

24 July 2024

To whom it may concern

I write to you on behalf of our Ehlers-Danlos Syndromes community.

This piece of work is extremely important to our community.

Respect | Fair Treatment | Dignity and independence | Appropriate standard of care | Effective Communication | Full information | Informed choice and consent | Support | Teaching and Research | Right to complain

Ehlers-Danlos Syndromes is a group of connective tissue disorders, currently classed as rare. Our community often involve multiple specialists, public and private, and **experience delayed care, mistreatment, judgement, misdiagnosis, and psychiatric claims, along with experiencing medical trauma (PTSD) and are often bullied/told there's no point in laying a complaint and continue to have fear of speaking out due to ongoing issues/treatment that may occur.**

Our condition does not discriminate, it impacts all genders and all races. Unfortunately, positive experiences are far and few between, the positive experiences often only come through a consumer's own research and investigation, and searching for the right professionals to see.

The entire reason Ehlers-Danlos Syndromes New Zealand exists is to help improve the health care system experience, as it has failed at least once with every single person with EDS in NZ.

This continues to be an ongoing situation for our community, which is leading to PTSD, anxiousness with worries about our own health, depression as are worried beyond belief and too scared to access care, and complete mistrust in the medical industry.

Our rights need to be the centre of our care. Being pressured to make quick decisions, being told important information without supporting people and only acting once someone outlines their rights as a consumer. Consumers need to know what their rights are, and 'reading a poster' shouldn't be assumed. This should be pointed out from the very beginning. This not only helps protect the individual, but will be a continual reminder to medical professionals and help imprint a holistic approach to care.

EDS is known worldwide as the condition that has been most neglected in modern medicine. *

Proactive, not Reactive. Using the data that HDC has, could help influence systemic change, ensuring further safety for consumers. HDC's information should be used cross government to help support changes in system policies.

Re The Code to children, young people, and people whose decision-making capacity is affected

Our concerns under this section are when abuse or cognitive impairment may be involved, either by carers, whanau, or medical professionals. How can we best support consumers who are unable to make decisions, legally, for themselves, to ensure these decision makers aren't abusers or taking advantage of this fragile part of our community?

Will there be a different pathway for complaints to be made that ensures ongoing safety of the individual? Will there be ongoing reviews to ensure the consumer is safe?

The Complaint process

Topic 1 – Supporting better and equitable complaint resolution

To the note 'to that end facilitate the fair, simple, speedy and efficient resolution of complaints' - **our community concerns are not only with their continued health impacts, and furthered delayed care that come from mistreatment and judgement (and worry of lack of care) from medical professionals relating to standing complaints, but they're also worried about others who may be impacted by the same situation.** Accountability and improved service and skills is the only way that this process is effective for others and their future. **Auditing professionals who have been found at fault is an incredibly important way to ensure that the system is being proactive and not reactive,** further making the professional more accountable for actions.

The impacts and harm felt at the hands of a Medical professional and service can be a lifelong impact.

When the complaints process is underway, **why isn't mental health support offered?** This should come hand in hand to ensure that the health system is best supporting communities

There needs to be more accessible advertising of our rights.

Currently those who know our rights advocate them, but when we bring these up to medical professionals when we feel push-back in situations, only then are we offered what we are entitled to. **Why aren't we being proactive and honouring one's mana and whakanoa?**

Carers also need to have more rights in this process, not just the ones in residential care. A large percentage of family members are carers at home, and are often unpaid/underpaid for the work they do. If they are abused, or are denied respite care, or disrespected or aren't seen to be a real carer by medical professionals, there needs to be more support for them.

There needs to be more staff, and staff that are more proactive, and a streamlined system that adheres to timelines to ensure timely resolutions. Making resolutions closer to the time of event ensures that there is more accurate information, and not just another patient note in a book from months/years ago.

Hospital advocates can have biases and have judgement, so this is another process that needs ongoing audits of service.

We agree, Restorative practice in complaint resolution can, in appropriate cases, support engagement, reduce risk of further harm and increase opportunities for healing, learning and improvement.

We support the non retaliation clause, but there are concerns on how this may look, so we would be interested in feeding more thought into this when there is a clause draft.

Implementation of legislation should be supported by a continuous workforce, guidance and training

Noting **cultural responsiveness section** - this can also relate to a person's mental state. We have multiple cases in our community where **we have been denied care,** or pushed onto mental health services instead. **If a person needs medical help, they should receive the appropriate medical help along with supporting their mental health.**

Topic 2 – Making the Act and the Code effective for Maori

Many people, of all backgrounds, hesitate to assert their rights because they fear the potential consequences. We need to foster a stronger desire for empowerment, reassuring individuals that they can confidently stand up for their rights.

