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To whom it may concern

Review of the HDC Act and Code

I am a specialist health and disability lawyer, acting for providers, managers, regulators and funders of health and disability services.

I engage most with health, disability, mental health, addiction and aged care services.

I am making this submission in an individual capacity, as a legal professional who regularly works with and advises health and disability service providers on the Health and Disability Commissioner Act and the Code of Health and Disability Services Consumers' Rights.

I am happy for my submission to be published, and to be contacted by the HDC regarding this submission. I would like to receive updates from HDC about this review and other mahi.

My response to the consultation questions is set out below.

Topic 1 — Supporting better and equitable complaint resolution | Kaupapa 1 — Te Tautoko kia pai ake te whakatatū amuamu, kia mana taurite hoki

1.1 *Did we cover the main issues about supporting better and equitable complaints resolution?*

Yes.

1.2 *What do you think of our suggestions for supporting better and equitable complaints resolution, and what impacts could they have?*

a. Amend purpose statement

I agree that the purpose statement in the Act should be broadened, and suggest that the following words in bold are added to the current purpose statement:

[T]o promote and protect the rights of health consumers and disability services consumers and, to that end, to facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights **in a way that is people centred and culturally responsive**.

b. Clarify cultural responsiveness

With respect to the explicit incorporation of mana into the purpose statement of the Act, it may be more appropriate to expressly incorporate the concept of mana

into Right 1 (the right to be treated with respect) and Right 3 (the right to dignity and independence).

I support the clarification of what is meant by cultural responsiveness and the proposed amendment to the wording of Right 1(3).

c. Clarify the role of whānau

In terms of clarifying the role of whānau, I support changing the wording in Right 3 (Dignity and Independence) from 'independence' to 'autonomy', although my support for this change is for reasons broader than that stated by the HDC i.e. to recognise the interdependence people often have with whānau and support networks.

My reasons for supporting this change in wording is that the term 'autonomy' more properly reflects the legal and ethical principles which underpin the Code.

I support strengthening Right 8 (Support) to include the right to have support persons of the consumer's choice involved even where they cannot be present physically. In this regard, I would suggest a slight change to the HDC's proposed amended wording to Right 8 (Support) to ensure the consumer's choice remains at the centre of the Right to support, as follows:

Right 8 Right to support

(1) Every consumer has the right to have one or more support persons of their ~~his or her~~ choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed. Where support people cannot be physically present, this includes the right to have support people **of the consumer's choice** involved in other ways.

I note that the current definition of consumer provides for a person entitled to give consent on behalf of a consumer to make a complaint – 'Consumer means a health consumer or a disability services consumer; and, for the purposes of rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer'.

I think that the use of the word 'representative' could introduce confusion, even with the introduction of a definition of 'representative' (the HDC proposes a definition of representative as - 'Representative means someone who has been chosen by the consumer to, or is otherwise entitled to, act on behalf of or speak for a consumer').

This is quite different to the definition of 'Representative' in the Health Information Privacy Code ("representative, in relation to an individual, means — (a) where that individual is dead, that individual's personal representative; or (b) where the individual is under the age of 16 years, that individual's parent or guardian; or (c) where that individual, not being an individual referred to in subclauses (a) or (b), is unable to give their consent or authority, or exercise their rights, a person appearing to be lawfully acting on the individual's behalf in the individual's interests").

The use of the word "support person" instead of representative may be more appropriate/less confusing. 'Support person' could be defined as 'Support person means someone who has been chosen by the consumer, or is otherwise entitled to act on behalf of or speak for a consumer'. Or, it may be considered

appropriate to broaden the definition of a support person to focus on supporting the consumer's decisions; and/or their will and preferences.

It is not infrequently the case that the HDC considers complaints from people other than the consumer themselves, where the consumer's consent to that person making the complaint is not provided, and/or where the legal status of the person making the complaint is unclear. I do not think that the HDC ought to investigate a complaint made on behalf of a consumer without the consumer's express consent, except in circumstances where the consumer has affected decision-making capacity such that they are unable to give consent to the making of the complaint.

Further clarity may be provided by introducing the word "legally" before the words "entitled to" in both the current definition of consumer, and in the proposed definition of representative or support person.

d. Ensure gender inclusive language

I support amendment of the Code so that it is gender inclusive.

e. Protect against retaliation

Although I believe that various rights in the Code already protect consumers from retaliation from providers, I support an amendment to Right 10 to explicitly protect consumers from retaliation from providers, with a view to encouraging people to feel safe to raise concerns and complain.

f. Clarify provider complaints processes

In my view, the proposed Right 10(5) remains unclear; and there is overlap with proposed Right 10(6), 10(7), 10(8) and Right 10(10).

