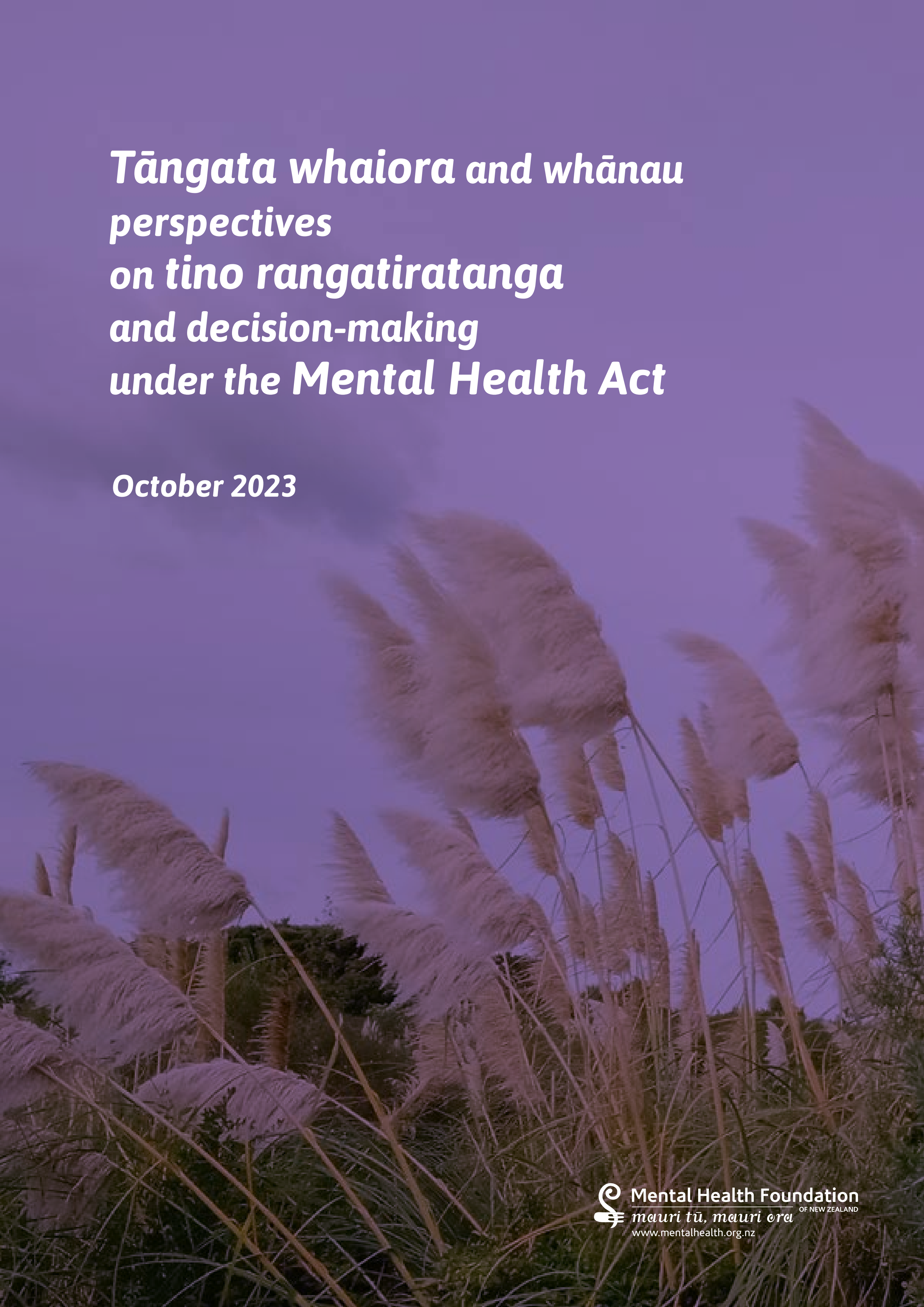

Tāngata whaiora and whānau perspectives on tino rangatiratanga and decision-making under the Mental Health Act

October 2023

Mental Health Foundation
OF NEW ZEALAND
mauri tū, mauri ora
www.mentalhealth.org.nz

This report summarises the themes from hui/focus groups with tāngata whaiora and whānau on supported decision-making and the Mental Health Act.

The ideas represented in this report do not necessarily represent the views or positions of the Mental Health Foundation of New Zealand.

