

# Lived Experience Position Statement

## **Our promise – “*nothing about us without us*”**

We, Te Hīringa Mahara, believe that people who experience mental distress and people who experience substance harm, gambling harm or addiction must be involved at every level of the mental health and addiction system in genuine partnership. We [monitor lived experience leadership and participation](#) across the system and advocate for improvement.

In our own mahi (work), we are committed to prioritising the voices and interests of people who experience mental distress and addiction. This includes in our system leadership mahi, monitoring the mental health and addiction system, assessing wellbeing, and advocating for meaningful positive change. We will always embrace lived experience perspectives and voices to inform our work and our decision-making. This promise is underpinned by our legislation, and we believe that honouring lived experience is fundamental to our effectiveness and our integrity.

## **Our whakapapa**

We hold deep respect for lived experience movements and recognise their advocacy in [He Ara Oranga](#) (the 2018 Government Inquiry) calling for the establishment of the Mental Health and Wellbeing Commission. These voices called us in to being.

We also recognise the long history of lived experience advocacy in Aotearoa prior to He Ara Oranga. This advocacy by the consumer / peer / survivor movements, by tāngata whaiora, tāngata mātau-ā-wheako and whānau Māori, by peers who experience addiction and the drug user movement, has spanned generations, calling for changes to address harms experienced in the mental health and addiction system and protect rights.

Our mahi honours the wisdom of these movements and their drive for decolonisation, self-determination, harm reduction, social inclusion and diversity, equitable wellbeing, de-centring psychiatry in mental health care, human rights, and an end to coercive and exclusively western-centric models of treatment.

## **Our language**

We value and uphold the right for people to choose how they identify and to reclaim language. We also commit to using strengths-based language that challenges misconceptions and prejudice. Being strengths-based means that we focus on the strengths of people, but we still clearly name the issues in the system.

In our mahi, we use the terms ‘personal experience’, ‘living experience’, and ‘lived experience’. We are intentional in naming what kind of lived experience we are talking about in relation to each project or area of our work e.g., “personal experience of opioid substitution treatment”, “lived experience of compulsory treatment”. Whenever we use the terms ‘personal experience’, ‘living experience’ or ‘lived experience’ on their own (for example when we say “we advocate for people with lived experience”), we are talking about people or groups who have their own, first-hand experience of distress, substance harm, harmful gambling, psychiatric diagnosis, addiction, using mental health or addiction supports or services, or experiencing barriers to accessing these support and services when they are needed (or any combination of these experiences).

## Our responsibilities

Our legislation ([Mental Health and Wellbeing Commission Act, 2020](#)) requires us to:

- “Advocate for the collective interests of people who experience mental distress or addiction (or both)”
- Effectively seek the views of “people who have experienced mental distress or addiction (or both)”
- Uphold Te Tiriti o Waitangi and its principles in all our work. Our approach to this is outlined in our [Tiriti o Waitangi Position Statement](#).

We recognise that our advocacy function gives us a unique mandate that no other agency has, and we choose to enact this advocacy role ‘alongside’ (rather than on behalf of) lived experience communities wherever we can.

## Our commitment

We welcome connection from people with personal experience, and we will believe and validate what people share with us. We also seek to understand and advocate for the collective interests of people with lived experience.

We will do this by proactively building relationships and working with people and groups whose lived experiences highlight the major issues across our current system and the possibilities for transformation. Therefore, we will:

- privilege the experiences and aspirations of **tāngata whaiora** and **tāngata mātau-ā-wheako Māori**
- amplify the voices of people who have experienced or overcome **loss, harm or exclusion** as a result of practices in the mental health and addiction system, or through being denied support
- **treat lived experience as an unfinished sentence**, asking ourselves “lived experience of...?” for each project or area of work that we undertake, so that we involve people with **directly relevant personal experience** in each project
- **monitor together** - the issues people share with us inform our monitoring, and we talk to people with lived experience when we monitor wellbeing and when we monitor what is happening in the mental health and addiction system
- **value and utilise lived expertise** by drawing on lived experience wisdom, research, methodologies, practices, lived experience roles, social movements, and leadership
- **prioritise our projects and focus areas** based on their importance to people with lived experience

## Delivering on our commitment

Lived experience Board members and designated lived experience and kaitohutohu wheako Māori whānau roles bring “lived expertise” into Te Hīringa Mahara. These roles are well-supported and sit at levels where they can meaningfully influence our decisions and action. Lived experience staff in these roles are responsible for facilitating our connections with lived experience communities, as a means for amplifying the wisdom that people share with us and ensuring it is understood and honoured in our mahi. We also see lived experience as an asset for all roles within Te Hīringa Mahara and seek to recruit, empower and support staff with experience of mental distress and addiction across our organisation.

When we connect with lived experience communities, we do so in a spirit of mutuality and openness, genuinely listening to and valuing the contributions that people make to our work. We will contribute to the development of lived experience communities and leadership.

### **Lived experience feedback leads our way forward**

We are accountable to lived experience communities and whānau in delivering on the commitments in this position statement. We welcome feedback and suggestions from lived experience communities, and we will actively seek feedback on how our mahi reflects the concerns and interests of people who experience mental distress, substance harm, or gambling harm. We will use this feedback to learn and grow, with the aim of being a genuine, courageous, and effective advocate.