HE KAI I NGA RANGATIRA
HE KORERO O NGA WHĀNAU WHAIORA

TE RAU MATATINI

Comments from whaiora whanau following their reading of the report

> “What an amazing report, I was captured by it **and the information was relevant and real**”

> “Nice work. I just read it now and I’m sitting at **my desk crying. Really nice work**”

> “Let us hope that we can carry on this korero… **well done**”

> “This is excellent – thank you”

> “I enjoyed reading it and forwarding it onward **to others**”

> “Well done ... the report is absolutely beautiful **and on point... the vision is very precise and clear**”

> “Its great stuff, so thank you for putting the **report together and giving us this opportunity. I look forward to seeing what else we can do in this space**”

Content

ISBN: 00000000000000

This document is available on:
Web: www.matatini.co.nz
Email: Maria.Baker@matatini.co.nz

Baker, M (2015). He kai i nga Rangatira He korero o nga whānau whaiora.
Wellington: Te Rau Matatini Ltd

Acknowledgement

E nga reo, e nga mana, tena koutou katoa. He mihi whanui tenei ki a koutou nga whānau whaiora e awhi nei i tenei kaupapa. No reira, e rau Rangatira ma tena koutou, tena koutou, tena koutou katoa.

Special acknowledgements to Take Notice Ltd, and whānau whaiora who participated in the hui, and contributed the gems that are represented in this report.

Executive Summary

People with lived experience of mental health challenges and receiving mental health services attended a one day hui in Auckland to share their thoughts of being under the mental health act and of acute mental health care. The hui encouraged shared discussions with key reflections, aspirations and insights.

The core themes identified by the participants of being under the mental health act, included not understanding the compulsory assessment and treatment process, and experiencing the converse to mental health professional advice on what was going to occur under the act. Some viewed the act as a bargaining tool to get out of the mental health unit quicker, others viewed the act as providing a false sense of security for access to medication with significant implications to livelihoods after being in acute care, with examples of overt discrimination. Lastly, the struggle to being released from the mental health act.

The core themes identified of acute mental health unit care included the recognition that admissions to mental health units usually occurred under the mental health act, also that acute care was provided in locked up and fenced in properties. The determination and motivation of treatment provided in units was mental health professional led. That the demand on acute beds nationally is in crisis with issues concerning the lack of an acute model of care which is contributing to early discharges of people, their placement in other areas because they continue to need support. Two overwhelming issues for participants was the lack of choice for acute mental health care, and the processes conducted with seeking consumer input into the build of new units where there is little will to change to consumer and whānau centred processes.

Participants identified three solutions to improve the effectiveness of mental health services to Māori, these included more Māori strategies to overcome challenges, with better access to Māori cultural approaches, and meaningful activities and programmes to foster connections to being Māori. A stronger Māori consumer voice and a centralised data base system, with recommendations for further action.

Background

With an increasing number of New Zealanders using specialist mental health and addiction services, there are valid concerns in regard to the way services are provided to Māori, especially in relation to the use of the mental health act and delivery of acute mental health care.

The majority of New Zealanders receive mental health services in the community . Yet, people being assessed and treated against their will under the mental health act, seems somewhat in opposition to a developed countries model of health care in 2015.

Over 10,000 people in New Zealand came into contact with the mental health act in 2013, with over 6300 people in a given day being subject to compulsory assessment or treatment under the act. Males were more likely to be subject than females and Māori were almost three times more likely to be under the mental health act than non-Māori [2].

Of the 7000 people who spent time in an adult mental health unit in 2013, 768 were secluded, often more than once (on average 2.4 times). Males were more likely to be secluded (70%) than females (30%) [3], and Māori were 3.7 times more likely to be secluded in adult services than non Māori [4].

It is difficult to elicit the exact reasons why mental health services are so restrictive in its delivery to Māori. It is obvious though that the significant trends in the increasing use of the mental health act seems to be occurring in communities with high Māori youthful populations. As mental health services main foci is in community based care, Māori are three times more likely to be treated under section 29 of the mental health act (community treatment order) than non-Māori.

