

Te Hiringa Mahara

Nau Mai te Ao

Understanding, honouring and
working with “Lived Experience”

Whakapapa o te ingoa - “Nau Mai Te Ao”

Tēnei te arā o Ranginui, e tū ake nei	This is the pathway of sky father above us
Tēnei te arā o Papatūānuku, e takoto nei	This is the pathway of earth mother below us
Tēnei te arā o Rangī rāua ko Papa, e takoto nei	The pathways of sky father & earth mother before us
Kia rarau te tapuwae o Tāne ki raro	Allow the soles of Tane to settle into
Tēnei te pō, nau mai te ao	The path that leads us from the dark to light
Karangatia te ao e piri	Beckon the light/wisdom to embrace me
Karangatia ko Tāne, e piri, e tata	Beckon Tane the bearer of light and wisdom
Whakamaua kia tina, tina	To embrace and hold till it is permanent
Hui ē Taiki ē	Gathered as one

This karakia was written by renowned tohunga, Anglican priest and university lecturer, Rangiahuta Alan Herewini Ruka Broughton at a time when he faced his own personal challenges. He told this karakia to East Coast tohunga, Mark Kopua who offered it to Te Kūwatawata (and subsequently Te Waharoa), a holistic model to address Māori mental health and addictions, as a karakia tīmatanga in wānanga with whānau who were presenting in distress.

The karakia reflects the pūrākau of when Tāne separated his parents, Ranginui and Papatūānuku, and brought light into a world that was once filled with darkness – Tēnei te pō, nau mai te ao. It is this phrase that describes the journey of one’s distress (darkness) to recovery (light) and why this is used in wānanga.

“Nau mai te ao” – literally translated as “welcome the world” – is applied to one who has navigated their distress to a state of wellness and consequently endured a “Lived Experience” in welcoming light into their world.

It is our aim here to acknowledge these lived experience journeys, forged by so many of us. We also hope that the discussion below helps to shed light on how the mental health and addiction system can understand, honour and work with this ‘lived experience’.

Te Hiringa Mahara has a leadership role in transforming the system - understanding “lived experience” is key for us to do our work with integrity

Te Hiringa Mahara (the Mental Health and Wellbeing Commission) is a new organisation, established in response to the recommendations of **He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction (He Ara Oranga)**. Our role is to contribute to creating a transformed system, where everyone in Aotearoa New Zealand has better and equitable mental health and wellbeing.

We are tasked with monitoring mental health and addiction services, publicly reporting on mental health and wellbeing in Aotearoa, and advocating for the collective interests of people with personal experience of mental distress or addiction (or both) and their whānau, family, and supporters.

To do this well, we want to work with people and groups who have personal experience and lived experience of mental distress, substance harm, harm from gambling, substance addiction or non-substance addiction. We recognise that many people will identify with more than one of these experiences.

The community expects us to build strong relationships and work in close collaboration – the catch cry of the lived experience movement, and the broader disability rights movement, is “nothing about us without us.” This view is reflected in the legislation that set up the Commission. The Mental Health and Wellbeing Commission Act 2020 directs us to effectively engage with, and advocate for the collective interests of people with experience of mental distress or addiction (or both).

We know that there are different ways to understand ‘lived experience’. Our understanding of ‘lived experience’ will impact who we engage with, what we hear, and how we respond. We need to understand ‘lived experience’ in a way that resonates for people who have personally experienced mental distress, diagnoses of mental health conditions, substance harm, gambling harm, substance addiction, non-substance addiction, and for lived experience movements. We also need to understand lived experience in a way that enables us to be a credible and effective advocate for transformation across all parts of the mental health, addiction and wellbeing system.

To do this, we need to work with people and groups whose experiences highlight the major issues and possibilities for transformation across our current system, while acknowledging the range of personal experiences that many people have

We are grounded in te Tiriti o Waitangi in all of our work

As a crown entity, we must take account of te Tiriti o Waitangi to achieve better and equitable mental health and wellbeing outcomes for Māori. We are committed to being grounded in te Tiriti o Waitangi, which we express in our [Tiriti o Waitangi position statement](#). This statement outlines our commitment to actively monitor racism and discrimination across the system and embrace Mātauranga Māori as an evidence base. We will advocate for rongoā, kaupapa Māori, and iwi approaches to mental health and wellbeing, challenge the system to address inequity and discrimination, and expect services to be culturally competent and inclusive of wairuatanga. Our te Tiriti o Waitangi position statement also outlines that we are committed to making things right when we get something wrong.

