raised these issues with Te Whatu Ora | Health New Zealand and made a number of recommendations in respect of our investigation into cancer care delays in the Southern region. We will continue to monitor progress in this area.

Emergency department delays

Complaints to HDC regarding care provided in emergency departments (EDs) are increasing. Concerns about delays in care are a feature of these complaints, with many complainants reporting extremely long waits to be seen. These complaints can, at times, highlight the tragic consequences that significant delays in emergency care can have, particularly where people are not re-triaged during their wait or where delays caused them to leave ED without medical review.

HDC acknowledges that the constraints on EDs are complex, and that a number of actions are being taken nationally to reduce demand on hospitals, improve infrastructure and address patient flow. However, that HDC continues to receive a high volume of complaints with people waiting well in excess of six hours is concerning. Providers also continue to raise concerns with HDC about the current pressure on emergency services.

Planned care capacity

One of the most common issues raised by complainants to HDC is long waits for planned care. Around 35% of complaints to HDC about surgical services relate to delays in care. These complaints reflect the negative impacts on people from a lack of certainty around when they can expect to receive care, and issues communicating with specialist care services, particularly for those with significant symptom progression or deteriorating conditions. For example, some districts are now reporting an average wait time of two years for orthopaedic surgery. Continuing geographical disparities in access to care across the country are also evident.

We have been pleased to see that Te Whatu Ora | Health New Zealand has been progressing the recommendations of the planned care taskforce and have set ambitious targets to reduce the planned care backlog. We will continue to monitor progress in this area.

HDC has also been concerned by changing access thresholds in response to current capacity constraints, with some services no longer seeing any non-acute patients or patients with benign conditions. While we understand that acute and cancer care must be prioritised, the patient harm that may be caused by people who would normally be accepted for specialist care being denied services is troubling. This also has the impact of increasing pressure on primary care, as well as districts losing visibility over the risk profile of their populations and exacerbating geographical inequities in care. We have raised these issues with Te Whatu Ora | Health New Zealand directly.

Informed consent

The principle of informed consent lies at the heart of the Code of Rights and is the foundation of all medical treatment. However, issues with informed consent processes continue to be a feature of complaints and are raised by complainants in around 18% of the complaints we receive.

Issues seen in regard to informed consent can include a lack of understanding of informed consent as an interactive on-going process between provider, consumer and their whānau; a failure to provide information in an accessible way or to engage people and their whānau appropriately in care in a culturally safe way; and the important role that culture and leadership play in ensuring that people's right to informed consent is upheld.

Complaints highlight the physical and psychological harm that can occur when a person's right to make an informed choice and give their informed consent is undermined. This can result in a significant loss of trust in the health system, and reluctance to seek further care.

HDC has been concerned by a loss of traction in relation to improving informed consent process across the sector. Improving informed consent requires ethical leadership and role-modelling from the health sector, as well as a whole-of-system approach to improvement. HDC has raised this as an issue at the National Quality Forum and will continue to champion improvement in this area.

Sustainability of aged care services

The sustainability of the aged care workforce is one of the most important challenges currently facing the aged care sector (home and community support services (HCSS), respite services and aged residential care (ARC)). It has serious ramifications for the quality of care provided to older people.

Older people are high users of the health system, and capacity constraints in aged care services are also placing additional pressure on emergency and specialist care and are resulting in longer lengths of hospital stay for older people. It is important that ARC and HCSS are valued as integral parts of the health and disability system and supported adequately to provide high-quality accessible care to a population with increasingly complex and acute needs.

The Aged Care Commissioner has recently highlighted significant concerns with Te Whatu Ora | Health New Zealand about the sustainability of psychogeriatric services in some areas of the country. Some regions lack appropriate care options for people with acute or complex psychogeriatric care needs, including a lack of access to appropriate facilities. Urgent action is required in this respect to ensure public safety is protected.

People with dementia are among the most vulnerable consumer groups in the health and disability system and are often not able to complain about the care they are receiving or advocate for themselves. Significant patient and whānau harm is caused by the lack of access to appropriate care options. Psychogeriatric beds across Aotearoa New Zealand have reduced. To the best of our knowledge, no provider in the private sector is currently including psychogeriatric level of care when building new facilities. This is a concerning prospect for the growing and vulnerable ageing population, particularly as we will see an increased number of people living longer with dementia over the next decade.

Access to quality health and disability care for older Māori must also be addressed. Current service models in aged care, especially ARC, do not meet the needs of Māori. There is a significant gap in the provision of kaupapa Māori services for people with mate wareware (dementia) and psychogeriatric care needs.

