



Disabled Persons Assembly NZ

July 2024

To Health and Disability Commissioner

Please find attached submission on Ko te arotake i te Ture me te Tikanga Mōtika I
Review of the Act and the Code 2024

For any further inquiries, please contact:

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Introducing Disabled Persons Assembly NZ

We work on systemic change for the equity of disabled people

Disabled Persons Assembly NZ (DPA) is a not-for-profit pan-impairment Disabled People's Organisation run by and for disabled people.

We recognise:

- Māori as Tangata Whenua and [Te Tiriti o Waitangi](#) as the founding document of Aotearoa New Zealand;
- disabled people as experts on their own lives;
- the [Social Model of Disability](#) as the guiding principle for interpreting disability and impairment;
- the [United Nations Convention on the Rights of Persons with Disabilities](#) as the basis for disabled people's relationship with the State;
- the [New Zealand Disability Strategy](#) as Government agencies' guide on disability issues; and
- the [Enabling Good Lives Principles](#), [Whāia Te Ao Mārama: Māori Disability Action Plan](#), and [Faiva Ora: National Pasifika Disability Disability Plan](#) as avenues to disabled people gaining greater choice and control over their lives and supports.

We drive systemic change through:

Rangatiratanga / Leadership: reflecting the collective voice of disabled people, locally, nationally and internationally.

Pārongo me te tohutohu / Information and advice: informing and advising on policies impacting on the lives of disabled people.

Kōkiri / Advocacy: supporting disabled people to have a voice, including a collective voice, in society.

Aroturuki / Monitoring: monitoring and giving feedback on existing laws, policies and practices about and relevant to disabled people.

United Nations Convention on the Rights of Persons with Disabilities

DPA was influential in creating the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),¹ a foundational document for disabled people which New Zealand has signed and ratified, confirming that disabled people must have the same human rights as everyone else. All state bodies in New Zealand, including local and regional government, have a responsibility to uphold the principles and articles of this convention.

The following UNCRPD articles are particularly relevant to this submission:

- **Article 3.1 - Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of person**
- **Article 12 – Equal recognition before the law**
- **Article 13 – Access to justice**
- **Article 14 – Liberty and security of the person**
- **Article 15 – Freedom from torture or cruel, inhumane or degrading treatment or punishment**
- **Article 16 – Freedom from exploitation, violence and abuse**
- **Article 17 – Protecting the integrity of the person**
- **Article 22 – Respect for privacy**
- **Article 25 – Health**
- **Article 26 - Habilitation and rehabilitation**

New Zealand Disability Strategy 2016-2026

Since ratifying the UNCRPD, the New Zealand Government has established a Disability Strategy² to guide the work of government agencies on disability issues. The vision is that New Zealand be a non-disabling society, where disabled people have equal opportunity to achieve their goals and aspirations. It identifies eight outcome areas contributing to achieving this vision.

The following outcomes are particularly relevant to this submission:

- **Outcome 5 – Accessibility**
- **Outcome 7 – Choice and Control**

The Submission

DPA welcomes the opportunity to feedback to the Health and Disability Commissioner Te Toihau Hauora, Hauātanga on the Ko te arotake i te Ture me te Tikanga Mōtika Review of the Act and the Code.

Both the legislation and the code have been key towards building a more rights-based approach to health and disability service provision over the last thirty years.

While the health and disability system has a long way to go in ensuring that all disabled people are treated with dignity and respect, these two documents have been the starting point for disabled people and non-disabled people alike to have their rights upheld.

The aim of the Act and the Code has been to promote and protect the rights of health and disability service users with the aim of educating providers about their responsibilities and educating service users about their rights when accessing services.

The other main purpose of the legislation has been to create a space where learnings can be gained from complaints and their resolution, which has been beneficial for both service users and providers.

However, the health and disability system continues to experience significant challenges, particularly when it comes to the care of disabled patients in hospital or other healthcare settings and disabled people living in residential services and receiving supports.

This review provides the potential for creating a more robust health and disability rights mechanism going forward as the legislation and code mark their 30th anniversary.

Our submission traverses the main questions asked in the consultation document.

Topic 1: Supporting better and equitable complaint resolution

Q.1) Did we cover the main issues about supporting better and equitable complaints resolution?

Yes, as they encompass the broad scope of concerns that we have heard from disabled people. One of DPA's main concerns has been that some health and disability advocates have sought to take the side of health and disability service providers and not consumers during their advocacy work. Doing so has violated the requirement that all advocates should always side with the consumer, regardless of their own opinion.

The proposal to insert a non-retaliation clause as part of Right 10 is long overdue. Disabled people are often at greater risk, particularly when making complaints, from being confronted by providers who have greater power than they have. This is due to the great imbalance that has traditionally existed between providers (whether they be health or disability-related) and disabled people.

