

Feedback on 'He Ara Oranga'
and priorities for the transformation process
from lived experience and whānau leaders
for the Ministry of Health and the Minister of Health

Balance Aotearoa and Wellbeing Coalition Aotearoa

18 February 2019



Background

Balance Aotearoa and the Wellbeing Coalition Aotearoa were contracted by the Ministry of Health to collect and collate lived experience and whānau feedback on the Report of the Government Inquiry into Mental Health and Addiction. Around 100 people responded to questions via an online feedback and voting platform (Mentimeter) and a diverse group of 26 leaders with lived experience of mental distress and addiction and whānau met on 13 February in Wellington to discuss the report.

Overall support for the report

Overall, people with lived experience and whānau responded to the report with feelings of 'hope' and 'optimism'. People believe the report presents an unprecedented opportunity for whole of system transformation. They want a future where their mokopuna experience mental health and addiction support as 'caring', 'inclusive', 'compassionate' and 'holistic'. They want people with lived experience to live in communities and walk into services where they feel safe and belong.

Gaps and limitations that need to be given priority in the transformation

People with lived experience and whānau also expressed concerns that some of the key messages in the report were not reflected in the recommendations and that some of the 'big issues' that matter to them were not emphasised enough.

In the transformation process we want to see more emphasis and priority given to the following big issues:

1. Ending forced treatment rather than just 'minimising' it.
2. Developing advocacy and better processes to ensure system accountability.
3. Ending the health-led system and moving towards cross-sector and community led funding and delivery.
4. Developing community-based replacements to acute inpatient services.
5. Defining and providing easy access to a broad range of responses.
6. Giving priority to developing peer support.
7. Funding and equipping whānau and communities, not just services.
8. Honouring Te Tiriti o Waitangi with tangible actions to develop Māori for Māori solutions and equitable outcomes.
9. Developing and funding lived experience and whānau roles as well as national lead agency.
10. Ensuring people who use services have decision-making power with the involvement of trusted whānau.

11. Focusing efforts on children and young people.
12. Preventing and responding to adverse childhood events (ACEs).
13. Stopping inequities and discrimination.
14. Creating a zero-suicide target.
15. Ensuring people with lived experience lead the Mental Health and Wellbeing Commission.
16. Developing a full co-production process for the transformation, not just co-design.

Summary of feedback

In the following table we outline the big issues, assess the report and recommendations in relation to them, and suggest ways forward for the transformation process and for getting quick wins.

We do not comment on the narrative or recommendations we fully support but only in those areas where we want to make additional comments or point out gaps or risks. Our purpose is not to contest the report and recommendations but to ensure the transformation process picks up on the areas we think need more attention.

| The big issues | Gaps and issues in report | Risks and limitations in the recommendations | Priorities for co-design | Quick wins |
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| <p>1. End forced treatment</p> <p>Why? It is traumatizing and violates the sovereignty of the mind. It also contravenes UNCRPD and is discriminatory because it creates lower thresholds for loss of liberty than for other citizens.</p> <p><i>Note: There is sometimes a divergence of views between</i></p> | <p>The report is not clear about ending compulsory treatment but instead states the need to 'minimise' it.</p> <p>The report does not state how seclusion and restraint rates will be brought down.</p> | <p>(Rec 34) There is widespread support from people with lived experience to repeal the Act, but some are skeptical that 'replacing' the current Act with a new one will mean 'force as usual'.</p> <p>(Rec 35) The national discussion on mental health risk needs to be led and</p> | <p>Align all legislative changes with UNCRPD and the Bill of Rights Act, starting with Articles 12 and 14 of the UNCRPD.</p> <p>Use the transformation process and lived experience leadership to create a roadmap for alternative approaches to shared management of risk.</p> | <p>Amend the current Mental Health Act to include choice of treatment and to ensure whānau are not required to instigate any compulsory processes.</p> <p>Ensure data consistency and transparency when reporting on coercive interventions.</p> |

