

# "This is the house of hope"

# **Peer Support Services Aotearoa**

Outcomes of value as identified by people who experience mental health and addiction problems and the ways in which Peer Support Services support these outcomes.

Full Report 2014



# Logo and Whakatauki



Toka Tū is the name chosen for this project and comes from the whakatauki:

### Ahakoa akina a tai, akina a hau, he toka tū toka ahuru tatou

Although the tides and winds may come crashing down upon us, like a rock we stand resilient and comfortable in the face of adversity.

The 'mango pare' part of the design represents the resilient rock or 'Toka Tū' while the koru on either side of the mango pare represents the tide and winds which crash upon the rock day in and day out.

The logo was designed by Henare Brooking, of Ngati Porou and Rongowhakaata descent. Henare was taught his skills by renowned master carver and tohunga ta moko Mark Kopua, which has enabled Henare to open his own ta moko business, Mokoira, in Lower Hutt.

 $\textbf{Toka}\,\textbf{T}\bar{\textbf{u}}$  - This is the house of hope



### **About Kites Trust**

Kites Trust strives for equal citizenship for people who experience distress. We seek out opportunities to ensure that people who experience mental health problems and/or addictions have equal opportunities to live, work and participate in the community.

As the name Kites denotes, the aim of our organisation is to try new ways of doing things and 'to make ideas fly".

Our belief is that consumer leadership is the key mechanism to achieve social inclusion. For the past three years we have placed emphasis on seeking and promoting innovative solutions and fit for purpose services that are useful to people during times of distress.



#### **Kites Trust**

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# **Peer Support is:**

Organised support based on shared experiences of emotional or psychological pain.

Based on a system of giving and receiving support.

Founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful.

The relationship is purposeful, nonjudgemental, strengths based and recovery focused.

Leads to hope and movement toward achieving goals and dreams.

Shery Mead



\*Despite their value peer services are not well known about or promoted and receive less than 2% of mental health and addiction spend.

# What Peers said about peer support:

"A highly valued and effective response to distress"

"Unique and different to mainstream approaches"

"Recovery in action"

"Supports the outcomes they seek"





### **ACKNOWLEDGEMENTS**

The focus group facilitators extend a heartfelt thanks to all those who supported and participated in the focus groups. Your willingness to share your experiences, thoughts and ideas was humbling and extremely valuable to this work.

We heard the value that you place on peer support and we hope that this research and any future work that flows from it will support your aspirations of increased availability of peer support for people who experience distress and addictions.

#### Kia Kaha.

Nei raa te mihi maioha ki a koutou ngaa hunga katoa ngaa hunga kua uru mai, kua tautoko mai hoki I a maatou nei roopu aroaro. Teenaa koutou mo to koutou kaha kit e whangai mai o koutou whakaaro, wheako hoki kaaore e kore ko eenei mea ngaa mea nunui.

Kua rongo maatou ki ngaa mea nui o teenei mahi te tautoko tangata whai ora, a, naa ngaa mahi maatou I mahia kee me ngaa mahi maatou e whakaarohia kit e tautoko, haapai raanei I o koutou tumanako e pa ana kit e pikinga waatea mo nga tangata whai ora e hia ana kit e tautoko tangata whai ora.

### **Participating Peer Support Services**

Balance Whanganui

Te Roopu Pookai Taaniwhaniwha now called Te Waka Whaiora- (Matahauriki Day Service)

Wellink Trust now Wellink Division of Richmond NZ- (Key We Way and Warmline)

Junction

Connect SR

Connect SR Mahi Marumaru

Jigsaw-Walsh Trust

Otago Mental Health Support Trust

Journeys to Wellbeing

Thanks to:

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Debbie Peterson and Fiona North for the literature review.

Kate McKegg and Debbie Goodwin expert evaluators.



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### **PREFACE**

In 2010, Kites Trust, with the support of Dr Sarah Gordon and Kate McKegg, was successful in receiving a Community Sector Research Grant from Lotteries Grants Board to research and evaluate the evidence-base for peer-support mental health services delivered by non-government organisations (NGOs) in Aotearoa.

The desire to pursue this work arose from wanting to ensure people who experience mental distress and or addictions have access to services and interventions which support their recovery. Peer Support has been emerging within mental health and addiction service provision, progressing from its grass roots, unfunded self-help origins.

Peer support services in Aotearoa New Zealand tend to be small and delivered by NGOs. Earlier investigations<sup>1</sup> had identified that the capacity and capability of smaller NGOs is limited when it comes to evaluation and research. Evidence is necessary to determine (in the first instance) if peer support services are supporting recovery; and secondly what particular characteristics of peer-support services are most effective

It was felt evidence could then be used to inform the future planning, delivery and funding of services in a manner which will ultimately maximise the overall effectiveness of services for mental health consumers.

### **EXECUTIVE SUMMARY**

This report presents the key findings of focus groups that were held with people who use NGO peer support services in Aotearoa New Zealand.

The information was gathered from May to October 2013 and is part of a larger project called Toka Tū.

The Toka Tū project commenced in 2011 and sought to answer the following questions;

- 1. What are the resources and procedures that will support peer support services to initiate and undertake ongoing evaluation; and
- 2. What outcomes are supported by peer support services?

This document presents the key findings of one of the activities undertaken to answer question two.

For the Toka Tū project, the leadership group, made up of leaders from participating organisations, drew heavily on Shery Mead's definition of peer support, and peer support was defined for the project as

"Organised support based on shared experience of emotional and/or psychological pain. Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. The peer relationship is purposeful, nonjudgemental, strengths based and recovery focused. The connections and trusting relationships that are formed lead to hope and movement toward achieving goals and dreams."

Over 100 people accessing support from participating mental health and addiction peer support services took part in 12 focus groups held in Auckland, Tauranga, Whanganui, Wellington and Dunedin.

Focus group participants were asked to share what outcomes they value and how the peer support service supported these outcomes.

The results indicate participants value outcomes that lead to a fulfilling and productive life. The outcomes most sought by participants were employment, positive meaningful relationships, a safe and secure place to live, emotional and physical well-being, self-belief and the ability to give back to the mental health and addiction sector in peer support roles. The desire to give back is largely due to the positive experiences they had in receiving peer support.

Peer Support is provided by people who have their own experience of mental distress and/ or addictions and are able to demonstrate recovery. This common experience and shared disclosure contributes to a level of understanding not experienced by people using other mental health and addiction services.

Participants reported the nature of the peer support relationship as crucial to their success in delivering support and in turn supporting the achievement of positive outcomes. They reported peer support workers understood them, did not judge them, and focused on their strengths and demonstrated respect and compassion.

<sup>&</sup>lt;sup>1</sup>As part of studies towards a Post Graduate Diploma in Social Sector Evaluation and Research, Massey University Marge Jackson (lead researcher of the Toka Tū project) undertook a small-scale study to gather preliminary information about the evaluation capacity and capability within the local mental health NGO sector. Unpublished. 2011.



The characteristics of the peer relationship and the demonstration of recovery lead to participants gaining self-belief, hope for the future and an enhanced desire to pursue their outcomes of value.

These ways of working alongside people who experience distress and or addictions are described as crucial to the success of people achieving valued outcomes. Specific programmes providing information, education and symptom management were seen as helpful and a useful way in which to overcome isolation. The diversity in the ways peer support is delivered reinforces the concept that peer support is a relationship based intervention.

In summary, participants highly value peer support services. The impact of peer support was described by many as life changing.

Given the value and positive outcomes of receiving peer support services, it is therefore recommended that peer support is evidenced against the principles of respect, shared responsibility, and mutual agreement of what is helpful, principles that underpin its practice.

It is also recommended that the uniqueness of peer support in terms of its delivery by people with experience of mental distress and/or addictions be protected. A significant risk to peer support is that its' uniqueness becomes eroded as mainstream services seek to incorporate aspects of it into their practice without understanding peer support principles and how it is different to mainstream/clinical services.

Despite peer support having such a positive impact on people's lives, people experiencing mental distress and or addiction know little about it. Many participants reported not finding out about peer support for some time, therefore people are missing out on a useful and helpful intervention. It is strongly recommended that the awareness of peer support is increased.

These findings inform a larger study that seeks to discover the resources and procedures necessary to support peer support services to initiate and undertake ongoing evaluation. The use of focus groups to engage with people who use peer support services was seen by participants as very valuable. Therefore it is recommended that focus groups become a legitimate means of evaluating peer support services.

"When they (the peer support workers) have acknowledged who they are, they walk beside you in all aspects of your life, not just in the mental and when someone does that, you don't just become a mental illness. You actually become a person. It's absolutely key toward recovery in my opinion, absolutely key"



### INTRODUCTION

Since 2011 and with the support of a Lotteries Community Sector Research Grant, Kites Trust has embarked on a project alongside ten non-government organisations (NGOs) peer support services from around New Zealand Aotearoa to answer the following questions;

- 1. What are the resources and procedures that will support peer support services to initiate and undertake ongoing evaluation; and
- 2. What outcomes are supported by peer support services?

In order to answer these questions a number of activities have been undertaken within the Toka Tū project, including trialling outcome measures within peer support services, identifying what constitutes 'good' peer support and developing an evaluative rubric for peer support services.

In order to answer question two of the research project, we first needed to understand what outcomes people using peer support services consider to be of value and secondly, to what extent consumers consider those outcomes are supported by peer support mental health/addiction services.

The findings in this report have arisen as part of the wider research project.

Research and evaluation is necessary to ensure peer support services continue to grow and develop as an effective response to people who are experiencing mental health and addiction problems.

Many peer-support services in Aotearoa New Zealand are delivered by small NGOs, with limited resource, which limits the capacity and capability to currently undertake research and evaluation.

### **Defining peer support**

Peer support occurs when people share common concerns and draw on their own experiences to offer emotional and practical support to help each other move forwards. Mead (2003) identified that peer support was about understanding another's situation empathetically through the shared experience of emotional and psychological pain, and referred to three key principles within her definition, "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (Mead, 2003, p. 1).

Peer Support Practice in Aotearoa New Zealand (Scott, Doughty, & Kahi, 2011) offered a slightly different definition, focussing on the outcomes for the peer, rather than the mutuality between peer and peer support worker, "Peer support is about building relationships that create a learning environment, in which the peer can reframe their experience, take risks, undertake challenges and direct their own life" (Scott et al., 2011, p. 21).

According to Davidson et al. (2006) peer support is based on the belief that people who have faced, endured, and overcome adversity can offer useful support, encouragement, hope, and perhaps mentorship to others facing similar situations.

For the Toka Tū project the leadership group, made up of leaders from participating organisations, drew heavily on Mead's definition and defined peer support as "Organised support based on shared experience of emotional and/or psychological pain. Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. The peer relationship is purposeful, non-judgemental, strengths

based and recovery focused. The connections and trusting relationships that are formed lead to hope and movement toward achieving goals and dreams."

#### What peer services do

There is significant variation in how peer support is offered. The most common forms are self-help support groups, such as 12 step fellowships where peers meet regularly to provide mutual support without the involvement of registered professionals. In recent decades there has been an increase in the types of peer run service provision to meet specific needs, especially in mental health. (O'Hagan, 2010).

For the Toka Tū project all the participating peer support services are contracted via District Health Boards to provide peer support. Some services are provided from within peer-run organisations whilst others are operating within mainstream organisations. They are all NGOs.

Peer support delivered in consumer or peer run services is less well reviewed in the literature than peer services delivered within traditional mental health services, although Peer Support Practice in Aotearoa New Zealand (Scott et al., 2011) provides an extensive summary of the role peer support plays within the recovery orientated services of the mental health sector of New Zealand, both as part of, or separate from, traditional services.

#### **Recognition of peer support**

Peer Support is a developing response for people who experience mental distress and/or addiction within New Zealand.

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Peer support is becoming increasingly identified in national policy documents such as *Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012-2017* (Ministry of Health. 2012). Despite this, in 2011 funding of peer support services accounted for less than 2% of the national mental health and addiction spend (Platform 2013).

### **Benefits of peer support**

There is also empirical evidence for the efficacy of peer support services used alongside more traditional services. For example, Jones et al. (2013) conducted focus groups of people involved with a Wellness Recovery Action Plan (WRAP) that had a strong peer support component. Participants found they valued the role of peer support and explicitly the non-hierarchical and empathic nature of their relationships with WRAP peer support workers. They felt a greater level of self-determination, often linked to the positive peer support and leadership, and greater awareness of triggers, warning signs and behaviour patterns, as well as medication use and the role of traditional providers.

