Auckland Disability Law

31 July 2024

Health and Disability Commissioner
PO Box 1791
Auckland 1140 *via email* review@hdc.org.nz

Tēnā koutou,

Auckland Disability Law Submission on Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights

Introduction

1. Auckland Disability Law ("ADL") is a community law centre. We are the only community law centre in Aotearoa New Zealand which solely provides legal services and activities to Deaf and disabled people around their disability related legal issues. We have a national scope of activity that includes, advice, information, representation, advocacy and legal reform.

2. ADL supports the Health and Disability Commissioner's ("HDC") intent to ensure that the Health and Disability Commissioner Act 1994 ("the Act") and the Code of Health and Disability Services

Consumers’ Rights (“the Code”) works better for tāngata whaikaha | disabled people to reflect modern understandings of disability rights by:

- Strengthening disability functions within the Act;
- Updating definitions relating to disability;
- Strengthening references to accessibility; and;
- Strengthening and clarifying the right to support to make decisions

Topic 1: Supporting better and equitable complaint resolution

3. ADL submits that the current process that must be followed for a complaint to be accepted, investigated, referred to the Director of Proceedings ("DP") and advanced to the Human Rights Review Tribunal ("HRRT") and/or Health Practitioners Disciplinary Tribunal (“HPDT”) is not satisfactory. The process takes too long and is cumbersome. A stark example of this are the consumers who have had Right 2 breaches, primarily in sexual exploitation cases. From the cases, it is clear that many of these consumers are women, with mental health issues, who have been sexually exploited by male providers. These are examples of the most egregious types of behaviour by a provider. And yet, in order for these types of consumers to receive what they might consider to be "appropriate remedies", including damages, these women need to go through multiple gateways, over long periods. They need to tell their stories to the HDC, the DP, and then again to the HRRT, which hears cases de novo. This is a process that re-traumatises victims. It also fails to educate or discipline (particularly unregistered) providers, many of whom have already admitted their ethical breaches,

therefore negating the educative function of HDC. The system needs streamlining for particular types of cases, to ensure justice and minimising re-traumatisation.

4. If a breach is found, but there is no referral to the DP, or the DP declines to takes the case, then the aggrieved party can still take the case. The action that allows access to the HRRT is the breach finding by the HDC. Even fewer breaches are referred from the DP to the HRRT or HPDT, raising the concerns regarding consumers' access to a robust system of justice (Manning, 2018; Diesfeld, Surgenor and Rychert, 2020), as required by art 13 of the CRPD.

5. When few breaches result in a Tribunal proceeding, access to justice is compromised. The Code does not fully engage with the principles of justice because, for example, there is no requirement by the person who breached the rights to then remedy or "correct" the loss caused by the breach (Wall, 2018). Limited access to the HRRT limits consumers' access to justice.

6. Most breaches of the Code are anonymised and uploaded to the HDC website for educational purposes. The process of how these are selected should be transparent, with details regarding the ages and broad description of complainants' disabilities. This information will aid research to access whether the complaints regime is equitable.

7. Consumers and the public are unable to identify which providers have breached the Code from the anonymised opinions. This is due to HDC's unduly strict naming criteria policy, rather than the Act or

the Code. It's worth mentioning for these review purposes, however. It should not be the case that providers breach the Code multiple times before being identified, particularly if they are unregistered providers who face no other consequences for Code breaches. Changing the policy should be an easy fix. Access to this information would offer greater protection to disabled people. This would also be in the interest of improving transparency and accountability.

8. Opinions and case notes should be available in Easy Read and other accessible formats.

9. The infrastructure appears to be overly protective of the provider and not to recognise the need and the right of the consumers to “fair, simple, speedy, and efficient” resolution. ADL has seen this in almost every complaint we have assisted with to the HDC and also when using the Nationwide Disability Advocacy Service who are supporting disabled clients who are making complaints under the HDC process.

10. ADL is also concerned that the Independent Advocacy Service has reduced the number of their advocates recently and that they do not appear to have enough advocates for the whole of Aotearoa. Disabled people are particularly disadvantaged when there are inadequate advocacy supports provided by the HDC.

11. Given the State Inquiry into Abuse Report released in July 2024, it is vital to develop a robust and independent advocacy service, particularly for people in residential care or other positions of

dependency within disability services. This should be designed and staffed by disabled people.

12. ADL routinely have to advise clients that it will take several years for them to be told that their complaint has been accepted for investigation in the first place. In addition, the most they can expect as an outcome is for their situation to be anonymised and posted on the HDC website for educational purposes. They might get an apology and the provider might get referred for follow-up. The complainant has no other alternative to this process as they can’t sue.

