



GOVERNMENT INQUIRY INTO  
**Mental Health and Addiction**  
Oranga Tāngata, Oranga Whānau

# **Submissions Summary Report**

## **Government Inquiry into Mental Health and Addiction**

**2018**

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# EXECUTIVE SUMMARY

## Context of this report

This report is a summary of submissions received by the Government Inquiry into Mental Health and Addiction (the Inquiry). This report is an overview of what submitters provided to the Inquiry Panel.

The work of the Inquiry will inform the Government's decisions and future investment priorities by identifying unmet needs and developing recommendations for a better mental health and addiction system (see the Terms of Reference in Appendix A). The work will also set a clear direction for the next five to ten years by signalling what the mental health and addiction sector, the wider health and social sector, and the community as a whole should focus on to improve the mental health and wellbeing of all New Zealanders.

## Consultation process and response

The Inquiry's consultation process was designed to be open and inclusive, encouraging feedback from a broad variety of people. The Inquiry held over 400 meetings, hui and *fono*, including 26 public meetings across Aotearoa New Zealand. The meetings were with people with lived understanding and experience of mental health and addiction challenges, family and whānau, mental health and addiction workforce, iwi, Whānau Ora providers, service providers, non-governmental organisations (NGOs), advocates, experts and officials from government agencies.

In April 2018, the Inquiry consultation document was released, inviting people to submit written and/or verbal feedback to five open-ended questions. Additional follow up information and prompts were provided under each question to provide more context for submitters (The consultation document is reproduced in Appendix B).

### FIVE OPEN-ENDED QUESTIONS ON WHICH THE INQUIRY PANEL SOUGHT FEEDBACK

1. What's currently working well  
He aha ngā mea e oti pai ana i tēnei wā?
2. What isn't working well at the moment?  
He aha ngā mea kāore i te oti pai i tēnei wā?
3. What could be done better?  
He aha ngā mea ka taea te mahi pai ake?
4. From your point of view, what sort of society would be best for the mental health of all our people?  
Ki tāu titiro, he aha te momo pāpori e tino pai ana mō te hauora hinengaro o ngā tāngata katoa?
5. Anything else you want to tell us?  
He korero anō āu?

The public response to the Inquiry's request for feedback signalled the importance of mental health and wellbeing in peoples' lives. The Inquiry received 5,363 submissions from individuals, groups and organisations. Most submissions were received from people with lived experience of mental health and addiction challenges, either personally or as family, whānau or friends supporting their loved ones.

Submissions were received in writing or verbally by phone, in meetings or via video. Sixty percent of written, phone and video submissions were from individuals, 9.1% from organisations, 5.6% from groups and 25.2% did not specify who they were from. Written submissions also included 16 petitions, with 339,217 signatures. Meetings were also treated as submissions – when people participated and spoke at meetings their words were paraphrased by Inquiry staff and summarised as 'meeting, hui or *fono* notes'. These notes were then included in the submissions process. Over 2,000 people attended meetings across the country, although not everyone spoke, and one or more members of the Inquiry panel attended every meeting, hui or *fono*.

People were encouraged to submit their responses in any format they liked. Many written and phone submitters chose to respond directly to the five questions. Many group and organisation submissions, as well as meetings, followed their own format.

### **Analysing submissions**

Submitters had valuable things to say across many different topics. This meant each submission (including meeting note summaries) needed to be split into smaller parts (what we have called 'references') so they could be grouped and analysed with submissions that were also about a similar topic. NVIVO, software that supports qualitative research, was used to organise this information.

This splitting of submissions resulted in 140,317 references. These references were grouped by theme, topic and population – and one reference could be used multiple times across topics. This report summarises references into 15 topics and 10 population groups. These topics are summarised and grouped into five broad topic chapters in this report, which follow chapter 1 (background to the Summary of Submissions).

## TOPIC CHAPTERS

**Chapter 2: System and society** – what people said about what society is best for mental health, future leadership, Māori perspectives, Pacific peoples’ perspectives, social determinants, wellbeing and health promotion, rights and legislation.

**Chapter 3: Services** – what people said about access, intervention treatment and support, and integration of services.

**Chapter 4: Specific topics** – what people said about addiction and suicide.

**Chapter 5: System design and implementation** – what people said about workforce, funding and commissioning, and monitoring and evaluation.

**Chapter 6: Population overview** – what people said about youth, older people, people in prison, disabled people, neurodiverse people, migrants, people with refugee backgrounds, people in rural communities, Rainbow communities, veterans and the Deaf community. Population summaries are from people who identify with those populations or have something to say about those populations such as child youth experts or NGOs that work in rural communities.

## Key messages from submitters

Many submitters showed their support for the Inquiry taking place and commented on the value of being able to participate in the process. They asked that the Inquiry panel honour their kōrero and reinforced the need for serious change to occur. Many submitters positively acknowledged the opportunity to share stories and express feelings, conveying gratitude that their voices have been heard. Some people acknowledged that although it was personally challenging to share their story, they were driven by the opportunity to make a difference.

Some submitters also commented on the serious need for major change and urged for this Inquiry not to be another token gesture.

What follows is a summary of the key messages from submitters. It starts with a wider system view, then moves into various aspects of design and delivery of services.

### *Transform the system: A new approach to improving health and wellbeing*

Across the views expressed, themes repeated and perspectives overlapped. Of particular note is that people talked about mental health and wellbeing from a broader viewpoint than solely the funded mental health and addiction sector. Submitters included comments about our society’s values, the wider health and social sector, community groups and NGOs, iwi, peer support, and family and whānau.

What do people need to be well as communities? They need homes that are safe and warm, food so they don’t go hungry, jobs that give them value, something to do. They need to be able to participate in community. They need health, dental hygiene. It’s Te Whare Tapa Whā. It’s up to us as communities to do stuff as well (whānau Māori)

Submitters highlighted that a new approach to improving health and wellbeing is essential.

They talked about the need to change the way mental health is understood and funded to significantly improve life outcomes for service users, tāngata whaiora<sup>1</sup>, whānau, families and whole communities. This different approach included requests for a system that is designed with an understanding of the following world views.

- **Te Ao Māori**, mātauranga Māori, tikanga Māori, whakapapa and tino rangatiratanga placed centre stage to bring about wellbeing for tangata whenua.
- **Focus on achieving wellbeing, equity and justice** with a public health approach, addressing determinants of health such as housing, employment and poverty, and viewing mental health and addiction challenges through a lens of hope and recovery, self-determination, family and whānau participation, and social inclusion.
- **Pacific world view** with a collective, relational and holistic view that reflects the diversity of Pacific cultures, values, religions and language.
- **Holistic view** in which people are understood to be more than a mental health or addiction condition. A holistic view recognises the physical, social, spiritual, cultural, family and community influences on health and wellbeing. Submitters were concerned about the harm caused by a system that is overly reliant on a medical world view and pharmaceuticals to address mental health and addiction challenges.

It will be recognized that effective support requires addressing all the areas where people are facing difficulties. Treatment and support for mental health and addiction will no longer be able to focus on only managing the presenting issue. Success will be judged on how well people are able to live life, not on the disappearance of symptoms or an ability to hold a conversation. Ensuring that people are adequately housed, have access to finance and immediate practical needs, are able to connect with others, have their cultural and spiritual needs met, and can make plans and set goals for the future will be the key measures through which success is established. It will no longer be acceptable to deny responsibility for helping people to achieve these and simply move people on (NGO collating the views of service users)

Submitters appreciated the positive impact of public campaigns contributing to prevention and raising awareness and understanding about mental health and addiction. They stressed the need to continue this work across the wider community including workplaces, and through other sectors such as education, corrections, social welfare and police.

### ***Shift service design from one-size-fits-all approach***

Many service users and their family and whānau acknowledged the individual kindness and expertise of the people providing services when responding to question 1, What's currently

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<sup>1</sup> In this report, the expression 'tāngata whaiora' refers to 'people seeking wellness' but is used in this report, where possible, to distinguish Māori service users from non-Māori (service users). Tangata whaiora refers to one Māori service user, while tāngata whaiora refers to more than one. Also, where possible, the term whānau is used in this report to identify whānau Māori, with the term 'family' used for all other submitters.

working well? In particular, people are appreciative when service providers are culturally safe, empathetic and professional.

While there was intense criticism of the systems in place, the people who work in these were seen as hard-working, committed and often described as 'going the extra mile'. Where whānau reported having had good support from services, this was virtually always associated with dealing with just one person who they were able to build a positive relationship with (NGO collating the views of service users )

Although variation existed across the country, it was clear that individual district health boards (DHBs), NGOs, PHOs (general practice), and local communities are offering some innovative services that are successfully meeting the needs of service users and their family and whānau. In many cases this was despite the current funding and commissioning model. Submitters who were service providers, service users, tāngata whaiora, and family and whānau spoke of new ways of working that were improving lives of people with mental health and addiction challenges, and their family and whānau.

[Organisation] has been going for over 28 years in the community. Their approach should be recognized as an example of what's working: Client and community led approach – outcomes are not based on the services provided; it's about who provides them and how. So our services are often designed from the ground up by clients and we use feedback that supports the journey and changes regularly to know what works – fit for each individual client (kaimahi Māori<sup>2</sup>)

Submitters said that a vital piece of making the system work better was moving away from a one-size-fits-all approach towards services that are more people-centric. They asked that services acknowledge the person in front of them as an individual with their own unique background and life stories, connected to loved ones, and with their own cultural needs.

A common theme from submitters who are service users and their families and whānau is the absence of services appropriate to meet their needs. Specific examples included information and services that were appropriate for:

- Māori wanting access to Kaupapa Māori services
- Pacific peoples
- young people
- older people
- Rainbow communities
- migrants
- refugees
- people living in rural areas
- people with addictions
- people at risk of suicide.

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<sup>2</sup> Kaimahi is used, where possible, to denote that the submission was from someone that identified as Māori who has experience working within the mental health or addiction workforce

Many submitters highlighted the current funding and contracting approach as an impediment to improving service design. For example,

Delivering Kaupapa Māori services costs more both in time and in finances. From a time perspective, there are many cultural practices that Kaupapa Māori Providers do that general services do not e.g. Karakia, Powhiri, Poroporoaki, Kapa Haka, Tangi, Tikanga training, cultural specific Kaimahi training etc. Further to this, the needs of Māori can often be more complex and intensive. These cultural practices are very much required to ensure we have a culturally competent workforce. The unfortunate thing about this is that Kaupapa Māori Providers are still expected to deliver the same outputs as their general counterparts within the same [full-time equivalent] and time resource (Māori NGO provider)

### ***People can't get the help they need***

Service users and their family and whānau appreciated being able to easily find the service they needed and being able to afford that service. They valued having access to preventative services, early intervention services, Kaupapa Māori services, Whānau Ora, and having services located close to where they were needed. Submitters spoke positively about experiencing co-ordination of information and care between different services.

I've never had, or come across, anything like this before ... I've never gone to a GP surgery and they've said, "oh, we have someone that's onsite and that can help you." So the fact it's so readily available there is really good, and that could really help a lot of people not give up (service user)

On the other hand, many service users, tāngata whaiora, whānau, family and service providers expressed frustration with the difficulty navigating the current system to locate appropriate services.

As a GP it is really hard to navigate the system, so I imagine it can be even harder for patients. The mental health services seem to be a big machine with different compartments ... from the outside it is difficult to find the right portal of entry. I have spent frustratingly long times on the phone being transferred from one compartment to another trying to get help (health professional)

..our mental health and addiction services are literally all over the place. So many times I have been confused by which service to contact, which service I am currently even engaged with and so many times when being referred somewhere I have heard "I'm not sure why they referred you to us" (service user)

Submitters shared their experience when seeking help for mental distress, anxiety and depression. The problems started with finding out where to get help, and then became getting access to the appropriate service. Service users and their families and whānau talked about not being able to afford to pay for services, particularly counselling, to access preventative and early intervention services, and to receive adequate ongoing support to live well.

There is currently no pre-emptive care provided in the community, it needs to escalate to a point of crisis before support is provided (service user)

Submitters were hopeful that they would experience improved services that focused on prevention, responded to all their needs earlier in a co-ordinated and integrated way, and better monitored the effects of medication.

Earlier intervention with lighter touch evidence-based programs across the country would provide a cost-effective way of ensuring quality of life improvements for the majority of families, reducing demand on more intensive family support services and therefore protect the availability of these services for those most in need (NGO provider)

### ***Mental health services are under significant pressure***

The picture of a system under pressure was clearly reflected in submitters' experiences. Service users talked about being turned away from services that had no capacity to address their needs. Service providers talked about the frustration of trying to meet demand for their services, and people in the health workforce talked about the high levels of stress and workplace bullying that they experienced.

Service providers emphasised the pressure of working in a system that was ill-equipped to respond adequately to the levels and types of need in their community. They also highlighted the challenge of providing co-ordinated and integrated services when the funding model discourages such approaches.

The mental health and addictions system is woefully underfunded, crisis-led and seems to chew up and spit out not only the patients, but the providers ... Just not enough resources. Our mental health teams are stretched to their limits and it is having a major impact on patients, their families, their employers. It can't go on like this, there needs to be more funding for support services (professional organisation)

Service providers appreciated being respected and supported by their peers and leaders. They also valued working in well-resourced services that didn't expose them to unnecessary risk and stress. They supported a revised outcome-driven system with better funding, commissioning and monitoring. They recommended implementing a system that encourages integration and co-ordination of services and that has careful oversight.

### ***More addiction services and support are needed***

At the broader level, there was a strong call to truly shift addictions from a justice or criminal response to a health focused response. At the service level, the clear message from submitters was that addiction services and support are lacking. Some submitters positively viewed addiction treatment options and access to services (for example, detox and rehabilitation services where available, peer support, some alcohol and other drug treatment in prison and the community, and the positive role of the Alcohol and Other Drug Treatment courts), but many raised concerns that demand for responsive detox and rehabilitation far outstrips availability with limited resourcing putting strain on existing services, workforce, waitlists and options.

even for those who are wishing to rehabilitate, the wait list for services may be months and months – this young man was recommended to keep drinking until there was a space available (bereaved family member)

looked into going to rehab twice however was told there were no spaces available throughout the country. He has not followed up again with the idea of rehab and has continued to drink (individual with lived experience)

Submitters commented on the deficiency of affordable local treatment options with a specialised workforce, particularly with the rise of 'P' and synthetic cannabis use.

I personally know people with addictions that have no support. They are only just coping day to day. There is nothing available in our community that they can access, for free (service provider)

Submitters wanted to have community-based addiction services located closer to families and whānau. They also asked that services acknowledge the critical place of families and whānau in the treatment and recovery of their loved ones.

some women who have entered detox have not stayed because it is a struggle for them and their children to be away from each other (service user)

[we] need residential rehab facilities in [region] so people don't have to leave community and support to enter rehab (Māori contributor)

Many tāngata whaiora and service providers stressed the importance of holistic, whānau-centred approaches to treatment, particularly whānau-based or kaupapa Māori approaches. However, funding was limiting the availability of suitable options.

Families and whānau talked about the impact on the wellbeing of the whole whānau when addiction services and support services were not available. They became the default option to support their loved ones. People in this situation spoke of the lack of respite care that was putting undue pressure on family and whānau.

Family get no practical support when a relative has mental illness - this puts a strain on those families. Respite care, counselling and practical support and guidance needs to be made available for those who are with loved ones with mental illness and addictions. When we were dealing [with] my [family member's] mental illness and addictions it was bloody hard. The amount of nights worrying if he was going to kill someone or us, it was a nightmare (family member)

Alcohol addiction emerged as a key concern for many submitters due to alcohol's cultural acceptability, ease of access, and implications in terms of addiction, violence and suicide. Many submitters called for tighter legislation around alcohol availability and advertising of alcohol.

### ***Address the prevalence and impact of suicide***

Many individuals, families and whānau shared their experience of suicide. Very few shared positive stories of care and support.

As someone who went through three suicidal incidents in [date], I can say that crisis incidents work well for those facing suicidal ideation. The support, phone lines and team are there, and easy to access. However it is obvious they are overloaded (service user)

Many more talked about themselves or their loved ones being turned away because there was not enough support available to meet demand. They believed that the thresholds for receiving help were too high and meant only those in crisis and immediate danger of harming or killing themselves received help – and many times this was not enough to access more than cursory services. Many times, submitters noted that even people with this high level of acuity received little help.

Many submitters noted that even if you had attempted suicide you were sent home that night with no or little follow up. There was a high need for support before people reached crisis. This situation was seen as being mainly due to a lack of funding, staff, integrated services, training and resources.

Caller's<sup>3</sup> ... [family member] involved with the mental health services for many years. Caller felt that he fell through the cracks in each part of the system and this resulted in his death by suicide. There is no set referral system in place. Health professionals are not clear of each service available. For example, caller took [family member] to the GP who referred to DHB mental health services. On meeting with the psychiatrist from DHB mental health, [family member] was then referred back to GP (family member)

Service users and their families and whānau who did access services shared their experiences of staff who often unnecessarily excluded friends, family and whānau from treatment discussions, sometimes contributing to deaths that might have been prevented. Many times the Privacy Act was seen to be misunderstood or misapplied by staff, and family and whānau were left uninformed.

I didn't know how bad he was. He lived in [town] and was taken to emergency psych services by a friend of his. If I have known that I would have gone and got him or advocated for him or looked after him and maybe he wouldn't have killed himself. I will never know now if this would have helped prevent his death and I will go to my grave of not knowing. However the staff in that Mental Health team misunderstood the Privacy Act and didn't inform me. However it was very clear that he was a danger to himself (family member)

The devastating impact on families and whānau who have lost someone by suicide pointed to the need to improve postvention support, including looking at ways to provide more culturally appropriate support more quickly.

Submitters recommended suicide prevention responses that included addressing the underlying causes of pain and trauma. In addition, many submitters recommended focusing on reducing alcohol availability and alcohol culture.

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<sup>3</sup> Where a quote refers to the term 'caller', these are submissions that have been received via trained staff through the Inquiry's 0800 number. These submissions were taken down and then checked with the caller to ensure their views are captured accurately, but are written in the third person.

Understanding the link between suicide and substance use should be included in suicide prevention strategies. People who misuse alcohol and other substances are more likely to suicide. Substance use, especially alcohol is associated with increased rates of violence, often to intimate family members. Research indicates that people exposed to domestic violence have a greater risk of suiciding. Public health initiatives targeted at reducing suicide must be cognisant of the role substance use plays in increasing the risk of suicide, both with the person living with addiction and those close family members who may be indirectly harmed by their substance misuse (professional organisation)

Submitters also recommended that there be more education about suicide and self-harm, including greater awareness about self-harm and suicide, teaching children how to deal with suicidal thoughts, and how people can provide support if others are in distress.

Wellbeing programmes and/or Mindfulness as part of the school curriculum. Education for those who have loved ones who might be sliding towards depression or suicide (what to look for, how to engage to help the person). The further into the tunnel you go the darker it is and the harder it can be to find your way out (service user)

Many hoped for change.

I visited [family member's] grave today. I pray that hurts can be healed and that people will learn the way of love and peace (family member)

# 1 BACKGROUND

## 1.1 Purpose of the Inquiry

The Government committed to setting up an inquiry into mental health and addiction as part of its coalition programme of work for its first 100 days. The key drivers for the Inquiry were:

- addressing inequalities in mental health and addiction outcomes
- underfunding of mental health and addiction services
- stubbornly high suicide rates.

### VALUES AND PRINCIPLES THAT GUIDED THE INQUIRY PANEL

#### *Values*

- Aroha – love, compassion, empathy
- Whanaungatanga – relationship, kinship, sense of connection
- Kotahitanga – unity, togetherness, solidarity, collective action
- Whakamana – respect for everyone’s mana and connections
- Mahitahi – collaboration, cooperation
- Tūmanako pai– hope, positiveness

#### *Principles*

- Open and inclusive engagement with a broad range of people
- Build on existing knowledge and work
- Focus on solutions rather than simply redefining the problems

The aim of the Government Inquiry into Mental Health and Addiction (the Inquiry) was to inform the Government’s decisions and future investment priorities by identifying unmet needs and developing recommendations for a better mental health and addiction system. This work was to contribute to setting a clearer direction for government, the mental health and addiction sector, and the community to improve mental health and wellbeing in Aotearoa New Zealand. The Terms of Reference for the Inquiry are in Appendix A.

## 1.2 Consultation process

The Inquiry's consultation process included:

- publishing a consultation document inviting interested people, groups and organisations to provide written and oral submissions (reproduced in Appendix B)
- meeting with people with mental health and addiction challenges, their families and whānau, service providers, tāngata whaiora, advocates, sector groups and experts
- meeting with officials from diverse parts of government
- meeting with non-governmental organisations (NGOs) and community groups
- holding public and private meetings, hui, *fono* and forums around the country
- connecting through our website, Facebook and Twitter
- advertising public meetings in local media outlets.

### 1.2.1 Mode of submission

The six ways to share views with the Inquiry – some included formal ways to self-identify, others did not – were to:

- respond to the online consultation document, which was available in six languages (English, te reo Māori, Simplified Chinese, Tongan, Hindi and Samoan) as well as in large text and Easy Read and a video version with a New Zealand Sign Language interpretation
- email the Inquiry directly
- make a hard-copy submission or complete an Inquiry form and send it in using post or give it to a secretariat or panel member at meetings
- participate in a meeting, hui or *fono* (where anonymised thematic notes were taken and included in the submissions process)
- submit a video (with an interpretation service being available for the Deaf community)
- speak to a trained operator using the Inquiry's free 0800 number.

New Zealand Sign Language interpreters attended most public meetings.

Twitter and Facebook were also used as a means of communicating and sharing ideas but were not part of the formal submission process. However, some submitters chose to participate through Facebook, and their comments were included in the submissions summary. The Inquiry's Facebook posts were shown to total nearly 497,000 people between May and early June 2018.

### 1.2.2 Submissions received

On 27 April 2018, the Inquiry released a consultation document, asking five questions.

1. What's currently working well?  
He aha ngā mea e oti pai ana i tēnei wā?

2. What isn't working well at the moment?  
He aha ngā mea kāore i te oti pai i tēnei wā?
3. What could be done better?  
He aha ngā mea ka taea te mahi pai ake?
4. From your point of view, what sort of society would be best for the mental health of all our people?  
Ki tāu titiro, he aha te momo pāpori e tino pai ana mō te hauora hinengaro o ngā tāngata katoa?
5. Anything else you want to tell us?  
He korero anō āu?

The Inquiry received 5,363 written, phone or video submissions, and over 2,000 people attended over 400 stakeholder and public meetings across Aotearoa New Zealand. Meetings were also treated as submissions. When participants spoke at a meeting, Inquiry staff summarised what was said into 'meeting, hui or fono notes'. The voices (anonymised and often paraphrased) of those who participated form part of this submissions summary report.

The Inquiry also received 16 petitions, with 339,217 signatures. Signatories sought improved funding, better access to services, free counselling, legal representation, and accountability for families and whānau and individuals engaged in the mental health system. Some noted the need for holistic, cross-sector co-operation to improve wellbeing for all New Zealanders. Others called for mental skills training for all children and youth.

Many submitters expressed their support for the Inquiry process. They asked that the Inquiry panel honour their kōrero and reinforced the need for serious change to occur. Across written submissions, many positively acknowledged the value of participating in the Inquiry process and having the opportunity to share stories and express feelings. A few submitters acknowledged that although it was personally challenging to share their story, they were driven by the chance to make a difference.

I do wish you all the best, as these are big questions. Well done for asking them, and for asking those of us with personal experiences to feed into creating the sort of society we actually do want to keep living in (service user)

Thank you for listening to NGOs, as mental health and addiction issues impact our work daily in communities across the country (NGO provider)<sup>4</sup>.

I attended your inquiry hearing at [town name] a few weeks ago and was both very moved by the experience and impressed with the empathy and kindness shown by the inquiry members and your team. I had intended to speak but there were many people wanting to and I decided to stop putting my hand up and that it was best that others were given the opportunity to have their voice heard. I thought it better that I provide this written submission instead (service user)

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<sup>4</sup> The term NGO provider is used to identify a non-government organisation that also provides mental health services, whereas 'NGO' is used for those who do not also provide services

Some submitters raised concerns with the Inquiry process. These concerns included the makeup of the panel, the location and timing of meetings, hui and *fono*, the perceived lack of sufficient promotion of the submission process, accessibility issues, the short timeframe of the Inquiry and its Terms of Reference.

I'd like to know how many women sit on your panel, what is the median age of your panel and how many Māori or Polynesians are on the panel. How many of your panel come from marginalised groups or poorer backgrounds? How many have suffered from mental illness? These people have the answers (whānau Māori)

### 1.2.3 Method of analysis

A summary of submissions condenses what people said into an accessible format that protects personal privacy, honours obligations of confidentiality, and complies with principles of natural justice. Names of individuals, organisations and groups, or other identifying information, is therefore excluded. This does not, however, preclude any individual, organisation or group publicising their own submission to whomever, and however, they wish.

Submissions consist of personal experiences, stories of heartbreak and hope, ideas for change from individuals, families and whānau, as well as more formal submissions from service providers, organisations, groups, Iwi, advocates, workforce representatives, NGOs and researchers.

There are many questions we can't answer with a summary of submissions – and we understand that often those who have had negative experiences with the mental health and addiction system are more motivated to participate. However, these submissions also carry with them solutions for change, of how to make the system better for the next person, and for Aotearoa New Zealand.

The aim of this summary of submissions, therefore, is not to produce more facts and figures, but to give a sense of what people are saying about mental health and addiction and to identify prevalent, recurring challenges and solutions.

#### **But how to honour these voices, solutions, and challenges given the number of submissions?**

With the volume of submissions in varying formats, we used the software NVIVO as a sorting and categorisation tool following the questions the Inquiry asked. Many written and oral submitters (over the phone and by video) shaped their responses to the Inquiry by answering the first four main questions asked by the Inquiry. Other written submissions, some video and many of the meetings, hui and *fono* notes did not follow this format.

Submitters had valuable things to say across different topics. This meant each submission (including meeting note summaries) needed to be split into smaller parts (what we call 'references') so they could then be grouped and analysed with submissions that were also about a similar topic.

This splitting of submissions resulted in 140,317 references. These references were grouped by theme, topic and population. This report summarises references into 16 topics and additional population groups (see Figure 1.1).

### **Why can't we give you full demographics?**

To keep the Inquiry process as open and accessible as possible, the panel did not make the provision of demographic information by all participants compulsory. People often submitted very personal stories – and the decision was made that, to encourage the greatest level of participation given tight timeframes, they should be able to share their stories without having to meet stringent requirements. Others chose to self-identify or tick demographic boxes.

### **Determination of ethnicity**

To enable themes from groups to be compared and contrasted, there were a range of activities undertaken to try and identify the ethnicity of the submitter, among other features such as organisation type. Identifying Māori and Pacific submitters was the highest priority in terms of determining ethnicity due to the emphasis on these groups in the Terms of Reference, the priorities set by the Panel, and the decision to develop separate reports presenting Māori and Pacific voice.

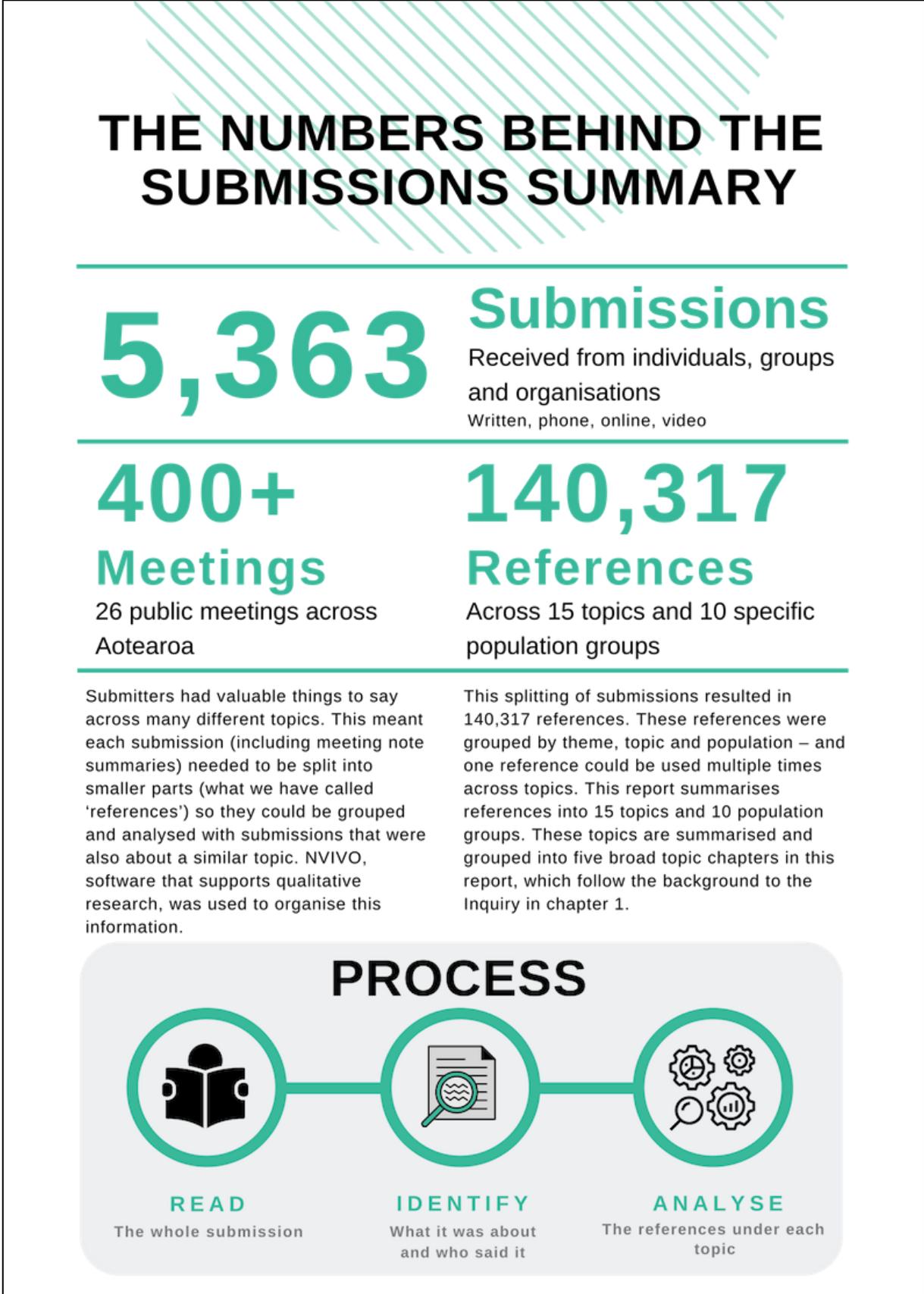
There were several challenges for identifying demographics:

- The number of email submissions and submissions from other channels (such as Facebook) that did not include any demographic information (approximately 1,765 submissions)
- The significant number of webform submissions (1,420 of 3,194 total) that did not fill out any demographic information
- The emphasis on providing information to the panel in face-to-face meetings by some groups, especially Māori and Pacific groups, where demographic information was not asked for.

The consultation document contained several, simple questions about demographics to help with determining ethnicity but these were voluntary, and were designed to be easy to answer questions rather than in-depth. These demographic questions were purposefully designed not to put people off answering the consultation questions by requesting too much information.

As a result, we received only partial demographic information on submitters and contributors.

FIGURE 1.1: SUMMARY OF SUBMISSIONS RECEIVED AND ANALYSIS PROCESS

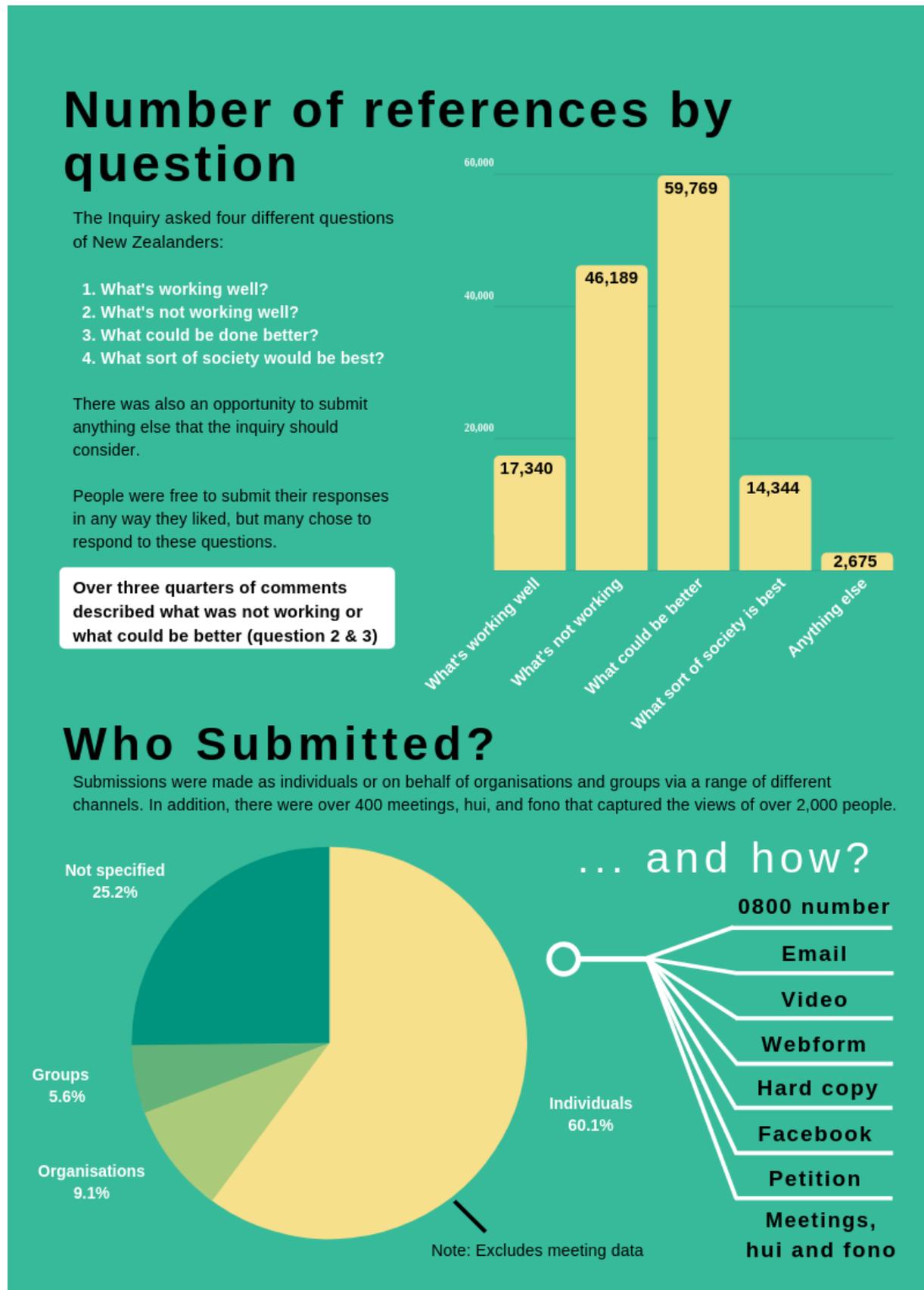


When written, phone and video references are viewed by question, the following picture emerges.

- Approximately 60% of submissions were from individuals; organisations and groups (three or more people represented on a submission) made up approximately 15% of identified submissions; and 25% of submitters did not identify as an individual or with an organisation or group.
- More references were sorted into what was not working and what could be better, than into what was working. Question 4, about what sort of society is best, also had a lower number of references. However, many of these were very detailed in their thoughts on our future society.

Meetings, hui and *fono* notes indicate who was speaking or what organisation was represented where this was possible. But it was not possible to get an accurate representation of everyone involved in meetings or listening in the audience. However, the content from those meetings (that is, the meeting notes) were used as part of this analysis. Paraphrased comments from these meetings, hui, and *fono* have been used throughout this report. In order to respect the confidentiality of the speaker and other attendees, we have not specifically identified these meetings, hui, or *fono*, but instead have identified the contributor with the same terms used for written submissions. See Figure 1.2.

FIGURE 1.2: SUMMARY OF RESPONSES AND WHO MADE SUBMISSIONS



### 1.2.4 Section analysis

Each section follows a similar structure:

- a brief overview of the topic to be summarised in the section
- a visual showing the number of references for the topic
- an overview of question responses and key themes within each section
- text expanding on the key themes with supporting quotations.

Each section is structured thematically or based on three questions, What's working well? What isn't working well? What could be better? There are some exceptions to this structure. The fourth question, What sort of society would be best for the mental health of all our people, is considered in full in section **2.1: What sort of society is best for mental health?**

#### **Few, some, many, most**

A figure at the start of each chapter illustrates how many references relate to that topic, and how they break down under the various questions the Inquiry asked. The amount of information for each chapter varies – some have thousands of references, some tens of thousands. For example, 35,381 references were in access to services, whereas 2,263 references were in leadership change.

We give an indication of how many references referred to a topic or theme by using quantifiers such as few (less than 20% of references), some (20%–40%), many to most (over 40% and up to 90% – the middle ground), and almost all (over 90%). Of course, this is an indication only and does not reflect a weighting of individual submissions. For example, a consumer group submission might represent the voices of thousands of people, or an Iwi or a workplace union, tens of thousands, or a bereaved mother, herself and her family.

It is not the purpose of the summary of submissions to assign value – only to give a sense of consistent and recurring themes.

This report is divided into the following chapters (followed by appendices).

**Chapter 2: System and society** – what submitters said about the sort of society that is best for the mental health of all New Zealanders (question 4) and what kind of system-level ideas and changes are important, including leadership, social determinants, health promotion, rights and legislation (questions 1-3).

**Chapter 3: Services** – what submitters said about access to services, intervention treatment and support, and integration of services (questions 1–3).