This imbalance has created greater vulnerability for disabled people when making and going through complaints processes. It has not been unknown for disability service and/or health providers to retaliate against disabled people in some way for making complaints.

Amending the purpose statement to incorporate the concept of mana is very important as it would acknowledge the role of Te Ao Māori and tāngata whaikaha Māori. As the discussion paper states, mana resides not only within Māori but in all people, giving them respect and autonomy, the upholding of which informs a great deal of HDC's work.

Clarifying the role of cultural responsiveness and that of whānau flows from the upholding of mana and Te Ao Māori. Given that disabled people span the population spectrum and have many intersectionalities/identities, it is important to specifically affirm and respect everyone's cultural identity, including that of the Deaf community, in the revised Code.

The proposed improvements to the language around complaint pathways in the Act is also a positive step. Stressing the mediative/facilitative approach to resolving

issues within the health and disability system is important on the proviso that further legal action is and should remain as a backstop if needed.

Q.1.2) What does DPA think of our suggestions for supporting better and equitable complaint resolution, and what impacts could they have?

Around strengthening the advocacy service, DPA recommends that this proposal include robust training, monitoring and complaints processes put in place by the HDC to ensure that advocates always support consumers/service users.

DPA acknowledges that all health and disability advocates are employed by providers contracted to HDC and this might mean that there is insufficient oversight of the activities of advocates employed by some contracted providers as well.

Recommendation 1: that HDC investigate employing all local health and disability advocates directly, through ending the contracting out model, which would enable the Commission to exercise greater oversight over all advocates.

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

Disabled people have commented on the delays and effectiveness of the complaint resolution system, the mental distress of going through the process due to the power imbalance between disabled people and the health professionals or providers, the financial cost of attending mediative/facilitative meetings and disabled people struggling to manage their physical and mental wellbeing during the process.

Fast tracking complaints where possible is important as this is an area regularly highlighted by disabled people, but it is also important that a balance is struck between the need for efficiency and effective resolution.

The availability of hui ā-whānau and hohou te rongo for tangata whaikaha Māori highlights the importance of a culturally responsive process for all tangata whaikaha.

In this section, there is a comment that this process is available 'where appropriate'. Appropriateness should be based on the needs and rights of tangata whaikaha Māori rather than those of organisations.

Recommendation 2: that HDC involve health and/or disability supervisory organisations in the the mediative/facilitative process, for example, the New Zealand Medical Council.

Recommendation 3: that HDC ensure that disabled people are provided with accessible advice on financial, legal and counselling processes during the mediative/facilitative process.

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

DPA recognises Te Tiriti o Waitangi as the rangatira document on the rights of Whanau Hauā (disabled Māori in connection with their whānau, hapū and iwi). It is promising to see that the voices of Whanau Hauā have been included during the consultation process as the Supreme Court now recognises tikanga as the first law of Aotearoa New Zealand and part of common law.

Tikanga Māori informed by mātauranga Māori within Te Ao Māori can be distorted when it is made to fit into frameworks that do not understand it or value it despite its ability to adapt to societal and technological developments. It is important that the mana and rangatiratanga of disabled Māori is retained through the process as many processes, systems and services can take away the mana and inherent dignity of disabled Māori.

Recommendation 4: that HDC ensures that tikanga Māori informed by mātauranga Māori within te ao Māori is implemented at all levels of the organisation.

Q.2.1) Did HDC cover the main issues about making the Act and Code more effective for, and responsive to, the needs of Māori?

The needs of disabled Māori differ from whānau to hapū to iwi, but it is important to acknowledge them as leaders in their own lives and their requests to include whānau during complaints processes. Some government processes remove the mana of an individual and it is the ability for disabled Māori to return to their whānau, hapū and iwi to have their mana restored that is crucial. When disabled Māori are isolated or alienated from their people and their land, this impacts on their wellbeing.

Traditionally, 'whānau' does refer to family members connected by blood but as tikanga Māori informed by mātauranga Māori within te ao Māori has developed, so has the concept of 'whānau' to include people with close relationships.

Another important aspect is understanding the whakapapa of the journey for some Māori who mistrust the system due to past hurts caused by processes that have not acknowledged them as Māori.

Q.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?

Recommendation 5: that HDC be directed by disabled Māori on their definition of tikanga Māori, mātauranga Māori and whānau.

Recommendation 6: that HDC ensure that sufficient safeguards are put into place to ensure disabled Māori are the key decision makers when it comes to their health and disability requirements.

Recommendation 7: that HDC support their staff to undertake training in tikanga Māori, mātauranga Māori and te ao Māori in relation to working with Whanau Hauā.

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

Q.3.1) Did HDC cover the main issues about making the Act and the Code work better for tāngata whaikaha I disabled people?

