



28 March 2024

Committee Secretariat

Health Committee

Parliament Buildings

Wellington

Lived Experience Community Perspectives on the Pae Ora (Healthy Futures) Amendments Bill, March 2024.

Tēnā koutou,

Thank you for the opportunity to provide feedback on the Pae Ora (Healthy Futures) Amendments Bill 2024 (The Bill).

Changing Minds is a Lived Experience-led not-for-profit organisation, that strengthens Lived Experience communities and Tāngata Mātau ā-wheako, people with Lived Experience of mental distress, addiction, or problematic substance use to challenge prejudice, self-stigma, discrimination and inequity. We do this through community building, enquiry and action, education, insights, research and advocacy work.

Changing Minds are committed to ensuring meaningful Lived Experience leadership, reflecting a broad range of perspectives is present in all stages of strategy, policy making and evaluation. A strong mandate for consumer and whānau focused, people-centred engagement and codesign has been established through legislation and policies already in place. This includes, He Ara Oranga, the Pae Ora Act, Oranga Hinegaro, Te Pae Tata, and the Code of Expectations for Health Entities.

We would like to acknowledge and thank the more than 40 members of our community from across the motu who have shared their expertise, insights, and experiences to this submission. In addition to seeking the support of our community on Changing Minds' position statements which are outlined below, our community members provided additional feedback and insights that we would like to bring to your attention as the development of this Bill, and any future Mental Health and Wellbeing Strategy progresses. This includes:

- Broader Lived Experience Leadership engagement.
- The need for a monitoring and evaluation plan that is accountable to Tāngata Mātau ā-wheako.



- Concerns regarding the future of the Te Hiringa Mahara | The Mental Health and Wellbeing Commission as an *independent* crown-entity.
- Observations of the challenges present in the current health system and related social policies and infrastructures.
- Equitable engagement and health outcomes following the disestablishment of Te Aka Whai Ora | The Māori Health Authority.
- The need for clarification on how existing systems, frameworks and policies will complement and support a Mental Health and Wellbeing Strategy.
- Concerns for how key population groups will be engaged and present in the strategy (including: peer support, whānau perspectives, migrant and refugee populations, and Asian communities).
- The need for equitable prioritisation, funding and resources for mental health, addictions, and disabilities in Aotearoa alongside physical health outcomes.

Changing Minds would like the opportunity to further discuss our submission with you at Select Committee stage.

If you have any questions regarding our submission, please contact Jodie Bennett at engagement@changingminds.org.nz.

Nāku noa, nā

Changing Minds



Changing Minds' Lived Experience-Led Community Insights.

Changing Minds engaged more than 40 members of the Lived Experience community to share their insights on this Bill. Further details of this feedback are attached in the Appendix to this submission.

Note: Throughout our community feedback and submission, we use the phrase “Lived Experience Leaders.” This refers to individuals with Lived Experience of mental distress, addiction or problematic substance use who are now at a place in their wellbeing journey where they are prepared to share their stories and experiences to challenge prejudice, self-stigma and discrimination to achieve positive changes to health outcomes for all Aotearoa. These individuals exist across communities, organisations, volunteer spaces and workforces, and some may also operate within existing systems and services.

Lived Experience Leadership and voices must inform the Mental Health and Wellbeing Strategy from individuals and organisations outside of the Government, system, and traditional health frameworks (e.g., community and consumer voices).

“We need someone who understands the consumers experience to represent our voice.”

Changing Minds are committed to ensuring genuine Lived Experience leadership, reflecting a broad range of perspectives is present in all stages of strategy, policy making and evaluation, and in line with *He Ara Oranga, Oranga Hinegaro, Te Pae Tata, the Pae Ora Act and the Code of Expectations for Health Entities.*

Many within our community were concerned that Lived Experience leadership will be excluded, or only limited viewpoints reflected in the design and implementation of the Mental Health and Wellbeing Strategy.

Our community have reiterated that Lived Experience Leaders exist within communities, consumer groups and organisations – beyond formal spaces such as the Te Hiringa Mahara (Mental Health and Wellbeing Commission / the MHWC) and the Manatū Hauora (Ministry of Health).



While Changing Minds and members of the Lived Experience community support greater inclusion of mental health and wellbeing data from the MHWC concerns have been raised about the ‘blurring of the lines’ between the MHWC as an independent crown entity, and a possible future as a ‘health entity’.

Our community felt it was important that the MHWC remains impartial and that insights are sought from a wide range of Lived Experience insights.

“I don't think the (Mental Health and Wellbeing) commission should be a health entity - it takes it more under control of the Government. They may think it's ok to stop asking Lived Experience for opinions because they have the commission”.