**Chapter 4: Specific topics** – what submitters said about addiction and suicide (questions 1–3).

**Chapter 5: System design and implementation** – what submitters said about funding and commissioning, monitoring, data and evaluation, and workforce (questions 1–3).

**Chapter 6: Population overview** – what submitters said about 10 population groups (questions 1–3): youth, people in prison, disabled people and neurodiverse people, people in

rural communities, older people, Rainbow communities, the migrant population, the Deaf community, people with refugee backgrounds, and veterans.

### **Terms used in this report to describe types of submitters**

**Commentator** – this term is used for individual submissions from recognised leaders or someone who has proven expertise in a field, for example addictions, mental health, or other sector-wide knowledge

**DHB** – this refers to submissions received by District Health Boards.

**Family member** – submitters who have spoken about a family member with mental health and/or addiction challenges

**Health professional, staff, or Kaimahi** – these terms are used to refer to submitters who identified as having experience working within the health or mental health and addictions workforce. Kaimahi is used, where possible, to distinguish Māori workforce from non-Māori workforce, whether that be mental health and addiction workforce, clinical specialists, nurses and general practitioners.

**Kaiāwhina Māori** – this phrase is used, where possible, to denote a supporter or volunteer who is Māori

**Lived experience** – this term is used when a submitter has identified that they have personal experience with the topic that they are discussing, for example, experience of addictions or mental health challenges

**NGO provider or NGO** – not all Non-Government Organisations who made submissions were also a service provider. The term NGO provider is used to identify a Non-Government Organisation that also provides mental health services, whereas 'NGO' is used for those who do not.

**Rainbow** - the term 'Rainbow' is used as an umbrella term for people who are lesbian, gay, bisexual, trans, intersex, queer, asexual, and other diverse sexual orientations and gender identities. The term 'LGBTIQ+' is another term often used in this context.

**Service user** – submitters who have identified as (currently or previously) using mental health and/or addiction services

**Tāngata whaiora or tangata whaiora** - the expression 'tāngata whaiora' refers to 'people seeking wellness' but is used in this report, where possible, to distinguish Māori service users from non-Māori (service users). Tangata whaiora refers to one Māori service user, while tāngata whaiora refers to more than one.

**Whānau Māori** – this term refers to the wider Māori definition of whānau, and is used in this report, where possible, to distinguish between whānau Māori and non-Māori family members.

## 2 SYSTEM AND SOCIETY

System and Society presents an overview of responses from submitters focusing on change – at both a societal level and at a system level. It provides the themes that were evident in submitters’ responses to question 4 of the Inquiry’s consultation document (What sort of society would be best for the mental health of all of our people?) as well as broader system-level themes across questions 1-3.

### TOPICS

The sections in this chapter summarise the responses into seven topics.

**Section 2.1: What sort of society is best for mental health?** A strong call for societal change focusing on different ways to think about mental health and addiction and different approaches that can be taken.

**Section 2.2: Leadership for change:** A focus on effective leadership, proposed structural changes, and ways to deliver equitable health and wellbeing through leadership.

**Section 2.3: Te matapihi ki Te Ao Māori (window to the Māori world):** Māori voices asking for true partnership for tāngata whaiora founded on Te Tiriti o Waitangi, including services and systems based on Te Ao Māori, with self-determined funding, commissioning and workforce.

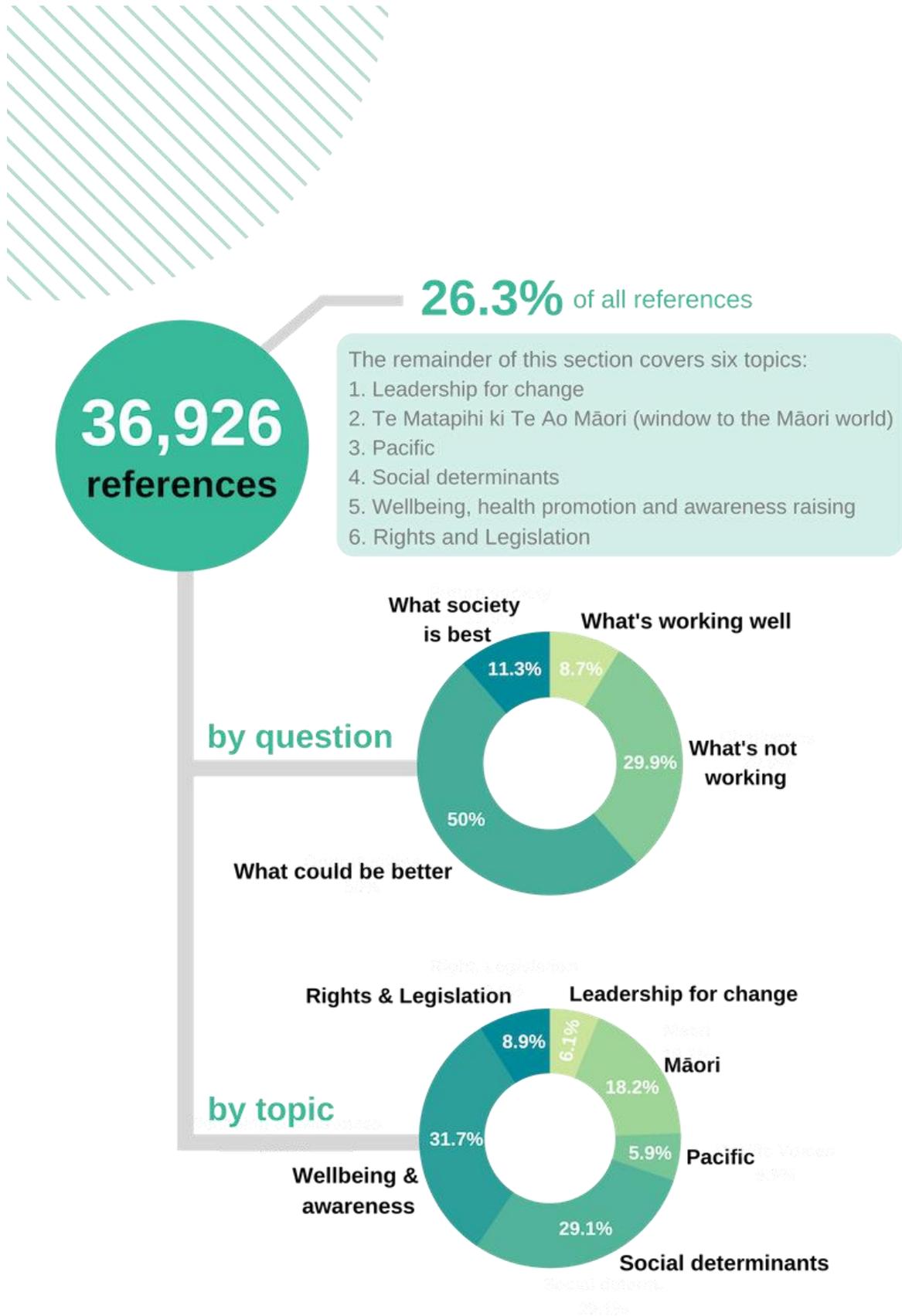
**Section 2.4: Pacific voices:** Pacific voices asking for system-level changes including Pacific commissioning of holistic services, realistic levels of resourcing for (particularly addiction) services, services based on holistic and clinical models that value Pacific specialists, healing approaches that prioritise relationships based on connection, kindness and dignity, and health promotion to reduce stigma and discrimination.

**Section 2.5: Social determinants :** strong call to address inequitable access to the social determinants of health and wellbeing contributing to high rates of mental health and addiction problems, to acknowledge the intergenerational impact of discrimination on Māori, and to address the impact for all New Zealanders of poverty, inadequate housing, unemployment, violence and social isolation with holistic solutions focusing on children and the impacts of trauma.

**Section 2.6: Wellbeing, health promotion and awareness raising:** A consistent call for holistic and inclusive approaches to wellbeing and health-promoting activities that reduce stigma, focusing on wellbeing initiatives and strengthening relationships within local communities.

**Section 2.7: Rights and legislation:** Aotearoa New Zealand has committed to national and international principles of rights. These include human rights, indigenous rights, and the rights of people with disabilities. Unfortunately, many submitters or people they know have experienced breaches of these rights. Submitters believe the principles of Te Tiriti o Waitangi are not well embedded in services and society. There is a call to modify existing legislation and policies to align with, and be centred on, people’s rights. Submitters want greater visibility and more accountability of people’s rights to promote widespread societal and workforce behavioural change.

FIGURE 2.1: SUMMARY OF RESPONSES MADE ABOUT SYSTEM AND SOCIETY



## 2.1 What sort of society is best for mental health?

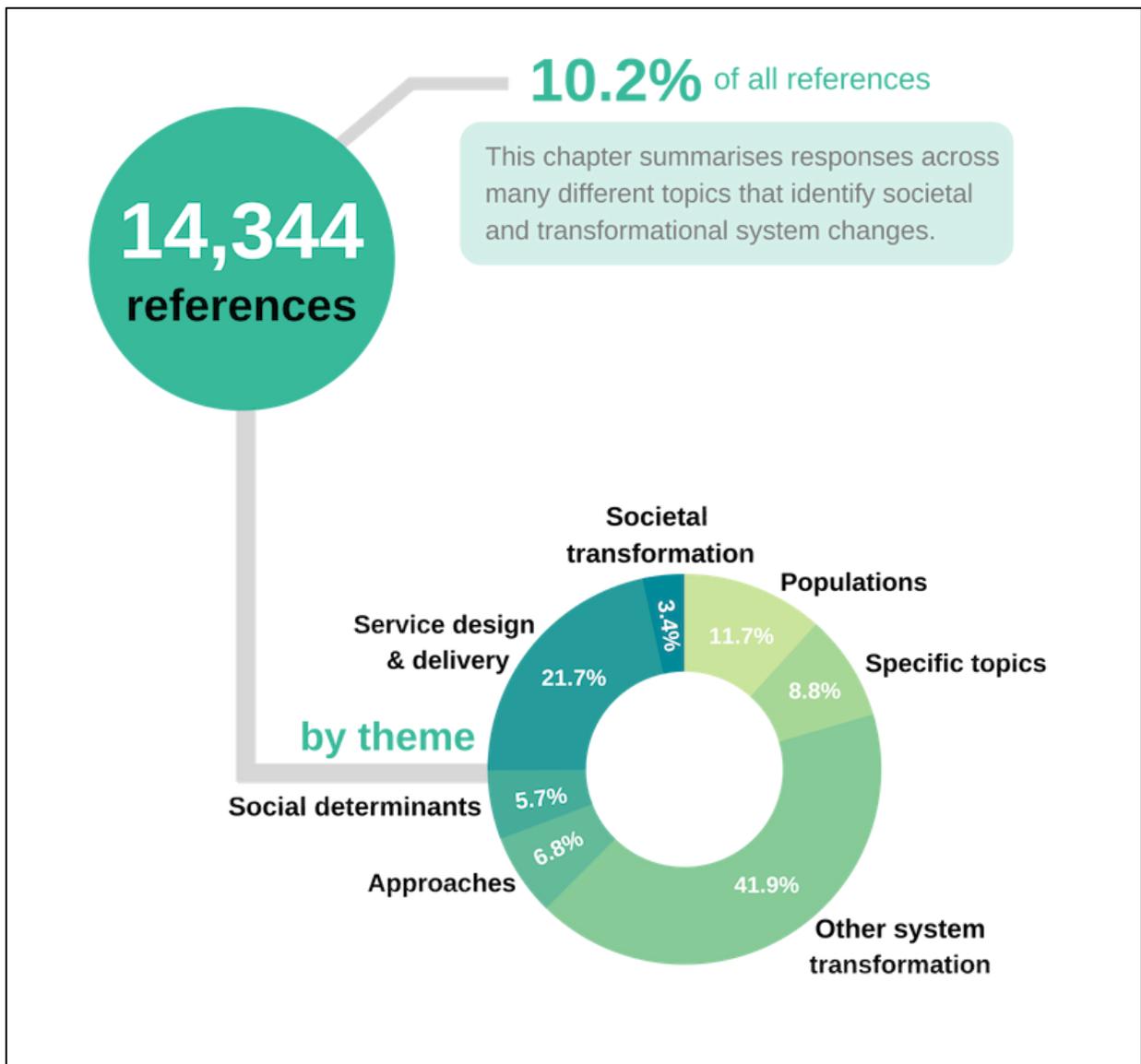
### 2.1.1 Overview

Submitters to the Inquiry were asked:

From your point of view, what sort of society would be best for the mental health of all of our people? Ki tāu titiro, he aha te momo pāpori e tino pai ana mō te hauora hinengaro o ngā tāngata katoa?

This section presents an overview of responses to this question – from broad societal changes to the kinds of approaches we can take for best mental health outcomes. Submitters made 14,344 references, directly or indirectly, to question 4 across various topics. See Figure 2.2.

FIGURE 2.2: TOTAL REFERENCES FOR QUESTION 4 – WHAT SORT OF SOCIETY WOULD BE BEST FOR THE MENTAL HEALTH OF ALL OF OUR PEOPLE?



**KEY THEMES FROM SUBMISSIONS FOR WHAT SORT OF SOCIETY IS BEST FOR MENTAL HEALTH (Q4)  
INCLUDE:**

**2.1.2 A society that views mental health in different ways:** submitters spoke of ways that mental health is viewed and treated and ways that they would like this to change. Submitters talked about:

- biomedical views of mental health
- a wellbeing view of mental health
- Te Ao Māori world view
- a society based on community
- Pacific world views
- a society based on human rights.

**2.1.3 A society that focuses on equity, justice, kindness and inclusion:** the key concepts submitters want to see in society are:

- kindness and inclusion
- equity and justice
- a consideration of social determinants
- tino rangatiratanga
- the targeting of child poverty.

**2.1.4 A society that requires different approaches:**

- whole of society integrated services
- early childhood and life course approaches
- community hubs and other solutions
- from punitive to therapeutic approaches
- Whānau Ora
- Pacific approaches
- Te Whare Tapa Whā
- recovery-based approaches
- resilience-based interventions.

These approaches (and others) are also covered in chapter 3: Services. Many submitters called for strong national leadership to focus on improving health and wellbeing, enhance equity and justice, and drive transformational approaches to wellbeing and distress, including cohesive national systems and transformed leadership models. This is explored in section **2.2: Leadership for change**.

### 2.1.2 A society that views mental health in different ways

The term ‘world view’ is used to mean a set of beliefs or assumptions about how the world is and should be. We may not know we hold a world view but each of us does – and world views are integral to the ways we structure society, and understand wellbeing, mental health and addiction. World view also includes how we decide to build the systems, services and supports society needs to produce positive mental health outcomes.

#### Biomedical views of mental health

Many submitters including service users, tāngata whaiora, non-governmental organisations (NGOs), community groups, researchers, clinical representatives and advocates referred to the medical or Western world view. They perceived this to include individualism, reductionism and a biomedical-only approach to responding to mental health and addiction challenges. Submitters contrasted the biomedical model, which was often seen as pharmacological interventions only, with approaches that took more holistic views of mental health. Although the biomedical model is a body of knowledge that has evolved to form the medical basis of diagnosis and treatment, many submissions challenged this view as the only approach that should be available or, indeed, as the correct approach.

Challenging the single lens biomedical approach to mental health was a strong theme across submissions in question 4. These submitters noted that the biomedical view of health is not in line with other views of health, it does not consider the person as a whole, and is not delivering desired wellbeing outcomes.

The biomedical perspective relies on the falsehood that people with psychological struggles have a defective brain that needs to be ‘corrected’ with neurotoxins. More often than not, once the complex suffering of an individual has been reduced to a simplistic diagnoses, any past history of trauma, abuse or deprivation is deemed irrelevant (NGO collating views of service users)

Key criticisms of a biomedical world view include:

- human experiences are reduced to symptoms and diagnoses
- people are asked ‘what is wrong with you’, not ‘what has happened to you’
- people are prescribed pharmaceuticals that may not be useful for them and are at times harmful.

One organisation noted,

Restricting the focus to only pharmacological treatments limits the options available for treatment and perpetuates a widening gap in the provision of mental health services. It leads to a narrow focus on only one aspect of a patient’s condition instead of considering the wider issues such as trauma, family/whānau, relational, cultural, occupational and developmental [and] personality factors (professional organisation)

This reduction of mental health and addiction challenges to a set of symptoms (while ignoring social, environmental, interpersonal, natural and spiritual dimensions of life) was not an acceptable world view for many submitters. This included those who took medication for depression or other diagnoses.

We are treating peoples' distress and problems as if they were a medical condition. This is not effective for people with emotional, psychological and spiritual issues and we cannot expect medications to deal with emotions such as grief, shame or guilt (individual submitter)

Therefore, many submitters called for a world view in which people are understood as holistic beings located in social, spiritual, cultural, economic, political and environmental contexts – and within interpersonal relationships including family, whānau and community. These submitters addressed the harm caused by a biomedical world view – sometimes with very personal stories of struggle and loss. They also addressed the failure of the system to recognise or respond to social determinants of health because of our mental health system's focus on pharmacological solutions.

In my experience, the patient is not treated as a whole, but a fragment of the area of expertise the particular doctor is trained in ... A band aid will eventually wear off, fix the wound and there will no longer be a need for the plaster (family member)

### **A wellbeing view of mental health**

Many submitters said that a focus on prevention and wellbeing (rather than an 'ambulance at the bottom of the cliff' mentality) was the best way to transform society and, in turn, address the suffering caused by mental health and addiction challenges.

Although the term 'public health' did not appear consistently throughout submissions, its characteristics did. There were strong calls for a holistic mental health and addiction system emphasising cross-sector integration, health and wellbeing promotion, health literacy, prevention and early intervention initiatives (both childhood and treatment intervention), and focusing on the social determinants of health and wellbeing appropriate for an Aotearoa New Zealand context.

[I]ndividuals will share similar elements but require differing levels of support across culture, language, community, relationships; finance, economic and natural environments: that will help shape their psychological, social, spiritual and physical wellbeing. However, as a nation we can predicate the acceptable levels of Wellbeing and in doing so, begin... to design the foundational elements of a national Wellbeing standard (NGO provider)

Submitters noted that a view of mental health that focuses on wellbeing requires transformational approaches to managing mental health and addiction challenges based on concepts of hope, aroha and recovery, self-determination, family and whānau participation, cross-sector collaboration and response and requires targeting underlying drivers of mental distress including social determinants.

Ultimately, we believe that wellbeing must be addressed as a cross-sector, whole of life, whole system, whole community issue and opportunity. This requires a response that transforms the system from thinking, practices and frameworks that were designed in the last century to responses that are relevant and responsive to the needs of people and communities in this century (NGO)

If as a nation we are to improve mental health and wellbeing in Aotearoa New Zealand, we need to take a population approach and look at prevention and early intervention strategies. Research is clearly indicating that this approach works (professional organisation)

Some submitters noted that a wellbeing approach also adopts a health focused approach to addictions.

## **Te Ao Māori world view**

See section **2.3: Te matapihi ki Te Ao Māori (window to the Māori world)**

Māori submitters consistently called for a society that integrates Te Ao Māori into the way Aotearoa New Zealand approaches wellbeing (including mental health and addiction). While there was diversity across submissions from tangata whenua including iwi and Māori organisations, there is overarching agreement that Te Ao Māori, mātauranga Māori, Whānau Ora, whakapapa and tino rangatiratanga must be placed centre front to bring about wellbeing for tāngata whaiora.

One submission from Māori, representing several organisations, described Te Ao Māori world views as a shift away from the current Western model to,

[A] frame of reference that is built on tikanga Māori (customs), which is founded on mātauranga Māori (knowledge), which in turn is founded on kaupapa Māori (philosophy), which informs and is informed by Te Ao Māori (Māori NGO collating views of Māori NGO providers, kaimahi, tāngata whaiora, and whānau )

This submission also highlights that such a shift requires change at all levels across policy, systems, resourcing and service delivery. By doing so, not only would whānau wellbeing improve, but all New Zealanders' wellbeing. As another organisation noted,

an ideal society for mental health of all people would be where, whānau enjoy good health, experience economic wellbeing, be knowledgeable and well informed, be culturally secure, resilient, self-managing and able to participate fully in Te Ao Māori and in wider society (NGO)

Some submitters, Māori and non-Māori, called for rights granted in Te Tiriti o Waitangi (Māori text) and the United Nations Declaration on the Rights of Indigenous Peoples to be upheld. One submission from 11 Māori leaders provided a comprehensive approach to how these changes would take place, including recognition of the Māori body of knowledge, accountability of the Crown to Māori (including recognition of Te Tiriti o Waitangi and the Declaration, an emphasis on a Māori world view (for equity and innovation), and “investment and respect for aspirations that build upon existing successful and prospective Māori models and achievements” (Māori health leaders and colleagues).

## **A society based on community**

Many submissions, service users, whānau, NGOs, and primary health care and advocacy groups challenged the decline in community services and opportunities to participate in community life and called for reinvestment in local solutions to local challenges.

This was not only in terms of mental health and addiction, but the innate human need for belonging, identity and purpose. As one submitter with lived experience said, “modern culture means that we often don’t even know our neighbours” (service user).

One submission, representing two organisations whose members have lived experience, is an example of a submission that called for a shift in society from “Big Psychiatry” to “Big Community”<sup>5</sup>. This submission outlined eight main changes in current thinking, system and service design,

1. Mental distress viewed as recoverable, social, psychological, spiritual or health disruptions
2. A wellbeing system with multiple entry points led by multiple sectors and communities
3. Resources used for a broad menu of comprehensive community-based responses
4. A mix of peer, cultural and traditional professional workforces
5. A commitment to partnerships at all levels and to human rights
6. A focus on equity, access, building strengths and improving long-term life and health outcomes
7. A response to people at risk with compassion and intensive support
8. A bi-cultural system that embraces many worldviews (mental health sector leaders)

Many submitters noted the value of identity and relationships, and a transformation of a system based on the importance of relationships. This sense of belonging came from community – friends, whānau, family, peer workers, church groups, supportive educators, cultural groups, marae, therapeutic groups – as well as opportunities to participate in a variety of activities, including work, education, volunteering, recreation and creative pursuits.

However, some submitters said both financial strain and discrimination were stopping their participation in the community, and many valued the opportunity to have safe, welcoming, free places they could feel part of society – drop-in centres, libraries, free transport, ability to volunteer, and community acceptance of those outside the ‘cultural norm’.

As one submitter with lived experience noted in her recovery,

I have a sense of belonging and community surrounded by friends and family that again, I never thought possible. So in answer to the question; how am I OK now? It is very, very simple. I have the financial and social privilege to be able to emancipate myself from everything that was destroying me mentally and spiritually. Without that financial and social privilege, I can assure you, I would not be alive today (service user)

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5 Big Community is a term used in a submission from a group of mental health leaders (and referred to by a number of other submitters) that refers to an alternative approach to mental health and wellbeing which stresses community support and prevention instead of psychiatric interventions.

For many submitters being able to offer community responses to mental health and addiction challenges were essential to delivering the right services, at the right time, in the right location.

### **Pacific world view**

(See section **2.4: Pacific voices** for more information)

Submissions from Pacific peoples called for collective, relational and holistic world views that reflect the diversity of Pacific cultures, values, religions and language. One NGO collective noted,

The mental health system in New Zealand for the most part, is informed by and dominated by secular, scientific and empirical understandings of human behaviour. Even the bio-psycho-social approach by mental health clinicians fails to take into account spirituality and cosmological beliefs connected to ancestry and tapu as 'evidenced based', validated factors that require addressing for Pacific mental well-being. This contrast in belief systems is likely to contribute to Pacific people's discomfort with using psychiatric services and has been reported as a contributing factor to many being committed to psychiatric hospitals as involuntary consumers (Pacific NGO providers)

Many Pacific peoples' submissions focused on the need to address social inequities and the underlying causes of health disparities, and have a Pacific for Pacific leadership, funding and commission model,

Identity is central to wellbeing which is essential to mental health—need Pasifika centric solutions in health, Oranga Tamariki, etc. Funding model is broken and now is the opportunity to look at how these services should work. We have the pan-Pasifika hub with medical practice and [early childhood education]—looking at integration ... Best practice shows that this is what works for communities like Pasifika. This is how we already work except we're confined by our national contracts which don't allow for it (Pacific contributor)

### **A society based on human rights**

(See section **2.7: Rights and legislation**)

Some submitters, including individuals, commentators and organisations, focused on the need to uphold human rights as a means to change society, urging the Government to guarantee fundamental human rights to liberty, security, safety and the highest attainable standard of health and to adopt international agreements.

New Zealand now has a unique opportunity to lead the world by responding to the call from the UN High Commissioner for Human Rights quoted on the opening page of this submission. We can and should take immediate steps to end the human rights violations being committed against people who experience mental distress and addictions in New Zealand. Evidence from some of New Zealand's leading mental health professionals supports such action (NGO providers)

A healthy society supports, nurtures and accepts diversity and is built on a foundation of human rights and equity (professional organisation)

### 2.1.3 A society that focuses on kindness, inclusion, equity and justice

While submissions vary in focus many are concerned with the relationship between wellbeing and fairness, safety, equity, justice, freedom from discrimination, social inclusion and the fundamental right to liberty and self-determination.

#### FIVE KEY CONCEPTS SUBMITTERS WANT TO SEE

The key concepts submitters want to see in society are:

- kindness and inclusion
- equity and justice
- a consideration of social determinants
- tino rangatiratanga
- the targeting of child poverty.

#### Kindness and inclusion

Many submitters called for societal transformation or a society based on equity, justice, kindness and acceptance.

As an alternative I have a vision of a society based on a paradigm of interconnectedness and the central Māori values of aroha, whanaungatanga, manākitanga and kotahitanga. From this foundation can be built an integrated holistic and empowering mental healthcare system that supports the mental wellbeing of individuals and whānau and embodies Sir Mason Durie's wellbeing model *te whare tapa wha* (health professional with lived experience)

A society where people treat each other with kindness, respect, dignity and love instead of judging and condemning (service user)

A caring, empathetic, understanding and respectful society is so important. Appreciating diversity in culture, gender and all aspects of our humanity are important. Advocacy and support for those in need and supporting those who do the caring is important (individual with lived experience)

Some submitters included a blunt critique of the values of capitalism while others noted the lack of political will to change the status quo.

The thirty years of neo-liberalism has created grave social inequity where many young people cannot see a future and the feeling of [being] excluded from participation in society. This is something that cannot be quickly corrected however unless a plan is instigated to move the whole of society to a more equitable space we can expect the status quo to continue (individual with lived experience)

Societal changes to reduce the pressure on people's lives. Get house and rent prices back under control, stop food prices going up far faster than wages, make public transport useable. Jobs that respect weekends and evenings should be the norm, not the exception. If people's lives are easier, mental health problems will be less frequent, or more manageable (service user)

Several submitters called for a fairer more equitable distribution of wealth through the taxation system, and the impact of climate change and the need to live in a society where the natural environment is valued given its significant impact on wellbeing,

Creating hope - on matters as widely relevant as acting upon climate change, before it's too late; and on matters as personally relevant as whether there is anything in this world worth getting out of bed for today - a meal? some exercise? some company? something that might bring a smile? something creative? some work? some education? something personally relevant? (individual with lived experience)

Many submissions said that a change in society must continue to occur challenging the stigma associated with mental health and addiction challenges.

## **Equity and justice**

(See section **2.7: Rights and legislation**)

Issues of justice and equity were important for many submitters and were seen to form the basis of a transformed system. These issues were addressed in varying ways and related to a particular context, population, or sector of society. Some submitters spoke of equity and justice in terms of equal access to healthcare, equitable health outcomes for all populations, provision of employment opportunities, equitable income distribution, targeting poverty, challenging stigma and discrimination, and inclusivity. Others, particularly some commentators, focused on human rights, indigenous rights or service user rights (including reference to the Mental Health (Compulsory Assessment and Treatment) Act 1992) as well as the human rights of refugees and the Code of Health and Disability Services Consumers' Rights.

Others spoke of the strong need for equity and justice in terms for those in aged care facilities without consent, those with mental health and addictions in prison without access to treatment, workplace discrimination for those with mental health challenges, and the high rate of seclusion, restraint and compulsory treatment orders. As one organisation noted,

In developing approaches for the future, we also need to acknowledge and learn from failures, including historic abuse associated with institutionalisation, and current over-use of compulsory treatment, seclusion and restraint (NGO)

## **Social determinants**

(See section **2.5: Social determinants**)

One submitter defined the social determinants of health as "the conditions in which people are born, grow, live, work and age" (professional organisation). These circumstances are

shaped by the distribution of money, power and resources at global, national and local levels.

Many who spoke of human rights also called for a transformational shift to a fairer society by addressing the determinants of health. In addition, many submitters equated a fair society with one that challenged the inequities of social determinants.

A more fair society where inequalities are reduced and people can afford to live in a warm, dry house, afford to eat healthy food and live as part of a wider healthy environment. A society should be judged on how we treat our most vulnerable and currently in New Zealand, we would get an F (individual submitter)

One human rights organisation noted that it is not possible to consider mental health and addiction in isolation from broader social concerns. It went on to cite the United Nations special rapporteur on the right of everyone to the highest attainable standard of physical and mental health physical and mental health.

Public policies continue to neglect the importance of the preconditions of poorer mental health such as violence, disempowerment, social exclusion and isolation and the breakdown of communities, systemic socioeconomic disadvantage and harmful conditions at work and in schools (government agency)

## **Tino rangatiratanga**

Several submissions from Māori and non-Māori addressed issues relating to tino rangatiratanga, and the impacts of colonisation, discrimination and failure to uphold Te Tiriti o Waitangi.

Some submissions referenced the negative impacts of colonisation and why this continues to be a determinant in health outcomes for Māori.

Colonisation permits the (mis)appropriation and transfer of power and resources from indigenous peoples to newcomers. This process of transfer is enabled by layer upon layer of new systems established to determine how resources will be obtained and how they are to be redistributed and to whom. These systems, therefore, construct who will benefit and be privileged. These systems are built on new values and new ideas of normal. Through this colonising process Māori move from being normal to being 'different' from Pākehā, non-Māori, non-indigenous norms. Māori rights as tangata whenua are appropriated and are marginalised and reclassified by 'outsiders' (Māori NGO collating views of Māori NGO providers, kaimahi, tāngata whaiora, and whānau)

Many submitters called for discrimination to end – particularly noting its impact on mental health and addiction challenges. As one peer-support worker noted,

Discrimination is known to be bad for psychological well-being, and New Zealand researchers have openly subscribed to the concept that Māori experience of 'racism' is responsible for a wide range of inequitable health outcomes including mental health (Māori professional organisation)

Many submissions from Māori social and health services promoted and recommended tāngata whenua rangatiratanga separate to Western-based funding and commissioning models, noting the need to fund from a different perspective.

Let's commission from a Kaupapa Māori methodology. "We need to create a system where whānau can come in and out as they see fit." We want them to be able to walk in the door under the principles of Whānau Ora and access whatever they need: point of access care to entire family (kaimahi Māori)

Some submissions from Māori, including iwi and Māori organisations, and several submissions from human rights leaders and non-Māori organisations, highlighted the importance of indigenous rights to wellbeing. A few submitters called for the Government to uphold the United Nations Declaration on the Rights of Indigenous Peoples urging the Inquiry to endorse indigenous rights to health, indigenous concepts of health and collective wellbeing, shared decision making, the protection of rangatiratanga and taonga, and participation on an equal basis with others.

Some submissions note the disproportionate rate of detention, seclusion, restraint and forced treatment of Māori and Pacific peoples, and the urgent need to rectify this situation has been commented on by the United Nations special rapporteur.

### **Targeting of child poverty**

For many submitters including individuals and prominent organisations, a fair and equitable society requires child poverty to be addressed and the rights of children to be upheld. They called on government to focus on equitable access to early childhood interventions (with their family and whānau supporting them) as a priority.

We ask the government to invest in children's wellbeing from the start of life, and ensure they are protected from deprivation by having adequate family income, good quality affordable housing, the ability to access health services and educational opportunities, and increased social engagement. This systemic level of change will require cross-party accord that spans the political cycle and ensures that the wellbeing of New Zealanders is always the political priority. Increased wellbeing from the start of life and connection to a thriving community will inevitably improve mental wellbeing (NGO providers)

A few submissions addressed children's rights, including the right to be heard, the right to child-centred services and supports, the right to safety, and for approaches consistent with children and youth aspirations.

Every child needs to be safe and have the right to participate. When we ask children and young people what they want, they talk about play and joy and the ability to be a child and they don't have to worry about the stressors of having to stay at home because mum has to go to work. They should have the freedom to be a child. The Government can't provide joy and love, but they can enable families to better support and care for their children (government agency)

#### **2.1.4 A society that requires different approaches**

When considering societal transformation, many submitters also commented on the way services are delivered. Many responses, therefore, focused on different yet integrated system and service models. As one submitter noted,

There are lots of gems and stardust but no overall coherent mental-health framework anywhere that is informed by good evidence, threaded through with compassion and humanity, aware of all the difficult places that humans can find themselves, and looking to the need for culturally aware structures and solutions (government agency)

The following sections overview different models or approaches that submitters noted – many of which already exist but are not driven from a cohesive system-level approach. These approaches are also reviewed in chapter **3: Services**.

##### **Whole of society integrated services**

Many submitters commented on the whole of system approach to health services including cross-sectoral responses and integration. For some submitters this required co-ordination at a national level (for example, health, education, housing, justice), whereas for others, it was local integration to target local challenges (for example, council, police, health services, NGOs).

Population-based approaches to mental health and addiction were expressed in different ways but generally included a whole population approach that involves every layer of the system and incorporates many different approaches including, critically, addressing early intervention, addressing social determinants and allocating resources to people at higher risk,

A population approach to mental wellbeing utilises ‘proportionate universalism’, where the aim is to move the whole population toward better mental health with greater targeting of resources for people at high risk ... This type of approach is crucial as mental distress, in the absence of a diagnosable mental illness, affects a far larger proportion of the population than clinical mental illness and collectively represents a larger burden of morbidity (professional organisation)

Most submitters described higher levels of integration as requiring transformational change based on different views and models of health.

##### **Early childhood and life course solutions**

Some submitters noted the need to truly heed the growing evidence base and shift approaches, funding and services toward early childhood intervention and prevention, and maternal care. This includes targeting the impact of adverse childhood experiences on mental health and addiction, increased maternal and parental support, and stronger investment in antenatal, early childhood, and youth services.

As one primary health organisation said,

[New Zealand's] record is not so impressive for children and young people, with our youth suicide rates among the highest in the OECD. We need to prioritise maternal health and the welfare of infants and children, given mounting evidence of the impact of adverse childhood events and of social and emotional bonding on future wellbeing (PHO)

This approach recognises that the first few years of life are critical to later life outcomes and emphasises the importance of prioritising investment in the early years. Submitters address issues relating to life course in various ways,

taking a preventative approach by increasing emphasis around the first 1000 days of life would significantly improve the life course outcomes for many (individual submitter)

### **Community hubs and other approaches**

There was a strong call from submitters for well-funded, well-resourced local solutions to local problems and a community-based approach to transform mental health and addiction challenges. This includes cross-agency co-operation and integrated services to address challenges (for example, local council, police and NGOs), well-funded programmes with oversight (either locally or nationally), and investment in community hubs.

We should have community mental health hubs in communities - warm welcoming centres where people's needs can be triaged to any service i.e. [Work and Income, Ministry of Social Development], housing NZ, budgeting, education, volunteering, psychoeducation, counselling or if need be some form of custodial care. People should not be passed (fobbed) off to other agencies they should be referred and introduced! So that none will fall between services, or go into a too hard basket (health professional)

### **From punitive to therapeutic approaches**

Many organisations working in the addiction sector, as well as those with lived experiences, called for a more compassionate, therapeutic approach to responding to addiction – shifting the emphasis of addiction away from incarceration to a rehabilitative system of care.

### **Whānau Ora**

Many Māori and Pacific organisations and some non-Māori recommended Whānau Ora as a preferred approach. This ranged from the overarching philosophy and principles, to the way the system is structured, commissioned and funded, and through to the design, configuration and delivery of services. Māori organisations commented,

as an overarching philosophy, Whānau Ora provides the rangatiratanga – self-determination for whānau (Māori NGO provider)

Whānau Ora is about whānau taking responsibility for whānau. It places whānau at the centre and empowers them to lead the development of solutions for their own transformation. The heart of Whānau Ora lies in building on whānau strengths and capability, growing whānau connections, supporting the development of whānau leadership and enhancing best outcomes for whānau (Māori NGO providers)

Submissions from iwi and Māori organisations strongly advocate for greater investment in Whānau Ora and Māori-centred models of care to better meet Māori aspirations and needs; they note that when this does happen, outcomes are positive.

There was a strong call to,

further support and develop Whānau Ora as a culturally embedded solution based on mātauranga Māori which is able to achieve equitable outcomes for Māori (Māori NGO collating views of Māori NGO providers, kaimahi, tāngata whaiora, and whānau)

[T]he perceivable challenges for clinicians and others trained in the health sector of working at the interface of different knowledge systems and cultural paradigms. While there is absolutely a place for high standards of clinical practice and technical expertise a hierarchy of standards which places their expertise at the center is no longer acceptable (Māori NGO providers)

Although Whānau Ora may be addressed in terms of Te Ao Māori, Whānau Ora is recognised by Kaupapa Māori services as,

an inclusive, culturally-anchored way of working with whānau and families across New Zealand (Māori NGO providers)

Whānau Ora, caring and supporting each other with a non-judgemental perspective. Keeping whānau in the picture. All services whānau [centred] with Te Ao Māori lens (tangata whaiora)

Some non-Māori submitters recommend the expansion and upscaling of Whānau Ora and other solutions that work for Māori, and view it as the most appropriate and effective approach for wellbeing.

## **Pacific approaches**

Many submissions from Pacific peoples also sought a Pacific Whānau Ora approach or similar conception of holistic health, but delivered in a way in which the locus of control is with Pacific peoples. One submission referenced the *Whānau Ora Commissioning Agency for Pacific Families* report 2013, which explained the Whānau Ora vision for Pacific families as supporting and building “āiga, kāiga, magafaoa, kōpu tangata, vuvale, fāmili, family capability” (Pacific professional organisation).

