

19 May 2022

Mental Health Act Review Ministry of Health PO Box 5013 Wellington 6140

By email: mhactreview@health.govt.nz

Tēna koutou,

Consultation: Transforming mental health law in Aotearoa New Zealand

Thank you for the opportunity to provide input into the formative stage of this important piece of work. By entrenching the power imbalance between consumers and providers, the Mental Health (Compulsory Assessment and Treatment) Act 1992 contributes to inequity and harm. I strongly support its repeal and replacement and the principles Government has agreed to guide the development of new legislation.

I look forward to providing further comment at subsequent stages in the process.

Introduction

As the Health and Disability Commissioner, my role is to promote and protect the rights of people who use health and disability services as set out in the Code of Health and Disability Services Consumers' Rights (the Code). The Code has been in place since 1996 and is enforceable by law and the powers of my Office. In recognition of the power imbalance between consumers and providers, the Code was established to reinforce people's right to be partners in their own care. Under the Code people have the right to be treated with respect and dignity, to make informed decisions about their treatment and to receive an appropriate standard of care that meets their unique needs and contexts, including their culture and beliefs.

These rights belong to all people using health and disability services and should be reflected in and reinforced by any new legislation. Having mental health issues or being in distress should not dispossess people of their rights. On the contrary, they become even more important when someone is in a vulnerable state. By overriding aspects of the Code by design, the current Mental Health Act devalues the perspectives of consumers and engenders an approach to their care that is heavily weighted towards risk-based, clinician-centric decision-making and coercion. Such an approach is not aligned with a recovery-centred philosophy, which stresses the importance of people exercising choice and autonomy and regaining a sense of control over one's life. It is also incongruous with government's responsibilities under Te Tiriti o Waitangi and both international and domestic human

rights law.¹ The evidence suggests that any benefits of such an approach are at best minimal² and are not achieved without significant and inequitably distributed cost to people.

Prioritising respect for people's rights in policy and practice is not only beneficial for people's wellbeing but has supported other countries to significantly shift their approach to care and reduce the use of coercion. I note that in Aotearoa, New Zealand, upholding the Government's commitment under the UN Convention on the Rights of People with Disabilities (UNCRPD) to treat people with psychosocial disabilities 'on an equal basis' as all others under the law'³ in regards to the provision of health care, means providing care in a way which aligns with the Code. I believe that ensuring legislation reflects and reinforces the Code provides the best balance between people's rights to liberty and autonomy and their right to the highest attainable standard of health, and I outline ways to do so in my submission.

Given the negative experiences many have had under the current Mental Health Act, I understand the desire to prohibit the use of compulsory treatment altogether. However I believe it needs to remain a mechanism of last resort for the exceptional circumstances where people are unable to make an informed decision about or give informed consent to care, even with support, and the benefits of providing care outweigh the harms of forcing care on someone. In those situations, it is critical that a person's interests are the central consideration, and new legislation must include provisions that support those interests to be expressed, understood, and to influence the decisions made when people are unable to advocate for themselves.

Significant shifts are needed to transform our approach that moves away from a 'medicate and manage' approach to one that is truly people-centred, and legislation alone will be insufficient to achieve change. I acknowledge the hard work and dedication of frontline mental health professionals, and the examples of good practice that is accomplished despite the pressures that the system and those working within it are under. For the new Act to meet its objectives – including being used as a last resort – it needs to be supported by a significantly different operating environment. Wider system

³ A Resolution on Mental Health and Human Rights from the United Nations Human Rights Council calls upon States to 'abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis' with others and to 'provide mental health services for persons with mental health conditions or psychosocial disabilities on the same basis as to those without disabilities, including on the basis of free and informed consent'.



¹ For example, the Act overrides people's right to refuse any medical treatment (s.11 of the Bill of Rights Act 1990); disabled people's right to equal treatment under the law (Human Rights Act 1996, s 19(1) of the Bill of Rights Act 1990, Convention on the Rights of People with Disabilities); and is used to justify cruel and degrading treatment (s9. Bill of Rights Act 1990 and the Optional Protocol on the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment). For a more fulsome summary of the relevance of international and domestic human rights law to the current Mental Health Act, please see Ministry of Health (2017). The Mental Health Act and Human Rights: a discussion document. Wellington: Ministry of Health.

² While the effectiveness of compulsory inpatient treatment has never been formally assessed given the practical and ethical issues of finding suitable controls, the evidence around the effectiveness of CTOs is mixed, and where benefits are shown they tend to be minimal and potentially attributable to the increased support received by people who are under a CTO compared to people not on a CTO. Gill SN et al (2020). Measuring the impact of revised mental health legislation on human rights in Queensland, Australia. *Intl. Journal of Law and Psychiatry*: 73.

3

transformation must be conducted in parallel with legislative reform, including culture change and an investment in workforce capacity and capability, the provision of environments and infrastructure that are conducive to wellbeing, and integrated, community-based services. A key objective of this review, and any supporting system transformation, must be to address unacceptable inequitable health outcomes for Māori and take a broader approach to care needs which reflect the principles of Te Tiriti o Waitangi and are cognisant of Te Ao Māori. Although I recognise that the Government has made significant investments in mental health recently, moving to a least-restrictive, culturally safe, consumer-centred system will require significantly more investment, and these costs must be met if the new approach is to be successful.

