

He Ara Āwhina

Pathways to Support framework

Summary of Lived Experience and
Tāngata Whaiora Consultation

July 2022

Acknowledgements – Nothing About Us Without Us

Kei te whānau te mana rangatira o tōna oranga.

We lead our wellbeing and recovery.

For those who have gone, never to be forgotten.

For those who remain we acknowledge and honour you.

For those to come we will keep you safe and cared for.

For we are all precious and you are all loved.

This document is **for people with lived experience of substance harm, gambling harm, and distress in Aotearoa New Zealand**. The voices of those with lived experience, their whānau, their communities that they belong to, and the vibrant organisations that they are a part of were heard and incorporated into He Ara Āwhina.

Te Hiringa Mahara (the Mental Health and Wellbeing Commission) recognises that the stories, aspirations, thoughts, and dreams of people are a gift. We see the submissions that you may have shared as taonga, and of great value, wisdom, and mana that was hard earned in their telling.

We acknowledge and thank every person, whānau, Lived Experience network, and peer organisation who made submissions on He Ara Āwhina. This often led to the sharing of deeply personal stories that highlight why we must monitor the Mental Health and Addiction system and bring about change.

We also wish to acknowledge everyone who helped us develop the draft framework for consultation. Our expert advisory group members, lived experience focus group members, tāngata whaiora Māori focus group members, the Addiction Consumer Leadership Group, Prevention and Minimisation of Gambling Harm advisory group, NYCAN, NAMHSCA, and people who contributed at the very beginning of this journey by sharing thoughts and advice during the ‘co-define phase’.

We hope that this summary report illustrates how we have heard and used the valuable feedback that you have shared.

We also hope that this report will be read by others working in and leading the mental health and addiction system. The voices in this summary report can help us all to understand what is most important to people who have the greatest, and most personal, interest in the transformation of the mental health and addiction system.

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Our development journey

Te Hiringa Mahara

Te Hiringa Mahara (the Mental Health and Wellbeing Commission) is kaitiaki (guardian) of mental health and wellbeing, and was established as one of the recommendations of [He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction](#) (Government Inquiry into Mental Health and Addiction, 2018). Our key objective is to contribute to better and equitable mental health and wellbeing outcomes for all people in Aotearoa. To do this, we **provide mental health and wellbeing system-level oversight, monitoring, and advocacy**. We also hold the Government and other decision makers to account for the mental health and wellbeing of people in Aotearoa.

As we work towards transforming Aotearoa's approach to mental health and wellbeing, we have a specific responsibility to people who have personally experienced mental distress or addiction. We are obliged to effectively seek and hear the views of people with lived experience – reflecting these voices in the work that we do, and we have a unique role to advocate for the collective interests of people who experience mental distress or addiction (or both).

He Ara Āwhina (Pathways to Support) framework

A core function of Te Hiringa Mahara is to monitor and report on mental health services and addiction services, and advocate for improvements to those services. This function was transferred from the former Mental Health Commissioner to Te Hiringa Mahara on 9 February 2021 by the [Mental Health and Wellbeing Commission Act 2020](#).

[He Ara Āwhina \(Pathways to support\)](#) is the framework that will allow us to monitor these services, and the wider mental health and addiction system. Work on He Ara Āwhina began with the Initial Mental Health and Wellbeing Commission undertaking a [‘co-define phase’](#) with communities between October 2020 and February 2021. Through this process, we explored together what our approach to mental health and addiction service monitoring should look like. We held conversations with lived experience communities around ‘what we should monitor’, ‘why we should monitor’, and ‘how we should monitor’. From these discussions we heard three important things, which we have honoured in developing He Ara Āwhina:

- **Support starts and continues with people and communities, not services.** The former Mental Health Commissioner’s monitoring framework was viewed as too narrow but was something that could be refined and built upon.

- The voices of Māori and tāngata whaiora are crucial in assessing whether services, and approaches to wellbeing, are meeting the needs of people and communities.
- There needs to be a shared view of what ‘good’ or transformative services and supports look like so we can monitor and assess performance and contribute to wellbeing outcomes.

After the co-define phase, an [expert advisory group](#) (EAG) was established and began their mahi (work) in September 2021, sharing expertise and perspectives to develop the framework. This included lived experience wisdom brought by EAG members who had their own personal journeys through distress or addiction.

The EAG included a Māori EAG roopū which have led the development of the Te Ao Māori perspective for He Ara Āwhina.

Advice from the EAG, as well as from lived experience focus groups (including Māori, youth, mental health, addiction, and gambling harm perspectives), targeted discussions, and hui with Māori helped us develop the draft version of He Ara Āwhina.

The draft version of He Ara Āwhina went out for public consultation for six weeks from 8 March to 19 April 2022. Te Hiringa Mahara supported many ways for people to provide us feedback and reached out to consumer networks, peer organisations, and people with lived experience to ensure that we heard from those who are most personally impacted by the mental health and addiction system.

The consultation asked three main questions:

1. Does He Ara Āwhina reflect your hopes for a mental health and addiction system?
2. Is He Ara Āwhina missing anything that is important to you?
3. Is there anything else you want us to know about how we should monitor services and system transformation?

