

“Pākarutia te Mokemoketanga”



Breaking our Silence for the Repeal and Replacement
of the Mental Health Act Submission 28 January 2022

take notice
MENTAL HEALTH & ADDICTION
EVALUATION • PROJECT MANAGEMENT • TRAINING



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Ingoā (Title)

Māori lived experience leader Tui Taurua (Ngāpuhi) gifted the ingoā for our submission. It depicts feeling broken and shattered during our experiences, and the pain and loneliness we felt in the confines of the mental health system. We felt unheard and alienated in a system that doesn't recognise mātauranga Māori and where our wairuatanga is diminished by a westernised clinical paradigm.

Tohu on front cover (Design)

Israel (Ngāti Porou, Ngāti Kahungunu) designed and gifted this piece for our submission. Close to the heart of the kaupapa as he walked the journey as well as contributed significantly to the submission, he describes this taonga as the manaia representing our own mātauranga (knowledge, wisdom and understanding) that is innate within us. The niho taniwha depicted in the piece represents our protection from the obstacles we faced, and our ability to slice through them. The koru represents the new beginning for us all.

Acknowledgements

We acknowledge and thank the brave and courageous whānau who entrusted us with their personal insights, lived experience, whānau, clinical and cultural expertise to inform this submission.

Our acknowledgements and appreciation to Dr Julie Wharewera-Mika and MAS Foundation for supporting whānau participation and collating a response for our submission. Also to Te Rau Ora and Alan Tawhi Amopiu for the support with designing the publication.

To our peers and allies across the sector who have supported and encouraged us with your responses to the submission we mihi to you also.

Ko wai mātou? - Who are we?

Take Notice is a Māori Lived Experience Led Organisation established in 2014 to advocate alongside whānau whaiora for ora ngā hinengaro determined by Tino rangatiratanga and Mana Motuhake.

‘To know what those places are like, you actually have to have been in them’ - Wahine Māori

To truly understand the magnitude of cumulative trauma, hardship and challenges from experiences of the Mental Health (Compulsory Assessment and Treatment) Act 1992 and subsequent detainment in an inpatient setting ‘you must have been there’.

Although our kōrero contained in this submission reflects our experiences as Māori, our korowai is extended to everyone who has been subjected to the Mental Health Act. We know that much of what we have shared will resonate and reflect the journeys’ of many others, and the mamae (pain) we feel as a collective. It is our hope and intention that our kōrero is a catalyst for change for us all.

Whakatakinga - Introduction

This submission is led by Māori subjected to the Mental Health (Compulsory Assessment and Treatment) Act 1992 and detained in inpatient settings in 2020/21, and includes whānau, clinical and cultural insights. It pertains to four parts of the discussion document with 13 recommendations for legislative and system changes.

We undertook a proactive engagement process where whānau were able to determine how they contributed providing the flexibility to have multiple opportunities to input and feedback on the submission. Insights and kōrero from 12 Māori who have experience of the Act, and 5 whānau informed this submission, complemented by an iterative peer review process which included insights from four clinical and cultural experts.

Some of us have chosen to be identified in the hope that ‘breaking our silence’ let’s others know they are not alone, and to break down the stigma and discrimination that often goes hand and hand with experiences of being subjected to compulsory treatment under the Mental Health Act. For others, the need to protect them from further repercussions does not by any means suggest that their voices and kōrero are any less valued.

Tō mātou moemoeā – Our Vision

Kaua e takahia te mana o te tāngata:

Do not trample on people's dignity

This whakataukī (proverb) serves as a reminder to the sector that it is the fundamental responsibility of services to uphold the mana of tāngata whaiora¹ entrusted to their care. A commitment is needed to understand the impact of decisions and actions that violate our human rights and obstruct our rights as tangata whenua.

Our Vision: To amplify the kōrero of tāngata (people) who have experienced the Mental Health Act and have been detained in inpatient settings against their will. We advocate for those who walked before us, beside us, and for those who have and may come after us, so no one ever experiences the trauma and difficult road we have had to journey in order to reclaim our mana, and to rebuild our lives.

The Consultation process for the Repeal and Replacement of the Mental Health Act

We acknowledge the members of the Inquiry panel who led the 2018 Mental Health Inquiry – He Ara Oranga², and extend our gratitude to the many who shared their kōrero and laid down the wero (challenge) calling for transformation of the mental health and addiction system.

We would like to bring to the attention of the Government that the public consultation period in the Repeal and Replacement of the Mental Health (Compulsory Assessment and Treatment Act) 1992 was inadequate.

The public consultation was released in October 2021 during a period when Aotearoa experienced multiple and lengthy lockdowns due to COVID restrictions. In addition to this the short time frame encompassing the Christmas holiday posed significant challenges to facilitate processes that would best meet the needs of those most significantly impacted by the Mental Health Act. Especially when many services people may access were closed or operating on skeleton staff during these periods.

We were cognisant of the fact that considered thought, time, and opportunities to wānanga (come together to discuss) were necessary to ensure a safe and collaborative process. The short time frame during these periods restricted our ability do justice to such an important piece of work.

It is imperative the Government prioritises the voice of Māori with lived experience of the Mental Health Act in future processes for consultation, in designing the legislation, and in transforming and monitoring the system. Accountability must be to the people who are most impacted by the Mental Health Act.

Our lives have been significantly impacted by the legislation, and we need and deserve the time and consideration to be able to come together kanohi ki te kanohi (face to face) to kōrero, to wānanga, and to explore the rich kōrero and narratives of our journey.

¹ Tāngata whaiora – People seeking wellbeing

² He Ara Oranga: Report of the Government Enquiry in to Mental Health and Addiction

In doing so we can be emancipated and find healing and meaning within our experiences to determine sector solutions for meaningful, effective, and sustainable change for future generations.

Acknowledgement of Mātauranga and Mātauranga Māori

We pay tribute to the courageous authorship of Dr Lyn Russell, Dr Lisa Cherrington, and Michelle Levy, and the wisdom of Matua Ron Baker, and Whaea Koromiko Richards in amplifying the voice of Māori through the publication of 'Whakamanawa: Honouring the voices and stories of Māori who submitted to the 2018 Government Inquiry into Mental Health and Addiction in Aotearoa'³. We emphatically agree that:

Māori solutions are cemented within the mana of Te Tiriti o Waitangi and its obligations, navigating across national and international boundaries, and based strongly within the notion of a paradigm shift that recognises wellbeing as fundamental to Māori concepts such as Pae Ora, Mauri Ora, Whānau Ora, Wai Ora and Wairua Ora. - Whakamanawa (2018) p.12³

The kōrero within the publication serves to ignite us into action and reminds us of the strength and passion innate within te ao Māori.

Their submission guided us, and let us know we are not alone, and that collectively we can continue to challenge the structures and systems that restrict us and impact on the wellbeing of Māori.

Insights from Māori lived experience sector leader Tui Taurua (Ngāpuhi) documented her 40 year journey in the sector, and the impact colonisation had to play in contributing to her sectioning under the mental health act. Her desire to 'understand what it was to be Māori' led to her finding her own solutions to wellbeing and recovery.

'Following my inner knowing, I turned to Mātauranga Māori processes which began with Sir Mason Durie's Te Whare Tapa Whā. I gave up work for two years, dismissed everyone from my life, and only listened, lived, and followed my tupuna directions. I developed the program "He Rapua te Hinengaro Tangata Toa" to "Seek the Mind of a Warrior". I used the concepts of Ranginui, Papatūānuku, Tāne Mahuta/Awa, Tangaroa/Moana, Tika/Pono, Aroha/Manaakitanga, Mātauranga, Tautokotanga/Whanaungatanga, Whenua/Whakapapa, Marae/Tangihanga and finally Hākari (celebrate each achievement.

I used all these notions to deal with trauma, pain, neglect, loneliness, panic attacks, and fear that overtook all my thoughts and feelings. I cried many a tear and worked hard with each challenge as I identified necessary changes, while continuing to be open to tupuna direction' – Tui Taurua (Ngāpuhi)

Te Wero - Call to action:

Māori with 'lived' and 'living' experience of the mental health act must have an integral role in the development and implementation of any new legislation. Our leadership and guidance throughout is crucial in 'Transforming the System'.

³ Whakamanawa: Honouring the voices and stories of Māori who submitted to the 2018 Government Inquiry Mental Health and Addiction in Aotearoa.