I want to take this opportunity to acknowledge the commitment the Ministry of Health has demonstrated to ensuring people with lived experience, including tangata whai ora Māori, have an opportunity to provide input into this consultation. For it to be successful in supporting people to become and stay well, it is essential that this legislation and the system it sits within continues to be shaped by their views and experience.

I appreciate the opportunity to provide input at the formative stages of the new mental health legislation. Please do not hesitate to get in touch to arrange this or discuss any questions you may have.

Nāku iti noa, nā

Morag McDowell

Health and Disability Commissioner

aux curon



The objectives of new mental health legislation should be clearly set out

New mental health legislation should contain clear objectives to provide guidance on policy direction and ensure a shared understanding of purpose, practice and expectations. I suggest that the overarching purpose of any new legislation would be similar to that of the Substance Addiction (Compulsory Assessment and Treatment) Act (SACAT), in that it is aiming to facilitate care with the objective of restoring people's capacity to make informed decisions about and engage in voluntary treatment. I **recommend** objectives similar to those in SACAT, adapted for this context. For example:

This legislation exists to:

- Provide a safe environment to stabilise a person's condition
- Facilitate a comprehensive assessment of a person's mental health
- Protect and enhance a person's mana and dignity
- Restore decision-making capacity in order for people to be able to make informed decisions about further treatment
- Facilitate treatment planning and the continuation of care on a voluntary basis; and
- Provide an opportunity to engage in voluntary treatment

Te Tiriti o Waitangi should underpin any new legislation and supporting system transformation

Data shows that the current application of the Act is inequitable, with tangata whai ora Māori disproportionately subject to compulsion, seclusion and restraint. The causes of this are multifaceted, including systemic racism and bias, and the dominance of Western paradigms in both policy and practice, which largely reflect both biomedical understandings of mental health and an individualist approach to rights.

Māori have described compulsory treatment as a "threat to mana" and something which impinges on people's ability to "live as Māori". This includes concerns about the lack of respect for the importance and significance of whānau, hapu and iwi or cultural identity and language in psychiatric assessments, the transgression of tikanga and disrespect of mana by people enforcing the Act, and the power imbalance between clinicians and whānau. All people have the right to services that are delivered in a way which respects their cultural needs, beliefs and values (Right 1(3), Code of Consumers' Rights) and upholds their dignity and mana. This is unlikely to be achieved for Māori without significant and systemic change which is undertaken in partnership with them.

⁷ Inquiry into Mental Health and Addiction (2019). Oranga Tāngata, Oranga Whānau: A Kaupapa Māori Analysis of Consultation with Māori for the Government Inquiry into Mental Health and Addiction. Department of Internal Affairs: Wellington. Oranga Tangata Oranga Whānau pg 46



⁴ Ministry of Health. 2021. Office of the Director of Mental Health and Addiction Services 2020 Regulatory Report. Wellington: Ministry of Health. pp 32-34

⁵ New Zealand Government (2018) He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction. Wellington, New Zealand: New Zealand Government.pg 40

⁶ New Zealand Government (2018) pg 40

I recommend that new legislation directly references Te Tiriti o Waitangi and its principles and outlines how they will be given effect. By definition, this would include requirements for Māori to be codesigners and co-deliverers of any new approach and for there to be mechanisms to share decision-making power at all levels. This would help to embed equity into mental health law, support a redistribution of the balance of power and resources and make legislation more reflective of te ao Māori and responsive to the needs of tangata whai ora and whānau Māori.

In spite of repeated directions from government to services to address equity and provide culturally responsive services, I continue to receive complaints from tangata whai ora and whanau Maori which indicate this issue is still not adequately addressed. These complaints highlight the lack of critical components including:

- Culturally safe assessment, care planning, decision-making and review, with a requirement for cultural assessments to be undertaken for all tangata whai ora Maori unless explicitly refused
- Strengthening the legal obligation to consult with whānau as part of assessment, decision-making, planning and review and ensuring people are able to define whānau for themselves (See the section on involving whānau on pages 13-14 for more detail)
- Greater provision of kaupapa Māori options and services, including acute and crisis support
- Taking a more holistic approach to mental health which reflects Māori models of health and wellbeing, including an appreciation of wairuatanga

Design new legislation to minimise the use of compulsion

"When you are under the mental health act theoretically you have a say in your treatment but we have no way to say what works for us, instead it's No you are under the mental health act, and the mental health system can dominate us and tell us No I can do this to you"⁸

<u>The threshold for compulsory treatment should be increased and compulsion should only be used as a last resort</u>

Respect for a person's autonomy is a central tenet in a recovery approach and is ultimately essential to a person's wellbeing. While some consumers view the use of compulsory treatment as an important safety net,⁹ the evidence also highlights that it is often traumatising¹⁰ and can cause a profound loss of trust in the people and services providing care, with unhelpful implications for the therapeutic relationship and people's willingness to seek help when in distress.¹¹

¹¹ Jaeger S et al. (2013). Long-term effects of involuntary hospitalization on medication adherence, treatment engagement and perception of coercion. Social Psychiatry and Psychiatric Epidemiology, 48(11), 1787-1796; Rose D, Perry E, Rae S and Good N. (2017). Service user perspectives on coercision and restraint in mental health. BJ Psych. International; 14(3): 59-61; Swartz MS, Swanson JW, Hannon MJ. Does fear of coercion keep



⁸ Tāngata whaiora quoted in Baker M (2015). He kai i nga Rangatira He korero o nga whānau whaiora. Wellington: Te Rau Matatini Ltd pg 8

⁹ Baker M (2015) pg 9

¹⁰ Frueh BC, Knapp RG, Cusack KJ, Grubaugh AL, Sauvageot JA, Cousins VC, et al. Patients' reports of traumatic or harmful experiences within the psychiatric setting. Psychiatr Serv. 2005 Sep; 56(9):1123–33.