Assumptions are made that it is hard to interpret what the range of issues are across regions if health and socio economic disparities exist across all communities. What is clear though, is there is little understanding of the effect services have on Māori and their whānau from their own perspectives [5] let alone a Rangahau Māori perspective.

A call to better understand why so many Māori are being treated under the mental health act was raised by Māori psychiatrists Dr Hinemoa Elder and Dr Rhys Tapsell. Their concern also emphasized the risk of bias in the diagnosis and treatment of Māori by a predominantly tauiwi workforce who seem to view Māori as a greater risk of danger, particularly to others than non Māori [6].

As a national Māori health workforce development organisation, Te Rau Matatini is concerned whānau ora for Māori is challenging to achieve if viewed in association with the high rates of Māori being placed under the mental health act, as well as the care provided by mental health services (with the high use of seclusion and restraint of Māori). To seek an understanding from Māori about these concerns Te Rau Matatini sought the expert opinion of Take Notice Ltd who coordinated and facilitated a hui for people with lived experiences in Auckland.

Purpose

The purpose of this report is to explain what people with lived experiences think of being under the compulsory assessment and treatment mental health act and receiving care from acute mental health units. A range of terms and quotes are utilised throughout the report to reflect what the participants said.

---

[1] Ministry of Health (2014). Office of the Director of Mental Health Annual Report 2013. Wellington: Ministry of Health. p5

[2] Ibid pp21-30

[3] p34

[4] p37

[5] Ministry of Health (2014). Office of the Director of Mental Health Annual Report 2013. Wellington: Ministry of Health.

[6] Elder, H., Tapsell, R. (2013) Māori and the Mental Health Act (chapter 14) pp. 249-267 in Dawson, J., & Gledhill, K. (Eds.). (2013). New Zealand's Mental Health Act in Practice. Wellington: Victoria University Press.

Method

Te Rau Matatini approached Take Notice Ltd for assistance to facilitate a hui with Māori to understand their experiences being under the mental health act and acute mental health care.

A panui was developed inviting people with lived experience to a hui, with a broad agenda. These were distributed amongst networks of consumers, mental health workforce development regional groups and placed on Te Rau Matatini face book page. The hui commenced with tikanga Māori supported by establishing a kaupapa and ground rules. Whitiwhiti whakaaro me nga korero was the method fostered to encourage people to korero in a safe environment

- *Panui of Hui was formulated and distributed amongst networks, placed on face book page prior to the Hui.*
- *Email and phone conversations occurred amongst interested parties about the hui.*
- *Hui: karakia, mihi whakatau, whānaungatanga, kaupapa (agenda), korerorero, karakia whakamutunga.*
- *Ground Rules established.*
- *Whitiwhiti whakaaro me korero.*

Participants

Ten people participated in the hui from Northland, Auckland and Christchurch also represented a range of whakapapa connections from Muriwhenua, Te Rarawa, Ngati Kahu, Ngapuhi nui tonu, Tainui, Kai Tahu and Tauiwi. Each person had personal experiences of overcoming challenge, with most having had experience being under the mental health act and having received care in an acute mental health unit during their lives.

Some had unique experiences in providing or being part of local and national consumer led groups, as well as positions such as consumer advisors or peer support workers, and contributing leadership qualities to emphasise a voice for other consumers, and the improvement of mental health services.

Finding Section

In amongst the vulnerabilities of each person's recovery stories are reflections and aspirations for things to change for people with lived experience.