Ka mua, Ka muri

We must acknowledge the role of tāngata whaiora Māori and the consumer / peer / survivor movements in Aotearoa

The incidence of mental health and addiction issues amongst Māori was low even up to the 1940's. It was not until the 1970's through to the 1990's that these numbers started to shift with mounting concerns about Māori mental health in government sectors and in the Māori community. By the mid-1980's the rates of Māori psychiatric admissions were two, and in some categories, three times that of non-Māori. These factors saw an increase in the numbers of Māori accessing services and the parallel development of the Māori workforce. Consequentially, a Māori lived experience workforce emerged and provided peer support and advocacy from a worldview grounded in te Ao Māori. Tāngata whaiora Māori initiatives formed to lead systemic advocacy that focussed on addressing the discrimination, prejudice, and the coercive and punitive practices that Māori were disproportionately subjected to. These movements, and their leaders, envisaged an Aotearoa where tāngata whaiora Māori and their whānau have their rangatiratanga respected, and experience Pae Ora.

It is important that we never forget our past, and the leaders who challenged and struggled against the system. Their legacy has shaped services and leadership today and this must not be forgotten. The growth of in recent years Te Kete Pounamu (National Māori Voice of Lived Experience) strengthens pathways for tāngata whaiora through the utilisation of their own personal experiences, skills, and knowledge, and continues the legacy of tāngata whaiora Māori and whānau advocacy, and indigenous advocacy to transform the system.

Māori lived experience workforces and advocacy did not exist in vacuum; they were part of what was happening within the landscape of the mental health and addiction system and the political make-up of Aotearoa. However, even though they're similar to other consumer / peer / survivor movements, they were not the same. The expression of Māori lived experience talked to the personal experiences of Māori

tāngata whaiora and their whānau, issues of mana motuhake, and the importance of tino rangatiratanga. They spoke to the experiences of exclusion not only by virtue of having lived experience, but also of the exclusion experienced as tangata whenua.

Te Hiringa Mahara recognises and honours the tireless work of tāngata whaiora, whānau and roopū Māori who have advocated for equity, for an end to coercive and exclusively Western-centric models of treatment, and for the right to self-determination. The challenges ahead of Māori lived experience leadership are critical as the mental health and addiction system transforms. The wealth of knowledge within Māori lived experience leadership, and the opportunities to develop and nurture mātauranga Māori lies at the heart of Pae Ora.

Alongside, and at times connected to the advocacy of tāngata whaiora and whānau Māori, have been consumer, peer, and survivor movements and the drug user movement. These movements, groups and networks in Aotearoa have been active for generations and have played a role in shaping international social movements for lived experience communities' rights. The drug user movement came out public health approaches to HIV / Aids epidemic and advocated for 'harm reduction' and an approach grounded in human rights and for people who use drugs. The work of the Like Minds Like Mine campaign has led the world in lived experience-fronted anti-stigma and anti-discrimination efforts. From the mid-1980's regional psychiatric survivors movements including *Auckland Psychiatric Survivors* and Wellington's *Madness Anonymous* began forming, and in 1990 the Aotearoa Network of Psychiatric Survivors (ANOPS) started advocating at a national level during a critical period of "de-institutionalisation" for the rights and inclusion of people who had experienced psychiatric diagnosis or hospitalisation.

It was in this context that Aotearoa New Zealand's first Mental Health Commission was created in 1996. Lived experience leadership and staffing enabled the Commission to advocate for a compassionate and recovery-based system that would listen and respond to people who experienced distress and mental illness diagnoses. Since the Commission's disestablishment in 2012, tāngata whaiora and people with lived experience have developed new forums to continue sharing stories of their experiences and the changes needed in the mental health and addiction system.

Most recently people with lived experience called for change during the Peoples' Mental Health Inquiry and the subsequent Government Inquiry into Mental Health and Addiction. Lived Experience voices were strong throughout the Inquiry publications [He Ara Oranga](#) and [Oranga Tāngata, Oranga Whānau](#). The establishment of a new, expanded Commission was called for - to provide leadership and rebuild trust in the mental health and addiction system. When the Government reviewed the findings of He Ara Oranga, the recommendation to establish a Mental Health and Wellbeing Commission was accepted in full.