The Act must state how Te Ao Māori representation and consultation will be prioritised following the disestablishment of the Māori Health Authority.

Changing Minds notes that it has recently (27 February 2024) been announced that Te Aka Whai Ora (The Māori Health Authority) has been disestablished.

“I am dismayed that the new government is disestablishing Te Aka Whai Ora. It is essential that the voices of Tāngata whai ora are actively sought and options for involvement promoted.”

Following the disestablishment of Te Aka Whai Ora several members of the community have expressed concerns regarding how equitable health outcomes and policy engagement will be achieved for Māori. The Bill still references Te Aka Whai Ora as a listed health entity. Our view is that any changes to the Pae Ora (or other) Acts must ensure the health outcomes of Māori are protected and upheld following this change.

“They should have two caucuses - one Māori, one including broad and diverse Lived Experience perspectives to act in a co-governance role alongside senior leadership. This is the way forward into real transformation.”



Lived Experience Leadership engagement on the Mental Health and Wellbeing Strategy and the Government Policy Statement on Health must be undertaken genuinely and in line with the Code of Expectations for Health Entities.

“I love the vision in Pae Ora. I’m so sad that the Māori Health Authority has been disestablished and so all further legislation and changes to the health system must have equity as a core value. We have so much work to do to improve the situation of people with disabilities and chronic ill health, so every step must be a step forward to improve outcomes and quality of life.”

The vision of the Pae Ora Act, He Ara Oranga, and the Code of Expectations for Health Entities all established a mandate for genuine Lived Experience-led policy development that goes beyond seeking ‘feedback’ on pre-determined direction or policy.

Our community have stressed the importance of engaging Lived Experience leaders from a broad range of perspectives and there is a concern that as currently outlined, Lived Experience expertise will not be adequately captured by the reliance on Te Hiringa Mahara (the MHC) alone.

Changing Minds has voluntarily adopted the Code of Expectations and believes that the Code provides a clear framework for embedding Lived Experience insights into policy design, development, and implementation from ‘day one.’

We urge the Minister and policy makers to work directly with Lived Experience Leaders and Consumers, and with Lived Experience organisations to achieve equitable and informed wellbeing strategies.



The Mental Health and Wellbeing Strategy must engage a range of Lived Experience perspectives on what meaningful health and wellbeing outcomes look like for them.

“How does it work with the Mental health Compulsory Assessment and Treatment legislation?”

Overall, our community showed support the formalisation of a Mental Health and Wellbeing Strategy. However, more information is required to understand how this will be implemented in a way that upholds the mana of Tāngata Mātau ā-wheako and their whānau, and to integrate with existing health frameworks. To be effective, outcomes of the Mental Health and Wellbeing Strategy, evaluation, and wellbeing priorities must align with the needs and wants of the Lived Experience community.

“I am glad to see actions to remove the "siloing" of mental health from wider health objectives and approaches, by the legislated inclusion of a mental health and wellbeing strategy... ..I think it is reasonable to expect some elaboration on how the mental health and wellbeing strategy will be expected to relate with the hauora Māori and other health strategies.”

Many people shared observations on the current system and frameworks and noted that we are already adapting to significant and uncertain changes, including Oranga Hinengaro (the System and Service Framework), changes to Te Whatu Ora (Health New Zealand) and the disestablishment of Te Aka Whai Ora, as discussed above.

“We now are forced to pivot and figure out where keys roles in the facilitation of necessary engagement sit within the existing structures. We need a clear strategy rather than ad hoc systems change or we risk losing trust in the system itself which is imperative.”

Further to this, our community has expressed a desire for clarification and inclusion in strategy and implementation of other key populations with unique mental health and addiction insights, including peer support, migrant and refugee populations, and Asian communities.



Finally, our community would like to see any Mental Health Strategy address how mental health, addiction and wellbeing in Aotearoa will be resourced and funded equitably alongside physical health outcomes.

“There is no mention of physical health inequities in the proposed amendment, but we know it is closely linked to Mental Health wellbeing. It needs to include this.”

Mental health, addiction and problematic substance use health outcomes are interwoven with physical health policies, disability and whānau support policies, and social infrastructures. Throughout the feedback received our community touched on each of these relationships and a Mental Health and Wellbeing Strategy must plan for how these systems will support one another.

Tāngata Mātau ā-wheako (people with Lived Experience) and/or Mental Health and Addiction consumers must have adequate opportunities to provide further feedback on the Mental Health and Wellbeing Strategy and the GPS. This includes timeframes for engagement, resources, and support for individuals to contribute and accessible feedback channels.