Reflections

> *There is a need to ensure there is a safe and protected space, especially when people with lived experience want to share their experiences with others, and provide constructive lessons for others.*
>
> *Problems are big in changing the mental health system, and improving the experiences of tangata whaiora.*
>
> *We want action, and to see the information shared develops something that will make a difference.*

Aspirations

The aspirations of the participants included desires:

- *To make a difference to others*
- *To have a bigger voice as people with lived experiences*
- *To set the kaupapa and vision for Māori*
- *To foster a positive and constructive approach that is solution focused to benefit people with lived experiences*
- *Goals and Objectives that will benefit people with lived experiences*
- *To build capacity, capability and sustainability of people with lived experiences*
- *To campaign critical issues politically*
- *Increase involvement of whānau*
- *Improve participation with key agencies, health services and Marae*
- *Increase access to tangata whaiora focused programmes in the community (which include accredited certificates upon completion)*
- *Improve health outcomes of people with lived experiences.*

Insights

The insights regarding the situation for people and especially Māori with lived experience was well understood by these participants.

- *High populated Māori communities experience high rates of mental health act use.*
- *Rates of mental health act use especially section 29 (community treatment order) are increasing.*
- *There is little choice offered to people requiring support for mental health needs.*
- *The mental health act is utilised as a false sense of security so that people with lived experiences can get easier access to medication and treatment.*

Being under the Mental Health Act

The impact of being under the mental health act and its compulsory assessment and treatment process is not easily understood. In most situations, even with legal stipulation in the act to seek consent for treatment, mental health professionals dominate and determine the treatment options for tangata whaiora.

"When I was unwell and put under the mental health act, I was told I was under the act. I never read anything then it was later on when I was better did I go to read about it. Really, when you are unwell, you don't really understand what the act is about, and then of course you can't get off the act afterward"

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

Often initial thought of the acts involvement extended on what really happened in converse to the advice given by mental health professionals. It usually meant that longer periods of time were spent under the mental health act, which frustrated people especially when they were told it would be for a shorter period of time.

"My concern is when I was under the mental health act I was told that I would only do a certain period of time by psychiatrists, that did not occur, and I was under the act longer"

One view is that the mental health act can be viewed as a bargaining tool to get out of the acute mental health unit quicker to return home or to appease mental health professionals, so they will make decisions for people to get out of the unit.

"it's the get out of hospital card – I remember saying to Mum if I go under this act I can come home if I go under this section she said You don't want to do that, she said that means for 6 months they can do what they like with you, they can bring you in at any time, so it was Mum who explained it to me"

Other views considered the mental health act provided a false sense of security by guaranteeing access to medication, which was paid for by district health boards, but with little choice for any other treatment options, let alone support to enhance ones recovery.

"Being under the mental health act became my safety net"

"It's like a tick box – will you take your medication? As long as I put you under the mental health act, there is nothing else that matters! there is no other approach –Like are you able to take care of yourself ? And what sort of skills do you need? , so we can support you, nah none of that"

Although, being under the mental health act meant compulsory treatment it did not ensure the necessary requirements extended with a person to reside in a community after an acute mental health admission, or would it ensure they had access to the right resources and were able to cope.

"Where I live, we are all under the mental health service and my neighbour was clearly not ready to live there, but this key worker says he is, because he was shown how to take his medication and he wasn't ready for it"

"It's like being in the hospital, you are around others, and will look after each other, when you go out to a flat, and you don't have anyone you lose that connection"

What is not considered is the varying implications of being under the mental health act, mostly there are repercussions for people trying to do their best to live and survive in their communities. Yet, evidence suggests overt discrimination is apparent in the refusal of accommodation, employment and overzealous responses by police and security in regard to tangata whaiora, especially those under the mental act.

"It's very hard if you are under the act. As soon as someone in the community knows you are under the act, it is too hard to get a flat or a job because of all the red flags get raised"

"If you under the act, and you are a disagreement with the neighbour all of a sudden the Police come in".

"I am in a housing flat and X who checks my alarms, they won't let him into my house without two security guards. One will stay outside of the house and the other will come inside, then the guy will check the alarms. I said to him, oh you're like my only visitor, and he says oh they think I am going to get beaten up! It's hard, you know, I am having a conversation with the guy, and the security guard is looking around in my house".