Mental health services consumers, like all other consumers of health and disability services, have the right to be presumed competent (Right 7 (2), Code of Consumers' Rights), and to have a say in the care they receive (Right 7, Code of Consumers' Rights). Any new legislation needs to reinforce these rights, and better balance efforts to protect people when they are unwell with efforts to ensure people are listened to and treated as partners in their care. Even when treatment is involuntary, it still needs to maximise people's agency if it is to support that person to gain direction and momentum in regards to their recovery.

The default position should be that people are capable of making their own decisions. **I recommend** that new legislation enshrine the presumption of competence and reinforce people's right to be involved in every decision that relates to them.

I recommend that new legislation clearly positions compulsory treatment as an option of last resort, formalises expectations that interventions should be the least restrictive option and for the shortest duration possible, and sets stricter criteria for the use of compulsory treatment to support its more targeted application.

Lack of decision-making capacity should be a key criterion for compulsory treatment

Reflecting both respect for a person's autonomy and a recognition that a collaborative approach to care achieves the best outcomes, health services can generally only be provided to people if they make an informed choice and give informed consent (Right 7, Code of Consumers' Rights). That is, they have been given sufficient information about their options for treatment and the risks and benefits of each one, and have then come to a decision about their care that they think best suits them. People have the right to refuse treatment altogether, even if it is not in their best interests, and are free to make a decision that goes against the recommendations of others. These rights belong to everyone.

However a person's ability to exercise their right to informed consent (or refusal) is reliant on their ability to make an informed decision. While the current Act goes too far in overriding the decision-making ability of anyone with a 'severe mental disorder', there will be times where people are too unwell 'to recognise the presence of illness, to consider advice regarding the risks and benefits of treatment or to make an informed choice.' While these states of mind may fluctuate, when they are present they may impair that person's decision-making to such an extent that informed consent cannot be achieved, even with support, and substituted decision-making would be required. To simply accept that person's decisions while they were in that state of mind would not equate to informed consent and could undermine that person's right to care and the highest attainable standard of health. To do so as a matter of policy would lead to significant inequity and would potentially exacerbate the stigma and criminalisation of people with mental health issues.

¹² Ryan C et al (2010). Clinical decisions in psychiatry should not be based on risk assessment. Australasian Psychiatry 18:5, October 2010.



-

people away from mental health treatment? Evidence from a survey of persons with schizophrenia and mental health professionals. Behav Sci Law. 2003;21(4):459–72.

While people have the right to be presumed competent (Right 7 (2), Code of Consumers' Rights) in relation to decision-making about their care, there is an onus on those providing treatment to ensure that this is the case where they have reasonable grounds for believing otherwise.

I recommend the introduction of a test to determine capacity for making decisions about treatment as a key criteria for ascertaining when people are unable to consent to care, even with support. I note that doing so is aligned with the approach of other similar jurisdictions, as well as domestic law regarding compulsory treatment for substance addiction (Substance Addiction (Compulsory Assessment and Treatment Act) 2017) and personal orders for care and treatment (Protection of Personal and Property Rights Act 1988).

I recommend the new law includes the same criteria for capacity as is found in s9 of SACAT, which aligns with the accepted standard for determining legal decision-making capacity. That is:

a person's capacity to make informed decisions about treatment.... is severely impaired if the person is unable to—

- (a) understand the information relevant to the decisions; or
- (b) retain that information; or
- (c) use or weigh that information as part of the process of making the decisions; or
- (d) communicate the decisions.

I recommend that legislation is clear that capacity is to be assessed in relation to the person's ability to make an informed decision about the specific decision or decisions in relation to treatment, rather than their decision-making capacity more globally. A lack of decision-making capacity at one point in time does not negate the need to seek informed consent for subsequent interventions. The legislation should also clarify that capacity cannot be determined by the decision/s a person makes. As is true for all other health and disability service consumers, people with mental health issues have the right to make decisions that other people don't agree with, including decisions that go against clinical advice, or that carry risk.

Capacity assessments should not just be about determining whether someone has decision-making capacity in relation to treatment decisions or not but should also be used to help to identify whether and how someone would benefit from support to make treatment-related decisions (see the section on supported decision-making on pages 10-12). I recommend that legislation include a clause outlining that a person should not be treated as unable to make a treatment-related decision unless all possible steps to help them do so have been taken without success.

As with SACAT, the purpose of compulsory treatment should be to support people to regain their ability to make decisions about their care. I **recommend** that where substituted decisions are made, they should be limited to the period of time that decision-making skills are impaired. There should be regular review to identify where there has been the re-establishment of sufficient capacity to make an informed choice about care or make shared or supported decisions, and a process for people to be able to challenge these decisions with an independent party.



