Rare Disorders NZ's response to the Health and Disability Commissioner Advocacy Guidelines - Draft Content For consultation (Submitted by web-form).

What would strengthen the Guidelines for your organisation / whānau / community? Please comment.

1) Explicitly include rare disorders as a population that will be routinely considered

There are multiple references to 'priority populations' within the guideline. The definition in the glossary refers to the HDC Statement of Intent for the definition of 'focus populations'. There is no mention of people living with rare disorders and their whānau in either document. Rare Disorders NZ urges the HDC to see people living with rare disorders as a group whose rights need special consideration, monitoring and promoting and ask that people living with a rare disorder are explicitly included in the focus population groups routinely considered by the HDC.

Explicit and routine consideration of the rare disorder population is required by the Ministry of Health's 2024 Aotearoa New Zealand Rare Disorders Strategy and the HDC is identified in the Strategy as an organisation that has a role in actioning it. The Strategy requires that:

i) Those involved in designing, commissioning or providing new policies or services routinely consider the needs of people with rare disorders.

ii) Decision-makers will consider rare disorders as they decide priorities for evolving and changing the system. Before making changes, system planners and stewards will look at the likely impacts of those changes on outcomes for rare disorders.

iii) People and their whānau living with rare disorders will become one of the population groups that decision-makers routinely think about when designing system improvements. Work programming to improve and invest in the system, and to evaluate these initiatives, will give priority to areas likely to produce greater benefits for people and their whānau living with rare disorders.

It also makes practical and ethical sense to include people living with a rare disorder as a focus population. Rare Disorders NZ's 2025 Voice of Rare Disorders Survey shows this community faces delayed diagnosis, misdiagnosis, fragmented care, poor coordination, and low awareness of rights and support. These challenges increase the need for effective advocacy and system monitoring. We ask the Guidelines explicitly include people living with rare disorders as a focus population routinely considered by the HDC and Advocacy Service.

2) The meaning of advocacy

As written, the guidelines risk creating an expectation that the Advocacy Service can support all health and disability advocacy needs, when the service may in practice be limited to advising on rights and managing concerns, complaints, and resolution.

The guidelines should clearly address the disconnect between what many people reasonably understand "advocacy" to mean and what the Advocacy Service is able to provide in practice. For people with a rare disorder and their whānau, advocacy includes practical, day-to-day support to navigate and communicate with health services, including in-person support at appointments and assistance before issues escalate, as well as support with raising and resolving complaints. However, the service is currently described and experienced as being largely focused on complaints once something has gone wrong.

This clarity is essential for patients, whānau, providers, and community organisations, and helps to highlight the unmet need for wider independent advocacy support within the health and disability system.

3) Monitoring, and using information to improve services

Under 'Compliance and Practice', the guideline includes objective 2: "Understand the importance of quality systems, monitoring, and using information to improve services". It also states that advocates should "Monitor the quality of services delivered and respond appropriately to evaluations and reports". However, the guideline does not explain how this will happen in practice.

For the Advocacy Service to contribute meaningfully to service improvement, the guidelines should specify what information is collected, how systemic themes are identified, and how these themes are reported, acted on, and evaluated.

Individual rare disorder cases can appear isolated and unlikely to recur, which may reduce the perceived value of system improvement. However, while the disorders themselves are rare and diverse, the underlying problems people encounter in health and disability systems are often shared. Rare Disorders NZ ask that the guidelines are written to enable and encourage related concerns (like all rare disorder cases) to be identified, grouped and analysed thematically, with the resulting insights used to inform action, public reporting, and measurable outcomes for that identified group and their health and disability care providers.

4) Evaluation of performance

The guidelines do not include any form of feedback loop or evaluation internal or external as to whether they are being followed and actioned appropriately. Evaluation mechanisms need to be included in the guidelines.