There were common experiences of poor conduct by staff and in the engagement with government agencies such as Work and Income, and especially so in regard to getting access to adequate support in order to live well in their homes.

"At work and income there are security guards everywhere, one on the door, one inside. I brought an umbrella in with me it was raining and was told oh no you can't bring your umbrella into the office. It just feels like it's getting worse"
"In the WINZ office I was asked for my photo id by the security guard, then told I couldn't go in. In situations where I will go in to support someone else, you are still asked for your ID. "

The major dilemma is once a person is under the mental health act, it is a struggle to get out from under its hold. Reflections by participants suggest the aim of the act is to protect mental health services and not people with lived experiences.

"I spent a lot of time under the mental health act. It's very hard to get out from under the act, the door and the act follows you" It's like the mental health act is protecting mental health services or staff members, it's sure not protecting us"

Acute Mental Health Care

Participants identified the mental health act and acute mental health care usually went hand in hand. A concern was that once a person entered mental health services at the acute end of the continuum of care under the act it was too difficult for them to get out of the mental health system.

"mental health act and acute inpatient care is a big issue, most whaiora come through mental health services at the acute end, and then get absorbed into this big system"

"You're made to feel like it's the only option and I have to go with the flow, there are so many people, like if you are 3-4 years in the system, then you are institutionalised, and it is too hard to get you out of the system"

The delivery of acute mental health care is commonly and increasingly being provided in locked up and fenced in facilities with commissioned seclusion rooms. Although some units had Māori wharenui or whānau rooms, most were too difficult to get easy access to unless Māori staff were available on the unit, or in the wharenui to provide customary practices of whānaungatanga and manaakitanga.

"I went from one unit to another, it was one locked up unit with a high fence to another one with big fence"

"In a new unit, yes it has a seclusion unit, which staff said oh no we won't use it – I mean really. Anyway, it has had issues and so now the CEO is thinking about building a big fence around it"

"When I worked in the unit, you couldn't get access to the Marae, and there is nothing in the unit it looks ugly, there is nothing there, the wairua of the place is shocking, whereas the whare is beautiful, but to have a whare you have to have people in the whare all the time. You have to have people to welcome you"

In acute adult mental health units, there are real issues regarding who determines the best treatment for each person, even when there is evidence a treatment approach has either worked well or not in the past for the person.

"When I was in the inpatient unit I was pregnant, and the service wanted to give me olanzapine and not risperidone and they kept giving it to me, and I was getting higher. It wasn't until my last admission, did I refuse to take it".

The demand on acute mental health beds seems to be a national crisis especially in regions where there are limited acute beds and resources. Seen by people being discharged too early, with the likelihood of either utilising additional resources such as respite care to help in their acute recovery or being readmitted to the unit shortly following an admission.

"If the mental health services is letting a person leave the unit without being ready it is a problem if they are being readmitted, there must be a loop hole if people are being readmitted into hospital if they are still unwell from their recent admission"

"What the mental health unit is doing when a whole lot of unwell people are going in, they will take the best on the unit and shift them to another clinic area for space, like respite"

Being offered alternative choice to meet ones acute mental health needs or being offered any options other than going to an acute mental health unit was a novel consideration amongst the participants. *"Do people want their acute care provided in a hospital? Or do you think they want it in their home or community or Marae? "*

"I do not want acute care in an inpatient mental health unit! yet some people might, we need to explore the conversations about acute care that highlights there is a choice of care "

Lip service was viewed in action instead of genuine consumer involvement in the development and planning of mental health services especially in the planning of acute mental health units, where the status quo is being continued.

"It was not like ok, if there were resources – how would you like your acute care provided, it was like. We are going to build a new unit, what kind of paint, design would you like, what sort of programmes would you like? , so mental health services are saying hey this is what they want, but there was no option given to people to say what do you want for your acute care needs"

People with lived experience want more than just mental health units for their acute needs, Māori also want acute care options that enhance being Māori and do not lock them up, restrain or seclude them.