## **Te Whare Tapa Whā**

Many Māori, Pacific and non-Māori recommended Sir Mason Durie’s model Te Whare Tapa Whā, which is based on four cornerstones of wellbeing.<sup>6</sup> Although the application of Te Whare Tapa Whā in practice is diverse, there is widespread agreement that this holistic approach needs to be integral to future approaches to mental health, addiction and wellbeing.

One Māori organisation noted,

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<sup>6</sup> Taha wairua (spiritual health), taha tinana (physical health), taha whānau (family health) and taha hinengaro (mental health).

the influence of Te Whare Tapa Whā is palpable; this resonates with Māori providers as a lightning rod to push back against service silos, ignorance of cultural beliefs, and non-Indigenous models that impose external interventions on Māori individuals while shutting out their whānau (Māori NGO collating views of Māori NGO providers, aimahi, tāngata whaiora, and whānau)

Although non-Māori submitters may not have referred directly to the model, they did note the importance of physical, social, cultural and spiritual whole-of-person approaches.

In this respect, some submissions noted that Te Whare Tapa Whā, despite being part of policy within Aotearoa New Zealand, needs more consistent and full application.

### **Recovery-based approach**

Some submitters recommended a recovery-based approach.

A society that does not box people into a diagnosis that is the medical model but recovery based, which provides hope and optimism and it is not just a tokenistic term. That every person experiencing mental distress has time, understanding, support, encouragement to heal in a positive way that allows Tino Rangatiratanga (self-determination) (NGO provider)

Some mental health service users called for recovery to be embedded in a way that is consistent with the former Mental Health Commission's publication *Our Lives in 2014: A recovery vision from people with experience of mental illness, for the second mental health plan and the development of the health and social sectors*. Fundamental to this approach is the expectation of recovery and living full lives.

A few submitters with lived experience commented that too often clinicians have low expectations about future education and employment, living independently, having relationships and children. These low expectations limit hope and restrict lifetime outcomes.

### **Resilience-based intervention**

Many submitters called for greater resilience-based intervention with children and youth.

We need to teach emotional intelligence and compassion at schools so that these qualities are valued by our society, and so that those who miss out on a safe emotional home with their biological families can experience secure attachment elsewhere. We need to find ways to fund more resilience based interventions for children, probably outside school environments until such a time as being withdrawn from class for extra support is unlikely to attract stigmatising attention (service user with disabilities)

Some submitters spoke of the value of mindfulness as an approach – starting in early childhood and being taught through the education system. There was strong support for some form of evidence-based mindfulness to be included in the school curriculum, in workplaces, in health care and in early childhood and parenting programmes and its value to health, wellbeing, emotional literacy and regulation recognised.

This approach was seen as both therapeutic and preventative.

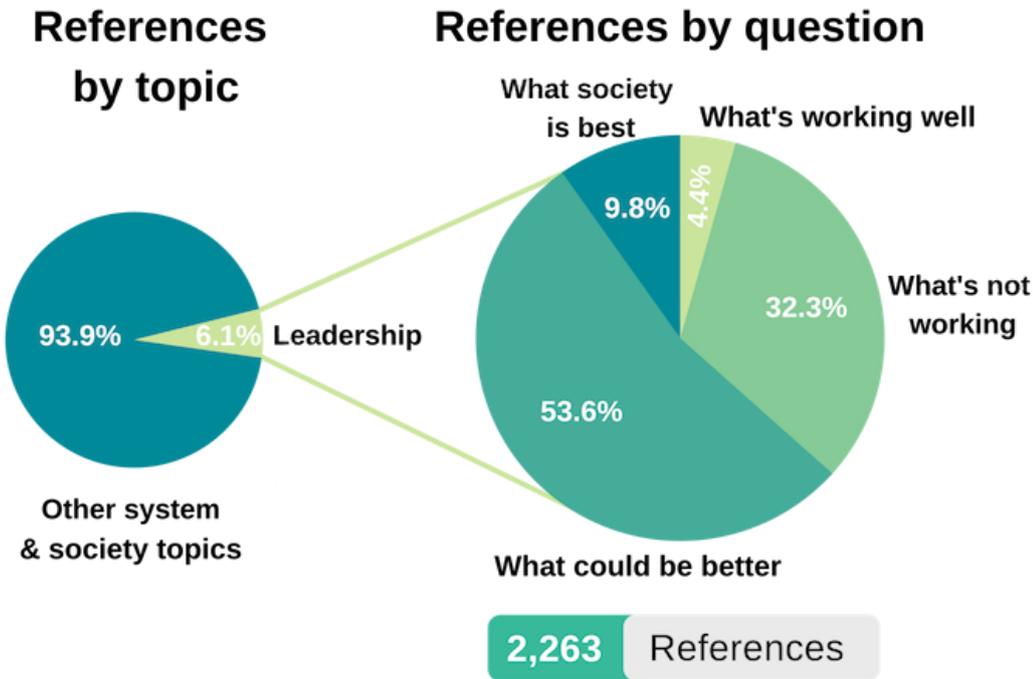
## 2.2 Leadership for change

### 2.2.1 Overview

This section presents an overview of responses from submitters related to leadership and associated ideas. Many submitters commented on the need for transformative leadership to improve health and wellbeing and to reduce the burden of suffering associated with mental health and addiction challenges in Aotearoa New Zealand. This included coherent leadership to enable new ways of working, with values based on equity, justice and kindness, and partnering with tangata whenua.

Submitters made 2,263 references about leadership for change (See Figure 2.3.)

FIGURE 2.3: SUMMARY OF RESPONSES ABOUT LEADERSHIP FOR CHANGE



KEY THEMES FROM SUBMISSIONS FOR LEADERSHIP FOR CHANGE INCLUDE:

**2.2.2 Leadership Challenges**

**2.2.3 Transformative National Leadership**

- government stewardship
- cross-party group to agree wellbeing vision
- Crown's obligation to partner with Māori
- cross-government policy and its implementation
- national leadership roles.

**2.2.4 Māori View**

**2.2.5 Leadership requirements in a new entity**

- structural options
- new Mental Health Commission(s)
- a new Commission – examples of alternative models submitted
- Ministry of Mental Health and Wellbeing
- Ministry of Wellbeing
- Ministry of Health

**2.2.2 Leadership challenges**

Many submitters commenting on leadership highlighted the limitations of the leadership of the mental health and addiction sector, and how it had failed to improve outcomes and to reduce disparities in mental health and addictions and overall wellbeing.

Many submitters often discussed the sector leadership limitations in the context of other topics including the impact that leadership has on what sort of society is best for mental health, approaches adopted for mental health and addiction, funding, commissioning, ability to address societal injustice and inequalities, social deprivation and the determinants of wellbeing, and an inability to view service users and tāngata whaiora holistically. Others noted less independent monitoring with “no single voice advocating and holding current services/government to account” (NGO).

Mental health has not had the required emphasis it deserves (NGO provider)

### **2.2.3 Transformative national leadership**

Many submitters called for national leaders to drive urgent and sustainable transformative change. Some NGOs said,

Urgent improvement in the availability of appropriate mental health and addictions support in New Zealand has become an issue of national significance (NGO)

Put simply, getting it right matters too much to us, and to almost every family/whānau in this country, for this issue to be rethought, reframed or reinvented within the term of each political cycle (NGO)

Another submitter noted community-level action started with Cabinet level planning,

We need communities with the opportunity for leadership and the resources to support and sustain wellbeing plus pan-government action to achieve a focus on wellbeing with Cabinet level planning and scrutiny (commentator)

#### **Government stewardship**

One submitter referenced the New Zealand Productivity Commission who considered that the role of system stewardship falls to government “because of its unique role as the major funder of social services and its statutory and regulatory powers that are unavailable to other participants”(NGO).

A re-established Mental Health and Addiction Commission could act as the independent watchdog and could hold government agencies and service providers to account for their part in realising the future that we want and need (NGO)

#### **Cross-government party group to agree to a wellbeing vision**

Submitters, particularly those in leadership roles, recognised the urgent need for cross-party leadership to enable all levels of society, and all government departments, to work towards an agreed long-term goal of wellbeing and mental health for all. They proposed the establishment of a Wellbeing Cross-Party group to establish a national agreed vision for wellbeing.

One submitter provided a diagram that proposed a Wellbeing Cross-Party Group with party representative membership, and a role that sets,

the long term strategic vision for whole of life and whole of community mental health and addictions support (or community wellbeing) based on information and advice from a cross-agency advisory group comprised of Chief Executives of: Ministry of Health, Oranga Tamariki Ministry for Children, Social Investment Agency, Department of Corrections, The Treasury, Te Puni Kōkiri Ministry of Māori Development, Ministry of Justice, Ministry of Education and any other interested Departments... as well as advice from the Mental Health and Addiction Commissioner and any other interested Crown Entities or Crown Agents such as the Health and Disability Commissioner, the Children’s Commissioner, the Human Rights Commissioner and the Police Commissioner ... and submissions and petitions from the public (NGO)

They considered that the national strategic vision could include specific targets for particularly at-risk population groups and could inform activity that is focused on workforce development with implications for the Ministry of Social Development and the Ministry for Pacific Peoples.

### **Crown's obligation to partner with Māori**

Many Māori submitters raised the urgent need to put in place mechanisms to honour the Crown's obligations under the Treaty of Waitangi and to address the lack of partnership with Māori leaders to develop strategies and policies, design, fund and deliver cross-sector approaches to reducing the impact of mental health and addiction problems on their people.

The Crown apology to [Iwi] recognises the Treaty principles of partnership, active participation in decision-making, active protection and rangatiratanga... [Organisation] expect te Tiriti o Waitangi to be a primary principle that guides the Inquiry's consideration of how to address the impacts of mental health and addiction on Māori. [Organisation] requests that any recommendations made by the Inquiry includes a commitment to the level of partnership and engagement, [organisation] expects, as the Treaty partner. Any recommendations by the Inquiry must also reflect a whole of Government emphasis (Māori NGO providers)

### **Cross-government policy and its implementation**

Some submitters raised the need for a mechanism to ensure cross-government policy is developed, and implemented consistently across government departments and at regional and local levels within sectors. These issues were raised alongside recommendations for new national entities with specific responsibility for this role such as the Ministry for Mental Health and Wellbeing.

A few submitters commented that to effectively perform its functions, each organisation requires adequate mandate and institutional capacity. These submitters also raised the need for an independent agency responsible for monitoring cross-government policy as a "reality check" to determine whether it has been achieved and raised that this entity be adequately funded and resourced to undertake this role.

### **National leadership roles**

There was general consensus among submitters for strong, cohesive national leadership to fill a perceived or real leadership vacuum. They proposed a variety of leadership roles to undertake the following responsibilities,

coordinate a national approach at the Ministerial level, across political parties, at a policy level with strong cross agency oversight, outside government, with approaches led at a community level that are well connected to the national vision and strategy, leadership by communities and individual champions, and linked with international leadership, research and action (NGO)

Submitters identified common features required in a national leadership entity for it to be effective in leading transformational change.

Various leadership roles proposed to oversee a cohesive national approach included:

- reinstatement of the Mental Health Commissioner (who may or may not have lived experience)

A reformed mental health commission would be in an ideal position to be an independent monitor of societal efforts to protect and promote mental health. The Commission could monitor agencies' performance and report publicly, as well as providing a fair and just point from which to advise departments and ministers (government agency)

- Mental Health and Addictions Ombudsman
- Youth Mental Health Commissioner (to advocate for youth across the sector)
- Suicide Prevention Commissioner
- a Minister Responsible for Suicide Prevention who works together with other ministers – this requires a joined-up approach that recognises that suicide is not just a health issue, but has a range of social determinants
- a Māori regulatory body mandated by the Health Practitioners Competence Assurance Act 2003 to ensure all practitioners are competent to work with Māori and that is an independent Māori national entity to provide oversight to improve quality of care for Māori
- independent Pacific mental health and addictions leadership  
mainstream is not serving us well, we could do it better. We are happy to fix ourselves, just need opportunity (Pacific professional organisation)
- leaders with lived experience  
I believe the lived experience leadership [that individual] brought to the whole sector when she was [Mental Health] Commissioner set NZ apart as a world leader (commentator)
- Ministry of Wellbeing – non-partisan cross-sector approach.

#### 2.2.4 Māori view

Māori submitters made a united call for transformational change to better enable Māori leadership and rangatiratanga (self-determination) in ways that align with Te Ao Māori. Most called for the establishment of a separate Māori entity for this purpose.

Joint submissions developed by Māori leaders recommended three options for establishing a new national entity for advancing Māori wellbeing:

- an independent Commission
- Te Tiriti o Waitangi partnership authority
- a national entity with a Whānau Ora framework operating alongside Māori self-determined commissioning and funding structures.

Submitters also proposed that these entities be assigned responsibility for key roles. One submission by a group of iwi leaders called for the establishment of a new entity to provide

for independent Māori oversight, Māori health leadership, policy and decision making, role sharing with Māori, and Māori service provision to Māori.

a National Māori entity ... to govern and oversee the provision of high-quality mental health and addiction services. Its role would be to support the development of consistent models of care, the development and integration of Māori models with contemporary psychiatric interventions. Equally, models for assignment of funding for service users, will enable access to proven evidence-based interventions (including cultural interventions) to drive consistency and adherence to accepted standards of quality. In this regard, a model of managed care oriented purely towards driving quality (with a lesser impetus for cost control) should be explored (Māori health leaders and colleagues)

Most Māori submitters recommended a distinctly Whānau Ora approach and noted that while this approach reflects Māori world views, it has wider applicability to the whole system.

Utilising a Whānau Ora approach to achieve a whole of systems approach that supports wellbeing, Whānau directed outcomes and connected supports is not only possible but also achievable with structural support and change (Māori NGO provider)

Submitters commented on the need for any new entity to focus broadly on wellbeing and on whānau wellbeing and to have enabling policy, systems and structures to deliver the services and supports needed for tāngata whaiora and whānau.

Submitters noted other roles for these new entities that included developing strategy, developing and overseeing cross-government policy, developing funding models, co-designing and implementing culturally safe service models, leading service quality improvement, setting targets, monitoring cross-sector performance and outcomes, building Māori leadership capability across all levels of society, and developing and training the workforce.

One joint submission by iwi leaders also pointed out that the new entity would need to build Māori health leadership to manage transformation. They called for investment in the development of Māori leaders and Māori health professionals who can operationalise in Kaupapa Māori service models. They also see the need to build the capacity and capability in Māori communities to focus on grassroots approaches and on early intervention and prevention, rather than sickness or illness models of care.

### **2.2.5 Structural options**

Most submitters who addressed leadership issues proposed solutions that included structural changes to enable a cross-government collaborative focus on improving health and wellbeing. They range from altering the current structures to establishing a variety of new cross-government entities. Submitters also proposed names for these entities and their purpose and functions.

Submissions from Māori organisations recommended an independent commission, Te Tiriti o Waitangi partnership authority, or other national entity. Common themes include the use of

a Whānau Ora framework and operating alongside Māori self-determined commissioning and funding structures to deliver services and support in ways that align with Te Ao Māori.

While submitters identified several common leadership themes associated with a new entity, they expressed a variety of views regarding the purpose, functions and responsibilities of an independent commission, reflective of their 'world views' as covered in chapter 3.

Most submitters discussing structural change proposed the establishment of an independent commission to facilitate sustained transformational change across government sectors.

### **Leadership requirements in a new entity**

**Mandate and authority.** A previous commissioner noted that for effective leadership to occur, irrespective of the nature of the entity, it will need to have legislative mandate and authority over other areas of government. Stewardship and authority are needed, rather than governance and accountability.

This will be required to create formal guides, design solutions and approve where resources will be allocated. In other words, the ability to 'sign off' other entities decisions. The new entity also needs to have real mandate and authority to access information in a timely manner across the whole of government.

For example,

- Commissioning guidance is sent out from 'the Commission' to DHBs, which requires them to develop local response, with a form for competing for review and authorisation.
- Mental health should be providing design guidance for justice and rehabilitation of prisoners (commentator)

**Independent monitoring and advocacy function.** Some submitters discussed the importance of an entity for independently monitoring progress of multiple sectors against a long-term strategic plan and advocating for changes as required based on their analysis of the information gathered. They also raised the need for the capacity and the sophisticated capability to deliver the results needed.

[Winning] arguments with well-resourced bureaucracy requires a properly resourced entity with significant sophisticated capability such as economics, policy, data, and language of mental health –an engine room requirement. Consider the forward liability [for Government] –it's a disaster if they don't do it –need to use an investment argument. Capability to engage with other government agencies is equally important as the capability to engage with the community. Don't want another bureaucracy (commentator)

**Lead new policy and service model development for wellbeing and support implementation.** Submitters identified the need for a national entity to be the leader in evidence-based policy and service development for mental health and addiction. They considered this approach was essential for it to have credibility and strengthen its mandate to lead.

establish a robust entity independent of government to integrate and synthesise evidence; and develop strategy and policy for [the mental health and addiction] sector. This should adopt the same principles used in ‘co-design’ ... the use of evidence from the scientific literature, in combination with our indigenous knowledge base (Māori), and evidence from those with lived experience. Evidence and experience should be given equal [weighting]. The credibility gained from use of the growing evidence base would give any such organisation’s recommendations the necessary weight (commentator)

Submitters also said an independent commission would need the capability to support implementation of new service models that are nationally consistent but locally responsive.

One submitter proposed the Wellbeing New Zealand Commission, which, to be successful, would require an operational arm to manage the rollout of activities.

Key responsibilities will include:

- Establishment, implementation and management of “Wellbeing Community Development Agencies”
- Identify and manage geographic parameters for implementing Community Development Agencies
- Determine Wellbeing services required for ‘whole-of-system’ to ‘whole-of-person’ needs within communities including identifying geographically specific service requirements (NGO provider)

**Robust funding models.** Some submitters proposed the new entities’ roles would include responsibility for leading development and use of evidence-based funding models. These models are needed to ensure nationally consistent levels of funding so that services can safely meet the local population’s needs.

Guaranteed safe level of staffing – ratio of [full-time equivalents] to population (our analysis and oversees, one psychologist to 5,000 people.  
E.g. National standard teachers class size (professional organisation)

Who decide the proportion of what DHB keep for secondary and other? The Ministry needs to set principles, so allocation could stand the scrutiny (Māori contributor)

Commissioning for outcomes, what was fit for purpose in 1996 and role of commission is not necessarily what will work now. Ringfence turned into silo (Māori contributor)

## **New Mental Health Commission(s)**

**Common features.** Submitters who recommended a new commission identified common strategic features that would need to underpin its establishment, namely:

- a broad mandate to focus on wellbeing
- a bipartisan approach to transformative change
- a cross-government commitment and accountability to support transformation
- a legislated independence from government
- an agreed national vision and long-term strategic direction.

Submitters commonly recommended that the responsibilities of a new commission would be to:

- provide a cohesive national approach to wellbeing based on a socio-cultural–ecological approach and a focus on social determinants, using a life course approach
- co-design new service and funding models and support their implementation
- lead suicide prevention as a priority across government departments
- monitor:
  - outcomes based on agreed targets with a focus on addressing inequalities for Māori, Pacific peoples, disabled people, detained people and marginalised groups
  - service user and tāngata whaiora human rights to ensure alignment and compliance between domestic legislation and obligations in international treaties (such as the United Nations Declaration on the Rights of Indigenous Peoples, United Nations Convention on the Rights of Persons with Disabilities, Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, and United Nations Convention on the Rights of the Child)
- direct policy development and funding decisions to ensure alignment with the wellbeing vision and direction
- undertake research
- support workforce development.

**Dedicated commissioner roles.** Some submitters recommended the appointment of commissioners to dedicated roles or commissioners who would bring specific skills and experience. Recommended appointments included:

- at least one commissioner who is a recognised consumer (service user) leader
- at least one commissioner with lived experience in mental health or addiction challenges
- commissioners with specific responsibilities such as a suicide prevention commissioner
- commissioners responsible for specific populations, for example, a youth mental health commissioner
- a dedicated disability rights commissioner for mental health within the Human Rights Commission.

### **A new commission – examples of alternative models submitted**

Submitters proposed a range of models for a new commission. Some of the more commonly raised examples included (but were not limited to) variations on:

- a national independent Māori entity – independent Māori oversight of outcomes
- an Iwi–Crown partnership – Te Ao Māori world view and Whānau Ora approach
- a Waiora Commission – inclusive of wellbeing paradigm

- a commission based in kaupapa Māori – kaupapa Māori wellness approach and Whānau Ora approach
- a Health Commission or Wellness Commission – Māori led to improve Māori outcomes
- a Wellbeing Commission – oversee the transition to Big Community
- a Wellbeing Commission – human rights approach
- a Mental Health and Wellbeing Commission – wellbeing and stronger families
- a Mental Health and Wellbeing Commission – human rights focus and consumer leadership
- a Mental Health and Wellbeing Commission – guardian of the strategy and oversight of wellbeing implementation plan.

### **Ministry of Mental Health and Wellbeing**

One submission from a Pacific NGO provider proposed the establishment of the Ministry of Health and Wellbeing. They recommended it be based in Auckland to utilise a wide talent pool and be connected to our largest population.

They proposed the new entity be charged with addressing the following:

- Use innovative, early intervention, co-designed programmes that are tailored to what people actually need, delivered in their communities.
- Enable employment support that is health-led to help people get back to work. Access to effective, good quality employment support needs to be improved. A national strategy on employment and mental health is needed.
- Address the disproportionate number of women who are homeless with significant issues around safety.
- Target current lost points of intervention, and where research tells us intervention is needed the most.
- Use a robust evidence base and build mechanisms for implementation.

The potential benefits include the ability to hardwire and roll out particular programmes at scale, central funding, standardisation of admin/auditing processes ...

- Gives mental health priority
- People get what they need when they need it
- Whānau are acknowledged and included and get help they need.
- Wellbeing approach with dedicated funding focused on community, prevention and early intervention (including programmes in schools)
- [Mental health and addiction] and public health wellbeing services all centrally funded – standardisation of admin and auditing processes, and centralisation savings.
- Hardwiring and build on success of particular programmes and initiatives (hard to do currently) (Pacific NGO providers)

## Ministry of Wellbeing

A few submitters recommended establishing the Ministry of Wellbeing, which would be charged with leading a non-partisan approach to re-frame the focus from ill-being to wellbeing. Its proposed role could have a positive impact on social and economic policy, access to government funding, tertiary training and professional qualifications, and local government decision-making. Different views were expressed on the name and specific responsibilities of such an entity. Two examples follow.

The **Ministry of Mauri Ora** or **Ministry of Oranga Whānau** would be an entirely new organisation with a mandated responsibility for mental wellbeing.

**Wellbeing New Zealand** would be a primary mental health provider and community development organisation with a focus on mental wellbeing. It would address the need to establish a non-partisan, central public service department with the objective of achieving a society with sustainable wellbeing for New Zealand. According to one submitter, its primary responsibilities would be to [paraphrased],

- a) Deliver a Wellbeing Constitution, Principles, and 100+ year Wellbeing Strategy across New Zealand; Vision, Values, and Culture, respecting Treaty of Waitangi
- b) Transition from existing fractured health models to 'whole-of-system' for 'whole-of-person' model
- c) Provide formal advice to Government, much like Treasury is regarding economic policy, the economy, and managing financial resources;
- d) Position New Zealand as a Wellbeing leader on the global stage
- e) Delivering operational requirements including:
  - Develop policies and regulations as required.
  - Determine short, medium, long term Wellbeing objectives
  - Fiscal management and reporting: distribute revenues to deliver strategic objectives
  - Ongoing research, development and implementation of wellbeing initiatives including implementation oversight of wellbeing strategic objectives (NGO provider)

## Ministry of Health

A few submitters proposed changes within the current health sector structures such as to abolish DHBs and to establish a national health service.

## 2.3 Te matapihi ki Te Ao Māori (window to the Māori world)

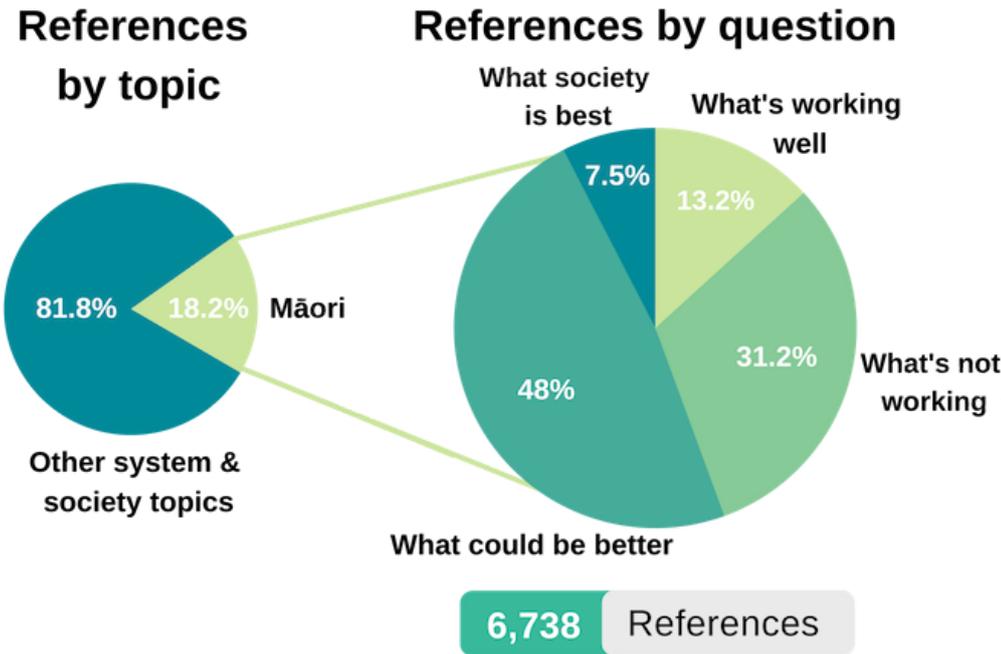
### 2.3.1 Overview

This section presents an overview of Māori voices from submissions, both written and kanohi ki te kanohi (face to face) at hui. The Inquiry will be releasing a separate, fuller summary of Māori voice on the Inquiry website in January 2019.

In addition to the Māori voices, non-Māori organisations and individuals spoke about their relationships with tāngata whaiora and their whānau. These views are captured elsewhere in this report in Services or Workforce but do not form part of this section. This section aims to capture only Māori voices.

Both Māori and non-Māori submitters made references to Māori world view, services and mental health and addiction challenges (See Figure 2.4), however only Māori voices have been used for this section summary. Māori submissions were identified independently of the calculations used for the references by topic image below so the reference by topic should only be seen as a rough overview and not indicative of the number of Māori submission analysed in this section.

FIGURE 2.4: SUMMARY OF RESPONSES BY AND ABOUT MĀORI (NOT ONLY MĀORI VOICE)



**KEY THEMES FROM SUBMISSIONS FOR TE MATAPIHI KI TE AO MĀORI INCLUDE:**

**2.3.2 Found systems and services on Te Ao Māori and Te Tiriti o Waitangi**

- true partnership based on Te Tiriti o Waitangi
- indigenous and human rights
- challenging the biomedical world view
- discriminatory care practices

**2.3.3 Recognise and respond to adverse impacts on social and health determinants**

- impact of social determinants
- earlier intervention and education

**2.3.4 Holistic collective impact approach works best for Māori**

- kaupapa Māori must take precedence
- devastating impact of suicide
- better culturally grounded help for suicide bereaved
- better responses to addiction
- oversight and monitoring

**2.3.5 Fund and commission services that are effective for Māori**

**2.3.6 Grow a mental health and wellbeing workforce that reflects needs of Māori communities**

Key themes from Māori voices are as follows.

**2.3.2 Services and systems founded on Te Ao Māori and Te Tiriti o Waitangi**

**True partnership based on Te Tiriti o Waitangi**

For many submitters, without the foundation of Te Tiriti o Waitangi and true partnership or tino rangatiratanga, outcomes for Māori would change little:

Our power/mana principles: 1) Impossible to achieve wellness for our people if we don't honour Te Tiriti o Waitangi—the policy and enablers we need to achieve wellness would be impossible. Historical traumas are related directly to injustice since the signing of Te Tiriti o Waitangi. Our whānau wouldn't have signed the Treaty if they thought we would be at the bottom of the stats in this country. Need to address inequities and give mana back to our people. Uphold indigenous rights and Te Tiriti o Waitangi. We need a Pae Ora system that partners with tangata whenua leaders as Tiriti partners (Māori contributor)

I would start by re-organising the mental health system to orient to Te Tiriti o Waitangi that holds people in their diversity, and works to heal people, their whānau, and communities rather than simply manage their symptoms (tangata whaiora and researcher)

Many iwi, Māori organisations and whānau called for the Treaty of Waitangi or Te Tiriti o Waitangi (Māori text) to be placed as the foundation for Māori wellbeing embedded in Te Ao Māori.

the relevance of Te Tiriti o Waitangi to health is well established and under international law, the Māori text of Te Tiriti o Waitangi affirms sovereignty. Though, most public health sector policy and strategies refer to the English version of the Treaty of Waitangi by ways of principles they do not refer to the Māori text (Māori health leaders and colleagues)

Applying the principles of the Treaty of Waitangi as a framework can apply to all ethnic groups as the saying goes “make it right for Māori and you make it right for everyone”. Therefore let’s move the sector away from being the ambulance at the bottom of the cliff and giving communities opportunities to determine their wealth and solutions (kaimahi Māori with lived experience)

Many submissions from Tāngata Whenua highlighted the importance of recognising Te Tiriti and the need for true partnership for equitable health outcomes, equitable funding and commissioning arrangements, and equitable leadership and workforce.

We believe the lack of Te Tiriti o Waitangi partnership awareness is setting kaupapa Māori service providers back (Māori NGO providers)

### **Indigenous and human rights**

A few submissions also called for the Government to uphold the United Nations Declaration on the Rights of Indigenous Peoples.

Human rights breaches in terms of seclusion, detention, restraint and compulsory treatment orders of Tāngata Whenua were also noted in submissions.

We know that Māori experience higher seclusion rates than non-Māori... the Office of the Director General Mental Health Annual Report 2015 announced that Māori were five times more likely to be secluded than non-Māori, and have the highest population-based rate of seclusion events reported internationally (DHB collating views from DHB, NGOs, other providers, and service users)

Many Māori voices called on the Government to recognise these breaches and discriminatory practices, to end seclusion and restraint, and to invest in the health of Māori earlier with increased access to tikanga-based interventions and solutions.

### **Challenging the biomedical world view**

For many submitters the biomedical model was the antithesis of Te Ao Māori.

Māori have been calling for a move away from the ‘disease model’ that pathologises Māori for years and to instead embrace more whānau, social and cultural approaches to the delivery of health care and wellbeing (Māori health leaders and colleagues)

I’m not sure what parts of your system are working and who they might be working well [for] but my family is Māori, and it is definitely not working for us (whānau Māori)

## Discriminatory care practices

Some whānau expressed fear at losing their tamariki or mokopuna into care should they reach out for mental health or addiction help, and some felt whakamā at the loss of culture and their inability to provide for tamariki.

The biggest threat our whānau face is losing their children to the Ministry ... Once a whānau loses a child to the Ministry, it's devastating. If there's no-one to intervene at that point they go down the path of drugs/meth – end up in addiction (tangata whaiora)

Some submitters focused on their experience of discriminatory care practice (not only mental health), continual misdiagnosis, or lack of communication, creating an inherent distrust in the current health system and unwillingness to return.

Many submitters noted the disproportionate use of seclusion and restraint for Māori as reflective of a discriminatory system.

### 2.3.3 Recognise and respond to adverse impacts on social and health determinants

#### Impact of social determinants

A strong theme across Māori submissions was the need to address social determinants including discrimination, racism, intergenerational trauma, colonisation, poverty, inadequate housing, childhood trauma and violence, the impacts of which are reflected in continual high rates of self-harm, suicide and addiction, incarceration, homelessness or inadequate living conditions, poverty and social isolation.

It was imperative from Māori perspectives that the Inquiry recognised impacts of colonisation, trauma and persistent discrimination, producing inequitable outcomes.

we note that this maldistribution is an expression of racism and colonisation, where the social determinants of health continue to be differentially distributed in NZ by ethnicity and especially, by indigeneity. Finally, that the history of institutional racism has predicated against kaupapa Māori services ever attaining any form of sustainability (Māori professional organisation)

Inequities were exacerbated for some whānau who lived rurally or remotely, in communities suffering from high rates of addiction, those who were takatāpui, disabled people, elderly whānau within the hospital system, and people with less access to services and the workforce. As one submitter noted in her battle to help her children with meth addiction,

I have helped two adult children to quit meth ... what a mission but my whānau stuck together to help. We had good and poor experiences with services. With 5 tertiary degrees between us ... we still struggled. What must it be like for whānau without any formal education, no money, no car, no house and perhaps unwell themselves. It nearly killed me but to see my [family members] clean, and our Mokopuna happy is all that we could ask for (whānau Māori)

Targeting social determinants through Whānau Ora approaches was essential for many Māori voices (see following theme).

Housing was also a significant concern for many Māori organisations dealing with clients who were homeless or who lived in substandard housing conditions that impacted on mental, physical and emotional health. As one tangata whaiora noted online, there “needs to be secure, healthy housing for everyone so that communities can grow, develop and thrive” (tangata whaiora). Cross-sector collaboration at national and local levels was required to target the housing crisis.

Some rangatahi<sup>7</sup> at a hui focused on the variety of factors contributing to mental health challenges that could be addressed, including transport and connection beyond social media to “more youth friend[ly] spaces like a skate park or resources available to them” (rangatahi Māori).

### **Earlier intervention and education**

Many submitters noted the importance of early childhood intervention and early treatment intervention as necessary to prevent or reduce escalation of mental health and addiction challenges.

Some submitters sought a stepped care approach with multiple entry points, including non-traditional entry points, whereby whānau are able to access health services in the least intrusive way possible and that respond to needs for as long as required.

Actively supporting whānau to access services when needed was seen as a core mechanism by which the demand for secondary and tertiary services could be reduced.

Early intervention services, whose workers and the philosophy of which resonate with Māori ideology, are likely to be able to stem the capacity-strain placed upon the mental health system by Māori with mental health distress, and the cultural capability issue inherent in the New Zealand workforce (Māori professional organisation).

For some submitters, part of the solution was heavier investment in tamariki and rangatahi. This included not only education but also paid options for children, including sport, sports coaches, life coaches and positive life skills.

Poverty is at such extreme levels in many areas, I believe a lot of NZers would be shocked at the living conditions that so many children live in and I think many NZers believe it is a result of ‘laziness’ and not a result of a system/society that has got it wrong for so many. I believe more needs to [be] done to support the early years education of young children. Support at educational and community level so that pressure is alleviated for whānau who are struggling with addiction and mental health issues. Once children’s basic needs are met support needs to go into supporting the wider issues of addiction (whānau Māori).

Many Māori submitters focused on the education system as the locus of generational change. Many submissions called for a stronger health literacy and education programme to

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<sup>7</sup> Rangatahi is used, where possible, to denote Māori youth

begin in schools, focusing on tamariki and rangatahi. This included learning about the role of medication, the generational cycle of behaviours, education about drugs from those recovered from addiction, where to go for help, and how to support those in need (including self-care) as well as an education system that was culturally balanced and relevant. The need for holistic health education required curriculum changes.

Engage our elders in the education sector. Connect elders and tamariki.  
Connect communities for the greater good. Grow pride, resilience and wellbeing – rangatiratanga and Whanaungatanga (kaimahi Māori).

A few whanau Māori, especially those who had suffered the trauma of seeing their children bullied in school (particularly those children with autism spectrum disorder and other forms of neurodiversity), recommended that school bullying be seriously addressed and, in some cases, made a criminal offence.

### 2.3.4 Holistic, collective impact approach works best for Māori

#### Kaupapa Māori

Many Māori submitters noted holistic, collective impact models worked best for meeting needs.

These include Kaupapa Māori programmes that are tikanga-driven, such as Whānau Ora and Te Whare Tapa Whā, and those offering a range of healing therapies and activities including rongoā clinics, arts, crafts, music, and cultural pursuits focusing on wellbeing.

Many tāngata whaiora spoke of their life-changing recovery with tikanga-based programmes, led by kaumātua, and the healing found in restoration of Māori identity and belonging. Many participants at one hui, speaking of programmes that helped in their addiction recovery, noted the impact of identity and belonging,

I found my identity here. I never knew my pepeha until here. Humbled and privileged to be part of it. This is working well (tangata whaiora)

Heard the haka at a hui and looked at [person] and said I wanted this, so she took me to Matua ... Once I got here they couldn't get rid of me. Feel at home on a marae. This is first time to speak te reo; Māori at the heart of recovery. Now can speak my pepeha and stand up and talk and get my confidence back (tangata whaiora)

This is a family, and they have supported me studying at kura kaupapa. I asked for help, Matua said they help. I moved into detox the weekend after Matua said he'd help. I've learnt a new language, I had a lot of knowledge I didn't know how to use. My tukakana has supported me to understand... This roopu have given me hope. I have healthy role models now. It's lifted me and loved me back to life (wahine Māori)

The effectiveness of whānau-centred approaches focusing on recovery and aspirations was reiterated by Māori voices, particularly in the face of a persistent biomedical world view that focuses on symptoms and diagnoses.

Our communities clearly identified examples where services were culturally and clinically excellent from their perspective. Whānau talked of feeling further alienated by services- they also identified success where cultural [connections] occurred with clinicians or kaimahi as navigators, of the importance of wrap-around for the whole whānau and the strengths of alternative pathways to mauri ora (Māori leader)

Models such as Te Whare Tapa Whā were seen as essential. There was a need to incorporate wairua for many Māori lived experience submitters, particularly as this is often ignored in 'mainstream' services.

