Mental Health Foundation
mauri tū, mauri ora
OF NEW ZEALAND

Submission: Review of the Health and Disability Commissioner Act 1994 and Code of Health and Disability Services Consumers' Rights

By the Mental Health Foundation of New Zealand

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Health and Disability Commissioner

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Tuia te rangi e tū nei
Tuia te papa e takoto nei
Tuia i te here tangata
Tihei mauri ora.

He hōnore, he korōria ki te atua ki te runga rawa
He whakaaro maha ki a rātou kua haere ki te wāhi ngaro
Rau rangatira mā, ānei ngā whakaaro me ngā kōrero nā Te Hauora Hinengaro.

Introduction

Thank you for the opportunity to comment on the Review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code).

The Mental Health Foundation of New Zealand (MHF) supports the overall intention of this review, especially supporting better and more equitable complaint resolution and making the Act and Code work better for tāngata whaikaha | disabled people and more effective for, and responsive to the needs of, Māori. Our submission will predominantly focus on these three topic areas given our remit and expertise. We also provide some advice regarding minor and technical improvements.

General comment

The MHF welcomes and affirms actions that the HDC have already undertaken, such as continuously seeking to improve the accessibility of the complaint resolution process (e.g., though introducing hui ā-whānau and hohou te rongo, clinical navigators, and feedback surveys for both service users and providers), establishing a Director Māori role, and improving the measuring of and reporting on disability issues.

The MHF notes that some of the proposed changes to the complaints processes will require sufficient and additional resourcing to enable the HDC to embed and implement accessibility enhancements fully and inclusively. If no corresponding resources are provided to support change, it will create a risk that the expectations of providers and consumers are not able to be met by the HDC. For example, introducing mana-enhancing elements into and increasing the availability for hui ā-whānau during complaints processes will require growth in internal HDC capability and capacity and corresponding resources.

Resources will also need to be carefully balanced across the HDC's goals to *promote awareness* of the Code and *protect the rights* of service users. There is a line of logic that increased systematic education and awareness of the Code will result in fewer, less egregious complaints that will take less resource to resolve. Careful consideration will need to be given to the short- and long-term trade-offs of resource allocation decisions of this nature.

The MHF supports advancing better and more equitable complaint resolution

In general, we agree with the proposed changes under this topic, such as clarifying cultural responsiveness in Right 1, using gender inclusive language, and clarifying provider complaint processes and including a non-retaliation clause in Right 10. We outline concerns and considerations regarding some of the other proposed changes below.

Amending the purpose statement

The MHF fully supports broadening the purpose statement for complaints resolution in the Act to include a focus on people-centred practice and outcomes, rather than just focusing on the principles for good complaint processes, and we support incorporating the concept of upholding mana into the purpose statement. We agree the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 provides a useful and relevant template for potential wording changes.

We note that the goal of a fair, and therefore rigorous, process may conflict with the goals of a simple, speedy and efficient resolution. It would be useful to understand, and provide transparency about, how the HDC might give weight to these different goals through its complaints resolution processes and in navigating this inherent tension.

We also note the HDC states that "enabling approaches such as restorative practice and hohou te rongo in complaint resolution can, in appropriate cases, support engagement, reduce the risk of further harm, and increase opportunities for healing, learning, and improvement."[1] The Health Quality and Safety Commission (HQSC) also encourages providers to use restorative practice and hohou te rongo in 'adverse' events (where harm has been caused because of health care).[2] The MHF fully supports embedding restorative practices into the HDC's complaint resolution processes not only to support understanding, healing and learning for those involved but to also contribute towards breaking the risk aversion cycle of the mental health system where clinicians adopt restrictive/defensive practices to protect their professional reputation or the reputation of a health service.[3]

Clarifying the role of whānau

The MHF supports the proposed changes to:

a. replace references to 'independence' with 'autonomy' under Right 3 (Dignity and Independence) to recognise the interdependence oftentimes had between a consumer and their whānau/support network,
b. strengthen Right 8 (Support) to include the right to have whānau involved even in their physical absence, and
c. clarify Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer.

We agreed that although the Code currently does allow for people to have their whānau involved in their care to the extent determined by the person concerned, how this works in practice is poorly understood by consumers and providers, and

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[1] See, for example, The National Collaborative for Restorative Initiatives in Health's *He Maungārongo ki Ngā Iwi: Envisioning a Restorative Health System in Aotearoa New Zealand* (2023).
[2] Te Tāhū Hauora | Health Quality and Safety Commission, *Healing, learning and improving from harm: National adverse events policy 2023* | *Te whakaora, te ako me te whakapai ake i te kino: Te kaupapa here ā-motu mō ngā mahi tūkino 2023.*
[3] See 'Risk aversion and the Mental Health Act' in *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction* (2018) (Chapter 11, page 193).

these changes should provide more concrete guidance around the processes involved.

