



He mana tō te mātau ā-wheako
Our lived experience is our strength

Lived Experience stories, insights and hopes for the future of mental health in Aotearoa

Submission by Changing Minds

Transforming mental health law in
Aotearoa New Zealand
Ministry of Health
By email: mhactreview@health.govt.nz

28 January 2022



*“When I was nineteen years old, I was put under the
Mental Health Act.*

Just imagine; being nineteen, young, female...

having some family difficulties...

*and having all of your rights - your freedom to move
around - completely taken away from you.*

It was pretty scary...

*It was really hard for me to understand what was
happening to me...*

I was being served with paperwork

and I couldn't read it.

Couldn't understand it.”

Account of Lived Experience of the Mental Health Act in Aotearoa

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Transforming our Mental Health Law: Repealing and replacing the Mental Health Act

Thank you for the opportunity to contribute the voices of Tāngata Mātau ā-wheako – people with Lived Experience of mental health and addiction to this phase of reforming mental healthcare in Aotearoa New Zealand.

The Transforming our Mental Health Law public discussion document acknowledges the Mental Health (Compulsory Assessment and Treatment) Act 1992 (“the Act” or “the Mental Health Act”) is no longer aligned with emerging and documented approaches to care. Legislation to repeal this Act will be introduced later in 2022; the intent of this discussion document is to inform the repeal and replacement of the Act.

Acknowledging the voices which came before us

We’d like to acknowledge everyone who has contributed to this mahi, and the mahi that came before it. A criticism we heard when speaking to our community of Tāngata Mātau ā-wheako was that it feels like more talk of change, without seeing anything tangible. It is often hard to be an individual, trying to measure progress on a scale as grand as reforming mental healthcare but we are heartened to see that momentum is gathering, and that a roadmap exists to incorporate these learnings into the wider legislative process.

Contributions to Changing Minds Submission

Changing Minds believes in amplifying the voices of those with Lived Experience of mental health and/or addiction. In creating our submission we sought views from any Tāngata Mātau ā-wheako in Aotearoa across a range of mediums. Twenty-seven individuals shared their voices with us, reflecting thirty-nine perspectives on mental health and wellbeing care in Aotearoa.

Our submission is therefore guided by the insights of our community and predominately focuses on the following sections of the discussion document:

- Part 2: Creating a new approach
- Part 5: Capacity and decision-making
- Part 6: Supporting people to make decisions
- Part 7: Seclusion, restraint and other restrictive practices

The future our Tāngata Mātau ā-wheako see

The future of mental healthcare our Tāngata Mātau ā-wheako desire, and which we describe throughout our submission, at its heart is not radical. We want a future, and any future legislation to:

- Recognise the intersection of social, community, emotional, spiritual and mental wellbeing factors as central to creating a safe and healthy future for Aotearoa and to design systems and supports with this in mind.
- Adopt a holistic approach to wellbeing which respects Te Tiriti o Waitangi and the diverse worldviews and experiences of Tāngata Mātau ā-wheako.
- Commit to resourcing the mental health sector in a way that aligns with the scale of harm caused by mental distress in Aotearoa.
- Learn from more modern legislation which respects an individual's autonomy and capacity to make decisions about their care and wellbeing.
- The absolute extent possible, trust an individual's capacity to make their own decisions, and respect their wishes or the guidance of their whānau or nominee.
- Entrench and individuals right to peer support.
- Facilitate and respect the creation of advanced directives.

- Use language that is reflective of the nature of our experiences under the Act, and which does not contribute to discrimination or prejudice.
- Uphold tino-rangitiratanga, self-determination, under which we see no place for coercive practice, solitary confinement (seclusion) or restraint.

To put it simply, we want a future that respects our whole selves and works with us to promote, protect and nourish our wellbeing.

We would be happy to discuss our submission with you further. Please contact Megan (Communications@changingminds.org.nz) in the first instance.

Changing Minds

January 2022

Qualitative methodology

Research design

Due to ongoing COVID-19 restrictions and health and safety measures, Changing Minds were not able to consult with our community and network of Lived Experience leaders by way of a hui (as would usually be our preferred method of engagement).

Leading our thinking in the design of this consultation was how to create space for Tāngata Mātau ā-wheako to share their stories and experiences in their own way. However, we also recognised that engaging with government consultation can be an unfamiliar and unusual experience that may deter individuals from sharing their insights.