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| <p><i>whānau and people with lived experience on this issue.</i></p> | | <p>framed by people with lived experience.</p> | | <p>Ensure HSQC and DHBs have sufficient resources for their programme to end seclusion and restraint within the timeframe established.</p> |
| <p>2. Develop advocacy and processes to ensure system accountability</p> <p>Why? People with lived experience and whānau are virtually powerless in comparison to the institutions of the state when things go wrong.</p> | <p>No mention of peer advocacy, free legal advocacy, or of the inadequacies of current arrangements, such as complaints processes, legal redress for system harm, District Inspectors and Mental Health Tribunals.</p> <p>No mention of lack of system transparency, for instance the lack of public reporting on serious adverse events.</p> | <p>(No rec) There are no recommendations on advocacy or creating an even playing field for people with lived experience and whānau who make complaints or appeals.</p> | <p>Ensure advocacy is considered to ensure citizens have the resources to counter medico-legal collusion, institutional interests and to ensure that HDC and Coronial processes are not weighted in favour of the system.</p> <p>Consider ways to make the system more accountable, such as public reporting on serious adverse events.</p> | <p>Fund peer advocacy, advocacy for suicide bereaved families and legal advocacy for people and whānau who seek accountability for harm done by system.</p> <p>Develop a process for wiping false information from consumer files.</p> <p>Publish anonymised collated summaries of serious adverse event reports by DHB and their progress towards improvements.</p> |
| <p>3. End the health-led system and move towards a cross-sector and community led one.</p> <p>Why? Mental distress and addiction are much more than health issues, but health</p> | <p>Does not fully identify the harms done by psychiatry or processes to publicly acknowledge these.</p> <p>Does not fully articulate the need for a cross-sector and community-led system.</p> | <p>(Rec 5) Universal support for the broadening of the range of services but need to define what the range is.</p> <p>(Recs 7 & 9) Support for a cross-government investment strategy but not</p> | <p>Bring multiple sectors to the hub and spoke co-design process and ensure they develop a plan for cross-sector leadership in funding and delivery.</p> | <p>Establish services that support people to safely withdraw from psychiatric medications.</p> <p>Use and develop outcomes measures that matter to</p> |

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| has taken most of the service resources and dominated the world view. | Empowers the system that failed to lead the transformation. | clear it will lead to cross-sector leadership in funding and delivery. | | people with lived experience and whānau. |
| <p>4. Develop community-based replacements to acute inpatient services</p> <p>Why? Community based crisis services have a good evidence-base. In addition, acute inpatient units are often experienced as traumatising, stigmatising and unsafe for all.</p> | Does not clearly indicate need for radical downsizing of acute inpatient units. | (Rec 5) Does not make any specific recommendation on community-based replacements for acute inpatient units. | <p>Create an implementation plan for shifting crisis services away from hospitals to communities.</p> <p>Ensure development of community-based crisis detox services.</p> | Publish an evidence review of hospital based acute services and crisis alternatives. |
| <p>5. Define and provide access to broad range of responses</p> <p>Why? People overwhelmingly support a broader range of responses because clinical services can be harmful, and even at their best, they are not enough to support recovery.</p> | Mentions the need for a broader range of responses but does not define what these responses are. | <p>(Recs 6 & 12) Does not make any specific recommendations on a broader range of responses beyond talking therapies and culturally aligned therapies.</p> <p>(Recs 6 & 12) Does not mention physical health care as one of the broad range of responses.</p> | <p>Define broad range of responses as part of co-design process starting with the Wellbeing Manifesto responses quoted in p 90 of the report.</p> <p>Design self-referral and easy access pathways and navigation to services across different sectors.</p> <p>Consider community wellbeing hubs where people can access different</p> | <p>Announce cross-sector agreements on the range of responses that will be provided.</p> <p>Develop a plan for developing workforces in other sectors and among whānau and communities to respond positively to people with mental distress and addiction.</p> |