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

13. ADL also agree that the Code and Act need to be more effective for, and responsive to, the needs of Māori to improve their outcomes in the health and disability system. The only reference to cultural considerations in the Code presently is in Right 1(3). This does not reflect the place of Māori as Te Tiriti partners.

14. ADL submits that HDC should offer trilingual interpreters. For example, more NZSL interpreters that Sign and people who speak Te Reo are required.

15. ADL submits restorative Māori processes should be integrated into the complaints and resolution process.

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

Did HDC cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?

16. ADL agree that the language relating to disability should reflect modern concepts of disability recognising that 'disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments'.[1]

17. ADL agree that references to accessibility should be strengthened. Specifically, the word "accessible" should be included in Right 5(1). For example, it should read "Every consumer has the right to effective and **accessible c**ommunication in a form, language, and manner that enables the consumer to understand the information provided".

18. Furthermore, Right 10, should state "Every consumer has the right to complain about a provider in any **accessible** form appropriate to that the consumer".

19. ADL also agree that the words "reasonably practicable" need to be removed from Right 5(1), where it is stated that "Where necessary and reasonably practical this includes the right to a competent interpreter". This would not place an undue burden on the provider, because Clause 3 of the Code still only requires providers to show they have taken "reasonable actions" to uphold the rights in the

---

[1] Ministry of Social Development, New Zealand Disability Strategy 2016–2026. Wellington: Ministry of Social Development; 2016, pg 12.

Code. Removing the words 'reasonably practicable' emphasises the importance of providing interpreters, while still not requiring providers to do the impossible.

20. A definition of “capacity” (or “competence”) is required. The importance of defining the concept of decision-making capacity was understood by Parliament when it passed the Substance Addiction Compulsory Assessment and Treatment) Act 2017 and the End of Life Choice Act 2019. Both define capacity. The Code was intended to be understandable to consumers and providers; the absence of a definition of capacity leads to confusion and may lead to unintended breaches. Abundant calls for clarification of capacity law in Aotearoa has recently been published (Ammundsen,2022; Douglass, Young and McMillan, 2020; Reuvecamp and Dawson, 2019). This is particularly important for disabled people who may be unjustly perceived as lacking decision-making capacity.

21. ADL also agree that the language in the Code needs to be strengthened and the right to support to make decisions should be clarified. We agree that Right 5 (Effective Communication) in the Code should be changed to explicitly reference the right for people to have *support to understand information* Right 5 should state “Where necessary, this includes the right to appropriate supports and/or support people, including a competent interpreter”.

22. ADL submits that Right 7 allows a provider to decide that someone lacks competence if "reasonable grounds for believing that the consumer is not competent". Arguably, as this is effectively removing someone's right to informed consent, this should be a

higher standard than "reasonable grounds". That low standard assumes that all providers are able to assess capacity and will recognise their own biases. This is particularly relevant for consumers with visible disabilities who are often the subject of discrimination.

23. ADL submit that Right 7 needs to be rephrased so that it aligns with other definitions of decision-making capacity.

24. Right 7(4) should not be applied to long-term residential arrangements. This should be explicitly stated in the Code. A detailed report commissioned by the Human Rights Commission (Fisher and Anderson-Bidois, 2018) revealed that many people are, in effect, contained within residential facilities without the protections afforded under the Protection of Personal and Property Rights Act 1988. Similarly, those residents who are not governed by the Mental Health (Compulsory Assessment and Treatment) Act 1992 do not have: routine review; free legal representation; or access to a District Inspector. Recommendations for reform are detained within the document and supported by the 12 contributors.

25. In short, the three statutes and the Code should be reformed in tandem to be complaint with the United Nations Convention on the Rights of Persons with Disabilities.

What does ADL think of HDC’s suggestions for making the Act and the Code work better for tāngata whaikaha | disabled people, and what impacts could they have?

26. We agree with all of them, subject to not having the necessary information to comment regarding the health and disability research section, as we have not seen this in our work with clients. However, we agree that a minimum requirement is that ethics committees have a mandatory requirement for membership by a member who identifies as having a disability.

27. These suggestions will impact Deaf and disabled people positively and bring them in line with both the United Nations Convention on the Rights of Persons with Disabilities ("UNCRPD") and with modern concepts.

28. ADL believe that HDC need to go further in making consumers rights to accessible formats and services more explicit. Providers need to be made explicitly aware of their obligations. Many ADL clients report to ADL that disability services are not sufficiently accessible.