To share an example of Lived Experience dialogue with our community who may not have otherwise seen themselves within the consultation process, the following actions were taken:

- 1.** Changing Minds reached out to our Lived Experience networks asking for contributions documenting what is important to them and sharing their thoughts and experiences of the MHA or Mental Health System in Aotearoa New Zealand (including, but not limited to experiences under the MHA, healthcare or service providers, whānau insights, and observations from within the wider mental health system).
- 2.** Audio and visual feedback from seven individuals was compiled into a 'kōrero starter' video which was then shared across Changing Minds' social media and other channels.
- 3.** Viewers were encouraged to share their own insights directly with the Ministry of Health via the consultation portal or to contribute to Changing Minds' submission by way of direct message (email or social media) or via a webform.

Demographic data

Changing Minds did not collect demographic data while seeking views and insights on our submission and it was imperative that people could express their views anonymously and honestly.

Table 1 Count of perspectives received during consultation

Perspectives	Count
Experience in mental health system (not MHA)	9
Experience under the MHA	6
Māori perspective	1
Not specified	10
Support or healthcare worker	8
Whānau or loved one perspective	5

Lived Experience Kōrero

While intended to raise awareness and participation in this consultation project, we encourage the Ministry of Health to consider our Lived Experience Kōrero video as part of our response to this discussion document.

A copy of the video is accessible via our [website](#).



Analysis

Feedback from 27 individuals was collected between November 2021, and January 2022.

To maintain the integrity of our community's voices a grounded theory approach to thematic analysis was adopted – that is to say, Changing Minds were guided by the responses we received to identify emerging themes from the data.

Analysis of verbal or written data was conducted by Changing Minds in an iterative process of coding data, synthesising emerging concepts, categorising these concepts and identifying key themes.

Transcripts of all feedback received have not been edited for content or tone, however, spelling and grammatical errors have been corrected.

Overview of themes

Table 2 Primary Data Categories

Code	Count
Choice and consent to treatment	24
Perceptions, feelings, and emotions	19
Effect of restraint or seclusion	11
Holistic care	11
Process improvement	11
Peer support – value and availability	9
Self-awareness and decision making	9
Absence of follow up or support services	7
Support or healthcare worker	7
Experience in mental health system (not MHA)	5
Social and community factors	5
Specific model, legislation, or support	5
Trust	5
Accountability of health system	4
Advanced directive	4
Related mental health challenges	4
Prejudice and discrimination	4
Whānau or loved one perspective	4
Empathy	3
Risk assessment	3

Code	Count
Equity, respect, understanding	2
Experience under the MHA	2
Labels & narratives of mental health	2
Positive view of quality of care	2
Pro legal treatment order	2
Whānau	2
Covid-19	1
Cultural support	1
Education	1
Experience of whānau	1
Inequity	1
Māori perspective	1
Past trauma	1
Physical barriers to service	1
Pre-clinical or pre-diagnostic	1

Perceptions, feelings, and emotions associated with the current Mental Health Act and system.

“I felt like why waste my time in trying to get help as no one wants to know me or help me?”



Most of the individuals who shared their experiences of the current Mental Health Act and wider mental health system in Aotearoa, spoke of feeling undervalued when seeking or receiving support for their mental wellbeing. Many spoke about beliefs that the status quo is damaging to those seeking support, those under the Act, and those trying to support loved ones.

For some, the possibility of losing your autonomy, being restrained or isolated is a significant barrier to seeking support for their wellbeing. This delays or prevents a person seeking help while creating more anxiety and distress.


“Although it was the Christmas and New Year period and no doubt they were under staffed, I felt so undervalued.”

Some of those who shared their experiences under the Mental Health Act with Changing Minds spoke about feeling like their lives are not worth saving because of preexisting mental health challenges or disabilities, that they don't believe any change will come from this consultation, that the system only creates false hope.

“Why would you have a ‘health system’ that is abusive and causes even more trauma?”

As the reform of mental healthcare progresses, and the process to repeal and replace the Mental Health Act continues, it is clear to us that a significant degree of trust needs to be earned by the wider health system, providers, and networks. Repealing and replacing the Mental Health Act with an alternative grounded in holistic and humanistic care is a significant opportunity to build this trust.