We must hold a humility and deep respect in our mahi (work) for the history of tāngata whaiora and whānau Māori advocacy and the consumer / peer / survivor movements in Aotearoa. This extends to all the people – too many to name – who have contributed to advocacy for the rights of tāngata whaiora, people who use substances, experience substance harm or gambling harm, substance addiction, non-substance addiction, people who experience psycho-social disability, distress, or psychiatric diagnosis. Everyone who has shared in this experience of telling their stories to create change has had an influence, whether they knew it or not.

We would like to particularly acknowledge those who have dedicated their lives to advocating for improvements, those who have shared their experiences in the hope of change, those who have died without their mamae (hurt) being properly acknowledged, and those who have been harmed by failures to make change happen. Knowing our whakapapa, and the people who did so much for us during the early years, lets us look to the past in order to look to the future – ki muri, ki mua.

Te Hiringa Mahara has a unique mandate to systemically advocate for people with lived experience

We are mandated to advocate at a systems level for people with personal experience of mental distress or addiction. We also have a role advocating for the collective interests of whānau, and the people including family who support those with lived experience (we are still to develop an approach to working with and advocating for the interests of whānau, family and supporters).

Advocating for ‘collective interests’ means that, although we cannot advocate for individuals or whānau directly (this **individual advocacy** support is provided through the Health and Disability Commission, the National Advocacy Trust and peer advocacy services), we advocate for the mental health and addiction system to understand and address the issues that people who experience distress or addiction face collectively. We undertake **systemic advocacy** so that systems and services improve based on the needs and interests of people with lived experience. We are in a unique role where we must understand the **collective interests** of people with lived experience and take action to address collective concerns and aspirations. For Māori, we must be holistic in taking a collective approach which includes whānau, hapū and iwi, and which challenges Western individualism.

Our advocacy role is outlined in the Mental Health and Wellbeing Commission Act – the legislation which established us as an independent crown entity. The Act also outlines that we must have effective means of seeking views from lived experience communities to fulfil our other functions.

These functions include to:

- assess and report publicly on mental health and wellbeing
- make recommendations to improve mental health and wellbeing
- monitor mental health and addiction services
- advocate for improvements to mental health and addiction services and approaches
- promote alignment in the mental health and wellbeing systems.

We know that experience of distress is common, and people with personal experiences are diverse

Many people have a personal connection to mental health and addiction through their own experiences. **He Ara Oranga** highlighted that 50 percent to 80 percent of New Zealanders will experience mental distress or addiction in their lifetimes. When we consider whānau and family experiences, most if not all people in Aotearoa have some connection related to mental distress and / or addiction. These people, whānau and families all may be impacted by decisions that shape the approaches, supports and services for people experiencing mental distress, substance harm or harmful gambling.

People who personally experience mental distress, substance harm, harmful gambling, substance addiction or non-substance addiction (or a combination of these) come from a range of backgrounds and have a wide variety of experiences. Some people use mental health or addiction services, some are supported by whānau, family or friends, and some people struggle to have their distressing experiences recognised, validated or responded to. For some people, it is difficult to access support or services, and others cannot access support services even when having formal support feels like the only thing that will help.

Some people feel like partners or leaders in their wellbeing – they are empowered to make decisions and health professionals respect and support these decisions. Other people experience coercion, forced treatment, being detained in inpatient facilities and have very little sense of control over fundamental aspects of their lives. Some people’s challenging experiences are socially constructed as moral issues rather than being acknowledged as distress. Some people face intense discrimination, while others do not. Some people are given diagnoses that are generally more understood and accepted, whereas other people talk about never being able to move on from receiving labels that attract prejudice and judgement.