I'd suggest that Right 10(5) is replaced by what is currently proposed as Right 10(10), in amended form. This is because the intention behind some of Right 10(5) and 10(10) appears to be related to ensuring the availability of information in accessible form about the complaints mechanisms available to consumers and their support people.

Accordingly, I'd suggest that Right 10(5) reads:

Providers must communicate to consumers and/or their representatives [support people] accessible information about:

- (a) the provider's internal complaints procedures and how to use these procedures;
- (b) Independent advocates provided under the Health and Disability Commissioner Act 1994/the Nationwide Health and Disability Advocacy Service; and
- (c) the right to complain to The Health and Disability Commissioner.

Right 10(6), (7) and (8) could then focus on the process to be followed by a provider once a complaint is received. For example:

- (6) On receiving the complaint the provider must —
 - (a) acknowledge the complaint within 5 working days of receipt, in a form and manner that takes account of the consumer's needs, unless it has been resolved to the satisfaction of the consumer within that period;
 - (b) use their best endeavours to resolve the complaint;

(c) ensure that the consumer and/or their representative is informed of what the provider is doing to resolve the complaint in accordance with 6(b) and the reasons why.

(7) If the complaint is not resolved within 20 working days, the provider must —

(a) inform the consumer and/or their representative of the reasons for the delay and how long they expect it will take to resolve the complaint; and

(b) appropriately update and keep the consumer and/or their representative updated about progress.

(8) As soon as is practicable after a provider has made a determination on a complaint, decides whether or not it accepts that a complaint is justified, the provider must inform the consumer and/or their representative of the determination and —

(a) the reasons for the determination the decision; and

(b) any actions the provider proposes to take; and

(c) any appeal procedure the provider has in place.

g. Strengthen the Advocacy Service

An automatic referral to the Advocacy Service in the first instance in relation to all complaints received by the HDC could assist in achieving better outcomes for consumers, better support for complaints, a more consumer focused process, a greater likelihood of local resolution, and an opportunity for a restorative approach to be adopted with respect to complaints received.

h. Improve the language of complaint pathways in the Act

(i) No action or no further action

I agree that the language of ‘no further action’ is disempowering, and that it is not reflective of the substantive work that has usually been undertaken by the complainant, the provider, and the HDC at the point the HDC decides to take “no further action”. However, I question whether the alternative wording proposed - ‘no investigative action’ - improves matters.

I note that ‘no action’ and ‘no further action’ reflects the wording used in s38 of the Health and Disability Commissioner Act, and that, in order to change the statutory language, an amendment of the Act would be required.

This may be more complicated than it may appear, as s38 effectively relates to the various tiers of actions able to be taken by the HDC. Further, a closer look at the wording of section 38 suggests that a more wholesale review might be required.

However, the categorisation of the options available to the HDC in relation to a complaint as specified by the Act, does not, in my view, prevent the use of more consumer focused and accessible language in the HDC’s decision letter, either alongside or even instead of the required statutory language.

(ii) Mediation conference

I agree that using different language such as ‘facilitated resolution’ to capture other forms of resolution such as conciliation, and a restorative practice approach as now articulated in the National Adverse Events Policy, would be appropriate.

A different term may be appropriate to explicitly recognise and provide for resolution practices from a te ao Māori perspective.

1.3 *What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaints resolution?*

In practice, there remains a lack of clarity around the HDC's processes, which contribute to delays in the responsiveness of the HDC, and in turn negatively impacts on consumers and providers involved in a complaint.

In particular, it seems to me that there is more scope for the HDC to undertake an immediate triage of complaints which may incorporate considerations such as whether the complaint has already been responded to by the provider; whether the matter has been referred to the Advocacy Service; and/or the seriousness of the complaint.

In my experience, it remains the case that the HDC's interpretation of a "preliminary assessment" can be quite extensive, and usually includes a very broad request for information from the relevant provider; and may involve the HDC seeking internal or external clinical advice.

In my view, greater clarity and transparency about the HDC's internal processes, and the various pathways progressed by the HDC, would be helpful.

Topic 2: Making the Act and Code more effective for, and responsive to, the needs of Māori

- 2.1 Did we cover the main issues about making the Act and the Code more effective for, and responsive to, the needs of, Māori?
- 2.2 What do you think about our suggestions for making the Act and the Code more effective for, and responsive to, the needs of Māori, and what impacts could they have?
- 2.3 What other changes, both legislative and non-legislative, should we consider for making the Act and the Code more effective for, and responsive to, the needs of Māori?

