Deaf Aotearoa's submission on the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights

12 August 2024

Overall, Deaf Aotearoa fully supports the policy proposals for amending the Act and the proposed wording changes for the Code.

In terms of some of the specific questions, our comments are below.

Question 1.1: Did we cover the main issues about supporting better and equitable complaint resolution?

An issue which is missing is Deaf cultural responsiveness. We would like reassurance that 'culturally responsive resolution' includes the need for the complaint assessors and the navigators to understand Deaf culture and the associated linguistic background. We understand that this may affect the speed of the complaint process if the assessor and navigator are not aware of Deaf people's cultural/linguistic needs (i.e. it may take extra time to apply a culturally appropriate response specific to Deaf people). This needs to be factored into decisions about 'reasonable timeframes'.

Question 1.3: What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaint processes?

Some marginal groups such as Turi Māori and the Deaf community may not initially self-advocate, nor put their hands up to share experiences. However, if they are engaged in a group session, and a person shares their experience, it likely will trigger others to share their experiences. This 'peer support sharing' often happens in a cultural safe setting. We recommend that the Advocacy Service proactively engages with marginal groups in a cultural safe way to raise awareness and discover potential complaints and help group of consumers make complaints collectively and individually.

Question 3.2: What do you think of our suggestions for making the Act and the Code work better for tangata whaikaha | disabled people, and what impacts could they have?

Deaf Aotearoa fully supports removing the words as "reasonably practicable".

In some circumstances, a family/whānau may already have had some involvement with the consent process, but what happens when the conditions for that consent changes? For example, a Deaf pregnant woman originally planned to have effective communication using an NZSL interpreter and with her partner during the birth and retain her decision-making powers. However, decision-making and communication is compromised during birthing due to pain or medications, therefore decision-making and communication burden unexpectedly fall onto the partner. This is where prior full informed consent discussion is required about when decision-making becomes compromised during a procedure. This issue needs to be addressed in Right 6, 7, and 8.

The intersectionality of cultural, linguistic and disability can create situations where rights are interpreted to ultimately provide the best care and safety for the consumer. For example, NZSL is often seen as 'disability accessibility language" rather than full cultural linguistic language in its own right. The 'best interest' test is where this becomes problematic. An ableist perspective plays out like this; babies born to a Deaf family can have a hearing screening test within 1-2 hours of birth without

any regard for cultural and wellbeing of the Deaf family. This is in the best interest of 'ear health', but it won't be in the best interest of the Deaf consumers.

Whilst we support reasonable timeframes for hearing screening tests, we recommend inclusion of cultural perspectives. For Deaf people, hearing screening tests are not considered urgent (if the baby is found to be deaf, then this can be a cause for celebration). Testing within a few days of birth is unreasonable especially when interrupting the bonding period. Determining "harm encountered in daily life" would be from ableist perspective, not a Deaf cultural perspective which can be at times distinct from other disabled perspective.

Question 5.3: What are your main concerns about advancing technology and its impact on the rights of people accessing health and disability services?

Question 5.4: What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

Remote NZSL interpreting is a double-edged sword. It may work for some, but not for others; it depends entirely on the consumer preference and needs. Ultimately if a consumer's wishes for NZSL interpreter face to face for appointment, it should be prioritised, and for emergency or short notice best efforts possible, while providing remote interpreting as option or meantime solution while physical interpreter is on the way. There is a concern that services may by default use remote interpreting rather than make effort to provide onsite interpreting.