"All that is happening is let's build this unit, and that unit, let's build prisons, instead of thinking about preventing people from developing acute mental health issues"

"Imagine if acute mental health units were led by service users"

"The problem is many of the services are pakeha for Māori, and they have got in there. We have been challenging services who have 80 – 90% Māori, yet pakeha's have the biggest say, and we don't have mechanisms to keep us safe"

Māori Strategies to overcome system challenges

Experiences from these participants, and the stories of others known to this group state the mental health system is ineffective in meeting the needs of Māori. What is needed is a change in the way mental health professionals perceive Māori, and provide services to them.

"The mental health system does not work for Māori, look at the stats. They have to change their mind set, we can provide the most brilliant programmes in the system but it doesn't work"

Māori want better access to Māori cultural approaches in their treatment and recovery process such as Te reo Māori, access to whenua and matauranga Māori.

"We have Te reo, culture, whenua in rohe, beautiful things important to Māori, yet you have pakeha structures"

"I found my own way, to connect with my whenua, my maunga in my recovery, then they say oh are you taking your medication? And they say oh you should do this, and I say no I need my own piece of mind and place to be because what I do sitting on my maunga helps me"

Māori want purpose, activities and programmes that foster meaning and connection to their strengths as Māori, as well as aid in their recovery and achieving their aspirations.

"If you think about mahi and Te Ao Māori – occupational therapy – when we are on the Marae, we mahi, we know what we are doing, its therapeutic. If you see a group of people do a tangi with no money, if we know how to do things then how can we make this evident in other areas?"
"Whatever we do needs to influence isolated thinking and result in programmes, skills around every day living, and offers more choices, changes in the community".

A Stronger Māori Voice

There is not a national Māori consumer network alike the Like minds like mind network of the past. Nga Hau e Wha, and NAMHSCA are national consumer networks yet do not provide a focus for Māori. Participants are calling for a stronger voice for Māori consumers that is positive, solution focused, that will contribute to policy, legislation, health and social initiatives. Whilst including whānau, and agencies to foster better awareness, and to break down institutional thinking.

"The bigger voice will contribute to better outcomes for Māori with lived experience"

"For people with lived experience to have a voice, there needs to be a leader, preferably Māori who will support Māori with lived experience"

With little national opportunity for a Māori consumer voice, there are concerns there will be nothing learnt or to leverage from to help new people coming through mental health services with lived experiences to manage well.

"It's the new ones coming into the mental health system for the first time that don't know the ins and outs, so they are the vulnerable ones. If we don't help them or put in place people who can mentor them they are going to be overwhelmed. This is where suicide is a real threat, because they can't handle the system "
Consumers fought hard to have their voices heard, yet progress in the consumer movement seems to have been silenced. Concerns by these participants suggest New Zealand's mental health system and the traction achieved in the past by consumer leaders has slipped backward.

"I bet the Mary O'Hagan's and other leaders like Debra Lampshire would never have thought we would be fighting the battle they fought in the past and had won for us again"

The fight for people with lived experiences to be employed in key positions across mental health and addiction services inclusive of consumer advisor and peer support roles is also a concern. Specifically of positions inside district health boards, where colleagues freedom of speech and advocacy for consumers seems restricted and tainted by the employing services priorities.

"We fought for consumer advisors and peer support workers we thought we would have our own services and to hear that whaiora whānau are not doing the mahi that they were employed to do we so fought hard for, is not ok"

"Consumer advisors are between a rock and a hard place because they are in the DHB thinking they are making a difference, however I know in one area they are disliked because they are viewed as the face of the DHB. You are trying to cone us by sending in a consumer advisor, I do feel for them as they don't know if they're meant to be a tangata whaiora or a DHB agent the next day, but they need employment too. "

"Consumer advisors in DHB's have their own challenges and priorities, and work on the things they feel are important but I wouldn't say these things are not important"

At the same time, there are persistent issues in regard to how mental health staff treat their peers who have lived experiences with mental health and addiction services. Especially if the colleague has had intimate experience of receiving the service as a client that they are employed by.