<u>Shift the legal criteria for compulsory treatment from a consideration of risk to self and others to a consideration of best interests, informed by the person's will and preferences</u>

"Risk assessment practice operates as a type of fiction in which poor predictive ability and fear of consequences are accepted in the interests of normative certainty by all parties. As a consequence, risk adverse options are encouraged by workers and patients steered away from opportunities for ordinary risks thereby hindering the mobilization of their strengths and abilities."¹³

I share people's concerns around the current Act's criteria relating to risk and dangerousness. He Ara Oranga highlighted the culture of risk-aversion the status quo has generated,¹⁴ including an 'increasingly risk averse and predictive approach in applying the legal standard of serious danger'¹⁵ in practice. Some commentators have noted the risk of bias in the application of this criteria from a largely non-Māori workforce who 'seem to view Māori as a greater risk of danger, particularly to others'¹⁶ and consumers argue that the current Act's focus on dangerousness has increased the stigmatisation of people who need compulsory treatment, with impacts on their ability to find jobs or accommodation.¹⁷ This in turn, can result in people being nervous about disclosing their concerns to mental health professionals for fear of hard line responses, or avoiding seeking help altogether.¹⁸

While the current approach can result in an unnecessarily restrictive and often stigmatising response, through complaints I have also seen numerous failures to act when people are obviously in need of care, with tragic results. The shortcomings of the predictive power of psychiatric risk assessment are widely acknowledged. Some commentators have noted that an accurate prediction of future violence or self-harm is impossible, and that inaccurate predictions in the context of legislation which allows for compulsory treatment for people incapacitated by mental illness only if they are considered to present a future risk to themselves or others means that some people will be deprived of their liberty unnecessarily, while others will be deprived of appropriate care. Large et al.'s (2008) example of people presenting with a first instance of psychosis illustrates how damaging this can be.²¹

I support a shift away from risk and dangerousness as criteria for compulsory treatment and believe that it is better replaced by consideration of whether mandated treatment is in the person's best interests. A focus on best interests necessitates an understanding of what that person's interests are. This would necessarily include safety considerations, which through a best interests lens must also include consideration of the likely harms of compulsory treatment. However it would also need

²¹ Large MM, Ryan CJ, Nielssen OB and Hayes RA (2008). Pp 879-880



¹³ Coffey M et al (2017). Ordinary risks and accepted fictions: how contrasting and competing priorities work in risk assessment and mental health care planning. Health Expecations June; 20(3):471-483

¹⁴ He Ara Oranga pg. 193

¹⁵ Ministry of Health (2021). Transforming our Mental Health Law: A public discussion document. Pg. 34

¹⁶ Dr Hinemoa Elder and Dr Rhys Tapsell cited in Te Rau Matatini (2015). He Kai I Nga Rangatira He Korero O Nga Whānau Whaiora pg. 6;

¹⁷ Baker M (2015) pg. 9

¹⁸ Ministry of Health. (2017) Submissions on the Mental Health Act and Human Rights Discussion Document: An analysis. Wellington: Ministry of Health.

¹⁹ See for example Large MM et al (2017). Can we usefully stratify patients according to suicide risk? BMJ 2017;359:j4627; Large MM et al (2008) The danger of dangerousness: why me mst remove the dangerous criterion from our mental health acts. Journal of Medical Ethics, 34: 877-881

²⁰ Ryan C et al (2010). Clinical decisions in psychiatry should not be based on risk assessment. Australasian Psychiatry 18:5, October 2010.

to include consideration of whether the intervention was likely to be effective, including whether it was likely to increase that person's capacity to participate in decisions about their care.

I believe that new legislation should reflect the provisions of Right 7(4) of the Code which state that if a consumer is not competent to make an informed choice and give informed consent and no person entitled to consent on behalf of the consumer is available, a provider may provide services to that consumer, where:

- it is in the best interests of the consumer; and
- reasonable steps have been taken to ascertain the views of the consumer; and
- either —
- if the consumer's views have been ascertained and having regard to those views, the
 provider believes, on reasonable grounds, that the provision of the services is consistent with
 the informed choice the consumer would make if he or she were competent; or —
- if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

I note that following the approach set out in Right 7(4) mitigates some of the concerns commentators have raised about the subjectivity and therefore paternalism²² of a best interests test by ensuring that there are built in mechanisms to ensure the will and preferences of the person are considered as part of this test.

While not specifically focussed on mental health, the UK Mental Capacity Act 2005 provides an example of how this can work. Section 4 sets out the "best interests" checklist, which tells decision-makers what they have to think about when making "best interests" decisions. They must consider the person's past and present wishes and feelings, values and beliefs. They must — so far as practicable and appropriate — consult with others engaged in caring for that person or interested in the person's welfare. Having followed these steps and taken these matters into account, the person making the decision about best interests must employ what the Court has described as a "balance sheet" approach, which means weighing the likely advantages for the person against the likely disadvantages. Only if the "account" is "relatively significantly in credit", will the intervention be in the person's best interests. If a best interest test were to be included in new mental health legislation I would support a similar checklist being included, and this being designed in partnership with people with lived experience, including tangata whai ora Māori.