During our public consultation process we received more than 260 submissions across all our priority population groups (Māori, Pacific people, former refugees, migrants, rainbow communities, disabled people, rural communities, veterans, prisoners, older people, young people, children in state care, and children experiencing adverse events). Through a dedicated Māori engagement team, we achieved strong input by Māori, including tāngata whaiora, whānau, and Kaupapa Māori supports and services.

Many submissions came from people who have personal experience of distress, substance harm, gambling harm, or using mental health or addiction services. We also

heard from people who have sought mental health or addiction support and have not been able to access this support when they needed it. Overall, 130 submissions were from people with personal lived experience, their networks, and organisations. 123 of these identified as having experienced mental distress whilst 48 identified as having experiences of addiction (see [appendix 2](#)).

Public consultation feedback has actively shaped changes to the framework, and Te Hiringa Mahara published the final version of He Ara Āwhina on 30 June 2022.

We have put this summary report together for our lived experiences communities in Aotearoa, to honour and acknowledge them and the taonga they have entrusted us with during the consultation process, and to show how we have used this feedback. There are three other summary reports that include what we heard from Māori, people who work in, support whānau with, or personally experience alcohol or other drug harm, gambling harm or addiction, and everyone - tāngata whaiora, whānau, and their supports, people providing mental health or addiction supports and services, and policy makers or commissioners of services.

What we heard and how this changed the framework

People who have experienced distress, harm from substances, or harm from gambling are varied, different, and diverse. To bring the voices of people with lived experience together has been a valuable and an important task for Te Hiringa Mahara. The mana given to these voices, thoughts, and suggestions ensures that we have been careful to make each individual and group submission heard and valued. The richness of what has been shared is an important part of this document.

While we have not been able to include quotes from every lived experience submission we received, the themes that they expressed are included here as well as, importantly, the changes to He Ara Āwhina that have resulted from these discussions and feedback.

General comments about He Ara Āwhina

He Ara Āwhina reflects many people's hopes

Overall, lived experience communities saw the goal, system aspirations, two perspectives and content of He Ara Āwhina as hopeful and positive. People shared their expectation that meaningful change will result from the monitoring framework. This is encouraging.

I was hoping for kindness, a holistic perspective and an understanding of the need for whānau wide input and support. Am delighted that this is woven right through your framework. (Lived experience of distress)

The opportunity to provide a system which is warm, welcoming and reassuring is an incredible one and I have high hopes for the future. (Tangata whaiora / lived experience of distress)

This is where we want to be – I loved the framework. (Addiction consumer leadership group)

For Māori with lived experience, the inclusion and positioning of the Te Ao Māori perspective of the framework was exciting and hopeful.

As tangata whaiora Maaori, with lived experience: the 6 Maaori aspirations resonate with me and my peers of maaori descent. The Shared perspective rings true for my whaanau and friends who know little of Maaori values/traditions/matauranga, who have been marginalised from their culture. These aspirations have the ability to transform the MH&A system if it is actioned. (Tangata whaiora / lived experience of distress)

So ambitious – love it. Never before in the history of Aotearoa has this happened [seeing Te Ao Māori and shared perspectives for the monitoring approach]. (Consumer and whānau network)

The importance of Te Tiriti o Waitangi, and the importance of addressing racism, and ensuring cultural safety are important aspects of He Ara Āwhina, especially for people who had personal experience of culturally unsafe practises in the system.

I'm just really happy to see the emphasis on a culturally safe space as well. I know through my own experience of accessing services, that cultural safety was not held. And I found that in my work with young refugees and young migrants, that is also a concern. (Youth consumer network)

That's what I really like about it is that it's based on te Tiriti because like I said [regarding my last hospitalization] ... there was like four or five Pākehā [staff] there and I was like, "I'm not here to educate you". And I just feel like this day and age, there's not really any excuse around [that]. So I really like all the decolonizing and naming racism. (Māori member of lived experience community)

Addressing racism – this needs to be stronger in the document.
(Consumer and whānau network)

People wished to see addressing racism strengthened in He Ara Āwhina, which we have done by adding that the system understands and acknowledges the impacts of colonisation and that workforces are fully culturally competent.

Clarity around Te Ao Māori and Shared perspectives

Māori peer workers also shared their concerns that people may think that the Te Ao Māori perspective is only relevant to Kaupapa Māori services, unless Te Hiringa Mahara clearly communicates that mainstream services need to uphold both the Te Ao Māori and Shared Perspectives.

Honouring te Tiriti o Waitangi above and beyond just the use of kupu Māori in documents and wondering, in terms of separating te Ao Māori perspective and a shared perspective, if they might run the risk of... mainstream services abdicating their responsibilities to te Tiriti o Waitangi. (Māori lived experience leader taking part in a lived experience workforce roopū discussion)

Feedback around this topic emphasised the importance of our system being truly grounded in Te Tiriti o Waitangi, and the need to decolonise practices. Because of this feedback we strengthened this language in the framework. We will also ensure that in sharing He Ara Āwhina with services and with communities, that we are clear that the Shared Perspective and Te Ao Māori perspective relates to mainstream services and supports.

Lived experience communities particularly supported some content of He Ara Āwhina

Tāngata whaiora and lived experience organisations commented on the monitoring priorities that they particularly valued seeing in He Ara Āwhina. The aspects that gave them the most hope and optimism for the future included:

- a focus on holistic wellbeing
- increasing whānau funding models
- upholding self-determination
- and looking beyond services to support provided by communities.