We need to expand advocacy service options through facilitated conferences, involving trusted medical professionals (with funding options to ensure equity), marae, family sit-ins, and both in-person and online formats.

While advocacy services are effective in principle, the associated multi faceted trauma often overshadows their benefits. Consumers may face challenges such as negative experiences with medical professionals, lengthy delays, continued ailments, a lack of trust in medical professionals, and long-term impacts.

To address this, **a comprehensive support system is essential.** This should include mental health support, other medical support necessary, funding options for support, consistent follow-ups, ongoing audits of the service, comprehensive training, and incorporating lived experience training. Regular surveys can help identify both successes and areas needing improvement, ensuring the services continually evolve to better support consumers.

We were surprised not to see a description of Tūrangawaewae as being relevant to consumers.

Tūrangawaewae is a sense of identity and independence associated with having a particular home base for all New Zealanders. In accordance with Te Tiriti o Waitangi our choice of our tūrangawaewae should be protected, but also to work in partnership with our community to allow our people to have the choice of health care providers, choice of therapy options, and more holistic care. We should be allowed active participation, where warranted, to allow consumers to be involved in their own care plans, and in turn future health concerns.

Topic 3 – Making the Act and the Code work better for Tangata Whaikaha

Consumer experience is the pinnacle to a successful health system. Not one person with a disability, not one person with EDS, has the same experience, we all come with a range of ailments, comorbidities and severities. We aren't simple, we don't fit 'in boxes' and there needs to be leniency for this.

This would be a great area to work directly with Human Rights/Disability rights commissioners, and other groups such as DPA, or other select committees for direct feedback on potential changes.

Data collection in New Zealand is broken. Coding systems do not work, and are not used correctly. This and the fact that services (public/private) do not speak to one another. **So it's concerning where this data collection may be coming** from as it would not speak for the vast majority and variety of situations. If the information is taken from census collection, the wording on these questions does not speak to a true disability, but one of identifying oneself as disabled.

We agree that there needs to be a better review of representatives and relationships with other entities to ensure a better understanding of disability needs.

One other item which keeps being highlighted in many similar communities to ours is one of the research access. Most conditions have a clear pathway of care backing internationally, but the issue is when **research, that has been experimental, is proven not to work but is continued to be used, and harm individuals.** There needs to be a pathway here for this research to be looked at, and identified as being harmful to a consumer. A case of being proactive instead of reactive. We are happy to talk more to this point.

Definitions also need to include 'equitable'. Disability services and providers need to allow consumers to have a choice. One of our rights under UNCRPD (under Article 19) states as such.

Ongoing audits of service providers should be done to ensure that a) they're providing services that support a consumer and enable them to live their best life and B) ensuring that their services are up to date with legislation and the forever changing culture and events around us.

Currently the **service providers are unable to take into account consumers who have complex and changing medical conditions**. There needs to be a way to be more flexible on this to ensure consumers aren't left behind, do not receive harm or trauma, and continue to receive service that enables a consumer to live their best life.

Strengthen References to accessibility:

Effective communication : **Within our community it is noted that hospitals have notes that consumers cant access**. This often is found when Medical Professionals say “we can see on previous notes that...” But when a consumer requests this information it's not available, giving thought to private files. **All information on a consumer should be available to a consumer**.

Before discharge in a service, both the consumer and the medical professional should agree on the notes being signed off. Consumers are often rushed through the discharge service, or told their discharge notes will be sent out to them. When receiving the notes, conversations that were had between consumer and professional can differ greatly from the notes, leading to confusion and worry that consumers will now not receive the correct treatment from other professionals. **Consumers rely on these notes** to be accurate for the next professional to pick up, since our hospital systems do not connect directly to GP/Allied health/Private/Other regions.

Freedom from Discrimination : **We have been finding hospitals have been asking for consumers' religion, but not their identity /pronouns or their actual cultural or religious needs. This needs to change**.

Dignity and independence : **Neurodiversity needs to be taken into account** here. Consumers may ‘act differently’ to other consumers, but this shouldnt be seen as a hindrance, but something to support better.

Support : **Mental health support should be included in all wrap around services**. One thing we hear is that after diagnosis, consumers are often left worried and unsupported. There needs to be an option for mental health support here to ensure consumers can come to terms with diagnosis.

Right 5 : Proposal to remove reasonably practicable, should not be removed but altered. UNCRPD often uses the words '**reasonable accommodation**', and we believe similar wording should be used.

HDC Should include people with lived experience as a requirement with reviews and on their specialist ethic committees. We would be happy to be included in conversations here.

[Topic 4 – Considering options for a right to appeal HDC Decisions](#)

Reviews on decisions can be hard when the decisions in the first place were delayed, and reliving trauma can be hard for an individual, including being worried that the review will not be reviewed sufficiently.