Repper and Carter (2011) reviewed the literature on peer support in statutory mental health services between 1995 and 2010, excluding reports on consumer led services or other services that were not provided within the statutory mental health services. Their review included seven randomised control trials during the period presented, and a wider evidence base (including follow-up studies and naturalistic comparison studies) to "paint a more complete picture of the impact of employing peer support workers"(Repper & Carter, 2011, p. 395). Their review discovered that, at worst, peer support workers made no difference to the mental health outcomes of those they supported, and found evidence of a positive effect in six areas: re-admission rates; empowering, providing social support and improving social functioning of recipients of peer support; and improving empathy and acceptance, reducing stigma, and increasing hope for both recipients and peer support workers.

Lawn, Smith & Hunter (2008), found the use of peers to provide hospital avoidance and early discharge support reduced the hospital admissions and length of stay, while Sells et al., (2006, p. 1183) found that "during the early stages in treatment peer providers possess distinctive skills in communicating positive regard, understanding and acceptance to their clients, as well as a facility for increasing participation in needed treatment among the most disengaged".

Repper and Carter's (2011) review of randomised control trials found no significant difference reported in admission rates between people supported by peer workers and those not, suggesting that people in recovery are able to offer support that maintains admission rates at a comparable level to professionally trained staff. That review found that people assigned to peer support workers had longer periods of community tenure before their first psychiatric hospitalisation than those assigned to non-consumer community teams. Review of the wider evidence suggested peer support:

reduced admission rates and led to longer community tenure; reduced rehospitalisation: and reduced bed days when peers were employed to provide early discharge support.

Pickett et al (2012) found that compared to a control group, participants in a peer led education intervention experienced significant increases in overall empowerment, self-esteem, self-advocacy and assertiveness that they maintained over time. Repper and Carter (2011) also reported a raised empowerment score in several studies of peer support provided as a part of traditional services, including: an increased sense of independence and empowerment by both peer support worker and recipient, with increased stability in work, education and training; and patients gaining increased control of their symptoms/problems and becoming more involved in their treatment. Several studies also reported increased self-esteem and confidence.

Several of the studies reviewed by Repper and Carter (2011) discussed the positive impact of peer support on social isolation, identified as "one of the most significant challenges faced by people with mental health problems". Peer support was said to "create relationships and allow people to practice a new identity", with improved social functioning, where "consumers are exposed to different perspectives and successful role models who may share problem-solving and coping skills and thereby improve social functioning" (Repper & Carter, 2011, p. 396). Studies reported higher community integration, and that those who received peer support reported more friends and social support, and demonstrated improved social support, enhanced social skills and better social functioning.

A higher health related quality of life of people with serious mental illness, is associated with sites that offer peer support and peoples' increased understanding of their treatment (Bowersox, Lai, & Kilbourne, 2012).

Repper and Carter (2011) found that studies identified a sense of empathy and acceptance gained through the sharing peer relationship, and that consumers felt more understood because of the experiential knowledge provided by peer support workers.

Paulson et al. (1999) indicate that the focus of peer support is different to that of non-peers, with peers emphasising 'being with' the client, rather than 'doing' tasks. Both sets of providers (peers and non-peers) said peers had a better understanding of what the patient was going through. Another report demonstrated that people receiving services from peers felt more accepted, understood and liked (Sells et al., 2006).

A sense of hope is one of the essential benefits gained from peer support. Davidson et al. (2012) reported that peer providers may have higher expectations and place more demands on their clients, knowing it is possible to recover, but also that it takes hard work to do so "I know how hopeless you feel now, but I also know you can work towards a better life" (Davidson et al., 2012, p. 124)



### **METHODOLOGY**

We wanted to understand

- What outcomes do people using peer support services consider to be of value?
- To what extent do people consider these outcomes are being supported by peer support services?

To answer these questions we chose a qualitative approach using focus groups. Focus groups were considered the

appropriate methodology because the group interaction supported participants in making sense of the topic of outcomes and constructing meaning about them. This methodological and analytical approach is exploratory in nature, but permits the amplification of participants' voices.

Ethics approval was received in 2012 from the multi-regional ethics committee (MEC/12/01/004).

### **PROCEDURE**

To ensure procedures as outlined in the ethics application were followed and there was a uniform approach across the sites, training was held with members of the participating organisations. The purpose, recruitment and preparation of the focus groups were explained. A component of this training included organisations developing work plans to ensure all preparation aspects were covered.

#### Sampling

Based on organisational size it was determined that either one or two focus groups would be held at each locality organisation. This was a purposeful sample which served both the study design and aims, for the following reasons:

- 1. We sought people's experiences rather than relevance or incidence:
- 2. The sample size needed to be limited to ensure we could analyse it thoroughly and not be overwhelmed by the sample size; and
- 3. A sample of this size was likely to be sufficient to meet data saturation.

### Recruitment

Participating sites were asked to invite people, between 18 and 65 years old who were using the peer support service to participate in the focus groups. Recruitment techniques used included face to face meetings, poster advertising and mail outs. Posters were supplied in both English and Māori. An information sheet was provided (Appendix One) along with contact details for any questions or queries. This included an O800 phone number and e-mail address.

To manage over subscription to groups, recruitment sites were provided with guidelines of how to ensure a "representative" sample of participants took part. This included reflecting on the age, gender and ethnicity of people who use their service and the length of time they have used the service. Over subscription did not become an issue.

### **Group not held**

A focus group was planned with people who used a telephone peer support service however this did not occur due to the difficulty of recruiting participants. The telephone service prides itself on anonymity and no personal details are kept of people who use the service. The focus group was advertised through consumer networks and on posters located in mental health service meeting rooms, however no participants came forward.

#### Consent

Participants were provided with consent forms and demographic data collection forms alongside the information sheets prior to the focus group. At the commencement of each group, facilitators again explained the purpose of the focus group and answered any questions. All participants gave consent (Appendix Two).

#### **Facilitators**

In order to develop trust with participants each group was facilitated by two members of the project team, one of whom identified as a person with lived experience of mental distress. Eight of the ten groups included a Māori facilitator, as a significant number of people using the peer support services were Māori. These qualities were deemed important in order to develop the trust of the participants. Short biographies about the facilitators were made available prior to the focus groups being held. Participants were offered refreshments and participants were acknowledged through a process of Whakaaro (Appendix Three).

Groups averaged one and half hours in length and were held at venues and times that suited participants. A weekend group was held to capture those who had weekday commitments.



#### Semi structured interview

The focus groups were structured to elicit responses to two questions:

- 1. What outcomes do people value?
- 2. How does the peer support service support these outcomes?

To prompt conversation within the group about outcomes of value, participants were given a projection exercise where they were asked to try to picture themselves in five years and imagine what their life would be like. Many participants liked the person focused nature of the question and said they enjoyed the opportunity to think about the future. For some participants this was challenging, as their current focus was to maintain their wellbeing in the here and now and to focus on getting through each day.

#### **Data collection**

Each focus group was audio recorded and transcribed verbatim. Main points arising from the discussion were also recorded onto paper.

### **Analysis**

The transcribed results were then entered into NVivo (a qualitative analysis software programme) as written text. The data was analysed by the researchers using a thematic content analysis focusing on the participants' experiences. Patterns and themes were verified by three members of the research team by a process of consensus.

### **MAORI PARTICIPATION**

Support was sought from local Kaumatua of the participating services and a Kaupapa Māori peer support service was engaged in the Toka Tū project early on to ensure Māori participation. The involvement of this group has been highly valuable as it enabled Māori specific

material to be gathered which has enhanced the relevance and responsiveness of the findings. The focus group held with the Kaupapa Māori Service was facilitated by a fluent Te Reo Speaker and followed Māori tikanga such as Karakia to start and finish.

### REFLECTIONS FROM FOCUS GROUP FACILITATORS

Facilitators really enjoyed visiting services and meeting people, and reported feeling privileged and humbled as well as surprised by the level of emotion participants connected to peer support services, for example, "it saved my life..."

The interview format worked well however for some participants, thinking of their future was challenging. Others reported that they liked the opportunity to think ahead.

# **FINDINGS**

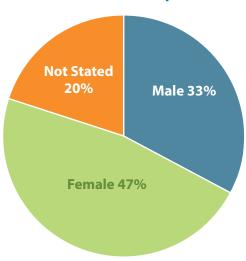




### **DEMOGRAPHICS**

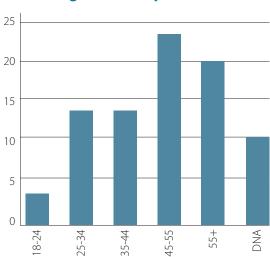
A total of 13 focus groups were held throughout New Zealand involving 102 participants from the 10 participating peer support services. The average number of participants in each group was seven. The smallest focus group had seven participants and the largest had 13.

### **Gender of Participants**



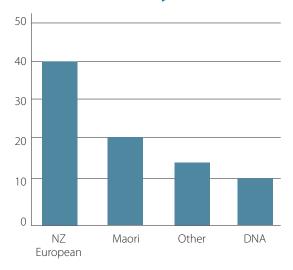
Of the participants, 33 were male, 47 were female and 20 people did not answer the question.

### **Age of Participants**

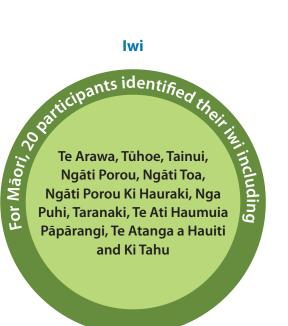


The majority of participants were aged over 45 years of age (43). 10 participants did not answer the question (DNA).

### **Ethnicity**



The majority of participants identified themselves as NZ European.





### **OUTCOMES OF VALUE**

Social acceptance The Month of the Month of

# Relationships Physical and emotional welllbeing

Safe and secure place to live **To Give Back** 

The key themes that emerged as outcomes of value to participants were employment, a safe and secure place to live, relationships, self-belief, independence, to give back, physical and emotional wellbeing and overcoming stigma. For some, interests and hobbies also rated highly.

These themes are explained in more detail below.

### **Employment**

Employment in this context is inclusive of voluntary and paid work.

Across all focus groups, participants identified gaining or retaining employment as a valued outcome. For some, employment was a way to be free of the benefit system and to be seen as a capable person as well as being financially secure. For others it was a means of reducing isolation and meeting people. A number of people identified a desire to give back to their mental health or addiction community. This was a way to use their life experience to support others. Working in peer support was a significant area of interest.

"I'd like to get my full licence and, get a full-time job"

"I mean we're working on starting a little business of my own. My peer support worker believes in me we're starting small, small steps and it might lead somewhere it might lead nowhere. But it might lead somewhere. And it's something I'm really interested in."

### Relationships

Relationships were identified across all focus groups as a valued outcome. For some maintaining current relationships with friends, family/ whanāu rated as significant whereas for others improving relationships that were strained or estranged was important. Many had aspirations for meaningful long-term relationships such as marriage and children. Some sought more meaningful relationships and company as well as connections to reduce feelings of isolation.

"It's really maintaining the personal relationships that I have at the moment you know, with my family and with my friends"

"My family is very much the centre of my existence and in my daily life"

"A sense of company, a sense of community is huge for me"

"It's being included, being included within the community that's outside of just mental health"

#### Self-belief

In all the groups self-belief rated as a valued outcome with the difference between self-acceptance and social acceptance being discussed. Participants spoke about the importance of self-acceptance in terms of self-confidence, independence, self-determination, hope and valuing themselves. Some people expressed the need to be assertive.

People described social acceptance as being free to express themselves and not hide who they truly are, to gain recognition for their achievements and to be treated with respect.

Educating the community, changing the narrative around mental illness, and society's views about the capability of people who experience mental distress were all factors that participants felt would contribute to social acceptance.

"The most important person in the world is me and that's who I value before anybody else and then the only way I can value somebody else is value myself"

"Being more assertive having more confidence and have a positive outlook or attitude, and keep on going on, and never give up"



"I'd like to be more independent. Stuff like that; be able to stand up for myself"

### A safe and secure place to live

A number of participants identified the need for safety, stability and security. For some this was moving from rental accommodation to owning their own home. Housing security was raised as a valued outcome in some groups.

"I'd like to have my own house, instead of renting all the time, and paying other people's mortgages"

"I really want a safe, stable place to live which is quiet and has a garden and is warm, and sunny and dry"

"I'd like to live in a place, where I feel at home. Like I don't have a sense of and I haven't had for a long time sense of being at home. And I really would like that"

"I would like to be in a safe place to live. A stable, safe place to live, where I can be long term"

### **Giving back**

A desire to give back to others was a strong recurring theme rating highly as a valued outcome. People talked about giving back in a range of different ways; either in a helping, teaching, advocacy or activist capacity. Working with Māori and working with youth were expressed by some participants as particular ways of giving back. Some were already giving back with one participant in a role educating teen mothers about alcohol, drugs and mental health. Others had ideas for the future such as working in peer support, establishing work programmes and delivering education in schools and mental health services to challenge stigma and discrimination.