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| | | | types of responses under one roof. | |
| <p>6. Give priority to developing peer support</p> <p>Why? Peer supporters make up less than 2% of the mental health and addiction workforce despite the evidence for their effectiveness. This workforce can be grown quickly due to the short initial training time.</p> | Mentioned in the text. | (Recs 10 & 12) Workforce recommendations do specify peer support. This occupation needs to be prominent in workforce development and in the staged funding path for expanding access. | Give top priority to workforce and service development plans for the peer workforce. | <p>Define peer support as a unique occupation and develop an infrastructure including a qualification and a national association.</p> <p>Urgently fund and implement the development of peer support in communities and services.</p> <p>Allow services to convert contracted support positions into peer support positions.</p> |
| <p>7. Fund and equip whānau and communities, not just services.</p> <p>Why? Responding to people earlier in their social environment improves outcomes and saves money on expensive services.</p> | The report calls for wellbeing and community solutions. | (Recs 1 to 6) Recommendations to expand access and choice are very service oriented. | Review literature as well as Inquiry background reports and submissions to identify best practice in whānau and community-led solutions. | <p>Publish a summary of whānau and community led best practice with a plan and budget for implementation.</p> <p>Develop integrated rather than separate support resources for the whole whānau - both the people with lived experience and the people who support them.</p> |

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| <p>8. Honour Te Tiriti o Waitangi</p> <p>Why? Te Tiriti creates the framework for: Kāwanatanga: Māori govern their own direction and resources. Rangatiratanga: Māori participate according to their worldview and tikanga. Mana taurite: Māori have equal status and equitable outcomes.</p> | <p>Mentions impact of colonisation and inequity but does not stress enough that Māori and Pasifika should have access to services run by their own communities</p> | <p>(Rec 39) Support the establishment of a Māori Health Ministry or Commission but do not wait for the Health and Disability sector review to ensure Māori control Māori for Māori responses.</p> | <p>Transformation process needs to be framed within Māori world view for Māori to engage with it.</p> <p>Māori expect their own leadership group as well as seats at every table.</p> | <p>Announce a structure and resources for the expansion of Māori for Māori responses.</p> <p>Ensure all health and social service workers achieve competence in basic te reo and tikanga.</p> |
| <p>9. Develop and fund lived experience and whānau roles and a lead agency</p> <p>Why? The system cannot make genuine improvements unless they are informed and driven by people with lived experience and whānau.</p> | <p>Did not mention the diversity of roles that people with lived experience and whānau need to fill – focused almost primarily on peer support and ‘strengthening consumer voice’ in service development.</p> <p>Did not mention the need for a ‘lead agency’ for people with lived experience and whānau.</p> | <p>(Rec 20) DHB reports need to be complemented by the views of local people with lived experience. NGOs should also report.</p> <p>(Rec 21) Support for work to strengthen consumer voice but it is very health sector focused.</p> <p>(Rec 22) This recommendation is weak - the HDC and complaints processes in general need a complete overhaul.</p> | <p>Consider how the diverse voices of people with lived experience can have equal power, through development and resourcing of leadership roles and a lead agency.</p> | <p>Extend the range of roles described and how they will be involved in the change process.</p> <p>Provide leadership development training for new lived experience leaders to develop their capability as effective partners in co-production.</p> <p>Fund a lived experience and whānau lead agency.</p> |

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| | | (Rec 15) Did not go as far as NGO recommendation in resourcing a lead agency for lived experience and whānau systemic advocacy. | | |
| <p>10. Ensure people who use services have decision making power with the involvement of trusted whānau.</p> <p>Why? Partnerships achieve better outcomes and are consistent with human rights.</p> | Mentions that people frequently feel powerless and disrespected by services. | (Recs 23 & 24) address whānau partnerships at the service delivery level but there are no recommendations on service user partnerships at the service delivery level. | <p>Consider ways to embed partnership with service users at the point of service delivery.</p> <p>Define supported decision making and shared decision making</p> | <p>Develop best practice guidelines in collaborative note taking.</p> <p>Develop more inclusive processes for information sharing with whānau - when person with lived experience consents.</p> |
| <p>11. Focus on children and young people</p> <p>Why? Young people are more at risk of developing distress and addiction than any other age group. Prevention and early responses create better outcomes.</p> | Mentions the importance of the first 1,000 days but we would like to see priority given to young people and people who are new to using services | (No rec) specific to focusing on young people or people new to services. | Ensure young people have leadership roles in the co-design process. | <p>Resource wellbeing hubs and peer support within secondary schools and tertiary institutions.</p> <p>Equip and resource schools and tertiary institutions to respond to people with the more severe forms of distress.</p> |
| <p>12. Address adverse childhood events (ACEs)</p> <p>Why? ACEs are a major contributor to mental</p> | The report mentions ACEs only in terms of the need to prevent them and ensuring all health and social | (No rec) on approaches to preventing and resolving ACEs. | Ensure the transformation process addresses prevention of and responding to the effects of ACEs. | Publish best practice strategies in preventing and resolving the effects of ACEs. |