Regardless of whether or not risk-based criteria remains in legislation, there needs to be a shift away from risk-prediction practice and the stratification of consumers into broad categories of risk, to a more collaborative, strengths-based approach to harm reduction, risk assessment and management and safety planning, which recognises the benefits of risk-taking to recovery. As per

²² Gooding, P., Carney, T., 'Australia: Lessons from a reformist path to supported decision-making' In Michael Bach and Nicolás Espejo Yaksic (eds) Legal capacity, disability and human rights: Towards a comprehensive approach. Supreme Court of Mexico, Human Rights Division 2021



the Deputy Commissioner, Mental Health's recent letter to the Ministry²³, I am concerned that the current Guidelines for Clinical Risk Assessment and Management in Mental Health Services (1998) are now out of date and no longer reflect evidence based best practice. While I am pleased that the Ministry and Health Quality and Safety Commission will be collaborating on reframing Aotearoa New Zealand's approach, and look forward to the results of the upcoming review, I reiterate our recommendation that the Ministry makes a written statement to providers to immediately cease this unacceptable and outdated practice.

Should government remove the option of compulsory treatment from the legislation altogether, Right 7(4) could potentially be used in its stead. This is the case in other parts of the health sector where there is a lack of legislative guidance, for example in relation to the long term assessment and treatment of people in residential care without proper court orders. This is not what it was designed for. Right 7(4) is intended to authorise clinicians to provide short-term treatment where the person lacks capacity and there is no authorised decision-maker (e.g. no welfare guardian or welfare EPOA) if treatment is in the person's best interests. It is designed for urgent or emergency situations and was not intended to authorise long-term, ongoing or indefinite treatment. If there is no provision for compulsory treatment in new legislation, my concern would be that through the inappropriate use of Right 7(4) compulsion would still be occurring, but with a lack of accountability, safeguards and oversight. Should government decide to remove the option of compulsory treatment, it will be necessary to protect against this.

<u>Provide a legislative framework for supported decision-making</u>

Supported decision-making is premised on the idea that no one is 'purely' autonomous – and that most, if not all, people are constantly making decisions with support from others. Supported decision-making brings this interdependence out into the open, and invites people to support but not take over the decisions of people in mental health crises....²⁴

Everyone starts at a different baseline in regards to their ability to understand their options and communicate what is important to them and their recovery. The social model of disability recognises that this is partly due to the way society works and the systems and processes we have in place. To support new legislation to be inclusive and uphold the rights of all people in distress, support needs to be available to help people to express their interests and make decisions to the furthest extent of their ability. This would help to make the use of compulsion a last resort.

Under the Code, even if people have diminished competence, they have the right to make decisions and give informed consent to the extent appropriate to his or her level of competence (Right 7(3), Code of Consumers' Rights). Capacity is decision-specific, and corresponds to the gravity of the decision being made. However even if someone has diminished capacity, their ability to make decisions can be increased with the benefit of support.

²⁴ Simmons MB and Gooding PM (2017). Spot the difference: shared decision-making and supported decision-making in mental health. Irish Journal of Psychological Medicine, 34 pg 279



²³ Letter to Phil Grady, Acting Deputy Director-General, Mental Health and Addiction, 12 January 2022.

Support does not have to be extensive to be effective. The Code guarantees consumers the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided (Right 5(1), Code of Consumers' Rights). Every consumer also has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively (Right 5(2), Code of Consumers' Rights). People with lived experience have also shared that some of the most basic things that could be done to support their ability to make informed decisions include having the time to discuss and think through their treatment options. Under the Code, a person also has the right to have people present to provide support, and the right to choose the people who will provide that support (Right 8, Code of Consumers' Rights).

I recommend legislation should ensure that those who have diminished capacity can maximise their ability to make informed choices and give informed consent to the appropriate extent possible. It should include minimum requirements for supported decision-making to enable this, which should reflect people's rights under the Code.

There are a range of approaches being used around the world to give effect to obligations under the UNCRPD to shift mental health practice towards supported decision-making.²⁶ These include:

- the use of peer support to help translate between clinicians and consumers
- the provision of trained, independent advocates to support people during decision-making processes²⁷
- nominated²⁸/named²⁹ persons schemes where consumers can choose a person to receive information about their treatment and support them if they require compulsory treatment, including representing their interests during care planning and decision-making
- legal recognition of whānau's right to receive information and participate in processes relating to their loved one's treatment³⁰
- 'Open Dialogues'³¹ where care decisions are made in the presence of the individual and their wider networks
- The development of joint crisis plans³² and advanced directives and the formalisation of expectations around these, their adherence and their oversight in law³³

³³ For example, in Scotland the use of advanced directives is embedded in mental health legislation, they are lodged with an independent body and providers have to report anytime they are not adhered to.



²⁵ Ministry of Health (2017) pg 17

²⁶ Article 12(3) of the CRPD says that: 'States parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'

²⁷ Scotland

²⁸ Victoria, AU

²⁹ Scotland

³⁰ For example, Scotland's listed initator provisions which are automatically granted to certain groups of people (including guardians and closest relatives) unless specifically excluded from being done so by the patient

³¹ Used in Finland

³² This sits part way between a crisis plan and a care plan and involves an independent facilitator to mediate between the service user and the clinician to develop a shared plan for future crisis

Any or all of these evidence-based initiatives could be used to support a reduction of compulsion in New Zealand. I note that SACAT already has provisions for a nominated person process, but that this does not go as far in regards to empowering others to support people as the provisions in some other jurisdictions.