Part 2: Creating a new approach



*“What I’d like to share today with you is my hope for a
new system that will work for everyone.*

*A team who are willing to walk alongside with you, and
make you feel normal for being there.*

*[Where] everyone has access to therapy, credible
education, resources and support groups for specific
mental health diagnosis....*

*Individually we all will all have a day filled with art and
craft, music therapy... ..animal therapy...*

An outlet to express one’s self.

*It will be a place where we can all feel a warm,
humanistic approach, that is filled with soul where
it also helps to fill up more than just managing the
symptoms.”*

A Lived Experience vision of a future Mental Health System
Support or Healthcare worker

Repealing and replacing the Mental Health Act is an opportunity to reimagine what it means to care for, and support Tāngata Mātau ā-wheako not only in their most acute moments of distress but also throughout their journey.

Changing Minds were honored to hear from so many people as part of this consultation who shared their experiences under the Act. From these stories, and from the insights of our community we have heard, that for most people and their whānau, the experience of being ‘under the Act’ is overwhelmingly negative even when we acknowledge clinical risk aspects of its application.

Changing Minds believes that any changes to the Act that fail to properly address and offer wider treatment choice, personal and collective autonomy as well as a re-definition from Lived Experience of safety (as opposed to risk) will continue to have negative consequences on tāngata whai iti ora and their whānau.

What Tāngata Mātau ā-wheako would like to see under a future Act or future mental healthcare

Social and community effects on mental healthcare

Through sharing their stories our community have touched on the importance of recognizing our mental wellbeing is not an isolated phenomenon. Our physical, emotional, spiritual, social and whānau wellbeing shape our experiences leading up to moments of distress and provide tools and bonds to guide us through.

The discussion document states that:

“Some parts of providing support to a person in a vulnerable and distressed state may fall outside the boundaries of what mental health legislation can do. A person’s mental wellbeing can be influenced by a number of factors, including whānau and social dynamics, living environment, financial stability, employment, and housing. Further, we know that the delivery of quality,

affordable and timely mental healthcare and treatment relies on a whole system of providers and services operating efficiently and effectively. This is beyond the scope of what the new legislation can do. These topics are therefore not covered in this document, which focuses on the future of mental health legislation in Aotearoa New Zealand with a grounding in te ao Māori and human rights.

We heard stories from people who are isolated – both physically and socially – having to travel great distances to receive mental healthcare and being left to find their way home after being discharged with no transport, financial means, or connections to do so. One individual described the experience of being asked to return to an abusive relationship or space for lack of suitable alternatives.

Our community have spoken about the prejudice, alienation and gossip that can follow an individual back into their community. Others spoke of identifying they need a ‘mental health day’ but resorting to using sick leave because they don’t feel they can tell their workplace their mental health is challenged.

While social and community structures can contribute to poor moments of wellbeing, other experiences can enhance wellbeing. Individuals spoke of the benefits they felt from small moments of social connection, of related services such as occupational therapy or of peer support networks.

Reimagining the future of mental healthcare is not as simple as deciding whether to have an Act. We need the systems, supports and infrastructure to support people across all aspects of their wellbeing. To be successful, this must include a broader and more diverse set of skills within the workforce and a diverse range of service offerings.

If we are imagining a future that will make a radical improvement to people’s lives and wellbeing, we disagree with the choice to exclude systems and aspects of our wellbeing from the scope of this discussion document and a future Mental Health Act.

As Government is moving to centralise and consolidate healthcare in Aotearoa by way of the Pae Ora (Healthy Futures) Bill currently before Parliament, it is more important than ever to be adopting an integrated and long-term approach which names good mental health and wellbeing as an explicit priority across all health, social and commercial systems.

If we are imagining a future that will make a radical improvement to people's lives and wellbeing, we disagree with the choice to exclude systems and aspects of our wellbeing from the scope of this discussion document and a future Mental Health Act.

A holistic approach

The groundwork for a te ao Māori perspective and shared perspective of wellbeing has been outlined as part of He Ara Oranga¹ – we know what is needed to achieve wellbeing, we now need to see this approach transferred to all legislative design.

“I wish in those moments; I and my family members were offered things as well as medication... I would have liked some other things to start working on. Some talking therapy, some peer support, some nutritional therapies and supports. Some cultural supports, that would have been helpful in helping me make sense of the experiences that I was undergoing.”

Overwhelmingly the individuals who engaged with Changing Minds' submission spoke of the harm and perceived damage caused to Tāngata Mātau ā-wheako through a constrained approach to mental healthcare and treatment.

