Submission on the Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers’ Rights

This submission is from the Office for Seniors.

Overall we are supportive of the issues and proposed solutions identified by the Health and Disability Commission. This submission focuses on strengthening the Act and Code for older people, as well as some specific concerns related to unconsented research and Right 7(4).

Making the Act and the Code work better for tāngata whaikaha | disabled people

We would be supportive of the Act and Code being improved for older people as well as disabled people. While there is certainly crossover between these two groups, older people who become disabled later in life may not always identify as disabled, which can impact their access to supports. While the cohort of 65+ year olds are more likely to be disabled, they are also accessing supports through a different system, meaning specifically targeting this group and ensuring accessibility will continue to be important.

We are pleased to hear about the work HDC is doing to make complaints and information easier to access for people living in aged residential care. We regularly receive emails from older people in aged residential care who express concerns over the care they are receiving. It concerns us that the quality of care appears to be inconsistent, and we have particular worries for older people with affected decision-making capacity, who may not have family or friends nearby who are able to advocate for and support them.

We support changes to the Code to improve recognition for supported decision-making and to align with the Law Commission’s review of adult decision-making capacity law. We are supportive of a move away from consumers views to their rights, will and preferences.

Unconsented research

We have concerns about the proposed changes to allow adults without decision-making capacity to be involved in research. Our concerns are for two reasons:

- the best interests test is out of step with the UN Convention on the Rights of Disabled People, particularly article 12
- we consider it inappropriate for providers to sign people up to research under Right 7(4).

In relation to the first concern, our view is that a wording change to Right 7(4)(a) is required. This would involve removing the best interests test and instead replacing it with rights, will and preferences. This would strengthen New Zealand’s framework to be better aligned with the UNCRPD. It would also better align with signalled direction in related work, such as the Law Commission’s review into adult decision-making capacity law. We note a similar suggestion is mentioned earlier in the consultation document but are not clear how that translates into considerations related to unconsented research.

In relation to the second concern, we find it difficult to imagine a situation where it would be appropriate to rely on Right 7(4) to allow a provider to sign a person up to research.

Our understanding is that Right 7(4) is intended to be used for only short periods of time and generally in urgent situations where no representative decision-maker has been appointed. For example, in a 2018 case the Commissioner found that the continued use of Right 7(4) over a 14-month period was inappropriate, and that after a few days steps should have been taken to clarify the legal position for continued care. Singing people up to research would likely require continued reliance on Right 7(4) over a period of time.

It is also worth noting that making this change could result in differences between what providers can consent to on behalf of people without decision-making capacity, compared to what attorney’s and welfare guardians can consent to (noting there is a restriction on consenting to the donor taking part in any medical experiment unless it is potentially life-saving or prevents serious damage to health). This change would create inconsistency between what providers and representative decision-makers are able to consent to on behalf of someone else. We also question whether this change would be compatible with the UNCRPD.

Other changes to improve the Code

Related to our comment above, we note that Right 7(4) does not specify a time-period, meaning it is unclear for how long it can relied on. We understand that it is unrealistic to include a timeframe. However, we do wonder whether it would be worth strengthening the Code to clarify the situations and time periods in which Right 7(4) can be relied on. For example:

- Right 7(4) should be relied on only when necessary
- steps should be taken to clarify the legal position as soon as possible
- when relying on Right 7(4) for the provision of services, regular reviews should be undertaken
- this review should include an assessment of the person’s rights, will and preferences.

These additions could clarify the Code, give assurance to providers and increase safeguards.