MH-SMART EDUCATION AND TRAINING PROGRAMME KEY DOCUMENTS

#### **TUITUIA**

AUTHORS: MH-SMART OUTCOMES INITIATIVE TANGATA WHAIORA/ MOTUHAKE ROOPU



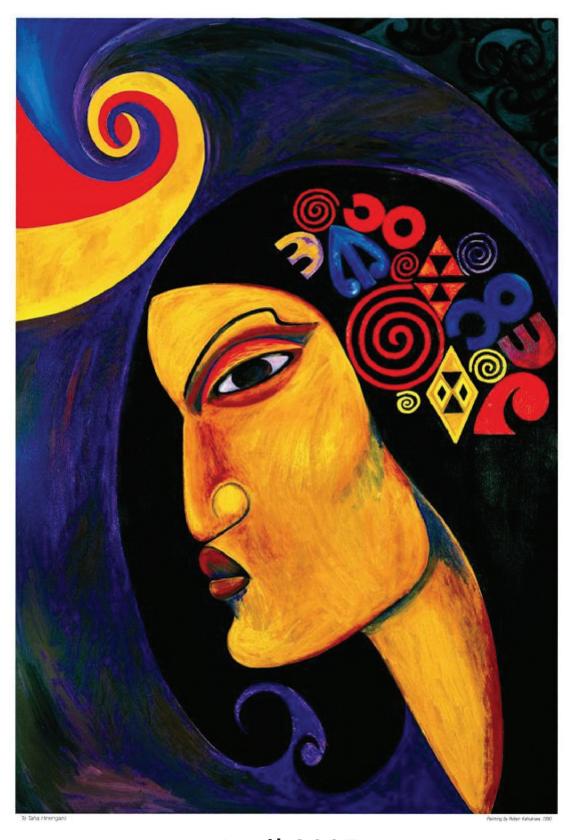








### Tuituia



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Cover Picture by Robyn Kahukiwa Part of a series Te Manawa Ora

Ko te kanohi a titiro taha ana, tae atu ki ngã tohu me ngã ãhua o te tikanga Mãori e noho mai rã i muri o te upoko, te ãhua o te ora e pã ana ki te hinengaro, arã, te Taha Hinengaro.

Te Taha Hinengaro, the mental aspect of health, is depicted as the profile face with symbols and shapes from tikanga Maori placed at the back of the head.

#### Acknowledgements

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#### **Tuituia**

The voices of tangata motuhake/whaiora create a taonga in this paper. The validity of the voices is in the experiences and courage of the roopu to share their experiences and wisdom; voices which in the past have not been provided with significant opportunities to be heard. Having said that, the paper is a representation of recovery from the perspective of those in this roopu. It is certainly is not intended to be representative of, or to represent the totality of tangata motuhake/whaiora experience. A one-size fits all approach is never useful. The authors ask that you remember this.

#### **Purpose**

The overall purpose of this paper is to provide perspectives on Maori world views of recovery. Its specific goal is to *inform, educate, guide* and *direct* the development and implementation of the MH-SMART initiative. It is primarily targeted at a mainstream audience. This paper explores core elements which are significant in tangata motuhake/whaiora pathways to wellness. These elements will not be exhaustive, but have been identified by our roopu as critical to consider.

It is expected that the issues raised in this paper will be considered across the total spectrum of activities MH-SMART is involved in and will provide a platform for how MH-SMART is progressed in relation to responsiveness to Maori. This paper asks all those involved in implementing the routine collection of outcome measures across mental health services, to consider how the core elements identified in this paper influence how outcome activities should be undertaken? For example, when examining the HoNOs we would ask you to be aware of its limitations when working with tangata motuhake/ whaiora and to encourage the use of Maori measures of outcome which align more closely with our needs. When considering other measures to be included in the suite, it is important to consider the extent to which the tools support or obstruct the core elements identified. At a broader level, of particular importance is to examine the extent to which the concept of Whanau Ora is supported or obstructed by MH-SMART activities.