Contributing to the wider community was another way of giving back that people discussed; some had specific dreams about what they wanted to do in the community, such as developing an eco-village community with shared resources, and setting up a place for mothers with experience of mental distress.

Being able to share knowledge, inspire others and overcome negativity were described as ways of giving back. People said helping others was a way to feel better within themselves and be more positive.

"I see myself working very successfully in a peer support environment"

"I imagine I'll be working in a helping capacity either with people with alcohol and other drugs and/or mental health issues 'cause I wanna be part of a solution and I want to use the skills that I have" "For me sometimes as bad as I can feel, it helps to have someone else that you can help"

"I've made myself like I said, determined to bypass all these obstacles, to break through them, and it can be done, you just need the right positive people, so I'd like to be one of those people to help"

### Physical and emotional wellbeing

Physical and emotional wellbeing was a valued outcome identified in all the focus groups. Desired outcomes in physical health were weight loss and fitness. People said having more stable moods and being able to relax were important to emotional wellbeing. Maintaining an alcohol and or drug free lifestyle was also valued along with not being dependent on prescription medications. People expressed a need to have less distress in their lives, to feel more resilient and to have a sense of control over their mental health and/or addiction problems. They wanted to gain new skills to overcome challenges and stay out of hospital.

"So maintaining what I've got is the challenge"

"I am aware of the fact that I better value my recovery over and above all else because without recovery like there's nothing"

"I like helping other people and it makes me mentally physically feel a whole lot happier in myself"

"Yeah it's positive and so, it would be quite nice to be off antidepressants and anti-anxiety medication; that would be awesome"

#### **Interests**

Not all the participants rated interests/and hobbies as important, but one service rated interests very highly. People wanted to travel internationally and locally, others wanted to follow creative pursuits such as art and crafts, singing, writing waiata, writing novels, and developing a garden. Other people said they wanted to do more physical activities such as tai chi and aerobics, and to take a family member fishing and diving.

"To be able to go on a holiday"

"I'd set up a permaculture garden at home which I'm just starting to develop"

"I can do, the designing of, Korowai"

"Well I write music for people, I actually give away song, waiata for various things so that's my big thing"



### HOW PEER SUPPORT SERVICES SUPPORT OUTCOMES OF VALUE

**Programmes and activities** 



### Supporting and facilitating connections and relationships

Peer support services provide opportunities for people to overcome isolation through socialising and connecting with others who understand what it is like to experience mental distress and/or addictions. People felt accepted and not judged by peer services which they said helped them overcome their own self-stigma about mental distress and/or addictions.

Participants spoke of how these relationships provide opportunities for talking about and overcoming problems, seeing other points of view and finding out about other supports and opportunities that may assist them. Many referred to the services as feeling like family and that meaningful friendships had developed through opportunities to meet other people. People felt cared about.

"Like if there's things that are troubling you and they can't help with but they can tell you other people that can help you"

"What I like about peer support is that it's not just about me either, they involve my family"

"Because you can't imagine the relief and the understanding and the wellness you get from talking to people with mental illnesses. So there's a group of us all go out like we went to the beach the other day and we just get to knock around together"

"So that's really good 'cause that's another place to go and healthy lifestyles, learn to cook, go to the gym, get with people, you know go and spend time with the residentials and things like that which is really good."

### **Give hope**

Many participants identified that the peer support services gave them hope. Recovery is role modelled as peer workers have their own experience of mental distress and/or addiction and demonstrate how they have worked through it.

Participants felt the peer workers truly understood what they were going through and by focusing on wellbeing, strengths and being positive, they provide a sense of hope for a better future. Participants felt they were truly valued as people

and that peer support workers believed in them, providing a sense of confidence and courage to try new things, to experience change and to evolve. They felt peer support workers accepted them during the more challenging times of their lives and offered support during these times as well as in good times.

"Dealing with stress is a big thing with me and since finding ------, it's really improved my standard of living, I'm more confident, I get out and about more"

"When I came here, what happened to me was I learnt that I can actually damn well do something, you're not an invalid, you're not useless ... you're one of us, I belong"

"Now what I was like five years ago, and what I'm like today is huge. And I couldn't have predicted it in a million years because I've evolved so much that I'm a totally different person. My coping strategies are better you know, it's endless"

"A big thing, which is everything to do with here and there, is actually hope"

"I feel really valued when I come here. I mean, people do encourage...but it's more practical than words, it's, people believe in me. And that gives me the courage, I get the courage from that to believe in myself"

"Yes having that hope, this is the house of hope"

"Yeah, can see they're doing well...they're doing well how they are. So you think, well I can do well. I believe it gives you a bit of hope as well, actually...that you're gonna get through it"

"I'm finally not afraid and I'm not, I'm not fearful, I'm relaxed, I'm happy I'm joyous but I'm not afraid"

"I can respect them, I can relate to them and all they do is you know, I can obviously see that whatever they're doing works so I just imitate them"

"I think the biggest thing is that ----- makes you see that there is a way forward, that you can go forward and they help you to see that and tell you how you can go about it and that's the brilliant thing"



### **Programmes and activities**

Peer support services offer a range of activities and programmes which were identified by participants as helpful. These include training, self-development, information, support, practical assistance, exercise and symptom management. Programmes and activities were often offered in groups as well as one to one. The range of activities included, peer employment training, gardening, outings and art. Sobriety parties were highlighted within the addiction Peer Support service. Advocacy rated highly.

Groups provided by the Peer Support services were identified as a way to make and maintain connections.

Support groups offered are loosely classified by diagnosis (anxiety, depression, addiction, bipolar) or practical learning and support (goal setting, problem solving, coping skills and healthy eating).

Many groups focus on leadership, by and for peers, through programmes such as Peerzone, Hearing Voices and Wellness and Recovery Action Planning (WRAP).

"My mosaics, they've helped with that. They've supported me doing my art"

"Before I came here, I used to have headphones on 24-7. But when I started coming to------ I've learnt other ways to deal with the audio that I have sometimes"

"If we're really, really upset about something.....like they might know that I love second-hand shopping, so they'll take me out in the car with others and all go second-hand shopping. And, I think that's really important, that we still. even though we're not well when we're there we still carry on our outside life"

"It ranges like, with my Peer Support worker, we celebrated my sobriety birthday"

"I'm just getting to know my Peer Support worker, and they're really good. It's like a working relationship, and they help you set goals"

"Because we're in this group, and because we have Peer Support we're actually actively searching for ways of dealing with that mental distress"



### **Cultural engagement**

A small number of participants referred to the cultural support provided within two of the Peer Support services. This included the Māori practices of karakia, manaakitangi, Te Reo and visits to the local Marae. For some this has the beginning of connecting with their culture.

"And that sense of being welcomed, you're kind of welcomed into the whanau"

"There's always karakia you know before we start and when we go for a feed and then when we finish, we'll close with karakia so it's very spiritual, you know for me it's a spiritual place"



### PRINCIPLES OF PEER SUPPORT SERVICES THAT SUPPORT OUTCOMES OF VALUE



Peer Support services are delivered in diverse ways with a no 'one size fits all approach'. Clear principles for guiding the way they work were identified by participants and included; mutuality, person focused, holistic, respectful, compassionate, supportive and reassuring.

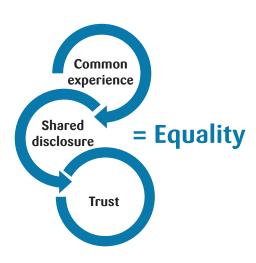
The findings from the focus groups support the concept that peer workers role model recovery. They provide hope. The shared mutual experience of mental distress/addiction is what participants stated they value. The personal experience of mental distress / addiction by the Peer Support workers is the knowledge base from which they work. Peer Support services provide a feeling of acceptance – everyone can have a life and people are not defined by mental distress / addiction.

### **Mutuality**

Mutuality is a key principle of Peer Support and incorporates reciprocity and a common shared perspective. This rated highly across all the focus groups with participants reporting that working relationships are based on a common understanding because the Peer Support workers "have been there". Through finding a common ground and shared disclosure, a high level of trust is developed, and people feel they can relate to each other which in turn reduce feelings of being alone and isolated.

This way of working results in feelings of equality as people feel they learn from each other, with both parties having something to offer. A number of participants expressed that this way of working made it easier to be honest and to find mutual agreement on what is helpful.

"Cause with Peer Support we're not clinical. We're all on the same journey, and we can help"



'There is, collective wisdom, like between all of us here, collectively we have an awful lot of wisdom"

"We really get on like a house on fire. And it's really quite an equal relationship for the two of us. And we talk about all sorts of things. Time just disappears like that, when I'm with her.."

"It's just good, you can be yourself, and talk about lots of different things, and yeah, challenge your own thinking and you hear a bit about them, rather than it just being one-way"

"We're on the same level as them"

"I think sharing their own stories makes you feel not quite so alone"

"Through sharing your experiences you gain perspective of your own self and of another person"

"They don't shut themselves away in the office... I think that's really important"



#### **Person focused and holistic**

Some participants reported holistic support as crucial to their recovery. Acknowledging the whole person in all aspects of their life and not focusing on illness and crisis was considered highly important. Participants reported they were treated as a person, not a problem, or a diagnosis. The peer responses felt personalised, individualised and strengths focused "You actually become a person".

Participants reported Peer Support services were flexible and responsive. They valued the importance of real choices, with the focus on wellbeing rather than ill-health and the opportunity to normalise their experience.

Practical approaches such as flexible locations to meet and knowing people's names are examples of how the services were seen to be person focused.

The use of humour was also valued.

"It's been a year-and-a-half, and he just feels like a mate"

"When they've acknowledged who they are, they walk with you in all the aspects of your life. You actually become a person. It's absolutely key towards recovery in my opinion, absolutely key"

#### **Respect and compassion**

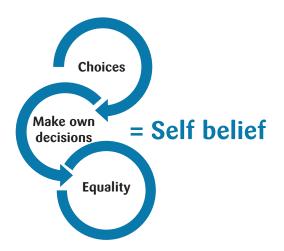
Participants reported relationships with the Peer Support workers as genuine, non-judgemental and respectful. Participants reported having choices and being encouraged to make their own decisions. Choices included who they worked with, and finding ways of working based on personal preference, for example texting, group or individual work.

"Each and every one of these people in this room, I could walk up to and say I need a hug, I live alone, I just need a hug, I need to be able to have the freedom to cry and not to be judged for it, so there's a lot of aroha here"

"Being with her and I just think it helps me accept myself and also there's an acceptance with the darker side of things that you just wanna shut off"

"Just being heard, you know you're always heard and understood"

"It's like they come from compassion, rather than...you know, a medical perspective"



Participants reported feeling supported and not pressured by their peer worker and felt their relationships were based on equality. People felt accepted for who they are (both positive and negative aspects of themselves) and were not seen as "a problem". A number of participants said they felt Peer Support workers genuinely cared about them and would willingly go the extra mile. Participants felt respected because Peer Support workers followed through with their commitments.

"These people they will never tell us what to do but they're there with it, willing helping hand of support, if you need it whether that looks like a text, an email, a hug, they're there to do that"

"He was there as a support and he wasn't gonna talk for me, he was there to explain anything that I needed and it just, it brought the anxiety right down, I was actually able to communicate with the guy in the office for the first time ever"

"They just let you guide your decisions, and then work with what you've decided on"

#### Supportive and reassuring

Participants reported feeling listened to, understood and encouraged by their Peer Support worker which led to feelings of trust, empowerment and confidence. Opportunities for problem solving rated highly and for many this came not only from the Peer Support workers but also other peers at the service. Problem solving was seen to be practical and helpful in focusing on what the person identified as important.

Participants said Peer Support services are accessible and inclusive with a wide range of responses to meet need.

"This is a close group. We come here...and you know we discuss, you know, our problems and then sit back and we listen and try to work things out. You've got a good support team here"





"And I have helped some people along the way. But I've had a lot of people help me, too"

"I think that the Peer Support worker really helped me accept myself and my situation"

"But it's easy to have a joke or just talk about music and movies, or but if you need to talk sort of about something deeper, then it's always easy to get to that place as well"

"And no matter what time of day or night, there's always somebody there."