OUR KEY RECOMMENDATIONS

RECOMMENDATION 1: Legislation must be developed with Māori and provide protection for Māori against indiscriminate use of the Act

RECOMMENDATION 2: Protections for Māori within the legislation must include processes, and principles that uphold our mana and that of our whānau and enable us to exercise our Tino Rangatiratanga. Explicit statutes must be evident in new legislation to ensure cultural assessments and interventions are mandatory.

RECOMMENDATION 3: The inequity of Māori indiscriminately subjected to the act must be addressed.

RECOMMENDATION 4: Seclusion (solitary confinement) must not be allowed for in new legislation.

RECOMMENDATION 5: Appropriate protections for Māori in new legislation must allow for independent and external cultural support, so we can choose to connect with whānau, hapū and iwi to facilitate these processes.

RECOMMENDATION 6: Assessment of trauma history and cultural support needs, must be evident as necessary in new legislation. Protections must be incorporated to ensure culturally informed and trauma responsive approaches to enable the workforce to prioritise authentic engagement, and non-coercive practices.

RECOMMENDATION 8: Legislation must enable protections for the workforce to work in ways that allow for shared risk and responsibility. Recognition of the value and expertise of kaimahi Māori must be evident in legislation.

RECOMMENDATION 9: The legislation must promote lived expertise and remove any legislative statutes that enable substituted decision making.

RECOMMENDATION 10: Legislation must protect the rights of Māori and ensure spiritual and cultural safety with interventions that are trauma responsive, non-coercive, holistic, and healing.

RECOMMENDATION 11: Legislation must protect our rights as citizens and tangata whenua and cannot allow for clinical judgements to override our code of rights and the right to protection from abuse and mistreatment.

RECOMMENDATION 12: Legislation must provide protection for Māori to ensure risk to our physical health and wairuatanga is independently assessed before any treatment options are imposed upon us or recommended.

RECOMMENDATION 13: Legislation must allow for independent Māori lived experience and whānau advocates to support with upholding our rights and those of our whānau

Embedding Te Tiriti o Waitangi and addressing Māori cultural needs

Current legislation denies Māori the right to Tino Rangatiratanga, Ōritetanga and Ritenga Māori in accordance with Te Tiriti o Waitangi. Protections must be evident in new legislation.

'The mental health system is Eurocentric and that does not work for Māori.' - Wahine Māori

The current system is bias and institutionally racist, underpinned by inadequate and culturally unsafe practices that often result in trauma, readmissions and damaged whānau relationships.

Te Tiriti o Waitangi is not recognised in current Mental Health Legislation, and the current Act is a harsh legal instrument that provides no protection for the physical, mental, spiritual or whānau wellbeing of Māori. The cultural appropriateness of the use of the Act was questioned during the Government Inquiry in 2018:

'Is it possible to challenge the New Zealand Mental Health Act on the grounds of spiritual, cultural and racial discrimination?' – Whakamanawa (2018) p. 64³

The processes that facilitate our entry into services lack cultural safety, exclude our whānau, and dehumanise us with the use of subjective assessment tools to determine mental disorder, capacity, and risk to ourselves and others.

'My Whānau were told by the crisis team they had 10 minutes to pack a bag as the police were coming. Their pleas to the team that they didn't need to do that, and that they would take me in were ignored. The police were way more compassionate than the crisis team....but it meant I had no whānau with me when I was assessed at the clinic. When she [the Psychiatrist] asked me 'who do you listen to?', I thought she meant [who do I listen to] about medication so I said 'my mum...she was a registered nurse'. She asked 'is that who you are listening to now?' When I said 'No, I'm listening to you' she got irritated, as she assumed I was lying and hearing voices ...that's when she said 'you're off to Tiaho Mai'. - Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

The inequity for Māori through the application of the Mental Health Act is a breach of Te Tiriti o Waitangi evident in the disproportionate rates of seclusion and use of compulsory treatment orders.

In 2020 Māori were 5.4 times more likely to be secluded in adult inpatient services than non-Māori and non-Pacific peoples⁴. Many of us were handcuffed and escorted to inpatient settings by police, and secluded on admission.

This is an undeniable indicator that the Mental Health Act is used discriminately against Māori.

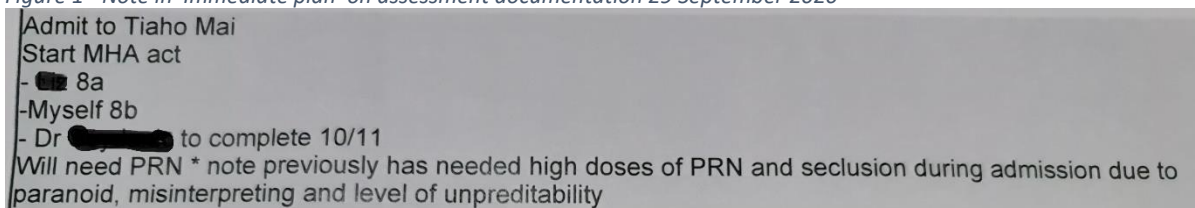
'On my arrival to Tiaho Mai, another mental health team came out and tried to force me in to the building. I then requested I be respected, and given personal space to feel safe. I'd also said to them 'don't we live in the South Pacific, how could you not know this?'....Still ignored.'
- Maraea (Ngāti Porou, Te Whānau- a -Apanui, Ngāpuhi, Ngāti Pākehā)

⁴ New Zealand Mental Health and Wellbeing Commission (2022). Te Huringa: Change and Transformation. Mental Health Service and Addiction Service Monitoring Report 2022. Wellington: New Zealand

Damning clinical notes (sometimes based on historical factors) preceding our arrival in to inpatient settings, coupled with an odds ratio of 5.4 times more likely to be secluded made it inevitable that the majority of us were secluded on admission, or during our inpatient stays.

'I knew the minute the police drove past the wharenuī and bought me in the back door that I was f#\$%ked.' - Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

Figure 1 - Note in 'Immediate plan' on assessment documentation 29 September 2020



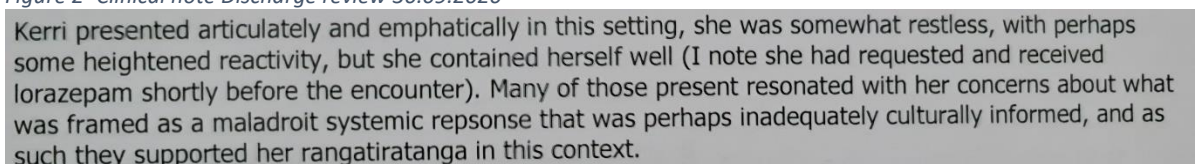
Admit to Tiaho Mai
Start MHA act
- 8a
- Myself 8b
- Dr [redacted] to complete 10/11
Will need PRN * note previously has needed high doses of PRN and seclusion during admission due to paranoid, misinterpreting and level of unpredictability

Fear and mistrust (due to historical trauma in the system) is misinterpreted as paranoia and unpredictability and introduces an immediate bias. This results in discrimination, cumulative trauma, mistreatment, restraint, seclusion, lengthy inpatient admissions, and readmissions.

'They simply fail to see us in the context of our whole selves.' - Wahine Māori

Protections must be embedded in new legislation to prevent the discriminatory use of the Mental Health Act. Clinical reviews need culturally informed processes that prevent the possibility of judgements based on assumptions, misinformation, and poorly guided responses.

Figure 2- Clinical note Discharge review 30.09.2020



Kerri presented articulately and emphatically in this setting, she was somewhat restless, with perhaps some heightened reactivity, but she contained herself well (I note she had requested and received lorazepam shortly before the encounter). Many of those present resonated with her concerns about what was framed as a maladroīt systemic response that was perhaps inadequately culturally informed, and as such they supported her rangatiratanga in this context.

The indiscriminate use of forcible entry into an inpatient setting does little to build an authentic or trusted relationship and exacerbates any fear we may already have of the system. As a result, we are less likely to engage, and we are subsequently given labels such as 'non-compliant', 'high and complex needs' and 'hard to reach' in addition to the already damaging and dehumanising diagnostic terms and labels used to describe us and our experiences.