Prejudice and discrimination can shape how people with personal experience of distress or addiction choose to identify, and the criminalisation of drug use creates a different kind of stigma that runs deep for people who use substances. Some people will identify with the term “lived experience” and others may not. We value and

uphold the right for people and groups to choose how to identify and to reclaim language, including as: 'tāngata whaiora', 'tāngata mātau-ā-wheako', 'matakite', 'consumers', 'service users', 'psychiatric survivors', 'peers', 'people seeking balance', 'people', 'people seeking belonging', 'citizens', 'people who use drugs', 'people seeking identity', 'people seeking a balm for pain', 'disabled people', 'trauma survivors', 'big feelers', 'exquisitely sensitive', 'spiritual', 'mad', 'neurodivergent', 'sane people reacting to a crazy / unjust world', and having 'personal experience', 'lived experience' or 'living experience'.

In conversations with Māori lived experience leaders we have heard the need to respect the meaning in te ao Māori of "tāngata whaiora" – literally people seeking wellness or wellbeing, and concerns about how "tāngata whaiora" has been co-opted to mean "service users" or "consumers" by others in the mental health and addiction system. We heard from young people that "lived experience" doesn't often feel right to them, and that "personal experience" feels more fitting to their experiences and worldview, especially if they are not ready to share their experiences widely or aren't employed in the lived experience workforce.

We are also aware that lived experience movements themselves are currently developing ideas around the meaning of "lived experience" and what "lived" means in this context. We want to be inclusive in our language, and we also want to avoid overstepping or precluding important discussion that lived experience movements are undertaking to self-determine the language that is used to refer to their experiences and their mahi. We use the terms "personal experience" and "lived experience" in this document, but do not attempt to specifically define these.

In the past, communities have experienced a disconnect when agencies have attempted to define what 'lived experience' means

When organisations have a role working with or supporting people with lived experience, there can be a focus on 'defining' lived experience or establishing who has lived experience for the purposes of their work. Because "lived experience" is a personal and closely-held identity, having this defined by others can be experienced as a kind of epistemic injustice – this means it can be invalidating, silencing, excluding and harmful when others control language that relates to peoples' identities. Where agencies have defined lived experience narrowly, people have felt excluded and unseen. This can result in people being left out of important work or decisions that impact their lives.

At other times, agencies have not clearly detailed how they will work with lived experience communities, or they have defined lived experience in a broad way. The statement that "everyone has lived experience" is an example of this. Lived experience communities have criticised the use of this phrase. It does not indicate how an organisation plans to work with and honour the views of people most

impacted by their work. Saying that “everyone has lived experience” also does not acknowledge the loss, harm, and exclusion that some people experience as a result of system decision making and practices and doesn’t give dedicated space to hear the perspectives of tāngata whaiora Māori.

Because we need to advocate for transformation at a collective, or system-level, not an individual level, we need a way of thinking about lived experience and connecting with people and communities that allows us to understand the “collective interests” of people with lived experience. We also need to include in our system monitoring work people who have personally experienced distress and addiction to highlight service quality from an experiential perspective.

While it is not our role to “define” what lived experience means, we need to develop an approach to lived experience which enables us to do our work intentionally and with integrity.

We need an approach that enables us to work with lived experience communities in an intentional way, effectively advocating for transformation across the system

To advocate for the concerns and aspirations of people with lived experience, we need to welcome connection from people with personal experience of mental distress, substance harm, harmful gambling, substance addiction or non-substance addiction (or a combination of these experiences) and we need to believe and validate the experiences that people share with us.

We also need to proactively seek involvement by people and groups whose personal experience and lived experience highlight the significant issues and possibilities for change across the system. Hearing these views will inform our advocacy work. We propose that our approach to proactively working with lived experience communities does the following (each point here will be discussed in more detail over the following pages):

- centres experiences of surviving loss, harm, and exclusion which occur as a result of the current mental health and addiction system (it is also crucial to acknowledge that the lived experience community has lost members who have not survived these experiences)
- privileges the experiences of tāngata whaiora Māori and tāngata mātau-ā-wheako Māori
- treats “lived experience” as an unfinished sentence - asking the question “*lived experience of...?*” (or “*lived experience of what?*”) - we are intentional about relevant ‘lived experiences’ to each piece of work that we are undertaking (e.g. monitoring Opioid Substitution Treatment services would involve people who have personal experience of these services)

- involves people with personal experience in system monitoring - including people who experience more specialist, restrictive, and coercive services in service monitoring and including the voices of people who cannot access the supports that they want or need, who face barriers or equity issues
- recognises that 'lived experience' provides a theoretical lens and an evidence base (*expertise*) as well as an experiential anecdote

Embedding lived experience roles and relationships within Te Hiringa Mahara and supporting the development of lived experience communities and their leadership will enable us to take this approach.