Several people expressed concerns that the treatment options available to them were limited to medication, hospitalization or, in the limited examples where a third option was available to them, a course of treatment which they felt did not align with their beliefs or was an additional source of trauma. are presented with limited 'choice' with very few acute alternatives offered despite the evidence and requests for peer, cultural, and holistic alternatives to both hospital and medication.

Many people, under the Act and when engaging with the wider mental health system, find talking therapies or peer support services are difficult to access.

Those who are hesitant to engage with the public mental health system (due to past experiences and/or trauma, for fear of the prejudice and discrimination a diagnosis can carry, or are scared that asking for help will mean 'being sectioned' or losing their autonomy) can find a range of therapies difficult to access. Waitlists for talk-based or alternative therapeutic services are lengthy, are regularly prioritised by 'severity' (often requiring medication as a precondition for accessing support) and can be financially prohibitive to many people.

We see a real desire from the Lived Experience stories shared with us for a future of mental healthcare that supports and encourages methods of care tailored to the individual's needs. Changing Minds sees no

place for a future Act or system that makes medication a precondition for access to support or services and it should be only one of many recovery choices. If we are considering a future where hospitalization and medication aren't mandated or coerced, more services need to be offered to allow people to choose from, so that when they are acutely unwell, they know what makes them feel safe, cared for and on the road to recovery.

Tools, resources, and supports identified as beneficial included:

- Peer support (discussed further below)
- Talk based therapies
- Creative therapies and resources
- Journaling and meditative exercises
- Family, whānau support, respite and education
- Specific tailored peer support for cultural groups, ages and identities
- Acute and crisis alternatives to ED, hospital
- Early intervention/prevention respite options
- Treatment and support for other areas, such as alcohol, substance use, gambling, and harm minimization.
- Cultural support and treatments such as raonga Māori, mirimiri and romiromi
- Nutritional support ^{2 3}
- Financial support

Several people have also commented on the need for support for their families and whānau such as their own networks of support, or the option for whānau to be more involved in care and treatment decisions.

Access and availability of care options

“We (NZ) need to do much better in the medical speciality and delivering quality services to many more people”

It is timely that as we are making this submission as Government is also considering consolidating health and mental health services by way of the Pae Ora (Healthy Futures) Bill. People who engaged with our submission have expressed concerns that access, and availability of services is currently disjointed and inconsistent.

Aotearoa needs to be resourced to offer a range of holistic services, this challenge must be met, regardless of whether choices and access to care are offered centrally or disseminated through community structures.

If there is an Act in future, we believe this should be orientated to provide priority care and resources to an individual when they need it – where they need it.

Last year, the Government released Kia Manawanui Aotearoa: Long Term Pathway to Mental Wellbeing. Having a clear, long-term pathway for mental health in Aotearoa is an excellent step, and the framework’s actions and approaches focus on the right areas. However, there’s a fine balance between getting it right long-term and making sure we don’t lose the good things we have right now.

Changing Minds have previously expressed our concerns in response to the Kia Manawanui Aotearoa report that many of the ideas and initiatives Government has earmarked as a future component of the mental health system, are already being implemented in a way we know works. However, community groups, services and other organizations like Changing Minds are not funded (or funding is uncertain) We have built strong evidence for new and improved holistic ways of delivering services and some of these amazing initiatives are at real risk of disappearing

If there is an Act in future, we believe this should be orientated to provide priority care and resources to an individual when they need it – where they need it. This will require Government and future Governments to commit to resourcing the mental health sector in a way that aligns with the scale of harm caused by mental distress in Aotearoa.

Specific models or legislation

As part of the feedback, specific models or other pieces of legislation have been recommended or referenced to which our community felt would make a positive difference to the future of mental healthcare in Aotearoa New Zealand.

We have shared the feedback and desires we have heard during this consultation for peer support services below, however, several individuals called for peer support services and advocate nominations (such as a family support person or trusted practitioner) to be entrenched in law. Changing Minds fully supports the right to peer support and availability of peer support services being entrenched in the future of Mental Health in Aotearoa, regardless of whether that includes a formal Act.

When considering the role or place of treatment orders in future, one submitter observes the *Substance Addiction (Compulsory Assessment and Treatment) Act 2017* (the SACAT Act)⁴ provides an example of how

compulsory treatment can be utilized with greater protections for the individual, than under the current Mental Health Act.