'It was like a continual cycle of neglect. They just put me in a loop, and they wouldn't let me out unless I did what the monkey was told to do basically, and then they finally gave in, but really....I was already in a bad situation gone from moderately tolerable to volatile and un hospitable quite quickly. For my personal circumstances it [what I was experiencing] was never really addressed either in the beginning.' - Israel (Ngāti Porou, Ngāti Kahungunu)

The implication of a system response that categorises us establishes little hope for recovery, and instead promotes the impression that we need to be 'managed' and 'controlled'. Thereby subjecting us to further restrictions, exerting control and establishing a frame of compliance with recommendations for compulsory inpatient and outpatient orders and depot injections.

Figure 3- Second Health Professional Recommendation presented during section 16 hearing 16.11.2020

Kerri requires a continued admission in the Acute Mental Health Unit for Compulsory Assessment and Compulsory Treatment under the MHA.
The MHA should continue to a CITO whilst admitted and a CCTO when discharged.
There is need to explore the option of Parenteral (Depot) medication during this admission and continued after discharge.

This deep seated negative culture of compulsory care provokes a revolving door, where Māori are fighting against a system that just 'doesn't get it'. We end up losing faith in the system, and our hope of ever returning to our lives is diminished.

Figure 4 - Clinical note 14.1.2021

If transferred to ADHB- would be best if [redacted] could accompany Kerri there.
Daughter's given pamphlet for yellow brick road counselling for families.
Called Kerri's mother to update her [redacted]
CTO application made

'I remember my daughter being in my section 16 and trying to tell them 'you have to understand my mum, she's not like other people. If she has a goal she is very focussed and she makes it happen...this is my mum. The kaumātua tried to advocate too, and I tried to show them my wellness plan I had developed. We were all ignored and she [the judge] didn't listen, so I ended up locked up missing yet another one of my daughters' birthdays. Instead they listened to the psychiatrist who didn't know me, hadn't seen me for three days and was recommending a 'complex clinical review', to cover up all their f#@k ups... then they applied for a 6 month inpatient order and didn't even tell me!!...'. – Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

Recommendations dominated by psychiatrists within the system are often supported by the Mental Health Act tribunals, where the clinical view is favoured over that of cultural expertise, our expertise, and that of our whānau.

- Māori are 1.8 times more likely than Pacific peoples to be subject to an inpatient treatment order and 3.5 times more likely than other ethnicities⁵
- Māori are 1.8 times more than Pacific peoples to be subject to a community treatment order and 4.1 times more likely than other ethnicities⁵

We are 2.9 times more likely to be subject to indefinite treatment orders than non-Māori⁵, facilitating the trajectory in our lives where Tino Rangatiratanga is overtly suppressed, through the use of forced medication further restricting our potential, and impeding our Mana Motuhake.

⁵ Ministry of Health. 2021. Office of the Director of Mental Health and Addiction Services 2020 Regulatory Report. Wellington: Ministry of Health

'They don't speak enough for Māori and the Māori way, it's not that I'm racist or biased, but there needs to be more than one approach to say... yanno... this is what we could look at, instead of this is it and there is nothing else....that is it!! You can't do that, and say that, and it's forever.' - Israel (Ngāti Porou, Ngāti Kahungunu)

Protections for Māori within the legislation must include processes, and principles that uphold our mana and that of our whānau and allow us to exercise our Tino Rangatiratanga. The mātauranga of our kaumātua and kuia must not be viewed as being secondary to clinical expertise and must instead be in partnership and reflected in policy, legislation, and practice.

Recollections of instances of the administration of the act where we were treated with compassion and kindness, whilst rare, highlight the stark difference when whanaungatanga, manaakitanga and aroha guide the interventions.

'I had been driving all night through the Waipoua forest in the Hokianga reliving the trauma of the seclusion incident in Counties in the previous week. When daylight broke I went to the police station to lay assault charges on those staff involved. The police were fantastic, and seeing my distress, and sensing something wasn't right they suggested I go with them to the medical clinic. The nurses were great, then a cultural support team arrived, who took me to another space and gave me cups of tea and biscuits and were so kind and caring. When the Māori psychiatrist arrived, I could immediately feel her wairua. I felt safe. She listened. She asked them to do some physical checks. Then she offered me medication, I took it, and then curled up on the couch and cried. That's what I needed, to feel safe, to trust the person caring for me, and to tangi tangi. I knew I was tired. I and wasn't in a good space. She explained that I was going to go to Tumanako unit (NDHB) and asked if the crisis team felt safe transporting me to the unit as there was a risk alert on my file. Even though they [the crisis team] took me in to the back room to be assessed, they immediately moved me, when I started to cry, and talked about the yucky wairua in there, as I could feel and see that it was a seclusion room.' - Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

With the establishment of the Māori Health Authority there is an opportunity to strengthen cultural support in partnership with local marae, kaupapa Māori providers, hāpori, hapū and iwi. This will enable Tino Rangatiratanga and mātauranga Māori to be the foundation for the solutions for Māori.

'We all have a part to play in the re-imagining of mental health and addiction as a Tiriti-led, Pae Ora driven sector in Aotearoa New Zealand. Finding our way together will require shared transformational leadership, investment in reindigenising our Māori workforce and equipping our entire Pae Ora workforce to lead and work within Tāngata Whenua models of care that are co-designed with whānau.' – Māori organisation/service provider/group Whakamanawa 2018 p. 367³

RECOMMENDATION 1: Legislation must be developed with Māori and provide protection for Māori against indiscriminate use of the Act

RECOMMENDATION 2: Protections for Māori within the legislation must include processes, and principles that uphold our mana and that of our whānau and enable us to exercise our Tino Rangatiratanga. Explicit statutes must be evident in new legislation to ensure cultural assessments and interventions are mandatory.

This will require the system to ensure the workforce is well supported and enabled to provide interventions that involve cultural support in partnership with iwi and Māori providers.

RECOMMENDATION 3: The inequity of Māori indiscriminately subjected to the act must be addressed.

The system must enable an urgent independent external review to assess all cases where Māori are subjected to compulsory inpatient, outpatient, and indefinite treatment orders. The review must include cultural, legal, clinical, whānau and lived experience expertise.

Seclusion, Restraint and other Restrictive practices

Use of restraint, ‘retreats’, open LSE (Low Stimulus Environments) and HDU (High Dependency units) must be rigorously monitored and only used as a last resort

We are concerned that the use of language and environments that facilitate similar restrictions will become common practice with Māori, thereby giving a false reality that the use of practices that are coercive and impact negatively on wairua and wellbeing have been reduced or eliminated.

‘They put their hands on me and locked me in the ‘retreat’ area within 24 hours of being admitted retriggering unimaginable trauma....Fight [to break free] then flight [disassociation due to trauma] kicked in alright, and I believe if they hadn’t put their hands on me in the beginning I wouldn’t have spent the next five months cycling through the system with five admissions in to three different inpatient units. After a cocktail of high doses of medication, restraint, seclusion, coercion, flashbacks and nightmares, all it has done is create fear and mistrust in the system!!.’ - Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

Figure 5 - Clinical review after being restrained and put in to 'the retreat' with 2:1 nursing 29 September 2020

introduced use to Kerri. Explained that Kerri is traumatised at being here as previously was in seclusion here when pregnant with her youngest daughter.

“It’s f***ing traumatizing” ... “I’m scared, I just want to get f***ing out of here” ...” all I asked for was my bag. Comments how she is not even wearing her own clothes

The use of force in any instance diminishes mana, compromises wairua and induces trauma. It is representative of a system failure. Whilst there are several incidences we recalled where restraint was used on others to protect us or other whānau within the units, we felt most of these could have been better managed by staff who were cognisant of cultural safety, and skilled in relationship building, therapeutic care and de-escalation, and with better use of the environment.

Seclusion (solitary confinement) should not be allowed for in new legislation

‘Secluding actually drove you deeper in to the whole rabbit hole so to speak... yanno...when they put you in a situation where you can’t absorb or engage in any other way’ – Israel (Ngāti Porou, Ngāti Kahungunu)

Māori disproportionately experience seclusion (solitary confinement) in adult mental health units, with almost half (48%)⁶ of the incidents of seclusion (solitary confinement) in 2020 experienced by Māori⁴. Instead of a human response we are met with brutal force.

'...yeah I was p@#\$d off when I arrived, It was Christmas day!! They had changed meds and not monitored me in the community, so they sent me through the roof...then they bring me back here even though there was an alert to say not too.

