# Briefing to the Incoming Minister of Health



**10 February 2025** 

# 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**

Appointed: August 2021 (resigned her position effective from 21 March 2025) 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, Operations**

Appointed: September 2021

Vanessa (Kāi Tahu, Te Rapuwai, Waitaha, Kati Māmoe) 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, protects the public and helps to preserve trust in the health and disability system. We use our insights and levers to improve the system. Importantly:

- HDC promotes and protects the rights of people primarily through the resolution of complaints about infringements of those rights. We use insights from complaints to identify and leverage change within the health and disability sector.
- We are an independent Crown entity independent from Government and health and disability service provision, enabling HDC to be an effective and impartial watchdog for consumers' rights.
- In a no-fault system for treatment injury HDC is the key independent avenue for people to formally raise their concerns about health and disability services.
- Through the making and monitoring of recommendations we also hold the system to account to ensure quality and safety is improved (over 90% of our recommendations are complied with).
- Our unique dataset is grounded in consumer experience and can highlight areas of emerging risk.
  We take a collaborative approach to address areas of systemic concern, and work closely with other agencies to ensure public safety issues are identified and addressed.
- An Aged Care Commissioner was established within HDC in 2021 with ring-fenced funding to monitor and drive quality improvement in health and disability services for older people.
- We have just completed a review of the HDC Act and the Code of Rights (a statutory requirement), and our recommendations report has been sent to your Office.
- HDC receives around 3,600 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 52% above pre-COVID levels. HDC currently receives 300+ complaints a month.
- Most complaints (70%) are resolved using early resolution methods, such as referring the complaint for direct resolution between the complainant and provider. About 7-8% of complaints are formally investigated which may result in a provider being found in breach of the Code.
- HDC is legislatively required to purchase independent advocacy services 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 2,500 complaints a year, with almost all complaints resolved within nine months. Advocates undertake over 2000 activities to promote the Code each year.
- HDC is introducing multiple process changes to improve efficiencies in response to rising demand.
  Many changes have been successful, with HDC increasing our number of closures (including within the current year to date).

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# HDC's role and priorities

HDC's role is to promote and protect the rights of people using health and disability services as set out in the Code of Rights. We do this primarily through the resolution of complaints about the quality of care people have received in the health and disability system. HDC has an important role in holding the system to account for rights' infringement, and in this way assists to ensure the public is protected, quality, safety and patient experience is improved, and public trust in the system is maintained.

The Code of Rights sets the benchmark for patient-centred care in New Zealand, shifting the focus from the needs of the system to the experience of the patient. The Code of Rights gives people the right to an appropriate standard of care that meets their needs and upholds their dignity, ensures that people are provided with the information they require to make an informed choice and give their informed consent, and gives them the right to complain about the services they have received.

HDC is an independent Crown entity. Our independence from service providers and Government policy allows us to be an effective watchdog for the protection of people's rights. In New Zealand's nofault system for treatment injury (where ACC operates), HDC is the key independent avenue for people to formally raise their concerns about health and disability services. We provide a critical layer of independence and accountability.

HDC receives around 3,600 complaints a year. There is an enormous breadth to the issues raised in these complaints – ranging from relatively minor concerns through to concerns about near misses, serious physical and/or psychological harm, significant public safety issues and professional conduct concerns. HDC also considers complaints about a broad range of providers, including primary care, disability support services, prison health services, regulated and unregulated individual professionals, aged care providers, private and public hospitals and complementary medicine services.

HDC has a broad discretion and range of powers to respond to the issues raised in complaints. HDC is focused on supporting the early resolution of complaints between complainant and provider where possible and appropriate. Around 70% of complaints are resolved using early resolution methods (such as referring the complaint to the provider or the Advocacy service to support resolution).

HDC also has a focus on taking an educative approach to complaints. We make over 400 recommendations on individual complaints each year designed to improve the quality of care provided and support adherence to the Code of Rights. HDC's recommendations have a high compliance rate of over 90%.

