

Submission: Law Commission Review of Adult Decision-Making Capacity Law

**Submitted by the Mental Health
Foundation of New Zealand**



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Law Commission

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Submission on the Law Commission's Review of Adult Decision-Making Capacity Law

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

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

Introduction

What is the point of living if I don't have autonomy? If I don't have rights? If I can't do life on my terms? (Tangata whaiora, 2022)

There have only been a few times where I have needed to be held for my safety and it is a very rare thing. But, in the lead up to that crisis, there were plenty of opportunities where they could have helped me or supported me before I got to that state. (Tangata whaiora, 2022)

Fear to utilise and collaborate with services is massive for our whānau. If you have bad experiences, how can you ever trust them again? (Tangata whaiora, 2022)

The Mental Health Foundation of New Zealand (MHF) welcomes the opportunity to submit on the Law Commission’s Review of Adult Decision-Making Capacity Law in New Zealand. Our submission focusses on decision-making in the mental health system – specifically, the experiences of those whose right to make decisions about their personal care and treatment is, or has been, overridden under the Mental Health (Compulsory Assessment and Treatment) Act (the Mental Health Act). We will also continue to advocate on this issue as the repeal and replacement of the Mental Health Act progresses through Parliament.

Throughout our submission we use the term *tāngata whaiora* (people seeking wellness) to refer to those with lived or living experience of the Mental Health Act.

This submission was prepared following hui/focus groups with tāngata whaiora and whānau in 2021 and 2022.¹ We have used quotes from these discussions throughout our submission.

The MHF recommends laws embed supported decision-making within Aotearoa’s mental health system.

What would [a different system] look like? I would be the captain of my own ship. (Tāngata whaiora, 2021)

The MHF has an established position that legal frameworks must embed supported decision-making within our mental health system by ensuring all services and supports (including whānau support) enable tāngata whaiora to make their own decisions about their mental health care, treatment and recovery (Mental Health Foundation of New Zealand, 2022). This includes all forms of support, including the most intensive, being based on the will and preferences of the person concerned. These supports should allow for and promote collective decision-making approaches (such as decision-making with whānau) informed by tikanga Māori and te ao Māori.

¹ We met with eighteen tāngata whaiora, most of whom whakapapa Māori, with recent or current experience of the Mental Health Act. We also heard from four whānau Māori members at two dedicated sessions for whānau.

Such a law change should be backed by strong implementation in government policy, guidance and service procedures and systems, and comprehensive checks and balances to monitor effective implementation and ensure substituted decision-making does not become the default practice. *He Ara Oranga* states that "Legislative change on its own will not drive systemic change... it needs to be supported by clear guidance and clinical best practice that promotes supported decision-making and provides measures to minimise compulsory or coercive treatment." (He Ara Oranga, page 194).

It is important that supported decision-making becomes the default approach in our laws, because without that guarantee, substitute decision-making may still prevail, as is the case in many European countries (European Network of National Human Rights Institutions and Mental Health Europe, 2020).

The MHF's position is supported by the following three arguments:

1. The CRPD General Committee's (the Committee) established view that legal capacity – the right to make decisions about oneself – is a fundamental human right and serious mental distress should not be able to infringe on this right.

Article 12 of the United Nations' Convention of the Rights of Persons with Disabilities (CRPD) states that legal capacity is an inherent right afforded to all people, including those with disabilities (United Nations, 2006).

Equality before the law is a basic and general principle of human rights protection and is indispensable for the exercise of other human rights. Therefore, people with disabilities have legal capacity on an equal basis with others, and an individual cannot lose their legal capacity to act simply because of a disability. Rather, all people have legal standing and legal agency simply by virtue of being human (Committee on the Rights of Persons with Disabilities, 2014).

Article 12 of the Convention makes it clear that a disability by way of an "abnormal state of mind"² is not a legitimate reason to deny legal capacity. Further, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.

² This is part of the definition of "mental disorder" in the Mental Health Act.