Subpart 3 of the SACAT Act is explicit that

the “objective or compulsory treatment given to a patient is – if possible, to restore the patient’s capacity to make informed decisions about the patient’s treatment and to give the opportunity to engage in voluntary treatment”

Importantly the legislation within the SACAT Act 2017 is an ‘and’ test – requiring all the criteria within Section 7 (a)-(d) to be met before compulsory treatment can be implemented. The legislation also specifies, what must be considered when determining an individual’s capacity to make informed decisions is severely impacted.

What the SACAT Act 2017 also does is broaden the rights a person subject to the Act has. A comparison of rights contained within the Mental Health and SACAT Act can be found below.

The more modern SACAT Act not only expands the individuals’ rights to representation and guidance, but also entrenches that treatment must be the least restrictive manner possible, the person’s views and the views of their nominee must be considered, and the aim of treatment is to restore the individual’s capacity to make their own decisions.

Table 3 Comparison of rights under the MHA and SACAT

Rights conferred under the Mental Health (Compulsory Assessment and Treatment) Act 1992	Rights conferred under the Substance Addiction (Compulsory Assessment and Treatment) Act 2017
Right to Respect	
You have the right to be treated with respect.	You have the right to be treated with respect.
Right to information	
You have the right to be fully informed about your legal status and all aspects of your assessment, treatment and review.	You have the right to be fully informed about your legal status, rights and all aspects of your assessment, treatment and review.

Rights conferred under the Mental Health (Compulsory Assessment and Treatment) Act 1992	Rights conferred under the Substance Addiction (Compulsory Assessment and Treatment) Act 2017
Right to judicial review	
You have the right to have your condition reviewed either by a Judge, or a Review Tribunal, depending on your legal status. You can also seek a judicial inquiry.	You have the right to have your compulsory status urgently reviewed by a judge if you think you do not meet the criteria for compulsory treatment in the Act.
	You have the right to be heard in Court.
Right to cultural and personal respect and autonomy	
You have the right to have your cultural identity and personal beliefs respected.	See “Right to treatment consistent with the Act”
Right to representation and nomination	
You can have someone who speaks your language with you or someone from your family or whānau, a friend or advocate, at your assessment or review.	You have the right to nominate any person (over 18 years old) to protect your interests under the Act and can change or cancel that nomination at any time.
Right to medical and healthcare	
You have the right to receive medical and healthcare that is appropriate for your condition. You must be told of the benefits and side-effects of your treatment before it commences.	You have the right to receive health and medical care that is appropriate for your condition and to be told of the benefits and side-effects of any treatment.
Right to privacy	
You have the right to refuse any video and audio recording of your treatment being made or used.	You have the right to refuse any images or video and audio recording of your treatment to be made or used.
Right to independent opinion	
You have the right to ask for the opinion of an independent psychiatrist.	You have the right to ask for an independent medical opinion from a specialist who is approved under the Act.
Right to legal counsel	
You have the right to ask a lawyer to advise on your rights and status as a patient, or on any other matter.	You have the right to ask for a lawyer to advise you on your status and rights under the Act.
Right to the company of others	
You have the right to the company of others. Seclusion can only be used, where necessary, for your care or treatment or the protection of others.	You have the right to the company of others.
You have the right to have visitors and use the telephone, at reasonable times. You can send and receive letters, unopened. These rights can be limited by your responsible clinician, but only for a specific reason.	You have the right to have visitors and use the telephone, at reasonable times. You can send and receive letters, unopened and emails. (These rights can be limited by your responsible clinician, but only for a specific reason.)
Right to treatment consistent with the Act	
	You have the right to be cared for in a way that is consistent with the objectives of compulsory treatment and principles in the Act, which means:
	<ul style="list-style-type: none"> • Your care is provided in the least restrictive manner possible • Your views and the views of the person you have nominated to support you are sought and taken into account wherever possible • There is the least possible interference in your rights; and your interests remain at the centre of any decision-making • Your cultural and ethnic identity, language and personal beliefs are recognised and respected as are your ties with your family, whānau, hapū, iwi and extended family • The aim of your treatment under the Act is to restore your capacity to make your own informed decisions about treatment.

If a legal treatment order is part of a future Act and is required in a specific instance one person also drew attention to the Protection of Personal and Property Rights Act 1998 or the use of advanced directives which are discussed further below.

