

Submitted to About the Act and Code Review
Submitted on 2024-07-17 13:03:05

Your details

1 What is your name?

Name:

[Redacted]

2 What is your email address?

Email:

[Redacted]

3 Are you submitting as an individual, or on behalf of an organisation or group?

I am submitting as an individual

4 How did you hear about this consultation?

Select from the following options:
Other (please specify)

If you selected other, please specify below:
Can't recall sorry

Questions for individuals

1 Which of these services do you engage with the most?

Health services, Aged Care services, Other (please specify)

If you selected other, please specify below:

[Redacted]

2 What is your gender?

[Redacted]

Share 'one big thing' or upload a file

5 Are you here to tell us your 'one big thing'?

Your one big thing::

I have two things - one big and one small.
Firstly with respect to Right 7 - this to my mind, alongside Rights 5 and 6, is one of the parts of the Code that has the greatest potential to guide and improve healthcare, social care and disability services provision. I agree with changing 'competent' to decision-making capacity' and 'affected capacity' -

we may as well try to be consistent within our legislation and this terminology probably makes more sense to clinicians.

I gather (happily) there is no plan to remove the 'best interests' approach. I admit I am disheartened and concerned by the indication from the Law Commission that it might come out of the new adult decision-making legislation and be replaced by language driven by the CRPD i.e. will and preferences. I do acknowledge 'best interests' is an imperfect standard and test but I do believe it is the best we have and captures the essence of the duty of care. Properly understood it not only weighs benefits and harms BUT ALSO takes account of the values and preferences of the person affected i.e. their autonomy, if and where they can be ascertained, and the views of other suitable persons where that is necessary and appropriate. I don't believe that common understanding of 'will' equates with values and its use to my mind poses a real risk of expressed intentions and choices of individuals being accepted uncritically without due consideration of their decision-making capacity and if it is affected/impaired the potential for their 'will' to result in choices and actions that are contrary to their best interests. I believe it is much less likely that a best interests determination that takes account of their values and preferences would be contrary to their best interests.

My suggestions/questions:

(1) Should the initial wording of 7(4) expand/clarify the first step "Where a consumer is not competent to make an informed choice and give informed consent" to include an obligation (or at least taking reasonable steps) to check/ascertain if there is someone else legally entitled to consent and maybe specify what that means - i.e. EPOA, welfare guardian, parental guardian (although I appreciate that changes to the PPPR Act might complicate the ability to specify) and maybe also an obligation to take reasonable steps to ascertain if the person has made any prior statements of their values and wishes such as an advance directive (AD) or advance care plan (ACP).

Then the next step becomes "the provider may provide services where-

(a) it is in the best interests of the consumer: and"

I'm personally not sure clinicians appreciate the importance of checking for EPOA, guardians first, and also for ADs/ ACPs as critical to determine first if someone else can legally give consent (and/or refuse in certain circumstances) and also to help determine what is in the person's best interests through being in keeping with their values and preferences.

(2) I realise that ACPs have not yet been tested in law in NZ but would be really keen to have them specified, added to the definitions section (I'm sure the ACP group could provide a definition or you could use the information on the MOH website), and included alongside ADs in the body of 7 (4). My personal view is that a well designed and valid ACP is of much greater value than many ADs.

(3) Maybe 'views' of the consumer throughout could be replaced by 'values and preferences' (but leave views in relation to the suitable others)

(4) Maybe also somehow add reference to the consumers 'values and preferences' in relation to the approach to decision-making i.e. do they prefer and use an 'independent' 'individual' approach or do they prefer a 'collective' decision-making approach

e.g. 7(4) (b) could say "reasonable steps have been taken to ascertain the values and preferences of the consumer, including their preference for individual or collective decision-making: and

(c) either"

I do appreciate that navigating collectively decision-making will add a complex dimension, but I think we need to specifically acknowledge it as part of honouring tikanga and te Tiriti, and cultural responsiveness.

Note: in the draft Code with wording changes - 'competent' still needs to come out of 7 (4) (c) (i)

I think the original wording of 7(4) (c) (ii) is clearer than the proposed new wording although I accept that whatever has been ascertained should be included. - maybe just needs tidying.