Monitoring to eliminate coercive practises was especially important to many people.

I was particularly heartened by the acknowledgement of trauma-responsive care providing a better and safer alternative to coercion and

seclusion. I myself have suffered this treatment, and it felt like psychological torture. (Tāngata whāiora / lived experience of distress and addiction)

When I think of coercive practices... I mean, seclusion's a very clear one to track, but when we're talking about particularly models or legislation, that is where people are more at risk of risk-averse decision making and where the balance may tend to favour that safety of the public... When I see that, I think of OST [Opioid Substitution Treatment]. (Consumer, peer support, and lived experience workforce roopū)

[I had] experience of being detained and forcibly medicated for three months. This was not ok and needs to stop happening to people. (Lived experience focus group)

We were reminded of how crucial system monitoring is in the lives of people seeking support, wellbeing, and recovery.

It is great to see this framework... Monitoring the system is a step towards justice for people who did not get treated well by the system, or who are no longer with us. (Lived Experience group)

The framework sets extremely high standards, that we (tāngata whāiora) deserve. (Consumer network)

Language in He Ara Āwhina

Explaining terms, plain language, and layout

People asked us to use plain language, include visual elements, use concise statements, and publish a simplified summary version of the framework with less text to read. People also emphasised the importance of explaining terms in a way that is meaningful to tāngata whāiora and whānau, and suggested that a language guide could support this.

It'd be nice to have a clearer description of what coercive practices might look like... Otherwise, people will tend to think, "Oh, that's just about seclusion." I think it's far broader than that. (Consumer, peer support, and lived experience workforce roopū)

I don't know if the framework is for me, if it isn't clear around what is meant by harm reduction. (Addiction consumer leadership group)

In response to this feedback, we have created a visual [summary version of He Ara Āwhina](#). There is also now a [Guide to language in He Ara Āwhina](#) to assist with terminology. These sit alongside the full version of [He Ara Āwhina \(Pathways to Support\) framework](#).

He Ara Āwhina needs to use language that is inclusive of people who experience significant distress

We heard how important purposeful and inclusive language is. Several groups felt that the language of “mental distress” did not include their experiences of “mental illness” or “mental health challenges.” People also expressed concern that mental health services, too, might see He Ara Āwhina as relating only to the care and support of people with “mild to moderate” mental distress. They stated our intention for He Ara Āwhina to be used to improve the system for everybody, no matter their level of distress, needed to be made clearer. He Ara Āwhina has a role monitoring and improving specialist secondary and tertiary services and crisis supports, and improving the experiences of people who experience extreme distress.

Sometimes I present in one way and sometimes I present in crisis. And so, that is an important part of my experience and sometimes those crisis experiences are the very pointy end of our experience with mental health services. And this is when it becomes absolutely crucial that the services are doing things right. (Consumer, peer support and lived experience workforce roopū)

Lived experience networks also shared concerns about the term “mental distress” as it implies that distress is “mental.” They stated it does not reflect a holistic perspective or acknowledge how “mental” is used in derogatory or stigmatising ways. Suggestions of language we could use instead of “mental distress” included: “mental health challenges,” “people with major and enduring mental illness,” “distress,” and, in place of “tāngata whaiora,” one organisation suggested that we should refer to people simply as “people.”

For those of us who have chronic and severe and enduring mental health challenges, sometimes the words, mental distress, don't capture it... we don't see ourselves in documents that only refer to us as having mental distress. (Consumer, peer support, and lived experience workforce roopū)

[We] find it a barrier in some of the language e.g. the continued use of the word “mental” is stigmatising. (Consumer network)

As a result of this feedback, we have replaced “mental distress” with “distress” in the framework; although, we still use “tāngata whaiora.” We have also included a [‘Guide to language in He Ara Āwhina’](#) that clearly establishes the framework’s relevance to anybody who is impacted by challenging thoughts, feelings, and experiences, including extreme distress and times of crisis, and the services that exist to support them.

Use of the term “harm reduction”

Peers with experience of addiction also encouraged us to look at our understanding of ‘harm reduction’ and to use this language in the broad way it is intended.

The placement of harm reduction under access and options, [has] the possible appearance that’s incongruent with the history, the wide history, concept and practice of harm reduction, especially in the addiction space... (Consumer, peer support, and lived experience workforce roopū)

Changes across the framework reflect this valued feedback are now included in the Safety and Rights, Access and Options, and Connected Care domains, and the Effectiveness domain includes a statement that: **We benefit from dedicated action across government to prevent suicide, distress, substance harm and gambling harm...**

Equity

For the system to show it is supporting people equitably, we were told that He Ara Āwhina needs to recognise and name the communities that people belong to, and the individual identities they hold.

We recommend the framework specifies that services will meet the needs of all New Zealanders and that the framework should specify a commitment to marginalised communities and groups. (For-peer-by-peer organisation)

Communities facing systematic issues highlighted by tāngata whaiora include: trauma survivors; Māori; Pacific peoples; Asians; migrants; former refugees; rainbow communities; disabled people and differently abled people, such as those with deafness, autism, and rare disorders; tāngata whaiora with communication needs; older people; young people, such as those experiencing abuse or unsupportive family environments, adverse events, and in state care; and people who are homeless, living in poverty, or living rurally.