Te Hiringa Mahara exists to serve lived experience communities, whānau, and the people of Aotearoa, and will welcome and actively seek feedback on how we are doing. This includes in our role as an advocate and system leader.

Valuing and being guided by lived experience perspectives means:



Privileging the experiences and aspirations of Tāngata Whaiora Māori is one way of upholding our commitment to te Tiriti o Waitangi

Whakapapa

Good mental health depends on many factors, and among indigenous populations cultural identity and healing from cultural disconnection is critical. Being Māori is considered the basis for recovery for tāngata whaiora Māori (Māori with distress seeking wellness) and lies firmly within the context of one's identity as Māori. The rediscovery of whakapapa – the connections of who we are and where we come from – is the foundation of recovery.

At the heart of current Māori 'mental un-wellness' is colonisation, institutionalised racism, unconscious bias, and a western model of mental health, with systems that strengthen that model and perpetuate further inequities than those already experienced by Māori. In the Government Inquiry into Mental Health and Addictions, tāngata whaiora Māori said that their mental health suffers as a direct result of a long-standing alienation from their land and the impact of colonisation and intergenerational deprivation. Reclaiming mental wellbeing requires reconnection to land, culture, whakapapa, and history, but many mental health and addiction services barely recognise or acknowledge the importance of this connection and therefore reinforce trauma.

Te Ao Māori

To begin to understand why this is so, we need to gain some knowledge through a Māori lens where values and beliefs are inherent within Māori culture. Māori knowledge, mātauranga, encompasses not only what is known, but how it is known – the way of perceiving and understanding the world, and the values and systems of thought that underpin those perceptions.

Mātauranga embraces all that is distinctive about Māori culture and identity. The defining principle is whanaungatanga, kinship between humans and the natural world where all elements of creation within the living and spiritual realms are interrelated. People are not superior to the natural order but rather they are a part of it. All animate and inanimate elements are infused with mauri (spirit or living essence) and related through whakapapa. Māori understood that they and all life is created from Papatūānuku (Mother Earth) and is supported by her in an intrinsically inter-connected way.

Overwhelmingly, submissions received from Māori during the Government Inquiry into Mental Health and Addictions said that the health and wellbeing of Māori requires recognition of indigeneity and affirmation of indigenous rights. It has been argued that approaches to mental health needs to acknowledge the Tangata Whenua status of Māori under Te Tiriti o Waitangi. In addition to more Kaupapa Māori services

and a strong Māori mental health workforce, Māori need to determine how services are commissioned, delivered, and evaluated.

Western Model

The Western model of mental health, enshrined in the health system and legislation, is based on beliefs that are not shared by all Māori and are not always helpful – for example, the separation of mental health from *oranga* (health and wellbeing) is contradictory to holistic understandings of health. Māori identity is rooted in *whakapapa*, *tikanga* and *kawa*.

Tāngata whaiora Māori are surrounded on all sides by non-Māori / Western perspectives. A group of *Kaupapa* Māori service providers and *tāngata whaiora* highlighted in the Government Inquiry in 2018 that there is conflict between Western and Māori ideas of best practice. Many Māori pointed out that current mental health services, strategies and policies do not reflect a genuine partnership between the Crown and Māori. They argued that the way our health system approaches mental distress and diagnoses mental illness reflects a colonising world view largely hostile to Māori understandings of wellbeing. They spoke of compulsory treatment as a threat to *mana* and to their ability to live as Māori.

It was heard that recognition of the significance of important ties to *whānau*, *hapū*, and *iwi*, including the contribution those ties make to wellbeing, and proper respect for cultural and ethnic identity and language rarely form part of psychiatric assessments. They are routinely not addressed by courts, tribunals or in other practice decisions relating to compulsory assessment and treatment. Furthermore, it was heard that *tāngata whaiora* are denied their entitlement to be dealt with in a manner that accords with the spirit of proper respect for cultural identity.