Some of the quotes in this report may be emotionally challenging or distressing. Please use your discretion about engaging with the content of this report and seek support if you need to.

Policy & Advocacy Team

Mā te kōrero, ka ora

Through conversation comes wellbeing

Mental Health Foundation of New Zealand
PO Box 10051, Dominion Road, Auckland 1446

The Mental Health Foundation of New Zealand (2023). *Tāngata whaiora and whānau perspectives on tino rangatiratanga and decision-making under the Mental Health Act.* New Zealand: Mental Health Foundation of New Zealand.

ISBN 978-1-98-855431-0 (PDF)

Acknowledgements

This report has been written by the MHF and reviewed by Kerri Butler (Take Notice Ltd.).

The MHF sincerely thanks all hui participants for sharing their stories and experiences with us. Your whakaaro will continue to inform advocacy from the MHF in the years to come. We also mihi to Kerri Butler, whose facilitation of these hui created a safe and supportive space to enable rich kōrero.

Introduction

This report summarises key findings from two online hui held by the Mental Health Foundation (MHF) with six tāngata whaiora and whānau of whaiora in November 2022.

These hui were held to support the MHF in preparation for their submission to Te Aka Matua o te Ture – the Law Commission's review into laws related to Adult Decision-Making Capacity. The MHF submission focussed on supported decision-making in relation to the mental health system and the Mental Health (Compulsory Assessment and Treatment) Act (the Mental Health Act), where compulsory treatment orders remove the ability of tāngata whaiora to make decisions about their mental health care and treatment.

A kaupapa Māori approach was followed in the delivery of the hui, with appropriate tikanga and the opportunity to wānanga. This created a safe space to honour the kōrero shared by hui participants.

The overarching theme we heard from hui participants was that the current mental health system for those who experience serious mental distress is not working, causes harm and removes autonomy of tāngata whaiora and their whānau.

> *The system is really broken for everyone*
> *and it needs to re-brand itself. (Tangata whaiora)*

They provided us with suggestions about how the system could be improved, including through approaches that support autonomy, tino rangatiratanga, connection and understanding to promote recovery and healing.

The report highlights:

1. Experiences of harm and trauma from being subjected to the Mental Health Act and services.
2. A strong view that supported decision-making, including advance directives, holds solutions to improve the experiences of tāngata whaiora and whānau.
3. The mental health system and associated services should be grounded in te ao Māori in order to reflect and value tino rangatiratanga, wairuatanga and whanaungatanga.
4. Whānau want to be valued and supported by mental health services, and included in decision-making where possible.
5. Other issues with the Mental Health Act and system.

Participants talked about the harm and trauma they experienced under the Mental Health Act

Participants shared with us their traumatic experiences involving care under the Mental Health Act, including the following description of how one tangata whaiora participant was taken into care.

> *I remember being taken out of my home, being dragged out of my home with no clothes on [by police and doctors]... I'd just gotten out of the shower... I didn't even have time to put shoes on and then they had the cheek to write in the notes 'she was frustrated and aggravated, and angry at the staff that were trying to speak to her once she arrived at the hospital.' Fair enough! You just retraumatised me... anyone's gonna be frustrated at that kind of thing.* (Tangata whaiora)

We heard from participants about their experience of coercion and threats to get tāngata whaiora to comply with treatment.

> *If you want to be part of services, you are forced into [the Mental Health Act]... if you want help.* (Tangata whaiora)

> *The last time I was under the treatment order, they told me if I didn't show up for the injection they would call the police... they said they would hunt me down until they found me.* (Tangata whaiora)

> *Going through the system was really demeaning.* (Tangata whaiora)

For some participants, these negative experiences with mental health services resulted in them not wanting to access services in the future.

> *The 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)

Most mental health services are centred around the Western clinical model of mental health. This is considered harmful and unhelpful to many of the tāngata whaiora and whānau we spoke to.