We also heard from tāngata whaiora that their particular diagnoses or experiences of distress have disadvantaged them, and that this needed to be addressed.

[Look at] equity for people who are placed in the too hard basket and when diagnosis is used as a rationale for either coercive treatment or no treatment... Look at the ways in which we divide people up into different categories within our service and see whether we have equity of outcomes across the board in that way. (Youth consumer network)

In response to this feedback, we strengthened the 'Equity' domain of He Ara Āwhina, by adding the concept: **We are valued for who we are. We are not disadvantaged by our diagnosis, ethnicity, age, identity, or disabilities.**

Tāngata whaiora define their experiences, needs, and aspirations

Self-defined experiences and needs

We heard positive feedback on the Access and Options domain, particularly around the range of formal support options, focus on community connections, and the mention of increasing whānau funding models. People also liked the statement “supports and services... respond to our experiences, needs and aspirations.” However, people raised that experiences, needs, and aspirations must be self-defined in a transformational system. If not, people’s experiences of distress could continue to be described using psychiatric labels that do not necessarily reflect their views and in ways that imply that something is “wrong” with them.

Rethinking a biomedical / medicalised model as being fit for purpose outside of the realm of physical illness... People are the experts in [their] own wellbeing and their own journey. This must extend beyond simply honouring human rights, or there is still a likelihood that people experiencing mental unwellness may have their own truth and knowledge devalued. (For-peer-by-peer organisation)

Some people described this as retaining ‘authorship’ of their experiences – being able to describe experiences using terms other than diagnoses. They stressed that their authorship shouldn’t be overridden when accessing services or create barriers to accessing support.

One of the things that many of us within our community experience when we connect to services is that we lose authority over so much of our life. We lose authority over the stories about us as well, so this is the authorship component... the author part is important as well. And

that was the bit that was missing [in the framework]... being able to maintain the story of our experiences.

So I would like to see a mental health system where I'm able to step in there and not have to take on “other specified dissociative disorder” and “borderline personality” and “depression” and “anxiety without agoraphobia” and “drug and alcohol dependence in sustained remission” and “gambling addiction”... I would like to be able to maintain authorship over my story as someone who lives with an internal collective, who's a big feeler, who experiences the big sad, the graying and the numbing over my life at times, that has learned to be fearful of people but pushes past that to still maintain connection with people. (Lived experience community)

Similarly, people wanted to be able to determine what their needs are, including their need for support when they are struggling, and when and how they get support.

When things start going wrong for me, I can't do the dishes. But I can't get any support with that... I can't then cook, or eat, and then I am really unwell. All I need is some help, on a one-off occasion to get on top of dishes and I am ok. But services will not do that. (Lived experience focus group)

To honour this feedback, we added the following content to the framework: **We define what our experiences, needs and aspirations are.**

Support to discover needs and aspirations

People who used mental health and addiction services emphasised the importance of not feeling judged or blamed by processes or staff when navigating their journeys. They told us that non-judgemental support can help people to discover and understand their experiences, needs, and aspirations.

Trying things and them not working out and that not being recorded or reported or perceived as failure. As someone who has huge issues with fear of failure, the idea of having a structure that supports things not working as part of learning is [needed]. (For-peer-by-peer organisation)

There is a missing piece of the puzzle in the framework here - the need for support options that help people develop a sense of what they need and want... creative approaches can be the best way to explore this with people. Whaiora led care requires drawing that information

out in the first instance, it's step zero before other things in the framework can happen. (Peer team)

We have added the following content to the Access and Options domain: **We can access different options and learn what works and doesn't work for us.**

Individualised funding models and self-referral services

We heard that lived experience communities see self-referral options as key to removing access barriers.

Any [of] those groups of people that don't feel they fit into traditional services or systems... having services that are self-referral is really important and having access to services that are not associated with the government... if they've already been traumatised by those services in the past, they're not going to want to go back. (Youth consumer network)

Additionally, some lived experience organisations, referencing developments in the disability sector, saw potential in individual funding approaches being applied in the mental health and addiction system. Individualised funding is where funding is given directly to tāngata whaiora (rather than to service providers), so people can choose the supports and services they want to meet their individual or whānau needs and aspirations. Individual funding approaches could enable tāngata whaiora to define their experiences, needs, and aspirations, and be leaders in their decision making.

Person-centred funding has worked well in disability sector and created opportunities for innovation and creativity with choice of how whānau could use the money. (For-peer-by-peer organisation)

Would like to see funding that can be used for alternative approaches, acupuncture, massage, etc. If this is what a person chooses to Support their Mental Health recovery. (Peer team)

Acknowledging this feedback, He Ara Āwhina now specifically mentions individualised funding as well as whānau funding models as choice-based models of support: **The system increasingly provides choice-based models of support such as individualised funding and whānau funding models.** We have also added that **[supports and services] are accessible when we need them, without barriers.**

Supports and services in an ideal mental health and addiction system

Support for people in their roles as parents, workers, volunteers or in education

Many of the needs that people want to see the system respond to were focused on beginning, maintaining, or re-gaining valued roles, including as parents, friends, learners, workers, or volunteers. We were told that supports and services that focus on supporting tāngata whaiora in these roles need to be explicitly included in He Ara Āwhina. People, however, cautioned against approaches that push tāngata whaiora into paid work when they are not ready.