2. The CRPD Committee's clarification that supported decision-making replace substituted decision-making, as the latter is in breach of the CRPD.

The Committee, in their General Comment No 1 clarifies that States must examine all areas of law to ensure the legal capacity rights of persons with disabilities are not restricted on an unequal basis with others (which is discriminatorily done under substitute decision-making regimes) and supported decision-making is enabled. Aotearoa New Zealand ratified the CRPD in 2008 and should reflect its recommendations in law by creating a supported decision-making regime, and abolishing substitute decision-making. The Committee recommended in 2022 that New Zealand "implement a nationally consistent supported decision-making framework that respects the autonomy, will and preferences of persons with disabilities." (Committee on the Rights of Persons with Disabilities, 2022).

The General Comment emphasises that legal capacity - the right to make decisions about oneself - is fundamentally human, and any assessment of perceived or actual impaired decision-making skills should result in providing necessary supports for individuals to make their own decisions. In other words, rather than affected decision-making resulting in a denial of legal capacity and justifying others making decisions on behalf of the individual (substitute decision-making), it should instead result in providing necessary supports to the individual, thus enabling them to make decisions in accord with their will and preferences (supported decision-making).

3. Evidence suggests supported decision-making can reduce the use of coercive practices within mental health services.

There is reasonable evidence that, when done well, supported decision-making tools (particularly advance directives) are effective means to reduce compulsory treatment and seclusion practices, and fear and anxiety associated with certain medications and treatments (Brophy et al; Tinland et al., 2022; Dawson et al., 2021; Barbui, et al., 2020; Brophy et al., 2019; Tinland, Leclerc, Loubiere, Mougeot, & Greacen, 2019; Lai, et al., 2019; De Jong, et al., 2016; Premski, et al., 2010). Individuals who actively participate in decisions about their treatment gain a variety of benefits, from reduced symptoms and improved self-esteem, to increased service satisfaction and improved adherence with treatment decisions (Delman et al, 2015).

What we have heard from tāngata whaiora about their experience of supported decision-making in the mental health system.

I just think that if we're determining capacity, like really? Based off of a twenty-minute conversation... textbook answers decide what's good for you? I just don't agree with it. (Tāngata whaiora, 2021)

We have heard from tāngata whaiora that their right to make decisions about their care has been taken away too readily or unnecessarily. They say decisions are often based on clinical histories and written notes from previous admissions, rather than clinicians assessing the current situation, taking the time to understand what is happening in their lives, and exploring what types of support and help they may need now.

I definitely think they need to take into consideration other factors about what's going on prior to them arriving... and not base it on notes that you might have from previous admission. (Tāngata whaiora, 2022)

Tāngata whaiora told us the lack of reviews of compulsory treatment orders under the Mental Health Act meant their status, and inability to make their own decisions, is prolonged unnecessarily and arbitrarily.

There is no accountability there either. How do you measure what is really happening? Because it matters a lot. (Tāngata whaiora, 2022)

One of the biggest things for me is the lack of reviews which kept me in that place for longer than I needed to be. (Tāngata whaiora, 2022)

Law Commission Review Questions

Note: we have answered questions related to the Mental Health Act or that were directly related to those who may experience affected decision-making due to serious mental distress or illness.

Terms and language (Q. 1)

We support the use of terms such as 'mental distress' and 'person experiencing mental distress'. You may also wish to include the term 'tāngata whaiora' (as defined above). We recommend you take guidance from those with lived/living experience, including Māori, Pasifika, Asian and other ethnic minority communities when confirming appropriate terms and language to use in your review, as there are differing preferences within communities.

Consideration of te ao Māori and tikanga Māori (Q. 2-4)

If we want to look at how processes can change, I think it's about how te ao Māori can be implemented in the process. The only way that can be done is to have Māori involved. (Whānau, 2022)

Aotearoa's decision-making laws should be grounded in Te Tiriti o Waitangi. We recommend the Law Commission, throughout their review, show how laws and policies relating to decision-making can relate to the preamble and four articles of Te Tiriti o Waitangi: Kāwanatanga, Rangatiratanga, Ōritetanga and Wairuatanga. For example, Māori should be equal or leading parties in this review: from the Law Commission's review process happening now, through to policy and legislative proposals and implementation within services. Our services and laws should provide access to supports that promote and are grounded in wairuatanga (Came, O'Sullivan, & McCreanor, 2020).