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| distress, addiction and poor health. | services provide ACE-informed responses. | | | Educate services and communities on the impact of ACEs and the need to prevent and respond to them. |
| 13. Stop inequities and discrimination Why? Discrimination, social exclusion and disadvantage are major barriers to recovery. | Inequities and discrimination are repeatedly mentioned in the report. | (No rec) on resourcing the reduction of discrimination or social exclusion. | Ensure consideration of inequity and discrimination and plan to expand social inclusion programmes. | Fund a programme to reduce discrimination for people with addiction. Expand current mental health discrimination work to focus on groups that experience multiple discrimination, such as Māori and Pasifika. |
| 14. Create a zero-suicide target Why? If all suicides are preventable, we need to have a zero-suicide target with the understanding that it is aspirational. | 20% reduction could imply that the government doesn't care about the other 80%. | (Rec 31): There is not widespread support for 20% reduction target. | Explore ways to frame and implement a zero-suicide target. | Announcement of zero-suicide target with milestones such as a 20% reduction by 2030. |
| 15. Ensure people with lived experience lead the Mental Health and Wellbeing Commission Why? People with lived experience and whānau are | Mentions the need for commissioners with lived experience. | (Recs 36 & 37) Ensure the Commission has 'teeth' to fulfill their advocacy for people with lived experience and whānau. | The new Commission needs to be established urgently and lead the co-production process. The new Commission needs to work closely with people | Appoint a well-respected lived experience leader as the lead commissioner. |

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| <p>best placed to oversee the system because they have unique insights and a strong interest in system improvement.</p> | | | <p>with lived experience and whānau.</p> <p>Integrate with the development of DPO co-governance programme proposed for 2019 Disability Action Plan.</p> | |
| <p>16. Develop co-production, not just co-design</p> <p>Why? Co-design is only one phase of a larger collaborative improvement process (design, development, delivery and evaluation) that is better captured in the terms co-production or co-creation.</p> | <p>Did not provide a full description of co-design principles that ensure lived experience is at the centre of decision-making.</p> | <p>(Recs 7, 8 & 9) refer to co-design but do not encompass co-production or co-creation</p> | <p>Agree on the principles and model for co-production or co-creation, using outside expertise to facilitate the process.</p> <p>Integrate the co-production process with the development of DPO co-governance programme proposed for 2019 Disability Action Plan.</p> | <p>Resource people with lived experience to educate funders and providers on the agreed model for co-production.</p> |

Thoughts on the transformation process

We need to refer to co-creation or co-production for the reasons outlined above.

The process needs to consider the narrative of the report as much as the recommendations.

People with lived experience and whānau need to make up at least 30% of the membership of the hub and spoke groups.

The people with lived experience and whānau involved in the groups need the resources and opportunities to meet together and to gather feedback from their wider constituencies.

About us

The Wellbeing Coalition is a newly formed network of individuals and groups of people with lived experience of mental distress and addiction and whānau. Our main aim is to facilitate lived experience and whānau leadership in the transformation coming from the Mental Health and Addiction Inquiry.

Balance Aotearoa is a Disabled Persons' Organisation (DPO) mandated under the United Nations Convention on the Rights of Persons with Disabilities, and is a member of the New Zealand DPO Coalition. Balance Aotearoa has a twenty-one-year history as a national advocacy and peer support organisation, working with government, communities, and across the mental health and community sector to provide advice and support informed by the lived experience of mental distress. It is a charitable trust registered with the Charities Commission.

We have collected and collated feedback from many individuals, lived experience leaders in mainstream organisations and the following networks:

- Ngā Hau E Whā
- Te Kete Pounamu: Whaiora Māori With Lived Experience
- Matua Raki Consumer Leadership Group
- Supporting Families in Mental Illness New Zealand
- Life Matters Suicide Prevention Trust
- Rākau Roroa
- New Zealand University Students Association mental health group
- National Association of Mental Health Consumer Advisors.
National Association of Mental Health Family Advisors.