



Re: Have your say: Health and Disability Commissioner Act and Code review consultation.

To: review@hdc.org.nz

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Submitted by: Rare Disorders NZ

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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract. This submission is in response to the Health and Disability Commissioner Act and Code review consultation.

Rare Disorders NZ

Rare Disorders New Zealand is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300 000 New Zealanders with rare disorders and the people who care for them. We help those affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand.



Our submission

Rare Disorders NZ urges the HDC to see people living with rare disorders as a priority group whose rights under the HDC code need promoting. The recently released Aotearoa New Zealand Rare Disorders Strategyⁱ identifies the HDC as an organisation that has a role in actioning the Rare Disorders Strategy.

People living with rare disorders have high utilisation of healthcare services compared to the general population^{ii,iii} and also often have a difficult journey throughout their interactions with the healthcare system^{iii,iv,v,vi}. The majority of people living with a rare disorder surveyed in New Zealand in 2023ⁱⁱⁱ did not feel informed at all around the rights related to the consequences of their rare disorder, felt that communication and information exchange between different service providers was poor, and felt that professionals were not well prepared to support their family, nor informed about the disorder and its consequences.

To support better and more equitable complaint resolution for people living with rare disorders we would like to see more promotion of the rights of people living with rare disorders to both health and disability services and the community. This would include a focus on what the right to services of an appropriate standard (right 4) would entail for someone presenting with an undiagnosed rare disorder, as well as how right 4 and the right to be fully informed (right 6) may apply in situations where there has been a misdiagnosis or delay in diagnosis of a rare disorder. Similarly, a focus is needed on how rights 4 and 6 apply to the management of a rare disorder for which there is not readily available expertise in GP, emergency and/or specialist settings.

Rare disorders NZ would welcome working with the HDC to create resources tailored to the rare disorder community.

Alongside the HDC promoting the rights of people living with rare disorders, Rare Disorders NZ would like to ensure that the HDC recognises delayed diagnosis and misdiagnosis of rare disorders as adverse events that can cause harm, and that require open disclosure. While misdiagnosis and delayed diagnosis of rare disorders are not necessarily in breach of people's rights under the HDC Act and Code, they can lead to people receiving inappropriate treatment and/or can delay treatment that otherwise would have prevented morbidity or mortality. This long 'diagnostic odyssey' in of itself can also cause harm as it has a negative impact on mental health and wellbeing.

Specific points in relation to consultation questions

1.1: It is noted in the consultation document that *certain groups face barriers to accessing complaint resolution processes, particularly in ongoing provider–consumer relationships or in residential care settings because of a fear of damaging that relationship or impacting their ability to access care*. We would like to highlight that this is a particular issue for people living with rare disorders as there may only be one specialist in the department or even New Zealand who is familiar with their disorder.

Rare Disorders NZ supports the initiative of introducing clinical navigators to help guide people in their complaint process. We ask that clinical navigators are rare aware and understand the diagnostic odyssey and difficulty accessing standard of care for their disorder that people living with rare disorders often face in New Zealand.



1.2c: Rare Disorders NZ supports the proposed changes to clarify the role of whānau in the consumer–provider relationship and to help providers to enable whānau participation appropriately. Whānau play a huge role in the lives of many people with rare disorders. Our 2023 Voice of Rare Disorder surveyⁱⁱ found an average of 2.4 whānau/family members and/or friends were involved in the care and support of a person with a rare disorder during an average week.

1.2e: As noted above (1.1), barriers to making a complaint because of concern that it may negatively affect a person’s ongoing relationship with their provider or impact their access to care is a particular concern for people with rare disorders where there may only be one specialist with any understanding of their disorder in the department or even the country.

1.2g: Rare Disorders NZ has heard from the rare disorder community that the Advocacy service is not working for them. Advocates need to better understand the additional barriers people living with rare disorders face when navigating the health system and accessing care and support. This includes difficulty obtaining an accurate diagnosis, misdiagnosis, challenges accessing standard of care and not fitting into tick boxes in a health system not designed with our rare disorder population in mind.

We also wonder if the name ‘advocate’ is creating an unrealistic expectation of the role. Our community are often looking for advocates that will attend appointments with them and support them throughout their journey, rather than someone with a role limited to promoting the code and helping with informed consent and complaint resolution, as set out in the Act.

2.1: 19% of Māori with a rare disorder surveyed considered visits to a nurse, doctor, health service, hospital service or genetic testing service to be culturally unsafe. This was higher than for non-Māori^{vii}. This statistic supports that there is a lot of work to be done and Rare Disorders NZ welcomes making the Act and the Code effective for, and responsive to, the needs of Māori.