    For example, in court the internet may be substandard, so it is difficult to use an online interpreter. Another example of this can include if someone from the Sign Language community is at a doctor's surgery they may not have an interpreter. If there was a role of on-call interpreters that were available both over the internet or in person then this provides equitable access for the Sign Language community. There is the need for a more specialised service for providing NZSL interpreters in emergencies just like providing interpreters for other languages.

What other changes should we consider (legislative and non-legislative) for making the Act and the Code work better for tāngata whaikaha | disabled people?

29. ADL is concerned about the low numbers of NZSL-English interpreters. University fees are a significant barrier to expanding the pool of NZSL interpreters and there is a special case to be made on accessibility grounds for significant fee subsidies.

30. ADL also believe that there should be an additional section under (Right 4) which states “Every consumer has the right to *accessible* services”. This would strengthen accessibility within the Code and therefore in services.

31. ADL believe that HDC should do more proactive advertising and communicating of the Code and the Act to provider organisations. i.e. Encouraging provider organisations to align their policies with it. This applies to both providers of disability *and* health services, widely defined.

32. ADL submit that HDC need to embed the Rights within all services through routine, free training by and with disabled people for prevention. Also, training that utilise HDC opinions (and HRRT and HPDT case studies) can be used as a breach deterrent.

33. ADL submits that there is no legal framework around supported decision making insofar. There is also no legal framework around holding 'supporters' accountable. Until we have this framework, support people could turn out to be predators and will get away with

it. For example, on the face of it the family member is logical 'support' - but it becomes clear that the person is acting in their own interests and manipulating the disabled person - usually because of money but of course there can be situations where the manipulation results in some other sort of abuse.

34. ADL submits that providers need to be more cautious about this. Supported decision-making needs to be more legitimised. Without an accountability framework, it will be harder for them to push back. It is important to be aware that whilst in most cases we are moving to will and preferences of the disabled person, this is great as long as the person really understands their decision making and the supporter is actually supporting them to understand, not to make the decision preferred by the supporter.

35. The Act does not appear to be available in NZSL or other accessible formats. People have a right to this information in accessible formats. Although the Code is incorporated into the accessible formats under the heading ‘Your rights when using Health and Disability services’ there should also be accessible versions of the Code itself.

36. ADL submit that the appointment criteria for the Commissioner and deputy Commissioners in the Act are amended to require that preference is given to the appointment of a Deaf or disabled person.

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

37. ADL agrees with HDC’s suggestions of introducing statutory requirements for review of HDC decisions and lowering the

threshold for access to the HRRT (Manning, 2018). Currently it is too easy for providers to breach the Rights with barriers to access to the relevant tribunals. Particularly unregistered providers, for whom there are often no other consequences for breaches of the Code.

References:

Ammundsen, V. (2022) A practical guide to capacity. Wolter Kluwer, Wellington.

Diesfeld, K., Surgenor, L., Rychert, M. (2020) Breaches of New Zealand's Health and Disability Services Consumers' Rights: Human Rights Review Tribunal decisions**.** *Journal of Law and Medicine*, 27(3): 679-692.

Douglass, A., Young, G., & McMillan, J. (Eds.)(2020) Assessment of mental capacity: A New Zealand guide for doctor and lawyers. Victoria University of Wellington Press & New Zealand Law Foundation, Wellington.

Fisher, M., & Anderson-Bidois, J. (Eds.) (2018). This is not my home: A collection of perspectives on the provision of aged residential care without consent. New Zealand Human Rights Commission Te Kahui Tika Tangata, Wellington.

Manning, J. (2018). " Fair, Simple, Speedy and Efficient"? Barriers to Access to Justice in the Health and Disability Commissioner's Complaints Process in New Zealand. *New Zealand Law Review*, *2018*(4), 611-656.

Manning, J. (2023). Access to Justice: The Quest for a Right of Appeal in New Zealand's Health and Disability Commissioner Complaints Scheme. *Journal of Law & Medicine*, *30*(4).

Reuvecamp, I., & Dawson, J. (Eds.) (2019) Mental capacity law in New Zealand. Thomson Reuters, Wellington.

Te Aka Matua te Ture Law Commission (no date) Nga Huarahi Whakatau: Review of adult decision-making capacity law. https://huarahi-whakatau.lawcom.govt.nz/#:~:text=We%20published%20our%20Preliminary%20Issues,Issues%20Paper%20in%20April%202024. Accessed 16.7.24

Wall, J. (2016) Law, ethics, and medicine. In what sense ‘rights’? Principles of justice and the Code of Patients’ Rights (pp. 293-309). In M. Henaghan, & J. Wall (Eds.), Law, ethics, and medicine: Essays in Honour of Peter Skegg (pp. 293-309). Thomson Reuters & New Zealand Law Foundation, Wellington.