Peer support, nomination, entrenched rights within legislation and advanced directives are all methods of building trust between an individual and the mental health system. We also received support for the adoption of Te ao Māori insights and perspectives such as the Pōwhiri Poutama, and Dynamics of Whanaungatanga models.

Part 5 & 6: Capacity and decision-making, and supporting people to make decisions



“I was being served with paperwork and I couldn’t read it. Couldn’t understand it.”

“I don’t know whether I believe in a capacity test, in a sense that immediately before, and immediately after our most acute moments; I think that we have the capacity to make good choices, and only that we need support to make good choices from those we love and trust”.

“I thought that I was a voluntary patient up until the moment that I wanted to leave. And then I was placed under the Act.”

When speaking about self-awareness and our confidence to make decisions about our mental health and wellbeing, individuals who contributed to our submission all recognised that shifting between states of wellbeing is not linear.

Some individuals commented that with the right knowledge and support we can better identify, mitigate and manage our well-being before reaching an acute moment. This awareness comes with experience and the support of others, which is why it's critical a future Mental Health Act actively considers the role of peer support and integration with a broad range of wellbeing services.

One particular comment found that knowing what to expect of the system and understanding the perspective of healthcare providers can empower our decision-making process. However, this requires a trusting relationship and confidence in our ability to self-advocate or have people we trust advocating alongside us.

“I think we need the time to develop a close and trusting relationship with the people who are helping to care for us in those moments where we feel unable to make good decisions for ourselves.”

Everyone who touched on the ability to lead their wellbeing journey felt that, to the absolute extent possible, they should be trusted to make their own decisions. Where this is not possible a trusted nominee (such as a family member) was the preferred choice to lead the decision-making process.

Peer support

“I think what would really help in the future with the Mental Health Act is for someone like me who is distressed to be able to have somebody to walk alongside me as I’m going through any kind of process. Somebody who’s been through the system... Somebody who understands and somebody who’s able to navigate that system with me. A peer support worker is what I would like.”

Through speaking with and hearing from Tāngata Mātau ā-wheako, one of the biggest concerns expressed to Changing Minds was the lack of support services, networks, and follow-ups available to them leading up to and directly after being placed under the Act.

We also heard from a whānau member supporting someone else under the Act who felt that while that *“[while] I found the hospital staff to be professional, helpful, and too busy to spare any time for supporting family members... Eventually, we were able to figure out the next steps however this part of the process could be sped up if there was a support network whānau could access before they came home.”*

Navigating times of mental distress can be a lonely and frightening experience. For many, when we think

back on what helped us to turn a corner in hard times was knowing there were others who had been in situations like yours, seeing how they got through and having them beside you as you enter an unfamiliar setting or system.

“One change that I would like to see is people being treated like people, and not the conditions that they’ve been diagnosed with. Treating them with kindness and empathy. Having a peer to walk alongside a whānau member under the Act can make a big difference. Not only to their experience within that moment but to their mental health journey”

Advanced directives

Several people who engaged with Changing Minds’ submission expressed a desire for advanced directives to be entrenched and respected in a future Act or mental health system.

“It’s really important that people feel that they have someone who’s in their corner, who’s advocating for them, who believes in their rights, and who is there to support them along their journey.”

Creating advanced directives can provide several benefits to the individual, as well as providing a guide and framework for health practitioners when supporting a person with Lived Experience of mental distress.

Outlining when we are well what support and resources, we believe would support our wellbeing when we are unwell, can be an empowering action. By entrenching respect and adherence to an advanced directive within the mental health legislation we can also build trust between individuals and the system. We heard a sense of uncertainty, grounded perhaps in existing experiences, that advanced directives would be respected by healthcare providers and the mental health system.

We have examples from other areas of the law on how rights can be codified, entrenching these within a future mental health law would provide individuals with a layer of certainty. For example, the Code of Health and Disability Services Consumers' Rights (the Code) establishes the following right to make and informed choice and give consent and includes the right for a consumer to use an advanced directive (emphasis added):

Right 7 (Right to make an informed choice and give informed consent)

*(1) Services may be provided to a consumer **only if that consumer makes an informed choice and gives informed consent**, except where any enactment, or the common law, or any other provision of this Code provides otherwise.*

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

*(3) **Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent**, to the extent appropriate to his or her level of*

competence.

(4) Where 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**, the provider may provide services where—

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

(b) reasonable steps have been taken to ascertain the views of the consumer; and

(c) either, —

(i) 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

(ii) 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.