#### Whanau Ora: Our korowai for recovery

Maori models of health have been discussed and accepted within mainstream health provision for many years now. From Te Whare Tapa Wha to Te Wheke and Nga Pou Mana, all have as their foundation the impacts of the wider social, economic, historic and cultural context within which we as Maori exist¹. Reflective of our own world views of health, the concept of Whanau Ora becomes our korowai for recovery. Recovery is not conceptualised as an individualistic process, focused solely on the attainment of individual autonomy. Whanau Ora is much broader than that and rests within a context of inclusiveness, collectiveness and interdependence. This context recognises that pathways to wellbeing need to be focused on building whanau capacity. This is about recognising the importance of whanau in processes of recovery, diversity of whanau, contributors to whanau breakdown, and the importance of rebuilding whanau. Whanau Ora is also about hapu ora and iwi ora.

With Whanau Ora as our korowai we are guided to the relationship between cultural identity and wellbeing. Being Maori is recognised as a foundation for

<sup>1</sup> Durie, M. (2001) Mauri Ora. Auckland: Oxford

health<sup>2</sup>. Cultural identity is necessary for wellbeing and pathways to wellbeing are about the reclaiming of cultural identity. Recognising that cultural identity exists on a continuum, along which we all occupy different spaces, this is about ensuring access to Te Ao Maori and to our culture which can support us in our cultural identity journeys and pathways. Ko wai? No whea? Naa wai? Knowing our connections and building and understanding relationships are the foundations of Whanau Ora and of recovery. Sadly for many, because of the effects of colonisation and urbanisation, this foundation is missing<sup>3</sup>.

Although the relationship between cultural identity and Whanau Ora is clear, Whanau Ora is an evolving concept, changing as our whanau change over time. Whanau Ora also recognises the differing realities for Maori who come into contact with mental health services. For some tangata motuhake/whaiora their cultural identity is strong, as are their other indicators of wellbeing, yet still they experience mental ill health. For some, interventions which lie within the context of the biomedical model assist in their journey towards Whanau Ora. For others this is not the case. The concept of Whanau Ora should not be used to classify us within rigid categories which can then be used to restrict our access to potentially beneficial interventions; interventions which may have a place in assisting us to wellbeing. However, nor do we want to have our only choices be biomedical interventions. We wish to have access to the range of interventions in their totality and to have the right to make informed choices about which of those we wish to use. Whanau Ora is about being able to recognise when we are unwell, and act on that through accessing a range of interventions and making informed choices.

What assists us to make informed choices are the relationships we have with those around us. As should be clear, recovery does not happen in isolation from the context within which we exist; it happens because of the relationships we have which support us in our pathways to wellbeing. In defining these relationships we are purposefully broad, not being confined to talking only about our close personal relationships, but critically also those we have with service providers, clinicians and whanau. The focus of all these relationships should be on creating pathways of wellbeing focused on Whanau Ora.

This paper does not define Whanau Ora in any detailed way. The way we have chosen to do this is to describe, both with diagrams and words, the elements which we believe comprise Whanau Ora and as such our pathways to wellness. These elements are presented descriptively, and with narrative. It is not a 'tick box' type approach. Instead we hope that amongst the narrative and the points made there will be issues with which you can identify and connect. By making this connection the concept of recovery will become more meaningful and real for you. By becoming meaningful it can have a real influence on the way in which you work.

<sup>2</sup> Durie, M. (2001) Mauri Ora. Auckland: Oxford

<sup>3</sup> Mental Health Commission. (2000) Four Maori Korero about their experience of mental illness. Wellington: MHC

## **Identity**

- Ko Au, Ko Whanau, Ko Hapu, Ko Iwi
  - Rongoa, Karakia, Mirimiri
    - Kuia, Koroua

## **Our Journey**

Self Determining Self Defining Diversity of approaches

#### **Daily Process**

- Freedom From:
   Imposition of the medical model
- Being regarded only as a set of symptoms

Opportunities to have a

healthy lifestyle

Physical Wellbeing

- Disrespect
- Exploitation
- Discrimination

Recognition from clinicians of

importance of listening and

Responsive Interventions:

Our perception of what we

need is valid

Isolation

## A Life Worth Living:

medication on our moemoea and wairua

Recognise negative impact of

responding

Recognise positive impact if our

medication is responsive to

Being able to take care of tamariki

Access to education

- Access to information
  - Access to choices
    - Access to advocacy
      - Access to kai
- Access to secure shelter
- Access to employment
- Access to income

### Whanau:

- Being accepted by whanau
  - Bridging, building and rebuilding relationships
- Providing whanau with real support