> *As long as that psychiatric assessment is the dominant assessment, that's always going to be the intervention.* (Tangata whaiora)

> *A more holistic assessment, maybe bringing in someone with a trauma-informed background, and also cultural, because the other part of my story is that, the wairua stuff that was happening for me, that was completely missed.* (Tangata whaiora)

> *Options [around care] have been very limited, very coercive and most often based around the DSM medications – being confined, seeing a psychiatrist, seeing a psychologist, doing certain courses. No choices based on what I think might be right for me, or a suite of options to choose from if I think that might be right.*
> (Tangata whaiora)

> *The medical system holds a lot of weight. It focuses on the deficit perspective of the person, so do community treatment orders.* (Tangata whaiora)

> *Medication was not my pathway to wellness at all, if anything, it disinhibited me from achieving wellness.* (Tangata whaiora)

> *The current mental health process is so clinical. It eliminates any time of whanaungatanga and any type of feeling in a healing space.* (Whānau participant)

Participants felt the system and some services are not currently focussed on recovery. They should be working towards getting tāngata whaiora to a place where they no longer need such intensive care.

> *I've been under community treatment orders quite often and for quite long periods of time and it is very hard to get off them. Very hard.* (Tangata whaiora)

> *Making the decision beforehand and before they see you is something they do a lot, and they don't see you with a view to try see how they can take you off [treatment orders].* (Tangata whaiora)

> *They [services] assume that if you are under the community treatment order they can stay in your life and they can be a part of your life. And it's not right for them, and now that I have the choice it's like, maybe sometimes you can be involved in my life, but it's mostly no, all good thank you.* (Tangata whaiora)

> *It's about being part of your life and how they can build bridges to enable people to be supported by them without compulsion. (Tangata whaiora)*

> *Services are mostly focussed on compliance and medication more than anything, and not a holistic worldview in terms of a person seeing their life as living and thriving as opposed to just surviving.* (Tangata whaiora)

> *I think the system needs to assume they are not going to be involved in people's lives forever, and from the very start they need to be talking about how to get that care back to the community or GP... We need to talk about recovery in the true sense of the word which for me, is I no longer have to rely on services anymore, and sometimes have support if I need it, but not necessarily from mental health services.* (Tangata whaiora)

Participants told us they want mental health care to be community-based, trauma-informed and culturally safe.

> *People should be able to have their rights as a human being upheld, within their own community. People should not be stuck on meds.* (Tangata whaiora)

> *It wasn't until I was able to say, 'actually what you're doing is no different to the abuse that I've experienced in my life, and you're continuing and perpetuating this abuse by continually keeping me under the Mental Health Act.' And it wasn't until I came across a psychiatrist that actually listened to me when I said that, and she asked questions about what I was meaning when I was saying that and she clearly understood the impact she was having. She said she didn't realise the impact she was having on me and other people in the same situation.* (Tangata whaiora)

> *We need upskilling in all our [mental health] professional spaces in terms of biases and institutional racism which dictates practitioners' decisions that impact our people.* (Tangata whaiora)

Participants want tāngata whaiora to be supported to make their own decisions about care and treatment as much as possible

Participants shared their experiences of having their decision-making capacity overridden under the Mental Health Act. Participants did not want this to continue; they felt tāngata whaiora should retain their autonomy and tino rangatiratanga throughout their recovery journey.

> *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)

> *There has not been one time I can remember where I have actually been a danger to myself or other people that warranted my choices being taken away from me.* (Tangata whaiora)

> *People should be able to opt out of treatment they don't want.* (Tangata whaiora)

Participants acknowledged there may be some situations where tāngata whaiora do require extra support to make decisions, but this should only be in the rarest of circumstances, for example where there is a real and serious danger to their health.

> *The only time when I really needed to have someone make decisions on my behalf [was]... when I'm so impaired that I can't think about my basic needs [like eating] that it is detrimental to my physical health.* (Tangata whaiora)

> *There have only been a few times where I have needed to be held for my safety and it is a very rare thing.* (Tangata whaiora)

Participants talked about clinicians listening to and favouring the opinions and views of whānau over their own views as tangata whaiora, which also infringes on their autonomy.

> *Even though I was legally an adult, for some reason, they were very much persuaded by my mother's decisions at the time... why were decisions being made for me?* (Tangata whaiora)

Participants discussed supported decision-making and how it should be available in the mental health system with the appropriate flexibility to respond to the specific and varied needs of whaiora and their whānau.

> *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)

Advance directives have the power to better support tāngata whaiora to make their own decisions, however participants had either not heard of advance directives, or these had not been upheld by mental health services.