DPA cautiously agrees with the proposal to strengthen disability functions through promoting a greater focus on disability issues. DPA fully endorses a greater focus on tāngata whaikaha/disabled people as well as the need to promote greater trust and engagement with HDC.

A requirement to report to the Minister for Disability Issues would be another positive step forward. DPA endorses all the other proposals made in this section including the need to update definitions relating to disability to ensure that they reflect a strengths-based approach based on the UNCRPD and removing the words 'reasonably practicable' in Right 5 in relation to the right to access a competent interpreter.

We are pleased to see that clarifying the right to supported decision making has been taken up in this consultation. We recently participated in the Law Commission's consultation over the issue of supported decision making for adults to which we made a written submission.

DPA endorsed the general direction of the Law Commission's discussion paper towards creating a system of supported decision making which upheld the need to respect the 'will and preferences' of individuals needing this support.

We see that HDC agrees with the Law Commission's proposals as well.

For all the above reasons, the need for both any updated health and disability complaints legislation and adult decision-making legislation to be well aligned is crucial.

Q.3.2) What does DPA think of HDC's suggestions for making the Act and the Code work better for tāngata whaikaha I disabled people, and what impacts could they have?

Our hesitancy stems from the need to clarify what is meant by 'a legislated role focused on disability issues could strengthen oversight of complaints from a disability perspective...'

The fact that there are already several government organisations tasked with receiving complaints from disabled people including the Human Rights Commission, Office of the Ombudsman and Whaikaha Ministry of Disabled People means that there is a need to avoid duplication and overlap.

Recommendation 8: that HDC's focus remain on promoting and upholding the rights of disabled people when receiving a health or disability service.

However, DPA recognises that there is already a significant degree of cooperation and dialogue between the abovenamed government agencies and others involved in the rights upholding space, including the Office of the Privacy Commissioner.

This level of cooperation and interaction between HDC and other rights-based government entities needs to continue, especially over proposals to update the Act and Code and adult decision-making legislation.

Q.3.3) What other changes, legislative and non-legislative, should we consider for making the Act and the Code work better for tāngata whaikaha I disabled people?

When tāngata whaikaha/disabled people visit medical centres, disability service providers, health professionals and other health and disability related agencies, the Act and the Code pamphlets and poster are usually on display. However, even if the format is accessible for disabled people, how that translates to disabled people accessing the health system does present challenges, especially when frontline staff are not adequately trained to provide information or uphold and respect our rights within the system.

In the section on tikanga Māori, the aspect of understanding the journey for all disabled who mistrust the system due to past hurts caused by processes that have not acknowledged their inherent dignity is important too.

Recommendation 9: that HDC provide information on their posters and pamphlets in accessible formats.

Recommendation 10: that HDC send all health and disability providers and DPO's regular updates.

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

Q.4.1) Have we covered the main issues about considering options for a right of appeal of HDC decisions?

Introducing a right of appeal for HDC decisions is crucial if the system is to maintain its credibility.

Earlier in this submission, we referred to the anecdotal evidence indicating that a minority of advocates were not always fulfilling their duty to support clients, irrespective of their own opinions.

In these and other possible scenarios, it is important to have a legal backstop in the form of a right of appeal on HDC decisions as, for example, a disabled person may have been unduly influenced by an advocate agreeing with the views of a provider or

facing a provider prepared to hide behind legal processes in simply dismissing complaints.

DPA also agrees with dropping the threshold to take health and disability complaints to the Human Rights Review Tribunal (HRRT). Dropping the threshold to the same level as that used to take cases to the HRRT under the Privacy Act will enable more people to take cases further if they are dissatisfied with HDC rulings.

Q.4.2) What does DPA think about the suggestions for considering options for a right of appeal of HDC decisions, and what impact could they have?

These changes extend the legal avenues for redress available to people if they are dissatisfied with HDC rulings.

Conversely, these changes could lead to more frustration and delay for some complainants, particularly if they choose to appeal any decisions. For disabled people, taking complaints and appeals often leads to additional stresses over and above those experienced by non-disabled people going through the same process. These stressors include the ability for disabled people to experience mental distress and poor physical health if appeals processes are too lengthy.

Another consideration is the need to avoid additional legal costs falling on people who cannot afford them. This includes for many disabled people who predominantly live on low, fixed incomes, being unable to pay any additional legal fees, something that has become more of a barrier due to changes to legal aid that have made it more difficult to access. This is why any HDC appeals process should remain cost free for complainants.

Recommendation 11: that any HDC appeals can continue to be taken free of charge by complainants.

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

It is vital that all complainants can access support if they need assistance with taking complaints and handling appeals.

DPA recognises that many complainants already access informal support, for example, in the form of whānau/family, friends, colleagues and communities during complaints processes.

Disabled people, still need to be able to access more formal support including independent lawyers, advocates or advisors who can support them, particularly when appeals are made against HDC decisions.