NB 7 (6) (c) I'd be inclined to say "the consumer will be given procedural sedation or anaesthesia" but if you prefer/want to specify the type and/or purpose of individual medications then you need to include analgesics/pain relief as these are usually essential parts of both procedural sedation and anaesthesia.

Right (10) does the "representative" who is not chosen by the consumer but is "otherwise entitled" mean legally entitled in the same sense as those legally entitled to consent - or is the entitlement different? Can it simply be a relative or friend who decides to make a complaint?

My second thing - a question: I always understood that the Code says nothing about rights to access healthcare services or disability services - only rights (and corresponding providers duties) once the consumer is a user of health or disability services. Is this correct? It seems sometimes to be interpreted as meaning that there is an unconditional right to healthcare in NZ which to me seems unrealistic and unworkable. I'm not sure if this needs to be or could be clarified in either the Act or the Code. It relates in part to the Provider Compliance clauses - these hint that resource constraints might preclude or prevent a particular service from being provided but I'm not sure if that covers my point. I also find it intriguing that provider duties are referred to on several occasions but never actually specified other than as "corresponding to the rights in this Code". Perhaps that is sufficient.

6 Upload a file

File upload:

No file uploaded

Not Answered

Topic 1: Supporting better and equitable complaint resolution

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

Please add your response below:

Perhaps the purpose could be reworded in (a) to "secure the simple, speedy, and efficient resolution of complaints relating to infringements of those rights that is centred on people and the things, including relationships, that matter to them, and is fair to both consumers and providers: and..."

I fully comprehend the history of the Code and the power imbalances involved but think it is time we stopped casting the providers as the problem (the Code seems to almost take a guilty unless they can prove their innocence rather than the standard innocent until proven guilty) and failing to acknowledge both the complexity of modern healthcare including contributions of both human factors and systems issues and the fact that the vast majority of healthcare professionals are good people working under extremely difficult circumstances

Personally I would not add "mana" here (in the purpose) but in Right 3 - making it "Right to dignity, mana and to live according to their own values". I'm not in favour of "autonomy" as I think it is still commonly misunderstood to represent the western libertarian perspective which regards and 'prizes' individuals as independent of others and fails to take proper account of "relational autonomy" and fails to recognize and value "interdependence".

I agree there is still widespread misunderstanding of cultural responsiveness and the existence multiple interrelated identities (I think referred to as intersectionality??) - not entirely sure how the wording could be improved. Including specific examples, such as the rainbow LGBTQIA+ community necessarily privileges those that are mentioned so needs thought. Given the name of the Act and Code it would certainly make sense to specifically refer to disabled people. I agree that the "including the needs, values, and beliefs of Māori" reads more like an afterthought rather than giving it the respect and priority it needs. I personally am comfortable in NZ with highlighting Māori and Pasifika, and usually like to add/specify 'and other ethnic groups' to reflect our multicultural society.

I agree that support people and the roles of whanau and other wider family and social groups as appropriate for the consumers culture, values and beliefs is important including in complaints resolution no matter what approach is taken. Complaints made on behalf of the consumer would need, in my view, the consent and agreement of the consumer, where they have decision-making capacity. Where they lack this then I do support others making complaints on their behalf.

I think whanau/family involvement and collective decision-making approaches can present real challenges in practice especially in relation to decision-making under Right 7(4) but we still have to find a way to try. (I appreciate this is not about complaints resolution - see also my One Big Thing comments

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

Please add your response below:

Most of the suggestions sound good - I wonder if some of the problem with people not using a 'direct to provider' approach to try to achieve resolution and the Advocacy service rather than a complaint to the HDC is that the Code and documents emphasize a 'complaints' based approach and the right to complain rather than encouraging and highlighting these other often preferable options and how to access them.

I agree the wording in Right 10 could be improved and maybe be less directive/restrictive - but have insufficient experience really to comment on this. It does feel onerous and is process-focused rather than 'aim', 'people' and 'relationship' focused. I'm not entirely sure what you mean by 'principle-based direction'. I understand a good robust process is part of how we ensure fairness, procedural justice, but maybe the tone and emphasis needs changing. I also note that even the consultation document itself is confusing in this respect - under the explanation of HDC Resolution pathways on p 17 the distinction between 'assessment' (which enables a decision of no action or no further action' and 'investigation' is not clear - to me you have to do at least some investigation to decide what to do next - and under the heading 'investigate' it rather implies that an investigation is what happens for a finding of breach and makes no mention that to investigate can result in a finding of no breach.