Recovery can come to a halt when people do not have Access to the finances needed to lead their recovery in ways that work for them... We want specialist professionals... rather than lumping extra tasks on generic workforce. Dedicated employment Support staff need to be visible in the document. (Peer team)

if the person assessing says 'you're not in paid work, we should be doing something more for you' that wouldn't be conducive to wellbeing and recovery for me. (Lived experience focus group)

My withdrawal from methadone was 12 weeks of hardly being able to walk, eat or sleep and six months until any normality returned. I needed daily support at home to raise my children... The support wasn't there from the addiction and mental health system, or any community outreach programmes. I did it alone. I did get better and kept my kids and they thrived... Young mothers and parents need to have viable options for withdrawal and home help. (Lived experience of distress and addiction)

To recognise this feedback, He Ara Āwhina now contains the statement: **We can access support to stay in, or return to our work, education, or parenting roles.**

Support to rest, heal, and be heard

We also heard people say that an ideal mental health and addiction system provided opportunities to rest, heal, and be heard for tāngata whaiora who experience distress, substance harm or gambling harm.

Tāngata whaiora and whānau will benefit from facilities and physical environments that support healing and recovery. (For-peer-by-peer organisation)

We added the following content to acknowledge this important feedback: **We have access to environments and supports that provide listening, respite and healing.**

Excellent physical health and support around psychiatric medication

Addressing harm from psychiatric medication was mentioned in many submissions by people with lived experience. People wanted to see acknowledgement of the risks of psychiatric medication and the over-use of medication in the current system.

People noted that He Ara Āwhina needed to monitor prescribing and ensure that everyone has access to alternative approaches as well as support to come off psychiatric medication. People with experience of Opioid Substitution Treatment services also stressed the importance of safe prescribing, support to come off Opioid Substitution Treatment, and a supportive service culture.

The psychiatrist believes that I have an inherent anxiety disorder though it is actually a side effect of the new anti psychotic I am trialling. This side effect is thus never reported to the drug company, as all side effect reporting relies on a clinician believing your experiences. (Lived experience of distress and addiction)

Because GPs are usually the first point of contact... whether doctors even offer any type of alternate resources... rather than just prescribing medication as the first option? This is something that a lot of [young] people talk about. (Youth consumer network)

[Recognise] the Equally Well perspective including: support to get off medication, [and] addressing inequitable health and life expectancy outcomes for people on long-term medication. (For-peer-by-peer organisation)

We have added content to He Ara Āwhina to address this feedback: **Medication is prescribed safely, and we have support if we choose to come off psychiatric medication.** We also more strongly reflect the need for high quality physical healthcare: **Physical health services provide us with excellent care, address access barriers, biases and diagnostic overshadowing.**

Timely, validating support without barriers

People who had sought mental health or addiction support named waiting times, geographical barriers, assessment processes, and cost as barriers that prevented them from getting support. Young people living in unsafe or unsupportive homes told us that expectations for family involvement were also barriers to them accessing services.

[There needs to be] more help when person has decided to change [there are] too long waiting times. It's seems faster if courts send u there. (Tangata whaiora / lived experience of distress and addiction)

Come back to me when I can get GP visits paid for and I don't have to choose between my mental health and putting food on the table. (Tangata whaiora / lived experience of distress)

Big problem we have in rural services is the population-based funding formula, that is not adjusted. There is no equity. The funding formula is wrong. The MHWC should be calling this out in the equity area because there is not equity in access. Other jurisdictions in Australia for example have different funding formulas in cities than in rural areas. This is also in the US. (Consumer and whānau network)

Every city needs multiple options not moving our tamariki to Auckland away from whanau and their rohe - it's criminal really. (Lived experience of distress)

In response, we have emphasised the need to have timely access to supports and services “**when and where we need them**”.

Peer supporters told us that in some areas there are no respite services, so the framework cannot just talk about improving existing services. There needs to be investment to set up new services too.

It doesn't seem fair that people living here do not have the same access to services which can support early and prevent things escalating. Being in hospital is traumatic and creates a longer time for recovery. Hearing about peoples experiences in Auckland - it's a very different scenario. Lots of support options. (Lived experience of distress)

Framework changes to reflect this include: **Investment in supports and services improves equity of access and outcomes (Equity)** and **A range of supports and**

services for tāngata whaiora and whānau are appropriately funded and staffed to provide high quality support (Effectiveness).

For people with lived experience, the idea of an accessible system was deeply entwined with a validating system. People shared personal stories of not being believed when they reached out for help, feeling like they weren't "bad enough," or of invalidating assessments or diagnoses.