Aotearoa's decision-making laws and mental health services should reflect te ao Māori approaches and follow appropriate tikanga. We recommend a legal system that enables services and whānau to support tāngata whaiora to exercise tino rangatiratanga, and promote manaakitanga, wairuatanga and whanaungatanga.

It is also important that collective decision-making is upheld to include whānau, iwi and hapū along tāngata whaiora healing journeys thereby creating better outcomes for many whaiora and whānau Māori.

It needs to be a partnership between not only the client and the clinician but the entire whānau, or if it's not whānau, the key relationship in a person's life, to work through together. (Tangata whaiora, 2021)

He would be discharged without me ever being told. Within two weeks, he would be readmitted. I kept telling them, if you include me in his recovery, I'll be able to support him. When they decided to involve me, that was the longest period that he stayed out of hospital. (Whānau, 2022)

Guiding principles (Q. 5)

We support the proposed guiding principles.³ We recommend principle four be amended to read 'Empower people with affected decision-making, *through the application of a variety of supports*, to live flourishing lives.' In addition, we suggest consideration be given to these concepts and principles:

1. Build a legal system that enables services and whānau to support tāngata whaiora to exercise tino rangatiratanga, and promote manaakitanga, wairuatanga and whanaungatanga.
2. Prioritise a legal environment that promotes safety, wellbeing and healing.
3. Recognise that people can make decisions without support and should have the opportunity to do so before support is provided, and at every stage in the support process, in order to maximise autonomy.

³ Respect and uphold the human rights of people with affected decision-making; Uphold the Crown's obligations under te Tiriti o Waitangi; Recognise and provide for tikanga Māori; Empower people with affected decision-making to live flourishing lives; Recognise and facilitate relationships built on trust; Keep people safe from abuse and neglect and promote accountability; Be accessible and strike an appropriate balance between flexibility and certainty.

4. Recognise that all people are different with different values and beliefs, cultures and languages. Different supports should be available to respond to this diversity.
5. Recognise a person has the right to make decisions, even when their support person or clinical services disagree with that decision, to enable people to exercise tino rangatiratanga/maximise autonomy: "Supporting someone to take risks does not mean turning away from someone in crisis or being prohibited from intervening in the risky scenarios. Instead, it invites supporters to consider the dignity that accompanies risk-taking and the personal growth that can come from making mistakes" (Gooding & Simmons, 2017). It is important for people to have control over their lives so they can be committed to and invested in their wellbeing journey.

Decision-making supporters (Q. 6)

Overall, most tāngata whaiora we heard from wanted whānau and family to be involved in their care; to help them navigate the system; and to support them to make decisions about treatment and medication. We heard that whānau want to be involved in decisions and care, and to have access to information to help them care for their loved one.

People should have the opportunity to decide, in advance, which people they wish to support them. Advance directives, wellness and recovery plans, health passports, and communication support plans can help in this regard, especially during crises. Supporters should be those who make tāngata whaiora feel safe and listened to. This may be whānau or family, partners, or a friend or peer advocate, and not necessarily in this order.

We recognise there may be conflict or disagreement between tāngata whaiora and their loved ones and that family or whānau can be a source of discrimination. Where conflict arises, tāngata whaiora must have the right to decide or decline the involvement of whānau or particular individuals, with the full knowledge that this decision may impact on their care or ability to transition back to their community or home. They should be able to change this decision at any time.

Once you have had your voice taken away and your whānau voice is louder than yours, how do you shift that? And how do you make your voice louder than your whānau voice? (Tangata whaiora, 2022)

Peer support and a personal advocacy system should be available to tāngata whaiora in situations where they need and/or want support to make decisions.