# Reclaiming Our Potential

## Identity

Ko lwi Ko hapu Ko whanau Ko au

## Whanau Ora

## Identity

## Responsive Interventions:

- Our perception of what we need is valid
- Recognition from clinicians of importance of listening and responding
- Recognise negative impact of medication on our moemoea and wairua
- Recognise positive impact if our medication is responsive to our needs

## Freedom From:

- Imposition of the medical model
  - Being regarded only as a set of symptoms
- Disrespect
- Exploitation
- Discrimination
  - Isolation

## Physical Wellbeing

 Opportunities to have a healthy lifestyle

## Whanau:

- Being accepted by whanau
- Bridging, building and rebuilding relationships
- Providing whanau with real support

## A Life Worth Living:

- Being able to take care of tamariki
- Access to education
- Access to informationAccess to choices
- Access to advocacy
- Access to kai
- Access to secure shelter
- Access to employment
- Access to income

#### **Reclaiming Our Potential**

- ~ Maori first, Maori last, Maori all the time
- Kaua e mataku, he Rangatira koe
- Don't be afraid in anything you do, you have the potential to achieve whatever you set out to achieve
- No bird soars too high if he soars with his own wings (William Blake)
- To reclaim your life back, self determining and defining.
- They conquer, who believe they can (Ralph Waldo Emerson)
- The treasuring of my own experiences
   He Taonga a gift, a blessing.
- Creating something positive from a negative experience

#### **Our Journey**

#### Acceptance, Reflection, Courage, Respect, True to Self, Humour, Hope

- ~ The starting point of all achievement is desire (Napoleon Hill)
- Acknowledgement and support by others and myself that the "journey" is small steps at first.
- Facing your own 'journey'. Forgive yourself, love yourself, so others may forgive and love in return.

#### **Daily Process**

- Acknowledgement of the daily changes of everyday life. It's a daily thing.
- Yesterday is the past, tomorrow is the future, today is the gift. That's why it is called the present. (Mahatma Ghandi)

#### **Diversity of Approaches**

• Acknowledge the diversity of approaches that assist the journey. Things are not always as they seem.

#### Self Determining

- Whaia te iti kahurangi ki te tuohu koe me he maunga teitei ki te aro ki te tuohu koe.
- Reach for the highest star that clothes the heaven, never yielding, not even to the highest mountain.
- The process can be challenging, requires tenacity.
- Taking a step into the unknown. If you can't see a light at the end of the tunnel, light a fire.
- Challenging misunderstanding Let us not judge until we have walked a mile in their jandals.
- Taking risks.
- Our aspirations are our possibilities (Robert Browning).
- You'll never know unless you try.
- Dealing with conflict. Pretending its not there doesn't make it go away.
- Acceptance Different strokes for different folks.
- Courage People strive for high ideals, life is full of heroism.
- Reflection Another day older, another day wiser.
- Respect Respect is earned, not given.
- True to self You are the face of your Tipuna.
- An ability to tolerate stress and challenge discrimination.
- Being healthy in all ways.
- Instilling, inspire and support hope. Where there is love, there is life.
- Humour. Common sense and a sense of humour are the same thing moving at different speeds. Humour is common sense dancing.
- Acknowledgement ... We must strive that each may call themselves the chief cause of the victory

#### Kia Oho, Kia Toa, Kia Mataara Responsive Interventions

- ~ Our perception of what we need is valid
- Recognition from clinicians of importance of listening and responding
- Recognise negative impact of medication on our moemoea and wairua
- Recognise positive impact if our medication is responsive to our needs
- Acknowledgement of the impact of medication ... promotes drug dependency and loss of enjoyment of life.
- Being off medication ... is like coming down from a bad trip.
- Positive effects if you are on the right meds is it a secret combination found by trial and error?
- Responsive to needs .... It is wise to look ahead but foolish to look further than you can see.
- Being able to recognise when we are unwell and have access to the range of interventions in their totality
- Interventions based on Maori models, focused on reinforcing identity

The meds I've been on include Largactil/Chloropromazine, Haldol, Epilim/Sodium Valproate, Lithium, Imovane, Thioridazine, Temazapan, Nozinan, and Cogentin.