Not being believed, not being believed unless you're screaming. (Lived experience community)

When I have to engage in diagnosis, NASC, assessments – I am seen through a deficit lens, and it makes me hate myself. I feel like I am not allowed to see myself the way I want to, which is that I love myself! The things that others frame as deficits or problems are some of the things I like the most about myself, so how can I engage in a process that only sees these as problems? (Lived experience focus group)

Trusting young people when they say they need help. (Care-experienced young person at a hui held by a non-government organisation for young people)

I'd like to feel believed. (Member of lived experience, not-for-profit organisation)

He Ara Āwhina now acknowledges this, specifying trust and validation as important to the way that the mental health and addiction system supports people: **Tāngata whaiora and whānau report trust and validation in supports and services...**

Focusing on supportive relationships and restoring relationships if harm occurs

Lived experience communities commended the statement "the culture of the mental health and addiction system is relational..." They urged us to monitor this as structural change to the system taking place. A relational system is one that builds trusting, supportive and enduring relationships between tāngata whaiora, whānau, and staff. Choice and continuity in staff who provide individual support and having time to build trust were raised as important issues.

Whakawhanaungatanga has always been a lifeblood for Pacific people to engage. We're really worried with [the changes to the health system]... that we're going to lose that whakawhanaungatanga that

we've had. (Pacific lived experience leader taking part in a Consumer and whānau network hui)

For folks who have experienced trauma... where long term therapy or counselling cannot be accessed, having to undertake short stints of brief counselling with different therapists each time is the only option. (Lived experience focus group)

I just see so many people having things done to them by people who don't know anything about their history, uninterested in their history... They're not a person with a whānau, with a story. They're just a number. (Youth consumer network)

Care experienced is a lifelong thing I still need support years later... The current youth system is like pass the parcel but the music never stops, you just get passed around until you reach 18 then you are on your own. (Hui held by a non-government organisation for young people)

Services and strategies should focus on building holistic wellbeing through strong, relationally focused approaches that uphold dignity and are devoid of harmful power dynamics. The role of leadership in enabling this is now reflected in the framework: **Training and leadership enable harm reduction practices and holistic safety.** We have also added that: **All supports and services are trauma-informed, culturally responsive and support our wairua, values and strengths.**

We were told that the system must not only build trusting and supportive relationships but must also be capable of restoring relationships if harm occurs.

The [current] systems are so punitive that people are afraid, staff are afraid, it can be traumatising to go through the process when something goes wrong to address it, and people (staff) can hide mistakes out of fear of these processes. (Lived experience focus group)

Seeing feedback and critique as a pathway to continual improvement and best-practise development, so that services can continue to flourish as well as the wellbeing of those accessing these services. (Member of lived experience, not-for-profit organisation)

[There are] some incredible [Māori] perspectives around [restorative] practices are being developed in regards to health. I'm really hopeful that we will see some of those picked up within our mental health... it's around getting the whole of the culture transformed to be able to practice differently. (Lived experience community)

We have added specific mention in the framework to restorative processes. Some of this wording has been provided by Thriving Madly: **Processes are in place to restore relationships when harm occurs, enabling transparency, learning and improvement.**

People also described the importance of advocacy and resources to self-advocate. He Ara Āwhina includes new references to advocacy support: **There is education and support to self-advocate and make informed decisions** (Participation and leadership) and **We have access to advocacy support when we need it, and timely resolution of complaints** (Safety and rights).

People told us the justice system must also take a restorative approach to people experiencing distress substance harm or gambling harm. People stressed that the justice system 'actively diverting' tāngata whaiora must lead to health and social support, and that people must never be diverted **into** the justice system to get care.

I am hopeful that we can, in the future, see a Justice System that has a separate pathway for those of us suffering mental distress, or influenced by substance abuse. (Lived experience of distress)

Diverting must be one-directional, towards support. We've had children and young people diverted into the justice system to get them in to forensic mental health services – just so that they could get a service. These kids end up with convictions, with a record, just to get support. (Lived experience focus group)

The changes we made to the framework to honour this feedback added detail around where people would be diverted to: **The justice system actively diverts and connects us to health and wellbeing supports and services when we are experiencing distress, substance or gambling harm.**

Staff wellbeing and support

Lived experience communities described staff wellbeing as paramount. Staff who are well supported and looked after are better able to support people.

I think if we get it right for staff, we're also getting it right for everyone else... There's a lot of bullying, a lot of burnout, a lot of real toxic workplaces. How can you do good work, caring for other people, if that's the environment you are going into? (Youth consumer network)

[We recommend that] The workforce is well-funded (in addition to being 'well-supported'). Workforce that is skilled and competent. The workforce is equipped with the resources, training, and support

required to thrive... Workforce leadership is nurtured and supported. (For-peer-by-peer organisation)

In response to this feedback, we have added specific reference to workforces across three domains: **Our workforces are safe, cared for and well-resourced to support us and our whānau** (Safety and Rights); **Our workforces are knowledgeable, skilled and fully culturally competent** (Connected care); and **A range of supports and services are appropriately funded and staffed to provide high quality support** (Effectiveness).

Enabling peers and communities to be a 'first port of call'

While training and development for staff was valued, people with lived experience told us that communities and whānau need to be prioritised in receiving education and resources to enable them to be the support networks people hope for.