Figure 6 - Clinical note 29.12.2020 (Added Post Submission)

_____ explained that during the admission process, Intake and Acute Assessment CIC, _____, discussed the assessing clinician's decision to admit Kerry under Section 11. There is an alert on the system from 01/10/2020 that Kerri should not be admitted to Tiaho Mai. However, no documented plan or directive in the clinical notes supports this alert. _____ further discussed the current issue with DAMHS _____. The assessing team with the support of _____ and _____ saw an admission to Tiaho Mai as in the best interest of Kerri considering the immediate need for further assessment and treatment.

They had 6 or 7 of them in a staggered line leading all the way to the door,. The kaimahi I knew sensed my distress at being back there, and [my] knowing that they were going to put their hands on me....AGAIN!!... I'm NOT violent, it made me feel less vulnerable to be angry than to feel unsafe and scared, so I was angrily quoting the code of rights, and Section 6 of the Health and Disability Standards 8134. Where's the imminent risk in that??!! ... they rushed at me, and grabbed me, and started dragging me.

'...yeah..there goes my trauma response...AGAIN!!.....I remember trying to reach out to the staff I knew, screaming.....then I blacked out, and I don't' remember anything else from then on....reading the clinical note just makes me hōhā. All that s@#t over a packet of cigarettes, when all they needed to do was back off, and let the kaimanaaki and kaimahi who knew me have the time to de-escalate my distress. Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākeha)

Figure 7 - Clinical note 25.12.2020

admission suite on arrival. Familiar faces made entry easier but K still verbally aggressive-our team in control at all times. I embraced her on arrival and waited until meds arrived, which she took and proceeded to Flexi. Even though search was done in admission suite, she still had stuff concealed inside of her bra. When team had approached she reacted causing high level restraint to take place. I had to stop the restraint process outside of flexi as it had got out of hand. We went to the floor,comfortably for her and got everyone to stop, take a breath whilst I calmed her down. We then proceeded to Retreat where search carried out and offending property taken from her. By 2pm, patient asleep in locked retreat.

Wāhine Māori have shared experiences of feeling violated when they are forced to the ground and overpowered by male staff members, forcibly restrained and injected. Locked in a room and left to deal with the overwhelming feeling of distress, and a lack of attendance to basic human rights is inhumane, degrading and assault.

'I was thrown into a room with a toilet and a blue mattress, where staff forced me onto the floor face down, and I said I couldn't breathe. I feared for my life. I was left alone, and when I tried pushing a button to ask for water I was ignored again. For days I felt lost with time'. Maraea (Ngāti Porou, Te Whānau Apanui, Ngāpuhi, Ngāti Pākehā)

Tāne Māori describe the violation of their mana, when 'tackled to the ground' and forced into submission, generally by the biggest staff on site including security officers. Done so to force them into submission with heavy medication so they are humbled into being 'compliant, complacent and easy to manage'. Being 'big and brown' they described feelings of being stereotyped as violent, aggressive, and dangerous, and subsequently experienced multiple incidents of restraint and seclusion all the time.

'it was really distressing to see a young tane Māori come in late at night. We gave him a hug, made him a milo and gave him some of our chips, as we could see he was scared.....he was shaking, and looked fearful and haunted. I could tell they had secluded him, it does something to a person's wairua, and when you have been in there yourself, you can feel it....as a mama it hurt, and made me bl#@%dy angry. How dare they put their hands on our babies!' – Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

Seclusion is traumatising and barbaric. We are dehumanised and disempowered. Several of us shared painful recollections of flashbacks, nightmares and post trauma experienced because of this condoned practice, and the cruelty we experienced when our basic human rights such as access to water were denied.

Trauma experienced is collectively felt by us, our whānau and often kaimahi involved. Whānau often become the scapegoats for decisions made during our admissions resulting in fractured relationships that sometimes take months and years to rebuild.

'This was such a disappointing outcome, and I felt responsible for the pain my friend experienced and we felt worried that this would sever our relationship.' - Aroha (Ngāpuhi, Ngāti Whātua, Tainui, Ngāti Kurī, Ngāti Awa) and Brody (Ngāti Kahungunu)

Most of us had been through the system before, and experiences of seclusion heightened distress, fear and mistrust, particularly when it came to forced medication. Failure to understand or recognise this meant that at times we were described as 'difficult', 'dismissive' and 'selective' with staff. Our risk averse response to medication due to lack of trust was interpreted as non-compliance, thereby facilitating threats of IMI's (Intra-muscular injections), and for some of us multiple and repeated incidents of restraint and seclusion representing a failure to build therapeutic relationships and deliver trauma responsive care.

None of those of us who experienced restraint and seclusion were 'medication hesitant' when skilled and compassionate senior clinicians were present, and cultural processes for engagement were enabled to happen.

Figure 8 - Clinical note 11.10.2020

-Kerri, reiterated "I trust you, to give me my medication, because you have taken the time to korero with me in a way that allows me to be listened to and share this journey with me, and not just expecting me to take the medication".
(in essence "Tino Rangatiratanga"/Self Perseverance, is up held)
-in response "we" embraced one another "manaakitanga"
-Kerri' agreed to take her medication, upon retiring back to her bedroom we again shared in a korero' pertinent to her mahi/work and the making of her bed
-Kerri, was given her nocte medication before we jointly made her bed
-we then again embraced prior to my exiting her bedroom

We need holistic healing approaches that uphold our mana and are informed by mātauranga Māori.

Authentic engagement prevents the need for compulsion

'I stand to represent not only myself but other vulnerable persons who have [been] degraded by people in positions of authority who are funded by the taxpaying Government to serve and protect us – not abuse and mistreat those in the community who are treated worse than dogs under the mask of New Zealand's Mental Health Act ... I felt ashamed and fearful. My mental state of mind further deteriorated due to their response. I felt traumatised and felt that my basic human rights as a woman had been blatantly violated. (Māori with lived experience)717 – Whakamanawa³

Our lives have been irrevocably changed and scarred because someone else holds the pen, and the power to enable the indiscriminate use of practices that occur when the Mental Health Act is used.

'I'm just lucky that I got transferred to another unit that had professional unbiased clinical support. The psychiatrist asked me to request [at my tribunal hearing] a deferment [28 days] for the 6-month inpatient order that had been applied for by the previous unit when I was transferred. They worked with me, so that I got out without a CTO, and was able to then begin the painful process of rebuilding my life again.' - Kerri (Ngāpuhi, Ngāti Porou)

Too often the Mental Health Act is used to compensate for an inadequately resourced, and culturally insensitive system that is under pressure, signalling failure and inability to form genuine and authentic partnerships with us.

'I had engaged on zoom the day before with a well-known tohunga and taken the medication they gave me the night before, sleeping 12 hours. I was sitting outside having a coffee and painting my nails with a close friend when they rocked on up to my door....Unannounced!!....and demanded to enter my home. When he wasn't listening [the psychiatrist], I told him I was no longer going to listen to him and I was going to follow the advice of my tohunga. My kids were crying as they were asking them where I should go, my mates were distressed, and I felt protective and angry, so demanded they leave my home. I was then served with papers [Mental Health Act] and threatened with police.' - Kerri – (Ngāpuhi, Ngāti Porou, Ngāti Pākehā)

Poor engagement processes, 'clinical anxiety' and a heavy reliance on diagnostic criteria, control, and compulsion, subsequently facilitates a relationship that is transactional rather than relational in nature and practice.

'I completed a Section 8a of the Mental Health Act (MHA) (1992), thus starting a legal process that Mental Health Services were required to continue. I informed him that he was now the subject of a legal process and could not leave the GP practice before I developed a plan with MHS [Mental Health Services].

I told him that if he did go, the consequence would be immediate police involvement. At the time, I believed I was practicing in a clinically sound way and that my enforcement of him remaining onsite was to ensure his safety. In retrospect, I ascertained that we could have explored several safe options preferential to him while he awaited MHS contact. It was my anxiety that drove my decision to remove his choice and autonomy.

I consider myself to have strong morals and ethics and advocate for MHS consumers and their rights. I was dismayed to learn that, although I acted with good intentions, I removed every opportunity in the MHA Section 8 process in which he could have exercised choice about the care he received' - Reflections of an ex-Duly Authorised Officer (Ngāti Ingarihi)

Many of us spoke of being coerced and manipulated into complacency and acceptance of compulsory treatment orders, as they were seen as a 'get out of jail' pass.