"They really treat you as a person, and look at your life, and see what they can do to help you in your life...not... it's not just one size fits all"

"I'm starting to have some dreams now, I'm starting to really

think there's a lot of things I can do 'cause they bring the good out of me"

"We celebrate each other's successes and we're there for the failures"

"You're always connected to the network, you know it's like a lifetime connection with you"

"The sessions ultimately left up to you, which is good. It's not like you're forced, or pushed or whatever and they're just supporting you"

"They were excellent at supporting you for appointments and everything"

"I just felt accepted, like, understood, and I think Peer Support that's like a fantastic tool to like equip myself with resources. And then allow other people, being able to access or build up support with other people, who are looking for others in the group for mutual support is a fantastic idea"



# PEER SUPPORT IS UNIQUE. IT IS DIFFERENT FROM CLINICAL SERVICES

Overall, the nature of the Peer Support relationship, the approach used, the choices provided and the acceptance at where a person is at in their life was highlighted as being very valuable to peers. These were seen as points of difference to the way mainstream/clinical mental health and addiction services operate. Whilst not explicitly asked, participants volunteered their thoughts on the ways in which Peer Support services differ from mainstream/clinical services. The differences reported include:

### **Nature of the relationships**

Participants felt the Peer Support relationships were genuine and authentic with the relationship being the process of change. Participants described mainstream/ clinical services as being task focused with the goal to treat illness.

### **Approach**

Participants felt mainstream /clinical services were service focused rather than people focused and that the subjective lived experience within Peer Support services provided valid and valued expertise.

### Acceptance

Participants felt the Peer Support services accepted "where they are at" and whilst having expectations, they did not feel pressure to "improve" or feel judged.

Participants felt their confidence and self-belief had grown since receiving Peer Support. Examples of this included, going from a traumatic experience to achieving a tertiary qualification, moving from a place of shame and secrecy for having a mental illness (self-stigma) to becoming a consumer leader and finding a new fulfilling relationship and meaning in life instead of being prospected to join a gang.

### **Concern for peer support services and workers**

Participants expressed a high level of respect for the Peer Support workers with concern for the Peer Support services in terms of ongoing viability and the safety and well-being of the Peer Support staff. Participants were well aware of demanding workloads and organisational pressures.

### Peer services are not well promoted

People commented that they had heard about Peer Support services through word of mouth, or by chance, rather than as a well promoted option. A number of participants expressed frustration that they did not know about the Peer Support services earlier.

When they did access Peer Support services everyone commented on how valuable they were and some participants commented that in comparison to other interventions, Peer Support was the most useful form of support.

#### Focus groups are a useful process

Peers found the focus group process used in this research as helpful, with some participants expressing the value of having an opportunity to reflect about the future.

"It's not personal to them (clinical services). But by the whole setup I end up as someone who needs to be helped, because I am of need. I'm still a person of need when I have a Peer Support worker but somehow the balance has been changed where they were a person of need, too and they walk beside me rather than hold my hands"



### **SUMMARY**

Our findings show similarities between the benefits of Peer Support described in our focus groups and the benefits of Peer Support identified in the literature. Participants said Peer Support workers practice mutuality, work in a respectful and compassionate way and facilitate social connections and relationships. The shared experience of mental distress/addictions was highly valued.

People described services as non-judgemental and personfocused. People felt accepted and found hope through Peer Support; Peer Support workers role model recovery, believe in what each individual can accomplish and support them to achieve their goals without pressure.

Peer Support challenges self-stigma and supports recovery; people learn not to self-stigmatise and they go on journeys of self-discovery leading to change.

Our findings from the focus groups are very similar to the international literature on Peer Support, illustrating the value of Peer Support and providing evidence of its usefulness as a response.

In the literature Peer Support gave consumers the opportunity to understand different perspectives and gain support with coping.

The findings from the ū focus groups highlight the need for a commitment to funding Peer Support and ensuring its unique qualities are preserved. This commitment is outlined in the Mental Health and Addiction Service Development Plan 2012-2017 "fund the delivery of Peer Support services across a range of settings and ensure staff employed in these services are have access to recognised Peer Support training. They will take great care to ensure the essential features of the Peer Support role are preserved whenever it works alongside or within other mental health and addiction health and addiction services."

(Ministry of Health, 2012,.P.28)

### CONCLUSION

The purpose of this research was to identify which outcomes people using Peer Support services consider to be of value and secondly, to what extent consumers consider those outcomes are supported by Peer Support mental health services.

Valued outcomes include safety and security, relationships, health and well-being and being able to give back to the mental health and addiction sector by drawing on personal learning and experience. The strong driver for this is the value peers placed on the support and assistance received from Peer Support workers during challenges and times of distress.

The shared experience of mental distress and or addiction validates the Peer Support relationship and participants report genuine and trusting connections between peers and peer workers. This mutuality and shared learning contributes to self-acceptance and reduced feelings of isolation.

Peer workers role model recovery, providing a sense of hope, and peers learn to see themselves as capable, finding new ways to achieve aspirations and goals.

Participants articulated clearly the differences between the Peer Support relationship and the support received by clinical or mainstream services. Peer Support services are closely linked to their communities, flexible and able to tailor responses according to individual need. This uniqueness and ability to adapt appears to be critical to their success.

Despite the strong evidence of its value, the findings show that Peer Support is not particularly easy to access, and is not well known as an option. People find out about Peer Support by chance, or through word of mouth. Peers expressed concern for Peer Support services; both their ongoing viability and the well-being of the Peer Support workers. Furthermore, funding allocation for Peer Support is minimal in comparison to mainstream/clinical interventions.

The findings show that Peer Support is highly valued and has a significant impact on people's outcomes, not so much by what they do, but how they do it. The success of Peer Support as a valued intervention appears to be because the peer relationship operates according to principles of mutuality, respect and shared responsibility. Working to these principles makes Peer Support a unique and essential response to people with experience of mental distress/illness and addictions.

While the Peer Support services in this study are diverse and operate in a variety of ways, they all appear to be operating from these principles. As it is the principles of Peer Support which appear to make the difference to individuals, articulating these principles may be as important as developing evidence.



### RECOMMENDATIONS

### 1. Evidence based principles

Funding and purchasing of services rely on evidence based practice and Peer Support services are in the early phase of evidencing their effectiveness. Peers highly value the ways in which Peer Support workers practice the principles of Peer Support. These ways of working directly contribute to people's valued outcomes.

It is therefore recommended that Peer Support services seek to evidence themselves against principles of Peer Support rather than practice.

### 2. Raise Awareness of Peer Support

Peer Support is a highly valued intervention to people who experience mental distress and/ or addictions. Peer Support is not widely promoted to peers and it is not presented as an early option for recovery. Potentially people are missing out on a useful and helpful intervention.

It is recommended that awareness of Peer Support services be increased. This awareness raising would include defining what Peer Support is, defining the principles of Peer Support and clarifying the difference between Peer Support and mainstream /clinical services.

#### 3. **Qualitative Evaluation**

Peers reported focus groups were aligned with the principle of mutuality practised within Peer Support. People found participating in focus groups was a good way to express their opinions.

It is recommended that focus groups be considered as an effective way to evaluate Peer Support services.

### 4. Maintain the uniqueness of Peer Support

Peers highly value the uniqueness of Peer Support services and their delivery by people with lived experience. Peers clearly articulate the difference between Peer Support services and mainstream/clinical services.

It is recommended that Peer Support services stand alongside, but separate to, mainstream / clinical services to preserve the unique way in which Peer Support is delivered.

# INDIVIDUAL PEER SUPPORT SERVICE FINDINGS





### CONNECT SUPPORTING RECOVERY

Connect SR offers personalised Peer Support services to support people in their recovery in Auckland.



The two Peer Support services participating in this research were:

- 1. Adults who experience mental health problems
- 2. Adults who are working toward recovery from alcohol and other drug issues (Mahi Marumaru)

These findings are from the focus group held with people using the mental health Peer Support service.

#### **OUTCOMES OF VALUE**

#### Wellbeing

Wellbeing was a highly valued outcome and defined as better physical and mental health, meeting spiritual needs, emotional security, engaging in fulfilling activity, feeling safe, increasing resilience to low mood and knowing and recognising personal limits.

#### Home

Having a safe and secure home was rated as an important outcome.

### Relationships

Relationships rated highly as a valued outcome, including new friendships, maintaining relationships with friends and family and having more secure relationships with challenging family members.

### **Employment**

Employment rated as a valued outcome, including aspirations to work full time and set up a business.

#### THE WAY IN WHICH CONNECT SR SUPPORTS

#### Person focused

"I was a human being to her, not a client"

Participants said Peer Support workers at Connect SR relate to them on a personal level, normalise their experience and see them as a person and not a problem that needs help. This was considered crucial to supporting recovery.

"When they've acknowledged who they are, they walk beside you in all aspects of your life not just in the mental and when someone does that, you don't just become a mental illness. You actually become a person. It's absolutely key toward recovery in my opinion, absolutely key"

"One of the strongest things from Peer Support is their ability to normalise you as a person"

Participants felt Peer Support workers focused on their needs by supporting them to pursue interests, making practical suggestions to overcome problems, working on long term plans for employment and offering help through tough times.

Participants did not feel a sense of pressure from Peer Support workers and were able to do things at their own pace.

Being able to choose a Peer Support worker at Connect SR was affirming.

### **Equality and mutuality**

Participants described the relationship with peer workers as mutual, equal, balanced and without prejudice.



Peer Support workers disclosed and shared their own experience of and knowledge about distress which peers valued and appreciated.

The two-way nature of the support was valued. In the peer relationship, people were no longer the person who is always helped.

"They walk alongside me rather than hold my hands"

#### Supportive and reassuring

One person said their Peer Support worker really believed in them and genuinely liked them, which gave them confidence to take steps towards starting a new career. This new found confidence gave them courage to continue trying new things, even after their time with the Peer Support worker came to an end.

"There are so many things she's helped me to achieve, just by believing in me, and walking with me"

One participant described the relationship with their Peer Support worker as being their first trusted relationship which gave them confidence to develop friendships with others.

#### Respect and compassion

Peer Support workers were described as genuine and able to acknowledge distress by just being there, which took the emotional "weight" out of the experience.

Peer Support workers supported people to develop courage and confidence to make changes in their life and give them a sense of hope.

"I have things in my life now that I didn't have before I met her"

People felt accepted, not pressured and encouraged to take action to pursue their goals.

### WHAT CONNECT SR OFFERS

#### Programmes and activities

Connect SR works alongside people and includes activities within their programme such as playing music, going out for coffee, walking, shopping and go-karting. A range of groups are offered, including, Hearing Voices, art, and "Two Worlds" (for people who experience Bi-Polar), under 30s group and WRAP.

These activities and groups were seen by participants as a means to reduce isolation as well as creating opportunities to meet new people. Hearing different points of view encouraged people to challenge their thinking and develop new coping mechanisms. People found goal plans a useful way to plan for the future and reflect on progress. People appreciated that their Peer Support worker also completed their own recovery plan.

"I write down when I've done.....when I've gone for a walk and I can see how much I'm achieving in terms of health. And then I can see the dips and I can see the highs and the lows throughout the month you know, of what's been going on. That really helps me"

# How peer support is different to mainstream mental health services

The dynamic between the person and their peer worker was described as being different to clinical staff, in that conversations were more personal and led to better communication.

People described their relationship with Peer Support workers as being a two-way relationship because they shared personal aspects of their lives. This differed from the clinical relationship where people reported they can feel exposed and so are more guarded about what they shared.

"It's the bud of something very, very special that is better than anything's ever been before"

#### SUGGESTED AREAS FOR DEVELOPMENT

Participants suggested areas for development including:

- Additional practical support to find safe and secure housing and employment
- Flexible times for support
- Investigate supporting informal Peer Support e.g. coffee groups
- Outcome measures to be used by both Peer Support
  workers and peers to identify what they want to achieve
  in their work together e.g. chart achievements in a
  spreadsheet and give the peer a certificate at the end of
  their time.

### **Discussion**

The most valued outcome sought by participants in the focus group was gaining and maintaining physical, spiritual and emotional well-being. Peer workers are contributing to this outcome through the way in which they work, for example, focusing on the person and working to Peer Support principles of equality and mutuality. Normalising a person's experience was identified as being just as important to recovery as achieving goals.

The programmes and activities Connect SR offers contribute to people's well-being. The way in which Peer Support workers provides support gives people hope, so they gain confidence to move ahead in their lives.

A safe and secure home was valued by participants and this is an area Connect SR may want to consider exploring further.



### CONNECT SUPPORTING RECOVERY MAHI MARUMARU

# Connect SR offers personalised Peer Support services to support people in their recovery in Auckland.

The two Peer Support services participating in this research were:

- 1. Adults who experience mental health problems
- 2. Adults who are working toward recovery from alcohol and other drug issues (Mahi Marumaru).