My own experience was that accessing community support was very difficult, probably impossible, and I think it will be a long time before all communities provide the level of accessible support required. (Tangata whaiora / lived experience of distress)

Equity for me looks like resourcing communities, resourcing people who are doing relational work not recognised in current ways of doing things. (Lived experience focus group)

Recognising this feedback, we have emphasised in the framework that communities are not only enabled but also resourced to develop and deliver their own responses. Further to this: **Funding models recognise and value volunteers, whānau, peers and community support groups.**

People also told us that, as well as connecting people with mutual support options in communities such as clubs, groups and creative spaces, services must also be mutual in recognising and creating opportunities for people to contribute from their unique experience and worldview.

Mutual support... is what I believe services should facilitate happening. (Lived experience community)

Tangata whaiora don't just receive services, but they participate in them and they bring their own experience and their own... lived experience perspective to that and how that can be heard alongside other perspectives and given the weight and value that it deserves. (Youth consumer network)

Development opportunities for tāngata who access services should be part of the systemic transformation, and intentionally supported into development pathways. (For-peer-by-peer organisation)

This is now expressed in the framework as: **We Experience reciprocal opportunities to contribute to Mental Health and wellbeing. Our knowledge of recovery is valued.**

Lived experience leadership needs resourcing and support

Lived experience communities valued the focus on leadership and participation, and leadership roles. However, we heard from people working in these roles that there is a lack of resourcing to support this leadership in the current system. People wanted to see resourcing for lived experience leadership in the framework.

Specific supports and resources that people mentioned included:

- training
- professional development
- a professional body
- mentoring
- peer supervision
- leadership development for youth
- pathways from being tāngata whaiora or service users to being a leaders
- spaces to share knowledge
- and national lived experience leadership infrastructure that sits outside of services.

Addressing isolation of sole lived experience roles and increasing diversity were also raised.

...while the framework identifies many of the themes the lived experience community and the mental health sector have been calling for, we would like to see a greater emphasis on the contribution of tāngata mātau ā-wheako and the value of our diversity of thought and experience in an ideal mental health system. (Member of lived experience, not-for-profit organisation)

[We're] not seeing our young people - rangatahi, being supported to step into lived experience roles - there isn't the succession planning, the support, supervision and leadership development needed.

Mentoring and nurturing is needed to bring them in. (Pacific lived experience leader taking part in consumer and whānau network hui)

We have all these aspirations... but there are very limited FTE for roles around whānau support and engagement, or whānau participation and leadership, so resourcing these roles and processes becomes the first step – there will need to be a lot done here. Same with the peer workforce, the funding is so minimal, so that needs to be addressed as well. (Addiction consumer leadership group)

Te Hiringa Mahara have acknowledged that resourcing and support is needed to grow lived experience and whānau leadership. The framework upholds the need for feedback, engagement, participation and leadership, and includes additional content to reflect these important themes: **We work in a wide range of leadership roles where our lived experience, whānau experience, community connections and diversity are valued. Resourcing enables diverse, quality and sustainable leadership, and supports emerging leaders.**

What next?

Te Hiringa Mahara have redrafted and published two versions of He Ara Āwhina – a summary version that is focused on the system aspirations, and the full framework that includes detailed descriptions of what an ideal mental health and addiction system looks like. These are published alongside a [Guide to language in He Ara Āwhina](#) and the voices documents on our website. Work to develop the methods and measures is underway and will involve input from lived experience communities.

Developing the methods and measures

The methods and measurement phase has started and will be guided by our monitoring strategy, strategic direction from our EAG and Ngā Ringa Raupā (comprised of Te Hiringa Mahara Chief Advisor Māori and Māori staff), technical direction from a new advisory network, and insights from our public consultation process about what people want to see measured and their expectations for how we monitor.

Throughout the consultation, interests and concerns were raised about how the aspirational statements of He Ara Āwhina will be actioned, measured, and monitored. People were interested to know about data availability and the specific indicators that would be used to monitor progress. We have taken this feedback on board as we commence mahi in the measurement and monitoring phase of the project.

People with lived experience have told us to make sure that the measures and methods used for monitoring reflect and show what peoples' experiences of the system are really like.

We generally experience a high degree of disconnect between how the services see these... and how the tangata whaiora and their whanau see them. We would be very interested to know how this will be monitored and whose opinion will be used to determine if these are being actioned. (Lived Experience Advisory Council)

Many groups and individuals reinforced the importance of the methods and measures that will enable Te Hiringa Mahara to monitor against the He Ara Āwhina framework.

Measurement is crucial - measure the things that are important to people with lived experience... Keep asking for input from people with lived experience, throughout this process. (Lived experience group)

Monitoring tāngata whaiora being leaders in care and decision making will require evaluation/feedback from tangata whaiora and whanau. (Lived experience and whānau advisor)

Locality-wise there are models of care that have been collaboratively developed, that might get drowned out and go unseen. Use this (monitoring) as an opportunity to raise up these exemplars. (Consumer and whānau network)

Lived experience communities cautioned us on the challenges with service-gathered monitoring data. We were told that many people do not share openly with services or make complaints and gathering experience data would best be carried out by Te Hiringa Mahara or by lived experience and whānau organisations.

There is ‘widespread’ fear of speaking out about MHA systems. The fear lies in that this may lead to even more difficulty accessing support/increasingly poor treatment. I believe data gathering must avoid the system or service and be with the Commission. (Peer support group organiser)

This next phase will be given an appropriate process, timeframe, and capacity. Tāngata whenua must be involved in leading the development of Māori methods and measures. The Te Ao Māori perspective of the framework includes concepts that speak to this in ‘Mana Whakahaere’. We will be thorough, and we will be respectful throughout this process.