Women's health and quality of maternity care

Recurring themes are identified by HDC during the assessment of complaints about women's health, particularly regarding delayed diagnosis and treatment for pelvic pain conditions, informed consent practices, and a number of quality and safety issues in maternity care.

Maternity care

The volume of complaints received by HDC about maternity care is small (around 110 complaints a year), but the profile of complaints is more serious than is seen for other services, and the frequency with which common issues recur is concerning. The outcomes for the whanāu involved can be tragic, and the harm caused is inequitable with life-long consequences. HDC holds concerns about the lack of progress in relation to systemic issues within maternity care over time.

We acknowledge that maternity and early years services have been made a priority in Te Pae Tata – the interim New Zealand Health Plan, and that the constraints on the system, including geographical disparities, are complex and will take time to address.

We have been pleased to see a focus placed by Te Whatu Ora | Health New Zealand on developing a new approach to primary maternity care and the early years services. This is an important opportunity to remove systemic barriers to care and improve equity of outcomes. However, it will also be important that focus is placed on improving specialist maternity services, including addressing workforce issues, improving integration between primary and specialist care and ensuring a whole of maternity system approach is taken to quality improvements.

Surgical mesh

Complaints about surgical mesh are small in volume but have been increasing, reflecting ongoing concerns among some consumers about the adequacy of consenting processes and the competence of surgeons with respect to the quality and safety of urogynaecological mesh insertion and revision surgery. The pause on urogynaecological mesh insertion was a necessary safeguard recognising the serious harm experienced by some women. HDC is a member of the Surgical Mesh Roundtable in the role of independent monitor, and we will continue to advocate for adequate safeguards across the system and improvements to patient safety and experience in this regard.

Mental health and addiction services for people with complex, acute and/or ongoing needs

Complaints about mental health and addiction services make up around 11% of all complaints received by HDC each year.

We have been pleased to see the significant investment and improvements made in addressing support needs for people with mild to moderate mental health and addiction needs. However, complaints to HDC continue to highlight the significant systemic issues that recur for people with complex, acute and ongoing needs. Issues identified by HDC on assessment of complaints include the lack of community support options for people with complex and acute needs; the lack of culturally appropriate support options; the management/treatment of coexisting issues (particularly for people with substance use disorders or intellectual/neurodevelopmental disabilities); the treatment of personality disorders; and access to forensic services.

It is positive to see the commitment Government has made to establishing a Minister for Mental Health, and I would be pleased to discuss the issues we see in this sector in more detail with him.

Assisted dying

HDC is monitoring complaints about assisted dying services closely. Since the End of Life Choice Act came into force in November 2021, HDC has received 14 complaints about assisted dying services. These complaints tend to reflect concerns about the readiness of facilities to undertake assisted dying services, as well as discriminatory attitudes and approaches by some providers towards those seeking an assisted death, and variable understanding among providers of their obligations when they are undertaking conscientious objection. HDC liaises closely with the Registrar (Assisted Dying) and relevant regulatory authorities in respect of these complaints.

HDC will be paying close attention to the upcoming review of the End of Life Choice Act.

HDC's funding pressures

HDC is funded under the Monitoring and Protecting Health and Disability Consumer Interests Appropriation in Vote Health. In the year ended 30 June 2023, HDC received \$18,944,000 from this appropriation. As at 31 October 2023, HDC had 136 staff members (121 full-time equivalents). HDC did not receive any additional funding in Budget 2023.

HDC's resources are insufficient to meet current demand for our services. Financial forecasts indicate service reductions will be required by 2025 without a baseline funding lift to match our service requirements. HDC service reduction would diminish consumer voice at a time where such voice is critical to accountability and improvement, including meeting the objectives of the Pae Ora (Healthy Futures) Act and the New Zealand Health Strategy. It will also have a negative impact on the well-being of consumers, the health and disability workforce and on HDC's ability to respond to public safety concerns and effect timely quality and safety improvements.

In addition, rising costs have reduced the size of the Advocacy Service. The Advocacy Service has re-configured its services and the way in which advocates are able to engage with people in order to continue to meet demand with limited capacity. There are advocates throughout Aotearoa New Zealand, but the number of advocates has reduced from 48 in 2013/14 to 24 in 2022/23. This reduction is a concern to HDC, and we will be working with the Advocacy Service and the Government to ensure the future sustainability and reach of this valuable resource.