These findings are from the focus group held with people at Mahi Marumaru

### **Outcomes of Value**

#### Give back

Inspiring others by sharing knowledge and personal experiences of recovery rated as the highest valued outcome by participants from Mahi Marumaru.

"Cause you know to keep what we've got, we've got to give it away"

#### Wellbeing

Participants expressed a strong desire to 'stay clean' – free from drugs and alcohol, particularly for their family's sake.

"I know I'm still going to be clean for my daughter"

The focus on living day to day positively without "mishaps" was valued. Many felt it was not always possible to look into the future. Living one day at a time is a philosophy underlying many alcohol and drug treatment programmes and whilst acknowledged as difficult, it rated highly as a valued outcome.

"I finally got a handle on it and you know, I'm sort of not looking to fix what is broken"

One person rated recovery to be important over and above anything else.

#### Self-belief

Participants spoke about the importance of valuing, accepting and cherishing yourself, in order to support family, friends and others in the community. For some, the experience with mental illness and addiction resulted in a sense of shame and something that needed to be hidden, however Peer Support was described as the reason for a change in their perspective.

"Having a voice and just knowing that your voice is gonna be heard by somebody and it counts, that are a lot of the thing, our networks, our steering group is to give the consumer a voice"

"I'm doing everything I can to inspire and share my story with others who've been in a situation like I was"

#### **Employment**

Employment rated highly.

#### Relationships

Developing trusting relationships rated highly, especially with family and children.

#### Home

A safe and happy home was a valued outcome.

# The way in which Mahi Marumaru supports Equality and mutuality

"They know exactly where you're coming from"

Participants found support from Peer Support workers and each other within their peer group to be extremely valuable. Participants said Peer Support brings people together, in an accepting, comfortable non-judgemental environment.

"You're not being judged and that is the greatest, one of the greatest things for me and that's why I love all these people, because they aren't judgmental, they do understand and they've been there a lot of the time"

Through mutual support, people are there for each other, gain ideas, learn skills learn from other people's mistakes, celebrate successes and support each other in their failures.

"Anyone in this room would be welcome to ring me up 24/7 and I'd be there like that, you know 'cause that's what it's all about"

Trust within the relationship between peer and Peer Support worker was seen as very important and participants reported valuing the ease in which workers could be changed if the relationship was not a good fit.

Opportunities to provide mutual support to their Peer Support workers were described as important.

"If you wanted to support your peer worker as well, it's giving you a meaning..."

#### **Person Focused**

Participants described Mahi Marumaru as person focused, for example, sobriety birthdays are celebrated, family members are included, appointments are flexible and Peer Support workers could come to people's homes or meet peers in the office.

### **Support & Reassurance**

"These are the people that pick me up"

People felt encouraged by Peer Support workers to pursue their interests and make their own decisions by supporting them to make realistic achievable goals.



"They get alongside me, not in front of me or behind me so they're not pushing me, they're not pulling me or anything, they're guiding me, helping me to become a better me"

People felt they had choices and variety in the way Peer Support was offered.

"These people they will never tell us what to do but they're there with it, willing helping hand of support, if you need it, whether that looks like a text, an email, a hug, they're there to do that"

#### Respect and compassion

Participants said they were able to be honest about their drug and alcohol issues because they are among people who are understanding and accepting,

I'd always tried to cover it up 'cause I was so ashamed of myself and not wanting to tell my family or my other friends that they didn't really know who I was"

Participants respected Peer Support workers because of their lived experience, and saw them as role models.

"I can respect them, I can relate to them and all they do is you know, I can see that whatever they're doing works so I just imitate them"

### **What Mahi Maramu offers**

#### **Programmes and activities**

In addition to one on one Peer Support Mahi Marumaru offers a range of groups including WRAP, Body and Soul, Men's Group, peer employment training, an annual camp (with a family day), Peer Zone, and training in cognitive behaviour therapy.

#### Support and facilitate connections

Participants reported feeling connected with each other, acknowledging strong bonds and friendships that had developed. This was attributed to their shared experience, which meant they supported each other, became less reliant on their Peer Support worker and became accountable to each other.

"It's like having your own family but this is the whangai (adopted) family you know"

"I think when we do go to our training and we're put into groups, we end up becoming friends you know and just by listening to each other's story that we share, we don't have to \_if \_\_ we don't connect but if we do have that connect, that's when our group gets wider and we tend to support each other instead of relying on our PSW all the time, we know there's somebody out there that's exactly like me, you know they're having the same experience"

### Provide hope

Participants reported that by attending the programme they had improved self-esteem, felt encouraged, were relaxed and no longer fearful.

"Starting to have some dreams now"

"Without the Peer Support I feel that I wouldn't be here today"

#### **Suggested areas for development**

Many participants reported that the service was discovered by chance and that Peer Support is not well known.

"I wish I had come across that sooner in my journey of recovery"

Participants expressed concern for the Peer Support workers and for the service being sustainable, citing burn out and lack of funding as the greatest risk to the service.

# How peer support is different to mainstream mental health services

A number of participants had tried a range of treatment interventions including rehab, detoxification and harm reduction plans, however they reported that they found Peer Support worked better and was more helpful than mainstream services.

"I mean, Peer Support has worked for me more than any psychologist, psychiatrist, groups..."

One example of difference outlined is that a mainstream clinician will diagnose through a bio-medical lens, whereas a Peer Support worker will talk about their own experience and coping strategies. Similarly, while a clinician would use a label to define the experience, a Peer Support worker would try and make sense of what was happening.

"it's like a medical professional, as you say they put a label on you, but if you go to your Peer Support worker and said I'm paranoid, they'll actually turn around and say well what does this mean for you, you know it's not, this is what paranoid means so that's obviously how you are..."

#### **Discussion**

Participants highly valued 'giving back'. As a result of the experience at Mahi Marumaru participants expressed a desire to work in Peer Support roles and some were already working in this field. People were also demonstrating "giving back" informally by supporting each other in groups. Strong connections and friendships had developed and through giving and receiving support. As a result, people felt less reliant on their peer worker and more accountable to each other.

Wellbeing and maintaining wellness was a highly valued outcome at Mahi Marumaru particularly the concept of living one day at a time. Providing hope for the future, in an accepting and non–judgemental way, contributes to this outcome being supported.



### MENTAL ILLNESS SURVIVORS TEAM (MIST)

Mental Illness Survivors Team (MIST) operates a drop-in centre for adults (18+) who have/had a mental illness and/or addiction in Whanganui.

#### **Outcomes of value**

#### Relationships

Relationships with whanau, family, especially partners and children were considered important by the majority of participants in the focus group. This included improving estranged relationships and becoming more considerate toward others.

#### Wellbeing

Weight loss, getting fit, personal growth, financial security and mental wellbeing were rated as valued outcomes. Being compassionate and helpful to others and maintaining spiritual beliefs were described as contributing to well-being.

#### **Employment**

Many of the participants were already in employment or working towards it and saw employment as a valued aspiration. A number of participants wanted to work in the mental health or addictions sector in the future.

#### Interests

Participants valued having interests including crafts, music (singing & writing).

#### Self-belief

A number of participants expressed the desire to be a better person in themselves as well as toward others.

### The way in which MIST supports

### **Equality and Mutuality**

People at MIST worked in a range of roles within the organisation such as Peer Support workers, management and administration, all of whom contributed to equality and mutuality. Participants felt everyone was like minded and this helped them stay grounded. MIST demonstrates equality by creating opportunities within the organisation, for example, being a committee member and contributing to a shared pot luck meal twice a week.

#### **Respect and Compassion**

Participants reported feeling accepted and that MIST was like a family. Due to past experiences of discrimination, not being judged by the organisation was important.

#### **What MIST offers**

### **Programmes and activities**

Some participants work at MIST, in roles such as treasurer, administrator and committee member. This experience leads



to learning and gaining skills from others. MIST collaborates with other organisations to offer courses such as WRAP and play volleyball. One participant said they found it helpful to talk to someone who was a peer.

### **Support and facilitate connections**

Participants reported MIST as an accepting place with a family feel. Participants were able to socialise and catch up with people at MIST and their families were included as well. MIST provided a place where families could meet.

Participants said MIST kept them on track, helped with problem solving and there was always someone available to help or direct people to another service that could assist.

#### **Provide Hope**

MIST was described as a positive place for to go. It kept people off the streets, stopped them from committing crimes such as stealing and gave them an alternative to joining gangs.

#### **Discussion**

At MIST, relationships were considered the most valued outcome for people. This included whanāu friends and partners, along with contributing and participating positively in the wider community.

Participants described MIST as a friendly and accepting place with a "family feel" where family /whānau was included, which would indicate people are being supported in sustaining their relationships. In addition, people found that MIST Peer Support workers were able to support and facilitate connections with other community organisations.

Peer workers treat people at MIST with respect and compassion, providing an environment where peers are accepted and not judged.

MIST is practising the Peer Support principles of equality and mutuality; many of the participants at focus group had specific roles within the organisation.



### JUNCTION PEER SUPPORT AND ADVOCACY

Junction is the amalgamation of Turning Point's drop in centre and the Consumer Action Network Trust services based in Tauranga. Junction offers one to one Peer Support, after hours phone support, purposeful events, support groups and peer group volunteer development.



#### **Outcomes of value**

### **Employment**

Participants reported employment (part-time, full-time work or volunteering) as a valued outcome. Aspirations for work included employment in a Peer Support environment. Employment was seen as the means to reduce dependence on the benefit system.

#### Relationships

Relationships rated as a valued outcome. This included developing and improving relationships with family/whānau as well as forming more relationships with people in the community.

### Physical and emotional wellbeing

Physical and emotional wellbeing was considered an important outcome by the participants and included natural health (homeopathy, iridology, massage). Finding enjoyment and being happy rated highly, as did the need to take action and some control over health.

### Self-belief

Participants expressed desire to feel more accepted by society, to "get rid of the labels" and feel free to be themselves.

### To give back

Participants reported that the support they received from peers at Junction created a desire to give back. Participants could see they could use their own experiences from their own journey to help others.

#### The way in which Junction supports

#### **Respect and Compassion**

Junction Peer Support workers were described as kind, respectful, dedicated and understanding. Junction was described as a safe and healthy place to come to where

people were not "bossed around" and had shared experience "There's nowhere else you get that."

Participants described Junction as a place to connect with others, to find friendships and be supported and not judged. Participants trusted in their peers and Peer Support workers.

"There's a lot of aroha here, just so much love and compassion, unbelievable, if you've got a problem you can bring it here and it will stay here"

#### **Equality and mutuality**

Mutuality is a key principle of Peer Support and incorporates reciprocity and a common shared perspective. Participants described their learning off each other as "collective wisdom", and said there was a lot of giving and sharing, which continued beyond the time spent at Junction.

Participants felt that Peer Support workers and peers genuinely cared about each other.

"It doesn't stop when you walk out that door...these people give a damn and you give a damn about them"

#### Supportive and reassuring

Participants described having a high degree of trust in Peer Support workers at Junction. The process of developing trust is reinforced through the support and reassurance Peer Support workers offer which leads to peers developing communication skills, self-confidence and the confidence to seek support from others.

#### **What Junction offers**

Junction was described as a supportive place where people can have discussions with others and learn strategies for coping. One participant described a poster that suggests taking things



one step at a time as an example of a coping strategy. They could see that peer workers role modelled taking one step at a time themselves.

#### "Suddenly I just went that's what these guys are doing..."

Such coping strategies were considered practical steps to take towards achieving goals.

Junction offers a range of groups and activities including anxiety and depression support groups, addiction support group, Peer Zone, walking groups, relaxation and art. They also provide resources and have an informal coffee and chat group once a fortnight.

### **Support and Facilitate Connections**

Participants said Junction was a place to connect with others who have a shared experience, to learn about different points of view, problem solve, find friendship and socialise in a relaxed and welcoming environment.

#### "It's peers, there's just nowhere else you get that"

The connections were seen to support improvements on a number of levels, for example, standard of living, selfconfidence, attitude, social contact and a feeling of being better able to relate to people.

### **Providing Hope**

Some participants described the extent to which Junction had impacted positively on their lives, it gave them hope, acceptance, self-confidence, education, and reduced self-stigma.

# How peer support is different to mainstream services

Participants acknowledged and valued the role of psychiatrists and psychologists however they placed more value on the relationship with Peer Support workers and peers.

"You can't put a price on it, it's really something that we absolutely need and it's top of the pinnacle... I mean God comes first in my life but Junction is second..."

### Suggested areas for development

An area of development suggested by participants was the opportunity to have less structured activities at times. Another suggestion was to develop a place like Junction for young people.