> *When I've been put in [an inpatient unit] I've had certain safety plans and then they have not worked out... so I think, what's the point? What's the point of having a safety plan at all? I just feel this powerlessness irrespective of having something written down."* (Tangata whaiora)

> *There is capacity where someone has made an advance directive and it's not fair these are not followed. They need to be seen as legal documents 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.* (Tangata whaiora)

> *These [advance directives] need to hold weight and be viewed and honoured first and foremost, before anything else is considered. This plan has been made directly from us and needs to be seen as a document of importance, not just something that's there for no reason.* (Tangata whaiora)

> *I just feel really strongly that advance directives should be a legal document. It should definitely be part of that suite of options and should be upheld and taken seriously because that is that person's voice when it is deemed they are not capable of making decisions for themselves.* (Tangata whaiora)

> *One of the things I really love about advance directives being created as a legal framework is they could include things in there about wairua, and it should be honoured.* (Tangata whaiora)

To facilitate supported decision-making, participants want better information and education available for tāngata whaiora and their whānau on navigating the mental health system.

> *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 he needed.* (Whānau participant)

Participants want care and treatment options to be available and discussed with tāngata whaiora and their whānau. These options should include flexibility about who delivers care, and adequate information about the impacts and side effects of treatment options.

> *People should be offered a suite of [treatment] options, which includes talking therapies among other things...* (Tangata whaiora)

> *In order to be able to be in a position to make a decision, the right people need to be in the room with us. It's not just about putting into the Act that people can make decisions, actually there might be different people we need involved in our care at the time you are trying to ask [us] what treatment... we want?* (Tangata whaiora)

> *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 didn't know?* (Tangata whaiora)

Participants identified the need for better access and choice of mental health supports across the whole spectrum of need. Having the appropriate services and supports when they first needed (or wanted it) could have prevented some tāngata whaiora from reaching the point of crisis when they received compulsory mental health treatment.

> *In the lead up to [my] crisis, there were plenty of opportunities where they could have helped or supported me before I got to that stage.* (Tangata whaiora)

> *Family and whānau therapy, and spiritual therapy should be available so that people are supported at any stage of their life to be well individuals who are resilient and able to look after themselves and others.* (Tangata whaiora)

> *I think there are very limited alternative [interventions]... I'm not talking about psychology, I'm not talking about counselling, I'm talking about something outside of that... the whole system needs to look at what they have to offer.* (Whānau participant)

Participants also discussed and pointed out the need for more investment and focus on prevention measures.

> *They are investing in the wrong business. There is far too much funding going into secondary mental health services and there should be a focus on prevention and community-based supports.* (Tangata whaiora)

Participants want services to be grounded in te ao Māori to support better decision-making and outcomes

Tāngata Māori participants discussed how mental health services that are grounded in te ao Māori would result in better healing and recovery for many tāngata whaiora and their whānau, including non-Māori.

> *The system is not actually designed for us as Māori... why aren't things shifting?* (Tangata whaiora)

> *What is good for Māori is good for all – it is not just Māori who are innately spiritual.* (Tangata whaiora)

> *I worked for a kaupapa Māori service... our approach to whānau coming in was always around manaakitanga and whanaungatanga. We would always karakia right at the start...* (Whānau participant)

> *That kaupapa Māori lens is so important. It's more than just a front. Even just having wānanga, wānanga for whānau and their loved ones. Having opportunities to come together and workshop or learn some of these things. It would have been really helpful for me to work through so many of the things that were going to happen that way.* (Whānau participant)

> *If we are really going to talk about being Treaty partners, then you can't go wrong with wānanga...on a marae setting...* (Whānau participant)

Te ao Māori services would place value on wairuatanga and this knowledge would be invaluable to many tāngata whaiora in helping them understand their mental distress and the different approaches to healing.

> *Take a look at what else is happening, beyond my physical body. It certainly wouldn't be medication, it would be rongoā and other healing processes... that was how I gained my wellness.* (Tangata whaiora)

> *Rongoā is not available through clinical spaces, but it should be.* (Tangata whaiora)

> *Wairua interventions should be independent... can we get kaumātua out of those spaces altogether? So they can carry their integrity.* (Tangata whaiora)

> *I've just been away [to a kaupapa Māori space] and people weren't judging me, it was really beautiful to be in a place where people just accept us as Māori, that it is not a foreign thing.* (Tangata whaiora)

> *Starting to understand my diagnosis from a wairua space, that is really where it started.* (Tangata whaiora)

Participants discussed how wānanga could hold many benefits for tāngata whaiora, their whānau and health workers in the mental health space.