'After I got the help I needed... not from any of these services that said they were gonna help me in the beginning.... after I left Tiaho Mai. I didn't get nothing, I got manipulated a lot more than I'd say others were because it became clear to me that my personal life and any social activity that I was doing was monitored quite closely by them in one service, and shared with the doctors, and that privacy information they were sharing was not even true. They were already bias towards what someone else had said.' - Israel (Ngāti Porou, Ngāti Kahungungu)

Clinical notes in some instances were worded to suggest it was a supported decision. Whereby 'it was explained it was 'in their best interests' and that the act would 'uphold their rights', failing to inform us of the serious consequences and risk this posed to our privacy and our lives.

Figure 9 - Clinical note 28.21.2020

Psychoeducation into mental illness and treatment discussed. Discussed how MHA could help her recovery as this would be a way for her to have treatment as well as a way to ensure her rights as a client is upheld. She is aware that the Quetiapine dose is currently being optimised, aware that this as recently been increased to help with her sleep.

There is considerable discourse within the sector about supported and substituted decision making, and their role within the new legislation with varied viewpoints and understandings.

Entrenched in tikanga Māori is whakawhanaungatanga, manaakitanga and aroha. This devoids the need for practices that strip us of our Tino Rangatiratanga, our human rights and subsequently paves the way for coercive practices.

We often experienced the system as a 'constant battlefield', our 'fight' for Tino Rangatiratanga, and the services 'fight' to remain in control by suppressing us with medication and oppressing us through the use of abusive power and forced compliance.

'..and the blackmail thing pretty much.. yanno, if you don't take the haloperidol you're gonna be put in the hīnaki [eel trap – used to describe hospital]...and I was like like ahhh I don't think you can say that... yanno, you can't threaten me.. plus that doesn't seem ethical. You can't f#\$%^g deem someone...On what grounds?!' - Israel (Ngāti Porou, Kahungunu)

The times we challenged the treatment, we were immediately reminded of the combined power of psychiatry and legislation, and that any attempts to exert our rangatiratanga were a risk that we needed to think carefully about.

'My psychiatrist told me 'you need to learn to be a good patient or you're going to end up somewhere you don't want to be again'. After weeks of battling with intense suicidal thoughts and begging for a change back to a medication I knew I could tolerate, I just stopped it. I knew I wasn't on a CTO [Compulsory Treatment Order], but after the experiences of the last five months I was still scared....after days of agonising I couldn't take it anymore, and I decided the risk of ending up in hospital again was far better than being dead. My whānau had been through enough. So I sent an email to my keyworker saying what I had done, and what I wanted forcing their hand to change my medication.' Kerri (Ngāpuhi, Ngāti Porou)

A collusive and coercive culture is fostered in poor leadership, with clinicians sharing experiences of the impact of having to work in ways that compromise their ethics and values. They are often restricted from practicing the fundamental principle of 'First do no harm'

'I am aware I have made risk-averse decisions with the intent of self-preservation above person-centred care in my clinical practice. Risk aversion was prioritised to protect from anticipated criticism from colleagues and leaders, avoid potential blame for practicing outside expected clinical responses, and maintain my professional reputation. However, this risk aversion became entrenched only after receiving negative feedback for my management of a situation that I perceived to be ethical. On occasion, my risk-averse clinical decisions have been in contrast to my values and ethics.' - Reflections of an ex-Duly Authorised Officer (Ngāti Ingarihi)

Stigma and Discrimination is perpetuated through the enforcement of the Act

The stigma and discrimination that goes hand in hand with the enforcement of the Act has far reaching consequences including loss of employment, impact on future employment, denied travel, loss of agency over where we live, and for many our children are removed from our care.

The use of the Act enables society to make judgements about us that are seen only in the context of our diagnosis.

'...they were basically just repeating stuff from what they had been told from where I was living, they were talking to everyone that was in the house with me about me and my behaviour and then going straight ahead with what they were saying about me and saying this is what you've been doing' - Israel (Ngāti Porou, Kahungunu)

A dual injustice was often experienced with feelings of ‘hopelessness and helplessness’ at being trapped in more than one system that ‘doesn’t listen’ or ‘see us in the context of our whole selves’.

‘Aesthetically they might look like it, but they’re not really achieving really, and everyone’s got a lot of excuses. I think the interlinked thing...the services are all interlinked, the police, the services, the health and housing.... creating laws and things that are making things more difficult... what’s that all about?... what the hell’s all that about!!.’ - Israel (Ngāti Porou, Ngāti Kahungunu)

The most painful challenge experienced by some of us was that of having our tamariki removed from our care, and our identity as a parent challenged. The overwhelming feelings of guilt and burden felt from the removal of tamariki to whānau or the system made the road to recovery even more difficult.

Made to feel like they had abused their children as a result of damaging and discriminatory affidavits had one parent stating ‘f#&k if I read this [the affidavit], I wouldn’t give my child back either’.

Recovery was impeded by the provision of facilitated and supervised visits. Whānau that supported with visitation felt compromised and made to feel like they were an add on ‘watchdog’ for the system. Made to sign affidavits stating they would provide constant supervision, one whānau member commented ‘who am I to hold this power, to sit watch over her and baby, she’s her mama and a good one at that’.

Lawyers entrusted to work in the best interests of the child reinforced narratives that were stigmatising and damaging.

‘[the lawyer for child said]...the problem with mental health is you just never know when these things might happen again, so we have to make sure the child is safe’. - Whānau

Stigma is exacerbated by the media, and lack of understanding in the community. It is imperative that efforts are made to provide education and support to reduce stigma and discrimination, so we can live our lives unimpeded further by our experiences.

The workforce must be protected and enabled to engage in ways that are non-coercive and remove the need for compulsion

It is evident in the high rates of workforce burnout and understaffing due to high turnover that the system is in crisis. The burden of responsibility clinicians carry facilitates a risk averse culture where there is a tendency to look for scapegoats and place blame, and as a result we bear the consequences.

Many highly skilled and compassionate staff are equally failed. Feeling disillusioned, some transfer to other services or roles, or leave the sector altogether. Again we bear the consequences of their loss.

‘I have disagreed with psychiatrists and found they can have authoritarian and inflexible perspectives which prioritise their control over the consumer. In exerting their power, the consumers’ fundamental rights of freedom and legal capacity are denied. My concern for coercive practice elevated when a psychiatrist decided to continue the Mental Health Act by implementing an Indefinite Community Treatment Order (CTO) on a mentally stable consumer.’ Reflections of an ex-Duly Authorised Officer (Ngāti Ingarahi)

Several of us shared insights in to challenges we saw experienced by nursing staff, and cultural advisors when they attempted to advocate for approaches to facilitate holistic support and a more culturally safe approach. These were often ignored or disregarded by senior management.

'They just need to change, the people who are managing these things. Whoever is managing them now doesn't know what they are up to, cos they need to flush whatever...they need to address or have some sort of system to run some of these pockets of people who aren't really cutting any mustard into yanno....they say they're doing it, but they're not doing it. They're just showing face.' - Israel (Ngāti Porou, Ngāti Kahungungu)

We often felt the diminished mana and compromised wairua of nursing staff, and the restrictions placed on them that were in direct contrast to enabling them to engage in ways that prioritised Mana Motuhake and our personal agency in being 'the experts on ourselves'. Evidence supports the need for Māori nurses to have access to practices embedded in te ao Māori, to create a healing environment that supports the whole whānau⁷.

RECOMMENDATION 4: Seclusion must not be allowed for in new legislation.

Ongoing initiatives to eliminate seclusion need to be supported locally and regionally by independent external bodies that include Māori with lived experience. Leadership, monitoring and auditing of all incidents of restraint and seclusion must be led by Māori and include people who have 'lived' or 'living' experience of the Mental Health Act.

RECOMMENDATION 5: Appropriate protections for Māori in new legislation must allow for independent and external cultural support, so we can choose to connect with whānau, hapū and iwi to facilitate these processes.

Any form of compulsory treatment should only be used as a last resort.

The system will need to invest in the development of anti-stigma and discrimination programs designed to educate other government agencies and their representatives on mental health and awareness of the impact of the Mental Health Act.

RECOMMENDATION 6: Assessment of trauma history and cultural support needs , must be evident as necessary in new legislation. Protections must be incorporated to ensure culturally informed and trauma responsive approaches to enable the workforce to prioritise authentic engagement, and non-coercive practices.

The system will need to partner with Māori with lived experience to enable a paradigm shift and support the workforce to engage in practice and interventions that are less reliant on compulsion, coercion, and criteria, and instead promote and protect and rights of Māori and enable Tino Rangatiratanga.