Around 7-8% of complaints are formally investigated which may result in a provider being found in breach of the Code of Rights. A small number of these breach findings also result in a referral to the Director of Proceedings to consider whether legal proceedings should be taken in the Health Practitioners Disciplinary Tribunal (for regulated providers) and/or the Human Rights Review Tribunal, noting that a consumer can only access the Human Rights Review Tribunal for legal remedies following a breach finding by HDC.

HDC has strong processes in place to ensure that public safety issues are escalated in a timely way to those authorities who can take action to protect patients. In respect of regulated providers, HDC works closely with the regulatory authorities, and any complaints that are primarily about an individual provider's competence or fitness to practise will be referred to those authorities. However, often health care is provided in a team environment. In these cases, HDC considers the contribution of organisational failings to individual behaviour — that is, our investigations seek to place individual

behaviour in its systemic context. Where care is provided in an organisational context, systems and organisations are found in breach of the Code of Rights more often than are individuals.

HDC has expanded our use of tikanga-led approaches to complaints resolution in recent years to support more effective resolution for Māori whānau where appropriate. We also have a focus on supporting tāngata whaikaha | disabled people to make complaints. In 2024/25 raising the capability of our staff to meet the needs of disabled people has been a priority.

### The role of the Advocacy Service

Under the HDC Act, HDC is required to purchase independent Advocacy services on behalf of the Crown to assist people to resolve their concerns directly with the provider and to undertake community-level promotion of the Code of Rights. HDC therefore contracts the National Advocacy Trust to provide the Nationwide Health and Disability Advocacy Service. Advocates have focus on those communities with the highest need and those who may be more reliant on the care provided (for example, people in disability residential support services). The Advocacy Service plays an important role in supporting HDC's focus on early resolution.

There are 28 advocates located throughout New Zealand, who resolve around 2,500 complaints a year. Advocates guide people to clarify their concerns and resolution needs and facilitate effective responses from providers. The advocacy process can assist to mitigate the power imbalance between consumers and providers, and to restore trust and rebuild relationships. Advocates also undertake over 2000 activities each year to raise people's awareness of the Code and complaint avenues. Advocates make over 20,000 contacts with enquirers each year – helping people to navigate the complaints process, understand their rights, and develop self-advocacy skills.

### The role of the Aged Care Commissioner

In 2021 Government established an Aged Care Commissioner within HDC, and Carolyn Cooper was appointed to the role in 2022. The Aged Care Commissioner's mandate is to drive quality improvement in health and disability services for older people, advocate for better services for older people and their family/whānau and report on emerging systemic issues and improvements.

The Aged Care Commissioner monitors the responsiveness of the health and disability system to meet the needs of older people. In March 2024 she published her first monitoring report which set out 20 recommendations for the sector to improve the quality of care provided to older people. These recommendations focused on:

- The need for better transitions of care for older people from hospital to home and aged residential care.
- Investing in innovative primary and community care models, including assisting older people to navigate health and disability services.
- Ensuring that people can access reliable, quality home care and community support services to age well at home.
- Preventative interventions for dementia mate wareware.

The Aged Care Commissioner's current focus is on evaluating and reporting on actions taken in response to her recommendations and identifying emerging issues in the sector. In 2025 she will also have a focus on driving improvements for older people in regard to: hearing health, bone health and oral health (all of which are preventative factors to assist people to age well).

As a Deputy Health and Disability Commissioner, the Aged Care Commissioner is also a statutory decision-maker on complaints about care provided to older people. This is an important aspect of her

role which allows her to: understand the issues of most concern to older people and their families and address these in her wider monitoring work; further drive quality improvement through the making and monitoring of recommendations on individual complaints; and hold providers to account for upholding the rights of older people using health and disability services.

### Responding sustainably to growing demand

Figure 1. Number of complaints received by HDC



	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25 (YTD)*
Number of complaints received	2393	2721	3413	3353	3628	1601
Number of complaints closed	2226	2404	2627	3048	3148	1622
Number of complaints open	934	1251	2037	2342	2822	2801

<sup>\*</sup>This represents 6 months' worth of data (1 July – 31 December 2024)

HDC is under pressure from a significant increase in the number of complaints in recent years. Complaints have increased by 52% over the past five years, and we are receiving on average around 300 complaints a month. While this increase in complaints was initially due to a rise in COVID-19 related complaints (which caused a 25% increase in volume in a single year), the increase in volume has continued despite pandemic restrictions ending.