> *It is about feeling like you are able to express yourself. In a clinical setting it feels like you can't, but in a wānanga space if you wanna cry, cry. If you wanna scream, scream. If you wanna swear, swear... being able to create an environment where you can express that frustration. Even be able to express how frustrating clinical services are. So if you can create an environment where that can properly be done, that would go a long way [to] not only help... the whānau but helping the loved ones too.* (Whānau participant)

Participants want services to value whanaungatanga so that they listen to, connect with and seek to better understand tāngata whaiora and their whānau from that first assessment and throughout.

> *I think the way we do things now needs to change. It needs to change how we address whānau and tāngata whaiora, especially for Māori.* (Whānau participant)

> *At that initial assessment... if I had those options and that assessment is done alongside [a] trauma-informed and holistic approach, then ... I might be pointed to the alternative services that we are going to have eventually as an option of treatment.* (Tangata whaiora)

> *I definitely think that they do need to take into consideration the factors about what's going on prior to them arriving, all of those things... not based on notes that you might have from previous admission(s).* (Tangata whaiora)

> *[Services should] look at the bigger picture, not just the symptoms but the environmental factors.* (Tangata whaiora)

> *A lot of the times I feel like they come and they have already made up their mind about you because they have read notes and then when they see you there is not really any point in you trying to speak because they have already decided you're going away.* (Tangata whaiora)

> *There has been a whole lot going on around what is happening with my mental health that is contributing to my mental health. When I got put under the compulsory treatment order, they only took in one tiny, little factor, whereas if they had of looked at what was happening – oh she just lost a baby, that's trauma, I wonder if we can do something different to help her heal from that? So the system misses all of the steps along the way.* (Tangata whaiora)

> *When you are talking about engagement that is about humanity and friendship.* (Whānau participant)

In order to have services which are grounded in te ao Māori, participants identified the need to grow the Māori mental health workforce.

> *While I was in the system I was asking and asking for someone Māori, and it just never happened.* (Tangata whaiora)

> *A lot of our whānau who should be in the system with that [wairua] knowledge aren't there because it is too difficult and it impacts [their] integrity.* (Tangata whaiora)

> *There is a real gap in terms of our whānau to offer those alternative approaches – there is a disconnect for them to be able to access the resource to carry that out and spread it across. It's not fair you have to say you have 'clinical training' and that is not common for those with mātauranga expertise and knowledge.* (Tangata whaiora)

> *If we want to look at how that process can change, I think it's about how te ao Māori can be implemented in that process, and the only way that can be done is to have Māori involved. I think it's about time that gets recognised and they take into account the approach and view we have as Māori will go a long way for a person's wellness.* (Whānau participant)

Whānau want to be valued and supported by mental health services, and included in decision-making where possible

Whānau participants we heard from want to be included in recovery alongside whaiora and to be valued by services.

> *[About a now closed mental health service in Gisborne] It was awesome, and we could relate to it. It wasn't just about our son, it was about our whānau.* (Whānau participant)

> *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 he stayed out of hospital.* (Whānau participant)

However, some tāngata whaiora participants had reached a place where they do not want their whānau involved in care or treatment decisions.

> *At the beginning I was very big about whānau being involved in my care, but now I'm like no. I don't want that.* (Tangata whaiora)

Whānau participants talked about times when they were not listened to, or included, by mental health services and how this hindered recovery for them and whaiora.

> *One of the worst experiences we had is where we weren't heard. My dad went to walk into the assessment and the doctor said "you can't come in, your son is over the age of 18." My dad ended up having a massive argument which really unsettled my brother and the rest of the whānau.* (Whānau participant)

> *There was no conversation with us around diagnosis or around medication. We would turn up to see him and he would be having a side effect from the medication and would be locked in seclusion while he waited for the side effect to wear off.* (Whānau participant)

> *We were there and were talking to the psychiatrist but he put his hand up and told us to stop talking, "I have everything I need on this paper." So we got shut down.* (Whānau participant)

Whānau participants talked about the guilt they have felt around requesting their loved ones be admitted to inpatient care.