We decided to go away from him/them, and do the therapy that I needed to heal my Spirit/Soul. We sat on marae, listened in Wānanga, Karakia... doing things that related to my core beliefs as a tūturu Māori ... I felt safe, comforted and strengthened to become well (tangata whaiora).

Kaupapa Māori was not a one-size-fits-all approach but responsive to individual communities and individual population needs.

## Devastating impact of suicide

Many submissions, written and from hui, shared stories of distress and loss through suicide – for whānau, friends and the wider community. Prevention strategies focused on both those who have passed away and those suicide bereaved whānau who are struggling with the shock and grief of overwhelming loss.

Whilst some submitters identified clinical support as important, there was a preference for growing the capacity of whānau and communities to respond within culturally aligned contexts.

Whānau believe that strong whānau connections and healthy relationships with each other can prevent suicide - whilst clinical approaches to suicide and attempts are necessary, it is whānau who play a key role in the prevention of suicide and recovery from suicide. Consequently, it is important to support and strengthen the capacity and capability of whānau and the community to respond to crises and or distress (Māori NGO providers)

One Māori provider advocated for Whānau Ora workers in Aotearoa New Zealand schools to work in preventative roles.

Have youthful qualified Whānau Ora workers in schools to act as a preventative measure, closing gaps of communication between schools, DHB and whānau separate from Social Workers in Schools ... [The] high numbers of self-harm and suicide in youth demonstrate a high need in that area (Māori NGO providers)

Some submissions noted *Tūramarama ki te Ora: National Māori Strategy for Addressing Suicide* and the *Tūramarama Declaration* provided important leadership and direction for Māori suicide and suicidality. Several submitters called for the Declaration to be embedded within their communities and practice. *Tūramarama ki te Ora* emphasises the importance of Te Ao Māori-based responses to suicide and notes in the key actions,

The implementation of the Strategy will require a range of actions:

- Facilitate culturally and clinically safe practices through effective community/whānau development, hopebuilding and leadership development
- Build safe collective networks that encourage all those with an interest in suicide prevention to participate
- Enable and support hope-building in suicide prevention. For example, include safe practices such as storytelling whakawhitiwhiti kōrero, kōrero tahi use of pūrakau and tā moko for cultural and whakapapa reconnection and healing
- Fostering Māori healing practices that are culturally valued and effective (Māori NGO providers)

## Better culturally grounded help for suicide bereaved

Co-ordinated, collaborative suicide postvention services were seen as essential to support those who have lost loved ones, but also break that cycle of grief and trauma that can often result in more whānau completing suicide.

Suicide bereaved, in particular, were often re-traumatised by the limited culturally appropriate care, resources and procedures following the trauma of suicide and the seemingly bureaucratic processes that excluded any help to navigate their grief, loss and depression following the loss of their whānau member.

Today I live with the last image of [my family member] hanging in my garage while dealing with the officials who just want to complete their process and this should not have happened if our cries for help had been [heeded] when she first showed crisis signs at [age] when she started cutting ... and if not for the strength and love of my whānau I know I too would have joined her (bereaved whānau Māori)

When someone passes through suicide you get referred to mainstream services Victim Support and if you're Māori this does not fit the need. There is no follow up care at all in the case of whānau or individuals who are traumatised from finding their loved one who has hung themselves or has committed suicide in a violent way. This trauma is left to the individual to work their way through and causes health and mental health issues (bereaved whānau Māori)

### **Better responses to addiction**

Many submitters wanted responses to addiction challenges to move from a justice to health response, particularly emphasising the high incarceration rates of Māori and lack of addiction-based help within the prison system. Many from regional communities noted the devastation of "P" and synthetic cannabis and lack of services or support.

We are also ill-equipped to deal with the effects of methamphetamine in our communities. Methamphetamine users often have needs beyond treatment for addiction, including mental health services, health, housing and employment (Māori NGO provider)

If the Mum and Dad are on drugs who are feeding the moko and the pepe? Nine out of ten people in [remote town] are affected by these drugs (Māori contributor)

Māori voices identified the need for people who are engaged in the justice system as a result of mental health and/or alcohol, other drug and other addictions, to undergo rehabilitative programmes rather than punishment. Court-ordered treatments, decriminalisation and more drug rehabilitation units were identified as essential. As one submitter noted,

People should never be punished for addiction, but [instead] given the tools to overcome it. See the Netherlands closing jails due to their treatment of causes instead of punishment (tangata whaiora)

Some submitters called for an increase in innovative solutions, including the need for significantly more Māori detoxification (detox) and rehabilitation services and a kaupapa Māori workforce. As one submitter suggested,

Māori Wardens need a policy change to allow them to work with first-time offenders. We want Māori Wardens to have unrestricted access to prisons for first-time offenders so we can tell them ‘your whānau is OK and your baby is being looked after and this is what to expect.’ They are currently looking after several people who have recently got out of prison; there are a lot of people inside who can be helped and don’t need to be incarcerated (Kaiāwhina Māori<sup>8</sup>)

## **Oversight and monitoring**

In terms of oversight and monitoring of service providers delivering to Māori, a few submissions recommended it become a statutory requirement that DHBs and all service providers demonstrate improved service delivery for Māori. For one submission, this necessitated all providers attain iwi-mandated criteria to ensure service delivery models were aligned to realise good outcomes for Māori, greater accountability from the Ministry of Health and DHBs for widening Māori inequalities, and, specifically, a need to require DHBs to be monitored and “report annual[ly] on the execution of Compulsory Treatment Orders for Māori” (Māori NGO provider).

### **2.3.5 Fund and commission programmes that are effective for Māori**

Many submissions noted the impact of current leadership, funding and commissioning models that did not stem from a Te Ao Māori framework of wellbeing and undermined tino rangatiratanga. There was a strong view from some submissions that it would be more effective to give Māori greater autonomy over funding and commissioning of services for their own people.

Much of the funding in health services is adult and individual centric, with little consideration for the investment in the future of mokopuna and tamariki from a Māori perspective (Māori health leaders and colleagues)

Submitters also commented that current funding and commissioning models failed to take into account (in many instances) the role of kaumātua in both Kaupapa-based and non-Kaupapa-based services.

Submitters said that the ripple down effect of the current system results in cuts to Māori services at a community level and limited options for whānau Māori located in their communities.

The Māori health team in [town] has been canned. This is very sad to take away a service that worked. They saved us with simple home visits and very good nurse. Not everyone can travel for help (whānau Māori)

Rehab facilities not here in the local community, too many are sent away from their whānau – they end up not fulfilling their treatment (kaimahi and whānau Māori)

Many submissions from Māori organisations recommended an independent commission, a Te Tiriti o Waitangi partnership authority, or another national entity with a Whānau Ora framework and funding model. This is in response to the current non-Māori-based care and

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<sup>8</sup> Kaiāwhina Māori is used, where possible, to denote a supporter or volunteer who is Māori

help available to many whānau and lack of equity investment in whānau-centred models of care. As one submitter noted,

The system in [region] is dominated by Western models of practice. Therefore, we are struggling. We believe iwi providers across Aotearoa are being squeezed out of this space where Māori are dominant; so the system is not allowing us to provide for our own. The system does not support iwi providers to look after their own – where are iwi in the NGO space? We are the last horse standing. ... it's the same message to Oranga Tamariki – we want to look after our own, but we are being squeezed out... the current system is not serving our people, and so there needs to be room for risk of innovation in intervention (Māori contributor)

Submitters said Mā Māori, mō Māori: By Māori, for Māori would ensure equitable funding for Māori services, based in a Māori world view, and supporting Māori within their own communities.

As an indigenous people, Māori have the right to determine and develop priorities and strategies for their people and to be actively involved in developing, determining and administering health and other programmes. Māori have the right to their traditional medicines and to maintain their health practices including the conservation of their vital medicinal plants, and taonga (Māori health leaders and colleagues)

Some service providers noted they are already moving beyond funding constrictions by entering collaborative arrangements.

Increasingly Māori providers are entering into alliancing and high trust arrangements to work collectively within a Māori framework to leverage common interests and aspirations including agreeing iwi or Māori community of interest boundaries to deliver high quality whānau centred services (Māori NGO provider)

### **2.3.6 Grow mental health and wellbeing workforce that reflects needs of Māori communities**

There was praise for kaimahi who reflected true aroha, manaakitanga, workforce professionalism and clinical skill. For many Māori submitters, the guidance of kaumātua and respect for their advice and wisdom were essential to healing. Some Māori submitters called for more access to and respect for tōhunga.

However, kaimahi spoke of their high caseloads, underfunding for extra or specialised staff and psychologists, and, for many, relative job insecurity given the short-term funding structure of many Māori services. Services are often bottlenecked with referrals, delays and lack of access. Some noted discriminatory responses to their practice.

A few submissions noted the continued impact of the Tohunga Suppression Act 1907, and the need for more tōhunga, and recognition of their skill.

A tōhunga was called into the cells to assess a young Māori male alongside crisis services—their assessments and recommendations differed. Tōhunga said to put him in the inpatient ward but crisis nurse said that because he had [alcohol and other drugs] in his system it was a police issue. It wasn't the tōhunga's recommendation that were followed... Māori advisors roles are not valued, their roles are subservient. So was the tōhunga (Māori contributor)

Enabling an appropriately sized and culturally relevant workforce was essential across Māori submissions, including appropriately funded roles of kaumātua, kuia, tōhunga, taurawhiri, and the lived experienced of tāngata whaiora (as peer leaders).

DHBs need to have open, honest real relationships with our kaumātua and with our people. They are not sitting with us, we have to go to them – they need to come to us (kaimahi Māori)

maybe it is only fair that Tōhunga are utilised more often to seek these things out, not everything is about being clinical or having a PhD (tangata whaiora)

This included peer-support workers, those with lived experience, who were highly regarded especially those seeking help for addiction challenges. As one Māori service provider noted,

The only ones getting through to our people are the ones who have overcome addictions, been through it themselves and now helping in the community (kaimahi Māori)

There were strong calls from workforce organisations and service providers to increase the number of Māori professional staff and focus and invest in the workforce pipeline to ensure Māori are represented across the health spectrum, whether specialists, general practitioners (GPs), social workers, nurses or psychologists.

A few Māori submitters noted difficulties with discriminatory practices evident in academic courses, including a lack of indigenous models within tertiary health programmes, and a lack of cultural awareness and training.

Although some progress had been made under new leadership, the list of solutions suggested by this submission indicates that true partnership in clinical training still needs extensive work – particularly in light of current workforce shortages and the pipeline of staff.

Several submissions referred to the need for a comprehensive national Māori health workforce development plan if any demonstrable change was to be seen for whānau.

Many Māori wanted a better trained, culturally competent non-Māori workforce. In addition, a true integration of Māori health and healing practices into medical and mental health training programmes was also wanted.

Some submissions noted the need for greater accountability and monitoring of the workforce.

Services must demonstrate their ability through key competency framework developed by Māori, to deliver a culturally driven and appropriate service without prejudice or racial stigmatization (Māori NGO provider)

A few submissions called for a Māori regulatory or health accreditation body that might assist in addressing situations where services or training programmes are purported to be Kaupapa Māori but are in reality offering no more than superficial support to the kaupapa.

Implement cultural competency auditing delivered by Māori to ensure cultural responsiveness and that people are not only 'learning' it, they are practicing it (Māori NGO provider)

## 2.4 Pacific voices

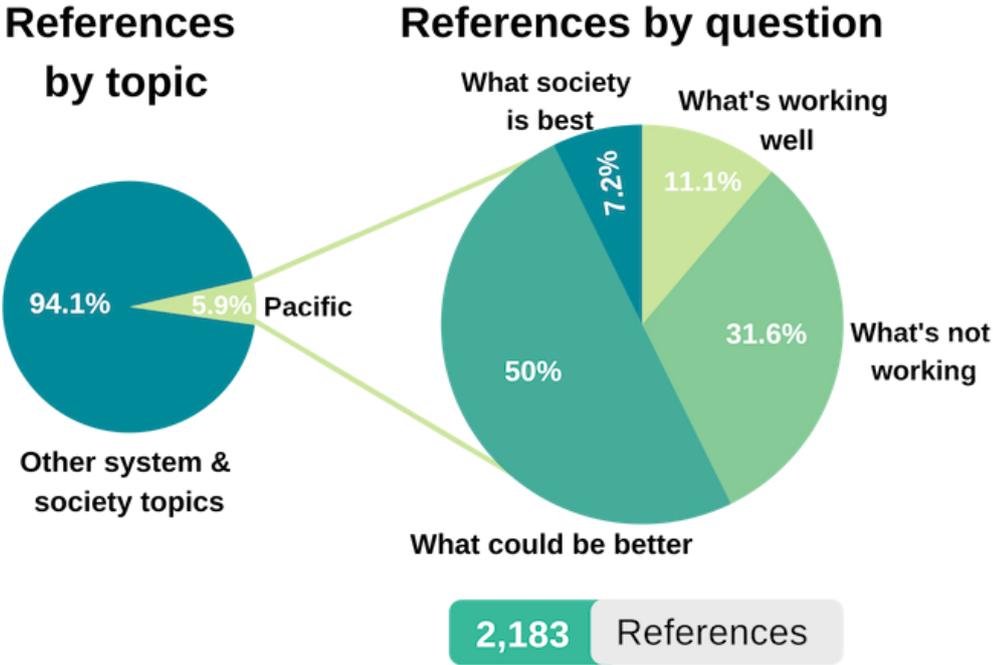
### 2.4.1 Overview

This section presents an overview of Pacific peoples’ voices from the submissions. For a fuller summary of Pacific voices please refer to the separate report available on the Inquiry website<sup>9</sup>.

Both Pacific and non-Pacific submitters made references to Pacific world views, services and mental health and addiction challenges (See Figure 2.5). The views of non-Pacific submitters are captured elsewhere in this report in Services or Workforce but do not form part of this section. This section aims to only represent voices from Pacific populations.

Submitters made 2,183 references on the Pacific world to the Inquiry (both from Pacific and non-Pacific submitters). Only a small number of submissions were strictly from Pacific service users and whānau. A greater number were from Pacific leaders, organisations and researchers.

FIGURE 2.5: SUMMARY OF RESPONSES BY AND ABOUT PACIFIC POPULATIONS (NOT ONLY PACIFIC VOICE)



<sup>9</sup> <https://mentalhealth.inquiry.govt.nz/>

KEY THEMES FROM SUBMISSIONS FOR PACIFIC VOICES INCLUDE:

**2.4.2 What's working well?**

- service users and families appreciated Pacific approaches to healing
- service providers delivered holistic services and capability building

**2.4.3 What isn't working well?**

- disproportionate impact of social determinants
- lack of acknowledgement of cultural world views and diversity
- limited access to and availability of 'by Pacific for Pacific' services
- inappropriate funding models and limits to evaluation

**2.4.4 What could be better?**

- by Pacific for Pacific
- address early intervention
- address health promotion and awareness raising
- focus on leadership and workforce
- focus on addiction (including gambling)

\*See Section 2.1: **What sort of society is best for mental health?** for responses to Q4

## 2.4.2 What's working well?

### Service users and families appreciated Pacific approaches to healing

There were very limited Pacific service user and whānau submitters during the Inquiry. Those who responded to what was working well spoke of Pacific-based holistic approaches to healing, including spirituality and physical health, medication when required, the role of education, and praise for the commitment and professionalism of the Pacific workforce. Healthy relationships were seen as critical to healing with one submitter noting about her family member's recovery,

[the] Love of [her] husband was far more impactful than any meds, [as well as the] support and love and understanding of children and parents (Pacific service user)

### Service providers delivered holistic services and capability building

Many Pacific service providers noted programmes or services that were working well. However, most were restricted by funding and commissioning models, workforce capacity and overwhelming demand.

Programmes or services that were seen by service providers as working for Pacific populations included:

- holistic and family wrap-around services based on Pacific Whānau Ora principles, targeting social determinants of their clients, and providing ethnic-specific *fono*

What's working well is our capacity to be with the family; we follow the family through the journey and hopefully we can pick up some small things to fix. We stay with them as long as we feel they need it; work on protective factors (Pacific provider)

- services targeting unmet needs as a basis of wellbeing, from helping to get a driver's licence for work through to providing emergency housing; as one service provider noted,

Some have literally walked through the front gates and have emotionally broken down into tears because this for them was more than a temporary accommodation. This service meant a place of refuge, their last beacon of hope (Pacific NGO provider)

- flexible, family-focused services with comprehensive family plans
- cultural and clinical partnerships integrated into DHBs and community services; for example, where cultural support goes side by side with a crisis team or Pacific cultural advisors in forensic services
- clinical health promotion delivered in formats relevant to audiences, for example, language radio, with flexibility of how to access help
- Pacific-led community training and awareness programmes to reduce depression and reduce suicide
- programmes aimed at reducing isolation for elderly Pacific peoples

Many of our members partake in not only our programmes but other programmes as a means of combating loneliness. This is something that many of our older people face as they are often at home alone while their household is at work or school ... By attending groups such as our own, it allows them to mix with their peers as well as taking up creative activities that will provide them with something to work on and focus on at home too (Pacific NGO provider)

- workshops and training that challenges mental health stigmas and raise awareness among Pacific peoples of entrenched beliefs. For example, "that associate mental illness with curse and sin that in turn cause isolation and segregation." (Pacific NGO provider)
- targeted financial capability workshops and other programmes that aim to build financial resilience, and other life skills opportunities.
- community support groups such as churches, sport, women's groups, focusing on general wellbeing and resilience
- emerging school-based services such as STEM (science, technology, engineering and mathematics) programmes in schools that improve Pacific students' NCEA results

### 2.4.3 What isn't working well?

Service users, family and service providers shared commonalities about what was not working.

#### Disproportionate impact of social determinants

Some Pacific submitters noted the disproportionate share of mental health challenges including suicide for Pacific peoples, with higher levels of psychological distress for Pacific populations.

One submission highlighted that Pacific high-school students were three times more likely to have attempted suicide than other high-school students.

Environmental and social stressors impacting on mental health outcomes were also over-represented across Pacific populations: poor access to good housing, unemployment, low income, less tertiary education, and poor access to quality health-care services – particularly Pacific-based services. As one Pacific service provider said about people in their care, “How can they heal or be well when worrying about core things to survive” (Pacific professional organisation).

Although Pacific peoples faced many social stressors, one submitter noted that,

while many Māori and Pasifika children are subject to inequities in material and socio-economic circumstances as well as institutional racism, they also experience the benefits of a rich cultural life and sense of belonging that is seldom accounted for in research reports that focus on deprivation (health professional and researcher)

#### Lack of acknowledgement of cultural world views and diversity

**Cultural world views dismissed.** It was noted by submitters that Pacific cultures are inherently collective and relational with a holistic perspective of wellbeing where cognitive, emotional, spiritual, physical, environmental and relational dimensions of the self are required to be in harmony for holistic wellbeing. The mental health system in New Zealand for the most part, is informed by and dominated by secular, scientific and empirical understandings of human behaviour.

University students told the Inquiry,

We top the stats for all the wrong reasons but there's nothing specifically for us—our cultures are all different—we're Pacific and then underneath that are all these different cultures. Need an ethnic specific approach for Pacific students—community and values are different, our form of respect is different and institutions don't understand that (Pacific students)

Failing to take into account spiritual and religious perspectives often meant excluding significant contributors to Pacific wellbeing.

Even the bio-psycho-social approach by mental health clinicians fails to take into account spirituality and cosmological beliefs connected to ancestry and tapu as ‘evidenced based’, validated factors that require addressing for Pacific mental well-being. This contrast in belief systems is likely to contribute to Pacific people’s discomfort with using psychiatric services and has been reported as a contributing factor to many being committed to psychiatric hospitals as involuntary consumers (Pacific NGO providers)

**Pan-Pacific approach is too blunt.** Some submitters and commentators noted that pan-Pacific approaches are often too blunt to be effective and fail to take into account the diversity of Pacific cultures and languages. One Pacific contributor rejected the terminology ‘pan-Pacific’, noting,

It’s a white way of saying we are all one. How would you know what fits for each culture (Pacific student)

**Privacy for the younger generation.** A contributor at a meeting stressed some difficulties with accessing help for the younger Pacific generation in terms of confidentiality.

In regards to Pacific programmes .... you feel that they may know someone who knows your mum or uncle. Our aiga love us but you don’t want to share certain pressures with them—confidentiality at every single level. At different leadership levels—same confidentiality we see with health services with volunteer (Pacific student)

Mental health and addictions support should not come from teachers, rather someone unrelated. In our experiences it shouldn’t also be people who are associated with the same ethnic groups, they might tell our parents at the next community meetings (Pacific student)

A few submitters noted that they preferred choice in terms of whether they attended Pacific or non-Pacific services, mainly due to feeling more comfortable with the fewer cultural expectations in non-Pacific services.

**Undervalued expertise.** Some submitters noted that the Pacific workforce at all levels is often undervalued for its understanding and knowledge of Pacific peoples in its care. This applied to both qualified workforce and peer support.

Pacific peer support workers were also under-acknowledged by professional staff. They “have on-going and strong relationships with their clients but their narratives and knowledge about their clients are not considered, particularly by clinical personnel” (Pacific NGO provider).

Community are seen as unqualified and useless while on the other hand the ‘experts’ are painted as the clinicians and academics that are trained or ‘studied’ suicides (Pacific health professional)

### **Limited access to and availability of ‘by Pacific for Pacific’ services**

**Limited access to ‘by Pacific for Pacific’ services.** Many service users and service providers said by Pacific for Pacific services were limited and community services had closed due to funding. Therefore, service and community options for people were limited.

In terms of mental health services, one Pacific submitter recalled that the establishment of culturally specific services in the 1990s was a good strategy, but many current Pacific

services and organisations “are mostly just brown services operating on a *palagi* medical tikanga” (Pacific health professional).

Another submitter said,

There seems to be some intention and emphasis given to the need for services beyond Western approaches. For example services that serve Māori and Pasifika more effectively. However, these seem to be mostly assimilated into existing Western structures. I believe this undermines the service and maintains reluctance to engage and access the services (health professional with lived experience)

A peer-support worker noted that many Pacific people turned to peers rather than the “Pākehā world that uses a lot of medication” (Pacific support worker).

Some family submitters told heart breaking stories of trying to navigate a complex, non-responsive system with professionals who appeared not to care, and offered medicated solutions. Lack of access, options and genuine care resulted in increased family stress and trauma, declining physical health, and sometimes, tragically, suicide. The impact on families, the lack of respite or relief options, and the cost and other financial pressures was at times overwhelming.

**Delayed care resulting in higher acuity.** There is a general trend towards under-utilisation of primary and preventative health care services by Pacific people and lower rates of selected secondary care interventions. Barriers to the utilisation of health care for Pacific people have been well documented and include,

- a lack of awareness of or discomfort with primary care services

Mainstream have let us down. Currently “you get what you get, if you don’t like it bugger off” (Pacific professional organisation)

- cost
- local transport or location
- language and communication difficulties; for example, one organisation notes,

[The] highest rates of seclusion are [among] Tongan men. Could be different if someone speaks to them in Tongan and respectful manner (Pacific professional organisation)

- cultural norms, stigma and health beliefs
- a preference for traditional medicines and healers

Some service providers noted that many Pacific people present with high acuity often due to delay in treatment.

When Pasifika people do access mental health and addiction services, it is often at the severe end of the continuum and in crisis. High rates of schizophrenia, paranoia and acute psychotic disorders among Pacific peoples are of particular concern. They account for two-thirds (66%) of Pacific inpatient episodes compared to 39% of New Zealand European episodes, and less than half (48%) of the overall population (Pacific NGO providers)

Sometimes submitters agreed that stigma regarding mental health within Pacific communities sometimes inhibited earlier help-seeking behaviour, which, in their opinion, exacerbated late presentation and higher levels of mental distress.

### **Inappropriate funding models and limits to evaluation**

Some submitters noted that the locus of control is still with non-Pacific funders and funding creates assimilation of services and start–stop initiatives. This results in little true power or innovation and extends into patch protection.

assimilation creates alienation and often Pacific like Māori become exposed to having to justify their models of care, to validate their experiences and as such validation is often pitched against Western measures and interpretations (Pacific NGO provider)

A few submissions noted a lack of focus on outcome data and limited investment in research and evidence for what works for Pacific peoples. The very act of measuring outcomes for holistic-based services is difficult.

it is difficult for Pasifika staff to collect evidence using personal stories and families' oral engagement on outcomes of recovery because the system does not work that way ... as a result the success personal stories are not counted and the Pasifika services methodology [is] thrown out (Pacific advocate)

There is paucity of research about online gambling and the so-called millennial generation - our young people [are] easily targeted (Pacific NGO provider)

A few submissions noted that Pacific voice was often missing from surveys that tried to gather information on health due to low levels of engagement and low response rates.

**Gaps in services for elderly and Rainbow Pacific people.** Some submitters noted complications for elderly and Rainbow Pacific populations.

Trans Pasifika youth who doesn't fit into rainbow NGOs or with Pasifika service—no support for the overlaps. You can be a Pasifika young person but there isn't much room for other overlaps (advocate)

They find that the mental health status of the Pacific rainbow community is undervalued and have often been 'left out' of the frame (Pacific NGO)

Mental illness doesn't stop when you get old and it is hard to get the services they require in aged residential services. They are told to ring the police for aged after hour service which is scary for elders (Pacific contributor)

Several submissions also noted critical gaps for special need populations particularly those in the criminal justice system, with co-existing problems or with high addiction needs.

#### 2.4.4 What could be better?

Imagine a future where Pasifika communities are fearless not fearful, are resilient and prosperous, where we all have safe health and respectful relationships. And when we do need help we get the right support at the right time (individual submitter)

The needs of Pacific are complex and cannot be met by simplicity. Although people experience mental illness and addiction, their worlds are not confined to the world of health (Pacific NGO provider)

Nobody's mental journey is the same as the person next to them, there are nuances within Pacific—we have Samoan, Tongan, Māori, generational differences... services needs to find a way to make it personal as not one of us are the same (Pacific youth)

#### By Pacific for Pacific

Some submissions noted that funding models need to consider Pacific aspirations – and true by Pacific for Pacific ways of operating, not simply a Pacific workforce. Several submissions called for funding and commissioning of services through existing or newly established Pacific-led agencies that identify aspirations for Pacific families, build family capacity, support workforce growth, develop funding, contracting and policy arrangements, monitor services, and grow an evidence base of Pacific service outcomes.

I would like to see a Commissioning Agency that allows providers to work together rather than worry about who gets the money for the services. There is no gain in getting someone to a different service if you going to lose funding. If community can put all they have to offer on the table then whānau get access to all the skills and providers. Then the whānau get to choose from the menu of providers. If a Commissioning Agency could do that we would advance the quality of care exponentially (Pacific health professional)

Many Pacific service providers said funding models must allow services to focus on integrated solutions, targeting social determinants, with strength-based approaches such as Whānau Ora models working well and needing to be expanded.

Identity is central to wellbeing which is essential to mental health—need Pasifika centric solutions in health, Oranga Tamariki, etc. Funding model is broken and now is the opportunity to look at how these services should work. We have the pan-Pasifika hub with medical practice and [early childhood education]—looking at integration ... Best practice shows that this is what works for communities like Pasifika. This is how we already work except we're confined by our national contracts which don't allow for it (Pacific contributor)

A focus should be on Pacific models of care that addresses diversity such as “Fonofale, Te Vaka, Tivaevae, Fonua and others; unique and distinct models that all recognize the importance of clinical care, culture, family and spirituality, as well as physical, sexuality, age, gender and socio-economics, time, environmental and context dimensions.” (Pacific NGO)

Funding wrap-around services was seen by many service providers as delivering the best outcomes for families. In fact, whānau-based care and investing in relationships were seen as critical to positive Pacific outcomes.

Investment in relationships is crucial, one needs to get this right first and it will all work out for Pacific communities. A family approach NOT an individual approach is desirable for effective and positive impact (Pacific NGO provider)

Whānau Ora is strengths-based and it's the only model that takes our culture into consideration. It's a model that unifies our strengths. It might be small but it's an important vehicle for inspiration because the strengths that I have are actually based on my culture (NGO staff members)

For some submitters funding better access to Pacific primary services, through the mental health sector, would enable earlier intervention and reduce escalation.

Care packages should be focused on primary care level, so that parents or teachers can refer to counselling earlier on without waiting to escalate. [We] Have Whānau Ora at [service provider] but not every family can be part of it; if it came through a mental health contract, we can provide some help to a family to wrap around care (Pacific contributor)

Integrated, flexible care was also essential for some submitters including step down services from hospital into the community that involve *aiga* and whānau, integrated supported accommodation, where applicable, and flexibility of funding that caters for transience in Pacific populations.

### **Address early intervention**

For some Pacific service providers being able to offer earlier intervention solutions were seen as necessary for prevention, de-escalation of distress and, in some cases, preventing devastating outcomes. This required services that are diverse, culturally safe and readily accessible:

there are limited services that they feel comfortable accessing and they are not showing signs [of] severe mental health issues. The reality is when these young people decide to commit suicide they do on their first go and they are unlikely to be regulars to [Accident and Emergency] or accessing services that they need (support worker)

Often, as one submitter noted, there is only “one chance to capture holistic approach and appropriate referrals” (individual contributor) so the need for more Pacific cultural awareness (among non-Pacific staff), family meetings, and having a toolbox of solutions is essential.

For some submitters early childhood intervention must focus also on poverty, and its impact on wellbeing outcomes. A comprehensive plan to alleviate poverty must sit alongside a child mental health strategy that is well resourced and developed in true partnership with communities.

## **Address health promotion and awareness raising**

Some Pacific submitters with lived experience recognised the need to improve wellbeing education (including prevention, drug information and mental health skills), and increase practical nutrition and health literacy.

Understanding depression and the suicidal thought process is knowledge, and that is what I see will be the most important aspect of what the Mental Health system should focus on (Pacific individual with lived experience)

Incorporating traditional perspectives was, for some few service users and service providers, “a very positive way of looking at mental illness from a cultural perspective” (Pacific contributor) , as was the need to incorporate spirituality.

The resilience factor: our sense of spirituality is important to us and is lacking in youth development and in school. There are solutions within our culture—our spirituality we were raised in gives us hope (Pacific contributor)

Youth also noted their interaction with peers and social media was very important, and that approaches to raising awareness of mental health and addiction challenges should use online and social media tools.

## **Focus on leadership and workforce**

In addition to Pacific-led funding and commissioning solutions for mental health services and support, some submissions called for the growth in Pacific leadership and governance across organisations.

We need to make sure we have pacific leadership within mainstream organisation to have a voice. The absence of our voice up there means we will never be heard. No non-pacific can understand what we are going through, feels like talking to a brick wall. The mainstream already have their model of care in place so we have to go with what they say. We need to insist pacific on governance board (Pacific NGO)

Similarly, youth were calling for a voice.

please provide the space for us to voice our thoughts. We understand in some ways it may seem hard/challenging to engage with young people but there are those of us who will speak for our peers [if] given the platform (Pacific and Māori youth)

Developing Pacific workforce capacity across mental health, primary and secondary services was seen by many submissions as essential so the workforce can respond to Pacific populations with Pacific identities.

Pasifika identity is the response they need to deal with their issues (Pacific contributor)

Lack of pacific workforce. NGO teams not big enough with work doubling and tripling. How pasifika see things is from a completely different perspective so need pacific people to have a conversation and different approach. Not culturally safe otherwise (Pacific health professional)

One submission noted the need for a Pacific workforce to skilfully manage personalised support yet working within a family system of support.

Many of the people we work with have a strong desire for family acceptance and belonging. Many of the young people ... recognise the importance of their peers yet still find their identity and sense of belonging within the structures of their family. Middle-aged and older service users are more than often concerned about their families' welfare and especially the welfare of their children. Although our service works with the service user who has been referred to us, this often cannot ignore the system that they belong to and to which they seek identity, that is, the family (Pacific NGO provider)

A shortage of doctors who could speak a Pacific language was noted. Pacific-owned health services have improved choices for Pacific people, but most of the Pacific population continue to be served by mainstream providers.

The Nursing Council of New Zealand (2015) reported that only 3% of the nursing workforce identified as Pacific and only 8.7% (4.4% community and 4.3% inpatient) of these Pacific nurses practice in mental health. Integrating Pacific world views into medical training in a meaningful way was seen as essential.

The Pacific worldviews around education and ways of learning and knowing are either superficially covered or otherwise ignored. There is a need to include Pacific frameworks, models and tools into our current nursing curriculum to attract and retain Pacific nurses and increase the need of the health system (Pacific NGO provider)

Improving broader workforce diversity was also seen as important.

New Zealand needs to be shaken upside down re: diversity—the public service makes policies that are for all New Zealand—you have to be good at neutral thinking but Pasifika people's opinions come from our passion but we are told we aren't capable of thinking neutrally. Systems like the public service need to change to allow the smaller systems to change so we can approach everyone to get the help they need. Huge room for improvement in that space for Pasifika (Pacific student)

Non-Pacific staff needed to increase cultural capacity with robust training programmes that were not a short 'add-on' to training programmes but integrated true learning partnerships. A culturally competent workforce is better for all New Zealanders, and several service organisations are running training programmes, but this competency needs to be better incorporated across the mental health and addiction workforce.

Professional staff have to come to [service provider] to be 'untrained' as their education and/or mainstream experiences have taught them to remove the emotional aspects from their role. [But] connecting and engaging with clients through a shared understanding and mutual respect is what makes us different to mainstream (Pacific NGO provider)

Similarly, given the high rate of seclusion rates for Pacific populations (see section **2.7: Rights and legislation**), the workforce needs culturally specific training "for those that work with Pasifika patients in seclusion to better support and assist them into recovery" (Pacific support worker).

## **Focus on addiction (including gambling)**

One Pacific contributor noted that addiction has always been the “poor cousin” to mental health with Pacific NGOs and other service providers calling for a significant increase in free Pacific-led addiction services. The high rates of incarceration and the focus on the justice response to addiction were seen to be majorly problematic – leaving Pacific men, in particular, without addiction support. One service provider described a time when a family member came to them concerning their child’s addiction,

we would love to have supportive accommodation for Pacific, where contained and appropriate support and services are provided for them – addressing his mental health issues (Pacific NGO staff)

There was a call for more therapeutic communities, a greater concerted health approach to addiction, and increased support for the Alcohol and Other Drug Treatment courts (where necessary).

For some submitters working in high-addiction areas (including gambling), children and others in the household need urgent intervention and trauma-informed care. One Pacific submitter working with those addicted to methamphetamine and their communities noted the rise in synthetic drugs was increasing the impact on communities and cultures noting,

We have had 90 deaths now from synthetics. If they had been from a rich area, would this still be a problem? (Pacific contributor)

The high rates of gambling within the Pacific population were noted by some submitters, who also recognised the lack of alcohol and other drug (and gambling) training within the mental health workforce, as well as the need for (funded) community action.

Need community action workforce to do this. Need to stop looking at just clinical staff—we have solutions. Nothing about us without us. Important our voices are heard (Pacific contributor)

Identified Pacific submitters with lived experience of addiction were relatively few but at least one noted that programmes that reconnected identity and a sense of belonging, as well as providing the tools to recover, helped keep them sober.

[Programme] helped me stay clean and sober away from home. Feel like I’m part of their family, helps me to build up my confidence level ... They helped me find myself (Pacific contributor)

A few submitters noted the need to work with the community to decrease easy access to alcohol (for example, distribution of alcohol outlets).

## 2.5 Social determinants

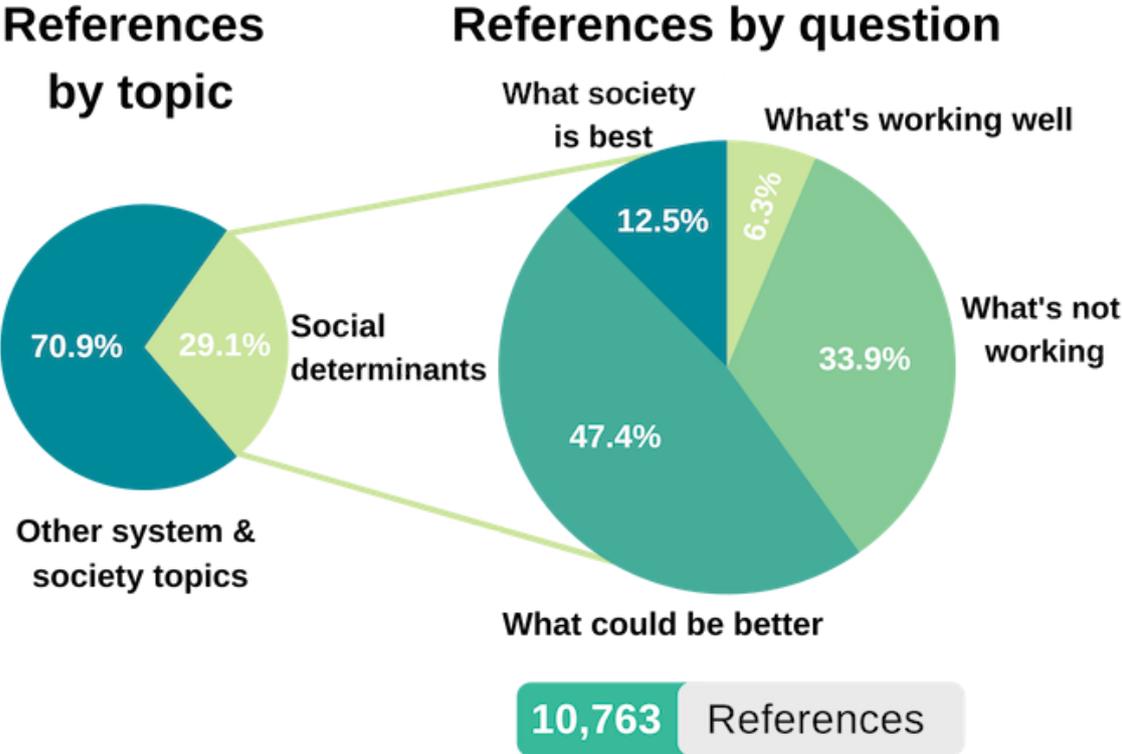
### 2.5.1 Overview

This section presents an overview of responses from submissions about social determinants and related topics. This summary overlaps with other sections in the report.