Access to people you can talk to and not just the psychiatrists but peer-led, a peer led advocate... who understands the journey you're on and can liaise with the nursing staff. (Tangata whaiora, 2021)

Peer support should be available throughout mental health services and facilities, to support tāngata whaiora to understand the system and make informed decisions about their care and treatment.

The shared experiences of peer support workers can help support the recovery of tāngata whaiora. Evidence suggests peer support workers can enhance tāngata whaiora outcomes through improving community integration, reducing hospital admissions and symptoms for those with severe mental health conditions, and improving feelings of empowerment and hope for recovery (Muralidharan, Peeples, & Hack, 2021; Schlichthorst, Ozols, & Reifels, 2020; Wusinich, Lindy, & Russell, 2020; Gordon & Bradstreet, 2015; Repper & Carter, 2011; Nestor & Galletly, 2008).

Tāngata whaiora should be able to nominate personal advocates (singular people and/or collective groups) to support them to make decisions and to advocate for their preferences during meetings or discussions where they might want and/or need this type of support. We recommend these nominated support people be required to reflect and promote the wills and preferences of those they are representing or supporting.

Advance directives (Q. 7)

Many tāngata whaiora and whānau we spoke with have not heard of advance directives (despite significant interaction with mental health services) or have not had their advance directives upheld by clinical services.

Nah, I've never heard of it [advance directives]. (Whānau, 2022)

Advance directives need to be seen as a legal document and a true representation of what that person wants and should be used as a decision-making tool. Otherwise, what is the point of doing it in the first place? It is an amazing document and enhances the possibility of outcomes and promotes everything we want to achieve and experience in life. (Tāngata whaiora, 2022)

I think if someone has a safety plan [it should be followed]. I know that when I've been put in and I've had certain safety plans and then they have not worked out... So I think, what's the point? I just feel this powerlessness irrespective of having something written. (Tāngata whaiora, 2022)

The MHF recommends advance directives become legally-binding where they are developed through a prescribed process. Legally-binding advance directives will better enable tāngata whaiora to gain control over their care and treatment in situations where they may be unable to decide or communicate their preferences at the time. The formal processes developed should ensure advance directives are easy to use and access, and have the flexibility to change where someone's will and preference may change. Any formal processes should seek to:

- Ensure all advance directives are easily accessible by mental health services, tāngata whaiora and others involved in the creation of these care planning documents. This could be done through creation of a central register that allows advance directives to be regularly updated, reviewed, stored and shared.

- Require advance directives to contain certain prescribed information such as the date it was completed, who was involved in reaching the decision, how tāngata whaiora were supported in reaching their decision and how whānau were engaged in the process.⁴ This could be achieved through question prompts in mandatory templates. The right balance will need to be struck so advance directives can be comprehensive but not overly complex.
- Permit advance directives to be developed in different formats, such as videos or written documents.
- Permit tāngata whaiora to involve whānau and family, peer support workers or other support people in the creation of their advance directive.
- Permit tāngata whaiora to change their advance directive when their situation and preferences change. This is important as some people can be under the Mental Health Act for long periods of time.
- Include service providers, where appropriate, to increase acceptability and awareness of the directives and decrease the likelihood they will be disregarded in the future (Reuecamp & Dawson, 2019).

There are several international variations of advance directives you may wish to consider:

1. The Netherlands – Self-binding directives.
2. Spain – Advance planning guides.
3. Ireland – Assisted Decision Making (Capacity) Act 2015 where any adult with capacity can make a legally binding statement.
4. Northern Ireland – Advance decisions must be followed if valid and applicable under law.
5. England and Wales – Advance choice documents.
6. Australia – Advance directives.

⁴ Whānau can mean different things for people, so this should reflect who the person at the centre considers whānau and how they wish for them to be involved.