⁷ Wharewera-Mika J, Cooper E, Wiki N, Field T, Haitana J, Toko M, et al. Strategies to reduce the use of seclusion with tangata whai i te ora (Maori mental health service users). International Journal of Mental Health Nursing. 2016:258-65.

Addressing specific population group needs

Whānau of choice must not be excluded from providing support and advocating alongside of us when decisions are made

'It's important I think to have those pillars of your whānau, your te whare tapa whā, to strengthen them. If one of them is short or not holding any weight your whole whare is not going to be able to stand under any pressure.. Israel (Ngāti Porou, Ngāti Kahungungu)

Many of us have experienced disconnection from our culture, through the damaging effect of colonisation and intergenerational trauma. Knowing who we are, and connection to our culture are vital for our healing, rather than detainment in environments that were foreign to what we innately felt and needed.

'They say they do things with programs and stuff, but really they don't address the underlying issues or speak to the person, or help that person to develop, or to be able to become aware of how they are within themselves and the conditions that they had or the problems that they had. They don't know how to get people to be as transparent and human as we can be as Māori, because we wear our hearts on our sleeves.

These c@#ts don't have hearts at all... yanno...there's not enough people you can relate to that can understand where you come from. They don't know your turangawaewae, they don't understand nothing but f#@ng degrees and dollars, and f#@ng pills and prescriptions.' - Israel (Ngāti Porou, Ngāti Kahungungu)

Where whānau had some understanding of the system, there was a magnitude of frustration expressed, as they felt equally powerless to support and felt unheard. The damage of poor process that exclude whānau impact on us significantly.

Figure 10 - Clinical note discharge review 30.09.2020 (Added post submission)

The assessment team took some hours before they could attend and seemed to form the view quite rapidly that Kerri needed to come to hospital, Kerri and her daughters presented the view that this decision seemed somewhat precipitous; it was experienced as shocking and to some extent traumatic.

Whānau are often blamed and it can take considerable time for healing and reconciliation. Collectively we feel the mamae

"We felt really concerned and hopeless when we saw our mate becoming unwell, and after talking with her whānau and employer, we decided to ask for a clinical intervention. When an intervention finally happened, we experienced a feeling of helplessness' Once under the MH Act she was separated from her support network. There was no collaboration or coordinated approach that included us, so we had to watch from the outside as the response became about coercion and containment and physically forcing a person into compliance.' Aroha (Ngāpuhi, Ngāti Whātua, Tainui, Ngāti Kurī, Ngāti Awa) and Brody (Ngāti Kahungungu)

Karakia and a quick round of introductions were often described as the services response to ‘ticking the Māori box’. The approach was seen as disingenuous, with a lack of value or respect shown to honouring tikanga Māori which compromised us, our whānau, and Māori clinicians employed in crisis teams and inpatient services.

Whānau experienced the processes as cold and clinical, and felt the inadequate response heightened the distress experienced by our whānau and us.

‘The clinical team came and sat around with poker faces, showing no concern when her daughter was crying while they were assessing the situation.’ Aroha (Ngāpuhi, Ngāti Whatua, Tainui, Ngāti Kurī, Ngāti Awa) and Brody (Ngāti Kahungunu)

Whānau described being ‘cut out of the loop’ or felt ‘used as bait’ to ensure compliance to treatment and decisions made by clinicians. They voiced frustration at repeated attempts to be involved, and shared experiences of the impact on their own wairua and mental wellbeing when they were refused.

‘We tried contacting her and were not allowed to speak to her and were not allowed visitations. Aroha tried several times to visit and was turned away. We were told she was only allowed 2 visitors a day.’ - Aroha (Ngāpuhi, Ngāti Whātua, Tainui, Ngāti Kurī, Ngāti Awa) and Brody (Ngāti Kahungunu)

A genuine commitment to honouring our processes with authentic engagement with us and our whānau that is grounded in Mātauranga Māori is needed to uphold our mana, and that of our whānau.

The power of recovery is in connection, identity, belonging, unconditional acceptance, working together, and wairuatanga – Whakamanawa 2018³

Authentic engagement with Māori with lived experience is integral to the transformation of the system

‘Why couldn’t more humane ideas have been thought of?’ What I needed was my own space, in my own home and to settle. Not to spend Christmas day in hospital with strangers’ - Maraea (Ngāti Porou, Te Whānau -a- Apanui, Ngāpuhi, Ngāti Pākehā)

Removed and separated from our whānau we often established our own kaupapa whānau and would spend time talking with one another about our lives on the outside, our māmā, our experiences, and our aspirations. Some of our fondest memories are of sitting together for karakia in the evening with Auntie C (Kaimahi Māori), playing the guitar where we would sing waiata and share kai together. It was during those times we felt safe, and life felt normal again.

‘[We need] A big hub that addresses that one issue, not little tiny things and little groups. Need one big one for all the different branches that you’re gonna have. For Māori... there needs to be one for Māori, because whatever they do, they don’t know what they’re doing. They can do their one, but let us do ours, because it was whānau that helped me get out of what I was in, how I was. They were the ones that helped me to see how I really am, to wake me up yanno...it’s a different approach....if it wasn’t for them, I’d still be lost - Israel (Ngāti Porou, Ngāti Kahungunu)

Several of us remained connected beyond our admissions, where we were able to talk about our experiences and the challenges we faced in the system. We felt compromised by the clinical paradigm that was forced upon us, fracturing our mauri (life essence), and challenging our wairua.

Figure 11 -Clinical note 22.10.2020

PLEASE NOTE THAT KERRI IS TRAUMATISED BEING IN HOSPITAL.
HER WAIRUA IS BEING CHALLENGED.

Our support for one another in our recovery journeys enabled us to develop resilience and to find the courage to challenge the diagnoses, the treatment and the system. We were able to talk about our experiences and emotions and strengthen our own meanings and understandings through te ao Māori.

We described our experiences as spiritual in nature and defined them as ‘traversing into the world of te ao wairua’.

‘So when it was my wairua and hinengaro were totally out of...like I’d get a f\$#%^g pill to fix the old mind but the wairua and everything else was up to me to sort of look at and try and fix, cos they don’t know what they are up to. They didn’t speak to it, they didn’t try and look at it like, or address it and try and acknowledge it. It was more of thing for some people than they realise, and they just see it as one thing and from what I’ve been learning its different and it makes more sense. Israel (Ngāti Porou, Ngāti Kahungungu)

Feeling failed by the system many of us discharged from the services within months of leaving inpatient settings.

‘You can’t have one box to put ‘em all in....and I don’t wanna be put in a box in the beginning. I’m a bit like Rūaumoko (Atua earthquakes), Ive got a bit of Rūaumoko in me, but yanno we all got all those different ariki and ātua and tupuna that speak to us aye..... and I think that they all have their role to play in a lot of people’s journeys, and it’s sorta becoming aware of where you have to go, what you have to do, holistically...find your direction or purpose what you really wanna do.’ - Israel (Ngāti Porou, Ngāti Kahungungu)

We chose instead to utilise networks and whānau connections to source the right support to facilitate healing and understanding including access to a Māori psychiatrist, kaupapa Māori programs in our communities, rongoā Māori, online te reo Māori classes and a Māori counsellor through university support services.

RECOMMENDATION 8: Legislation must enable protections for the workforce to work in ways that allow for shared risk and responsibility. Recognition of the value and expertise of kaimahi Māori must be evident in legislation.

The system will need to invest in workforce development to embed these practices, and foster leadership that encourages and promotes an environment of learning and being guided by lived expertise. Best practice approaches, and positive mentorship and preceptorship must be valued.

RECOMMENDATION 9: The legislation must promote lived expertise and remove any legislative statutes that enable substituted decision making.

The system will need to enable and resource a Māori lived experience workforce to be involved in crisis interventions, inpatient settings and in the community to walk alongside of us and our whānau to facilitate engagement grounded in te ao Māori enabling a tuakana-teina way of being.

RECOMMENDATION 10: Legislation must protect the rights of Māori and ensure spiritual and cultural safety with interventions that are trauma responsive, non-coercive, holistic, and healing.

The system must enable independent monitoring and auditing of use of the Act, inpatient settings, processes, and practices to ensure Māori are safe within the system, and that our mauri and wairua remain intact.