The different effects I had from these meds - I couldn't laugh, I knew that things were amusing to me but it was like whatever triggers a person to laugh, that just went away and got lost somewhere. I felt about twenty years older than I was and I walked around really slowly like there was a ten ton bag on my shoulders all the time; it felt like I was in permanent slow motion; asleep with my eyes open and when I did sleep I did not dream, it was blank and black. My face and body twitched and when I talked it felt really hard to keep my mouth moving. My hands and arms just moved, were spasm all the time and it was embarrassing when you're with people making a cuppa and your hands are shaking, spilling the sugar, the milk.

It was uncomfortable to sit properly for days after I had injections.
I felt the cold more than usual and my limbs ached now and again.
I had a funny taste in my mouth for days after taking some meds and when I ate food it tasted like an antiseptic taste, like if you were to drink disinfectant.
Sometimes when I walked around I felt like I was a piece of cardboard, stiff and wooden.

Had a huge build up of saliva and every time I talked, I would spit. I dribbled a lot and couldn't stop it from coming out.

My hair started falling out.

The embarrassment of all this wasn't half as bad as the constant worry I had whether I'd get me back. The more meds, the less chance. The doctors never took me seriously and just told me that they were common side effects and that I needed side effect medication. They would often pull out their medical journals on side effects and when I tried to describe what it was if it wasn't in the journal then I must have been making it up.

Sometimes I would get an increase in meds, sometimes a decrease, sometimes side effect meds

#### Puarengia tou ngakau ki te Ao Marama Freedom From ...

- ~ Imposition of the medical model
- ~ Disrespect
- ~ Being regarded only as a set of symptoms
- ~ Exploitation
- ~ Discrimination
- ~ Isolation
- To not be humiliated and disrespected
- To not have single, culturally offensive approaches imposed
- To not be spoken about as set of symptoms
- Needing to ask for permission for the smallest things: it is so disempowering
- To not be racially discriminated against
- To not be exploited
- To not be isolated and discriminated against by others, systems and institutions
- Not for all my reactions to be read as symptoms
- Freedom to remain Maori when fighting for other causes e.g : Consumer movement, Maori Women's' Refuge etc
- Having the freedom to support these movements without having to justify who you are as Maori.

Freedom from not having to explain that my anger is anger,
Frustration is hoha
Sadness and tears are part of my nature

Freedom from not being treated like a set of symptoms
That I have natural feelings
And that my reactions and interactions are different in different situations or when different things are happening to me

Freedom is also about sometimes having to expose yourself to get acknowledged. You need to unfold your arms otherwise people can't embrace you.

#### Mau ano ka ora koe Physical Wellbeing ...

- ~ Opportunities to have a healthy lifestyle
- The first thing to get dropped; the last things to get picked up
- The opportunity to have a healthy lifestyle, to exercise and to be well
- Living a healthy lifestyle having all that you need to do that

The effects on the tinana are huge .... talking is difficult, thinking is difficult, keeping my ears and eyes open is difficult, just saying the word 'difficult' is difficult

I feel like a 100 yr s old

My limbs don't work

I am lethargic, sluggish and it's hard to get out of bed in the morning Exercising is difficult when I am feeling slow, lethargic, breathless and tired all the time

There is the breathlessness .... You lose Te Ha when you have too much medication .... It removes you from your being and is so hard to get back because it is a wairua thing ... but we need to find some way of getting it back

I want to eat well, to have the finances to buy healthy kai and to be satisfied

To be satisfied

#### Ma te whanau, ka ora ai, te hapu, iwi

- ~ Being accepted by whanau
- ~ Bridging, building and rebuilding relationships
- ~ Providing whanau with real support
- How you are treated by the whanau reflects on the whanau.
- Working out relationships with whanau.
- To not be isolated by whanau ... It is hard enough as it is.
- Acceptance by whanau ...
- Being able to build ... is a two way thing.
- Whanau and tamariki are as perennial as grass.
- Real support for whanau creates real support for us.
- Openness ... is as shameful as you make it. It may instil hope and guidance for others.

My whanau haven't known how to help me before. They have always loved me but didn't know what to do. But this time my whanau have been tops ... coming to see how I am, ringing up and inviting me over for breakfast or tea. It makes me teary eyed because I have never had that before. Getting to this point has been about coming to terms with each others different ways ... we are all so different.

We need to accept the way we are but this can bring sadness, shame, resentment, anger, hostility, avoidance, and embarrassment. There are the everyday things that the whanau needs to learn how to deal with ... we need to learn to be open and honest, accepting our differences.