While I note that some definitions of supported decision-making include situations in which there is '100 percent support', I recommend that legislation clearly delineate between supported³⁴ and substituted decision-making³⁵ and ensure that appropriate safeguards are set up for each situation, with the most robust safeguards applied to situations where decision-making is substituted.

<u>Support the development and use of advance directives</u>

Advance directives support people to express their interests in situations where they are less able to do so themselves. Under Right 7(5) of the Code, people already have the right to make advance directives in accordance with the common law. However there has been limited uptake of advance directives by mental health consumers³⁶ and both scepticism about the likelihood of them being adhered to by clinicians (particularly when a person is under the Mental Health Act) and a desire for support to develop one are factors that likely contribute to this.³⁷

The evidence for the benefits of advance directives in terms of reducing compulsory hospital admissions is strong, with studies showing a statistically significant and clinically relevant reduction in compulsory admissions to psychiatric hospital for adults who were using them.³⁸ In a randomized control study, Swanson et al found that support (a facilitated session) to make an advance directive significantly increased their use (61% vs 3%), and those using advance directives had a greater working alliance with their clinicians and were more likely than those in the control group to believe they were getting the mental health support they needed.³⁹

I recommend that the new legislation places expectations on clinicians to check for and refer to existing advance directives (or similar plans) before making decisions, clarifies the situations where advance directives can be overridden, and requires clinicians to report on instances where advance directives were not followed, the rationale for not doing so and the demographics of the consumers involved.

³⁹ Jeffrey W Swanson, Marvin S Swartz, Eric B Elbogen, Richard A Van Dorn, Joelle Ferron, H Ryan Wagner, Barbara J McCauley, Mimi Kim. Facilitated psychiatric advance directives: a randomized trial of an intervention to foster advance treatment planning among persons with severe mental illness. Am J Psychiatry 2006 Nov;163(11):1943-51.



³⁴ Where the decision is made by the person themselves

³⁵ Where the decision is made by someone other than the person, even if that person has been nominated to act on behalf of the person by the person themselves

³⁶ Nicaise P, Soto VE, Dubois V, Lorant V. Users and health professionals' values in relation to a psychiatric intervention. The case of psychiatric advance directives. Adm Policy Ment Health. 2015; 42:384–93; Weller P. Psychiatric advance directives and human rights. Psychiatry Psychol Law. 2010; 17(2):218–29.

³⁷ Thom K et al (2019). Service user, whānau and peer support workers' preceptions of advanced directives for mental health. Intl Journal of Mental Health Nursing 28(6)

³⁸ de Jong MH, Kamperman AM, Oorschot M, Priebe S, Bramer W, van de Sande R, et al. Interventions to Reduce Compulsory Psychiatric Admissions: A Systematic Review and Meta-analysis. JAMA Psychiatry. 2016;73(7):657–64.

I recommend that new legislation outlines a simple process for people to lodge, amend or cancel an advance directive, which takes into account the fact that people's will and preferences are likely to change over time. I note that where statutory provisions for advance directives have been put in place in other jurisdictions, these tend to be given a 'lifespan' and must be reviewed at regular intervals.

I recommend that resources are provided to support the development of advance directives by mental health services consumers and note that facilitation by peer support has been shown to be effective.

Involving Whānau

While s7A of the current Mental Health Act places obligations on practitioners to consult with family or whānau when providing assessment and treatment, this is not happening routinely, with significant variation in practice around the country. Complaints to my Office, as well as the experiences shared as part of the Inquiry into Mental Health and Addiction Inquiry highlight the frustration whānau feel when they are left out of planning and decision-making about their loved ones, despite having a significant role in their support and important insight into the person and their well-being. Whānau often complain to me about how the Privacy Act is used inappropriately by services to limit information sharing, and how this makes it difficult for them to advocate for their loved one.

Not all consumers want their whānau involved in decisions related to their care⁴⁰, with some even viewing them as a source of trauma. New legislation will need to balance an individual's right to privacy, with the ability of whānau to have the information and input they need to effectively support their loved one when they are unwell. It should include mechanisms to include whānau at every level of planning and decision-making, as well as mechanisms for tāngata whai ora to be able to identify the people they want to be involved and their level of involvement, or to exclude others as necessary. As relationships fluctuate over time, it will also need to provide mechanisms for people to change their mind about who they want involved.

While I encourage the development of an approach that is tailored to Aotearoa New Zealand's particular cultural context, including a recognition of collective decision-making and support, I support the approach taken by Scotland, where certain people (including whānau) are automatically granted the right to receive relevant information about a person's care and provide information to support decisions in relation to that care, but where this right can be removed from people by the consumer when they have the capacity to make that decision. I also prefer the Scottish and Victorian approaches to the nominated person process in comparison to the one outlined in SACAT, as there is a greater obligation on decision-makers to consult with a nominated person, they can act independently of a consumer when that consumer is incapacitated, and they are notified at all significant decision points. Again, a nominated person's designation as such can be cancelled by the consumer.

⁴⁰ Thom K et al (2019). Service user, whānau and peer support workers' perceptions of advance directives for mental health. International Journal of Mental Health Nursing, 28(6), 1296–1305. https://doi.org/10.1111/inm.12637 pp 5-6



I recommend culturally tailored provisions for whānau support are included in new legislation and that there is a more pro-active legal obligation for the engagement of whānau in all aspects of a person's engagement with the Act.