#### **Discussion**

Participants rated employment and relationships as their most valued outcomes. Junction is supporting these outcomes by providing hope which helps people develop confidence to take steps toward their goals. There was no clear focus on attaining employment, which may be an area to consider for development.

The way Junction's Peer Support workers work with people is a significant factor in contributing to the well-being of peers who use the service. Clear principles for guiding this way of working were identified by participants including; respect and compassion, equality and mutuality, being supportive and reassuring and taking a holistic approach. There was a sense of real friendship among the people at Junction, both among the peers and Peer Support workers. This indicates that the valued outcome of relationships is being realised.

Analysis identified that participants highly value Peer Support.

"One of the greatest things I'll reiterate again is that Junction has supported me in so many ways through Peer Support, you know, going to appointments, doctors and things like that and that has helped the emotional and the mental and it gives more happiness to the likes of my life"



### **BALANCE WHANGANUI**

Balance Whanganui is a peer run mental health charitable trust aiming to make a difference in the lives of those affected by mental health and addiction issues. They provide support group meetings and education such as Wellness Recovery Action Planning.

#### **Outcomes of value**

#### To Give Back

Participants expressed their desire to give back to peers and to provide Peer Support in some capacity. Some of the ways of doing so included teaching people in the community work skills, working with people who have alcohol and drug issues, teaching art and being employed at Balance Wanganui as a Peer Support worker.

#### Relationships

Participants expressed the importance of relationships such as finding a partner and/or getting married.

#### Wellbeing

Staying well was a valued outcome, for example staying out of hospital.

### Self-belief

Self-belief was a valued outcome. Participants talked about themselves as being capable and wanting to educate the community about the ways people who experience mental distress can contribute to the community.

#### Safe and Secure Home

Participants rated having a safe and secure home as a valued outcome.

#### The way in which Balance Whanganui supports

### **Supportive and Reassuring**

Participants described their fellow peers at Balance as an honest, close group, where people build friendships, solve problems, work things out, and help is reciprocal. One person said that at Balance, they were able to "bounce my ideas off other people."

Encouragement from peer workers was described as helpful as it enabled participants to follow through on goals such as lifting their mood. Participants felt understood because of their shared experience. Peer Support workers were described as easy to talk to and trustworthy.



"People like us.....we understand one another...'cause some of them might be going the same road as what we are"

#### **Respect and Compassion**

Some examples of the ways participants felt respected and valued at Balance Wanganui include not being judged, having trust, socialising with people "on the same level" and having choice.

"It was my decision to come to Balance..."

### What balance Whanganui offers

### **Programmes and Activities**

Balance Whanganui offers a wide range of activities including self-help and education courses such as support groups, mindfulness, WRAP and social activity such as film nights. Other groups focus on physical well-being such as swimming, tai chi, weight management programmes and going to the gym. Balance also has a consumer forum, intentional Peer Support training and produces a newsletter. Peer Support is offered either as one-on-one or in groups.

"Like before I came here, I used to have headphones on 24-7. But when I started coming to Balance, I've learnt other ways...to...deal with the audio that I have sometimes"

#### **Support and facilitate Connections**

Participants were very positive about Balance as an organisation and described it as an enjoyable place to socialise and talk to people. One participant described Balance as "one happy family".

Participants described how they had learned to ask for help and become independent. Being provided with the opportunity to help with a group gave people something else to think about other than personal issues. Making connections with others in the community and actively working on how to address stigma in the community and with people at Stanford House was described as helpful.



#### **Provide Hope**

Participants spoke of feeling valued, supported by others and that people believed in them which gave them the courage to believe in themselves.

# "A big thing, which is everything to do with here ... is actually hope" How peer support is different to mainstream mental health services

Participants reported they liked Balance Whanganui as it is non-clinical, they could give suggestions for improvements to the service and that the support they received was valuable, for example advocacy at WINZ, housing agencies or with clinicians. Participants felt on more of an equal level with their Peer Support workers than clinical staff.

"Yeah...it's not like when you go and see the doctor, and he asks you...ah, how was your week and everything else...he doesn't tell you about his week"

#### Person focused

Participants valued the way Balance Peer Support workers work with them on a one on one capacity, either informally, such as having a coffee and chat, or by giving practical advice. Other ways Balance Whanganui is person focused is by offering groups, for example a specific group to voice hearers

There was a real sense of pride in belonging to Balance Whanganui.

#### **Discussion**

Giving back to others who experience mental distress/ addiction is a highly valued outcome for the people who attend Balance Whanganui. Encouragement from Peer Support workers to follow through with their goals and to jointly problem solve indicates the "giving back" is already occurring on an informal level. Participants described Balance Whanganui as a space where they can discuss ways of "giving back" to their wider community.

Balance Whanganui is providing hope not only for individuals but also for the wider community as people explore ways in which they can educate others in the community about mental distress.

The wide range of programmes and activities offered on both an individual and group level appear to be providing a number of opportunities for learning and development.

Participants highly value Peer Support, to such an extent that people reported its impact on their lives as a revelation and life changing.

"It's ours. The people in it make it different"





### WELLINK DIVISION OF RICHMOND: KEY WE WAY

Key We Way is a peer-run recovery and crisis service that provides home-away-from-home support, helping people recover from mental distress. Located on the Kapiti Coast it provides Peer Support to people using Capital and Coast DHB mental health services. People using the service are described as guests.



#### **Outcomes of value**

#### Wellbeing

Participants rated maintaining wellness (mental and physical) as a valued outcome. Mental wellbeing for participants meant being medication free, relaxing, practicing mindfulness, thinking positively and having more stable moods. Physical wellbeing was described as keeping fit and active.

### **Employment**

Participants rated employment as a highly valued outcome. Some people wanted to return to the careers they had in the past, others wanted to set up business and some wanted to become Peer Support workers and give back.

### Relationships

Relationships (friends, family and romantic) were important to participants. Goals included having their children stay with them, meeting more people, and having another child.

Social inclusion was also considered important.

#### Give back

Giving back was a valued outcome and this was described by participants as wanting to work in peer roles in the future, using their experience to support others.

"For me sometimes as bad as I can feel, it helps to have someone that you can help, even in the worst of it, even if it's to make them smile or laugh"

Another way of giving back that was described was challenging unhelpful attitudes, for example, working with school age children to teach them about tolerance and difference.

"..the indifference we show towards other people, you know someone's got a disability or someone's slightly different, we just don't even acknowledge them, you know we just walk past them, you know that's isolating a lot of groups of people that you know, sort of isolating both yourself and you isolate other people when you do that"

#### Self-belief

Participants discussed the importance of acceptance, differentiating between social acceptance, where society and others do not discriminate and judge and self-acceptance, relating to personal happiness and making connections with others.

#### The way in which Key We Way supports

#### Respect and compassion

Participants described Peer Support workers at Key We Way as respectful and compassionate, understanding, warm, friendly, non-judgemental and sympathetic. People said Peer Support workers were reassuring and supportive without being overpowering, gave people space and supported guests to become more independent. Participants reported that they felt respected because they had the freedom to self-medicate, and sleep and eat at times that suited them. One person commented being at Key We Way made them feel like a person, not a patient.

People appreciated that Peer Support workers were willing to go the extra mile.

"I think it's more than a job for them.... a lot of them go beyond their means... and it's just great"

"It's being included, being included within the community that's outside of just mental health, so that you know...
So everybody has a place"



Participants described respect being mutual and a "two way street".

"The respect that they gave us when we were in the respite meant more than, it means the whole gamut of what you've written up there". (Referring to the notes taken during the focus group)

#### **Support & Reassurance**

Participants described Peer Support workers as offering support in varied ways; giving practical assistance, offering advice, problem solving, and supporting their families and children. People felt very welcomed at Key We Way, "you actually feel the warmth of the place" and described it as a "home away from home". At Key We Way, participants said there was always a Peer Support worker around and if someone returned at a later date, they were remembered.

"I think the best thing is if you've been back there again is that the ladies that work there, they know your name... and even if they don't, they're hello or come in, come into the kitchen, come into our house, this is, it's not only our work place, it's our home... that first interaction at the beginning is the most important sort of thing"

Participants described Peer Support workers at Key We Way as reassuring and offering hope, which extends beyond respite, with Key We Way supporting peers' future goals and giving people the incentive to pursue their dreams.

#### Person focused

Participants felt Peer Support workers at Key We Way were inclusive of family, friends and pets.

Participants described feeling understood and supported, especially with practical issues, with family and making new friendships. Relationships were focused on individual need and not a one size all fits all approach.

#### **Equality and mutuality**

Participants felt equal to the Peer Support workers, and this arose from having similar experiences and sharing their stories.

Sharing experiences gave people the opportunity to gain perspective and establish trust and respect. Being peer run was important.

"I think it is more important for us that it is peer run more than if it came out of somebody who was not, you'd know the experiences of going through what we've gone through because they can always sit back and say I know how you're feeling..."

Participants liked the way Peer Support workers interacted with them, such as eating meals together, helping with baking, watching TV and having conversations.

Mutuality meant support is a "two way thing". One participant spoke of how they offered to support a Key We Way Peer Support worker when they were having a difficult time, which was appreciated.

### **What Key We Way offers**

#### **Provide Hope**

Participants described Peer Support workers as positive role models; it was useful to know that Peer Support workers had been through similar experiences, but were now well, employed and happy. It gave people hope that they can do well also.

"Yeah, can see they're doing well. They're doing well how they are. So you think, well I can do well."

Peer Support workers give hope in a range of ways, including help with maintaining health, support to become more independent and giving positive feedback. Participants felt the peer workers truly believed in them which improved their self-esteem.

"Key We Way saved my life"

#### **Programmes and activities**

Some of the activities Peer Support workers engaged in with participants included baking, second-hand shopping, crafts, and fitness. Participants found it very helpful to have support to do things they enjoy and carry on with their "outside" life even while being unwell.

Participants appreciated Peer Support workers teaching them how to make short and long term goals, learn social skills and make new friendships. Key We Way was described as a stepping stone transition from the hospital to going back home.

#### Support and facilitate connections

Key We Way provides an opportunity to be with others experiencing similar distress, which counters feelings of isolation. This extended to the focus group in which participants suggested reconnecting in the future.

Key We Way was seen to support connections including opportunities to make new friends and sustain family relationships.

"I like it how they have meals with you as well, actually... and they actually make chit-chat over tea. And I'm thinking wow...you know, this is great! [Laughs] And they're talking about interesting things...like how they went overseas...and how they met all these people, and how they can speak different languages. It's bloody brilliant!"



#### Different to clinical

Participants described the Key We Way experience as different to services based on the medical model.

## "It's like they come from compassion, rather than...you know, a medical perspective."

People attributed this compassion to Peer Supporters understanding from their own experiences. This was seen in contrast with staff in the inpatient hospital facility who were seen to draw their experience from medical training. One person described feeling like "another number" on the ward and another person expressed they would prefer going to Key We Way than the ward. Other people remarked that it was good to have access to the food and not have knives locked away.

Participants liked the way Peer Support workers spoke to them, did not write notes about them immediately after a conversation or remove themselves away in an office.

# "I like the way they ask if you're alright, aye? Like "Are you okay?" Not... you got a problem?"

Participants preferred Key We Way over non peer-run facilities where they had felt bored. Being around other people who were unwell could contribute to people feeling worse.

Key We Way was described as being like a home.

"Home away from home"

"Like going in another home...where the other places are houses"

#### Suggested areas for improvement

Participants felt because of the popularity of Key We Way, it was hard to access it or stay longer than a few nights, which some felt was not long enough. Some commented they would like to see planned respite return, as it had really helped in the past.

Suggested improvements were for the Peer Support workers themselves, such as a wage increase and a cleaner.

#### **Discussion**

For focus group participants, maintaining their well-being was rated as the most highly valued outcome. Peer Support workers at Key We Way are providing hope, which is strongly connected to wellbeing. Given that Key We Way is a place where people can receive support in a crisis, providing hope is a key indicator that Key We Way is proving effective. Peer Support workers are described as positive role models who show that recovery happens and is achievable.

Participants also highly rated employment as a valued outcome. People spoke of Peer Support workers encouraging people with their future goals and assisting them in short and long term goal planning, all of which may contribute to achieving an employment outcome. While Key We Way is a place where people stay for a short period of time, and the focus may not necessarily be on gaining employment, employment did rate as a highly valued outcome, and may be an area for development.

Key We Way Peer Support workers are respectful, compassionate and reassuring. Key We Way aims to offer a home away from home environment and that they are working to that philosophy is evident in the feedback. Participants described Key We Way as a very warm and welcoming place to stay, that was supportive of families.