The system is not kind to whanau and it takes its toll on them. Whanau are protective. They try to protect you but they don't know how and this can lead to resentment and frustration. We need to help them to understand and to tell them that's its okay to say they didn't know how to help ... that they were confused and frightened and didn't know how to protect ... letting them know this will help.

They are trying to be everything but they can't be and they are judged for not doing enough for me. We need real whanau support ... having a forum for the unknowingness and uncertainty whanau have ... having a forum where it is okay to say about not knowing what to do or who you were ... that they are frightened and unsure ... a forum where someone can hear their stories. Whanau are just expected to be forgiving and understanding but we can't expect them to know what to do and we need to help them in real ways.

It is whanau who can be the most healing and accepting. They show the power of love. After all the anger and pain they can still love you for who you are because you are one of their own and that pure love can only be found in whanau. It is softening and makes you feel a sense of belonging – that they belong to you and you belong to them.

#### A Life Worth Living

- ~ Access to a secure identity
- ~ Being able to take care of tamariki
- ~ Access to education
- ~ Access to information
- ~ Access to choices
- ~ Access to advocacy
- ~ Access to healthy kai
- ~ Access to secure shelter
- ~ Access to employment
- Access to education. Opens our eyes and offers opportunities to grow.
- Good information. Keeps everyone in the picture.
- Advocacy. Provides guidance and clarification. Promotes transparency.
- A 'life worth living' is a life well lived.
- Security.
- Having access to kai, shelter ... Food + Shelter + Water = Survival.
- A life beyond basic necessities
- Having income, ability to pay bills is good for self-esteem, allows us to grow and integrate well into community.
- Ability to feed and clothe your tamariki allows us to fulfil our role as rangatira.
- Employment-secure job is not a myth.

A life worth living is different for everyone. For me a life worth living is about being part of the community. It's about having the ability to pay your bills – rent, phone, power, having food in my cupboard, and a car. But a life worth living is also about the quality of your life – a quality of life which is satisfied and contented – having peace of mind, a good sleep, a nice breakfast, to be taken out for dinner sometimes. It's about having a sense of security that comes from having your finances accounted for but also about having a life beyond the basic necessities. Having the money for the small things like going to see a movie or to get a CD or a book is so important – to just be able to get little things for yourself. I am so lucky because I have my guitar. My guitar is my soul mate and friend. I can pick it up and it's healing - so sweet, healing, soothing, and beautiful.

A life worth living is being able to provide for my children - clothing, food, recreation, sports. It's about when my son rings me and asks me to do his washing I have the washing machine, the power to run it, and the petrol to go pick up his washing and to take it back to him. It's about being able to go out and help my whanau. It is about not feeling like I am a bad mother because I have not got enough money and am not providing enough for them when trying to keep my own head above water is hard enough ... accepting myself for what I can and can't do.

A life worth living is about having access to good information and the key to that is about how people communicate with you. They might give you information and it might be good information but they don't communicate it in a way that is understandable – you don't know what it means. I am a good communicator and if I don't understand I will ask because if I am confused so is everyone else. The information can be as basic as what time is kai and when are visiting hours. It can also be about how to access important services like WINZ and advocacy.

Interlinked and interdependent, Tino Rangatiratanga and Whanau Ora provide our korowai for recovery. Achieving Tino Rangatiratanga and Whanau Ora means treasuring and reclaiming our own potential: our *identity, our potential as Maori, whanau, hapu and iwi*. Recovery happens within this broader context. Recovery is about a journey of acceptance, reflection, courage, respect and being true to one self. Humour and hope are also important in that journey. The journey is a daily process which must be self determining and defining, filled with a diversity of approaches. Our journey consists of several stepping stones each of which interact and combine to form Tino Rangatiratanga and Whanau Ora.

Responsive interventions is a first step on our journey. Having Responsive Interventions means recognising that our perception of what we need is valid, the importance of having clinicians who listen and respond, and having access to the totality of interventions. These interventions include those based on Maori models – karakia, mirimiri, rongoa, tohunga, kuia, koroua - which reinforce our identity.

Freedom is another stepping stone. Freedom from having interventions imposed, being disrespected, isolated, exploited, discriminated against, and being regarded only as a set of symptoms is part of our journey.

*Physical Wellbeing* is another step in our journey. Often the first aspect of our life to be disregarded, and the last to be picked up, the opportunity to have a *healthy lifestyle*, to *exercise* and be *well* is critical.