Protecting and monitoring people's rights

He Ara Oranga: The Mental Health Inquiry gives us a starting place for a vision of future legislation stating:

'..at a minimum, the legislation needs to reflect a human rights-based and recovery approach to care' – He Ara Oranga: The Mental Health Inquiry 2018⁸

This is supported by the discussion document 'Transforming our mental health law'⁹ which states that current legislation is 'Inconsistent with human rights law' with many people and organisations saying compulsory mental health treatment doesn't uphold people's rights, including:

- the rights of Māori as tāngata whenua contained in Te Tiriti o Waitangi and their Indigenous peoples' rights to self-determination regarding their health and wellbeing
- the universal rights of all people to autonomy (independence) and freedom from interference.

We must be protected from trauma and re-traumatisation

'No where do they assess the risk [from the treatment and practices] to us, to our whānau or our Māoritanga' – Wahine Māori

The failure to include known trauma history and necessary cultural support and interventions highlights the lack of protection for Māori in current legislation. A paradigm shift is needed so the Act moves from an instrument of forced compliance, to one that facilitates trauma responsive care and interventions and protects Māori from further injustices.

⁸ He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction

⁹ Ministry of Health. 2021. *Transforming our Mental Health Law: A public discussion document*. Wellington: Ministry of Health

I was secluded in their 'retreat' area on Manaaki tangata ward. It was a dark, cold and frightening. The wairua in there was really yuck, and I could feel the mamea in there. Then it I had a severe panic attack.. it felt quite surreal...I thought I was going to die. I couldn't breathe, and my head kind of exploded with all the memories and flashbacks from all the other times they secluded me. Especially when I was 6.5 months pregnant almost 18 years ago. It was barbaric... they wouldn't turn the water on, and the nurse sat there smirking, and ignoring me and playing on her phone on the other side of the locked door while I kept begging for water,. That experience was anything but manaaki'. Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā) (Added post submission)

Culturally safe and trauma responsive services can only be enabled with leadership that honours obligations to Te Tiriti o Waitangi, and a workforce who have a genuine commitment to protect and provide compassionate and humane treatment.

Legislation must have protections in place to ensure physical wellbeing is not compromised

The clinical approach we encountered was focussed solely on our minds and the need to 'find the right medication', so our physical wellbeing was often compromised by the harsh medication regimes forced upon us.

Complaints from medication side effects were dismissed, and other health issues that arose such as diabetes due to significant weight gain were ignored and seen as secondary to compliance with anti-psychotic medication.

Our concerns about the disabling side effects and the impact on our physical health were ignored.

'Listen to the complaints. I complained and no one listened. I got given a drug that I didn't even need to be given, and when I complained nothing happened, and now I'm f@#%king coping with something I didn't even have before [physical health condition].' - Israel (Ngāti Porou, Ngāti Kahungunu),

At times it felt like we were 'human guinea pigs', with constant changes to medications and the threat of intimidating security guards and injections if we didn't comply.

'I experienced hyponatremia [low sodium] twice with my levels dropping to 121, and 123 and was admitted to ED at one stage because of it. They didn't listen to how I was feeling, and had no clue that some of what they were seeing was not in the context of the diagnosis, it was because of the low sodium. So I was threatened with injections, and they kept upping the psych meds, so I ended up with concussion on top of it, because I was so over sedated I couldn't make it to bathroom in the night and stumbled out of bed and whacked my head'. Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākehā) [added post submission]

We need a system that is holistic and, facilitates a genuine commitment to enabling a workforce that is not 'solely focussed on managing symptoms and behaviours contextualised by diagnostic framing of mental distress', to one that understands that physical wellbeing is integral to our overall wellbeing.

*'...like I was taking quetiapine and....f@#^&*g what's the other one...lorazepam...not lorazepam..what they say, it wasn't what I was telling them...yanno, they need to encompass some sort of Māori focussed unit that would develop different policies that would facilitate a Māori direction or have one to govern them all.'* - Israel (Ngāti Porou, Ngāti Kahungungu)

We need to be able to function in our daily lives. All of us shared insights of the damaging effects physically, mentally and spiritually of high doses of medication that were used to chemically restrain us, contain us, and to manage and control our behaviour rather than for any therapeutic effect.

'...Especiallly the haloperidol. When I was getting that, I was getting like...numb feet and numb fingers. I was wondering 'what the f@%k was that!' and when I stopped....they weren't listening, I told them that f#@%king s#%t was making me malfunction and they just didn't listen to me. They didn't even acknowledge what I was saying. I like f##@king moaned about it aggressively and I was like look this is happening yanno...., what the f#@k?!. Do something about it, instead of just putting that thing in me, I'm sure that's the thing. You made me like this, cos I could hardly walk sometimes... bloody out of it'. What the f#@k's going on.' - Israel (Ngāti Porou, Ngāti Kahungungu)

Police must follow up on serious incidents and the legal system must uphold our rights as citizens

Interactions with police are often traumatising with details of these interventions recalled as 'three squad cars coming to my home, and they dragged me out', along with 'there were five of them and they handcuffed me even though I said I would go willingly'.

Many of us experienced gross negligence and mistreatment where a health response became instead a police response which further obstructed our rights as citizens. Many of us felt fearful to make complaints about some of the inhumane treatment we endured, as we didn't think we would 'be believed' or 'taken seriously'.

We were aware of the power clinicians held, and conscious that even if we complained clinical notes and documentation would be unlikely to reflect our experiences accurately. In many instances, whānau and other staff were fearful to speak up if they witnessed mistreatment for fear of further repercussions for us.

We all shared stories where staff had blatantly colluded in their retelling of events, and those of us privy to our clinical notes felt they were often manipulated to justify and 'cover up' abuse and mistreatment.

'Just don't lie about what you want to say. I got mistreated all the way.' – Israel (Ngāti Porou, Ngāti Kahungungu)

Many of us experienced mistreatment, enduring flash backs, nightmares, and trauma from abusive practices including restraint and seclusion from our inpatient stays. Despite our ability to clearly articulate what happened, nothing was done, 'we were simply ignored again'

‘..I was on the phone to the police for 45 minutes telling them how unsafe I was in there. I knew with the staff on that night that they had it in for me because I had complained, and so they rarked the situation up.....they refused to open the door to my room so I could have a shower so I could wash the hara [bad feelings] off...then one of the other whānau came out of his room, said I could use the tap in his room to splash water on me while he made a cup of tea....when I got out they started sectioning off that area of the ward and they grabbed me.....Two big six foot plus males...they yanked my arms up behind my back and when I dropped to the ground five of them dragged me down to the seclusion room.... They held me down while they ripped my shoes off, and then made me give them my apple in my pocket..... When they shut the door two of them hi-fived one another it was the most oppressive wairua I have ever felt in that room. I started panicking, and kept pushing the button to get some water out of the tap, but they had turned it off.....Survival mode kicked in, and I didn't know how long it would be before they gave me a drink so I ended up using the cup to drink out of the toilet. The next morning, I checked in with the whānau [who let me use his room] to see if he was ok. He was a big guy and I saw the look of guilt and fear on his face when he saw what they did. He said to me 'it was funny when you tried to run away from the, it wasn't funny when they grabbed you' - Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pākeha)

Figure 12 - Clinical note 29.10.2020

Kerri said she asked for 100 mg of quetiapine at 515 am. She said there was some confusion and she said she “made a dick of herself, as I do when people upset me”

She said she requested water for six hours (then changed this to two hours) and she drunk the water from the toilet bowl when the supply was shut off.

She said she saw [redacted] and another staff member high fiving and she interpreted this as “look, we got her”. Feeling persecuted by many of the nursing staff, but is happy that [redacted] is looking after her this morning.

We experienced multiple failings by other agencies and Government bodies, and an increased feeling of alienation from society.

Our attempts for retribution and resolution when the intervention is nothing less than assault were non-existent, and the system was seen as ‘untouchable’. Any attempts to involve the police when we were grossly mistreated or witnessed other whānau being mistreated were intercepted and ignored.

Figure 13 - Clinical note 27.12.2020

Additional note

Received p/c from Sergeant [redacted] of Otahuhu police station regarding multiple calls from Kerri regarding complaint of being mistreated. Sergeant [redacted] informed writer that he will not consider complaints from Kerri, all complaints will be withdrawn.

Police need to take all complaints seriously. It is our right as citizens but more importantly it is our right as tangata whenua under Te Tiriti o Waitangi to the same protections as all other citizens of Aotearoa. These rights must be upheld to protect us from further abuse and mistreatment.

