

Tōfā Mamao Collective – HDC Act and Code Review Submission

Date: 13 August 2024

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Type of Submission: On behalf of Tōfā Mamao Collective

About Us

Tōfā mamao means navigating the future guided by the past.

We are a grassroots collective of *tagata sa'ilimalo* (Pacific disabled people, their families/*nofo-a-kainga*, and carers/supporters/*tautua soifua* in Aotearoa). As a proudly independent national non-profit led entirely by tagata sa'ilimalo, we play a unique role in advancing the voice of lived experience from a Pacific and collectivist worldview.

Our Vision

Tagata Sa'ilimalo (tagata = people or person, sa'ilimalo = pursuit of success) is a new vision of Pacific disability in Aotearoa and also a term of identity to replace "Pacific disabled people, their families, and carers/supporters."

Tagata Sa'ilimalo is an aspirational vision of the pursuit of success underpinned by sheer determination and sustained by the collective vitality of Pacific peoples. It is a vision that reflects the hopes of the disability community to imagine better for their future. It is inclusive of all Pacific peoples in Aotearoa and all disability types.

Q1. What has been your experiences of HDC

- There is a lack of awareness and understanding of who HDC is and the purpose of the organisation. Therefore, making HDC inaccessible for Pacific communities.
- There is a lack of awareness and understanding of the code of rights. So, Pacific people are not aware that they have rights when accessing and utilising health and disability services.
- When people know their rights, they don't feel like their complaints are significant enough to raise. Which can lead to a mindset to be grateful for the service/treatment they are receiving.
- There is no standard of care, so people are not aware of what good/bad care looks like.
- There is no clear distinction between HDC, HRC and Whaikaha.
- Culturally Pacific people also don't want to inconvenience people with the issues they are going through.
- There are housing shortages in Auckland, so people are living in housing condition that may cause further health issues or are inaccessible.

- There is a lack of knowledge of the Health and Disability Advocacy Service, so we are not aware of how and when to access this service.

Q2. How could HDC and the Advocacy service work better for Pacific communities to know about their rights?

- Engage with Pacific communities with a Soalaupule approach, this means a non-transactional and adversarial approach. The only way this can be done is by utilising our eco-system which is based on collectivism rather than an individual worldview. The collective perspective considers the individual, their family and carers in order to form the best outcome for the whole. Ideally it would be beneficial having Pacific employees who understand the eco system who can offer in depth perspective around Soalaupule if it is a concept that is unfamiliar or new.
- The complaint processes need to be clearer. When information about complaints process is provided, we don't receive additional information on how or where to seek support for this process.
- Pacific communities prefer in person engagement, so we suggest engaging with all Pacific communities throughout the motu. This will help to build better relationships between your organisations and the communities, also developing the Soalaupule approach.
- Developing resources in our language. Often our Pacific communities are provided with Easy Read formats, but this doesn't always work for our communities, as people have different levels of understanding, so sometimes we need to breakdown this information further. It would be great for resources to be in our languages with visuals to support.
- Having content in video form as well not just in writing.

Q3. How can the code work better for people?

- Consent element, people are not given the time to understand what they are consenting to. This is where the individual worldview/approach of the rights does not work for Pacific people. This is where the Soalaupule approach is taken, because the individual is reliant on the family to support them in understanding the process for them to make an informed decision.
- Respecting and understanding the cultural norms within the ecosystem. When family members leave the hospital or receive home support, the family members often continue the care when at home or during the time when support workers are not available, so it is important that they are involved in the care process from beginning to the end.
- Strengthening family awareness through group meetings and helping them to understand their rights from the outset. Making information available when visiting health and disability services and making time to share this

information so that individuals and family understand their rights, and complaints process.

- Understand pacific people with disabilities and understand the family dynamic. Guardianship laws work against the pacific ecosystem, when parents who have provided care for 21 years to their child who is nonverbal and cannot consent, are made aware that they can no longer provide support in this way puts the family in a difficult position, especially if they are not aware of this.
- State takes the lead, but what the state doesn't realise is that the families end up taking over the care when they fail to provide support. Rights are good but it needs to be extended and be realistic in the context of the South Pacific. Our values and the way we understand and engage with information need to be reflected from this side of the planet. A reality check on all the spaces that occupy within the eco system. Individualistic, transactional means of engagement is wrong. Hard to pursue my success without the people behind and beside me.
- Navigating the future guided by the past – a process our ancestors established. Code of rights is very individualistic in its process. Tofa Mamao have worked to reframe the narrative of how things impact our lives – with the concept of Tagata Sa'ilimalo, which is both a vision and our identity. We start by looking at people's aspirations and strengths around collectivism – Disabled people, carers and supporters. Code of rights are wrapped around the individual. That works for cultures that celebrate the individual. But will struggle to connect with communities that are collective. The principles of individualism are not indigenous to this side of the planet.
- The Code creates negative conflict that ends up being more of an impact on our lives, and then services pull away and our families still pick up the damage. Want to enter conversations knowing that equally responsible for the outcome whether good or bad, a Soalaupule approach means we are equally accountable.
- The ecosystem often gets undermined by organisations like HDC coming in and out. HDC can seem selective as to what part of ecosystem to interact with. This affects your workforce, because you have to be of that eco system to understand, add, and engage actively. Language is one consideration, but cultural insight is another. Move away from transactional and individual means.