People who have shared an interest in He Ara Āwhina will continue to be involved in this mahi and we will continue to share information to help people understand how we will monitor using the framework.

Undertaking system monitoring

He Ara Āwhina methods and measures once developed will over time replace the measures that we used in [Te Huringa: Change and Transformation – Mental health service and addiction service monitoring report 2022](#). Some of the data needed to monitor under He Ara Āwhina will be available from March 2023. Other important methods and measures will need a longer timeframe for development as the data does not exist or is not easily available nationally.

The challenge ahead for Te Hiringa Mahara, as we begin to use the framework to monitor the system, is to ensure that our monitoring leads to change. He Ara Āwhina can’t “just sit there.” It must be “used and influential” (Consumer and whānau network).

I have spent so many sessions in rooms with great policy goals stuck to a wall while the actual experience of the system is dreadful. I want to know that the experience for the user will be different than it was... It must be that as soon as someone contacts the organisation - which can be very hard to do in itself - then that person is cared for and awhi-ed, and supported. (Tangata whaiora / lived experience of distress)

When carrying out our monitoring role, people with lived experience urged us to make a real difference to their lives and to the future generations who will experience distress and seek support. The way we should do this, people told us, is with upmost kindness and respect while acknowledging that there is a long road ahead and that people's experiences must be validated along the way.

[Be] caring, warm, genuinely understanding, and well-informed... be aware of social justice issues and different identities. (Member of lived experience, not-for-profit organisation)

The Commission needs to be clear in communicating around the framework that we are a long way off some of these aspirational visions at the moment - so that people feel validated. (Addiction consumer leadership group)

I want our mental health system to feel cared for and understood and loved, because if it's not, then it won't be able to love us when we journey through it. (Lived experience community)

We will remember this valuable advice as we begin to use He Ara Āwhina in our system monitoring mahi.

How we will use He Ara Āwhina

We will use He Ara Āwhina to:

- monitor mental health and addiction services
- monitor changes as the mental health and addiction system transforms
- advocate for improvements to the mental health and addiction system and services.

He Ara Āwhina will be used alongside the He Ara Oranga wellbeing outcomes framework, which will be used more broadly to monitor wellbeing.

We noticed in the feedback that people wanted to see the incorporation of wellbeing outcomes, including other social determinants of health and wellbeing. This highlighted the need for us to share the [He Ara Oranga wellbeing outcomes](#)

[framework that](#) was developed by the Initial Mental Health and Wellbeing Commission and published in June 2021. Te Hiringa Mahara use this framework to assess and report on wellbeing for people in Aotearoa. He Ara Oranga wellbeing outcomes framework has been re-published alongside He Ara Āwhina, and includes material to demonstrate how the [two frameworks are designed to work together](#).

We will begin monitoring the mental health and addiction system using He Ara Āwhina from 2023.

References

Government Inquiry into Mental Health and Addiction. 2018. **He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction**. New Zealand: Government Inquiry into Mental Health and Addiction.

Mental Health and Wellbeing Commission Act 2020.

Appendix 1

Methodology

We applied an intentional approach to ensure we received a diverse range of views to inform the He Ara Āwhina framework - shared perspective. Therefore, multiple options for participation in the consultation process were supported. This included:

- A proactive hui approach, involving invitations nationwide, encouraging participation at either a number of online hui being held, or
- 1:1 hui
- Phone calls
- Online survey
- Email submissions
- Post submissions.

Where permission was granted, hui were recorded and transcribed. All submissions were saved in a secure location that only a few people could access on a need-to-know basis.

Submissions were analysed and coded using NVivo. This involved identifying whether a submission was from a tangata whaiora or individual; whānau, family members, or supporter; or an organisation or group, and whether they identified as tāngata whaiora or had lived experience of distress or addiction (or both). Sections from every submission were coded to the most relevant domain, with some being coded to more than one.

Themes were then drawn out of the data, which influenced the changes in the final He Ara Āwhina framework.

Appendix 2

Overall, 130 submissions were from people with personal lived experience, their networks, and organisations. 123 of these identified as having experienced distress whilst 48 identified as having experiences of addiction.

	Tangata whaiora	Whānau	Organisation	Not specified	Totals
Identify as having lived experience					
Hui	3	1	27	-	31
Email	17	3	11	-	31
Online form	37	16	11	3	67
Social media	1	-	-	-	1
Total	58	20	49	3	130
Tāngata whaiora					
Hui	2	1	18	-	21
Email	2	1	4	-	7
Online form	20	8	9	2	39
Total	24	10	31	2	67
Lived experience of both distress and addiction					
Hui	-	-	17	-	17
Email	2	-	7	-	9
Online form	8	5	5	1	19
Total	10	5	29	1	45
Lived experience of distress					
Hui	3	1	26	-	30
Email	17	3	11	-	31
Online form	35	14	9	3	61
Social media	1	-	-	-	1
Total	56	18	46	3	123
Lived experience of addiction					
Hui	-	-	17	-	17
Email	2	-	7	-	9
Online form	9	6	6	1	22
Total	11	6	30	1	48