Our Human Rights and the Code of Rights must be upheld in legislation. Supported and substituted decision making should not be used with Māori

A Ministry of Health consultation in 2017 reviewed ‘how well the current Mental Health Act upholds human rights’ whereby it was found that the Act is based on a medical model of mental health, rather than a social model of disability¹⁰. The review also found that the Act doesn’t consider legal capacity (whether a person is able to make choices for themselves) and uses substituted decision-making (where people make decisions on behalf).

The code of rights offers little protection when we are subjected to the Mental Health Act, as our complaints go unheard. When we exercised our right to complain it resulted in a negative impact on our care where our clinical notes state we were ‘litigious’ and subsequently medication was increased to silence us.

‘It’s a lack of communication aye...really...holistically there was no communication, honesty, transparency.’ – Israel – (Ngāti Porou, Ngāti Kahungunu)

In theory, the only right that is removed when we are subjected to the Act is ‘Right 7 – The right to make an informed choice and give informed consent’. We do not believe the legislation should remove this right, allowing for decisions to be made on our behalf.

We have the right to be fully informed (Right 8), and at times these rights were overridden by clinical judgements excluding us and our whānau from important discussions about our care and treatment.

The outcomes from these discussions often resulted in care and treatment that exerted further control over our lives and impacted further on our wellbeing.

Figure 124- Response to complaint received 5.3.2021

Generally, a complex case review in Tiaho Mai is a meeting of professionals involved in the care of a tangata whaiora. It is a forum held with clinicians involved in the provision of care to tangata whaiora, and does not routinely involve the whaiora directly. You have raised your concern of not being involved in this forum in light of your experience; both lived and professional. While we acknowledge your wealth of experience in this area, as you were staying at Tiaho Mai in the capacity of a whaiora, we did not include you in this discussion.

Fortunately some of us were able to connect to good advocacy support through District Inspectors and legal representatives so we could halt or prevent the use of compulsory treatment orders. Others we were not so fortunate, and often found it hard to get hold of, or difficult to engage with district inspectors and health and disability advocates tasked with ‘holding the system accountable within the legislative framework’.

This resulted in the majority of us being discharged with compulsory treatment orders, and forced on to depot injections that resulted in physical health challenges, delayed recovery and impacted on our ability to ‘live a normal life again’.

¹⁰ <https://www.health.govt.nz/our-work/mental-health-and-addiction/mental-health-legislation/mental-health-compulsory-assessment-and-treatment-act-1992/mental-health-and-human-rights-assessment>

Complaints must be acted upon without bias or discrimination, and we must be well supported by independent external advocates who understand and know the system to support us to elevate our concerns

There are many times we described where our rights were breached and complaints went unheard, or practices were justified.

All of us made complaints through different mediums including internal DHB (District Health Boards) complaint processes, District Inspectors, Consumer and Whānau advisors and Health and Disability advocates. Several of us attempted to escalate complaints to the Health and Disability Commission, and the justice system.

The process for complaints to the Health and Disability Commission was found to be unhelpful and described as ‘clunky, prejudiced and unsupportive’. The length of time it took for any action and progress on our complaints further invalidated us and our experiences. Responses received to concerns raised were seen as favouring the services and once again we felt unheard and not acknowledged:

‘Unsatisfied with the delayed response from the DHB [the complaint was lodged in October 2020 and my response was received in March 2021] and the explanation of ‘I had delayed sending you out this response because I wanted to ensure that you were well enough to receive it, and I understand that you are now in a much better space’.... I escalated my complaint to the HDC [Health and Disability Commission], and four months after receiving my complaint letter they told me they had forwarded my letter to the DHB and had finally received a response and would be in touch. That was it.....when I asked for a copy [of the DHB response] I was told ‘We will be able to provide you with the copy of the response later on in the response. You will be able to provide any comments or feedback you wish to make’. Still waiting. Kerri (Ngāpuhi, Ngāti Porou, Ngāti Pakeha)

We need be supported to make complaints and be able to trust that the processes is timely and the investigating organisations are fair and unbiased.

RECOMMENDATION 11: Legislation must protect our rights as citizens and tangata whenua and cannot allow for clinical judgements to override the code of rights and the right to protection from abuse and mistreatment.

The system will need to be responsive to the needs of police to ensure they are supported to engage effectively with us when complaints are made about mistreatment and abuse, and we must be supported by cultural, and lived experience expertise to advocate alongside of us.

RECOMMENDATION 12: Legislation must provide protection for Māori to ensure risk to our physical health and wairuatanga is independently assessed before any treatment options are imposed upon us or recommended.

Mātauranga Māori is evidenced, and the system will need to resource and invest in approaches that support and enable the protection of our physical health and wairuatanga.

RECOMMENDATION 13: Legislation must allow for independent Māori lived experience and whānau advocates to support with upholding our rights and those of our whānau.

The system will need to establish an independent Māori body that is enabled to protect and advocate for Māori who are subjected to the Act. Investment is required to develop a Māori workforce that can provide education for us and our whānau about the legislation and our rights, and who are enabled to support us in our efforts to advocate for Tino Rangatiratanga and Mana Motuhake.

Next steps

An embargoed copy of our submission was sent to 85 people for initial feedback. We received 27 responses via emails, survey feedback and phone calls. We received feedback from people with lived and living experience of the Mental Health Act, whānau, academics, clinicians, peers, and sector and organisation leaders commending the courage and bravery of those who contributed to the submission, along with resounding support emphasising the need for change. Some of the feedback is quoted below:

Thank you for being our avenue of voice xox

Loved the raw message and the wero that was put out!!! Absolutely captured the breaking of spirit that we all have experienced!!!

For me the kōrero shared throughout has impressed on me even more now, the importance of listening to and being guided by lived experience

A very rich and raw submission – from the heart. Thank you for the privilege of being able to see it. Authentic change has got to occur

It's extremely powerful. The system has to change!

I hope this document is received, heard and treasured as it should. I could feel and hear each and every voice who has bravely shared their story

'These informed, realistic, and achievable recommendations speak to ensuring individual human rights, cultural safety, and humanism are threaded through practices. The recommendations highlight the need for the integration of cultural assessment and interventions to everyday practices, define authentic engagement with tāngata whaiora and whānau, and ensure non-maleficence (doing no harm) is actually achieved'

We simply have to get change!!

We received specific feedback for further hui and discussion around the elimination of seclusion. Whilst there was support for its elimination, particularly when supporting tāngata with a history of trauma, there was some concern expressed around the lack of an appropriate system response when other factors such as methamphetamine use and violence are involved.

We intend to collaborate with key stakeholders to wānanga this further, along with the other recommendations, and explore continued opportunities to advocate and support change.

A note from the Author:

'One of the greatest risks is the risk we remain silent'

Debra Lampshire – Conference in Auckland 2013

This was not an easy document to write, and only touches the surface of our experiences of the Act. It was at times for many of us hard to read and relive the events that had a significant impact on our lives.

I am eternally grateful to all the amazing people who were in my life before, during and after that period, as well as the whānau I was blessed to meet during that time who have played a significant role in my recovery. They held the hope and gave me the courage and strength to pick up the pieces of my life and start again.

I doubt I will ever fully recover from the trauma of my experiences and the impact the Act had on my life and that of my whānau in 2020/21. There were important family events that I was absent from that we will never get back as a whānau. It was by far the most difficult thing as a mum to not only feel like 'the cause' of all the trauma my girls experienced, but to not be there to protect them and support them. Instead they were my strength and my 'why' to not give up.

There has at times been a hesitancy to publish this, knowing that whilst there are many who support us, we may also be further scrutinised and judged by the system and society because of our experiences and the labels we were given.

Our voices were silenced too often in the use of the Act, and we know that many whānau are still being silenced, so we leant on one another and our whānau for the collective courage needed to share our submission publicly.

Ngā mihi

Kerri Butler

Director – Take Notice Limited

Amendments to the published submission

Where possible the submission has been left in its entirety, however minor changes have been made to the following:

- Updated figures for the use of seclusion with Māori in 2020
- Inclusion of the ingoā 'Pākarutia te Mokemoketanga'
- The inclusion of the tohu designed for the front cover
- Amendments to grammatical errors, and inclusion of some quotes and context that were inadvertently omitted when submitted
- Duplicated quotes have been removed
- Inclusion of the next steps and the note from the author