(5) Every consumer may use an advance directive in accordance with the common law.

Some individuals expressed a view for advanced directives to be mandatory when entering the mental health system or wellbeing system in any capacity. Support while creating an advanced directive should be collaborative and involve the people and whānau we trust as well as alongside our responsible clinicians.

In addition to setting out tools and types of care which support our wellbeing, advanced directives can specify the people we trust to support our decision-making process when we are distressed, and to advocate for us in the moments where we cannot advocate for ourselves.

“In the event that I feel that I need support to help make my decisions... then I would like the ability to nominate someone whom I trust from my whānau... [they] should be involved in sitting alongside me and supporting me to make decisions... Those are just some of the things that I would like to see out of a future Mental Health Act.”

Part 7: Seclusion, restraint and other restrictive practices



*“The key issues of the Mental Health Act for me
are that it breaches people’s human rights.*

*Rights to freedom,
expression,
and movement”*

In speaking to our community, we heard mixed views of whether there should be an Act in future that contains an element of compulsory treatment. Some individuals believe there is possibly a place for compulsory treatment orders, or that if compulsory treatment exists in a future framework, it is closely aligned to (or requires) an advanced directive.

Changing Minds advocates for tino-rangitiratanga, self-determination, to be upheld in which there is no place in our future for coercive practice, solitary confinement (seclusion) or restraint.

One of our core values at Changing Minds is “He mana tō te kōrero | Words hold great power”. The reality of our experiences can often be minimised or softened when using legal language. How we speak about mental health experiences respects our Lived Experiences and can challenge prejudice and discrimination.

“I believe that the Act, and the incarceration in a locked ward harmed me. As did the diagnosis.”

The use of “seclusion” softens and sanitises what is a distressing experience for and their whānau and loved ones ⁵. In addition to using language in any future mental health Act that is reflective of the nature of our experiences under the Act, legislation should not be framed around language and diagnostic descriptors which contributes to discrimination.

“The biggest harms to vulnerable people who seek help from the system I believe, come from the narratives, diagnose, medicate, and incarcerate”.

Language such as “mental disorder” and “serious danger” sets a baseline for health practitioners and the law that an individual is regarded as a threat, or someone who cannot make decisions for themselves. It does not respect a person’s autonomy and self-determination.

No support for solitary confinement (seclusion) or restraint

All individuals who spoke of the use of solitary confinement (seclusion) and restraint found these to be harmful and resulting in people becoming more unwell.

Aotearoa's high reliance on seclusion and restraint has seen us criticised by many human rights organisations and the United Nations.

Changing Minds does not see a future where solitary confinement (seclusion) or restraint is considered an ethical option for mental health treatment and recent evidence⁶ including that contained in the discussion document outlines the damage and trauma caused by seclusion and restraint to both the individual and health workers, and the disproportionate use of seclusion and restraint on Māori⁷.

While current standards require that the use of restraint must be minimised, we would like to see future standards adapted and contained within the legislation, and with a greater emphasis on upholding the rights, dignity and safety of the individual.

“When it comes to risk... the best person to tell you if they are a risk is the person themselves.”

The issue of solitary confinement (seclusion) or restraint can't be considered without also speaking of our approach to risk and risk assessment.

Rather than looking at a system encased in risk, we would like to see a focus on safety.

- Does our mental health and wellbeing system allow people in distress to feel safe under its care?
- Does the environment people are in when receiving treatment allow us to feel safe and at ease?

- Are our clinicians and health workforce provided with the resources, training and skill to feel safe and confident in their roles?
- Do our mental health systems and environment support whānau and loved ones to feel safe and supported in their role to support someone experiencing mental distress?

As part of the feedback we've received, there was a sense that a heightened focus on risk detracts from a clinician's ability to form a trusting relationship with an individual under their care and contributes to a blame culture – in turn feeding a cycle of restrictive practices.

Concerns outlined in the discussion document relating to what will “fill the gap” left by seclusion are genuine. Replacing the use of solitary confinement (seclusion) and restraint with increased use of compulsory medication – specifically sedatives – is not aligned with a holistic or Hauora approach to mental healthcare. Recent work in other areas of mental healthcare and operations⁸ has outlined how we can systematically move away from a risk-based approach by incorporating mental health support and monitoring earlier in an individual's wellbeing journey and by resourcing and supporting our health workforce adequately.