The need to ensure that any support - especially when complaints are made about the HDC itself or its decisions – remains independent of the Office itself is paramount.

DPA would like to see another government agency, such as the Ministry of Justice should fund Disability Community Law Centres and other avenues of support for people taking cases/complaints against the HDC to ensure that that support is available and independent of the Office.

Recommendation 12: that the Ministry of Justice or another government agency fund legal advice and support needed by complainants taking appeals against HDC decisions.

Topic 5: Minor and technical improvements

Q.5.1) What does DPA think about the issues and suggestions for minor and technical improvements, and what impacts could they have?

DPA endorses the proposal to increase the maximum fine for an offence under the Act from \$3,000 to \$10,000. Increasing the fine will act as a deterrent in signalling to health and disability providers the need to always respect the rights of health and disability service users.

DPA cautiously agrees to giving the Director of Proceedings the power to require information.

Recommendation 13: that any power to require information include several caveats, primary amongst them that any information requested by the Director is deemed vital to the resolution of a complaint or complaints and that it be released to the Director only with the consent of the individual whose information has been requested.

DPA cautiously agrees to providing HDC with grounds to withhold information where appropriate. We are cautious given that there is an outside risk that HDC could withhold information that might later prove crucial to a case or make a mistake around the handling of that information which might impact on the organisation's integrity.

Recommendation 14: that grounds for the reasonable withholding of information are clearly outlined in any changes to the HDC Act.

We welcome the requirement for written consent to sedation equivalent to anaesthesia as this will enhance that the rights of all health system users when undergoing such procedures. Sedation can impact on the ability of people to respond during procedures and the need for anaesthetists and other health professionals to outline the benefits and risks of procedures beforehand through both written and oral means is also vital.

The same extends to the need for written consent to be required when there is a significant risk of serious adverse effects around any procedure or treatment. For disabled people, obtaining written consent can sometimes present a barrier due to, for example, being unable to physically write or experiencing literacy issues.

Recommendation 15: in situations where a person cannot give written consent due to disability, other accessible ways of doing should be recognised including, for example, the ability to use New Zealand Sign Language, alternative communication boards, or other means of communication used by that person.

Recommendation 16: in terms of the definition of ‘teaching’, it should be defined as any situation where a consumer/service user will be involved as a participant in an educational and/or training setting where ākonga/students, researchers or other persons will receive training or instruction in the provision of health care or disability support and where the service user/consumer is being used as either a case study or participating in other ways.

This should also include situations where the service user is either directly present (whether in person or online) or indirectly referred to, even if anonymously, during any teaching. All individuals should give their active, free consent to participating via written or other means of communication used by that person.

Recommendation 17: ‘research’ should be defined as any activity where research is being undertaken on health or disability matters and where individuals are being used as subjects for the purposes of acquiring data or other information during that research. All individuals should give their active, free consent to participating via written or other means of communication used by that person.

Q.5.3) What are DPA’s concerns about advancing technology and its impact on the rights of people accessing health and disability services?

DPA acknowledges the changes happening in the advanced technological space, including the rise of artificial intelligence (AI). For disabled people, and wider society, AI presents both opportunities and risks in the health and disability area.

The opportunities include the ability to improve communication technologies for disabled people, which will mean that health service users will have a greater ability to communicate with health and disability providers in a wide range of ways.

The ability to do so will enhance the efficiency and ease with which otherwise overstretched health professionals can record medical and other data, including through the ability to upload audio and files to secure databases.

Conversely, there is a risk that data can be stolen and/or altered as the result of electronic hacking without the knowledge of either individuals or the healthcare workers supporting them.

Already electronic hacking has seen the potential risk for identity theft, or the malicious altering of health and disability information rise exponentially.

Malicious data hacking, whether on an individual or systemic basis, could have detrimental consequences in that information may be lost or altered impacting on the ability of individuals to receive timely, accurate and effective health care or disability support.

Similarly, in the disability space, there is more emphasis on Enabling Good Lives (EGL) which will see many disabled people transition away from using disability support agencies meaning that either they, their whānau/family or support workers will have more responsibility for inputting information about the supports they need plus other relevant information into cloud-based databases.

Q.5.4) What changes, both legislative and non-legislative, should be considered to respond to advancing technology?

For all the above reasons, it is important that the privacy of any health and disability data receives greater protection in this age of advancing technology.

At a practical level, this can be done through increasing the level of training and support for disabled people and workers within the health and disability workforce as well as ensuring that there is a high level of cooperation between HDC and the Office of the Privacy Commissioner.

Recommendation 18: that disabled people and disability support workers receive training and support from HDC on the need to protect health and disability data, especially that which is created and stored electronically.

Recommendation 19: that HDC collaborates with the Office of the Privacy Commissioner to develop policy, training and support for all health and disability workers in the safe storage of personal data and use of AI technologies.