Across submissions, there was a focus on social determinants as a major contributing factor to high rates of mental health and addiction challenges.

Submitters made 10,763 references on social determinants, which account for about 29.1% of comments made to the Inquiry overall. Of the comments made about social determinants, 47.4% focused on what could be better, 33.9% focused on what isn't working well and 6.3% focused on what's working well.

FIGURE 2.6: SUMMARY OF RESPONSES TO SOCIAL DETERMINANTS



**KEY THEMES FROM SUBMISSIONS FOR SOCIAL DETERMINANTS INCLUDE:**

**2.5.2 What's working well?**

- cross-sector initiatives
- protective factors of culture
- protective factors of community and housing
- programmes that target physical as well as mental health challenges
- free or accessible services
- education, mentoring and mindfulness
- work and participation in community
- Whānau Ora approaches

**2.5.3 What isn't working well?**

- poverty and income
- employment and unemployment
- diverse forms of discrimination and stigma
- lack of housing as a significant driver of poor mental health
- education equity and bullying
- poor physical health, diet and nutrition
- poor attachment and early childhood adversity
- trauma and violence
- social disconnection and loneliness

**2.5.4 What could be better?**

- integrated, innovative approaches
- life-course approach, early intervention and maternal health
- trauma-informed care

## **2.5.2 What's working well?**

There was a wide understanding from both service users and service providers on the impact of the social determinants of health – with many submitters acknowledging that mental health and addiction challenges have many underlying drivers that need to be addressed.

### **Cross-sector initiatives**

Several cross-sector initiatives were outlined by submitters that involved collaboration among local council, police, NGOs, mental health services and other charities – successfully targeting local issues. These initiatives were dependent on strong consensus and buy-in from all participants and clear delineation of goals. They also required funding – and many successful initiatives struggled with funding challenges.

### **Protective factors of culture**

Many submitters noted the protective factors found in connecting with cultural values and practices. This included belonging, identity, whānau-based approaches, practices and approaches incorporating spiritual as well as physical, environmental and cultural practices (including for migrant and refugee populations).

### **Protective factors of community and housing**

Many submissions regarded social connectedness as a key component to wellbeing.

All humans have an inane drive to feel connected and accepted, to have purpose and love (individual with lived experience of addiction challenges)

Access to community-based services that enabled participation, connection and belonging were seen as crucial to the mental health of submitters. Some found this in libraries, drop-in centres, abstinence addiction groups, group therapy,

Housing was also seen as connection to community, security, and identity. One caller to the Inquiry was paraphrased as saying,

from experience of moving around a lot and living in her car, that having a stable house has made a big difference for her. It allows her to fully participate in her community (attending groups, workshops, activities) and also helps her to manage her mental health concerns due to the stability that the house provide (individual with lived experience)

### **Programmes that target physical as well as mental health challenges**

Some programmes that incorporate physical health were appreciated by submitters – particularly addiction services that recognised the need to target chronic pain, dental health care, physical health and nutrition.

### **Free or accessible services**

The cost of talk therapies was a deterrent for many submitters – subsidised, free or sliding scale access to help was highly valued. A few submitters recognised that their ability to overcome mental health and addiction challenges was in part reliant on their ability to afford care, in addition to other significant protective factors.

Being able to earn enough to access good private mental healthcare means that I keep working, I have a full rich life, I have loving relationships – I've survived dark depressive episodes that could have killed me by the skin of my teeth (service user)

### Education, mentoring and mindfulness

Receiving an education, a safe schooling environment, and opportunity to fully participate in education were regarded as protective factors as well as significant to one's self-esteem. One submitter in prison discussed his own experience with education,

Education is a big factor I have received qualification I never thought I would ever get and I feel real proud of myself, which has boosted my self confidence (prisoner)

Some submitters noted the value of education as a protective factor and “a key to building resilience in young people necessary for wellbeing” (youth NGO provider). A few submitters noted the value of mentoring programmes for young people.

Some mindfulness programmes were noted by submitters as being evidence-based and working to reduce stress and enhance resilience.

Stigma reducing programmes such as *Like Minds Like Mine* were noted as increasing help seeking behaviours and openness about mental health challenges.

### Work and participation

Many submitters focused on growing a healthy community and targeting belonging, identity and loneliness. Many submitters spoke of employment as a vital component to their recovery and maintaining wellbeing.

Those who had found meaningful volunteer, peer support or other employment described its impact on wellbeing,

Mana is restored when you have work and can provide for yourself and your whānau (service user)

I found the road to full recovery was to have purpose and meaning in my life, which was evidenced by the voluntary role which helped me get my work ethic back on track, ready for me to take up paid employment once again (service user)

### Whānau Ora approaches

As noted in both the Māori and Pacific sections, Whānau Ora is considered by both tāngata whaiora and service providers as addressing holistic needs and social determinants to the extent that funding and commissioning models allow.

### 2.5.3 What isn't working well?

I am a crisis nurse, we see more people who are stressed out due to social stressors than we do people with a diagnosed or diagnosable psychiatric illness (health professional)

#### Poverty and income

For many submitters, however, poverty or low income was seen as both an underlying causal factor of mental health and addiction challenges as well as a result of living with these challenges.

The significant link between poverty and mental ill-health is quietly spoken about, but never addressed (family member)

Many submitters spoke of the negative impact and toxic stress of living in poverty – for both themselves and their tamariki or wider community. For many organisations as well as professional bodies, the evidence-based impact of poverty on child wellbeing is well documented.

Children living under the poverty line are less likely to have the bare necessities, have poorer nutrition, and are likely to live in overcrowded conditions. There is an accepted relationship between experiencing childhood poverty and experiencing mental distress in later life (DHB)

Several submitters spoke of the link between poverty and inaccessibility of healthy food, lower educational achievement, exposure to violence and crime, homelessness and inadequate housing, incarceration, addiction and trauma. Some submissions from those with lived experiences, parents, families and whānau expressed whakamā or shame at not being able to provide for themselves or their child.

I'm begging for help here, not for me, but for everyone struggling. I can't afford food, medication, rent or anything else and I'm always being told it is my fault, I should have made better choices (Pacific service user)

Some submitters spoke of living on the benefit and being unable to meet basic needs.

I am not getting enough to survive on the benefit (invalids), it all goes on paying rent and bills. So I haven't enough money for food, I trade things (tangata whiaora)

we need to be honest there is massive poverty and people feel trapped on benefits that don't pay for very much ... rents are sky high and the buildings are cold and very old but seem to be very expensive causing [over] crowding which has worse effects on people mental health (Individual with lived experience)

Similarly, low skilled, low paying jobs that did not cover basic cost of living or the high cost of living was entrapping families with many unable to afford rent and bills, feed their families, heat their homes, or give their children opportunities like sports or school trips. Having little money not only impacted on opportunities to participate in society (even have a coffee in a café, use transport or attend courses) but also inhibited access to primary health care, secondary and specialist health services.

Mental health challenges that affected ability to work were also noted by submitters as contributing to poverty,

Mental health issues can mean that people suffer a loss of income, can only work part time or are not able to work. People often lose track of their finances, can't keep on top of things, have reduced capability for decision making and need more resources for their health needs (NGO)

Some submissions discussed how a lack of skills for effectively managing finances can leave people stuck in a cycle of debt and poverty.

## **Employment and unemployment**

A lack of employment or underemployment was often a significant driver of poverty and social dislocation.

Boredom was seen as having a significant impact on whānau's wellbeing and a driver of addictive behaviour. Whānau clearly expressed the need for positive and valued activities. Ideally this was seen as finding paid employment (NGO collating the views of service users)

Those in regional or rural locations, or with high needs and multiple disadvantages, noted that unemployment had significant impacts on both their own wellbeing and that of their communities. Lack of employment opportunities was contributing to boredom, drug use and selling, addictions, despair, depression, suicide and poverty.

The cycle and interplay between mental health or addiction challenges and employment was discussed often, whereby mental health challenges made it difficult to obtain or maintain employment, and consequently losing employment or being unemployed further exacerbated poor mental health.

I could no longer operate my business due to my mental state as I became once again depressed and was withdrawing from life and society ... Due to me not being able to hold down a job I became more mentally unwell (service user)

Some service users recounted difficulties returning to full time employment during or immediately after experiencing mental health or addiction challenges, and valued the flexibility of some work environments.

Personally my 2 hours per week assisting with administration duties has been a big part of my personal development, communication confidence, feeling like I am giving back and especially hope that I will eventually be able to return to the work force (service user with ASD)

Some submitters noted barriers to employment for those with mental health conditions, despite discrimination laws.

Under legislation it is illegal for employers to discriminate based on mental illness, however if this can impact on your ability to carry out the job it must be declared or can be grounds for dismissal... With the current rates of unemployment and the amount of people applying for positions, declaring mental illness often means that others who don't have this condition are considered over and above the person declaring mental health issues. This is indirect discrimination (Deaf service user)

A few submissions spoke of workplace culture as tolerating or encouraging bullying. Others mentioned media as a negative influence by glamorising bullying behaviour in television and movies.

Stop bullying. It is rife in schools and workplaces. In my workplace the bullies all got promoted (service user)

### **Diverse forms of discrimination and stigma**

Many submitters noted the impact of discrimination and stigma on their lives, or lives of friends and whānau. These terms were used interchangeably or distinctively.

Discrimination was often used in reference to racism, colonisation, gender or sexuality-based discrimination, workplace discrimination or diagnosis discrimination (for example, schizophrenia, psychosis).

Parts of the rainbow population experience intersecting and multi-layered minority stress related to other aspects of their identity. For example, Takatāpui may experience minority stress related to being Māori, as well as related to their sexuality, sex or gender; additionally they may experience exclusion from rainbow communities due to racism, and exclusion from whānau and te ao Māori because of rainbow-negative discrimination. Similarly, disabled rainbow people may experience discrimination related to their disability as well as their rainbow identity (Rainbow sector grouping)

Many personal submissions spoke of discrimination against the submitter due to ‘mental illness’.

I mentioned before about feeling discriminated against when it comes to looking for jobs, housing etc. As a community and a country, I think that people need to be educated more on mental illness, and also addiction, so that they can realise that we are not bad people, we are just sick people. We deserve the same amount of care and respect as any other human, but I don't think that this is the case currently (service user)

People living with an enduring psychotic illness are often stigmatised and discriminated against relating to employment, education and housing. Despite the ‘like minds, like mine’ campaign, 20 years on the stigma and discrimination relating to the diagnosis of schizophrenia remains (DHB health professional)

Discrimination was also felt by those with mental health challenges seeking help in other government sectors as submitters with lived experience noted,

I've been waiting over two years for a house from Housing NZ but still nothing. The street is my home (service user)

I rang a motel for some temporary accommodation, but they told me they don't take mental health patients (service user)

For many Māori submitters, tāngata whaiora, whānau, kaumātua and kaimahi, the continued impacts of discrimination based on colonisation were ongoing and felt in terms of misdiagnosis, mistreatment within health services, lack of culturally safe services, higher levels of addiction and incarceration, higher rates of seclusion, and a biomedical-based paradigm that treated holistic whānau wellbeing as secondary.

most non-Māori will ask why do Māori keep going on about colonialization?  
It impacts Māori mental health (Māori researcher)

In submissions, stigma often referred to the shame and embarrassment people felt at being diagnosed with mental health challenges, having addictions that were illegal or not socially acceptable, or feeling unable to fully participate in society due to perceived differences. These differences could be things such as diagnosis, drug withdrawal symptoms, feeling lonely, or feeling culturally unsafe.

Many submitters noted that John Kirwan's and Mike King's campaigns were highly valued in shifting attitudes toward mental health challenges and opening conversations about depression. However, many still perceived stigma as a barrier to help-seeking behaviour.

### **Housing as a significant driver of poor mental health**

For many submitters across the Inquiry, housing significantly impacted on health, stress levels and sense of belonging. This included the impacts of poor-quality housing, unaffordable housing, overcrowded housing, a lack of housing, being unable to find a suitable place to live, and difficulty retaining a house.

The Inquiry heard from those working with homeless people, as well as from homeless people themselves (whose stories were often captured by the NGOs who worked with them). One NGO noted that many of those who are homeless also have unmet mental health and addiction needs and are isolated from their whānau, therefore it is difficult to sustain any kind of accommodation without wrap-around support.

[homeless service user]who are in emergency accommodation such as backpackers or motels are often being evicted (or at risk of eviction) due to anti-social behaviours, including aggression towards others, failing to pay rent, damaging property and inviting people over who should not be there. Taumai who are housed in social housing, city council flats and private tenancies experience the same instability and risk of eviction when their addiction and/or mental health concerns leads them to engage in anti-social behaviours. When the options for emergency accommodation dry up or they are evicted from their tenancy, taumai find themselves couch surfing, sleeping in cars or rough sleeping. This further exacerbates their mental ill health and addictions (kaimahi Māori)

The lack of integration between services, or inadequate respite, was also significant for other submitters in terms of housing outcomes. Some submitters spoke of being released from services or sent away from emergency care with nowhere to go – some telling personal stories of their own experiences or of their whānau sleeping on the street or in unsafe places. The result of this inadequate post-care housing and integrated approach to health created a revolving door effect. One NGO noted from its clientele that,

Whānau would often state being told by health providers that “we look after your health, not housing. That's someone else's job”. Yet health, housing and environment cannot be arbitrarily separated. All whānau agreed that effective support requires a holistic approach if it is going to be successful (NGO collating the views of service users)

## Education and bullying

Many submitters were fully aware of the importance of education (including tertiary education) and schooling as both a place of learning and a significant setting for teenagers and young adults to learn and grow beyond academic outcomes. A few submitters spoke of school education as not adequately preparing students for life outside of school.

At school they turn you into marketing tools by year 13 and they've shaped you into what they see is perfect, not what will help you in the real world (student)

I think Schools don't realise the impact of their definitions of success (student)

Some submissions noted that the current education model does not work well for disabled children or children with dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD), auditory and visual processing disorders, or children on the autism spectrum.

many young people with dyslexia and ADHD fall through the cracks and leave school without qualifications (family member and educator)

Some submissions noted that many tertiary students also suffered from isolation, including many international students who were lonely and unable to connect into the local culture. Tertiary students, for example, noted stress from university arose through high workload pressure, the concentrated period of time for assessments, and high cost of living resulting in many having to work while studying.

It would be more useful if Uni extended its terms and there was more time, instead of more stress in a concentrated period of time (tertiary student)

Many submissions were concerned with the widespread occurrence of bullying.

One submitter from a professional organisation quoted research that said,

A recent report from the Organisation for Economic Cooperation and Development (2017) indicates that Aotearoa New Zealand has the second highest rates of bullying in the OECD. Bullying is also an identified risk factor for mental health difficulties including suicide. This is of significant concern given Aotearoa New Zealand also has some of the highest rates of suicide in young people (professional organisation)

Bullying, including cyber-bullying, was largely identified in submissions as contributing to mental health challenges, as well as low self-esteem, suicidality, social isolation and stress.

Bullying now is worse than ever before and nothing ever gets done about it (service user)

The epidemic of bullying (online, school, workplace, parental, and domestic) is intertwined with our mental illness (academic with lived experience)

School bullying can have serious impacts on children's and young people's mental health and wellbeing (service user)

Why are we not jumping up and down in school yards and stopping every example of school bullying? (advocate)

Many submissions mentioned that it is good to see an increase in awareness of the impact of bullying and an increase in anti-bullying action taken in both schools and workplaces, but more needs to be done given the consequences of persistent bullying.

A whole-of-school approach was suggested as one best evidence-based approach to combatting bullying, including parents, teachers, students and professionals. This approach targets systemic issues of bullying and buy-in from the whole community.

### **Poor physical health, diet, and nutrition**

Some submitters spoke of how the population appears to be unaware of how physical health, diet, and nutrition are connected to health and wellbeing. A few service users expressed frustration with the lack of integration between mental health and physical health with specialists ignoring the impacts of exercise or other physical health factors on their recovery and a lack of input from dietitians or exercise physiologists in treatment.

Some submitters discussed aspects of poor diet, such as a high intake of processed foods, carbohydrates and sugar, a low intake of vitamins and minerals, and the link to obesity and diabetes. Others mentioned how a poor diet is largely influenced by high prices of fruit, vegetables and other health foods.

Coke is cheaper than milk and wonder why people have diabetes and bad teeth ... Stop making fruit and veg really dear and crap food inexpensive  
(Māori contributor)

Other physical health issues that submitters regarded as having a negative impact on mental health and wellbeing included low rates of physical activity or regular exercise; poor dental health, particularly within vulnerable communities; insufficient amount of sleep and poor sleep practices; physical pain; and issues with eyesight.

his dental pain contributed to depression and employment issues, affecting his overall mental well-being (NGO)

Those who experience mental health and addiction challenges, particularly with chronic pain, also experience disparities in physical health outcomes compared with those without, including lower life expectancy.

Service users and family members in particular also spoke of how negative side effects from medications contributed to physical health issues such as weight gain and cardiovascular disease.

People with mental health issues die earlier in this country than the general population, and experience a huge raft of poor physical health outcomes  
(health professional with lived experience)

Some submitters noted discriminatory care practices for those with mental health and addiction in relation to physical health outcomes.

it is clear people with mental health conditions experience unmet need in relation to their physical health. In New Zealand, the rate of premature mortality (death from natural causes before age 65) is twice as high for people using mental health and addiction services compared to the general population. For people diagnosed with a psychotic disorder, it is three times as high (professional organisation)

In part this is due to diagnostic overshadowing, “when health practitioners may attribute signs or symptoms of illness or disease to one condition, where in fact it may be strongly associated or caused by another long-term health condition” (professional organisation). As such, effective treatment may be delayed or inadequate.

### **Poor attachment and early childhood adversity**

A safe, secure and loving first 1,000 days of a child’s life and good maternal health were seen as critical protective factors for later onset mental health and addiction challenges.

Many submitters who spoke of early childhood noted the importance of caregiver–child bonds. Some noted the impact of adverse childhood events more directly, more of childhood trauma in general.

There is increasing evidence that sensitive responses from primary caregivers to their child’s emotional and physical needs are the foundations for healthy outcomes in the long term. Secure infant mental health is the path to mental health and well-being as an adult (NGO provider)

### **Trauma and violence**

Many submissions spoke of the traumatic outcomes of violence. For submitters this included intimate partner violence, family violence, sexual violence and violence from strangers. Many submitters felt violence had shaped their life yet they had little or no help with the trauma resulting from it. One clinician noted that,

Trauma does not only stem from sexual abuse or an accident. There is almost no help for those traumatised (both adults and children) from family violence; again the gender issues of this crime are hidden; calling this ‘family’ violence when perpetrators are overwhelmingly male against women and children is colluding with the reality of this abuse (academics)

Many submitters who spoke of violence focused on sexual violence – both their own and the experiences of family, friends, and whānau. One organisation who assists people who have experienced rape and sexual abuse said,

The impacts of sexual abuse and rape on people are life-changing and can be life-threatening. They include a range of negative effects such as a sense of loss of control or powerlessness, depression, fear, anger, relationship problems, eating disorders, sleeping disorders, shame, guilt and self-blame, flashbacks and nightmares, self-harming, substance abuse and a sense of being detached from reality or separate from your own body (NGO providers)

The impacts of sexual violence for those submitters who had experienced this were devastating and far reaching.

As a victim of child sexual abuse, psychological abuse, violent battery ... the effects of trauma have changed the entire profile of my life, ultimately leading to a nervous breakdown and suicide attempt... I will always wonder what my life may have been like if the help and care I so desperately needed had been available to me... I would like to know my own experience may prevent someone else enduring the loss of quality of life, happiness, productivity and isolation I've experienced. Along with the shame of being damaged, fragile, and frequently judged because of others ignorance (service user).

I believe children who suffer sexual abuse often go on to have addiction problems and abusive relationships (service user).

My depression has stemmed from my upbringing, from physical, mental and sexual abuse (service user).

Rates of abuse also intersected with sexuality, gender identity, ethnicity and disabilities. Many submitters who had experienced sexual violence either as a child or an adult shared their heart breaking stories of how abuse had changed the course of their life. How, as a result of the trauma they experienced, they suffered from depression, suicidal ideation, addiction abuse, post-traumatic stress disorder and anxiety disorders. Many spoke of friends and whānau who had died by suicide due to trauma suffered from violence.

### **Social disconnection and loneliness**

Social disconnection, cultural disconnection and loneliness were associated for many submitters with a variety of poor outcomes, including suicide, addiction, poor physical health, boredom, lack of integration into the community and purposelessness.

Some submissions noted that rates of loneliness and social disconnection are increasing, particularly for youth, older people (over 75 years ), disabled people, unemployed people, and rural populations.

Tragically for [other youth], their disconnection from, or total absence of, meaningful, person to person relationships profoundly disables their sense of meaning, purpose and connection – and ultimately their potential (NGO)

Once you are retired it often feels as if you are redundant within the community. Instead of being given an opportunity to perhaps assist in schools, sports environments, or other community activities, people get left isolated, or sent off to retirement villages (individual with lived experience)

A few submissions attributed increased loneliness and social disconnection to wider societal changes, such as the increased use of technology, internet and social media; less connection to communities, including decline in use of social clubs and closure of night classes; decline in religion; and changes to work system and family structure.

The core of society, and the fabric of the community, have changed and are severely affected. We have lost connection with people and communities. We have lost the sense of belonging to a group and to each other (family support worker)

Many submitters highlighted how the cost of community activities can be discouraging and leave those with mental health challenges unable to participate fully.

Joining groups in the community have a cost attached to them which on a low income becomes a barrier to participation. Even finding a Koha of \$2 can be impossible. Or meetings occur at cafes where the expectation is you buy a drink (service user)

I joined a quilt group. Once a month they go out for lunch or a workshop. I can't afford those so stopped going as I was always missing out. It was embarrassing. The long term effect of this then makes me more isolated and not included (service user)

Similarly, submitters suggested that limited or inadequate funding opportunities have made many community options obsolete. Drop-in centres, soup kitchens, free creative classes, community centres, places that are culturally safe and welcoming, and support groups have increasingly had to close their community doors due to an inability to win commissioning contracts in an increasingly competitive and outcomes-focused environment.

Submitters said that this feeling of disconnection is exacerbated for those with mental health challenges who required more care, or perhaps were in a therapeutic village (now closed) or an institution (now closed), yet now live in the community. Some submitters commented that loneliness, and lack of community connection were debilitating for their recovery and that money was not invested in the community to provide opportunities. As one caller commented,

When psychiatric hospitals were closed, the services did not follow the patients out into the community. Many are now distressed, lonely and discriminated against (not seen as worthy individuals) because of their condition. Isolation and loneliness are killers. We have seen a decrease in the services that provide supported employment or a place (such as a drop in centre) to provide this connection and have some form of community (service user)

#### **2.5.4 What could be better?**

##### **Integrated, innovative approaches to targeting social determinants**

Many submitters, both individual and organisations, noted that integration – at both local and national levels – was required to tackle the impact of determinants on health as well as strong leadership, a population-based approach to wellbeing and cohesive planning across sectors.

As noted throughout this report, submitters spoke of holistic views of mental health and addiction challenges, holistic services, better access, a variety of options for service users, integrated services, Whānau Ora models, wrap-around care, family- and whānau-based intervention, and whole-of-government approach. Responses to social determinants also rested in addressing persistent discrimination in the system and uphold Te Tiriti o Waitangi and true partnership models. Many of these solutions are expanded in other chapters.

Broadly, submissions focusing on social determinants noted the following solutions:

- Housing initiatives could only be successful with cross-sector collaboration.
- Housing approaches need an innovative and fresh approach. For example, the New Zealand definition of homelessness needs to be reviewed to include

homelessness in the mental health sector, a new housing status category introduced to measure the cycle of homelessness for mental health, and a co-housing initiative established where architects and designers, providers, consumers and funders co-design and co-produce accommodation that supports wellbeing.

- Community needs investment and regeneration – including community funding, more places to go to relax and mix with people without high financial cost, more art and recreation options, drop-in centres, support groups – places where people could connect, reconnect, feel part of society and receive help if necessary. Community hubs were seen as a vital link to community resources, and mental health and addiction help. As those with lived experience noted at one NGO,

The features that they had in common were that they were low threshold, non-judgmental, there was nearly always food involved and that they were available at a wide range of hours. These included professional non-government organisations, churches, community groups and self-help groups. One person described how for many years she had been running a small group from her flat where whānau could gather for a shared lunch and the opportunity to talk. These services were seen as essential and meeting a specific need that was not met by mental health and addiction services (NGO collating the views of service users)

- Council must play their part at enabling access, including access to community resources that revolve around physical activity, such as swimming pools and gyms.
- Physical health cannot be separated from mental health - integrating physical health and mental health at every level – many submissions considered separating the two as counterintuitive. This includes subsidising dental care for vulnerable communities.
- One-stop-shops are required as single points of entry, offering navigation through a complex system, including across the social, justice and welfare sectors.
- Whānau Ora needs to be expanded and whānau-centred responses to mental health and addiction challenges increased.
- Public health campaigns are required (including for addiction) to address persistent stigma and discrimination.
- Address the impacts of legalised drugs, such as alcohol and smoking, and gambling addiction.
- Adapt and implement international bullying programmes in every school (like the programme in Finland).
- Amend the Crimes Act 1961 to include workplace bullying (physical and psychological) as an offence under the charges of assault.
- Adopt a zero tolerance approach to bullying and harassment in workplaces, including government departments and DHBs.
- Create legislation to allow financial compensation to be granted to survivors of workplace bullying or harassment.
- Provide meaningful employment or volunteer opportunities.

Many submitters appreciated the Accident Compensation Corporation's fully funded sensitive claims for sexual abuse. Some submitters noted this should be expanded to include all forms of violence and trauma (see section **2.7: Rights and legislation**).

### **Life course approach focusing on early intervention and maternal health**

We need a much better understanding of how malleable fetal, infant, and adolescent brains are and how much they can be impacted by both beneficial (good parenting, love, appropriate direction and discipline, good nutrition) and malign (alcohol, tobacco, violence, abuse, absence of care) influences throughout the first two decades of life (government agency)

While stages across one's entire life course were considered precious and important, many submitters emphasised the need for a preventative approach that targets maternity and early childhood.

It is crucial that we invest in children and caregivers to build a healthy and flourishing society (professional organisation)

Prevention! Prevention! Prevention! We need to focus on early childhood. Attachment. Parenting. Love. Pregnancy. A system that enables parents (support worker with lived experience)

Prevention and intervention strategies applied early in life are more effective in altering outcomes and reap more economic returns over the life course (NGO)

Submitters widely recommended significant investment into the first 1,000 days of a child's life, stating that a focus on giving children the best start to life will provide the greatest social and economic benefits. Submitters noted that factors that interfere with this healthy development, while complex, need to be addressed and targeted as a means of reducing poor outcomes such as addiction and mental health challenges later in life.

A few submitters recognised that while some efforts are in place in New Zealand that invest in early childhood wellbeing, sector-wide efforts are minimal compared with in other OECD countries, and it is imperative that more is done.

Targeting an early childhood intervention was seen as crucial by some submitters as a means to increase protective factors against a range of social determinants.

Recommendations from submitters included:

- prioritise children in all public policy development and decision-making processes, taking a 'children in all policies' approach
- enable parents and caregivers to spend more time with children in their first three years by ensuring families have adequate incomes and family-friendly working conditions, including sufficient paid parental leave

Ensure at least one parent is enabled to stay at home with children to care for them and still have adequate income to provide warm, safe, dry housing, proper nutrition and money for transport and some activities for at least the first two to three years of life (NGO providers)

Ensuring families are able to have time to spend together, have money to meet their basic needs, and are able to access support in their communities is essential (NGO)

Parents shouldn't be pushed out to work before child is 3 years old (NGO staff members)

- allocate more resources to this area of prevention, including expanding the capacity and capability of those who work with infants and families (midwives, Plunket nurses, Tamariki Ora workers, iwi-based support workers and early childhood educators) and increasing availability of services such as evidence-based antenatal and postnatal care and evidence-based parenting programmes (such as Triple P and Incredible Years)

In an ideal society, the investment of resources would be redistributed, and a greater portion allocated to families with infants/young children and services that care for and address the needs of infants, children and their primary caregivers (Pacific researchers)

- conduct risk assessments during pregnancy to identify issues such as violence, substance abuse, and poor maternal mental health (prenatal and postnatal depression and anxiety)

Every women of child bearing age is routinely screened for family harm, child abuse and neglect at every contact with a registered professional (individual submitter)

- increase public education on the harms of tobacco, alcohol and other substances on foetal development during pregnancy
- use early childhood education to promote social emotional (empathy and self-control) and cognitive skills (language and literacy)
- look at overseas models that have positive results, such as the Scandinavian 'baby box' model where every family receives a box [baby box of necessities] regardless of level of need
- improve data collection so it is more comprehensive and inclusive of earlier years, that is, record data before a child is 3 years old
- make frequent and comprehensive support and education available to parents or caregivers about warm, sensitive and appropriate parenting practices, including support around bonding and attachment.

A system that enables parents. Teach them but make it possible for a parent to spend time at home with newborns. Teach them to show unconditional love and acceptance to their children. Teach them the importance of the early years. Maternity [classes] focused on the emotional stuff (support worker with lived experience)

Submitters noted that parenting interventions for Māori needed to be culturally informed and Māori led with tikanga-based approaches.

Whānau Ora and other holistic, family-centric approaches were also regarded as beneficial for the wellbeing of Pacific children and families. A small number of submitters noted that,

given the low average age of Pacific people in New Zealand, it is important to ensure these parents and caregivers have timely and appropriate support to care for their children.

Many submissions recognised that families, whānau, parents, grandparents, matua whāngai and caregivers need more support in the role of childrearing. This needs to be a wrap-around 'circle of support' that is comprehensive, holistic, culturally sound and integrated across multiple sectors, locally and nationally. This includes government departments, local authorities, health and social services, schools, employers, iwi, churches, and other community groups all working together to meet the needs of infants, tamariki, families and whānau.

Better collaboration between Health, Education and Government and Community Social Services for children and their whānau. So therapy can be put in place and any other support systems for the child and whānau as soon as possible (health professional)

In the context of wraparound perinatal mental health and well-being this means not just the health and addiction sectors and its various professionals, but our communities, social support services, education and justice systems all of which need to be able to respond to the needs of that mother family/whānau and child (NGO)

Many submitters said that the workforce for children is under-resourced and underfunded. Although some submitters noted excellent clinical specialists, nurses, peer and other supports, often waitlists for specialised help were too long, specialists too few or non-existent, and age limitations arbitrary. As one Māori educator noted,

Don't understand mental health, some severe cases we haven't been able to access wraparound support as child (8 years) too young. Couldn't give support till he was 10. Even though told behaviour similar to teenage behaviour, he should've got support. But our answer was sorry for 2 years. We have to hold out for 2 years and hope nothing bad is happening (Māori educator)

One NGO provider described their ideal society as one where,

Every government department in New Zealand would take the role of parenting seriously and play a role in extending universal evidence-based support to families to ensure no one is left behind (NGO provider)

While submissions raised the importance of immediately helping the current generation of young children, families, and whānau, it was also recognised that it may take a generation before improvements are seen in New Zealand and,

change will require cross-party accord that spans the political cycle and ensures that the wellbeing of New Zealanders is always the political priority (NGO providers)

## FOCUS ON POSTNATAL DEPRESSION

Submitters who had lived experience of postnatal depression (PND) described traumatic birthing experiences that impacted their mental health, a lack of education and awareness around PND, feeling “*incredibly alone*” (individual lived experience) with a newborn, experiencing symptoms of psychosis and PND yet not having this detected by a health professional, of these symptoms interfering with how they bond with their baby, of feeling suicidal, and of the negative impact these experiences had on their partner.

Parents also faced difficulties accessing services due to the cost of services, long waitlists, understaffed services, and not being considered severe enough to receive help. Some submissions also highlighted the glaring gaps in support for men or partners of women experiencing PND.

Too many mums, and their babies and families, are left to fall through the cracks, with no effective system to help them in the midst of what is a crisis (individual with lived experience)

Birthing centres and hospitals that did not allow partners to stay with the mother overnight were distressing and against the cultural belief for many as described by one Māori mother.

Many other mothers have shared with me the impact that not being able to have your partner or significant other with you overnight at the hospital has on you. I felt that this separation goes against my cultural beliefs and practices and therefore had a huge impact on both my tinana and wairua (wahine Māori)

One submitter reflecting on their experience with postnatal depression described how symptoms began appearing in her third trimester of pregnancy, acknowledging that “maybe the potential for me to develop a mental disorder could have been identified at this stage” (wahine Māori).

Suggestions of what could be better included:

- Detect antenatal and postnatal depression earlier by introducing antenatal and post-partum depression screening as standard care for all women. This includes supporting midwives, Tamariki Ora workers, Plunket nurses, family planning, and GPs to provide comprehensive risk assessments for all women who may need antenatal or postnatal support
- Increase home visits by Plunket nurses, support workers, and mental health workers, particularly in the first 6 months after birth
- Raise awareness of PND during antenatal classes to reduce stigma and ensure that parents receive “more open information about PND prior to the baby arriving” (individual with lived experience)
- Increase access to evidence-based antenatal and postnatal mindfulness programmes
- Listen to mothers and ensure that the individual needs of mothers are considered and taken seriously by health professionals in areas such as birthing plans and maternal mental health treatment

#### FOCUS ON POSTNATAL DEPRESSION CONT.

- Fund treatment and support for all mothers diagnosed with PND, such as counselling and talk therapies, and mother-and-baby support groups
- Increase access to support units for new mothers with PND and their babies, ensuring that mother and baby are treated together and are not separated
- Increase the amount of training that all midwives receive regarding mental health to ensure that midwives are equipped to identify PND
- Provide more support to men and the partners of women experiencing PND, including counselling and support groups

I would open centres where women with children can go and vent, cry, sleep or just sit and be with other women who feel the same. Not just in cities but everywhere, create safe places, phone lines anything so these women at 3am struggling or 3pm have somewhere to go, someone to talk to (individual with lived experience)

#### Trauma-informed care

Many submitters discussed the role of trauma in their lives, the lives of whānau and community, intergenerational trauma of whānau, and trauma in the lives of their clients or people with whom they work.

Much of the discussion in the submissions around trauma and adversity centred on the need to respond to their mental health effects by meeting the cause, rather than the symptoms.

What has happened is the growth of understanding around trauma as a key determinant in mental ill-health and addiction. Trauma informed care is becoming a common term and most NGOs are underpinned with an understanding of the role of trauma (NGO)

Trauma-informed care must be embedded properly throughout service provision... There are great guidelines out there, but they aren't being implemented. This is particularly disappointing when we know a huge percentage of those with mental health issues have a history of trauma (service provider with lived experience)

As one submitter who was helping navigate a family member through the system noted,

PLEASE can we pay attention to neuroscience and the evidence relating to trauma. Trauma has a toxic impact on the brain, body and behaviours. Unless we provide trauma informed services the system will remain broken (family member)

Many Māori submitters noted the necessity to address intergenerational trauma with an emphasis on funding models of care that are based in Te Ao Māori and emphasise connection, identity and whakapapa. As a speaker at a hui said,

Identity and whakapapa issues. Generational harm; put the funding into trauma, into grief, into loss. Address the trauma first before anything else (kaimahi Māori)

We need to go back to good kai, to help us change our ways: For too long we've had different tikanga engrained in us. We should normalise good stuff for our whānau (kaimahi Māori)

Some submissions focused on the need for more trauma-informed care, including adequately training staff who have a better understanding of the impacts of abuse, neglect and violence and of a person-centred, culturally applicable, leadership-driven approach to trauma care across the sector.

If we get it right with dealing with abuse and violence to children we will have far less distressed, addicted and mentally ill people in society. Then we may achieve a generational shift (mental health professional)

Trauma informed care is working well as it teaches people to use natural methods that are alternative to medication or can be used in conjunction with medication until the person reaches a point where they are confident that medication can be reduced and eventually stopped (support worker)

Some mental health specialists, nurses and peer supporters, as well as researchers, NGOs and primary health care providers spoke about the need for greater trauma-informed care, noting New Zealand is not keeping up with international care standards. Among these submitters, there was acknowledgement that many people working in mental health and addiction are not using trauma-informed models.

The whole system lacks any trauma-informed perspective and is way behind in its knowledge of mental health care compared to other countries. The most vulnerable of our young people e.g. those in the care of Oranga Tamariki are especially being neglected in their mental health care; they are very traumatised young people who are not getting trauma treatment (NGO provider)

Trauma informed care and trauma informed practice is essential - but most practitioners are not even aware of this concept (mental health professional)

In regards to trauma informed supports and responding to adverse childhood experiences submissions noted:

- acknowledge peer support as integral to trauma-informed organisations – a few submissions noted that peer support for some services is “inherently trauma informed and inherently culturally responsive” (advocates and support workers with lived experience)
- address the impact of adverse childhood experiences with trauma-informed systems – in schools, social services, health services, and local and national government
- develop trauma-informed care treatment plans for young people identified at risk, and increase the ability for this to be a multi-agency approach

- pilot a trauma-informed approach in forensic youth services
- understand the key principles of trauma-informed care – with a workforce of skilled professionals who understand different support methods, including dialectical behaviour therapy, cognitive behavioural therapy and other appropriate therapies and who recognise power differentials, signs of trauma, community-specific contexts and empowerment strategies
- increase access to specific services for refugees who have typically experienced trauma, including specialists, the number of which is extremely limited.