These participants believe there is a different way to 'influence change' rather than complaining, being aggressive or taking a deficit perspective all of the time.

There is recognition that mental health staff, and the way they are trained influences their practice, so if they have been told to practice in a certain way, then that's all they will know. So one way to overcome this is to work beside mental health staff and to facilitate models of change to challenge their perspectives and to problem solve solutions collaboratively to benefit consumers.

"We worked with the people who administered what they did to us, so in a positive way, the exercise we completed, helped by getting them to work with us so that we could help them change their own culture"

'" you have to be collaborative, the system is there to stay, but we can influence it as a consumer and also from a kaupapa Māori perspective"

Centralised Data Base

Positive strategies, programmes and resources have been created and embedded by people with lived experiences whilst in consumer advisor or quality roles, yet these are not well known, nor shared amongst consumers or organisations. There is a call for a 'clearing house' where all consumer led programmes, resources are made available to others who are seeking solutions to challenges in mental health service delivery, and achievement of recovery from a consumer perspective.

"There is a need for mobilisation, a ripple effect where there is a connecting of all the people, in the consumer advisory type roles and those with common interests in being one voice".

" we should not have to reinvent the wheel, I was working on a project and there was another group who said Great, I like what you have developed, can I use it, so we were all on the same page, but we spent all our time alone doing reports and that. Sadly, a lot of good mahi by consumers, and a lot of work is never readily available to others. We had all the same perspectives, and to a point we were saying the same things in our individual reports but our collective approaches and solutions were never mobilised as a collective"

The purpose of a clearing house or a centralised data base would be to provide a place to gather evidential resources for consumers by consumers that could contribute to working models of care.

"So people do not have to fight all the time to get heard, I heard that we have all the same whakaaro, and we have probably sat in our roles as consumer advisors, and say similar things but no one listens to us"

"It's about information on experiences about how to change things, it should not be the onus of one organisational group because otherwise if it's a working model, and you have it yourself it could save lives in other regions"

This includes learning from the successes and challenges from people with lived experiences in New Zealand rather than engaging in models and theories from overseas which continue to be applied in health services.

"There will be lots of Māori who will be able to share how they turned around what they went through into a success story"

"For example, I have seen seclusion for Māori is a real issue, you might say can someone please give me all the information, all the research for Māori from a consumer point of view and to then mobilise it. Often consumer advisors who are sitting around the table with clinicians with just their voice. With this [data base] you can go here you can go there, you can have some documents behind you, to back your points of view, and strategies"

Conclusion

The opportunity to meet together was highlighted by the participants and the need to keep this discussion about Māori being under the mental health act, receiving acute mental health care, and the need for a stronger Māori consumer voice on the agenda.

It was evident from the discussions of varying concerns in relation to the utility of the mental health act with Māori , and the delivery of acute mental health services, with significant implications to a person's livelihood.

The participants suggested three solutions to contribute to effective mental health services to Māori, such as better access to Māori cultural approaches, and meaningful activities and programmes to foster connections to being Māori. A stronger Māori consumer voice and a centralised data base system.

A list of recommendations were also communicated by the group with the overall aim for strategic change in improving the experiences of Māori and people with lived experiences, and the care they receive.

Recommendations

- *Te Rau Matatini to support Māori with lived experiences to meet together to contribute to the workforce development required to improve service delivery of mental health care to Māori.*
- *Develop an action plan:*

  Scope for a centralised data base to hold Māori consumer informed information.

  Scope new resources to contribute evidence of the current experiences and successes of Māori with lived experiences.
- *Seek connections with key leaders to aid in the campaign for stronger Māori voice, and improved health services to Māori.*

Notes