These amendments will support all consumers to maintain autonomy over who is involved in the decision-making regarding their care and particularly benefit cultural groups who value collective decision-making, which is an essential move towards ensuring Māori have a right to tino rangatiratanga, as guaranteed through Te Tiriti o Waitangi.[4]

We recommend consideration be given to obtaining consumer consent for a complaint made on their behalf by their whānau or support network, or otherwise setting a threshold regarding the nature of the complaint, to help manage instances where there may be conflicting views or wishes between consumers and their whānau about a provider or services received.

We also stress that the HDC's capacity and capability to support increased whānau involvement must be adequately resourced.

Strengthening the advocacy service

The HDC's contract with the National Advocacy Trust to provide the independent Advocacy Service for consumers is valuable, as it provides a person-centred way to resolve complaints early and directly with the provider. Fair, simple, speedy and efficient resolutions for consumers are paramount. Given the shared agenda of promoting the Code and resolving complaints in this manner, **we recommend the advocacy service and the HDC is strongly connected and coordinated in the achievement of their common goals.** This could be formally established through the Advocacy Guidelines (section 28) or the advocacy service agreement setting out a shared agenda and strategic approach.

Improving the language of complaint pathways in the Act

We agree the language of the complaint resolution pathways could be clearer. **We recommend the choice of wording going forward is strongly guided by advice from consumers**, in order to capture the spirit of the decision or pathway and language that resonates with them.

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[4] https://www.waitangitribunal.govt.nz/treaty-of-waitangi/meaning-of-the-treaty/

The MHF supports strengthening the responsiveness of the Act and Code to Māori and Te Tiriti o Waitangi

The MHF generally supports the range of suggestions put forward to strengthen the responsiveness of the Act and Code to Māori and Te Tiriti o Waitangi.

Incorporating tikanga into the Code

The MHF strongly supports focusing on a broader dissemination of the te reo Māori version of the Code, including by placing utmost importance on upskilling service providers, HDC decision-makers and Tribunals regarding their cultural competence and the appropriate interpretation of this version of the Code.

As proposed, the necessary legislative protections, education, and guidance would need to be put in place to ensure true interpretations of mātāpono (principles, values, and tikanga) and support provider understanding. This should include workforce training and guidance for interpretation and good practice. The suggestion for the HDC to explore building strong Māori sector, iwi and hapū relationships will be essential to effectively deliver on these promises.

The MHF supports adding to Right 1 of the Code that every consumer has the right to have their mana upheld. If the above safeguards are effectively put in place, resourced appropriately and maintained, then it should follow that mana is upheld. We do not feel best placed to advise on the incorporation of other elements of tikanga.

Giving practical effect to Te Tiriti in the Act

We agree with creating strong processes to ensure equitable Māori engagement and leadership in the operation of the Act and the Code, such as requiring the HDC to make and maintain effective links with iwi/Māori and engage with iwi/Māori when reviewing the Act and the Code in the future, and in the development of Advocacy Service guidelines.

We support legislative requirements to ensure the HDC has sufficient expertise in te reo and te ao Māori in its leadership team. We suggest this is better achieved by amending Section 10 by:

1. **adding a requirement for leadership skills in this area, and**

2. **requiring that one or more Deputy Commissioners have responsibility for leadership in this area.**

It may be overly prescriptive to specify only one Deputy Commissioner has this responsibility (and we suggest the same approach in relation to the role focussed on disability issues proposed under Topic 3). Legislating for the structure of the HDC in a siloed manner limits its ability to respond to changing circumstances, limits wider responsibility of the leadership team, may create unsustainability of key roles in relation to sector engagement, complaint resolution and internal leadership, and limit the relationships and knowledge held in this area.

To achieve this, you may wish to also **consider other legislative models that require agencies to give effect to a requirement for Commissioners/Boards to have expertise, knowledge and skills in tikanga, te reo and te ao Māori, and whānau-centred approaches (and disability issues)**. Some useful models could include:

- Section 8 of the Mental Health and Wellbeing Commission Act 2020, which sets out the skills and knowledge that board members must collectively possess, and
- Section 6(k) of the Pae Ora (Healthy Futures) Act 2022, which requires the board of Te Whatu Ora | Health New Zealand to collectively have 'knowledge of, and experience and expertise in relation to, te Tiriti o Waitangi (the Treaty of Waitangi), tikanga Māori, mātauranga Māori, kaupapa Māori services, cultural safety and responsiveness of services, mātauranga Māori, and Māori perspectives of services.'

Legislative provisions to uphold obligations to Te Tiriti

We recommend all Articles of Te Tiriti o Waitangi (kāwanatanga, rangatiratanga, ōritetanga and wairuatanga) are explicitly mentioned and incorporated in the Act, and we recommend implementing all suggestions for legislative improvement that the HDC has put forward in the consultation document relating to each Article of Te Tiriti.