3.1: We note that the consultation document includes that a particular focus is on hearing from people who have a harder time making their voices heard, including people in residential services. People living with rare disorders are often overlooked as for each individual disorder there are only a few affected, and others don’t understand the disorder or have not even heard of it. We ask that the HDC ensure that people living with rare disorders are included in this focus.

Along similar lines, there is a paucity of data about people living with rare disorders in New Zealand. We note the consultation document states HDC have been improving data collection to better analyse and report on tāngata whaikaha | disabled people’s concerns and their experience of mainstream health services and disability support services. We would be very interested to see an analysis of complaints from people living with rare disorders and with an estimated 300,000 people in NZ living with a rare disorder, we ask HDC to focus on this patient group.

3.2b: Rare Disorders NZ asks that you ensure that the Act’s definition of disability is inclusive of people with rare disorders. A large number of people living with rare disorders are currently not able to access services from Whaikaha due to their disorder being labelled a personal health condition. Section 21(1)(h) of the Human Rights Act 1993 includes *Physical illness and loss or abnormality of physiological or anatomical structure or function* in its definition of disability and is much more inclusive of the rare disorder population.



4.1: As rare disorders can be poorly understood or very specialised, an appeal may be indicated where the correct expertise was not initially involved in the decision making.

5.1d: Rare disorders NZ supports the introduction of a definition of an aggrieved person to widen the criteria of those able to bring proceedings against a health or disability service provider, including *access by family members of deceased consumers*. Approximately half of people with rare disorders are children, and many rare disorders shorten the life expectancy of those affected. As previously noted, whānau tend to be very involved in the care and support of people with rare disorders and Rare Disorders NZ supports them being able to bring proceedings against a health or disability service provider.

5.1j: Rare Disorders NZ supports the Act being responsive to advancing technology. We ask it is ensured that any changes balance upholding ethical standards concerning privacy, data security, and safe use, alongside not inhibiting the use of advancing technology that could be very beneficial for the rare disorder community, for instance the use of AI for the diagnosis of rare disorders (e.g. Face2Gene).

Other recommendations

Rare disorders NZ endorse Arthritis NZ's submission and support their recommendations, namely the following:

- *That there is clarity within healthcare organisations about the process, and who patients can approach with a complaint. We understand and support the preference of HDC to have complaints advocate involvement at the earliest possible stage of the complaints process to enable a triaging of complaints before they are escalated. That more consideration is given to the reasons patients are reluctant to make a complaint (especially fear of future treatment for them and/or their families being denied), and that there are options for reporting breaches of good practice that include patient anonymity.*
- *That the HDC better considers the patient voice in all areas of HDC work, including the incorporation of accredited patient organisations within the process of identification, investigation, and resolution of patient complaints, and considers the appointment of patient advocates within health services.*
- *That greater transparency and dissemination to parties with a legitimate interest is progressed.*
- *Consideration is given to HDC staff having portfolios that allow regular engagement with consumers with the intention of resolving issues before a complaints process is triggered -for example, a portfolio covering aged care could be the first port of call rather than a way down the track of a complaints process.*
- *Utilisation of NGOs (non-governmental organisations) to assist in triaging of complaints and supporting consumers to use the HDC well.*
- *Proactive use of social media to communicate information about the role of HDC and using consumer friendly language to outline how to best utilise the HDC processes. Consideration needs to be given to how resources are best used in an age of digital communication.*

References

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- ⁱⁱⁱ HealthiNZ. Impact of living with a rare disorder in Aotearoa New Zealand: Key priorities to deliver improved outcomes for people living with rare disorders, their family and whānau. 2024.
- ^{iv} Garrino L, Picco E, Finiguerra I, Rossi D, Simone P, Roccatello D. Living with and treating rare diseases: Experiences of patients and professional health care providers. *Qualitative Health Research*. 2015;25(5):636-51.
- ^v Gimenez-Lozano C, Páramo-Rodríguez L, Cavero-Carbonell C, Corpas-Burgos F, López-Maside A, Guardiola-Villarraig S, Zurriaga O. Rare diseases: Needs and impact for patients and families: A cross-sectional study in the Valencian Region, Spain. *International Journal of Environmental Research and Public Health*. 2022;19(16).
- ^{vi} Currie G, Szabo J. 'It would be much easier if we were just quiet and disappeared': Parents silenced in the experience of caring for children with rare diseases. *Health Expectations*. 2019;22(6):1251-9.
- ^{vii} HealthiNZ. Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand: Delivering improved outcomes for Māori living with rare disorders and their whānau. 2024.