Whānau also need support in their own right, including access to information and advice, and support to navigate the system and provide care. I recommend that there is investment in dedicated tools and support for whānau to understand and engage with the Act and to provide support and care for their loved one, including access to support for their own wellbeing. Whānau have expressed the benefits of having access to whānau advisors, and I recommend that this type of support should be readily available, with dedicated training for those taking on this role.

Repeal s71(2) of the current Act and encourage the use of safe and respectful practice in legislation and through investment, support and transparency

While Government has had a commitment to reducing and eliminating seclusion and restraint for over ten years now,⁴¹ restrictive practices, including seclusion (solitary confinement) and chemical, environmental and mechanical restraint continue to be used in mental health services across the motu. Complaints to my Office from those who have been subjected to these practices highlight that they can have a profoundly detrimental effect on people's feelings of safety and trust in services, particularly when they are carried out without respect for people's mana and dignity. There is also significant evidence of harm associated with these practices,⁴² including worsening physical and mental health and even death. This is particularly likely when these practices are used frequently or for a prolonged period.

Despite the stipulations in the current Act, there is evidence that restrictive practices are not always being used a last resort⁴³ and are being used for extraordinary lengths of time for some patients.⁴⁴ Use of these practices is also inequitable, with tangata whai ora Māori and Pasifika⁴⁵ being subjected to seclusion and restraint at a disproportionate rate.

Under Right 4(4) of the Code of Rights, every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer. While the negative impacts of restrictive practices are well recognised, they are often described as a 'necessary evil'⁴⁶ to protect the safety of other patients and staff. Although I agree that the safety of patients and staff is a critical consideration, there is a substantial body of evidence which highlights much more therapeutic and collaborative approaches to care, which can achieve the same

⁴⁶ Mental Health Commission (2004). Seclusion in New Zealand Mental Health Services. Pg 8



⁴¹ Ministry of Health. 2012. Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012–2017. Wellington: Ministry of Health.

⁴² See Dr S Shalev and the Human Rights Commission (2017). Thinking Outside the Box? A Review of seclusion and restraint practices in New Zealand. Pp 17-19 for a summary of evidence.

⁴³ Op cit.

⁴⁴ For example, Ashley Peacock, who spent 8 years in seclusion.

⁴⁵ Ministry of Health. 2021. Office of the Director of Mental Health and Addiction Services 2020 Regulatory Report. Wellington: Ministry of Health. pp 32-34

objectives without contributing to harm.⁴⁷ Thanks to the Zero Seclusion project initiated and led jointly by Te Pou and the Health Quality and Safety Commission, services all over the country are now practised in evidence-based and collaborative approaches which support safe and respectful practice and there is evidence that the use of seclusion can be avoided in most cases.

I agree with Dr Shalev⁴⁸ that the time has come to lend the necessary legislative weight to drive further change. I **recommend** section 71 (2) is repealed completely and new legislation makes it clear that all practices need to uphold a person's Rights under the Code to have services provided in a manner that respects their mana and dignity.

However I am concerned about the unintended consequence of such a change in the current service context, including infrastructure which is not fit for purpose, with gaps in service provision, and limited workforce capacity and capability. There needs to be investment in, and ongoing support for safe and respectful practice. I recommend that services are given sufficient lead in time to prepare for legislative change, with ongoing resourcing to support these preparations. This should include a dedicated work programme, in partnership with tangata whai ora, to eliminate seclusion, improve safe practice and reduce the use of restraint, and investment in community-based acute and crisis services, better designed infrastructure - including the replacement of those IPUs that have been found to no longer be fit for purpose - and staff training and capacity.

Transparency in relation to the use of restrictive practices is important. I **recommend** that new legislation includes a definition of seclusion (even if it has no provisions for it), and that services should continue to have to report on incidences that meet that definition, regardless of whether or not they consider this seclusion. I **recommend** the introduction of national reporting on restraint practice, including the use of chemical restraint as an important balancing measure.

Monitoring and safeguards

When people are unwell and subjected to coercive and or restrictive practice, it is critical that there is independent oversight and accountability. New legislation should strengthen protections for people subject to compulsory treatment, make it easier for them to raise and resolve issues and be involved in decisions about them, and ensure transparency and accountability.

Under the Code, people have the right to raise concerns about the care that they receive in any manner that is appropriate for them (Right 10). However Tāngata whai ora and whānau have shared their concerns with me about how difficult they find it to influence or challenge decisions with providers or make complaints. The key barriers they have expressed include:

- They have too much going on in their lives and/or are too unwell to be able to effectively advocate for themselves
- They don't understand what their rights are or how they can challenge things

⁴⁸ Dr S Shalev and the Human Rights Commission (2020). Time for a Paradigm Shift Pg. 38



⁴⁷ See for example, Gooding, P et al (2018) Alternatives to Coercion in Mental Health Settings: A Literature Review, Melbourne: Melbourne Social Equity Institute, University of Melbourne.