Court ordered decisions (Q. 9)

We heard from tāngata whaiora that engagement with lawyers through the Mental Health Act Tribunal system needs to be reviewed and improved. They say lawyers are not meaningfully engaging and representing tāngata whaiora, or engaging with whānau and family.

With my brother going to court through the acute unit, not once did they consult with our whānau before going into the court... even the option to speak to the lawyer, never got that either. (Whānau, 2021)

The lawyers coming in and just going "here's a lawyer" like five minutes or even a minute before the meeting. That happens so often. (Tāngata whaiora, 2021)

Lawyers representing tāngata whaiora in their mental health hearings should follow supported decision-making principles and should be acting on behalf of their client. For this to work, tāngata whaiora should be able to whakawhanaunga (build authentic relationships) with their lawyer ahead of the hearing so they can make sure they are working towards a shared outcome.

People should be able to access lawyers independently if they want to, or have a selection of lawyers they can choose from. (Tāngata whaiora, 2022)

The way lawyers are involved at the moment is appalling. If they were able to [do it] like the public trust office or something like that, where you could go make an advance directive with the clinical team as well if they want to be involved. So everyone agrees what needs to happen when you need to make those decisions for themselves. (Tāngata whaiora, 2022)

What things might make decision-making arrangements easier or more effective? (Q. 12)

Sometimes you can make decisions one day and then you are not so confident or not so good at making decisions for yourself another day. It's not a constant thing. You can't just assume that because you are under compulsory treatment you are unable to make decisions at any time. There should be some flexibility so that at some stage you can make those decisions and that you are supported to make those decisions. (Tangata whaiora, 2022)

The MHF believes supported decision-making can be facilitated by the below recommendations. Some of these recommendations do not require legislative changes but rather clinical and system changes within mental health services. However, it is important to view these recommendations as a package - legislative change alone will not create an environment that enables effective supported decision-making.

1. Ensuring there are adequate practical processes in place to support tāngata whaiora in their decision-making.

[It] is about supporting them to become self-determining. Supporting tāngata to make their own mistakes. And the thing is, we are gonna make mistakes no matter what we do. But, we need to be able to be involved in these choices. (Tangata whaiora, 2021)

Several practical arrangements will need to be in place to facilitate effective supported decision-making. These include:

- Policies and resourcing to support the routine use of supported decision-making in all mental health services.
- Where possible, enabling tāngata whaiora to determine where and when their advance planning or other decision-making takes place, including outside of normal working hours, or inside one's home where they may feel more comfortable. This type of flexibility from mental health services will show

tāngata whaiora they are important, that their decisions matter and that they will be listened to and respected.

- External oversight and regular review of advance directives, to ensure they are used throughout clinical practice with appropriate documentation showing where, how and why plans were followed or not followed.
- The ability of supported decision-making practices to reflect tikanga Māori and work for tāngata whaiora Māori, such as through valuing wairuatanga and facilitating collective decision-making. After significant efforts have been made and it is deemed not practicable to determine the will and preferences of an individual, then all efforts should be made to support the person to begin to make their own decisions again, within as short a timeframe as possible.
- Where a particular decision is not urgent, it is important to take time and not pressure the decision. People may need time to consider and research options, and to consider and confer with those they trust and value.

There are future planning tools other than advance directives in use in different health services across the motu. These include Wellness and Recovery Action Plans (WRAPs), Health Passports and recovery communication plans. The MHF supports the continued use of these future planning tools and recommends clear education and communication of these plans, and any future legally valid tool, such as an advance directive, and other available tools. It is important that the rights of all tāngata whaiora are upheld, including those who do not have any plans in place or those who have communicated their preferences in other ways.

2. Providing tāngata whaiora (and their family and whānau) with full and accessible information on their rights and treatment options.

I knew the system, I knew who to talk to, I knew how to get him in. I knew what he was going through because I'd been working in mental health. So, for me, the process was quite seamless and we were able to get him the support that he needed. (Whānau, 2022)

It is important that tāngata whaiora, and their family or whānau, are provided with full and accessible information about their rights and treatment options under the Mental Health Act. This information should be provided in a variety of resources, languages and means, with the appropriate amount of time and support for the audience to comprehend and engage with the information. This sort of access to information is essential to enable tāngata whaiora to make their own decisions and may also help alleviate fear and mistrust of the system.