I support making the Act and Code more effective for, and responsive to, the needs of Māori, and defer to Māori submitters regarding the above.

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

3.1 *Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?*

Yes.

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

a. *Strengthen disability functions in the Act*

I support adding a legislated role focused on disability issues on the basis that it could strengthen oversight of complaints from a disability perspective, enhance HDC's focus on the rights of tāngata whaikaha | disabled people, and support trust in, and engagement with, HDC.

I also support adding a requirement for HDC to report to both the Minister of Health and the Minister for Disability Issues, with a view to strengthening HDC's ability to promote and protect the rights of tāngata whaikaha | disabled people using health and disability services.

b. Update definitions relating to disability

I agree that definitions relating to disability ought to be updated.

The definition of "Disability services" could be amended to refer to "Disability Support Services" and reflect the definition set out in section 4 of the Pae Ora (Healthy Futures) Act 2022, namely:

disability support services includes goods, services, and facilities—

(a) provided to people with disabilities for their care or support or to promote their inclusion and participation in society and their independence; or

(b) provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of their inclusion and participation in society and their independence.

The HDC may also wish to consider whether it is appropriate to amend the definition of health services to mirror the definition of [personal] health services in the Pae Ora (Healthy Futures) Act 2022, namely:

health services—

(a) means goods, services, and facilities provided to an individual for the purpose of improving or protecting the health of that individual, whether or not they are also provided for another purpose; and

(b) includes goods, services, and facilities provided for related or incidental purposes

There may then not be a need to define health (noting that the definition of "human health" is not particularly helpful; and there is no definition of disability); and a health and disability services consumer could simply be defined (together or separately) as a person receiving health and/or disability [support] services.

There may also not be a need for a definition of health [care] provider, health care institution, health care procedure or health treatment.

c. Strengthen references to accessibility

I agree with the proposed strengthening of references to accessibility.

d. Strengthen and clarify the right to support to make decisions

In my view, the Code currently implies that a person should be supported to make decisions about their care to their fullest decision-making ability.

I agree that there is a need for good-practice guidance, education, and resourcing to support providers to put this Right into practice.

In terms of the proposed strengthening of the Code, and proposed Right 7(2) and Right 7(3):

(2) Every consumer must be presumed **to have decision-making capacity competent** to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer **does not have decision-making capacity-is not competent**.

[Proposed changes relate to Topic 3, proposal d. Strengthen and clarify the right to support to make decisions.]

(3) Where a consumer has **affected decision-making capacity-diminished competence**, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to **their-his-or-her** level of **decision-making capacity-competence**. **Where necessary, this includes the right to support to make decisions.**

I would suggest that Right 7(2) should be amended to make it clear that decision-making capacity is not global, and that it is decision specific. I therefore suggest adding the following words in bold:

(2) Every consumer must be presumed to have decision-making capacity-to make an informed choice and give informed consent **with respect to a particular decision**, unless there are reasonable grounds for believing that the consumer does not have decision-making capacity **to make that decision**.

With respect to the proposed changes to Right 7(3), I suggest that this ought to read:

(3) Where a consumer has affected decision-making capacity, the consumer has a right to support to make decisions and retains the right to make informed choices and give informed consent to the extent appropriate to their level of decision-making capacity.

In my view, the above wording gives greater primacy to the right to support, and the right to make informed choices and give informed consent.

I also support the proposed amendment to Right 7(4), noting that Right 7(4)(c)(ii) could be amended to expressly refer to whānau – for example, it could read “...the views **of whānau and** other suitable persons who are interested in the welfare of the consumer and available to advise the provider” (words in bold have been added).

e. Progress consideration of HDC’s draft recommendations relating to unconsented research

I note that the HDC consulted in 2017, and published its report in 2019. I believe that it is important that the HDC’s recommendations in relation to unconsented research are progressed – namely that some health and disability research not currently permitted involving adults unable to consent should be allowed in order to build greater knowledge of certain conditions, treatment, and services - but only in limited circumstances and with robust safeguards, including:

- the introduction of comprehensive set of principles with an appropriate regulatory framework to underpin the legal and ethical settings for health and disability research involving adults unable to consent;
- a specialised ethics review and approval process and enhanced governance system in relation to health and disability research involving adults unable to consent; and

- monitoring and evaluation of any changes to the legal and ethical framework, systems, and processes relating to health and disability research with adults unable to consent, with a particular focus on outcomes for participants.