Despite 70% of complaints to HDC being closed within 6 months, the increases in complaint volume have put significant pressure on the time it takes HDC to resolve more complex complaints and investigations. This has led to a growing number of complaints under assessment.

HDC has implemented a number of changes to our process to increase our efficiency and productivity, including:

- Increasing the proportion of complaints closed by early resolution methods (such as referrals to providers and the Advocacy service) and streamlining our early resolution processes thereby supporting the timely resolution of complaints and ensuring that HDC's resources are focused on those complaints which require our intervention.
- Using our early resolution powers more flexibly to achieve resolution for the individual while also using the themes in these complaints to advocate for quality improvement on a systems level.
- Putting more senior and clinical resource into our triage processes to improve our prioritisation of complaints.
- Implementing a mid to long term plan to reduce our cohort of complaints aged 2 years and over.
- Exploring alternative resolution pathways for some appropriate complaints awaiting investigation.

These changes have proved largely successful with HDC continuing to increase the number of complaints we close, including a significant increase in the proportion of older complaints closed. At the end of December 2024, we had increased our closure rate to over 100% (meaning we closed more complaints than we received), with 18% of complaints closed being over 2 years old (as compared to 7% during the same period in the previous year). However, the proportion of complaints aged over two years is proving hard to reduce as this cohort shows the impact of a 25% increase in complaints within a single year in 2021/22.

HDC is currently working closely with the Advocacy Service to explore how more complaints could be directed to advocates in the first instance thereby reducing demand on HDC. However, the Advocacy Service has reduced substantially in recent years in the context of static funding and rising costs.



### **Review of HDC Act and Code of Rights**

We have just completed a review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Rights, sending our recommendations for proposed amendment to your predecessor, Minister Reti, on 20 December 2024.

HDC's Act requires us to undertake these reviews regularly and to make recommendations to the Minister of Health as to whether any changes are required. It also requires the Minister of Health to table our recommendations report in Parliament within 12 sitting days of receipt (6 March 2025 in this case).

Our latest review was initiated following the enactment of the Pae Ora Act, and focused on how the HDC Act and the Code of Rights could better meet the needs of all New Zealanders, including those involved in service provision. We undertook significant consultation throughout the review and had a particular focus on Māori and disabled communities and other groups who experience more of a power imbalance when engaging in care and are less likely to raise concerns. There was substantial agreement by stakeholders on the priorities for the review, and for changes to the Act and Code, particularly to support timely, people-centred resolution.

Our recommendations for change are designed to support us to use our resources where they are most needed, including through clarifying expectations for the sector, and providing us with greater capability and flexibility to respond efficiently and effectively to complaints. Much of what we heard is better addressed by operational change, and we are progressing this as resources allow. The insights gained from our consultation are also being shared with other agencies to support learning and improvement.

We are mindful of the intersection of our review with current reviews of other legislation, particularly the Health Practitioners' Competence Assurance Act and the Mental Health Act, the Law Commission's review in the adult-decision-making capacity law as well as the government's response to the Royal Commission of Inquiry into Abuse in State Care. As you will see from our report, our view is that changes to the Act should be progressed alongside this work to ensure consistency and cohesion, with changes to the Code finalised once policy direction is clear.

# What are complaints telling us about the system?

### HDC's focus on public protection and system monitoring and improvement

HDC plays a key role in improving quality and safety. We closely monitor the trends that emerge across complaints, and aim to take a timely, collaborative approach to raising issues of systemic concern. HDC works with sector leaders and other agencies (including groups such as the National Quality Forum), who have a role in quality and safety to share intelligence, ensure that timely action is taken on public safety concerns, and support a multi-agency approach to areas of shared concern.

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 other 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.

HDC also has the power to undertake own motion investigations in the absence of a complaint. These investigations can be a powerful tool in bringing attention to and addressing significant systems issues. A recent example is our investigation into <u>cancer care delays in the Southern region</u>.

### How HDC can support the Minister

HDC has a unique role in the health and disability system. Our data is grounded in people's experience and can provide insight on emerging risk and the issues people care about most.