We believe that at an absolute minimum, the following should occur:

- Strengthen the qualifications for appointment of Commissioner and Deputy Commissioners in relation to Māori (Section 10(1)(f) Qualifications for

appointment, or additional subsection), and look to examples, such as in the Pae Ora Act, for doing so.
- Expressly include promotion and protection of tikanga in the functions of the Commissioner in relation to the respect for, and observance of, the rights of health and disability services consumers (Section 14(1) Functions of Commissioner).

The MHF supports making the Act and Code work better for tāngata whaikaha | disabled people

The MHF agrees with most of the proposed changes under this topic, including updating the definitions relating to disability, and strengthening the disability functions and references to accessibility. Further considerations are outlined below, particularly in relation to the issue of supported decision-making for adults. We do not believe it falls within our area of expertise to fully consider HDC's draft recommendations relating to unconsented research.

Strengthening disability functions

The MHF supports expanding the HDC's reporting requirements to include the Minister for Disability Issues, as well as the Minister for Mental Health and the Minister of Health. However, **we recommend the wording is future-proofed, for example, by referring to 'the Minister(s) with responsibilities for health, mental health and disability issues'**, rather than referring to current ministerial portfolios that may be subject to change over time.

As mentioned in relation to Topic 2, there are potential risks associated with taking overly prescriptive approaches to legislating for subject matter-related appointments. **We recommend the HDC consider requiring that one or more Deputy Commissioners have responsibility for leadership in this area and adding a requirement for the leadership team to be proficient in matters related to priority populations** (such as disabled peoples and Māori), so these skills are held collectively by the leadership team, as suggested above.

Strengthening and clarifying the right to support to make decisions

The MHF strongly supports all proposed changes put forward, especially the focus on improving the Code and Act's alignment with the language used in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the suggestion to strengthen Right 7(3) by referencing the right to receive support to make decisions.

We believe there is an opportunity for the HDC to provide extra guidance about how the Code interacts with the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act), for example, how Rights 7(1) to (4) may be affected when the Mental Health Act is used.

We understand that people with lived and living experience of being under the Mental Health Act are not always aware the Code applies to them (or may not be aware they have *any* rights), and clinicians may not understand that the Code remains relevant when a person is subject to a compulsory treatment order. This suggests a failure of providers and advocates to make sure the rights of tāngata whai ora are understood.

Service providers and District Inspectors have an obligation to work within the Code and ensure people subject to compulsory assessment and treatment are aware of their rights. **We recommend this obligation could be made clearer either through**:

- a memorandum of understanding between the HDC and the Office of the Director of Mental Health and Addiction, **and/or**
- a clear statement within the revised Code to make it explicit that the Code applies to everyone, including people subject to compulsory assessment and treatment under the Mental Health Act.

The MHF also believes there is an opportunity for the HDC to strengthen Right 7(5), which states that "every consumer may use an advance directive in accordance with the common law".

While the Code achieves simplicity and flexibility about the right to create an advance directive, it does leave room for uncertainty about what exactly makes an advance directive valid (in the eyes of the common law), and therefore more likely to be adhered to and upheld by clinicians.

We note the Law Commission's Review of Adult Decision-Making Capacity Law (Second Issues Paper) identified that:

- "There is uncertainty about the requirements for making a valid advance directive arising from the gap in statutory direction about how an advance directive should be set up and the absence of cases in New Zealand", and
- "Reference to "the common law" [under Right 7] in the Code leaves open how the position and practice in New Zealand is affected as the position in England and other commonwealth jurisdictions evolves."[5]

We recognise there are many practical barriers to using advance directives, such as the lack of data infrastructure to effectively record and store, regularly update, be made aware of and use advance directives at a relevant point in the future; the time required to support consumers to make an advance directive in the first place; and concerns regarding a consumer's decision-making capacity[6] and the document's validity.

However, there is an opportunity through this review for the HDC to address some of the uncertainty expressed by clinicians, for example by:

1. Consider codifying the qualities that will generally make an advance directive valid, rather than referring to the 'common law', such as:
    a. the directive is created by a person who has decision-making capacity to make the directive,
    b. the directive is made freely and without undue influence,
    c. the person intends the directive to apply to the current circumstances,
    d. at the time of making the directive, the person understood the benefits, risks and consequences of consenting to or refusing the specific treatment, and[7]
    e. he directive is up to date.

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[5] https://huarahi-whakatau.lawcom.govt.nz/wp-content/uploads/2024/04/NZLC-SIP52.pdf

[6] The MHF has noted, in our submission to the Law Commission, that the standards and processes for assessing decision-making capacity, and the consequences that flow from the assessment, need to be amended to prevent unjustified discrimination, address practical issues, and better reflect the diversity of social and cultural contexts that are relevant to people's decision-making.