3.3 *What other changes should we consider (legislative and non-legislative) for making the Act and the Code work better for tāngata whaikaha | disabled people?*

None.

Topic 4: Considering options for a right of appeal of HDC decisions

4.1 *Did we cover the main issues about considering options for a right of appeal of HDC decisions?*

a. *Introduce a statutory requirement for review of HDC decisions*

I support introducing a statutory requirement for review of HDC decisions.

I do not consider that a statutory right of appeal is appropriate or necessary, noting the status of the HDC's final decision as being an opinion only; and that, in the event a breach of the Code finding is made, an aggrieved person has a right to file a claim in the HRRT.

b. *Lower the threshold for access to the HRRT*

I do not support a lowering of the threshold for access to the HRRT.

The HDC receives extensive information, undertakes a full investigation, invariably with the benefit of independent expert evidence, and consults with the complainant and the provider on its draft opinion.

The vast majority of matters referred for investigation result in a breach finding.

In my view, there is a significant risk that lowering the threshold for access to the HRRT would lead to a significant increase in complaints that are not appropriate for the HRRT (eg, minor, frivolous, or vexatious complaints).

The introduction of a statutory requirement for review of HDC decisions would, in my view, provide an adequate additional safeguard for the protection of the right to natural justice, noting also the existing mechanisms available, including a right of complaint to the Ombudsman.

4.2 *What do you think about our suggestions for considering options for a right of appeal of HDC decisions, and what impacts could they have?*

As above.

4.3 *What other options for a right of appeal of HDC decisions, both legislative and non-legislative, should we consider?*

None.

Topic 5: Minor and technical improvements

5.1 *What do you think about the issues and suggestions for minor and technical improvements, and what impacts could they have?*

a. *Revise the requirements for reviews of the Act and the Code*

I note that the HDC considers that it would be helpful to update the sections of the Act relating to the requirement to review the Act at least every five years, and the Code at least every three years, and the different requirements on the Commissioner when reviewing the Act versus reviewing the Code in order “to make them clearer, reflect a context where we are updating an existing Code rather than developing a new Code, and better align the requirements of reviews of the Act and the Code”.

Exactly what amendments are proposed are not clear. However, it makes sense for there to be consistency in the applicable timeframes for a review of the Act and the Code. 5 years seems appropriate, with 10 years likely to be too long (noting the significant shift towards a more human rights-based focus in the law in all respects over a similar timeframe).

b. Increase the maximum fine for an offence under the Act from \$3,000 to \$10,000

I am unaware of the extent to which offences are committed under the Act. If few, or no offences are prosecuted under the Act, it may not be necessary to amend the maximum fine available.

I also note my view that the offence of failing to provide information to the Commissioner only applies to circumstances where the Commissioner has referred a complaint for formal investigation (pursuant to section 59 of the Act), which again limits the situations in which offences are likely to be committed.

c. Give the Director of Proceedings the power to require information

I support an amendment to enable the Director of Proceedings to require any person to provide information up until the Director decides to issue proceedings.

d. Introduce a definition for ‘aggrieved person’

I do not oppose the incorporation of the definition of ‘aggrieved person’ in the Act, but do oppose a broader interpretation beyond consumers of health and/or disability services, with the exception of allowing for certain specified family members/an appropriate representative of the deceased consumer to bring proceedings on their behalf in accordance with usual legal principles.

e. Allow for substituted service

I support an amendment allowing for substituted service when the HDC can’t find someone — for example, giving them notice via registered post, or through their social media account/s.

f. Provide HDC with grounds to withhold information where appropriate

I support the HDC having a similar ability to the Privacy Commissioner’s office to withhold information relating to an investigation.

g. Expand the requirement for written consent for sedation that is equivalent to anaesthetic

I support this proposed amendment.

h. Clarify the requirement for written consent where there is a high risk of serious adverse consequences

I support this proposed amendment.

i. Clarify the Code's definition of teaching and research

I support clarification of the Code's definition of teaching and research.

j. Respond to advancing technology

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5.2 What other minor and technical improvements, both legislative and non-legislative, should we consider?

None.

5.3 What are your main concerns about advancing technology in relation to the rights of people accessing health and disability services?

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

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Thank you for the opportunity to make submissions in relation to your review of the Act and Code.

Please do not hesitate to contact me in the event you would like to discuss any of the above further.

Yours sincerely



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