Some submitters noted that time was critical to responding to trauma and that the current system was not set up to respond adequately. As one GP noted (paraphrased from a meeting),

[they are working] with Māori and Pacific—so many people were talking about sexual abuse, needed to be there to talk to people. Pressured like every doctor is to see as many people as possible—people have cobbled together 18 dollars and tell their story. They’ve been everywhere but not directed to the right area—gets her (the speaker) into trouble with her workmates because she will not let them leave. Bureaucracy gone mad—when we’ve got our specialty we’re supposed to put the patients first but that doesn’t happen (health professional)

Similarly, the need for cross-sector training in trauma-informed approaches was noted.

Contributor referred to ACC and [Work and Income, Ministry of Social Development] as part of a failing, failing system; failing miserably. She found it disgusting, repulsive and offensive to have to sit with someone you’ve just met and dredge up your trauma in repeated reassessments; retelling your trauma story over again: “I hope this is actually going to do something” (service user)

Submissions focusing on those in prison noted that trauma counselling was particularly significant for mental health and addiction challenges, particularly noting some initiatives for women,

The emphasis on counselling recognises that women in prison have frequently experienced trauma, including violence and abusive relationships. A significant component of the social worker's role is supporting mothers who are concerned about their children and supporting them through Family Court and Oranga Tamariki processes (government agency)

## 2.6 Wellbeing, health promotion and awareness raising

### 2.6.1 Overview

This section presents an overview of responses from submissions related to ideas about wellbeing, health promotion and awareness raising.

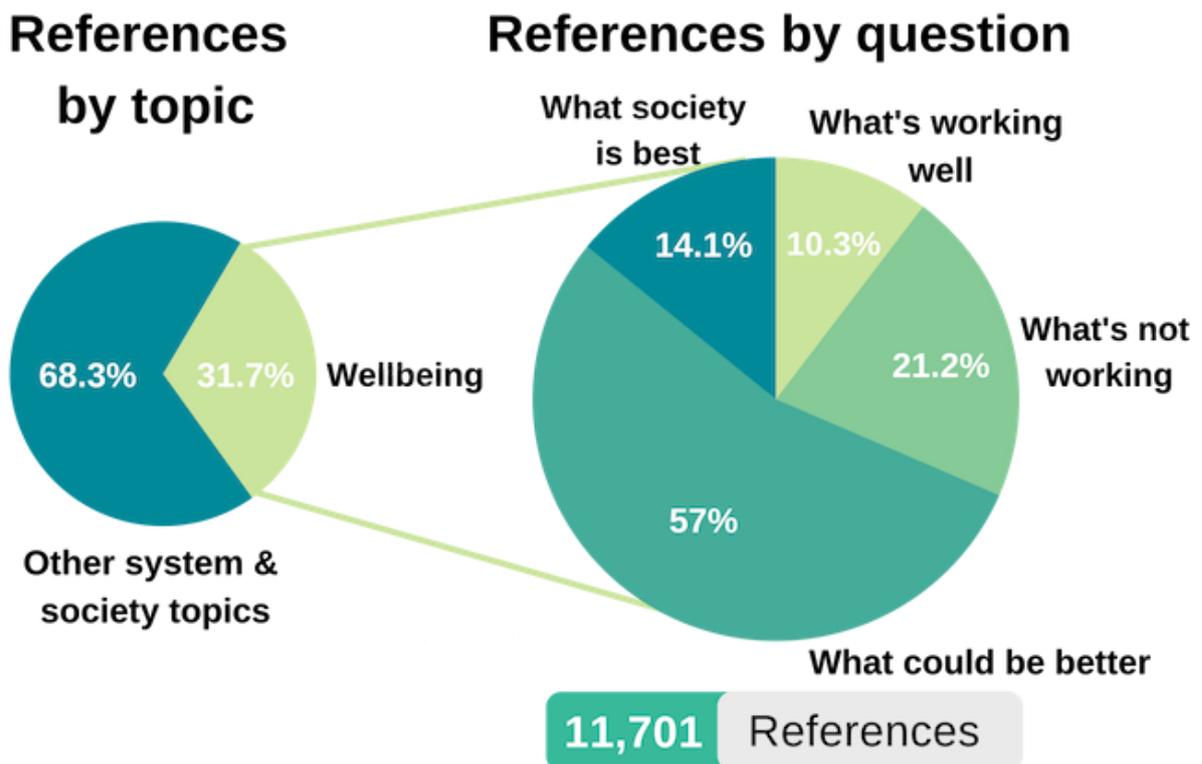
Many submissions from individuals, providers and consumer groups called for a narrative shift towards strategies that promote wellbeing at a population level.

This trajectory can be averted for most people. We will not create better mental health within New Zealand by continuing with an imbalanced focus of resources on acute mental health services. Instead, New Zealand must increase its efforts in promoting wellbeing and preventing mental health problems from occurring (NGO)

Although services are considered in the next chapter, many submitters noted that there cannot be promotion and awareness raising without corresponding service access and options, particularly focusing on prevention services. To do otherwise is counterproductive.

Submitters made 11,701 references about wellbeing, health promotion and awareness raising. Of the comments made, 57% focused on what could be better, 21.2% focused on what's not working, 10.3% focused on what's working well, and 14.1% on what society is best.

FIGURE 2.7: SUMMARY OF RESPONSES ABOUT WELLBEING, HEALTH PROMOTION AND AWARENESS RAISING



**KEY THEMES FROM SUBMISSIONS FOR WELLBEING, HEALTH PROMOTION AND AWARENESS RAISING INCLUDE:**

**2.6.2 What's working well?**

- wellbeing promotion and programme initiatives
- media, advertising and awareness raising campaigns

**2.6.3 What isn't working well?**

- successful wellbeing relies on community options
- raising awareness not linked to access to services
- mass campaigns not effective for some populations
- gaps in knowledge and understanding are hurting communities

**2.6.4 What could be better?**

- grow practices that align with iwi heritage, development and wellness
- reorient the current system
- shift perspectives of health promotion
- increase peer leadership and support
- use the right channels of communication
- expand the message

**2.6.2 What's working well?**

When we look at community as a whole, we find three attributes which play a large role in wellbeing: connectedness, liveability, and equity (health professional)

**Wellbeing promotion and programme initiatives**

The concept of wellbeing promotion is broad in the submissions, encompassing specific campaigns as well as community and sector-wide initiatives.

Some submitters noted various community, school and work initiatives and health promotion campaigns specifically designed to foster wellbeing. These included initiatives in the workplace to promote wellbeing (WorkWell), evidence-based mindfulness courses and other education interventions (Pause, Breath, Smile, wellbeing@schools), mindfulness for parenting (Mindful Parenting), yoga and other health programmes, and specific regional or general population campaigns (All Right? Campaign and the Health Promotion Agency campaigns). Many of these initiatives developed Māori-specific and Pacific-specific

campaigns, utilising multiple media, and underwent robust evaluation. Some inpatient units noted programmes that include a rehabilitation and wellbeing focus.

The community was also seen as a place to enhance wellbeing through access to everyday activities including art, creativity, recreation, spirituality and hobbies:

the development of recreational activities like sport and hobbies, positive relationships with parents, family members and other role models, being engaged in a school or community environment, and spiritual beliefs. These factors can all help minimise risky behaviour around alcohol and other drugs as well as improving mental wellbeing (government agency)

Several submitters noted Iceland's community-based investment policy to reduce risky adolescent behaviours and enhance wellbeing as an exemplar for change.

Some submitters also talked about wellbeing more broadly in regards to community and culturally based participation, not a series of programmes or initiatives.

The word 'Wellbeing' should recognise the wholeness of an individual and their ability to thrive, within the context of community. An individual is supported by culture, language, family, Elders, community, finances, environment, housing, spirituality, and physicality – all underpinned by a shared set of values (NGO provider)

Peer-support groups were very much appreciated by many submitters as a way to enhance wellbeing (through connection). This included addiction-related groups (such as Alcoholics Anonymous and Narcotics Anonymous) and other non-specified support groups.

I cannot overstate the difference our peer support group has made to my wellness. It has allowed me to unpack small worries before they become overwhelming. It has allowed me to no longer feel an exception in a world of normal. It has validated the lessons learned through my life and helped give me further skills. I have had a reason to leave my house and still feel safe. The support between meetings has made me feel valued and connected to the community. Peer Support works for me (service user)

## **Media, advertising and awareness campaigns**

Many submitters acknowledged the positive differences that mental health advertising, social and media campaigns, and public role models were making. For many submitters these campaigns have helped to normalise some mental health challenges, particularly depression, create conversations, challenge their own and societal stigma toward mental health challenges, and increase awareness.

We think it is really positive that discussion around mental health is becoming more open, honest and transparent. It has been great to see dedicated campaigns featuring important Kiwi role models talking about the need for this conversation to be an open and honest one. We need to continue making this conversation happen, in a prominent space with prominent people (government department)

Individuals such as Mike King and John Kirwan have been doing amazing work using the platforms, they have to break down stigma and raise awareness around mental health in NZ. Encouraging people to ask for help, directing people to organisations for support and creating a community where people with mental health issues do not feel judged or ostracized. As someone who suffers from mental health myself and have done for many years, these people and the organisations they have created have helped me immensely feel less alone with my struggles (service user)

### **2.6.3 What isn't working well?**

#### **Successful wellbeing promotion relies on community options**

Wellbeing and health promotion is one thing, but many submitters noted that without community, social and recreational options no amount of promotion will matter.

Some submitters working with youth noted that wellbeing promotion campaigns were fine, but if there is nothing to do, no recreation opportunities, no engagement with community, then wellbeing diminishes.

If people had activities to go to and keep them occupied this would help them from becoming bored and becoming addicted to things (NGO providers)

High needs populations are missing out on wellbeing promotion and initiatives. Some submitters, including those in prison and in respite and inpatient facilities, talked about the lack of programmes for them.

Make every person working in mental health spend a week locked in a room with continual rattles and drips without being able to leave or talk to anyone with nothing to distract them from the isolation, annoying sound and boredom (service user)

#### **Raising awareness not linked to access to services**

Many submitters commented on the disconnect between awareness raising campaigns that encouraged help seeking, and lack of health. This was captured by one submitter who lost their family member to suicide,

The awareness campaigns, as necessary as they are, now make me angry. "It's okay to ask for help". That is a cruel and dishonest message to send to the public if you're not going to provide the resources to provide that help (bereaved family member)

#### **Mass campaigns not effective for some populations**

Mass communication campaigns that aim to change the social landscape have been praised by many personal submitters in their ability to shift thinking about mental health. However, there was an increased call from some submitters for more community-level promotion based on strong understanding of marginalised population groups including transgender, intersex, and Rainbow populations, the Deaf community, and people with addictions.

Similarly, many submitters noted a dearth of addiction anti-stigma campaigns.

[caller] notes that the first mental health inquiry resulted in the Like Minds, Like Mine campaign. It has been referenced in government documents/reports that stigma around addiction would also be addressed ... however she is yet to see a similar initiative or campaign developed to support building awareness and reducing the stigma of addiction (family member)

In addition to targeted campaigns, most submitters talking about addiction noted there must be corresponding help such as an increase in detox and rehabilitation access and options.

### **Gaps in knowledge and understanding are hurting communities**

Submitters most often described mental health knowledge gaps such as:

- understanding the 'normal' nature of mental health, that it fluctuates, is affected by different stressors, and is important to be considered along with other aspects of one's life
- knowing what things usually support and detract from the maintenance of good mental health, such as social connection, home environments, exercise and substance use
- understanding how to recognise distress in yourself and others, including techniques and approaches to promote and allow help seeking
- knowing where to go to seek information and help, including self-help information (online), helplines, family and friends, community members and groups, health professionals, and more
- having their own toolkit of strategies and approaches to cope better, and reduce contributing factors and symptoms; for example, mindfulness, meditation, nutrition, sleep hygiene, discussion with a trusted person, meaningful work, and de-escalation techniques
- understanding and belief that people can get through mental illness and live well with it.

The same diverse range of submitters often identified that a lack of understanding of mental health and addiction inadvertently contributes towards stigma and discrimination. There was general agreement across submitters that if this understanding is not targeted in our children and youth, then attitudes and outcomes are unlikely to change in the future.

Under resourcing and lack of measures for prevention is destroying our society. We live in a pressure cooker. There is no one answer but please start with our young people, our future (individual with lived experience)

#### **2.6.4 What could be better?**

##### **Grow practices that align with iwi heritage, development and wellness**

Māori voices noted that growing wellbeing for their communities rested on cultural wellness.

Growing practices that align with Iwi heritage, development and wellness alongside growing specialised expertise for methodical and proven practices to align and work in a parallel shift to wellness (Māori NGO provider)

Providing a range of community based Kaupapa Māori programmes is integral and leads to the delivery of a culturally appropriate programme for Māori (Māori NGO providers)

As a potential service delivery framework, both individual and collective needs and aspirations can be addressed through maximising opportunities for change. All touch points with Whānau can actively contribute to the long-term wellbeing of Whānau. As a service framework, it provides a greater range of potential opportunities to contribute to overall wellbeing across the life course of the Whānau as a whole (Māori NGO provider)

As noted throughout this report, many submitters, both Māori and non-Māori, focused on the benefits of whole-of-person approaches such as Whānau Ora.

In addition, submitters spoke of community-led cultural wellness. As one participant at a hui described it, “ways of looking at wellness differently” (whānau Māori).

Contributor spoke about the work he does with [name of organisation] in youth suicide prevention; how he would take kids up to [beach town] to go surfing if he couldn't get them into [Child, Adolescent and Family Services]. Would go surfing at the beach and get the kids up at 6:00 in the morning even though they said it was too cold; they still ended up in the water. “Their healing came from Tangaroa”—cultural wellness. How does he know about all this? Because he has tried it with 150 kids; has been doing it for 11 years (whānau Māori)

We have to be creative about what we do and we can't moan about the problems. We need to look for solutions—money isn't going to come and we need champions in communities, people who stand up and do something. “We need leaders in the homes making connections with the whānau”: if you want our rangatahi to be who you want them to be, get alongside them. Here is an opportunity to put up good solutions to people who can make a little bit of a difference (whānau Māori)

Other submitters noted that integrated services can provide opportunities, for example,

when sports clubs and Council help rangatahi thrive when they have parents incarcerated—this works well (Kaiāwhina Māori)

Some submissions called for stronger education, particularly around the harms associated with drugs. As one meeting participant noted,

Everyone knows how to make drugs today. Education is everything... Something extraordinary needs to happen: we need prevention and education ... Not scare mongering but something real, through schools, Plunket and antenatal classes (Pacific contributor)

I wish there was a way to get through to people about how dangerous this drug [methamphetamine] can be – and how it's affecting all levels of society (family member)

One submitter noted,

What does a fit for purpose mental health system look like for Māori, locally and nationally? We need to be able to give ourselves permission and space to dream the dream – our wawata. Looking at the future of technology, able to grasp global opportunities, maintaining the things important to our culture as whaka ruruhoe. To create our own vision for the future. Looking at [the year] 2042 – awa is healthy, and vibrant, clean water and air, oranga tangata, whānau, Māori taiao. What do we need to be doing now given this. From models of illness to wellbeing (kaimahi Māori)

### **Reorient the current system**

As noted in other chapters, many submitters called for a system-level shift toward wellbeing located within the community.

If we aspire to end the stigma surrounding mental illness, we must not solely rely on educational campaigns, but must also provide the care and treatment people need at times of crisis. We must create effective support systems following the crisis, in order to prevent the tragedies that so often influence the public's view of mental health challenges (PHO)

Submitters noted that national health promotion that encouraged 'proactive help-seeking' must be matched with the provision of timely, good quality services. Many submitters stressed that help-seeking behaviour must be met with the right service, at the right time, in the right place, otherwise 'proactive help-seeking promotions' would be ineffective.

### **Shift perspectives of health promotion**

Some organisations noted that health promotion must be everyone's business, not simply that of a specialised organisation. This would be at the point of intervention and connection. As one organisation noted,

There is potential for the development of opportunistic wellbeing screening and brief intervention tools, encompassing mental distress, addiction, sleep, nutrition and physical activity, which could support this approach (government agency)

Youth health nurses are increasingly prepared to screen and identify secondary school students who have mental health concerns. Screening of year 9 students has highlighted the benefits of access to early intervention and has created opportunities for students to be heard (professional organisation)

This includes community development (see services and social determinants chapters), and integration of wellbeing with all parts of life. More specifically, submitters spoke of both workplace, education and marae as settings for intervention.

**Workplace.** Submitters noted specific workplaces and industries have room to share responsibility and focus on wellbeing promotion campaigns, tools (including e-tools) and initiatives. Partnering with hard to reach communities or rural initiatives was also suggested by a few submitters.

An increasing body of evidence shows that interventions programmes within the work environment can improve wellbeing. Countries such as Sweden, Canada and the UK are recommending that an eco-system approach is needed that pays attention to both changes in the workplace (structure, culture, workflows, etc) and early interventions for employees (government agency)

Some submitters said that workplaces need to be supported in developing appropriate tools and resources for workplace wellbeing, with emphasis on certain industries that employ people from priority backgrounds, recognising “this is a shared responsibility and industry [work places] need to play their part” (government agency).

A few submitters suggested that workplace wellbeing models should be led by exemplary hospital, and mental health workplaces.

DHBs have an opportunity to take the lead in this by being the best employers at a wellbeing level by fostering and modelling good health and wellbeing practices within their workforces. This workforce wellbeing focus needs to be monitored with regular audits across the whole health sector (NGO provider)

Physical health was also emphasised in a few submissions specifically relating to the workforce.

[organisation] has been working on an [initiative] to support the Kaupapa Māori workforce to develop basic physical health competencies to sit with the Mental Health Support Workers Certificate. This is in conjunction with the Kaiāwhina Workforce Initiative with Careerforce. This understanding of basic physical health alongside mental health assists Whānau to have a more holistic focus on their general wellbeing (Māori NGO provider)

**Education.** There were strong calls for the education system to provide cohesive, consistent and curriculum-based wellbeing programmes, including evidence-based initiatives that talk about depression, suicide, drugs, and health literacy. Programmes included mindfulness and emotional resilience training, and, as one agency called for,

[an] end-to-end school-based mental health framework ... covering the continuum from early childhood to secondary school (government agency)

For young people I think resilience is important. Failing an exam, parents breaking up, being dumped, being gay or trans or not fitting in or being in a low socio economic community isn't the end of the world, although it can feel like that. Learning to live with what we have and loving ourselves and trusting in ourselves is important. Knowing that life won't always be easy is important (service user)

It is important that children and young people have access to programmes that build positive wellbeing. Such programmes could be built into school based and education programmes for students. Evidence has shown that these activities are best delivered when they are fully integrated (DHB)

For some submitters, the education system as a basis for mental health literacy would have downstream impacts and preventative outcomes.

Normally [organisation] receives clients at the 'crisis level' and is often onerous. Much needs to be done around early intervention and improving mental health literacy throughout the education system and for families (Pacific NGO)

Some submissions noted many successful pilots and evidence-based wellbeing and mindfulness programmes. However, many submitters called for a cohesive, nation-wide approach to wellbeing education (including bullying) that also included teachers, parents, and other community buy-in.

To be more effective in something like teaching healthy relationships we also need significant investment in parallel campaigns for teachers and parents who at times act as gatekeepers to information that is critical for keeping young people safe, especially where parental, social or community attitudes and expectations about young people's behaviour is greatly out of step with the realities of young people's experience (individual submitter)

In addition, a few submitters noted that the education system is a place where high-risk children can be given extra help, such as school mentoring and non-clinical services, and that this should be across all schools.

Positive school environments. Programs that identify high risk kids and introduce through schools mentoring, outdoor courses (such as outward bound type things that challenge them). This should be across all schools not just those areas considered low social economic background (family member)

**Marae.** Some submitters called for more marae-based services and awareness raising and more investment for marae-based activities promoting wellbeing, including marae visits.

Cultural wellness is about tikanga and kawa—it happens on marae, it's when we come out that we need it. We need training around cultural awareness and a mind shift—the space we're in doesn't work. Wānanga with kids: talk with kids 13 and up about suicide. Kids learn and parents are a part of the situation; consistent messages going through (Māori contributor)

A few submitters noted maraes that had a cohesive approach to mental health support and health initiatives.

**Primary health care.** Some submitters, both service users and organisations, noted it was important for health professionals and the health system "to recognise and be responsible for their role in influencing mental health literacy" (DHB).

Responsibility is often placed on the individual to acquire health knowledge, but with prescribing practices showing an increasing reliance on drug prescription as treatment for mental health challenges it is important that practitioners explicitly spell out the advantages and disadvantages of medication.

Many submitters using prescription drugs talked about wanting more information, not having their questions addressed, or not being told about side-effects. Some submitters called for tighter oversight of information given regarding prescription drugs.

## Increase peer leadership and support

A significantly high number of submissions from both providers and service users called for peer leadership and the peer workforce to be recognised, funded, integrated and accessible and to be extended to include promotional activities, wellbeing promotion and prevention.

At each of these levels, our national approach needs to value and include leadership from people with lived experience of suicidal behaviour and suicide bereavement, through service design, research, education, advocacy and facilitation of support groups and other contributions (NGO sector grouping)

Peer support was seen as distinct as it offered both support from a lived experience perspective and a mechanism for social inclusion – a key determinant of wellbeing. For example,

[Alcoholics Anonymous, Narcotics Anonymous,] and AI Anon have also played pivotal roles. To be able to connect with people in my community who are in recovery. To be able to socialise with them. I've had to find a whole new social group. My 12 Step family has become that for me (service user)

The current ad campaign says go for a walk, pick up a guitar etc but it ignores the reality that severely depressed people CANT get themselves out of bed or motivated to eat or shower. I would consider having teams of people who understand depression to go to people's places and say come on, I know you feel really crappy right now but you have to have a shower. Now you are showered we are going to sit outside in the sun (family member with lived experience)

A few submitters called for peer-led or participatory promotion and funding extended to resource the growth of lived-experience leadership initiatives mimicking successful promotions such as *Like Minds Like Mine*.

The funding for these community-empowering initiatives should be increased as a cost effective way to reach masses, promote inclusion, reduce discrimination and suicide and support communities to support each-other. These projects and programmes remove the whakamā of help-seeking and promote the expansion of supportive peer-networks through community development mentorship models based on the cultural concepts of 'Tuakana/Teina' and 'Feagaiga' (NGO provider)

## Use the right channels of communication

It was stressed by some submitters that targeting culturally appropriate channels of communication, particularly as regards language barriers, was necessary for effective health promotion. For example, it was suggested through a Pacific submission that this may take place not through mass media but through churches or language media programmes.

Use the media communication that works well for Pasifika youth. Pasifika youth has a lot to offer in their own learning strengths to help their own peers to raise awareness in mental health and addictions. Create more funds are to target projects and initiatives which the needs of young people (Pacific advocate)

### **Expand the message**

Many submissions called for more targeted campaigns to counter stigma and discrimination (including for addictions and Rainbow communities, including intersex and transgender communities), to increase education about how to help friends and whānau, to increase awareness about eating disorders and to celebrate people overcoming challenges.

I'd like to see things like "Relay for Life for mental health" that celebrates people getting better. I am Māori – but I want more celebrations of people who have overcome, where whānau who have been affected by it can come together and celebrate it (rangatahi)

## 2.7 Rights and legislation

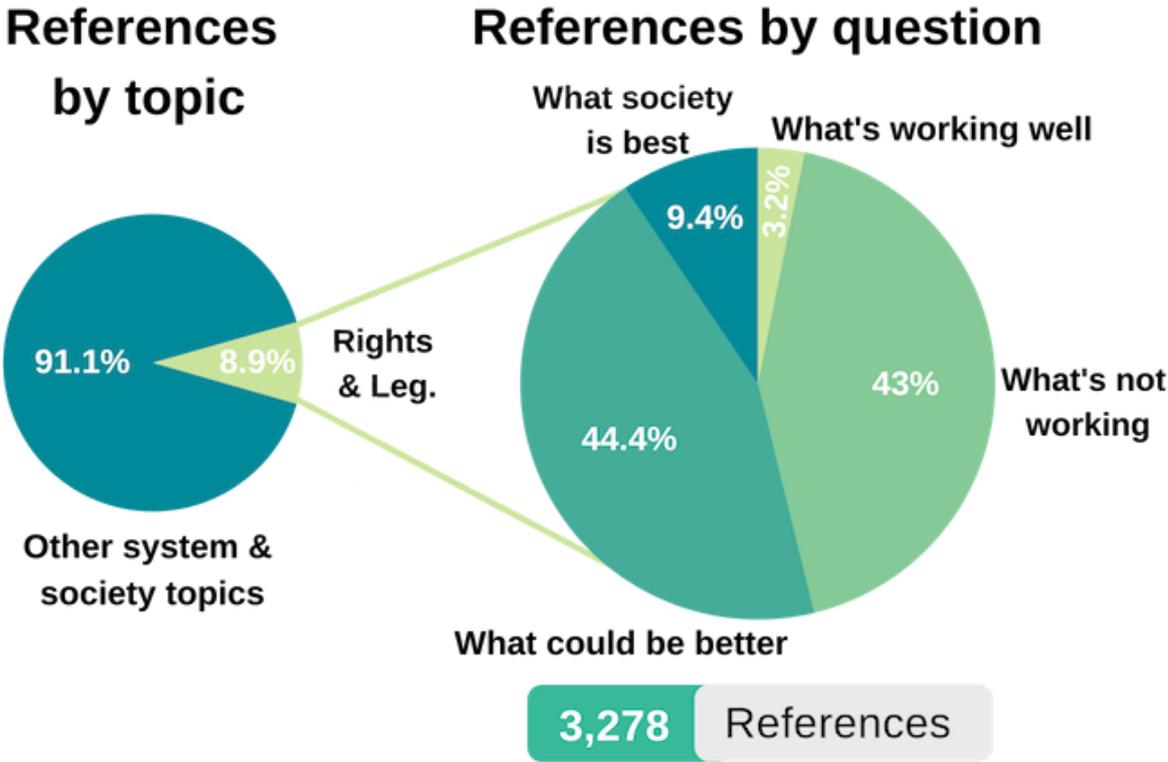
### 2.7.1 Overview

This section presents an overview of responses from submissions about rights and legislation. Submitters noted that although Aotearoa New Zealand has, commendably, committed to national and international principles of rights, many submitters or people they know have experienced breaches of these rights.

Submitters believe the principles of Te Tiriti o Waitangi are not well embedded in services and society. There is a call to modify existing legislation and policies to align with, and be centred on, people’s rights. Submitters want greater visibility and more accountability of people’s rights to promote widespread societal and workforce behavioural change.

Submitters made 3,278 references on rights and legislation. Of the comments made about rights and legislation , 44.4% focused on what could be better 43% focused on what isn’t working well, 3.2% focused on what’s working well and 9.4% referred to what society is best. See Figure 2.8.

FIGURE 2.8: SUMMARY OF RESPONSES ABOUT RIGHTS, LEGISLATION AND POLICY



## KEY THEMES FROM SUBMISSIONS FOR RIGHTS AND LEGISLATION

### 2.7.2 Rights

### 2.7.3 Legislation

#### What's working well?

##### Rights

- government commitment to human rights
- upholding individual privacy
- activities and services that support people's rights

##### Legislation

- some alcohol and drug regulations
- Accident Compensation Corporation
- Compulsory Treatment Orders for a few submitters
- Health and Safety legislation

#### What isn't working well?

##### Rights

- human rights concerns including seclusion and restraint (and CTO)
- indigenous rights
- disability rights
- Privacy and information (particularly whānau)

##### Legislation

- Mental Health Act
- Privacy Act and disclosing information
- criminal and other supporting legislation
- criminalisation is detrimental
- alcohol and tobacco are too accessible
- fear of a punitive police response

#### What could be better?

##### Rights

- embed rights across society
- five focus areas

##### Legislation

- review and reform

## 2.7.2 Rights

### What's working well?

**Government commitment to human rights.** Some submitters said Aotearoa New Zealand's commitment to the United Nations Convention on the Rights of Persons with Disabilities was an important step to provide a positive direction for our own laws and policies to align with. However, many also described that, despite this commitment (made about 10 years ago), minimal progress had been made from service user, tāngata whaiora, and family and whānau perspectives. A few submitters working in mental health and addiction also described the mismatch between intention and reality.

Most submitters said that the Convention was appropriate for Aotearoa New Zealand and that the Government should (and must) hold itself and others accountable to it. The New Zealand Bill of Rights Act 1990 was frequently cited in a similar vein, where its existence was great in principle – but again – not well demonstrated in policies, processes and attitudes.

I like that NZ government supports recovery-oriented ways of working with people with severe mental illness and that we have a strong human rights constitution at the highest levels (individual submitter)

**Upholding individual privacy.** A few submitters stated that the right of service users and tāngata whaiora to privacy is maintained. The principles of the Privacy Act 1993 were described as being well embedded throughout organisational policies and practices. Within the mental health and addiction system, maintaining an individual's privacy can be complex, particularly when harm to one's self or others is at stake. Most submitters described that both mental health and non-mental health organisations that work with people with mental health or addiction challenges, typically err on the side of caution – withholding the transfer of information when in doubt. Thus, health records and status information are tightly controlled in efforts to protect the individual's privacy. However, as described later, sentiment was strong that privacy constraints may have gone too far and, in many cases, may even hamper the individual's best interests and outcomes.

Privacy structures within services were seen as being relatively strong, and this allowed participants to feel comfortable speaking openly and without fear of their information being leaked (service user representatives)

**Activities and services that support people's rights.** Submitters identified various activities and services working well to support their rights.

- Advocacy – where individuals and families can turn to get advice and support, particularly when conflict occurs.
- Community initiatives – such as working with multiple organisations to put supports in place to retract long-term compulsory treatment orders.
- Informed consent – the requirement for an individual to give their informed consent to treatment plans is positive and should continue. Occasionally submitters described this as working well, where they were provided information about different treatment options and were empowered to choose the most suitable option.

There is an emphasis on an informed consent process for service users, whānau and significant others (DHB)

- Protective activities within the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act) – such as the ability to appeal decisions, request independent reviews, obtain regular re-assessment and obtain legal representation.

There are substantial protections for tāngata whaiora/service users under the [Mental Health Act] in terms of listed rights, clear means of appeal against compulsion, legal representation, and the requirement for regular reviews by both clinicians and by judiciary (DHB)

- Removing the use of seclusion

### **What isn't working well?**

Many submitters who discussed human rights described current issues with regard to upholding people's rights. Human rights, Māori and indigenous rights, and disability rights were all frequently highlighted as inconsistently or poorly supported for people exposed to the mental health and addiction system. A few submitters highlighted a degree of misalignment of various pieces of legislation and policies with the rights standards and principles agreed by the Government. Many submitters identified the main sources of agreed rights as:

- Te Tiriti o Waitangi
- the United Nations Declaration on the Rights of Indigenous Peoples
- the United Nations Convention on the Rights of Persons with Disabilities
- the New Zealand Bill of Rights Act 1990
- the Code of Health and Disability Services Consumers' Rights
- the United Nations Convention on the Rights of the Child.

The CRPD [Convention on the Rights of Persons with Disabilities] was signed and ratified by NZ 10 years ago. The heart of the shift were two concepts, reasonable accommodation and supported decision making. The CRPD is international law, NZ is obliged to comply with international law just as DHB's, NGO's, or private institutions are obliged to comply with NZ law. Sanctions however, are limited and not seen as powerful deterrents (commentator)

Submitters scrutinised the Mental Health Act and other Acts (such as the Privacy Act 1993) against the agreed rights and found some inconsistency, gaps and conflicts. Many of the conflicts and recommended changes are outlined in section **2.7.3: Legislation**. Even knowledge and disclosure of rights have been identified as issues:

The right to equal recognition before the law is not protected when people using services are:

- a) not informed of their rights;
- b) not informed about how the [Mental Health] Act is being applied; and
- c) when the [Mental Health] Act is used arbitrarily rather than in situations of extreme danger (consumer leader)

List of rights were pinned to the wall of psychiatric units that the caller has been in. Despite this caller feels that his rights were not upheld during his time in the unit (such as the right to contact friends or write letters, he was not allowed to have his own clothes or his watch) (service user)

The following section outlines submitters' perceptions where rights are not upheld.

**Human rights concerns.** Many submitters who spoke of human rights were concerned several human rights violations are accepted within society and the mental health and addiction system. Many submissions described support (partly or wholly) of the human rights ideals and principles of wellbeing, fairness, freedom from discrimination, safety, privacy, equity, justice, social inclusion, liberty and self-determination.

However, in mental health and addiction, the four main areas where human rights are challenged are:

- **seclusion** – confining a person to a room in which they cannot freely exit
- **restraint** – using physical force, mechanical devices or chemicals to immobilise a person
- **compulsory treatment orders** – making a person accept treatment for a period of time under the Mental Health Act
- **discrimination** – treating a person unfairly or less on the grounds of race, sex, sexual orientation, religious belief, age, body size, marital status, country of origin or disability.

Submitters overwhelmingly wanted the use of seclusion for people with mental illness or addiction issues to reduce. Most service-users, tāngata whaiora, families and whānau support the removal of seclusion entirely, citing the lack of therapeutic value and harm it causes the individual.

Locking people in seclusion when incredibly distressed. Caller had the experience of being locked in a room with no windows, no toilet, no hand basin, no water. He explains that if a person is very angry or upset about something, then something like this will make it much worse (service user)

There have been increases in the number of people secluded, number of seclusion events, and number of hours in seclusion ... for many DHBs. We know that Māori experience higher seclusion rates than non-Māori ... the Office of the Director General Mental Health Annual Report 2015 announced that Māori were five times more likely to be secluded than non-Māori, and have the highest population-based rate of seclusion events reported internationally (DHB collating the views of DHB, NGOs, other providers, and service users)

There was, however, some support for the continued use of seclusion in specific circumstances. Maintaining the safety for others – particularly mental health workers – was mentioned as a prime reason for using seclusion, and some submitters described a growing number of staff assaults by patients. With a recent focus on reducing seclusion and restraint, some indicated that mental health workers feel unsafe and subsequently more stressed. A

few even described increases in staff burning out and people leaving the workforce due to a constant fear of assault.

Seclusion and restraint minimization initiative: would have been beneficial to have been consulted around this prior to starting this ... Don't want to push for seclusion as intervention but nurses fear that zero seclusion will mean they will be at risk. "If zero seclusion comes in I'm not going to stand around and wait to be seriously assaulted, will leave mental health nursing." (professional organisation)

Similarly, some submitters want minimal use of restraint. In particular, drug-induced restraint was cited as overused and harmful, particularly when alternative approaches could be used. They explain that a foreign inpatient environment, surrounded by new and different people causes increased distress and usually there was not enough inclusion of family or whānau to help de-escalate situations.

Human rights issues around seclusion and restraint; it looks like prisoners, people under mental health act, children in state institutions, people with intellectual disability in state care all have more rights than people with dementia; we have bottom of the barrel legislation (national representatives of Seniors)

Her [family member] was also immediately chemically restrained because of her agitated state. We need nurturing environments for these kids, not medication (whānau Māori)

Compulsory treatment orders are supported by the Mental Health Act to protect vulnerable individuals and the public from harm. However, different submitters demonstrate some fundamental human rights tension where the rights of the individual can be challenged by the rights of others, including family and whānau and people working with high-risk individuals.

Some submitters identify that compulsory treatment in any form undermines the principles in the United Nations Convention on the Rights of Persons with Disabilities and the New Zealand Bill of Rights Act 1990. Compulsory treatment orders do not support the right to have informed consent and self-determination. As described by a consumer network, some United Nations Convention rights challenged by compulsory treatment (or threat of) and seclusion include,

The right to be free from arbitrary detention is inconsistent with the way the [Mental Health] Act is currently used and the way compulsory treatment is applied

- People are effectively, arbitrarily placed under the [Mental Health] Act
- People are arbitrarily transitioned from voluntary status to compulsory status
- Coercion (by way of the threat of compulsory treatment) is often used by clinicians during the transition to voluntary status and while under voluntary status (consumer leaders)

Much like seclusion and restraint, most submitters want to minimise (and in some cases remove entirely) the use of compulsory treatment orders for service users and tāngata whaiora. However, a few families and whānau support the continued use of these orders as they described their experiences when compulsory treatment allowed a person to manage

through periods of acute distress or to maintain constructive participation in society. They report that it reduces the number of people committing suicide and the risks of harm and stress on families and whānau.

Discrimination is a broad issue that affects many different people to varying extents. Submitters regularly cited discrimination across the mental health and addiction system and across society as a whole.

Discrimination is mostly covered in other sections of this report. Submitters' key points are as follows.

- For Māori, the dominant biomedical and Western approaches to wellbeing and health do not favour positive Māori outcomes.
- Racism affects psychological wellbeing and contributes to many social determinants and inequitable health outcomes.
- Stigma acts as a barrier to the individual and those they interact with.
- 'Ableism' means people with varying degrees of ability have more difficulty accessing services, lower chances of being selected for employment, inadequate support with having mental, physical and/or cognitive challenges. With the higher incidence of mental distress, they are not provided with adequate preventative advice, support and treatment.
- In relation to gender diversity and sexual orientation it can be difficult to overcome stigma and discrimination to seek help, be taken seriously and access adequate support.
- 'Ageism' means appropriate (and enough) support to overcome mental health challenges is not available for the very old and the very young.

Disabled people have the right to choice and control in the services that support them to live independently and be included in the community (commentator)

It appears that once the 'othering' of people through the use of diagnostic labels takes place, patients find themselves [stripped] of their fundamental human rights, in particular freedom from discrimination before the law and being subjected to unsafe treatment and practices (family member)

**Indigenous rights.** Some Māori and non-Māori submitters cited the systemic breach of Māori indigenous rights across society and within the mental health and addiction system. They described a consistent threat and failure to uphold the protection, participation and partnership principles of Te Tiriti o Waitangi. A few submitters supported the principles outlined in the United Nations Declaration on the Rights of Indigenous Peoples, but, similarly, these were also described as being poorly upheld.