[7] Opinion regarding the legal status of an advance directive, commissioned by the HQSC from Duncan Cotterill (2021).

2. Requesting additional resources for the HDC to increase their education function and promotion of the Code to clinicians, for example, training and development of case studies relating to advance directives based on upheld complaints to support best practice. The HDC already provides some useful guidance of this nature, especially the advice to help ensure that an advance directive is respected, acknowledged and acted upon.[8]
3. Working with the HQSC, bodies responsible for setting sector standards and professional bodies to provide guidance to clinicians, especially how advance directives might interface with the Mental Health Act.
4. Recommending the Minister of Health/Minister for Mental Health direct the Ministry of Health | Manatū Hauora to embed in the new mental health Bill provisions that clarify the legal status of advance directives in relation to the Mental Health Act.

The HDC could also consider what obligations the Code could place on services to uphold the cultural factors in advance directive development and use. We note findings that, for Māori, important factors in the creation and use of a psychiatric advance directive include the inclusion of whānau in decision-making and the importance of reassessing all aspects of one's life journey.[9]

We envision the recommendations we make for strengthening the Code would be interim steps in the move towards embedding an active obligation for all services to provide supportive, collaborative opportunities to develop and utilise advance directives, in order to support a better model of care underpinned by supported decision-making.

We recognise there is potential for a collective impact for change between the Act and Code Review, the repeal and replacement of the Mental Health Act and the

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[8] https://www.hdc.org.nz/your-rights/about-the-code/advance-directives-enduring-powers-of-attorney/

[9] Potiki, J., Tawaroa, D., Casey, H., Thom, K., O'Brien, A., Lenagh-Glue, J., & Glue, P. (2023). Cultural Influences on the Creation and Use of Psychiatric Advance Directives. *Psychiatric Services*, *74*(12), 1299–1302. https://doi.org/10.1176/appi.ps.20220565

Law Commission's Review of Adult Decision-Making Capacity Law, if there is a successful sequencing of decisions.

Minor and technical improvements

We agree there is merit to better align the requirements of reviews of the Act and the Code, including clarifying that a full consultation is not required for proposed minor amendments to the Code. We recommend that it is made a requirement in Section 23 of the Act for Māori or iwi organisations to be consulted regarding any future (full) reviews Code, as well as the relevant agencies and representatives already set out under this section.

We understand there are currently no legally binding consultation requirements to guide a review of the Act. We recommend that the same requirements set out above are also applied to the Act.

The MHF supports reducing the frequency of full reviews of the Act and Code to every ten years, with the option of an earlier review to ensure they are fit for purpose. As such, we also support creating better alignment between the timings for review of the Act and Code, which are currently every five and three years respectively. It would be useful for the HDC to clarify, if this change is implemented, what the criteria will be for triggering an earlier review of the Code, and whether it will go beyond the criteria set out in Section 21(2) of the Act. We understand that the current criteria for earlier review of the Code is "whenever the Minister so requests" (Section 21(2)(a)) or "at any time, on the Commissioner's own initiative" (Section 21(2)(b)).

Summary

Thank you for the opportunity to comment on the Review. We are overall supportive of the intention and content of this Review and make recommendations to the Health and Disability Commissioner to help strengthen the proposed improvements to the Act and Code. The MHF is hopeful that these changes, if implemented, will support better, more equitable mental health, addiction and wellbeing outcomes for all in Aotearoa New Zealand.

Mauri tū, mauri ora,

Shaun Robinson
Chief Executive

About the Mental Health Foundation

The MHF's vision is for a society where all people flourish. We take a holistic approach to mental health and wellbeing, promoting what we know makes and keeps people mentally well and flourishing, including the reduction of stigma and discrimination (particularly on the basis of mental health status).

The MHF is committed to ensuring that Te Tiriti o Waitangi and its Articles are honoured, enacted, upheld and incorporated into our work, including through our Māori Development Strategy. We are proud that Sir Mason Durie is a Foundation patron.

The MHF takes a public health approach to our work, which includes working with communities and professionals to support safe and effective suicide prevention activities, create support and social inclusion for people experiencing distress, and develop positive mental health and wellbeing. Our positive mental health programmes include *Farmstrong* (for farmers and growers), *Mental Health Awareness Week, Pink Shirt Day* (challenging bullying by developing positive school, workplace and community environments) and *Open Minds* (encouraging workplaces to start conversations about mental health). Our campaigns reach tens of thousands of New Zealanders each week with information to support their wellbeing and help guide them through distress and recovery.

We value the expertise of tāngata whaiora/people with lived experience of mental distress and incorporate these perspectives into all the work we do.

Established in 1977, the MHF is a charitable trust, and our work is funded through donations, grants and contract income, including from government.