Changing Minds has previously shared our support for Aukatia te noho punanga | Towards eliminating seclusion by 2020 project by the HQSCNZ. Current figures indicate more than ten per cent of people in adult mental health services have experienced seclusion. Inequities are still prevalent as this project has seen the least improvement for Māori health outcomes. As we are here in 2022 reiterating our support for a future without seclusion or restraint, our hope is that removing the option for such practices from the legislation will see the use of seclusion reduce quickly.

Shifting from coercive and restrictive practices in mental healthcare creates an opportunity to enhance the experience of the individual within the system, but also to build trust and counter wider societal beliefs and discrimination⁹. Building trust and countering discriminatory beliefs is critical to the success of this transition.

Appendix One

About Changing Minds

Changing Minds' believes in upholding, protecting and nurturing the mana and potential of all Tāngata Mātau ā-wheako – people with personal experience of mental distress and/or addiction, right across Aotearoa.

We are a national not-for-profit organisation that is committed to 'living' our whanaungatanga – connection, identity and purpose within te Tiriti o Waitangi for the hauora – wellbeing of all Aotearoa and providing a space for all our staff to enhance and express their own cultural confidence and connection.

We also pride ourselves in being operated entirely by those who have navigated their own Lived Experience who now stand tall as living examples of what is possible when we recognise and embrace our experiences as taonga – sign of the potential we all hold to influence greater hauora.

We embrace and nurture whānau mātau ā-wheako to embrace the mana of their Lived Experiences as a source of collective strength to activate equitable wellbeing across all of Aotearoa.

We work in the broad area of hauora services, advocacy, human rights, and health policy, and we collect, articulate, and activate the strategic voice of Lived Experience.

Our Values



Ngākaupono | Absolute integrity

We fight for what is right, we stand for what is true, we are driven by our pursuit of equitable wellbeing for all of Aotearoa.



Hei tiaki | To protect what is sacred

We acknowledge all Lived Experiences as a taonga. We protect and nurture these taonga throughout our journey together with all whānau as a source of mana.



He mana tō te kōrero | Words hold great power

We tell our stories, we speak as one, we support the voices of whānau to be heard.



Tino-rangatiratanga | Leaders of our own pathway

We recognise whānau mātau ā-wheako as the leaders of their own journey, just as we are of ours.



Whanaungatanga | Connection and identity

Our unique experiences, relationships and connections allow us all to find our own individual identity within one united whānau.

Endnotes

- 1 <https://www.mhwc.govt.nz/our-work/he-ara-oranga-wellbeing-outcomes-framework/>
- 2 For more information on Lived Experience insights on nutritional therapies refer to our web article <https://www.changingminds.org.nz/storiesdb/nutrition-a-glaring-gap-in-governments-health-report?rq=nutrition>
- 3 In particular we would draw attention to the work of University of Canterbury Professor of Clinical Psychiatry Julia Rucklidge, including her (et al.) most recent review of micronutrient therapy to address PTSD in disaster survivors <https://econtent.hogrefe.com/doi/pdf/10.1027/2157-3891/a000003>
- 4 <https://www.health.govt.nz/our-work/mental-health-and-addiction/mental-health-legislation/substance-addiction-compulsory-assessment-and-treatment-act-2017>
- 5 A recent example and description of conditions with a Health and Disability Unit can be found on page 47 of the 2020 study undertaken by the Human Rights Commission “Seclusion and restraint: Time for a paradigm shift: A follow up review of seclusion and restraint practices in New Zealand.”
- 6 James K, Vanko E. 2021, April. The Impacts of Solitary Confinement. Vera Institute of Justice. www.vera.org/publications/the-impacts-of-solitary-confinement
- 7 Shalev S. 2020. Seclusion and restraint: Time for a paradigm shift: A follow up review of seclusion and restraint practices in New Zealand. Human Rights Commission. Auckland. www.hrc.co.nz/files/9216/0749/3332/Time_for_a_Paradigm_Shift_Print.pdf
- 8 Such as the Zero Suicide initiative <https://zerosuicide.edc.org/>
- 9 Further discussion of suggested alternative practices can be found in Zinkler, M., & von Peter, S. (2019). End Coercion in Mental Health Services—Toward a System Based on Support Only. *Laws*, 8(3), 19. MDPI AG. Retrieved from <http://dx.doi.org/10.3390/laws8030019>



He mana tō te mātau ā-wheako

Our lived experience is our strength

Changing Minds

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