When I think about the decisions being taken away from me, part of the problem is all of the options weren't given to me. What if these medications had serious side effects and I don't know? (Tangata whaiora, 2022)

There should be more opportunities for collaborative note-taking and open dialogue⁵ within mental health services, including access to clinical notes when tāngata whaiora request them. This can help to increase understanding of their condition and improve their sense of empowerment.

If I want to go and argue that point, [but I can't even] get my notes from the DHB. How am I meant to challenge that? (Tangata whaiora, 2022)

3. Ensuring there are a wide range of care and treatment options for tāngata whaiora to choose from.

Services can further support tāngata whaiora to make decisions by providing them with a suite of options to choose from regarding their care and treatment. Providing access and choice to alternative supports, services and interventions means tāngata whaiora would be able to choose what treatment might suit their needs better, based on their knowledge of themselves.

[There were] no choices based on what I think might be right for me, and no suite of options to choose from. (Tangata whaiora, 2022)

⁵ See Finland's open dialogue model which evidence suggests has a high rate of recovery and is credited with minimising the need for medication (Wusinich, Lindy, & Russell, 2020).

Rongoā is not available through [the] clinical space but it should be.
(Tangata whaiora, 2022)

In order for options to be presented to tāngata whaiora, these options need to be available within our system. The MHF recommends a wide range of options for care be available including variety and choice in:

- Facilities – including gardens, activities, paintings etc.
- Locations for care – such as your home or marae.
- Alternative interventions – such as mātauranga Māori and rongoā, talking therapies and wānanga, open dialogue and collaborative note-taking.

4. Educating and upskilling services to ensure they reflect the values of manaakitanga and whanaungatanga.

I think it is about how services engage. I don't think it is done well.
(Whānau, 2022)

When you are talking about engagement that is about humanity and friendship. (Whānau, 2022)

We need an upskilling in all of our professional spaces in terms of biases and institutional racism which dictates practitioners' decisions that impact our people. (Tangata whaiora, 2022)

Evidence suggests that when services are more open to engaging with tāngata whaiora, they are more likely to actively engage with their treatment and care decisions because they feel valued, respected and connected to services.^[4]

Services also need to support whānau so they, in turn, can support their whānau member. Whānau can be important pillars of knowledge and support for tāngata whaiora, they can provide support and advocate for their rights, as well as provide much needed context for mental health services at times of crisis. Generally, when whānau feel informed and supported, outcomes for tāngata whaiora will improve.

It wasn't just about our son. It was about our whānau. (Whānau member, 2022)

You [mental health services] have to deal with this for a few hours a week, whānau have to live with it 24/7. (Whānau, 2022)

One of the worst experiences we had, we weren't heard. (Whānau, 2022)

I feel a bit isolated. (Whānau, 2022)

Is there anything else you would like to tell us for our review? (Q. 18)

We heard that some tāngata whaiora receiving treatment under the Mental Health Act have been unable to speak to a Mental Health District Inspector to access information about their rights as a patient and discuss how they can apply for a review of their condition under the Act. While monitoring and review mechanisms will be considered as part of the repeal and replacement of the Mental Health Act, the role of Mental Health District Inspectors in providing access to information is an important part of challenging substituted decision-making arrangements.

Where are the District Inspectors? They are the ones who are meant to legally help us, it is just not working. What is the point of that function? (Tangata whaiora, 2022)

District Inspectors, I never saw any of them. I was ringing them and my friend was ringing them. (Tangata whaiora, 2022)

Summary

We thank you for the opportunity to comment on your review into adult decision-making laws in Aotearoa. We look forward to seeing how you progress in your review and are eager to engage again during the next round of consultation.

Mauri tū, mauri ora

Shaun Robinson

Chief Executive

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