Māori do not have self-determination under Tiriti o Waitangi. Service users and families feel like an optional extra—here is a window for you—oh, you want glass in it?—that's an optional extra (mental health professional)

Many submitters described the immense negative impact of colonisation, racial discrimination, and systemic marginalisation of Māori values and beliefs. Poor access to culturally appropriate approaches to wellbeing and mental health further affect Māori health outcomes as mainstream Western approaches receive more funding and inherit

greater credibility across Aotearoa New Zealand. Some submissions noted the disproportionate rate of detention, seclusion, restraint and forced treatment of Tāngata Whenua. Māori rights of self-determination and whānau inclusion are regularly compromised.

As an indigenous people, Māori have the right to determine and develop priorities and strategies for their people and to be actively involved in developing, determining and administering health and other programmes. Māori have the right to their traditional medicines and to maintain their health practices including the conservation of their vital medicinal plants, and taonga ... the [relevance] of Te Tiriti o Waitangi to health is well established and under international law, the Māori text of Te Tiriti o Waitangi affirms sovereignty (Māori health leaders and colleagues)

Māori ways of working are secondary to the dominant Western model. People who need the most support can be put off engaging with [mental health] services for fear of Mental Health Act and compulsory treatment and restraint and seclusion. I would not advocate/encourage a family member to receive support from [mental health and addiction] services for these reasons (individual service provider)

**Disability rights.** Service users with physical or cognitive challenges, their families and whānau, and organisations consistently identified issues where the rights of people with impairment or disabilities were frequently disregarded, intentionally or otherwise. These submitters described the positive intent of United Nations Convention on the Rights of Persons with Disabilities, the Code of Health and Disability Services Consumers' Rights, and the New Zealand Bill of Rights Act 1990, yet acknowledged that the reality is far from those ideals.

Submitters described the main challenges as discrimination, lack of self-determination, poor maintenance of integrity and privacy, and a lack of access to appropriate services delivered by skilled and competent staff familiar with the nuances of their challenges.

Re: dementia and restraint—under the Convention Against Torture the ombudsman has responsibility to inspect facilities but there is a gap re: private facilities. Need education of care facilities on the rights of people with dementia (national representatives of Seniors)

**Privacy and information (particularly whānau).** Many submitters described an obvious tension between maintaining the privacy of the service user or tāngata whaiora and sharing information more openly to facilitate more effective intervention and better outcomes. Many families, whānau and health organisations highlighted many instances where the inclusion of caregivers, families and whānau during assessment, planning and treatment phases would benefit the service user. Submitters report strict adherence to internal policies and an underlying fear of the Privacy Act 1993 that prevent or limit the sharing of this information. This is likely to hamper efforts to integrate services better and support Māori wellbeing frameworks and to significantly hamper the potential value of involving an individual's support network to provide higher quality and more person-centred care.

Families need to be heard more. Don't hide behind the Privacy Act!!  
Families need greater support to access services on behalf of their loved ones and to be involved at all stages of their care and treatment. They are the ones who know more about what is happening than anyone – listen to them and their concerns and don't fob them off. Families also need practical support and information about where to get help (family member)

## **What could be better?**

**Embed rights across society.** There was strong support from submitters to make fundamental and transformative changes across legislation, policy, priorities and resources to shape them around people's rights. They recommended greater commitment and accountability for aligning national frameworks and activities to better support and drive a societal shift towards people's rights.

Some submitters note that the foundations for a rights-focused society are not entirely absent. Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities, the New Zealand Bill of Rights Act 1990, the United Nations Declaration on the Rights of Indigenous Peoples and many other rights-based documents provide a good platform, but these need to be better reflected across other legislation such as the Mental Health Act.

Submitters stated that it is critical that these principles are embedded throughout organisations, education and training institutions, services and society. They described this approach as multifaceted, but involving, at the very least, clear accountability, high governmental priority, requirements, measurements, and useable guidance for organisations to adopt truly rights-focused policies, processes and training.

Human rights approach is more than just applying legal minimums to inhuman treatment. It is underpinned by respect for the inherent dignity of every person. A human rights approach includes:

- Development of law, policy, and practice consistent with internationally agreed norms (such as [the United Nations Convention on the Rights of Persons with Disabilities and the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment])
- accountability against those norms
- anti-discrimination
- Participation of individuals and representative groups in decisions that affect them (nothing about us without us)
- Recognition of all rights and rights holders in a given situation, balancing those rights, and prioritising the rights of the most vulnerable (leave no one behind) (commentator)

**Five focus areas.** To improve rights for those with mental health and addiction challenges across Aotearoa New Zealand (outside of legislative change), submitters from many Māori organisations, health organisations, families and whānau, and diverse individuals and groups who represent people who routinely experience stigma and discrimination collectively described five key focus areas.

- Embedding the principles of Te Tiriti o Waitangi across policies and processes. This includes the ability for Māori to govern decisions, particularly regarding services and funding.
- Support to reduce (or possibly remove) seclusion and restraint. This includes better measures that capture data on use of all types of restraint (that is, including chemical), training and guidance on de-escalation, adequate people resources, and an explicit definition of 'last resort'.
- More national initiatives to combat stigma and discrimination wherever they exist.
- Reconsider Aotearoa New Zealand's position on privacy and information sharing to ensure rights are supported (that is, whānau are involved) and the best outcomes can be achieved.
- Ensure equitable access to appropriate services for all people of different ages, races, genders, sexual orientations, and physical and cognitive abilities.

the [Mental Health Act] should make explicit that the use of restraint and seclusion should be an intervention of last resort, following attempts to help the tāngata whaiora / service user using other means. Reporting requirements on restraint and seclusion should be required to outline these other measures. It is our belief that this is more in keeping with the principles and rights listed in both the [United Nations Convention on the Rights of Persons with Disabilities] and [New Zealand Bill of Rights Act 1990] (DHB)

The default position about information sharing between tāngata whaiora and families consistent with international jurisprudence, when there is a history of ongoing positive contact, and abuse is not alleged or evident, should be for family to be part of a seamless support team involving professions across disciplines and themselves. Tāngata whaiora have the same right to choose or to exclude support or services from family as to choose or exclude support from non-family professionals... Māori and Pasifika communities in particular historically have played a stronger role in the care and support of whānau, including through whānau decision making process. Aotearoa NZ is uniquely place to develop this cultural wisdom into a modern supported decision-making context (commentator)

### 2.7.3 Legislation

#### What's working well?

Most submitters said that while there were opportunities for improvement, the foundations of much of Aotearoa New Zealand's legislation is fit for purpose and supports the achievement of good health and mental wellbeing.

**Some alcohol and drug regulations.** The limitations and restrictions placed on alcohol and other drugs was seen as positive by some submitters. They felt that cost, age, licensing, and advertising barriers effectively reduced access to these harmful substances.

Currently, the regulation of alcohol and tobacco are working well. The awareness and knowledge available is detailed, tailored to the audience and allows informed decisions to be made by the user (individual with lived experience)

We are doing a good job by restricting advertising for addictive substances, such as alcohol, cigarettes, and gambling. This can help to keep substance abuse from people's minds – by not allowing gambling sites to be advertised on national television, hopefully we will keep the addictive behaviour/substances from people's minds (service user)

**Accident Compensation Corporation.** Submitters sometimes cited that the legislative backing for the mental health services of the Accident Compensation Corporation (ACC) was good, effective and free. If people were eligible for support from ACC, getting access to counsellors, psychologists and psychiatrists was seen as mostly positive when compared with public health.

ACC Mental Health Services provide fully funded services for those who meet ACC's legislative criteria. There are services available nationally, provide some culturally responsive support and using validated outcomes measurement tools. The result of the service has been easier access and a wrap-around service that includes sessions for family and whānau (NGO)

[caller] feels lucky to live in a country where we are paid while being unwell as this has freed him up for time to focus on becoming well (including extensive research into mental health, trauma, [and post-traumatic stress disorder]) (service user)

**Compulsory treatment orders for very few submitters.** While not a majority, a few submitters found the Mental Health Act's compulsory treatment order was beneficial for service users, their family and whānau.

His being sectioned under the Act has facilitated access to professional help. He is currently indefinitely under the Act, and this is even better (family member)

**Health and safety legislation.** A few submitters cited the inclusion of mental wellbeing into health and safety legislation as a positive step that would benefit employees.

The provision in the Health and Safety legislation is important and emphasizes the role of employers in taking into account mental wellbeing of their workforce (academic with lived experience)

### **What isn't working well?**

Some submitters identified a few key issues with current legislation, mostly the Mental Health Act, the Privacy Act 1993, and criminal legislation. As described in section **2.3: Te matapihi ki Te Ao Māori (window to the Māori world)**, many Māori submitters also reported a lack of commitment and adherence to Te Tiriti o Waitangi principles across different legislation, and recommended that the Treaty becomes more prominent.

**Mental Health Act.** Submitters sometimes described issues with the Mental Health Act that prevent the rights of people being appropriately served. In addition, a few submitters highlighted a lack of compulsion to comply with human rights and Te Tiriti o Waitangi obligations.

The Mental Health Act breaches the [Convention on the Rights of Persons with Disabilities] and results in significant human rights violations. The Mental Health Act also breaches the UN Declaration on the Rights of Indigenous Peoples (consumer leader)

NZ's courts have judged the Ministry of Health to be actually merely taking into account rather than complying with Human Rights obligations including the [Convention on the Rights of Persons with Disabilities] (commentator)

Stuff needs to change in Parliament and society: Te Tiriti is not actually enforced or put into place in government; many disadvantaged groups need help. Bureaucrats don't sit in those communities (advisory group)

However, some submitters described the main issue as, not the legislation itself, but its implementation in a politically charged and risk-averse environment.

I think most problems with the [Mental Health Act] lie in its implementation, not in its text. It seems to be implemented in an extremely risk-averse manner by the staff of DHBs, by the courts, by the Review Tribunal, and by the national officials and politicians responsible for managing the special patient regime... Much of the risk that is being managed in this way appears to be risk to DHBs themselves: that is, the perceived risk to their staff and their reputation when things occasionally go wrong, and the financial risks involved in managing the damage, in inquiries and the media (academic)

Compulsory treatment orders were also described as problematic by many submitters. They have concerns regarding their use, describing them as being used inappropriately. In particular, submitters said these orders are used unnecessarily and extend longer than they should. A degree of clinical interpretation may be required as to what is 'appropriate', and submitters described it as a grey area. However, given the importance of the decision to use an order submitters report that it lacks much second-opinion, review or shared decision making. Even when initially used appropriately, informed consent is not always gained as early as it should be and, in longer-term scenarios, there is not enough scrutiny and review as to what is appropriate.

**Privacy Act and disclosing information.** As discussed previously, submitters have concerns about the sharing of information. Across the submissions, a minor theme emerged – the workforce is inhibited from disclosing and discussing information that might be beneficial to share. Fear of the Privacy Act 1993, tight organisational policies and severe breach consequences have led to minimal disclosure of information. This may impact on the quality and appropriateness of assessment, planning, treatment and, ultimately, the service user's or tāngata whaiora's outcome.

People are terrified of the Privacy Act (prison staff)

The legal restraint on the people treating [service user] which stops them from talking to family. I know they are overburdened and under-resourced, and I have to assume that [service user] is a particularly difficult case, but surely cutting family out does not help anyone? [Service user] is so alone in the world, and I find it harrowing being so far away and not knowing what to do (family member)

**Criminal and other supporting legislation.** Criminal legislation comprises different Acts. Typically, submitters did not cite a specific Act, but the themes are consistent. Three main points are discussed in more detail in the relevant sections, but in summary are as follows.

**Criminalisation is detrimental.** The criminalisation of individuals with alcohol and other drug issues is detrimental for the service user, families and whānau, communities, organisations, and tax payers. Putting people on a criminal justice path rather than a health path increases costs, reduces outcomes and begins negative cycles of reoffending. Some submitters did not think medicinal use of marijuana should be illegal in Aotearoa New Zealand.

Misuse of Drugs Act 1975 – locking people up for addiction related offences prevents recovery (service user)

All drugs being tarred with the same brush. Caller makes specific mention of marijuana and methamphetamine being seen in the same category due to them both being illegal (individual with lived experience)

**Alcohol and tobacco are too accessible.** Alcohol and tobacco are too freely accessible, and their use can lead to other patterns of addictive behaviours with more dangerous drugs. Submitters described the age and locations to access as too available for young people and that the laws are not doing enough to discourage or totally stop access to ‘gateway’ drugs.

Every supermarket sells alcohol and is stones throw away from liquor store. Alcohol is too available. They have a lot of power. E.g. In France you can’t sponsor sports teams if you’re a liquor person. New Zealand should do that. Scotland have introduced minimum pricing, which has been turned down here (health professional)

**Fear of a punitive police response.** Some submitters feared that when they call the police about a family or whānau member who is in a state of significant distress, the response will be too punitive. Therefore, they are less likely to seek help in the first place or to tell the truth (for example, when an assault has occurred). After disclosing instances of assault, families may regret the consequences for the service user or tāngata whaiora.

## **What could be better?**

**Review and reform.** Submitters were consistent with the themes identified above when describing possible solutions to improve mental health and addiction within Aotearoa New Zealand.

Submitters’ solutions regarding legislation include:

- reform the Mental Health Act to align with and focus on human and indigenous people’s rights to:
  - better reflect and reinforce the principles of Te Tiriti o Waitangi
  - reduce or eliminate the use of seclusion and restraint
  - clarify, reduce or eliminate the use of compulsory treatment orders, particularly indefinite orders, and monitor a person’s status and incapacity more closely
  - strengthen the informed consent process
  - reinforce equity without discrimination

- implement the Mental Health Act better so organisational strategic priorities and policies align more closely with it to:
  - ensure people are advised of their rights.
  - increase the structure and consistency of the second-opinion process
- reform criminal and other supporting legislation:
  - decriminalise substance abuse to facilitate a societal change from a criminal justice pathway to a health pathway (which had significant support across submitters)
  - legalise medicinal marijuana
  - tighten restrictions on alcohol and tobacco (that is, taxation, licencing, age and advertising restrictions)
  - more leniency towards crime when driven out of mental illness or addiction. this may help address submitter concerns that families are hesitant to contact police or truthfully report incidents involving assault for fear of conviction.
- review and reform the Privacy Act 1993 and key information legislation to enable more shared decision-making, particularly to include families, whānau, and caregivers.

Submitters made a variety of comments about legislation.

If the [Mental Health Act] were to be reformed, I would like to see:

- ‘incapacity to consent to treatment for mental disorder’ added to the criteria for compulsion under the Act, meaning that a person who regained that capacity would have to be discharged immediately from compulsory patient status (though not necessarily from special patient status)
- the abolition of ‘indefinite’ Compulsory Treatment Orders, with all such Orders then being time-limited (though the times involved could be on a sliding scale: eg, 6m, 1y, 2y); this would require clinicians to justify the person’s continued compulsion at each renewal
- abolition of the urgent ‘section 16 hearings’; these seem to perform no useful function, and virtually no patient is ever discharged at one
- a proper national structure established for the administration and oversight of the ‘second opinion’ scheme under ss 59 and 60 of the Act, as in England, bringing some consistency to the process, and generating a proper flow of (anonymised) information about its operation into the public domain
- avoiding loading too many review hearings on to an over-worked Review Tribunal, to prevent its reviews becoming perfunctory, as is the case in many other jurisdictions; in principle, using the Family Court for the ‘front-end’ hearings under the Act is a good idea, in light of the geography and dispersed population of this country (if only the Family Court was not in crisis) (academic)

There are significant changes required to the Mental Health Act, and within the mental health system, to achieve compliance with the [Convention on the Rights of Persons with Disabilities] and its Optional Protocol, the New Zealand Bill of Rights... and the [Declaration on the Rights of Indigenous Peoples] (consumer leaders)

His community carer eventually ignored the... Privacy Act and made contact with me despite my son's wish otherwise. He spent time in educating me on the illness and the care systems available. This meant I was able to re-establish frequent contact with my son and contact his carer if I felt my son's condition was of concern (family member)

the protections for the tāngata whaiora / service user could be enhanced by strengthening two of the rights listed in the current [Mental Health Act]. Firstly, the right to a second opinion... Secondly, the right to be informed about treatment (DHB)

## 3 SERVICES

This chapter presents an overview of submissions that referred to services.

Submissions that referred to services include the full spectrum of mental health and addiction services and supports across community, inpatient, district health board (DHB) and non-governmental organisation (NGO) services.

Submitters made 35,381 references about this topic, which accounts for 25.2% of comments made to the Inquiry overall. Of the comments made about services, 45.5% focused on what could be better, 33.9% focused on what isn't working well, 13.7% focused on what's working well and 7% referred to what society is best.

The three key topics under services that submitters referred to were access (36.5%), intervention (54.2%) and integration (9.3%). See Figure 3.1.

### TOPICS

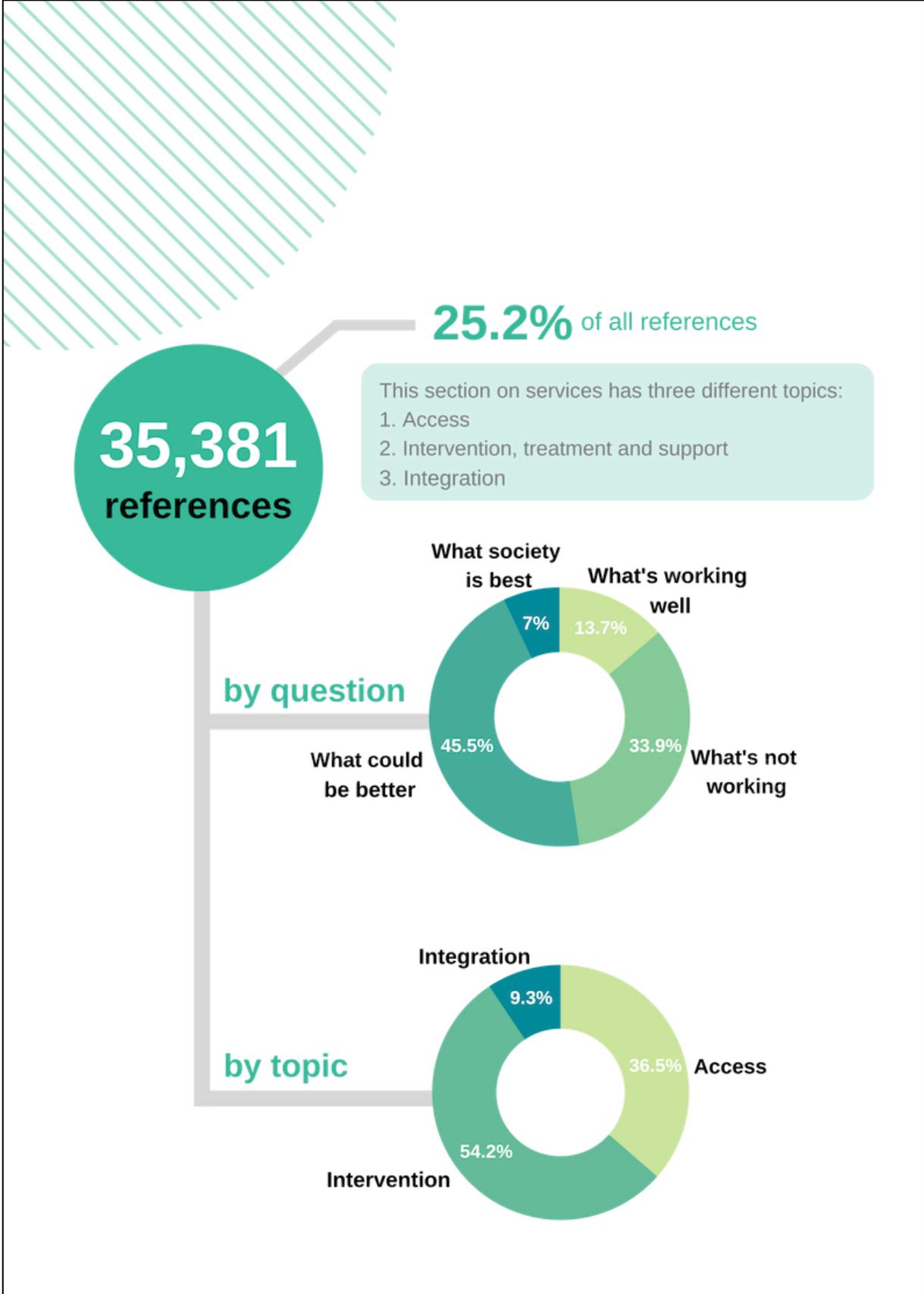
The sections in this chapter summarise the responses into three topics.

**Section 3.1: Access:** Lack of access to the right service, at the right time, in the right place and at the right cost was one of the most significant themes across the Inquiry. Submitters were calling for more services, located within their community, that were affordable and catered for the diversity of population. Lack of access had devastating consequences for many submitters, including the death of their loved one through suicide and escalating mental health and addiction challenges.

**Section 3.2: Intervention, treatment and support:** The current biomedical model alone is ill-suited for people with mental health and addiction challenges, and pressure on both primary and secondary services means they are struggling to meet needs adequately. There is a strong call for new models of intervention, treatment and support based on maintaining and restoring wellbeing and addressing the social determinants that contribute to the development of mental health and addiction challenges. An expansion of Kaupapa Māori services, particularly in communities affected by high rates of suicide and addiction. Whānau Ora provided holistic solutions for Māori, but also non-Māori. Better integration is needed across the entire system to reduce service gaps, better involve family and whānau, and improve points of transition between services.

**Sections 3.3: Integration of services:** There are early signs of integration across some organisations and services, and those making progress are seeing improved outcomes. Typically, significant service fragmentation remains, which parallels the system-level fragmentation above it. Submitters request more collaboration and co-ordination across organisations, information sharing, and involvement of more holistic supports to improve points of transition while avoiding service overlaps, repetition, service gaps and burdensome administrative efforts.

FIGURE 3.1: SUMMARY OF RESPONSES MADE ABOUT SERVICES



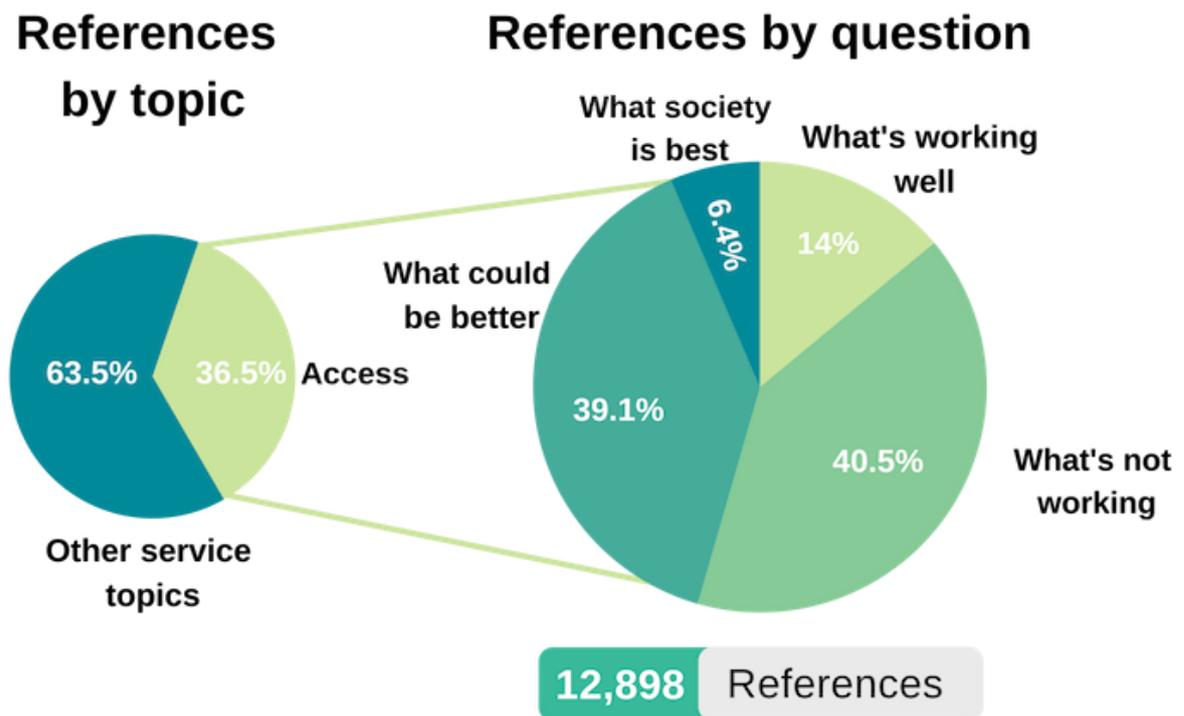
### 3.1 Access

#### 3.1.1 Overview

This section presents an overview of responses from submissions related to access to services. Access to services is defined as the ability to receive help at the right time, right place, right cost and right person – as being permitted entry into the mental health and addiction system. This includes receiving help when asking, being admitted into further care and treatment, receiving the right help, being able to afford help. Most submissions were concerned with access, and there is significant overlap with other themes including funding, workforce, and commissioning.

Submitters made 12,898 references to this topic, which was about 36.5% of the comments made about services. Of the comments made about access, 31.9% focused on what could be better, 40.5% focused on what isn't working, 14% focused on what's working well, and 6.4% focused on what society is best (see Figure 3.2).

FIGURE 3.2: SUMMARY OF RESPONSES MADE ABOUT ACCESS TO SERVICES



#### KEY THEMES FROM SUBMISSIONS FOR ACCESS TO SERVICES

##### 3.1.2 What's working well?

- access to fully funded community-based services and support
- location of services specific to the type of service user, family and whānau
- access to services responsive to specific needs

##### 3.1.3 What isn't working well?

- mind the gap – between what's needed and what's being offered
- cost is a significant barrier accessing what is needed
- finding your way – then being turned away

##### 3.1.4 What could be better?

- addressing service gaps
- early intervention
- the right care where and when it's needed
- continuity and support for as long as it's needed
- affordable services

### 3.1.2 What's working well?

Getting timely and affordable access to the right services in a suitable place is a challenge for many. However, there were some submitters who described positives regarding access to some elements of mental health and addiction services.

In particular, submitters said that the system was working well when access was to:

- fully funded community-based services
- services in places specific to the needs of service users and families and whānau
- services responsive to specific needs.

#### Access to fully funded community-based services

A few submitters appreciated having access to publicly funded community-based services. These services included:

- brief intervention services within general practice
- free counselling sessions accessible through primary health organisations
- services for Māori – kaupapa Māori
- addiction services travel assistance scheme
- other community support groups and services.

Hauora Programme provided by [organisation]. [Caller] feels that this was a good example of a service connecting with a previously hard to engage community. The programme showed working in partnership with a community that was otherwise uninterested in engaging with addiction support (addiction support worker)

### **Access to services in places specific to the needs of service users and families and whānau**

A few submitters valued receiving services and information in locations that worked best for them, their family and whānau. Specific examples included:

- national telehealth service for people who live remotely and need support outside business hours
- online services to find information and guidance to help themselves or others
- schools to provide ready access for children who seek help on their own accord
- prison-based services for people incarcerated
- emergency services for people in crisis, regardless of where they are located
- day activities for people who want to reconnect socially in their community
- hospitals for people to receive escalated levels of care during crisis and acute distress
- community spaces for people who need local support
- home-based support for those who struggle to travel.

### **Access to services responsive to specific needs**

Some submitters welcomed services that were able to respond to their specific needs. They mentioned fast and quick access as well as access to culturally appropriate services.

[Regional community service] shows to have good access points including better waiting times to access their services compared to DHB services (addiction support worker)

Virtual health services such as those run by [organisation], including the Alcohol & Drug helpline, depression helpline, gambling helpline, Lifeline, the Low Down; public access to signposting, and an ability for anytime, anywhere access via phone, text and web, is effective and should be further promoted and publicised (NGO provider)

Access to services that offered a full range of health practitioners including counsellors, psychologists, general practitioners (GPs), nurses, psychiatrists, other medical specialists, pharmacists and ambulances were valued by some submitters – particularly when these practitioners worked in a co-ordinated and cohesive way. This is covered in more detail in section **3.3: Integration of services**

Some submitters were positive about access to:

- crisis support that was readily available for them in states of severe distress or emergency if they met the threshold that warrants it
- respite care available for families and carers if planned in advance

- access to the Alcohol and Other Drug Treatment Court – well received by offenders, their families, and whānau to help break the cycle of offending
- holistic and alternative services (that is, spiritual, nutritional, physical fitness)
- housing and food parcels to help with immediate needs and transition from in-patient facilities
- peer support, as it was free and supportive
- community-based support were both willing and free, which helped individuals get support for a wide range of needs
- postvention victim support for families and whānau who are bereaved by suicide
- Māori health and kaupapa models of care, which could be easily facilitated
- a single point of entry to navigate the system and facilitate access to other services
- CAPA – choice and partnership approach to acute distress.

### **3.1.3 What isn't working well?**

Many service users and tāngata whaiora, and their family, whānau and friends said the system was not working well when:

- unmet need existed because the service is either not offered or overloaded, such as when need does not meet entry criteria or thresholds, transitional support is lacking, or wait times are excessive
- cost was a barrier to accessing services affecting when, and if, people seek help, and how long they can receive it for
- confusion existed about where and how to access the services required.

NGO and service providers were overwhelmed with need, thus affecting their ability to respond. This was exacerbated by location, time of need, type of need and workforce availability.

### **Mind the gap – between what's needed and what's being offered**

Submitters identified four broad gaps in access to service, namely the need for:

- a service not offered
- a service difficult to access due to high demand for it
- ongoing support following a treatment episode
- culturally appropriate services.

A very strong theme in the stories and submissions was the chasm between the services that are needed and what is being offered. In some it was access to a particular service in a geographical area that was needed, for example youth/rangatahi services and respite services. In other cases, the service was not offered nationally, for example specialist dementia services, or was not consistent between regions. For many submitters in these situations, the option became either to use existing health services that could be inappropriate, or no care at all.

Younger dementia patients are poorly served by current services. There are few or no suitable facilities.... they are often fit and strong and may pose a health and safety hazard to frailer resident and existing facilities many not have sufficient trained staff to safely manage them (professional organisation)

I get given pills but no actual support. Being in jail makes it so much worse (prisoner)

Access to substance abuse services is very limited for this population [older people], who are on low incomes, not driving and/or have low mobility thus cannot attend outpatient clinics (professional organisation)

Many submitters noted a gap between what they were wanting support for and the capability of that service to respond. There was frustration about long wait times and no response when attempting to access community based early intervention services such as counselling, crisis services, and addiction services.

Inaccessibility of Mental Health Care Services, unacceptably long waits of several weeks or longer especially in the cities, unless it is a [mental health] crisis and then admission often required. Cutting those lengthy wait times could save millions of \$ (mental health professional)

Another significant gap that was identified in submissions was accessing ongoing support services after seeing a health practitioner or being in hospital.

Since the appointment with the psychiatrist, she has had no access to any other supports and is sitting on the wait list for these (family member)

For Māori there was an identified gap in accessing culturally appropriate services. Many Māori and some non-Māori submitters indicate that poor access to Whānau Ora and Kaupapa Māori approaches is leading to poor outcomes for Māori. This is particularly the case in some regions.

Our main concerns relate to the disregard and disrespect of an appropriate cultural response (family member)

The traditional medical model appears to reign. Not a hope filled experience for many as observed by my team when advocating for tangata whaiora (NGO provider)

There are still deficit orientated models, focused on illness and not the whole person (Māori NGO provider)

Submitters from Pacific and Asian populations or who were speaking on behalf of refugees, also said there was not enough access to culturally appropriate services.

There is significant disparity in access for Māori, Pacific and Asian populations to specialist mental health services. These populations are underutilising tertiary services, with anecdotal reports that Asian patients are presenting later and more unwell (DHB)

### **Cost is a significant barrier to accessing what is needed**

Many submitters highlighted cost of services as a barrier to accessing primary care and counselling services. Private specialist services were also mentioned as difficult to access due to high cost. For many people already over-represented across key socioeconomic measures

(that is, employment, poverty, health) then the cost barrier becomes even greater. Māori submitters regularly pointed to overwhelming financial access barriers which prevent them from accessing services in the first place, or continuing services once they have begun. The people who need support the most are not able to access it.

GPs can refer a person for up to six funded counselling sessions. Submitters noted seeking further counselling services was not an option due to cost.

Cost is a leading barrier to accessing primary health care for young people, including GP's, nurses, counsellors and specialist (youth NGO provider)

GP fees are way too high for most low-income people to go to their GP with mental health issues until these are quite serious (professional organisation)

### **Finding your way – then being turned away**

Many submitters who mentioned difficulties with navigating the system included service users, family, whānau in addition to health practitioners, GPs and specialists.

They highlighted issues such as:

- lack of information about services that are available, including NGO services
- lack of information and support about how to access services
- lack of clarity about what happens to referrals from primary to secondary care and vice versa
- dealing with complexity of how services are delivered and interface with each other.

The system as a whole is utterly confusing making it difficult to know what is best (NGO)

As a GP it is really hard to navigate the system, so I imagine it can be even harder for patients. The mental health services seem to be a big machine with different compartments... from the outside it is difficult to find the right portal of entry. I have spent frustratingly long times on the phone being transferred from one compartment to another trying to get help (health professional)

Access to addiction services is not easy to navigate with families struggling to find services and then accessing them (professional organisation)

Submitters also encountered issues with gaining entry to a service. For some service users they were told they were not sick enough. For others the services were oversubscribed with long wait times.

We have very limited access to funded counselling via our PHO... programme. Based on my patient numbers... I am allowed to refer three people per three-month period for counselling. This is woefully inadequate. I could refer three per week (health professional)

Why do things have to get to crisis point before anything can be done? (whānau)

### 3.1.4 What could be better?

Many submitters suggested opportunities to improve access.

- Addressing service gaps (unmet need between what is needed, and what is offered).
- Early intervention, which includes access to services that promote early recognition of mental distress and addiction problems, and which enable people's wider needs to be met (that is, financial and housing).
- The right care where and when its needed. People who are distressed can immediately access a range of different supports that are appropriate for them and their context.
- Continuity and support for as long as it's needed. Access to the right services is not cut-off prematurely and is continuous.
- Affordable services.

#### Addressing service gaps

Identifying the service gaps that would promote and facilitate access to help and support is broad due to the nature and continuum of mental health and addiction. For instance, services that raise awareness and reduce stigma enhance access to support. Also, during times of increased stress a 'diagnosis' may or may not be present, but the individual may have difficulty accessing services to meet their mental health needs. Furthermore, consider established or more moderate-severe situations, and there can be poor/no access to some of these services. An overview of some of these elements is provided below, and described in more detail in the appropriate section (that is, 'awareness and prevention').

Submitters identified better access to services and initiatives that would help to keep people well as being important. Prevention activities that were mentioned included:

#### **Raising public awareness and educating our society about mental health and addiction.**

There were suggestions to embed mental health knowledge in the education system and to have easy access to on-line and offline resources, books, and information on mental health and addiction. Short courses and training for the general public workplaces such as a 'mental first aid training' programme to give people more confidence to recognise symptoms and how they can help was also suggested.

**Overcome stigma as a barrier to seek help.** To overcome stigma, submitters identified three suggestions:

- enhance the human rights and dignity of people with mental illness and addiction problems; for example, people in prison and those with significant mental illness
- view people who misuse drugs and have addiction problems as vulnerable and in need of public health support
- encourage workplaces to better support people with mental illness.

**Connection with the community.** Some submitters suggested programmes that aimed to reduce loneliness and social isolation by enhancing meaningful connection.

**Address social determinants nationally and locally.** Submitters wanted access to protective supports – housing, work, education and reducing inequity. And investing in community programmes to reduce drug, alcohol, and tobacco use.

**Access to wellbeing services.** Many submissions suggested that access to range of holistic services and approaches that focus on wellbeing, cultural and spiritual approaches, physical health, and social connection would be beneficial. Others suggested that support and guidance on how to create low stress environments and support wellbeing in the workplace to reduce job dissatisfaction, job loss, and subsequent family/ whānau financial pressure would be of value.

**Navigation support.** Some submitters identified that mental health, physical, and social navigation services would be beneficial. Easy access to this type of service would inform, support choice of intervention, and facilitate access to other services.

**Access to transition support.** Many submitters indicated that access to more support during periods of transition between services or at the completion of services would benefit service users, tāngata whaiora, family and whānau alike. This includes access to short-term residential facilities, or services such as counselling, psychology, and Māori wellbeing.

### **Early intervention**

Many submitters supported earlier intervention. Both early childhood intervention (see section **2.5: Social determinants**) and early treatment intervention. Many service users, tāngata whaiora, NGOs, and health professionals called for a range of support and services to be accessible and common-place much sooner than they are now so that there is a much greater chance of preventing and managing mental health and addiction challenges.

**Early identification or diagnosis.** Most service users mentioned early identification of mental health issues as critically important. Submissions identified different opportunities and approaches could be taken to improve early identification, but that ultimately, the responsibility sat with the individual themselves, their whānau, peers and wider support group, and members of the community who meaningfully interact with the individual. This last group, it was noted, is numerous, as it is made up of teachers, healthcare professionals, community groups, team members, and more. Once presence or risk of mental illness has been identified, many respondents highlighted the need to reduce or remove any barriers to seek help.

**Provide a range of easy-to-access support and services.** The types of support that respondents have suggested as being beneficial during the early stages of mental health and addiction challenges were numerous. This indicates that there are many possible approaches and that restricting an individual to one alone might not result in the best outcome. It also suggests that integrated and holistic support and services might more effectively meet the needs of the individual and their whānau.

Earlier intervention with lighter touch evidence-based programs across the country would provide a cost-effective way of ensuring quality of life improvements for the majority of families, reducing demand on more intensive family support services and therefore protect the availability of these services for those most in need (NGO provider)

## FOCUS ON EATING DISORDERS

Submissions from those with lived experience of eating disorders, or their family members, recounted frustration and heartbreak in accessing timely, responsive, local, specialist, and integrated care – especially given the speed at which eating disorders can become deadly.