HDC has an important role to play in supporting the Ministry of Health, 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 its commitments under Pae Ora (Healthy Futures) Act and the New Zealand Health Strategy.

HDC is supportive of the focus of the GPS on access to timely, quality healthcare which reflects many of the issues we see in complaints. The obligations on providers as set out in the Code of Rights set the standard for quality care that focuses on and improves people's experience in the system. HDC holds providers to account for providing timely, quality care where appropriate, and makes associated recommendations to improve care in this regard.

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

### **Current issues raised in complaints**

The number of complaints made to HDC represent a small proportion of the thousands of interactions New Zealanders have with the health and disability system every day. Most of the time people in New Zealand experience quality patient-centred care.

HDC has been pleased to observe a health and disability sector that is largely committed to learning from complaints, improving consumer and family/whānau experience and providing high quality consumer-centred care. However, we hold concerns about the slow pace of progress, and a lack of sustainable improvement in response to patient harm in some service areas.

Below are some of the issues people are currently raising with HDC and the systemic issues that HDC is currently focused on. We would be happy to discuss our insights from complaints further with you if this would be helpful.

### Importance of strong clinical governance frameworks

Transparent, permanent clinical governance frameworks and clear risk escalation pathways have been slow to emerge across Health NZ. We have been pleased to see significant progress in these areas has been made recently. However, at times, we have observed a disconnect between local districts and national structures, and it will be important that clinical governance pathways are clear to clinicians and support timely risk management at a local level.

It is our hope that clear governance frameworks at a regional level will support more regional models of care to emerge. We acknowledge that progress has been made in some areas and that significant workforce issues and complex structural roadblocks make regionalisation of waitlists and models of care difficult. However, complaints indicate that persisting geographical inequities are a source of significant frustration and concern to people and disproportionately affect rural and high need communities.

Digital systems and digital integration are important enablers of safe, quality care. Complaints to HDC continue to show the harm that can be caused by fragmented digital systems, and the use of paper-based referral and medication management processes. The nationalisation of some data and digital functions is positive in regard to greater consistency across the country. At times, HDC has been told that due to this nationalisation, local districts are unable to comply with HDC recommendations for digital improvements. It will be important that priorities in this area are communicated effectively to local leaders.

### Capacity in the system to undertake quality improvement and respond to complaints

Compliance with HDC recommendations has decreased a little over the past two years. While much of this is due to individual provider compliance, some is due to a lack of capacity in the system to undertake quality improvement work (such as implementing sepsis pathways). We have also observed that some serious events have been contributed to by a lack of staff capacity to undertake improvement work (such as updating clinical guidelines in line with best practice).

In addition, some districts are experiencing long delays in undertaking complaints resolution. These delays can result in complaints being escalated to HDC that could have been resolved at district level and increase complainant frustration and distress. Delays in undertaking adverse event reviews and poor communication with bereaved families in the context of such delays is also contributing to the escalation of complaints and increasing distress, as well as impacting on the timeliness of any associated quality improvements.

### Constrained access to care

The most common issue in complaints to HDC are the impacts that current constraints on the system are having on people's access to care and the physical and psychological harm that can be caused by long waits for care. Many of these complaints are exacerbated by poor communication with people or the lack of a people-centred approach to communication, for example, lack of information about service reductions, timeframes for treatment and alternative options for care.

Concerns currently being raised in complaints include:

- Changing access thresholds and service reduction
- Radiology delays
- Delay in access to emergency department care
- Cancer care delays
- Primary care delays

### Health of tāngata whaikaha | disabled people

HDC plays a critical role in improving the quality of care provided to tāngata whaikaha | disabled people by health and disability providers and in ensuring tāngata whaikaha | disabled people's rights are upheld. Disabled people experience overall worse health outcomes than non-disabled people despite being proportionally higher users of the health system.

Currently around 30% of complaints to HDC relate to the care provided to tāngata whaikaha | disabled people, with the majority of these complaints being about health services. Learnings from HDC's complaints demonstrate the need to build understanding of disability in the health sector and understanding of tāngata whaikaha | disabled people's rights under the Code of Rights – for example, the need for better understanding of adult decision-making capacity and supported decision-making and the need for accessible and effective communication by health providers.