Connecting and working together

Across all of our connections with lived experience communities – in relationship building, system monitoring and advocacy projects, we need to ensure that *tāngata whaiora* Māori are involved and heard. This involves taking a *by Māori, for Māori* approach, creating spaces and relationships where *tāngata whaiora* and *tāngata mātau-ā-wheako* Māori can be Māori, and not have to fit in to a *tauwi* (non-Māori) way of connecting and working together. This responds to the need to indigenise our spaces.

The lived experience research and expertise that we draw on in our work will also reflect a *te ao Māori* worldview, for example through ensuring that we utilise Māori lived experience research wherever possible, and ensuring our expert advisory groups include strong *tāngata whaiora* Māori, *tāngata mātau-ā-wheako* Māori and *whānau* representation.

Equity for lived experience communities, and within lived experience communities, needs to be a focus for our work. We need to develop strong connections with Māori

lived experience networks, service users and Kaupapa Māori peer organisations, and we need to understand experiences like seeing visions and hearing voices through a te ao Māori lens. Our work must be strengths-based – focussed on recovery and hope, challenging racism and prejudice, and illuminating the perspectives and wisdoms that tāngata whaiora tāngata mātau-ā-weako and whānau Māori have to share.

Amplifying the voices of people who have experienced ‘loss, harm and exclusion’ allows us to see structural problems that need to change

We need to be aware of the systemic harm and exclusion that people in distress can experience when seeking or accessing support. We believe that we can learn the most from people who have experienced significant challenges compounded by systemic harm, and from people who have developed a vision of what needs to change informed by these particularly challenging experiences. These experiences reflect the journey spoken of in the karakia “tēnei te pō, nau mai te ao” – from the depths of darkness into the light of hope, possibility and significant change.

Centring these experiences requires us to be proactive in engaging with people and networks who can share personal or systemic experiences of loss, harm, and / or exclusion, as well as wisdom about the possibilities for change. Working together will help us to describe what “system transformation” looks like. It will help us to advocate for change that improves the system for everyone, especially those who are most marginalised by the current system.

Centring experiences of loss, harm and exclusion



Loss, harm and exclusion impact people in many ways

Loss can result from engaging with the mental health and addiction system. It may include the loss of employment or parenting roles, loss of connection with whānau, family or friends, or more existential experiences of loss of identity, or an eroded sense of trust in oneself. Loss can also occur when a person reaches out to services and is denied access and support, for example in loss of relationships or relational mutuality with whānau, friends and family as they “burn out” or become “carers”, and loss of work or education while people are trying or waiting to access support. For people with ongoing journeys through distress, having to “struggle against” system processes to be re-assessed for support many times can cause a sense of losing energy and hope. When people experience loss as a result of systemic issues, their recovery journeys often involve a process of rebuilding connections to what they value.

Harm that results from service use, diagnosis, or treatment (iatrogenic harm) is becoming more recognised by the mental health system, including harm from practices like solitary confinement (seclusion) and restraint. It also refers to harm to physical health caused by psychiatric medications or diagnostic overshadowing (where a focus on mental illness prevents healthcare providers from seeing physical health issues), harm from abstinence-only approaches in addiction services or punitive and risk-averse practices, and harm caused by an approach that triages people and provides access to support based on risk.

The Mental Health Act should also be mentioned here. The impact of the loss of control and autonomy when subject to the Mental Health Act is harmful, and the experience of having been under the Act can stay with people beyond its duration. So too are the experiences of being given particularly stigmatised diagnoses, which can cause an ongoing harm as preconceived ideas attached to these labels and experiences can “follow people around” for years or for a lifetime.

Being unable to access support can also cause harm. Examples include criminalisation where health approaches to addiction are absent, physical harm as a result of ongoing substance use or self-harm, financial harm, harm to cultural identity and pride (when support is inaccessible because of a lack of culturally competent supports or services, or when accessibility barriers exclude disabled people), harm to relationships and connectedness, and existential harm of feeling ‘helpless’ or like a ‘bad person’. For children, young people and their whānau, long waiting times can cause harm as their usual social, educational development and their whānau and family relationships are impacted by ongoing distress.

Exclusion that results from using mental health and / or addiction services can include experiences of self-stigma and prejudice and a resulting disconnection of relationships. Practices in the mental health and addiction system, such as relying on police to attend and transport people in a crisis situation, can lead to people being

judged or excluded by whānau, family or neighbours, as can being treated away from home in large, locked mental health units or being put under the Mental Health Act.