Eating disorder support is woefully inadequate and unavailable to most people (service user)

Many submitters spoke of complex, co-occurring needs with eating disorders such as Borderline Personality Disorder, Autism Spectrum Disorder, trauma, self-harming and suicidal behaviours, and other mental health challenges that were considered too complex for services to accommodate for, leaving families to pick up the burden of, often 24/7, care despite being ill-equipped.

Suggestions for what could be better included:

- increasing availability and timely access to eating disorder treatment and care, particularly for youth: the number of specialist eating disorder clinics around the country, more Dialectical Behaviour Therapy and psychological treatments, and addressing current gaps in service provision and eligibility criteria between community-based treatment and hospitals
- expanding current eating disorder services to include treatment for all eating disorders instead of only the most severe, and ensure all services are appropriately resourced to reduce waiting times and meet demand.
- allowing those with lived experience to have a voice and be included in treatment planning and delivery
- ensuring families are included in, aware of, and recognised as key players in the treatment and care of their loved one
- upskilling medical staff with training and specialist knowledge in how to identify and effectively care for those with eating disorders
- launching a public education and awareness campaign around the signs of eating disorders to reduce stigma and help family and friends detect struggles earlier on
- collecting meaningful data around eating disorders such as rates of admission, type and duration of treatment, and rates of recovery, relapse, and readmission.

This is an illness with the highest mortality rate of any of the mental illnesses and it has been proven the sooner help is given the better the outcomes (family member)

I should have had my concerns and fears about my eating disorder listened to. I should have been given the treatment and support I needed. I should not have been left to deteriorate physically and mentally to the extent I did (service user)

**Services delivered in the community by the community.** A very high number of responses wanted improved access to mental health support and services within the local communities. There was a strong desire for expert high-quality, affordable (or free), holistic and inclusive support available as close to home as possible. There were many who believed that communities would be better situated to provide earlier, more effective, and less expensive support for those in need, with a much greater reach. They also commented that effective and co-ordinated community led services would reduce the demand for, and pressure on, secondary and tertiary level care.

Community services provide low threshold and ease of access. They are places of community and people and provide immediate and practical support. Many services offer activities or provide for spiritual and cultural needs. In this way, they are often highly successful in supporting whānau and have a broad knowledge base of what works (NGO collating views of service users)

A key theme from many submitters was, 'Bringing services to the people, not people to services', for instance:

- an inclusive 'one-stop shop' catering to the needs of all the diverse groups within the community
- community mental health services of high-quality community mental health services delivered by experts and workers
- health care centres and GP practices with dedicated mental health services
- mental health professionals are linked to, and placed in, schools
- awareness and preventative programmes delivered in schools
- access to community hubs to allow support groups and people to meet
- re-establish home-based treatment services to manage acutely unwell people in their home environments rather than admit to hospital
- home-visit models of care where professionals that are experienced in assessing the parent-child relationship can provide much needed support to family/whānau
- mobile multidisciplinary services delivered in communities with poorer access to mental health services
- mental health expertise on-call to quickly attend more urgent situations wherever and whenever it is needed, including for isolated communities.

**Proactive access to support during periods of situational distress.** The notion of being proactive and offering support through predictably stressful life events and life stages was supported. For instance:

- new mothers
- relationship difficulties and breakdowns
- loss of job
- loss of a loved one
- children and youth experiencing social challenges including peer pressure, relationship difficulties, and bullying

- older people and those living alone at risk of social isolation

**Greater mental health and addiction support to those at risk.** Submitters also suggested more proactive support for populations and groups who have been identified as at-risk and over-represented in mental health and addiction statistics. For example, Māori, Pacific peoples, people with disabilities (physical, intellectual, cognitive, or developmental), prisoners, and Rainbow (LGBTIQ+) communities are all examples of higher risk groups. Many submissions also outlined the importance of addressing social determinants to support early intervention activities.

**Family and whānau, caregivers and support people are involved.** Providing information for whānau, partners, and carers to understand how to best support the service user, understand the issues, the options, and what they can do to help was supported by many submitters. This included the involvement of whānau in the design of support plans as they are ideally placed to support these and to ensure plans are suitable for their context.

We should begin by investing in families! ... Families being supported to look after one another so we have a preventative approach rather than the ambulance at the bottom of the cliff way of doing things (family advisor)

Many respondents also indicated the need to provide support and services for whānau specifically, so they can get the assistance they need. Appropriate accommodation for whānau to stay close to those admitted to hospital overnight was also identified.

### The right care where and when it's needed

For people that self-present there is a critical window of opportunity, they are wanting the help then & there, don't make them wait for help or they won't come back (DHB consumer group)

Submitters presented suggestions to improve the access to the most appropriate care when it was most needed. These are presented below.

**Low or no thresholds to access care.** Submitters highlighted the need to ensure unnecessary barriers to access were removed. Their solutions were:

- more mental health workers (both trained mental health professionals and community workers) to ease the pressure on staff, provide more timely access and loosen access thresholds
- access to quality care earlier, particularly for those who are low to moderate severity on the continuum of distress
- a single point of entry and robust assessment criteria, so referrals are made based on the service user's needs
- more direct referral pathways from anyone working with the service-users and tāngata whaiora, without needing to go through a gatekeeper (that is, GP)
- access without requiring a diagnosis – 'every door is the right door'
- the Whānau Ora approach
- 18- to 25-year-olds having their own system or remaining in the youth system, rather than being exposed to the adult mental health system.

Rather than waiting for people to reach the depths of despair before help is given, treatment and support systems should be anticipating the challenges that these people, their families and whānau will potentially face and ensure that our public health system is adequately funded (NGO provider)

The current entry processes to Māori NGO services are directed via Secondary Services. This is a barrier to Whānau accessing [Māori NGO's] services earlier themselves. We believe that to actively support Whānau, at the earliest possible time, to access support when they need it could prevent them needing to access Secondary Services (Māori NGO provider)

**Culturally appropriate.** Tāngata whaiora, whānau, Māori mental health workers, and Māori community workers all strongly recommended better access to Māori services and wellbeing approaches. With much criticism of the medical deficit-based model, Māori wanted there to be quick and easy access to strengths-based Whānau Ora approaches that address the wellbeing of individuals in the context of their whānau. Including kaumātua, cultural specialists, healers and people that work with Wairua will enhance self-determination, mana, and wellbeing. To achieve access to Māori-appropriate support, many advocate focusing on a multi-skilled and more diverse workforce, appropriate training for non-Māori, and appointment of Māori liaison staff to support navigation of mental health services in a culturally appropriate manner. In addition, Kaupapa Māori options should be available to all residential treatment services and programmes.

The submissions identify three main cultural groups, Māori, Pacific peoples, and Asian, yet many others are also referenced.

**Facilities available – day and night.**

able to meet the needs of service users in any healthcare setting, including within hospital and in the community – 24 hours a day, 7 days a week (mental health professional)

Many submissions identified possible improvements in facilities and the availability of services, including the following.

- Invest in a range of alternatives to inpatient care in settings that are as least restrictive as possible. More group home stays with people who understand their struggles and other home-like settings will often provide a better environment for support and recovery.
- Provide emergency and short-term accommodation options for people during times of crisis, outside of the hospital or police cells.
- Establish health and education facilities to support emotionally dysregulated children.
- Have residential care units for Forensic Mental Health sufferers.
- Establish dedicated facilities for the assessment and treatment of mental health sufferers. Experienced mental health workers could offer crisis services, better assessment, treatment, and pathways, whilst also offloading the emergency departments. They could also offer remand accused prisoners an opportunity to be granted bail and be supported in the community if these facilities could be staffed by providers with knowledge and experience working with offenders.

- Provide separate inpatient facilities for different mental health conditions. It is detrimental to introduce people with behavioural disturbances (such as BPD) into the same environment as those with depression and anxiety, as it may distress them.
- Provide access to a weekend drop-in centre staffed by mental health professionals.
- Make better use of digital and telephony technology to expand remote reach and support 24 hours a day, 7 days a week.
- Use mobile, multidisciplinary facilities to provide greater local access to services.
- Continue and increase efforts to eliminate seclusion.

**Integrated and person-centred.** There is much support in the submissions for the delivery of integrated care. Multidisciplinary teams of health and non-health professionals working cohesively together to wrap support around the individual and their whānau.

Key to a joined-up approach is removing the barriers between agencies and services to allow access and fluidity of support based on Whānau need. A creative funding approach facilitated through a community commissioning model would support a more integrated method to focus on Whānau rather than eligibility or service scope (Māori NGO provider)

Taking person-centred approaches which inform the individual (and their whānau), provides good options, and places them at the centre of the decision-making, have moderate support in submissions. Specific suggestions include:

- co-responding to an emergency mental health situation with ambulance, police, and a mental health worker
- integrated mental health care facilities that act as 'one-stop-shops' to provide a wide range of co-located services and support
- collaboration across organisations with shared access to electronic health information to promote joint problem-solving/care planning, and enable co-funding.

**Clear pathways to navigate the journey.** Many submissions pointed to immense difficulties individuals, and even health professionals, have when trying to understand what support is available and how to access it.

We believe there needs to be clearer and more well-defined pathways for addiction (NGO provider)

One option to address this issue is the creation of pathways for prisoners to continue to live in therapeutic communities (government agency)

The two main improvement opportunities identified in most of these responses were about having:

- clear pathways relevant for their context
- navigation functions or roles within the mental health services.

Some respondents stated that defining pathways for specific illnesses and situations would reduce frustration, speed access, and improve understanding for the individual, their family or whānau, and all others involved. A few calls were made for a single-entry point and/or referral pathway to then provide access to a range of services appropriate for the individual.

**Access to the right expertise.** Moderate numbers of submissions requested better access to more specific or expert levels of mental health and addiction intervention.

All DHB's to include a specialist infant mental health service that is well-resourced and dedicated to the needs of infants and their whānau (professional organisation)

Specific suggestions are:

- better regional access to treatment centres and health professionals that can treat people with addiction to “P” and other substances
- facilities specific for responding to people with bipolar disorder
- crisis response resources
- beds for alcohol and other drug detoxification
- youth and attention deficit hyperactivity disorder specialists
- geriatricians and neuro-psychiatrists
- better regional and remote access services to counsellors, psychologists and psychiatrists
- harm minimisation supports
- well-resourced peer support (particularly those with lived experience).

### **Continuity and support for as long as it's needed**

Many submitters highlighted opportunities to provide more continuous and better wrap-around support for people with mental health and addiction challenges.

**No duration limits.** Many submitters suggested no time limits (or vastly extended) to access free and appropriate care. This applies across the whole spectrum of services from early intervention to complex and severe mental illness.

**Wrap-around services to support continuity at transition points** (discharge, de-escalation, and reintegration).

This transition from treatment to post-treatment was seen by the majority to be one of the most difficult transitions. Whilst they leave treatment with a transition plan, these seem to be virtually useless for the client (consumer leaders)

Many submitters requested better support or transitional services to address the service gap following the end of a particular intervention or episode of inpatient care. Solutions they suggested are:

- a transition co-ordinator or navigator role who can access a broad range of supports
- programmes and short- and medium-term accommodation facilities to support people discharged from hospital settings
- programmes that support those with more complex needs
- newsletters and social media groups to build a community of support outside other services
- better and cheaper access to GPs at points of transition

- established pathways after discharge or at the end of courses to self-progress strategies.

### **Affordable services**

Many submitters, service users and NGOs, family members, grandparents caring for mokopuna, and whānau indicated cost of service and cost of access to speciality care needs greater subsidisation or lower cost points of entry.

These services should not be limited to ethnicity or if you have a 'community services card', so many of our clients are waged, but struggling to make ends meet, they cannot afford private services, but do not meet the criteria for funded services, yet these are the clients who we need to keep well and working (DHB)

**Free or almost-free services and support.** There was strong consistency across responses to provide people with sustainable fully funded or partially funded access to mental health professionals and community support groups. The services mentioned most regarding affordability were talking therapies including counselling, clinical psychology, and psychotherapy or general practice. Specific requests are:

- increase significantly or remove funded treatment limits (or timeframes) to allow for these services to be provided for as long as they are required
- have more than the three free brief intervention counselling services (accessed via GP)
- increase funding so more people can access brief intervention counselling, as current funding is limiting the numbers of people being referred through
- increase funding for longer sessions to properly assess and manage patients with mental health or addiction problems (recommended by GPs)
- remove the cost barrier to accessing GPs by either bypassing GPs as gatekeepers or removing all appointment costs with GPs for those who cannot afford them
- address affordability of other professional services, for example, pharmacy costs medical reviews, access to nurse practitioners and occupational therapists, and wider community-based services
- locate services closer to home and in the regions to reduce the cost of travel to treatment
- address health insurers' inadequate or low annual funding caps (that is, \$750) and intervene to increase this value (government intervention)
- streamline access to funding from the Ministry of Social Development (Work and Income) to remove unnecessary administrative barriers.

## FOCUS ON FOETAL ALCOHOL SPECTRUM DISORDER (FASD)

Foetal Alcohol Spectrum Disorder (FASD) was described by one family member as a “preventable lifelong brain damage as a result of prenatal alcohol exposure.” (family member of FASD child)

Some submissions described how in New Zealand, FASD is largely unrecognised, rates of presentation are growing, and demand for services such as assessment far exceeds the resources available. The current data on FASD was not considered indicative of the true representation of all those experiencing FASD due to current under-diagnosis in New Zealand. It was also noted that people with FASD experience a number of complex needs, including an increased risk of poor outcomes such as depression, substance abuse, incarceration, and suicide.

Further investment in this area is needed urgently as many of these people with FASD have complex needs involving Health, Disability, justice, education and Oranga Tamariki (mental health professional)

Submitters spoke of the negative impact that the alcohol culture in New Zealand can have on rates of FASD. The normalisation of high amounts of alcohol consumption contributes to this highly preventable neurodevelopmental disability.

Our current drinking culture is a complex and involved problem. I want my voice to count for the many, many unborn children who don't have a choice in their alcohol consumption. In my view, exposure to alcohol in the womb is child abuse. It must be stopped (family member of FASD child)

Suggestions of what could be better included:

- Launch targeted public health campaigns to educate the public around the harms of alcohol consumption during pregnancy
- Provide more support for individuals, families and whānau who are affected by FASD
- Ensure all alcoholic products contain government warning labels that are appropriately visible, including ‘use of alcohol can damage an unborn baby’
- Increase resources for FAS screening and assessments, including ensuring that FAS assessments are available in prisons
- Increase public education and understanding of FAS/FASD through foetal alcohol public awareness days
- Train frontline staff in current evidence-based treatments for FASD
- Take strong action to address and minimise the harm from alcohol by making changes to alcohol policies and regulations including: increase the price, reduce the availability, and ban advertising and sponsorship of alcohol.

Overall it is obvious that the system is not geared to help a person with permanent brain damage. Changes need to be made and far more resources given to help families and individuals in the FASD section of our communities. They have been left to flounder on their own for too long (NGO)

## 3.2 Intervention, treatment and support

### 3.2.1 Overview

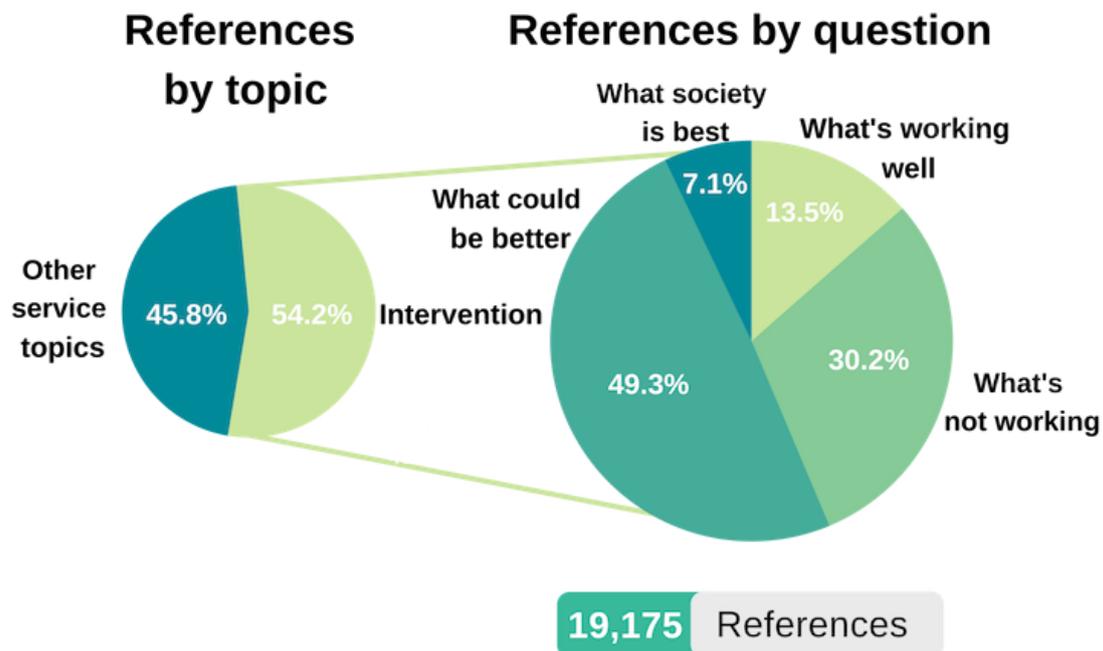
This section presents an overview of responses from submissions related to specific interventions, treatments and support, as well as approaches to provide interventions, treatments and support. It covers the full range of services and supports across community, inpatient, DHB and NGO services.

Submitters made 19,644 references about intervention, treatment and support.

Of the comments made about intervention, treatment and support, almost half (49.3%) focused on what could be better, 30.2% focused on what isn't working well, 13.5% focused on what's working well, and 7.1% focused on what society is best (see Figure 3.3).

The sheer volume of responses by submitters on 'what could be better' demonstrated a tremendous desire across New Zealand for positive change for mental health and addiction services and support. It was clear that many submitters had invested great effort, thought and consultation to provide such a high calibre of responses. The scale of change suggested ranged from the smallest of tweaks to sweeping societal and system changes in terms of how people are supported and the types of services that are provided.

FIGURE 3.3: SUMMARY OF RESPONSES RECEIVED ABOUT INTERVENTION, TREATMENT AND SUPPORT



**KEY THEMES FROM SUBMISSIONS FOR INTERVENTION, TREATMENT AND SUPPORT**

**3.2.2 What's working well?**

- positive impact of professionals and services across the community
- Kaupapa Māori services
- Well-functioning services

**3.2.3 What isn't working well?**

- delays and service gaps across the system
  - deficiency in service delivery for Māori
  - services not meeting needs
  - poor continuity of care
  - service users with complex issues
  - poor use and monitoring of medication
  - negative attitudes or responses by mental health workers
  - deficiency in providing information or feedback
  - system is underfunded and under-resourced

**3.2.4 What could be better?**

- improve current services
  - better services for Māori
  - increase resources to reduce waste and cost
  - improve the standards and quality of services
  - training and development
  - continuity of care
  - inpatient improvements
- fix service gaps
  - services in local communities
  - person, family and whānau-centred approaches
  - early information and navigation
  - alternative primary care services

### 3.2.2 What's working well?

Many things are working well as evidenced by the great variety of submitter responses. The main areas identified related to:

- the positive impact of other professionals and service in the community
- Kaupapa Māori services
- well-functioning services.

#### Positive impact of professionals and services across the community

Some submitters identified instances where other service workers (not in health or mental health) demonstrated excellent and appropriate intervention for those in need. Teachers and police were occasionally described as having a very positive impact.

School health services are working well, where there are some. In some schools there is a team of pastoral care teachers including the Deputy Principal, the school counsellor, youth workers and or social workers, nurses and visiting GPs. Where these teams meet together regularly the pastoral care is effective in ensuring better care for young people (commentator)

**Telehealth.** The National Telehealth Service was sometimes cited as playing an important role for service users and families.

Services such as help lines are working well to draw people who need help out from the sense of isolation that manifests from addiction and other serious emotional challenges. Help line services also rescue people from the bottom of the cliff. Lives are being saved when these help lines call upon police to rescue people who are in imminent danger of committing suicide (individual with lived experience)

**Online tools:** Online tools provide another means of support.

[tool] is an online structured problem solving tool co-designed for teens. It is based on cognitive behavioural therapy which have shown to be effective in reducing symptoms of depression in adolescents and promising practice for preventing suicide (Pacific NGO providers)

**Empathy and expertise of those providing services.** Submitters frequently acknowledged that while the mental health and addiction system is imperfect and poses many challenges, a great many devoted, tireless and effective people do their best every day for the benefit of others. Submitters generally found that the genuine care and positive attitude demonstrated by individuals and teams was crucial for recovery, whether that be community groups, whānau, health professionals, mental health workers, support groups or other members of the public.

While there was intense criticism of the systems in place, the people who work in these were seen as hard-working, committed and often described as 'going the extra mile'. Where whānau reported having had good support from services, this was virtually always associated with dealing with just one person who they were able to build a positive relationship with (NGO collating views of service users)

**Characteristics that were appreciated and effective.** These included having one consistent central point of contact (that is, a key support person, co-ordinator, health professional or navigator). Trust and a relationship are then formed and can be maintained for as long as is required. Other characteristics included:

- those involved asking about and considering the individual's wider, more holistic needs (that is, cultural and spiritual needs) and facilitating support for areas of need
- those involved being person-centred and involving the service user and whānau in decisions
- good understanding, communication, co-ordination, and integration across people and teams.

### **Kaupapa Māori services**

Māori submitters occasionally identified positive instances where holistic and culturally appropriate intervention is taking place (particularly Kaupapa Māori and Whānau Ora approaches).

The benefits of providing Māori with the appropriate interventions and at the right time is clearly articulated by one submission by Māori health leaders who stated that,

Māori primary health care provider success is due to the provision of comprehensive programmes that incorporate treatment and management, prevention and health promotion, as well as addressing the social determinants of health. The culture of Māori primary health care services underpins the core characteristics of ensuring accessible health services, community participation, continuous quality improvement, and a culturally appropriate workforce, holistic health care, empowerment and self-determination (Māori health leaders and colleagues)

### **Well-functioning services**

#### **Community-based support meets the real needs of service users and whānau.**

The superstars in this challenge have been local community individuals and small groups of well-connected community-minded individuals. A superhuman volunteer relief effort got underway almost immediately, and this network based on word of mouth and personal visits to affected homes, has resulted in a large degree of support being available and taken up, from within the community (individual with lived experience)

Many service users described instances where they experienced high quality, wrap-around services that met their individual needs, delivered by community groups within their area. These are typically providing support for service users and non-mental health service users. Their examples are wide-ranging across many different geographic areas and types of services. However, commonalities included:

- culturally appropriate support
- support that addressed the immediate needs of the service user (often not necessarily mental health specific) such as food, financial and housing support
- support that was targeted at helping families and whānau

- support that provided information, navigation and access across mental health services
- respect and appreciation for those with lived experience and their peer support of others
- self-help and group-based support groups (that is, 12-step programmes, Alcoholics Anonymous, Community Alcohol and Other Drug Service, Needle Exchange Programme)
- national programmes delivered locally (such as the Equally Well initiative)
- supported employment programmes
- access to after-hours support.

Māori Mental Health & Addictions Service consists of three components – a clinical arm, a drug and alcohol service and a cultural support service. The cultural support service is made up of taurawhiri who are able to support tangata whaiora and their family/whānau through their recovery journey, ensuring that cultural needs are identified and addressed in addition to clinical needs. The taurawhiri also support Māori service users under the care of other mental health teams. The service kaumātua are part of the pōwhiri that every new tangata whaiora receives (DHB)

Supported employment is internationally recognised as an effective way of supporting people who experience a mental illness into the workforce. The approach tries to place people in work settings where they receive intensive on-the-job support (DHB)

**Positive and influential role of health workers.** Service users frequently identified the positive and influential role of health professionals, teams, and non-health professionals working specifically within the mental health and addiction sector. Service users described situations where the input from these workers led to positive outcomes and, in a few cases, saved their life. Submitters frequently cited counselling, psychology, community and home-based mental health nursing, Māori specific mental health services, psychiatry, and general practice as of significant benefit.

Having HOME VISITS helped normalise my perception of my illness and give me some expectation of acceptance in the community. This also reduced the anxiety of going to energy sapping appointments. It allowed me to believe there was no uncrossable gap between being ill at home and getting into hospital when needed; or between being ill at home and being ok in the community (service user)

**Access to health professionals with expertise in both mental health and other challenges.** Access to health professionals who had expertise that spanned both mental health and their other specific challenge(s) (such as cognitive or physical challenges) was identified. For instance, a geriatrician who had expertise in mental health and dementia.

Many respondents commented that once they found a professional service provider that was specifically medically trained and understood Eating Disorders then treatment and the information they were provided with were excellent and in one case described as 'world class' (NGO provider)

If they manage to see the right person with the right attitude and adequate knowledge in autism, then they are likely to have a positive and successful experience (NGO)

**Well-co-ordinated and integrated service more effective.** Many workers and groups described the positive difference they have seen first-hand, and the benefits of collaborating across other organisations. They are regularly described as having a great impact despite their consistent funding challenges.

**Access to free and out of hours mental health and addiction services beneficial.** Like the community-based services, a few submitters had access to mental health services after-hours, which was commended and practical.

Having a social worker attached to the ward enables service users/tangata whaiora quick access to [Work and Income], etc... Having resident medical officers... on site and excellent after hours support so medical support is timely for the service user/tangata whaiora (DHB)

We have a well-established Maternal Mental Health Service that works with strong partnerships with women's health services, primary care, neonatal intensive care and a range of NGOs to provide primarily community-based care for women experiencing post-partum mental illness. We are able to manage a very low rate of admission to hospital this group through our community partnerships and strong support to the existing networks of these women including family/whānau and primary care providers (DHB)

#### **Availability of respite care very useful**

Availability of respite care was regularly identified as very useful for families and service users to keep service users in the community and remain out of higher intensity inpatient care. Whānau greatly appreciate the dedication of people who work for these services, while expressing concern for the workers wellbeing and the pressure that the system puts them under.

Although limited, the funding to access up to 28 days planned respite supports people to continue living well in their own community (NGO provider)

## FOCUS ON DEMENTIA

Dementia is a disease which affects the mental ability and state of mind of the person diagnosed, this diagnosis has an outcome which also affects the carer too (family member)

We received a few submissions from families and whānau who had lived experience of caring for loved ones with dementia.

These families and whānau spoke of difficulties navigating the system of care, limited information about diagnosis, and feeling ill-equipped to care for their loved one. One submitter said the lack of support for carers was “indicative of the regard for the work they do and the value society places on those they care for”(family member).

We knew nothing about Alzheimer’s disease; we were given no information about where to from here – we were just left in limbo (family member)

my experience of support for [family member] or I (as the carer) were sadly lacking (family member)

Despite recommendations by health professionals to use respite care regularly, family and whānau members were frustrated by the difficulty in accessing respite. Respite options were of varying quality, not offered for long enough, or simply unavailable.

Although, at this stage, home is by far the most appropriate place for the care of my husband, it does not work as all the time I am battling exhaustion and emotional stress with very little respite (family member)

Families and whānau struggled with inadequate care of their loved one in rest homes. They described discrimination, loneliness and social isolation, and how the detailed care plans that were provided to rest home staff were often ignored or not properly implemented. Some noted that their loved one appeared to deteriorate faster or exhibited uncharacteristic behaviours during this care. In contrast, one family noted the positive effect when one rest home followed the care plan that was provided.

In the rest home in which our care plan was used, the attitude and demeanor of my [family member] was strikingly different. There was no mention of aggression; I was told that people in the regular rest home looked forward to his coming to visit in the morning and everyone loved having him around. At the end of this experience, he was very happy, contented and mentally well (family member)

Some family and whānau members spoke of the impact that Dementia had on their loved one’s mental health, particularly the onset of depression. Their loved one became confused and found it difficult to communicate, experienced a loss of friends, and lacked meaningful activities or engagement with the community where their dementia was accommodated for.

Experiencing a drop in competence in small things, such as making tea, wiping the dishes, brushing hair, leads to feelings of a lack of competence which then leads to depression (family member)

Simple tasks became impossible – putting a spoonful of sugar in his cup, was a huge challenge. These frustrations caused big mood swings (family member)

## FOCUS ON DEMENTIA CONT.

Suggestions of what could be better from those supporting family members with dementia included:

- Increase support for carers, specifically in the form of regular access to good-quality respite care, and adequate financial support. Provide counselling and navigation services.
- Provide adequate, age-appropriate support for those with dementia that enables them to live as they want for as long as they can. Includes significant in-home care. This was particularly important for those with early onset dementia.
- Raise public awareness of dementia to remove the stigma that is often attached, and to provide more information to family and whānau members
- Ensure that places like rest homes are sufficiently resourced, with staff who are appropriately trained in how to care for those with dementia
- Fully implement a National Dementia Framework in all DHBs – one that includes family consultation, and the right to live in an environment appropriate to that person

### 3.2.3 What isn't working well?

This section is structured with the major and common themes described initially, followed by the minor and less frequent themes.

#### Delays and service gaps across the system

##### *Deficiency in service delivery for Māori*

For Māori, many of the current service issues identified by Māori submitters are related to access, and these issues are shared with many non-Māori submitters. These access issues are covered in more detail in the topic 'Access', but include:

- high cost of earlier intervention services
- difficulty overcoming the high entry thresholds to many services
- delay to get the service when it is needed
- unable to access the right service locally
- difficulty navigating the mental health and addiction services.

In particular, there is a strong sentiment from Māori that there needs to be much more progress from somewhat superficial and symbolic Māori gesture, to one that is deeply rooted, accepted and functional across New Zealand. There is a belief that mainstream models of care are not empowering Māori providers and services to meet the needs of their people.

Delivering kaupapa Māori services costs more both in time and in finances. From a time perspective, there are many cultural practices that Kaupapa Māori Providers do that general services do not. Karakia, Powhiri, Poroporoaki, Kapa Haka, Tangi, Tikanga training, cultural specific Kaimahi training etc. Further to this, the needs of Māori can often be more complex and intensive. The cultural practices are very much required to ensure we have a culturally competent workforce. The unfortunate thing about this is that Kaupapa Māori Providers are still expected to deliver the same outputs as their general counterparts within the same [full-time equivalent] and time resource (Māori NGO provider)

Many submitters noted a lack of Māori workers across the mental health and addiction services meant that Māori were much less likely to have their needs met, when services are predominantly delivered by non-Māori. This was seen to expose both tāngata whaiora and whānau to ingrained and institutional racism. There were a few Māori submitters who identified cultural barriers, undermining attitudes, and racism towards Māori within the training programmes designed to develop and upskill our mental health workforce.

We have dealt with covert and overt racism, defensiveness, personal attacks, gate-keeping to promotions, undervaluing of our academic research and publications, dismissal of clinical judgment and opinion; witnessed Māori experiencing inequitable treatment choices; had to continually justify the existence of Māori worldviews and their relevance; responded to undermining behaviour from non-Māori colleagues, and worse, from Māori colleagues (Māori professional organisation)

### *Services not meeting needs*

**Whānau and family and support people are not involved.** A strong theme emerges from submitters regarding the involvement (particularly the lack) of family and whānau and other key carers or support people. Most submitters cited a lack of involvement and input in relation to:

- being advised of mental health crises
- understanding what approach and interventions have been undertaken and why
- providing context and background and influencing factors to a service user's situation and clinical presentation
- planning an effective intervention and approach
- knowing how they can best help and effectively support the person when at home
- receiving follow-up.

In addition, some submitters identified that the family/whānau and carers do not receive the support and services they need themselves to manage their own increased stressors and demands when caring for those with mental health and addiction issues.

**Lack of medium-term to long-term inpatient or supported accommodation and residential facilities.** Some submitters identified a large service gap in the provision of medium to long-term accommodation for service users with more complex or demanding mental health and addiction needs. Many of these submitters reported that there are not enough (or any) residential or supported accommodation facilities outside of a hospital setting to provide a supporting and positive environment when there is a need beyond the short-term. Home (if

they have one) might not be the best place for some service users and their families, and they outlined how service users will have a better chance of improvement if temporarily supported in the right facility, surrounded by the right people.

Submitters described how prisoners also face a poor transition from incarceration to bail or release. There are few community re-integration facilities to smooth this transition for those with mental health and addiction issues. The high prevalence rate of these issues for prisoners and those released means that there is great need for higher levels of support. Some submitters believed that a good transition into the community will prevent much reoffending and enhance public safety.

**Lack of short-term 'safe-places' for periods of crisis.** Some submitters identified a service gap where there are no or few short-term accommodation facilities that provide safety and mental health support outside of inpatient care when going through critical periods of high need, or immediately after discharge from an inpatient setting. These submitters identified that a lack of these facilities puts pressure on hospital inpatient beds, and means there is no clear path for people to transition from the inpatient ward when they might be improving, but are not yet ready to go home. Submitters believed that not having an alternative to hospital inpatient wards for the slightly less severe cases (but still high risk) is shutting out people in need due to the thresholds and resource constraints. A short period to de-stress, receive some time and space, with access to wrap-around services to better prepare for dealing with home and day-to-day life again is not available to service users.

**Not meeting service users' need at all hours or places.** A few submitters identified a lack of support options when they need it. In particular, access to services at night and outside of normal working hours is minimal. The national telehealth services are generally acknowledged to be a great initiative, but some submitters feel this is not enough by itself, and people sometimes need access to people in their area who can intervene. This is particularly apparent in rural and remote areas where 24/7 support is not really present.

We hear that it is difficult to access mental health services because of the process that clients need to go through, and that services and resources are limited. In a smaller centre like ours there is not a 24 hour service (NGO staff members)

**Range of services is not holistic enough to meet needs.** Another strong theme from submitters identifies that the current mental health and addiction services are not holistic enough. The range of various supports and services that was described as missing or inadequate by submitters is wide, but includes:

- an holistic assessment of an individual's and their family's needs
- services targeted at the key factors and influencers contributing to distress (relationship situation, work stress, financial pressure, social isolation)
- cultural and spiritual approaches
- physical conditioning and wellbeing programmes
- community-based services that encourage and support social participation and integration
- support directly for family or whānau
- transportation assistance

- support for day-to-day activities such as childcare, meal preparation, grocery shopping, gardening, maintenance and repairs
- advice on healthy homes
- assessment and treatment of lifestyle factors that may lead to some symptoms (lack of vitamin D or vitamin B12)

Unsurprisingly, many of these gaps in services and support are mentioned by submitters as possible solutions.

**Providing addiction versus mental health services.** Submitters described some complexities and different perspectives in relation to addiction and mental health. Predominately the submitters who commented on this topic said:

- service users and tāngata whaiora with addiction problems need specific addiction expertise and should not be treated using the more mental health approaches most health professionals are more comfortable working under
- service users and tāngata whaiora have both addiction and mental health needs and health professionals are managing them under one of two different siloed approaches, which need to be more joined-up when people suffer from both.

The second scenario is described more fully in section **4.1: Addiction**.

#### *Poor continuity of care*

**Lack of support following inpatient discharge.** The overwhelming submitter voice highlights a lack of support following inpatient discharge. The nature of the many comments highlights a significant gap in continuity of care during this period when people are very vulnerable. Driven by pressure and demand on inpatient beds, many service users and families feel they are being discharged too soon, and are not yet ready to cope without significant daily support. Service users described an experience of where health professionals stated they are 'ready', and wish them 'good luck out there' – but minimal follow-up, transition, or support is arranged or provided. From a health professional perspective, there seems acknowledgement that the situation is not ideal, but they must serve those in most need – which means freeing up inpatient space for others with greater need.

**Lack of support and follow-up after completing services.** Following on from the previous point, submitters often stated that follow-up and transition into lower levels of support following periods of intervention (that is, psychiatry, psychology, counselling) is poor. Services in the community (that is, one-stop-shops) or provided at the service user's home are sometimes seen as limited or non-existent. A few submitters wanted someone to regularly touch-base with them to see how they are going and help them navigate the next steps, but again it was not known if there was this support available.

**Treatment and support end too soon.** Many submitters described how services end prematurely, well before long-term sustainable benefits of intervention can be realised and before the service users feel ready to successfully manage or cope. This opinion is often cited in relation to talking therapies where funding and availability act as constraints. Submitters reported that the cost to continue these services privately limits completion of intervention, and enhances the risk of deterioration in the future. Submitters also indicated

that it takes some time to build rapport and trust with health professionals, and this support can end before it has fully developed.

**Losing continuity with a trusted health professional significantly disrupts progress and sets them back.** Frequent, unexplained, and sudden changes to mental health professionals are occasionally highlighted by submitters who stated that these changes act as a barrier to progress. The most regularly cited relationships at risk are with GPs, counsellors, nurses, psychologists, and psychiatrists. The reason for a change, and a period of notice was often cited as lacking when changes occurred. The service users and family both place a lot of importance and weight on the value of a positive, trusting relationship with their health professionals, and where this was absent, progress was described as minimal (and in some cases regression). For those moving to a new region, it obviously meant new relationships needed to be formed, but it also introduced an unhealthy gap in the continuity of care as service users had to go through the referral system from the beginning.

They appointed another counsellor without giving her any heads up that this was to occur. The session made her feel revictimized (service user)

#### *Service users with complex issues are not fitting funding/service criteria*

Service users and family with more complex needs find it hard to receive enough support. In many instances there are people who have more than just mental health needs, or they have conditions that place them at high risk of developing and sustaining mental illness. Submitters also frequently identified that people with complex personality disorders find that services and supports do not meet their more complex needs. In some cases, people with complex needs are deemed too difficult for a particular service and are referred elsewhere. Simultaneously, the same people are not meeting the threshold or criteria for intervention when considered under each specific 'diagnosis' independently. An integrated approach is lacking, and entry criteria or thresholds act as significant barriers.

People with complex personality disorder—the service tries hard not to provide a service to them, they're not going to go away. They've grappled with this in Australia; they recognise that these people needed a form of service that wasn't being made available to them and keeping them away was not the answer (mental health professional)

**Lack of consent and control of recovery pathway and options.** Service users feel like they do not have much control over their treatment plan. