Valuing, respecting and utilising people's mental health experiences

Ka wāriu ka whakaute a ka whakapau e ngā wheako mate a hinengaro o ngā tangata

KITES STRATEGIC PLAN 2018 - 2021

INTRODUCTION

The intent of this strategy is to share with our stakeholders the contribution Kites plans to make and focus on in the next three years to achieve our vision of an inclusive society.

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

We welcome the opportunities to work with others as we know we cannot achieve our vision on our own.

We will measure and report on our progress against these strategic goals.

OUR VISION

Equal citizenship for people who experience distress

This is based on the strong belief that people who experience mental distress have the same rights and responsibilities as other members of society to live, work, and play in their communities.

OUR GOALS / THE CHANGES WE WANT TO SEE

1. Increase the influence and accountability of people using their lived experience in decision making positions
2. Increase the availability and effectiveness of peer support
3. Eliminate discrimination and increase inclusion

OUR VALUES

Integrity: Embodying and following our ethical principles

Creativity: Developing new ideas and innovative approaches

Collaboration: Cooperating with others, with shared interests, to add value and achieve more

Being cooperative and working well with others

Social Justice: Seeking and acting with respect, fairness and equality

Courage: Challenging the status quo, being transparent and keeping it real

![Kites logo]

GOAL 1

Increase the influence and accountability of people using their lived experience in decision making positions

WHY IS GOAL 1 IMPORTANT?

Leadership by people with personal experience of distress is key to achieving social inclusion on an individual and societal level. Evidence[1] shows that outcomes improve when consumers are actively involved in the decision making process. High quality leadership, advice and guidance from people who use mental health and addiction services leads to improved services and responses. Active participation and leadership in planning, implementing and evaluating responses leads to meaningful outcomes for people.

WHAT DIFFERENCE WILL ACHIEVING GOAL 1 MAKE?

- An increasing number of people with experience of distress are in positions of power and influence and are supported to be successful in these positions
- Contact or direct equal-status interactions with people with experience of distress become a key tool in effectively countering stigma and discrimination
- Health and legal systems based on people having the same rights and responsibilities
- A holistic view is held and recognised of the many and varied contributing factors to the experience of wellbeing and distress
- A broad range of responses will be available for people with experience of distress and they have the freedom to choose which response(s) they use

WHAT WILL KITES DO TOWARDS ACHIEVING GOAL 1?

- Systemically advocate for more tangata whai ora with lived experience of distress to be appointed to, and supported in, positions of influence
- Create peer-led support structures and networks of and for people with personal experience of distress
- Improve the range and quality of information, training and mentoring programmes which support people with experience of distress getting into and contributing in positions of influence
- Ensure peers in positions of influence are accountable to their communities and this reflects and honours their community mandate
- Peer leaders and influencers support and develop the next generation of leaders and influencers

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[1] See Appendix 2: Evidence that peer participation improves outcomes

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GOAL 2

Increase the availability and effectiveness of peer support

WHY IS GOAL 2 IMPORTANT?

Peer support happens when people who are experiencing distress are supported by people who have lived experience of distress. This similarity of experience is the basis of the peer support relationship. The peer support relationship is underpinned by principles of trust, respect and shared responsibility which supports recovery.

Self-determination, choices and mutual support to achieve valued outcomes equip people with the knowledge that they can and do have control over their life. A respectful and reciprocal relationship between peer workers and people experiencing distress builds empowerment and equality, and helps balance the inequalities inherent in medico/psych expert - patient dynamics.

WHAT DIFFERENCE WILL ACHIEVING GOAL 2 MAKE?

- As a result of experiencing peer support, people's recovery and wellbeing are enhanced
- Policy, practice and funding recognise and embed peer expertise and support as an integral intervention
- Peer support becomes a service option that is widely known, promoted and freely available to all tangata whai ora and/or whanau who feel it is right for them
- People with lived experience lead the development and implementation of peer support models and practice
- Consumers, communities, health and social sectors and government value and support the benefits and use of peer support
- Practice-based evidence is enriched by implementing and evaluating the effectiveness of peer support

WHAT WILL KITES DO TOWARDS ACHIEVING GOAL 2?

- Increase the evidence base for peer support by supporting evaluation and research of peer support services
- Increase the awareness of peer support as an effective intervention for people who experience distress
- Support the development of peer support workers through mentoring, training and education programmes
- Drive and/or support the development of peer support initiatives

GOAL 3

Eliminate discrimination and increase inclusion

WHY IS GOAL 3 IMPORTANT?

New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities which has the stated aim of enabling those with an impairment to participate as active members of society and enjoy the full range of their human rights.

The social model of disability identifies that it is society that disables an individual through its stigmatising attitude, and subsequent response, to impairment. Such disablement is discrimination in action, which is unjust and effectively victimises those affected. People may not actually consider themselves to be impaired at all, but can still be treated unjustly.

Those with lived experience of mental distress are frequently stigmatised, discriminated against and disabled (e.g. in employment, education, health, financially, socially, housing, and the justice system) and are prevented from thriving. In addition, this discrimination creates a barrier to disclosure, and therefore a limitation in the provision of support to those with lived experience by those who might otherwise provide accommodations. At times, despite best intentions, the predominant medicalised approach in our culture disables those with lived experience of distress and violates their human rights (e.g. segregation, compulsory treatment, and seclusion).

By contrast, where allowance is made for impairment and special needs are accommodated the individual is supported to thrive and be fully included in their community. In a just society, an individual would be able to disclose their special needs and be supported, not stigmatised or discriminated against.

WHAT DIFFERENCE WILL ACHIEVING GOAL 3 MAKE?

- People experiencing or having experienced distress are not discriminated against and not excluded from full opportunities and participation as citizens
- Law, policy and practice ensure that discrimination is identified and eliminated
- Stigma and discrimination can be reduced by using essential elements of peer support (equal status, active participation, "Power of Contact", knowing each other, dealing with negative stereotypes)
- Consumers, communities, health and other social sectors actively engage in reframing interventions and support within an holistic equal citizenship framework that looks for and values the whole person, their individual circumstances and their relationships in their communities
- Establishing respectful and equal relationships between peer workers and tangata whai ora builds empowerment and recovery, self-determination, freedom to choose and mutual support
- The community becomes actively engaged and supported in challenging discrimination in the home, workplace, health system, and wider community

WHAT WILL KITES DO TOWARDS ACHIEVING GOAL 3?

- By working to eliminate discrimination and increase inclusion Kites seeks to ensure that those with experience of mental distress have their human rights met and enjoy the benefits and responsibilities of full participation in society

- Promote equality and inclusion through system change

- Engage with consumers, communities, health and social sectors and government in healthcare and support towards equal citizenship

- Influence delivery of effective awareness raising methods to eliminate stigma and discrimination through the use of evaluation and taking corrective action

- Advocate for the elimination of the practice of seclusion through on-going engagement with DHBs and other relevant organisations

- Actively promote 'Power of Contact' as a key tool in effectively countering stigma and discrimination

GLOSSARY

Peer: Broadly speaking, a person who has *lived experience* (see below). However, the word peer is often specifically used to describe those who seek to use their own experience and knowledge to help those with similar needs, as in "peer support".

Lived experience: Someone who has experienced unusual thoughts and behaviours, which others may find hard to understand. These unusual thoughts and behaviours may be beneficial, or distressing, and have commonly been regarded as "mental disorder". Lived experience of diverse mental and emotional states is meaningful and should be valued as part of the range of experiences that make us human.

Tāngata whai ora: A Māori term which can be translated as "people seeking wellbeing", as for the Māori concept of "ora" is broader and more holistic than the English term "health" and more like "wellbeing".

Consumer: A person who uses ("consumes"?) mental health (and other health/social) services, including primary care. Some people with lived experience object to being described this way, as they may not actually (yet) have used services, and there are other problems with the terms "consuming" and "using" in the addiction world.

Service user: A person who currently uses mental health services, including primary care GP services. Some people with lived experience object to being described this way (see above).

Power of Contact: A model or tool used to help address discrimination. For contact to be effective, the following conditions should be present: equal status, the chance for individuals to get to know each other, information challenging negative stereotypes, active participation, and pursuit of a mutual goal.

APPENDIX 1: WHO WE ARE

Kites Trust (Registration Number CC10276) is a well-established community development organisation working nationally and in the wider Wellington region in the mental health and addictions sector. We are committed to peer leadership as reflected in the majority of Kites' trustees and staff having lived experience of distress.

OUR CULTURAL RESPONSIVENESS

Kites is committed to active promotion of and adherence to Te Tiriti o Waitangi. This is reflected in our Trust Deed and demonstrated through our values and practices of whānaungatanga, manaakitanga and oritetanga.

Kites seeks to improve our responsiveness not by what we say but by what we do. We accept Te Tiriti o Waitangi as the founding document of Aotearoa New Zealand and that it is a constant and unchanging statement of partnership, tino rangatiratanga and mana motuhake.

We recognise Māori as tangata whenua of Aotearoa New Zealand and believe Māori are able to define their own priorities and develop their own capacity for delivery of services to their communities.

OUR WAY OF WORKING: MODELLED ON COMMUNITY DEVELOPMENT

- Work with people to explore and identify their own problems, issues and solutions
- Value and use the skills, knowledge and experience of people who experience distress
- Promote people working together rather than as individuals
- Develop local solutions to local problems
- Facilitate processes toward resolution where there are conflicting interests
- Engage in policy development at both community and government levels

OUR WAY OF WORKING: SPECIFICS

- Model, promote and develop peer leadership
- Seek out, promote and initiate innovative ideas and solutions, and build capacity
- Educate, challenge and advocate systemically
- Bring about positive change in behaviours, services and systems which affect the lives of people who experience distress
- Be innovators and champions for socially just and inclusive communities

OUR MANDATE

![Kites logo]

- Kites Trust Deed outlines the aims and rules of the Trust (see Trust Deed)

- Kites is a registered charity and adheres to the requirements of the Charities Act 2005 and amendments

- Meeting expectations of stakeholders

WHAT WE DO

Our services and activities include: peer leadership, peer support, facilitating forums and workshops, anti-stigma and discrimination education and training, research and evaluation, systemic advocacy and submission writing.

We specialise in delivering nationwide, regional and local projects in the mental health and addictions sector. Our current contracts include: Like Minds Like Mine national training and education projects; Buddies peer support service, mentoring and leadership; Toka Tu peer support evaluation and research; peer workforce advocacy; and sector support activity.

Who we work with includes: Ministry of Health, Health Promotion Agency, Capital & Coast District Health Board, Hutt Valley District Health Board, Mental Health Foundation, New Zealand Lotteries Commission, Wellington City Council, the University of Otago, Whitireia Community Polytechnic and a number of other agencies, NGOs and private trusts.

APPENDIX 2: EVIDENCE & REFERENCES

The following is a short summary of evidence which "shows that outcomes improve when people experiencing mental distress are actively involved in the decision making processes" (page 2 in this document). The phrase "active involvement in decision making" is used in the strategy document, but other terms are also used for such consultation in the literature, such as "participation", "involvement", "collaboration," "partnership". In addition, the term "patient self-advocacy" is regarded here as a form of participation. We will use the term "participation" for brevity in the following sections.

Participation is an ethical requirement

It accepted practice in medical ethics that patients should be fully consulted, be provided with all information about any proposed or ongoing treatment, and that informed consent should be obtained for such treatments. Vahdat *et al.* (2014, p.6) write: "Today, patient participation is regarded as a legal right of the patient as well as an international gold standard for healthcare systems". Also see Gadow (1989) on patient rights to self-determination in general.

The New Zealand Ministry of Health published a report in 1995 which argued, among other things, for "consumer participation" at the individual level. Thus patients would have "input into the treatment and services they use as an individual" (p.2).

In psychiatric care shared decision making is an ethical imperative (Drake and Deegan (2009) in the journal *Psychiatric Services,* one entire issue of which is devoted to promoting shared decision making). In 2012 Picket *et al.* (2012, p. 420) write concerning the US situation: "Despite federal mandates for client-driven services ... mental health consumers commonly report concerns about their involvement in decisions regarding their treatment."

Evidence that participation improves outcomes

In non-psychiatric medicine, informing and involving patients in their health care has been proved to improve compliance with treatment, self-management, and quality of health outcomes (Coulter and Ellins, 2007). Vahdat *et al.* (2014) carried out a large meta-analysis of 100 articles and 5 books and they concluded that "patient participation causes improved health outcomes, enhanced quality of life, and delivery of more appropriate and cost effective services" (p. 6).

Specifically in psychiatric treatment, Shafer *et al.* (2016, p.344) write: "evidence suggests that patients who experience greater decision-making and empowerment during their hospitalization are significantly less likely to be readmitted to the hospital".

Self-advocacy can be regarded as a specific form of participation, where the patient is able to speak for and determine their own treatment outcomes. Picket *et al* (2012) conducted a randomized trial and concluded that peer education may improve the ability of those experiencing mental distress and recovery to self-advocate. In their abstract, Jonikas *et al.* (2013, p. 260) write that, "A fundamental aspect of successful illness self-management for people with serious mental illnesses is the ability to advocate for themselves in health and rehabilitation settings" and go on to list a number of research articles in support of this claim. This study also reported that involvement in peer-led education improved their ability to self-advocate.

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