There needs to be a strict time frame to meet for non-consumer and consumer alike. A busy workload for a medical professional should not be an excuse for potential harm they've caused for a consumer, and there should be some importance given to this being done in a timely manner, and fines for delays should be considered here, as this impacts HDC and the consumer. Consumers should be updated along the way to help give confidence that items are moving along, and not leaving this with a consumer to follow up.

[Topic 5 – Minor and Technical Improvements](#)

Reviews for HDC definitely need to be more than every 10 years as noted by previous Commissioners. We are an evolving nation and so a system that is actively looking for improvements in new climates is a proactive system which has consumers as the center of care. With our aging population and restrictions on how many people can enter our medical population, there will likely be an increase in complaints in years to come, and the system needs to be proactive. **We suggest reviews should be done 4-5 years, or when it warrants a further review within that time period**.

Written consent/Informed consent. Currently the process to **consent to medical intervention is not consistent**

throughout New Zealand, and as such, consumers who use multiple services, will likely experience differences, and confusion, here. It is vital to have consistency in practices for informed consent, including ensuring the consent process is accessible to all. Consumers need to understand what's happening, and as such need to be provided with language that they can understand, and not medical language that isn't appropriate in this setting.

Teaching and Education. This follows through after studying has been completed. Ongoing lived experience seminars, and education around different areas of work, and incentives to research should be mandatory to help improve our ongoing understanding of consumers, and increase the knowledge to prevent harm to consumers.

Part of **research is** also investigation. There should be passion and **duty of care** to help identify illnesses and best ways forward with care, treatment, management. We should be talking to worldwide contacts, strengthening our relationships overseas, and not restricting consumer experience to knowledge only in New Zealand. For our rare communities this is pinnacle to our overall well being. Currently consumers are the ones who have to reach out overseas and provide this information 'in house'. This needs to change.

With continuing into the future with AI, there needs to be an overall need to not have any information put into these systems that may be identifiable.

Other items that we have highlighted previously to other various government departments. Some are being worked on elsewhere in the government, and should also be seen as a priority to HDC. One would hope that the research your teams have done over the years would feed into the importance of these items to happen. Such as :

Ensures medical professionals have the correct information and do no harm to individuals

- **A way to access specialist notes**, the systems are not linked, nor are these easily accessible to consumers.
- **Access to information/catalogues** on medical conditions, medications, treatments and surgeries.
- **Medical professionals looking to international colleagues for input** and research, and assessing how other medical conditions may impact existing medical conditions, and providing an information loop **internationally** to help improve overall health outcomes for conditions.
- **Emergency/treatment plans/considerations for conditions created and honoured within an emergency environment.**
- **Lived experience seminars for health care professionals** will help add more knowledge into that consumer experience, but will also help with empathy and understanding of one's condition.

This helps with support, mental health, Mana, Wana, Manaakitanga, Mauri, Whakanoa and Whānau

- **Access to support group information** so consumers are able to connect with other like-minded people and gain support in our community.
- **Carer and family support.** Each disabled person has a community of people around them that is also impacted, there needs to be better acceptance and support around this.
- **Accessing family appointments** so that more than one person can have their concerns heard at the same time.
- **Access and better mental health services and information.** This needs to be run like the ACC model. If you need help you should be able to find a pool of medical professionals in your area that can help you. If our mental health is not serviced in a timely manner, our health can decline - this has been proven time and time again. This needs to be an overall government priority, as this is a serious issue in Aotearoa. This needs to be a direction from the top down. Our culture needs to change when it comes to our mental health, and a more holistic approach is vital.

Items that are more HDC Facing

- **Better ways to complain that help protect the consumer** and make the medical professionals more liable, and ways to help mediate appointments to make sure both parties are taken seriously. This is more than just an advocate role.
- **More focus on just another poster in the waiting room'.** We are not numbers, and not one person will have the same journey. – **better bedside manner**
- **Options if your own doctor is busy** - other trusted doctors in the community system, without having to pay a

whopping cost of going to A&E. – **Delays in care cause more trauma. There needs to be easier and more accessible ways for consumers to receive more timely care if their condition is decreasing, without having to pay more money at the doctors.**

Wāhine and takatāpui

Other communities that continue to have dire experiences are our wāhine and takatāpui. There needs to be lived experience and consumer led experiences for Hospitals and medical facilities to help improve, and to continue to improve, the consumer experience. There needs to be a better and more seamless complaints system, as delays in this system cause more stress and weaken accountability for medical professionals.

The pressure and judgement that society puts on wāhine in our community socially disables us further. This is not okay.