“The position of Changing Minds, in my opinion, highlights the critical elements of effective mechanisms of policymaking for Tāngata Whaiora.”

Upholding commitments to genuine and pervasive Lived Experience engagement and expertise takes time. Changing Minds specialises in engagement, insights and advocacy with the Lived Experience community and are happy to support Government and policy makers to undertake this mahi in a manner consistent with the Code of Expectations for Health Entities. Beyond this, we have recently undertaken community research into “What makes sharing Lived Experience insights feel meaningful, valued and respected?” – we would be happy to discuss these findings with you further.

This feedback prioritises:

- The ability to share with people with similar Lived Experiences.
- Choices regarding when and how feedback is given.



- Being able to see our feedback within the final product, and cyclical feedback loops.
- Recognition of the time, and energy it takes to gift our experiences through putea aroha or compensation.

In our Appendix below, outlining our engagement approach for this submission, we note that in this instance, the timeframe and resource for engagement with the Lived Experience community is insufficient and recommend a minimum timeframe for engagement.

The roles and responsibilities of the Minister of Health, and the Minister of Mental Health need to be clarified under Section 10 (Overview of Minister's role) of the Act.

Finally, as part of the National, ACT and New Zealand First Coalition Government we now have a Minister of Mental Health. The Bill does not refer to this Minister, and because of this the decision making and ownership of the Mental Health and Wellbeing strategy still sits with the Minister of Health.

Changing Minds would like to see the Minister of Mental Health's roles and responsibilities for creating this strategy be clarified as part of the Act.



Appendix One

About our Community Feedback

Due to the short period of consultation, Changing Minds decided in this instance to share our proposed position statements with our Lived Experience community for feedback. This is not our preferred method of engagement, which would include more time for co-reflection and co-creation with the community through hui and other engagement before framing our position. To enable Changing Minds and other organisation to undertake engagement with the Lived Experience community in a more meaningful and reflective way, we urge Government and policy officials to provide adequate time for consultation in future. In our opinion, this would be a minimum of six weeks for the first public introduction of a policy or Bill.

How we prioritised Lived Experience Community feedback in this instance.

Changing Minds released a feedback survey on 15 March 2024, which was circulated to our community via our newsletter database and social media. This was open for feedback until 22 March 2024. For individuals who do not prefer to share feedback online, the option was provided for a one-to-one phone, Zoom or kanohi ki te kanohi kōrero.

We provided the community with a short summary of what the Bill is aiming to implement (with links to the full draft legislation), before asking individuals to rate our seven position statements to indicate their support for these. A five-point scale was used; Strongly Agree, Agree, Neither Agree or Disagree, Disagree, Strongly Disagree.

The community was then invited to share any thoughts, comments, or observations they wished.

Finally, participants were invited to share optional demographic information with us to support our community understanding. This survey was optional and anonymous (unless participants chose to provide an email address for follow up kōrero). To recognise our community's contributions, we offered a random draw to win one of three prezzie gift cards to each participant.

41 members of the Lived Experience community shared their views with us, and 24 of those individuals provided additional insights and expertise beyond the feedback on our position statements.

About our community responses:

- Participants ranged in age from 25 – 65+.
- 75% of participants identified as women, 16% as men, and the remainder either as genderfluid, non-binary or agender.



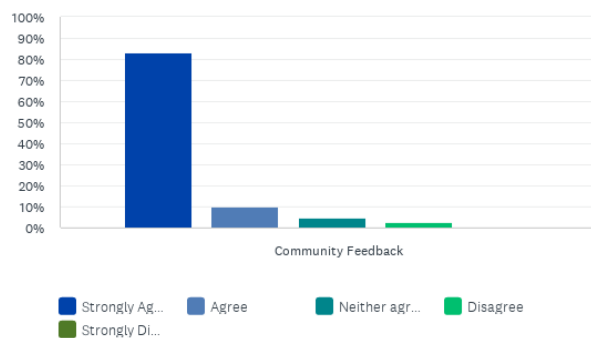
- A third of all feedback comes from Māori individuals, and a further 15% from people from the Pacific Islands. Feedback was also received from individuals from South East Asia, Sri Lanka, and Europe.
- While the majority of participants are located in the Auckland Region, feedback was received from 11 regions around the motu.