I appreciate the intent to use complaints as a quality improvement mechanism but think there are other ways as well the Code can be used to improve practice. It should be considered a 'guide to practice' and tool for educating for healthcare professionals - and so needs to show respect for them as well as consumers or it risks remaining seen as it certainly has been in the past too unfairly weighted to consumers and unsympathetic to professionals/providers.

The 'protection from retaliation' sounds good in theory but I think in reality could be very difficult to ensure. But to include it is still a good idea.

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

1.3 changes - supporting better and equitable complaint resolution:

The Section 3 Provider Compliance clause (and the entire Code) is really quite 'light' on exactly what is entailed in the providers duties, and entirely silent on consumer duties and obligations. It would be good in my view if we could address this. I am aware of statements and guidelines outlining expectations and responsibilities of consumers to provide more balance. I do appreciate that this is something of a deviation from the original purpose and intent of the HDC Act and Code but think it is time we moved on. It would reflect the sentiment that the consumer-provider relationship is valuable and needs attention as well as the rights of the consumer.

I'm not sure how this could be done or if this is the right place and mechanism (through the review to the Act and Code) but think it is overdue. Healthcare is so much more complex and in my view better not cast as a battle between consumer rights and provider duties.

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

2.1 Did we cover the main issues about making the Act and Code more effective for, and responsive to, the needs of Māori?

Please add your response below:

I feel insufficiently qualified to comment on this

2.2 What do you think about our suggestions for making the Act and the Code effective for, and responsive to, the needs of Māori, and what impacts could they have?

Please add your response below:

The changes already made and your suggestions for further change seem appropriate but I have no real experience in this area

My only other comment as I have already indicated - I would see "mana" as fitting better under Right 3 than in the purpose of the Act.

2.3 What other changes, both legislative and non-legislative, should we consider for making the Act and the Code effective for, and responsive to, the needs of Māori?

Please add your response below:

Nil to add

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?

Please add your response below:

I think so.

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?

Please add your response below:

Agree in general.

I do understand the NZ is a signatory to the CRPD but I have concerns about the term 'will and preferences'. Will seems to be being interpreted as 'values' and I don't believe they are the same. As I have indicated above in the One Big Thing section I think the common understanding of 'will' is likely to result in decisions and actions which are not in the best interests of the person and neglect our duty of care. I personally tend to use 'values and preferences' and wonder if this would be acceptable. In people with affected decision-making capacity, including but not only disabled people, they can often appear to be expressing a strong 'will' or intention which may or may not have validity in terms of reflecting intact decision-making capacity. I think the wording 'will' potentially makes it harder to recognize and respond appropriately to circumstances where the expressed will / intent does not represent a valid expression of the persons values and should not necessarily be honoured or respected.

My other concern about the CRPD and the approach it recommends is that it seems to imply that all disabled people have the same legal entitlement and capacity to make their own decisions when patently this is simply not true or possible. It tends to represent disabled people as more alike and homogenous as a group than they are in reality. I fully appreciate the direction of travel and better understanding of the relationship between impairment and disability and societal barriers and responses but think the ideology has lost sight of the real world and actually risks a neglect of duty of care to the most disabled in particular those who have never had, and never will have decision-making capacity (whether or not they are identified as disabled).

I do fully support the further development of supported decision-making and the importance/right of disabled people to have their access to communication and informed choice/consent optimised and specifically matched to their needs.

I suspect if we honour additional appropriate rights for and obligations to disabled people it has the potential to slow and complicate some important decisions - but accept this is the right thing to do - it will need to be recognized and appropriately resourced alongside greater education and training for healthcare and social care professionals and staff within HDC.

I admit ambivalence about research matters - I agree with no recommendation to include a person with 'lived experience' on ethics committees and see this more as tokensim - it is better that we are all more informed and understanding of the issues and that committees are obliged to take account of relevant factors than to rely on one individual whose lived experience may or may not have any relevance to the matter at hand.