Detailed Summary:

Community Experience and Challenges:

- The Ehlers-Danlos Syndromes (EDS) community faces delayed care, mistreatment, misdiagnosis, and psychiatric claims. These issues often lead to PTSD, anxiety, depression, and a mistrust of the medical industry. Consumers are often discouraged from making complaints due to fear of repercussions and ongoing mistreatment.

Advocacy and Support:

- Ehlers-Danlos Syndromes New Zealand would like to see improvement in the healthcare experience for those with EDS/HSD. Key areas of focus include:
 - Expanding advocacy service options through various formats, including trusted medical professionals, marae, and family sit-ins, both in-person and online.
 - Comprehensive support systems that include mental health support, consistent follow-ups, and ongoing audits of services.
 - Training for medical professionals on patient rights and incorporating lived experience training.
 - Regular surveys to identify successes and areas needing improvement.
 - Equitable pathways

Complaints Process:

- Concerns include continued health impacts from mistreatment, delayed care, and the fear of further negative treatment. There is a call for:
 - Better and equitable streamlined complaint resolution processes.
 - Audits of professionals found at fault to ensure accountability and to ensure safety of other consumers.
 - Provision of mental health support during the complaint process.
 - More accessible advertising of patient rights.
 - Increased rights and support for unpaid and underpaid carers.
 - Facilitated resolutions should include measures to prove there are no biases or conflicts of interest involved, ensuring fairness and trust in the process.

Systemic Improvements:

- There needs to be a streamlined system adhering to timelines for timely resolutions.
- Ongoing audits to ensure hospital advocates and services remain unbiased and effective.
- Support for non-retaliation clauses and the need for continuous workforce training and guidance.
- Medical professionals need comprehensive training on patient rights to ensure these rights are respected and upheld consistently.
- Strengthening accountability measures for medical professionals and institutions is crucial to prevent mistreatment and ensure high standards of care.
- Facilitated resolutions should include measures to prove there are no biases or conflicts of interest involved, ensuring fairness and trust in the process.

- Regular audits of medical professionals found at fault are essential to ensure accountability and proactive improvements.

Cultural Responsiveness and Equity:

- Advocacy for the protection of Tūrangawaewae, ensuring choices in healthcare providers and holistic care in line with Te Tiriti o Waitangi.
- A focus on the unique needs of those with disabilities and chronic conditions, emphasizing flexibility and comprehensive support.

Review and Feedback:

- Collaboration with Human Rights and Disability Rights commissioners, and other relevant groups for feedback on potential changes.
- Improved data collection and coding systems to better reflect the diverse experiences and needs of the community.

Research and International Collaboration:

- Addressing the use of outdated or harmful research practices and advocating for proactive rather than reactive approaches to medical care.
- A pathway for consumers to ask for a review of harmful practices being used, to ensure medical professionals are using the correct information to ensure harm is not caused.

Accessibility and Communication:

- Ensuring effective communication and access to all medical notes for consumers.
- Agreements on discharge notes between consumers and medical professionals to avoid discrepancies.

Discrimination and Inclusion:

- Addressing issues of discrimination, particularly regarding cultural and neurodiverse needs.

Appeals and Timeliness:

- Strict time frames for reviews of decisions and penalties for delays to ensure timely resolutions and maintain consumer confidence.

Continuous Improvement:

- Regular reviews and updates to ensure the healthcare system evolves with changing needs and maintains high standards of care.
- Standardization of informed consent processes across New Zealand to ensure clarity and accessibility for consumers.
- Incorporating training sessions based on resolved cases, focusing on lived experiences, will enhance understanding and empathy among healthcare providers.

Holistic Support:

- Access to support group information, carer and family support, and better mental health services similar to the ACC model to ensure comprehensive care and well-being.

Facilitated Resolution Needs to Include Proving There is No Bias or Conflict:

- Ensuring that facilitated resolution processes are unbiased and free from conflicts of interest to build trust and fairness in the resolution process.

We thank you for this consultation period. Improvement can only be done within **co-design**, involving those with lived experience, and maintaining a flexible and adaptable system. An overhaul of the current complaints system is necessary as it is increasingly harmful to our communities due to delays and added pressure. This was made abundantly clear during COVID-19.

Our rights as consumers need to be at the forefront of focus. Our holistic health, Tūrangawaewae, and taha wairua must be taken into account. We deserve equal respect, dignity, partnership, protection, participation, access, research, information, education, and employment as anyone else in Aotearoa. Let's do better.

We look forward to the responses after this consultation period.

Noho ora mai,

A handwritten signature in black ink, appearing to be 'K. McQuinlan', written in a cursive style.

Kelly McQuinlan (on behalf of our community.)
Chief Visionary Officer and Co-Founder
Ehlers-Danlos Syndromes New Zealand