Key We Way Peer Support workers were described as an extended family.



## **JOURNEYS TO WELLBEING**

Formally known as 'Pathway's to Wellbeing', Journeys to Wellbeing operates Peer Support services in Palmerston North and Levin. The organisation believes in communities where people who have a lived experience of mental distress are valued and able to participate and contribute fully.

#### **Outcomes of value**

#### Wellbeing

Participants rated wellbeing as an important outcome and described what that meant for them in a variety of ways. For some it meant getting back to their old self, for others it meant being physically healthy, travelling, having good memories, or working in a job that made them happy. The importance of staying well was emphasised.

Participants spoke of the importance of having access to support quickly if needed.

#### **Employment**

The majority of participants valued employment. Goals for employment included nursing training, starting up a catering business or returning to a previous job. Others spoke of their desire for job security, job satisfaction or working in the voluntary sector.

#### **Interests**

Participants expressed an interest in travel.

Others talked about wanting to "find their niche" or to "get back on track".

#### Relationships

Relationships with their families and friends were valued as was a sense of belonging to the wider community.

"A sense of company, a sense of community is huge for me"

## Self-belief

Participants spoke of their desire to hold down a job, be confident and believe in their own capability.

## The way in which Journeys to Wellbeings supports

## Person focused

Participants spoke positively about the person focused way in which Peer Support workers work. Support was delivered in a personalised, individualised and flexible way. Participants reported feeling listened to and if Peer Support workers did not know something, they would find out. People reported that Peer Support workers focus on people's strengths.



"Which I'm not very good at doing myself"

#### **Equality and mutuality**

A number of participants spoke about the importance of lived experience and how it was important to receive support from people with similar experiences. Participants spoke of "being in the same boat" and "knowing we're not alone". Sharing food together was an example of equality and mutuality.

"I think we're really fortunate here that our support workers are quality, they're really quality people, they've got life experience, huge wisdom, being able to tap into that wisdom and life experience is awesome"

## **Respect and compassion**

Participants felt that they were respected and treated with compassion at Journeys to Wellbeing. People said they felt valued, not judged, heard and understood, and had developed trust. They spoke of the importance of one on one support and the sense of support.

"They've got your back"

## What Journeys to Wellbeing offers

#### **Programmes and activities**

Support is provided on a one-to-one basis and in groups. At an individual level, people said they were assisted with daily living such as shopping and paying bills, advocacy, pursuing hobbies or making individual plans.

Journeys to Wellbeing works to the Intentional Peer Support model. They offer activities such as WRAP, anxiety support group, anger management, role playing for job interviews, and social activities. They also provide information and collaborate with other organisations to offer a wider range of programmes.



#### Provide hope

"Knowing that I'm going to get better one day"

Participants felt hopeful, they were able to make a plan they were happy with and were working towards something useful.

"yeah there's no judgement and it's kind of helped me to achieve, I want to have goals 'cause I never had goals, I always thought you know next year I'm gonna die so I never had goals until I came here"

Journeys to Wellbeing was described as a brilliant place to come to, where the cycle of medical and WINZ appointments was broken and where support was accessible straight away in a welcoming way.

#### Support and facilitate connections

Participants spoke of the connections they had with other organisations, including the Salvation Army's Recovery Church, LUCK venue (voluntary), MASH and Palmerston North community services.

"They do collaborate with other services and they have a putea that they use to let people know (about other services)"

#### **Cultural engagement**

Participants felt that Journeys to Wellbeing provided an atmosphere that was supportive of other cultures and nationalities and one person described it as a spiritual and welcoming place. They felt a sense of being welcomed into the whanau. One example of a cultural practice they engage in is karakia before a meal.

## Suggested areas for development

Participants felt there was a need for a "one stop shop" where people could also access a doctor and get assistance immediately. Others wanted to see increased, sustained funding rather than the organisation working from one funding application to the next.

Participants felt that more people should know about Peer Support, because many people in the community were not aware of the type of support being offered. Another person felt that having a small, more personalised service such as Journeys to Wellbeing was a good thing, and if it was to grow too large it would not be so effective.

One person spoke of their stress and frustration about waiting to see clinical services and having limited sessions. Building up trust took a long time, which added to their stress.

In contrast, at Journeys to Wellbeing people felt that there is support there all the time and a sense of community. People felt the service was more flexible with what they could offer compared to a DHB service. They said they were different than a clinical service because they do not judge and were there to listen rather than prescribe medications.

#### Discussion

At Journeys to Wellbeing, the highest rated outcome of value to participants was wellbeing. This included maintaining health, distress tolerance, gaining self-awareness, and having enjoyable experiences in their life. Peer Support workers are contributing to people achieving this outcome by supporting peers in a person focused way and focusing on people's strengths. Along with a range of programmes and activities for individuals and groups, Peer Support workers contribute to the wellbeing of peers by providing hope and being inclusive of other cultures and providing a welcoming and spiritual environment. Cultural engagement was highlighted as a positive way that Journeys to Wellbeing works with people.

Peer Support workers demonstrate they work to principles of equality and mutuality. Participants felt able to speak openly about their experiences to the Peer Support workers who shared similar experiences to their own.

Participants rated employment as a valued outcome. As it rated highly, it is an area that Journeys to Wellbeing may want to further explore for development.



## **JIGSAW PEER SUPPORT**

Jigsaw Peer Support Services operates with Walsh Trust and is based in Auckland. Jigsaw is for people who are looking for ways to enhance their lives beyond their experience of mental illness/addiction. It is offered by people who have their own experience of mental health/addiction issues and have recovered.

#### **Outcomes of value**

Participants described a range of things they would like to happen in their future to improve their wellbeing. This included changes to medication, being medication free as well and looking at alternatives to pharmaceuticals. Specific goals for well-being include maintaining current health, improving physical health, losing weight, having a job and being financially secure.

## **Employment**

Participants expressed a range of goals for future employment including becoming an author, working with animals, doing voluntary work and establishing their own business

#### Relationships

Participants identified relationships as a valued outcome, particularly with their families.

"(Family) are very much the centre of my existence and in my daily life"

#### Give back

Participants expressed their desire to give to others, in different ways; through educating people about stigma and discrimination, getting involved in activism, and supporting others that have been through similar experiences.

#### Self-belief

Hope for the future was a valued outcome.

"Free from my illness and the system, free to live my life, free, free to be me, free to do all I want to be,- to look forward to all the wonderful, wonderful things yet to come and it's like the best is yet to come"

Participants who had experienced discrimination in the past, wanted to be treated with more respect.

#### The way in which Jigsaw supports

#### **Respect and compassion**

Participants described the service as being respectful and compassionate by staff showing their understanding, and empathy, and by being caring, genuine, and non-judgemental.

"I got totally deserted before, Jigsaw, the rest of the staff; make me feel like a normal person, a valued person"

Peer Support workers are seen as easy to contact and readily available.

"I've got two Peer Support workers, if one's away, the other one's available so they don't let me down, they arrive on time, they're very respectful"

#### **Equality and mutuality**

Peer Support workers were described as understanding and empathetic, and like friends. These positive relationships were described as being important to recovery.

Participants described an absence of stigma and connections due to their shared personal experiences.

"There's no up or down there, they're not higher than you or you're not lower"

#### Support and reassurance

A number of participants said Jigsaw provided them with much needed emotional support.

"One of the other things is that with the Peer Support worker, when he came and saw me, he said when was the last time you walked out past your gate and I said 5 years and he said you've been in this house for 5 years, yep, he said how would you like to go past your gate and he helped me"

The service is seen to demonstrate support and reassurance by creating circumstances where people can gain confidence in unfamiliar situations. Peer Support workers help people achieve their goals by encouraging them to take manageable steps and see possibilities. One participant took their dream of starting their own business further and was supported by Jigsaw to get their business cards printed.

"What they have done for me over the last couple of years is give me back a sense of self- worth."



#### **What Jigsaw offers**

#### **Programmes and activities**

A range of activities are offered at Jigsaw, some are groups; Christmas art group, walking group, relaxation, mindfulness. Other activities are educational such as Peer Support courses, WRAP, and work skills (C.V writing), support with medication and assessment questionnaires. Jigsaw participated in a restoration project cleaning up the Opanuku Stream.

A number of participants spoke about the value of working with their Peer Support worker on individual set goals. By working on short-term goals, and exploring options people were gaining confidence to work on longer term goals.

One person described their Peer Support relationship as a "working relationship".

#### Provide Hope

Participants reported gaining hope by attending Jigsaw. It became easier to achieve things and Jigsaw played a vital role in recovery. A Peer Support worker was described as giving someone "building blocks" to bridge a gap to get from a difficult place to a better, "sweeter" place.

"You know you've got that crevasse behind you so you can sail clearly, so that's what my worker has helped me through"

One person directly attributed their future goals to the support they received from Jigsaw.

"I feel my future aspirations are strongly tied in to the help that I'm getting now by the Walsh Trust "

#### Support and facilitate connections

Participants said they enjoyed being able to socialise with like-minded people and go to events such as the Big Day Out. They also appreciated their families being made to feel welcome.

## "What I like about Peer Support is that it's not just about me either, they involve my family"

Several participants found it useful that Jigsaw had contact details for other agencies that could offer support. Jigsaw could also offer advocacy at mental health appointments and with agencies such as Work and Income and ACC.

# How peer support is different from mainstream mental health services

Participants described Peer Support as being different to mainstream services in range of ways. These include more one on one support, flexibility around discharge, more consistency, easier access to services and less focus on medication.

#### **Discussion**

Physical health, making medication changes and maintaining their current level of wellness were all identified as important wellbeing outcomes by participants at Jigsaw. The respect and compassion demonstrated by the Peer Support workers contributed to people maintaining their well-being and supporting their emotional health.

A valued outcome for people using Jigsaw was employment. The focus on work skills, such as CV writing suggests Jigsaw is already contributing to this outcome. In addition, by receiving reassurance and encouragement from Peer Support workers, people are encouraged to work towards longer term goals such as employment. People had gained hope which played an essential role in their recovery.



## TE ROOPU POOKAI TAANIWHANIWHA (now called TE WAKA WHAIORA)

Te Roopu Pookai Taaniwhaniwha is a Kaupapa Maori mental health service based in Porirua. They provide an activity based day service for Tangata Whaiora (peers) called Matahauraki. Recently following a merger they changed their name to Te Waka Whaiora.



#### **Outcomes of value**

#### Wellbeing

Participants identified wellbeing as a valued outcome and examples included, growing as a person with freedom to do as they choose, physical fitness, weight loss, more self-confidence, a positive attitude and hope for the future.

#### Self-belief

Participants spoke of wanting to be more self-confident, assertive and independent.

"I've made myself determined to bypass all these obstacles, to break through them and it can be done"

### **Employment**

Employment was a valued outcome. Giving back to others was important and one participant described they had something to offer because of their own experiences. They felt that many people had unanswered questions and were facing things in life that were stopping them being able to progress. Due to having had experienced similar issues and making progress, they wanted to support people to move ahead in their lives.

## Relationships

Participants valued relationships, they would like to have more company, spend more time with mokopuna and have family of their own.

#### Interest

Designing Korowai, writing novels, tai chi, aerobics, fishing and diving were all highlighted by participants as valued outcomes

## How Te Roopu Pookai Taaniwhaniwha support

#### **Equality and mutuality**

Participants said equality and mutuality was demonstrated in different ways at Te Roopu Pookai Taaniwhaniwha, for example, through positive interactions with others, and by workers understanding what they had been through.

One person commented that since they had received a diagnosis, they were less discriminating towards other people with a diagnosis and more interested in their experiences. They felt that each individual had a fascinating story to tell.

#### **Respect and compassion**

Participants described the respect everyone has for each other at Te Roopu Pookai Taaniwhaniwha and examples included not feeling pressured to speak, but free to share their experiences if they wished to. If necessary, someone else would "speak up for you" if there were things that needed clarifying.

"You gotta step into their shoes, to see where they are coming from... to help them I suppose to still guide them... you just need the right positive people, so I'd like to be one of those people to help"



## What Te Roopu Pookai Taaniwhaniwha Offers

#### **Programmes and activities**

A range of physical activities are offered such as tai chi, walking and aerobics. Tangata whaiora are encouraged to lead exercise groups when the trainer was not there.

Cultural activities are paramount in keeping with the Kaupapa of the service and examples included, Te Reo, karakia, waiata, visits to places of cultural interest such as marae and visiting other groups. Supportive groups were seen as helpful ways to learn from each other.

"I sometimes sing Māori songs at home"

## Support and facilitate connections

Participants reported that being at Te Roopu Pookai Taaniwhaniwha helped them make social connections and countered feelings of isolation without anything being forced upon them.