> *It is hard enough to have to section your son… you walk away knowing he was in this place that was incredibly run down… I made the mistake of asking to see him when he was admitted and they took me to one of those rooms where they sedate you and I was horrified. It was just this cold room with bars and a mattress with no coverings on a cold floor and that's it. And I was just regretful as a mother, I was just like, what have I done?* (Whānau participant)

> *My husband is at a point that he can't even engage anymore… I know that is connected to his own trauma that he needs to deal with, what happened between him and his son [when he admitted him].* (Whānau participant)

Whānau participants told us they want there to be more support for whānau in the system.

> *We haven't had any support really. Ah well, looks like we have to look after this boy for the rest of our lives.* (Whānau participant)

> *I feel a bit isolated.* (Whānau participant)

> *Even though our son is the one on the meds, what about us? We are not feeling good. I am feeling my own physicality suffer, just from worry or stress. It is about the health and wellbeing for everyone, for the whānau and whaiora.* (Whānau participant)

> *One of the things I say to staff is, you have to deal with this for a few hours a week, whānau have to live with it 24/7… As time has gone on my worry has lessened, but it is still there. It is something I think that people who work in the system don't understand because for whānau it is something we live with every day.* (Whānau participant)

> *It is all about support networks. But we don't know any.* (Whānau participant)

Other comments from participants about how to improve the mental health system

The physical environments of mental health facilities are important and participants shared how these should be improved to better facilitate wellbeing.

> *When we went into the [mental health facility] it was next to the WINZ Office, and the WINZ Office at the best of times is not a welcoming space, and no one likes to go there. When we walked up, [the mental health facility] didn't even look like a place where you would want to heal, there was no waharoa or any sort of welcoming spot.* (Whānau participant)

> *The environment is not conducive with healing.*
>
> *There is all this art work out the front, but it's not where [tāngata whaiora] are.* (Whānau participant)

Participants expressed their frustrations with trying to access help from District Inspectors.

> *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)
>
> *District inspectors seems like a conflict of interest that they hold positions in the sector.* (Tangata whaiora)
>
> *District inspectors – I never saw any of them. I was ringing them and my friend was ringing them.* (Tangata whaiora)

Participants suggested some ways in which the relationship between lawyers and tāngata whaiora could be improved for the Tribunal Hearings.

> *There should be free lawyers involved. The way lawyers are involved at the moment is appalling... as you go into the hearing they are at the door and are like "what do you want?"* (Tangata whaiora)
>
> *Why don't we fund law degrees for our peers?* (Tangata whaiora)
>
> *People should be able to access lawyers independently if they want to and have a selection of lawyers they can choose from.* (Tangata whaiora)

Participants raised their concerns about the lack of accountability for mental health services in relation to coercive practices that are used.

> *Someone needs to be in there that actually is accountable to us. My rights were smashed in there. They did not honour any of them.* (Tangata whaiora)
>
> *The lack of reviews kept me in that [inpatient unit] longer than I needed to be.* (Tangata whaiora)

Participants shared their concerns about people falling through the gaps and not able to access the help they need.

> *It's not uncommon in the system when people haven't been able to get their family treatment when they really need it... Whānau need help and they are not getting it.* (Tangata whaiora)
>
> *You go to town and all our homeless people are part of the mental health system, and I'm like, why are they on the street if they're part of the system? Where are the services? Where's the help?* (Whānau participant)

We heard from participants that admission under the Mental Health Act can prevent tāngata whaiora from getting life insurance.

> *My family decided not to get services involved at one time, I still suffer the consequences of some of my times in services. One is, I am not able to get life insurance. But, if I do want to go and argue that point, even if I can get my notes from the DHB, how am I even meant to challenge that? Why is it blacked out?* (Tangata whaiora)

> *[Not being able to get life insurance] paints a picture like our lives are not worthy of life insurance.* (Tangata whaiora)

Conclusion

The kōrero we heard from hui participants provides valuable insight into changes we need to see throughout our mental health system to create a choice-based, supportive and person-centred environment. Change is needed not just in the legislation but also in the environments and facilities, the practices and culture of mental health workers and staff members, the design and development of the workforce, and through wider cultural change to reduce stigma and discrimination towards those who experience serious mental distress, particularly for tāngata whaiora Māori.

For tāngata whaiora and whānau we spoke to, the overarching message we heard was that our mental health sector and systems should be grounded in te ao Māori. This will better support tāngata whaiora and their whānau, and enable safe, supportive and holistic care.

What works for Māori, works for all.