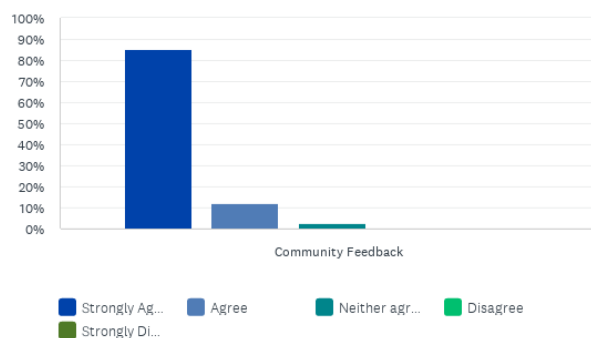
Appendix Two

Community Support for Key Positions

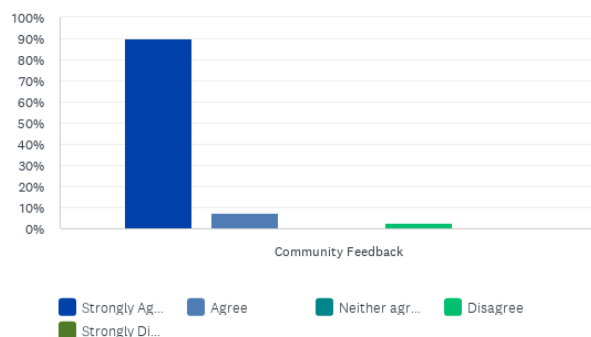
Q1 The Act must state how Te Ao Māori representation and consultation will be prioritised following the disestablishment of the Māori Health Authority.



Q2 Lived Experience Leadership and voices must inform the Mental Health and Wellbeing Strategy from individuals and organisations outside of the Government, system and traditional health frameworks (e.g., community and consumer voices).

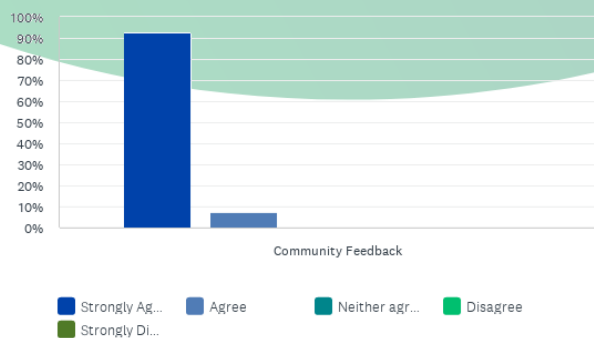


Q3 Lived Experience Leadership engagement must be undertaken genuinely and in line with the Code of Expectations for Health Entities.

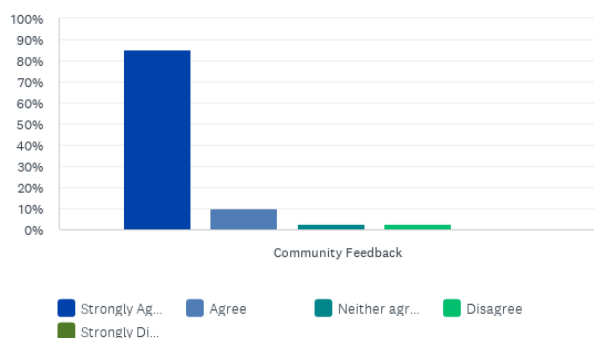




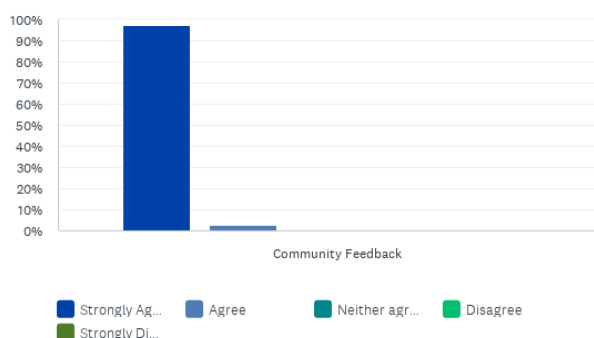
Q4 The Mental Health and Wellbeing Strategy must engage a range of Lived Experience perspectives on what meaningful health and wellbeing outcomes look like for them.



Q5 The preparation of the Government Policy Statement on Health (the GPS) must include genuine Lived Experience Leadership engagement in line with the Code of Expectations for Health Entities.



Q6 Tāngata Mātau ā-wheako (people with Lived Experience) and/or Mental Health and Addiction consumers must have adequate opportunities to provide further feedback on the Mental Health and Wellbeing Strategy and the GPS. This includes timeframes for engagement, resources and support for individuals to contribute and accessible feedback channels.





Q7 The roles and responsibilities of the Minister of Health, and the Minister of Mental Health need to be clarified under Section 10 (Overview of Minister's role) of the Act.