#### **Discussion**

At Te Roopu Pookai Taaniwhaniwha, people rated physical and emotional wellbeing and self-belief as highly valued outcomes. The focus on physical fitness and nutrition at Te Roopu Pookai Taaniwhaniwha contributes to this outcome. In terms of emotional wellbeing, people felt that socialising with others was positive and connecting with others who shared similar experiences helped reduced isolation.

Several participants expressed a desire to develop their confidence, assertiveness and independence and this may be an area for development. Te Roopu Pookai Taaniwhaniwha practises cultural engagement in a range of ways and this was evident in the focus group as people enjoyed learning about other cultures and took pride in their cultural practices.



## OTAGO MENTAL HEALTH SUPPORT TRUST

The Otago Mental Health Support Trust is based in Dunedin and promotes full lives for people experiencing mental distress. The Trust affirms the right of all people to be treated with dignity and respect and believes that people with personal experience of mental illness can be uniquely qualified to provide support and education.



#### **Outcomes of value**

#### **Employment**

Employment rated as the most valued outcome by participants. Aspirations included specific careers, for example, working in an office or working with youth. People wanted jobs that did not involve too much stress, were paid positions with reasonable work hours. People wanted work in roles where they could share their personal skills and experiences to help others, within the wider community and the environment.

#### Wellbeing

Participants wanted to feel a sense of self-worth, and to be free of spending time in hospital. Wellbeing goals included, improved health, having a more "normal" life with their friends and family and feeling more settled. One participant said they hoped the future would be better than how things had been in the past.

### Self-belief

Participants shared it is important for them to find something that gives them a sense of self-worth, especially if their self-worth had been eroded by being in the mental health system.

#### Relationships

Being able to enjoy family relationships was a valuable outcome.

## **How Otago Mental Health Support Trust supports**

#### **Respect and compassion**

Participants said Peer Support workers at Otago Mental Health Support Trust demonstrated respect and compassion by offering practical support and communicated clearly in preferred ways, such as texting, being flexible around appointments and going the extra mile. They offered emotional support and were described as non-judgemental. Peer Support workers were trusted and peers had confidence in them. Participants described feeling supported and empowered to make decisions without being pressured.

Peer Support workers also offer advocacy which equipped people with skills to work on their anxiety and stress. This helped them communicate effectively with other agencies in appointments.

#### **Person Focused**

Participants said Peer Support workers provide a different perspective (to their own), are open-minded, encourage people to make their own decisions and provide a menu of options to choose from.

Otago Mental Health Support Trust focuses on wellness rather than crisis.

"The door is always open"

"You actually feel like a human being"

"I was actually able to communicate with the guy in the office for the first time"





People appreciated Peer Support workers wanting to spend time with them and "walk in their shoes". Working one on one was reported as helping people move ahead in their life.

"They were amazing. They dropped their appointment, or shifted their appointments and gave me a support person. And I met them like an hour outside before the meeting. That was -----and still is to this day"

#### Support and reassurance

Peer Support workers provide emotional support to peers; peers reported the workers were on the same wave length, made them feel accepted and provided a sense of safety. Peer Support workers took pride in the achievements of peers and gave practical support such as developing routines and setting goals.

In some instances, people felt they needed extra support but either preferred not to, or could not use clinical mental health teams. Using the services at Otago Mental Health Support Trust was described as providing a much needed connection.

"I think Peer Support is a fantastic tool to equip myself with resources"

## **Equality and mutuality**

Peer Support workers were described as understanding because they had experienced distress themselves and could share strategies they could use. The balance of power was equal and participants felt this led to trust and mutual respect. Otago Mental Health Support Trust focuses on wellbeing and strengths, not problems and crisis.

## **What Otago Mental Health Support Trust offers**

#### Hope

Peer Support workers were described as positive and contact with them could help shift their mood from negative to positive. Participants stated the Peer Support workers could show people a way forward and that it is possible to take your life in a positive direction. One person described Peer Support as a "lifeline" feeling it was preventative rather than an "ambulance at the bottom of the cliff".

#### **Support and facilitate connections**

Otago Mental Health Support Trust support a group called INSIGHT where key issues are discussed (for example the use of ECT) and where connections in the community are supported. With one-on-one support people described developing connections that led to teaching others a new skill. Otago Mental Health Support Trust run Peer zone, operate a library and produce a newsletter. They also support other peer groups starting out e.g. Parents Affected with Mental Health Issues (parents supporting other parents).

#### Advocacy

Advocacy rated highly by participants and support was offered when engaging with agencies such as Work and Income, mental health teams, employers and the Justice system.

# How Peer Support is different to mainstream mental health services

"The thing about the peer group, they treat you like a human being and the clinical system doesn't, it's just a machine"

One participant did not feel clinical services had anything to offer and were unsupportive. The hierarchy of clinical services was seen as particularly unhelpful.

"They're up there, you're down here"

In contrast people felt the peer service was there for them, would listen and understand.

## Suggested areas for development

Participants expressed their concern for the future of the Peer Support service due to funding and decision making. They would like to see the service developed to offer expanded services.





#### **Discussion**

People who use Otago Mental Health Support Services spoke highly of the way Peer Support workers deliver support, particularly the respect and compassion they show towards people. Peer Support workers were described as flexible and person focused with a "door is always open" approach.

Otago Mental Health Support Trust offers advocacy, something which a number of people found very useful in their communications with other agencies. As well as offering programmes and activities, Peer Support workers demonstrate their support through facilitating connections with the community and essentially, giving people hope.

Peer Support workers at Otago Mental Health Support Trust are examples of how to take your life in a positive direction and provide people with an opportunity to get the support they require before reaching crisis point.

People who use Otago Mental Health Support Trust services had a number of highly valued outcomes, two of which were wellbeing and employment. The positive way in which Peer Support is delivered by Peer Support workers at Otago Mental Health Support Trust, enables people to see there is hope for the future. The respectful and compassionate way in which they support people contributes to a sense of wellbeing.

Interestingly, people valued gaining employment most highly, with different visions of the work they wanted to do. However, few people reported working towards this goal with Peer Support workers. Given employment was rated so highly as an outcome, Otago Mental Health Support Trust peer support workers may consider further developing employment support.



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## **APPENDIX ONE: INFORMATION SHEET**

Researching and Evaluating the Evidence Base for Peer Support Mental Health and/or Addiction Services Delivered By Non-Government Organisations (NGOs)

## **Information Sheet**

Principal Researcher: Marge Jackson, Kites Trust

We invite you to take part in this study which aims to evaluate peer support mental health and/or addiction services.

Please take your time to decide whether to take part. Your involvement is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future access to this peer support service.

If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason, and this will in no way affect your future access to this peer support service.

You are welcome to involve a support person, friend, family or whānau in asking questions about the study and considering your involvement.

#### About the study

We are inviting people with experience of mental illness and/or addiction aged between 18 and 65 who are using peer support mental health and/or addiction services to take part in the study.

We are organising focus groups at peer support mental health and/or addiction services around New Zealand to ask what are outcomes of value to people with experience of mental illness and/or addiction services and how well peer support mental health and/or addiction services support these outcomes. If you decide to take part in a focus group it should take about one hour.

Before the focus group we will ask some general questions about you. This information will be used to make sure we get feedback from a range of people.

We will then ask questions about how effective peer support mental and/or addiction health services are. We hope this information will help in the development and promotion of the most effective services for people who use mental health and/or addiction services.

#### **Risks and Benefits**

We don't expect you to experience any ill-effects from taking part in the study. If you do, you can contact one of the study researchers on free phone 0800 4 KITES (0800 454 837) who will help you to access the support you need.

We expect that talking about your recovery and outcomes of value to you may be a positive experience of self-reflection.

There will be no cost to you for being involved in this study, nor will you receive any payment for taking part.

#### How data and information collected will be used

The facilitator will record the audio of the focus group. Information that you share with us will be available to the project researchers only. Due to the nature of focus groups we cannot assure complete confidentiality, but each focus group participant will be asked to respect group confidentiality.



The results of the project may be published and every attempt will be made to preserve your confidentiality. No material which could identify you will be used in any reports on this study. You are most welcome to request a copy of the results of the project should you wish.

The information collected will be securely stored in such a way that only project researchers can access it. At the end of the project any personal information will be destroyed except that, any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

Your participation in a focus group is part of a bigger project that will take three years. At the end, we will write a report on the results. If you want to know any more about the study, please indicate this on your consent form or contact the Principal Researcher, Marge Jackson on free phone: 0800 454 837

E-mail: margej@kites.org.nz or address: PO Box 9392, Wellington.

#### Need an interpreter?

If you need an interpreter please indicate this on your consent form.

#### **Information on your Rights**

If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone, NZ wide: 0800 555 050

Free Fax, NZ wide: 0800 2787 7678 (0800 2 SUPPORT)

Email: advocacy@hdc.org.nz

The Lotteries Commission funded this study.

This study has received ethical approval from the Multi-region Ethics Committee, ethics reference number: MEC/12/004



## **APPENDIX TWO: INFORMED CONSENT**

## Request for interpreter

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	lo	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	loe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	loe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	lo	Ikai

## Please check the box beside each statement

for yes or <b>X</b> for no.				
I have read and I understand the information sheet dated July 2012 for volunteers taking part in the study which aims to evaluate Peer Support mental health and addiction services. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.				
I have had the opportunity to have a support person, friend, family or whānau to help me ask questions and understand the study.				
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my access to future peer support mental health and addiction services.				
I understand that, while confidentiality cannot be assured due to the nature of focus groups, no material which could identify me will be used in any reports on this study.				
I understand my focus group interview will be audio recorded and transcribed				
I know who to contact if I experience any ill-effects from taking part in the study.				
I know who to contact if I have any questions about the study.				
I would like a copy of the results when they become available <b>yes / no</b>				
If yes, please provide email or postal address:				
l hereby consent to take part in this study.  (full name)				
Signature: Date:				



**Full names of Researchers:** Ms Marge Jackson; Dr Sarah Elizabeth Gordon; Ms Sarah O'Connor; Mr Tane Rangihuna; Ms Kate McKegg; Dr Debbie Peterson, Ms Debbie Goodwin

Contact Phone Number for researchers: <b>0800 454 837</b>		
Project explained by:	Project role:	
Signature:	Date:	
We would like to gather some information about the peop understand who has provided information.	le who participate in the focus groups. This helps	us
Please tick the box which applies to you.		
1) Which age group do you belong to?  18-24 years (1)  25-34 years (2)  35-44 years (3)  45-54 years (4)  55-65 years (5)		
2) Are you?  Male (1) Female (2) Transgender (3)		
3) Which ethnic group do you belong to?  New Zealand European (1)  Māori (2) lwi  Samoan (3)  Cook Island (4)  Tongan (5)  Niuean (6)  Chinese (7)  Indian (8)  European (9)  Other (10)		
4) How long have you been involved with this peer suppo  1-6 months (1)  6-12 months (2)  1-2 years (3)  2 years +(4)	rt service?	



## APPENDIX THREE: WHAKAARO

#### Inducements & Koha

We at Kites understand the traditional concept of koha as being a 'direct gift to the gods'. During the days of lore visitors would bring things such as pounamu, toka and even food as koha and would place them at the Pou tuarongo (back wall) of the marae as recognition of the gods. In today's society money is often the currency which is being gifted as koha as recognition for a person/groups time, resources and effort. Seeing this is not intended in any way for the 'gods' many Maori interpret this as being 'Whakaaro' or 'a thought' for the work and/or time that a person/group has given you.

In terms of ethics the National Ethics Committee state the following with regard to inducements to participants involved in research:

- 1.1 Investigators may seek to create legitimate motivation for participation in studies, but may not exert pressure by offering inappropriate inducements.
- 1.2 Risks involved in participation should be acceptable to participants even in the absence of inducement.
- 1.3 It is acceptable for investigators to repay the incurred expenses of participants (for example, travel costs).
- 1.4 A koha may be offered in line with the cultural norms of the study participants, but should not be of such a value that it could reasonably be interpreted as an inappropriate inducement or as a payment for participation. For this reason, it is often not appropriate to discuss koha before getting an agreement to participate.

(Traditionally, koha is an acknowledgement of the knowledge and/or hospitality extended by tangata whenua to manuhiri. It is presented as part of the powhiri onto a marae or other venue of the tangata whenua. However, the definition of koha should not be restricted by reference to its traditional roots; contemporary meanings include the giving of koha in a different manner during research.)

**Referenced from:** National Ethics Advisory Committee. 2012. Ethical Guidelines for Observational Studies: Observational research, audits and related activities. Revised edition. Wellington: Ministry of Health.