- They don't feel like they are taken seriously, or their opinion given as much weight as the
 opinion of clinicians. Tangata whai ora specifically mentioned having their concerns
 dismissed as being related to their mental illness
- They fear a punitive response if they 'kick up a fuss'
- Whānau are prevented from advocating on behalf of their loved ones under the context of privacy considerations

Advocating for oneself or loved ones, particularly within a complex legal and clinical environment is a daunting task for most people, particularly when they are unwell or juggling other commitments. In a series of hui my Office held last year, tāngata whai ora universally pointed to the benefit of having peers involved in services, in being able to reduce barriers, translate between themselves and clinicians and help them understand how to navigate the system. Some noted the importance of these peers being independent from, rather than employed by the services. I strongly support an increase in peer support for people who are under the Act. I recommend that new legislation includes provisions for independent advice and support to assist people and their whānau to influence and challenge decisions, navigate the system and its processes and make complaints.

Although I understand the concerns that some people have about the effectiveness and equity of some of the safeguards under the current Act, I think there are important functions in the current legislation which I recommend are included in some form within the new legislation. These include:

- Independent, unannounced inspections and audits of facilities where compulsory treatment and restrictive practices are taking place
- Independent review of decisions made under the Act and legal support to challenge those decisions in a timely manner
- A central point of accountability and oversight over the Act, with the power to undertake investigations and responsibility for public reporting

Wider system transformation is necessary if the Act is to be reserved as a last resort

"In the long term, the solution to the problem of coercion in psychiatry is to design services that patients find helpful and actually want to use" 49

To achieve the transformation of the Act envisioned in He Ara Oranga and reflect the principles agreed by Government, any legislative change must be supported by, and shape system transformation. While compulsory treatment should only ever be a last resort, complaints to my Office, as well as the stories shared with the Inquiry into Mental Health and Addiction, highlight that it is too often becomes the first response, when efforts to seek help elsewhere have failed and the person is now in crisis. If the Act is truly to be used as a last resort then there needs to be a focus on preventing crisis before it happens, and when it does, providing people with options other than compulsory care.

Although I recognise the work the Ministry is doing to increase the capacity of the sector to respond to demands for mental health support – for example through the Access and Choice programme -

_



⁴⁹ R Bentall cited in Kinderman P (2019) Manifesto for mental health pg. 230

options to support tāngata whai ora in the community – particularly those with more significant mental health issues, remain limited and hard to access. There are significant geographic disparities in service provision and some people's needs are not well catered for anywhere in the country. ⁵⁰ International evidence points to alternative options for support as a critical success factor in reducing compulsory care. ⁵¹ The World Health Organisation urges mental health services to develop models of care which actively address broader determinants like housing and employment and notes that "it is essential to scale up networks of integrated, community-based mental health care to accomplish the changes required by the CRPD."

Gaps in the system response also mean that there are currently perverse incentives for the use of compulsory treatment. Anecdotal evidence suggests that the Act is being used to reduce barriers to medication and health care in a context where most services are under pressure and rationing care. We understand that people are being maintained on a community treatment order, even when stable in their mental health in order for the cost of their medication to be covered. If the use of compulsory treatment is to be removed, or the threshold for compulsion is lifted without efforts to reduce these barriers through other means, then inequities will only increase.

Complaints to my Office also highlight the lack of supports for people who are in crisis but either do not have a severe mental health issue, or who have significant and complex needs, but who are being inappropriately placed under the Mental Health Act because there is nowhere else to go. This includes people with neurodevelopmental issues, traumatic brain injuries and acute drug reactions. People in these situations are not well served by the current model of care and the workforce is not currently well equipped to respond appropriately to their needs, resulting in a disproportionate and often prolonged use of restrictive and coercive practice, and/or exacerbation of their issues.⁵³

Significant cultural change is also required, to support practitioners and services to shift attitudes and approaches to align with a new direction. This will require dedicated leadership and workforce development, and accountability within the system to drive change.

I recommend that the Mental Health and Addiction Annex to the Health Plan and the System and Services Framework set out and resource changes to service provision that will support transition to a new approach. This should include accessible crisis and step-down supports; greater treatment and support options for people with addiction issues, neurodevelopmental disorders or complex conditions; a diversification of the workforce, including an increase in cultural, peer and whānau support roles; and resourcing to reduce barriers to medication and healthcare.

⁵³ For example, people with acute drug reactions are not always getting withdrawal support



⁵⁰ For example, people who are intoxicated by substances and people with high and complex needs due to comorbid mental health issues and cognitive impairments e.g. intellectual disability and other neurodevelopmental disorders

⁵¹ See, for example, Light EM et al. How shortcomings in the mental health system affect the use of involuntary community treatment orders. Australaian Health Review 2017 (41): 351-356

⁵² World Health Organisation (2021). Mental health crisis services: promoting person-centred and rights-based approaches. Geneva

I recommend that dedicated sector leadership and workforce development is put in place to drive culture change and support the development of the necessary skills and abilities to support a more collaborative approach to care and shift people's focus from managing risk to promoting best interests.

I recommend that there is dedicated investment in preparing the system and those working within it to better meet the needs of people in crisis with co-existing neurodisabilities and/or acute drug reactions. Complaints to HDC highlight that the current model of care is not well suited to their needs and that current environments and approaches can exacerbate existing issues and put people at risk of harm, including through disproportionate use of restrictive approaches. Holistic models of care for people with complex and co-existing needs will be an important enabler of any reduction in coercive and restrictive practice.