I agree that the 'best interests' test makes no sense in the context of research - but am unsure if I can imagine any research that would entail no greater probability or magnitude of harm than ordinary daily life. The concept of 'no more than minimal foreseeable risk and no more than minimal foreseeable burden' makes sense but needs something additional identifying maybe a 'reasonable potential benefit' - which clearly cannot be guaranteed but surely there needs to be some expectation that it might accrue for the participant and for populations to which that person belongs - in other words I think it needs to consider both sides of the benefit: harm analysis. The group might for example share an underlying impairment and the research aimed at prevention and/or remediation. I appreciate that some reject attempts at 'fixing' the impairment as inappropriate and unacceptable but personally I hold a different view. I think individuals are entitled to hold that view for themselves but not entitled to impose it on others or society at large. And presumably there might be some people with impaired / affected decision-making capacity where they could contribute to the decision with support and taking account of their values - even if the consent would not be legally recognized.

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

Please add your response below:

Nil to add

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

4.1 Have we covered the main issues about considering options for a right of appeal of HDC decisions?

Please add your response below:

Its not clear to me if the current system allows for review of all decisions or only decisions reached after investigation - maybe this needs clarification

Otherwise no comment here

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

Please add your response below:

I personally think the right to appeal is important - I like the option to "include a statutory requirement for HDC to review decisions if requested, and to publicise this requirement." and I think the right to appeal must be equally available to both complainants and providers. It would seem more accessible and reasonable in the first instance rather than escalating to other authorities however those options would presumably still remain.

I do appreciate the resource implications but think justice and fairness are more important.

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

Please add your response below:

Nil to add

Topic 5: Minor and technical improvements

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

Please add your response below:

In essence agree with your suggestions except for

(f) - I worry that denying the provider the information being used in the investigation during the investigation process is inconsistent with procedural fairness and justice - surely it is a fundamental part of the right to defend yourself against allegations and respond and sooner rather than later might actually result in better decisions/outcomes. Maybe if the information was shared more readily then OIA requests, and all the huge amount of work that goes with them, would not be required.

To me this is another example where the Code seems to be biased in favour of the complainant/consumer starting from the assumption that the provider is at fault. I do also get the power imbalance than might work against the consumer in this regard although also think that sometimes the momentum has shifted such that providers, particularly junior healthcare professionals, are less powerful and more vulnerable than can be appreciated.

(i) Maybe in Right 9 replace "teaching" with "education" (more commonly used terminology these days). And define education as "an activity where a healthcare professional and/or healthcare professional student/trainee is present and/or participating either solely or primarily for the purposes of learning rather than service provision."

It is perhaps easier to make this distinction in students, although not so easy as they get more senior and closer to graduation and more included as part of the service provider team, and much harder in qualified and/or registered professionals who are arguably always learning all of the time but sometimes they too are more obviously learning, especially if undergoing specialty training and undertaking a task or practice which is being actively supervised.

[REDACTED]

https://www.otago.ac.nz/_data/assets/pdf_file/0029/329393/medical-students-and-informed-consent-a-national-consensus-statement-2015-691853.pdf and more recently revised

<https://nzmqj.org.nz/media/pages/journal/vol-136-no-1579/informed-consent-for-medical-student-involvement-in-patient-care-an-updated-consensus-statement/29>

I think you are aware of this.

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

Please add your response below:

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

Please add your response below:

I have insufficient expertise/knowledge in relation to technology to make any comments other than to agree this will add all kinds of additional challenges and that whatever wording is used in the Act and Code ideally is such that it doesn't need frequent changes to be made.

I do worry that open-source software and AI pose greater risks than currently appreciated (as well as potential benefits) and obtaining truly 'valid' (informed, voluntary and competent) consent for use will be pretty difficult, but currently have no specific suggestions sorry.

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

Please add your response below:

Publishing and data protection

May we publish your submission?

Yes, but please remove my name/my organisation

Please note any part(s) of your submission you do not want published::

[REDACTED]

Reasons to withhold parts of your submission

Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.:

Yes

I think these parts of my submission should be withheld, for these reasons: :

Only name and personal and work details as above

If needed, can we to contact you to follow up for more detail on your submission?

Yes, you can contact me

Would you like to receive updates about the review?

I'd like to receive updates about the review