Complaints can also highlight gaps in care for tāngata whaikaha | disabled people with complex health conditions. Other notable gaps include timely access to diagnosis which impacts on access to disability supports, and shortages of allied health professionals impacting on access to care (for example delays in accessing speech language therapists can put some disabled people at greater risk for choking incidents (HDC is managing a cohort of five complaints received over the past year relating to the deaths of disabled people by choking in residential disability settings).

### Care for an aging population

Actions the Aged Care Commissioner continues to advocate for include:

- Quality discharge planning by hospitals for improved transitions of care for older people from hospital to home and residential care.
- Addressing gaps in psychogeriatric care across the country noting the potential for harm due to some regions of the country lacking appropriate care options for people with acute or complex psychogeriatric care needs.
- Addressing gaps in kaupapa Māori aged care services, particularly for people with dementia mate wareware.

- A focus on preventative interventions to reduce the incidence of dementia mate ware ware and improve older people's well-being, including hearing health, oral health and bone health.
- Investing in innovative models of care e.g. consistent community-based acute models of care to prevent and treat cognitive conditions.

Aged care providers are a crucial partner to reduce pressure on other areas of the health system and to ensure the health and well-being of older people. Innovative models of care with a focus on preventive interventions and the care of people with complex needs will be required to address capacity constraints and meet the needs of an increasingly diverse population.

### <u>Informed consent</u>

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 16% of the complaints we receive.

HDC has been concerned by a loss of traction in relation to improving informed consent process across the sector in recent years. We are pleased to see that exploring a national informed consent policy is a priority for Health NZ in 2025, although this will need adequate resourcing. HDC will continue to liaise with Health NZ about action being taken in this regard.

### Quality of maternity care

HDC has held concerns over many years about the lack of progress in respect to quality and safety issues in maternity care, including a failure to implement multiple recommendations made by different agencies. While the volume of complaints received by HDC about maternity care is small (around 150 complaints a year), the profile of complaints is more serious than is seen for other services, and the frequency with which the same issues recur is concerning. The outcomes for the families involved can be tragic, and the harm caused is inequitable with life-long consequences.

The workforce constraints in maternity are significant and complaints to HDC highlight the impact they are having on the quality of care provided, particularly for regional maternity units. National guidelines have not always been implemented successfully, and a common issue seen in complaints is a failure to appropriately follow clinical guidelines.

Health NZ's work to develop a new approach to primary maternity care and the early years services is an important opportunity to remove systemic barriers to care and improve equity of outcomes. However, there is an urgent need to improve 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. Strong regional and national clinical governance frameworks for maternity services may go some way to addressing these persistent issues.

### 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, many of which relate to care provided to people with complex needs.

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, improving coordination of care for people who require specialist services across several 'departments' or systems (including mental health, disability and aged care) needs urgent attention. HDC has called on leaders in these areas to work collaboratively on solutions that ensure people receive appropriate

coordinated care and are well supported when their needs change. This has yet to be realised and we continue to see people both inappropriately admitted to inpatient units due to inadequate support from other care providers, and being required to stay in inpatient units for longer than clinically indicated due to difficulties with finding appropriate support and accommodation for people on discharge.

In addition, complaints to HDC can often reflect differing expectations between family members and clinicians about appropriate care for people with complex or acute needs. There remains a pervasive misunderstanding in the general public about appropriate supports for people in high distress. Many complaints and public concerns would be mitigated by improving general understanding about what works for people who are in high distress.

We would be pleased to discuss these issues further with the Minister for Mental Health.

#### Assisted dying

HDC has a role in upholding the rights of people using assisted dying services and is monitoring complaints about such services closely. Since the End of Life Choice Act came into force in November 2021, HDC has received 22 complaints about assisted dying services. HDC liaises closely with the Registrar (Assisted Dying) and relevant regulatory authorities in respect of these complaints.

HDC notes the recommendations made by the Ministry of Health in their review of the End of Life Choice Act many of which address issues seen in complaints. In HDC's view, there would be additional value in agencies working together to develop guidelines and competencies to guide best practice and clarify expectations for people accessing the service, and we continue to work with relevant agencies on this issue.