Widespread prejudices around addiction, and some psychiatric diagnoses impact many people including when people connect with the mental health and addiction system seeking support and are told that they cannot access support based on their labels or experiences. Where a person cannot access support that explains and validates what they are going through, other damaging explanations for their struggles might emerge from those around them e.g., being treated as 'lazy'. When people are excluded, recovery may mean people developing a new identity of self-worth by taking apart and countering the messages that have devalued them.

Exclusion resulting from criminalisation impacts people who experience substance harm or addiction to drugs which are currently illegal to use. People with lived experience of addiction describe the social stigma, prejudice and exclusion faced by people who use drugs as very different to the exclusion experienced by others. This difference is due to the illegality of their particular experience.

Compounding exclusion can occur when people have other, intersecting identities that are socially devalued or oppressed. We are particularly aware of the equity issues faced by young people, children experiencing adverse childhood events or who are in state care, Pacific people, migrants including Asian people, former refugees and forced migrants, rainbow communities, rural communities, veterans, prisoners, older people, and disabled people. Compounding exclusion can magnify barriers to accessing support when people want or need it, which can cause disproportionate loss or harm. It can also result in inappropriate placement of people in rest homes or disability services where the mental health support people need is not available. Systemic issues impact some groups of people to an even greater degree, for example, police attendance in a mental health crisis poses a different kind of harm for former refugees who have travelled from countries where authorities treat people violently. Understanding the particular experiences of people who face compounding exclusion, prejudice or discrimination is important for us to fully understand and amplify the voices of people who experience loss, harm and exclusion across our work, and address equity issues.

We acknowledge that, even in the face of significant harm, loss, and challenge created by structural behaviours and barriers, people often draw on their agency, resources, and relationships to survive or overcome these systemic challenges.

Loss, harm and exclusion are an important part of the bigger picture



Taking an approach of amplifying the voices of people who have experienced loss, harm, or exclusion enables us to see the bigger picture of personal experience but allows us to ensure that we focus on those who have experiences which most need to be heard, understood and addressed at a systems level.

Loss, harm and exclusion can shape a powerful vision for change when people are given space to talk about their experiences and what needs to be different. This is sometimes described as ‘radical imagination’. We are not only interested in connecting with and hearing from people who have lived experience of loss, harm and exclusion to understand the challenges faced and the harms caused in the current mental health and addiction system. We believe that people who have been through these experiences can lead the way forward. It is through the most challenging experiences that people develop the skills, wisdom and perspective to guide themselves and their whānau through their recovery journeys, and this wisdom extends to being able to see a ‘way forward’ for the mental health and addiction system as a whole. When people who have experienced loss, harm and exclusion contribute to conversations about “what could be” their visions for change are likely to benefit and work for others who are most in need of system transformation.

Taking an intentional approach involves asking “lived experience of...?”

We need to take a nuanced and intentional approach to understanding lived experience in relation to specific areas of advocacy, monitoring and leadership work. This involves approaching lived experience as an unfinished sentence, where we benefit from asking the question ‘lived experience of what?’ In practice this would mean that, as we explore and provide commentary on services and approaches to mental health and addiction, and wider wellbeing issues, we proactively involve people who have direct, relevant, personal experience of that specific issue. For example:

- advocacy to expand Kaupapa Māori peer services would involve tāngata whaiora Māori who have used these services, Māori peer workers and leaders
- assessment of the availability of addiction services should involve people who have accessed addiction services and people who have not been able to access these services
- a submission on the Mental Health Act repeal and replace should involve people who have been sectioned under the Act

Assessing and monitoring the mental health and addiction system needs to involve people who know first-hand what services are doing

Personal and lived experience input into system monitoring should involve hearing from people with a personal experience of using supports and services, and people who have wanted or needed those supports and services but have been unable to access them. Hearing from Māori with these experiences is particularly important.

In primary care, there is evidence that Māori present more often with mental health challenges but are not adequately responded to. In secondary care, Māori are more likely to be admitted to hospital, to be readmitted after discharge, to be subject to solitary confinement (seclusion) including during admission, and to be compulsorily treated under the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act) and in forensic services. The outcomes for Māori who access mental health services are poorer across a variety of measures and diagnoses.

Because the mental health and addiction system is set up to provide additional support as people's need increases, all levels of the system should be accessible and supportive for people with experience of 'significant distress' or who have been diagnosed with 'severe mental illness'. Monitoring at all levels of the mental health and addiction system should therefore include the voices of people with the greatest distress and / or service use experiences.

Assessing and reporting on wellbeing should also involve people with lived experience, as we have a particular focus on equity, and we know that people who experience mental distress or addiction face social exclusion, poverty and physical health disparities.

Drawing on lived experience 'expertise' provides a knowledge base for understanding the system and what needs to change

Lived experience is often used to describe the 'expertise' developed by tāngata whaiora, consumer, survivor, and peer communities. This takes as its start point an intentional naming of lived experience – people openly identifying with their experiences in some way – and taking actions to use this experience to impact change.

Lived experience or expertise can be understood to denote specific skills, including the ability to hold multiple truths, open and transparent facilitation, developing validating and mutual relationships, and telling personal experiential stories in ways that connect and make sense to others. When 'lived experience' is paired with words like 'research', 'evidence', or 'knowledges' it describes a theoretical approach; a 'way of seeing' that can be applied to policy, strategy and service-level change.

Te Hiringa Mahara can include lived experience perspectives across our work by intentionally drawing on lived experience research to shape our thinking and our 'sense-making'. Lived experience theory values qualitative and ethnographic approaches which enable people's stories to be heard in their own words.

It could be described as an approach underpinned by a privileging of:

- human rights frameworks
- tikanga
- mana-enhancing and self-determination enabling approaches
- contextualised understandings of distress e.g., those that make trauma, colonisation, and power-imbalances visible and relevant
- self-defined experiences (rather than centring clinical definitions)
- lived experience social movement calls and actions
- hopefulness that is founded on an unwavering belief that all people have strengths, can experience wellbeing, recovery and live lives that they value

Māori lived experience and whānau leaders remind us that, for Māori, personal narratives are collective narratives and whakapapa narratives cloaked in whānau, hapu and iwi context.

Roles exist across the lived experience sector in Aotearoa, including Māori lived experience leadership roles, consumer advisory, auditing and research roles, peer support and peer advocacy roles, and monitoring and management roles, which apply this lens to practises and structures within the mental health and addiction system. Forming strong connections with people in these positions will be integral to our leadership work around lived experience and system transformation.

Embedding lived experience roles and relationships

Lived experience communities have told us that they want engagement with Te Hiringa Mahara to be with "peers" – staff who have their own personal experience, or who are in designated lived experience roles. We have also heard that, along with engaging and gathering people's feedback and ideas, the analysis and reporting of what we hear from lived experience communities should be undertaken by people who bring a lived experience lens to this work.

In addition to supporting strong, effective lived experience roles within Te Hiringa Mahara, lived experience communities emphasised the importance of supporting the growth and development of lived experience networks and their leadership. We need to be supporting the development of the next generation of lived experience leaders. This was also seen as essential for sustainability of lived experience input into the work of government agencies and independent crown entities into the future.

Working with lived experience communities means genuinely valuing peoples time, energy, and contributions, and engaging in a spirit of mutuality.

Bringing these strands together, we aim to make a tangible difference

He Ara Oranga highlighted the need to hear the ‘voices of lived experience’ and to ‘put people at the centre’. Having a clear approach to valuing lived experience within the Te Hiringa Mahara will not only enable our own work to have a strong compass, but it will also enable us to share a potential ‘way forward’ with other agencies and organisations, as a part of our leadership role in the system.

In June and July 2022, we shared a draft version of Nau Mai te Ao with lived experience communities and heard feedback from Māori lived experience groups, consumer advisory and advocacy groups, youth advisors, lived experience leaders working to counter stigma, prejudice and discrimination, addiction consumer leaders, people working in and supporting the peer workforce. Based on this feedback, we have made changes to Nau Mai te Ao that have strengthened and clarified our approach. Many thanks go out to everyone who contributed to this conversation.

Based on Nau Mai te Ao, we have also published a “Lived Experience Position Statement”. This shares how we value lived experience in all of our work and outlines our commitments to lived experience communities.