Whanau who support and accept us take us further on our journey. Rebuilding whanau relationships, being accepted by whanau and providing whanau with real support are important.

These steps lead us to having a *life worth living;* back to our korowai for recovery - *Tino Rangatiratanga* and *Whanau Ora*. A life worth living is about being able to take care of tamariki and having access to education, information, choices, advocacy, healthy kai, secure shelter, employment and income.

#### **Challenges for MH-SMART**

The Government is committed to fulfilling its obligations to Maori as a Treaty Partner (King 2000). The special relationship between the Crown and Tangata Whenua is ongoing. Within the context of the MH-SMART initiative it will be paramount to ensure that Maori, as Treaty Partner are considered at each stage and therefore reflected in actions that are taken. It is of prime importance to the success of this initiative. The framework for how this will occur at each and every stage of the initiative will be by: Maori Participation; Active Partnership and Protection and improvement of Maori Health Status.

The key objective of MH-SMART is to *support recovery* by promoting and facilitating the development of an outcomes-focused culture in the mental health sector. The principle means of achieving this will be by implementing a suite of standard tools or measures to measure changes in the health status of mental health service users. It is anticipated that such tools will assist consumers,

clinicians, service providers and funders to identify the possible contribution mental health services have made to the recovery journey. An outcomes focused mental health sector culture that supports recovery involves the processes of assessment, planning and provision of treatment and discharge planning to be consistent with this desired end.

The key strategies of the MH-SMART initiative have been broadly categorised as follows:

- a) Develop a management and support structure of the MH-SMART Outcomes Initiative
- b) Developing a framework for the implementation of routine standard measures of consumer outcome in mental health services
- c) Development of a Communication Strategy to actively engaged to educate, inform, discuss, take advice from and create a shared vision
- d) Development of an Education Plan for mental health staff which will strengthen assessment processes for direct care mental health staff and facilitate an outcomes culture in mental health services
- e) Development of the business rules or protocols for routine collection, extraction and use of outcomes data
- f) Development of system specifications and an interim mental health information system for routine collection and reporting of the standard measures
- g) The development of a National Outcomes Data set and the development of integrated mental health information system for the routine collection and reporting of the mental health information through the National Mental Health Information Plan
- h) Assist Regional Structures and/or DHBs to develop local plans for implementation of the Initiative through a process that will develop local capacity
- i) Developing a framework for the identification of the suite of standard measures of consumer outcomes in mental health services
- j) Plan and implement an evaluation of the Initiative

All strategies listed above, and the activities which descend from them, must genuinely ask the question – Are our actions supporting the goal of Tino Rangatiratanga and Whanau Ora? Does the way in which we are implementing this particular strategy ...

- support responsive interventions
- freedom from the imposition of interventions
- discrimination and isolation
- the importance of physical wellbeing
- the rebuilding and supporting of whanau relationships
- the elements which combine to form a life worth living

The potential of this initiative to support our recovery is much enhanced if mental health services understand our elements of recovery and how these interact to create our pathways to wellness. By understanding our pathways to wellness,

you will understand that recovery happens within a context much wider than the individual and has a goal broader than the individual, that of Tino Rangatiratanga and Whanau Ora. Understanding our elements of recovery means that those engaged in the implementation of MH-SMART can formulate questions to ensure their activities are recovery focused. Commitment to asking the questions above, seeking answers and acting on those answers will ensure MH-SMART achieves its ultimate objective of supporting our recovery.

This paper is to be viewed alongside the MH-SMART Implications for Service Users paper. It can be viewed alongside, but should not be seen as a subset of it. Our paper acknowledges the differences in perceptions which exist between service users and those who choose to define themselves as tangata motuhake/whaiora. Producing this paper hopefully emphasises the range and importance of those differences.

Acknowledgement is made of the voices of the MH-SMART Tangata Motuhake/ Whaiora Roopu who have shared their stories to create this paper. However, we also acknowledge that our stories are not ours alone to tell. For those who do not have the opportunity to share their stories, it is our wish that this paper be heard and in doing so contribute to all of our pathways to whanau ora.

Mahingia nga mahi I runga te tika Me te whakapono Ka puta mai te aroha.



The NATIONAL CENTRE of MENTAL HEALTH RESEARCH and WORKFORCE DEVELOPMENT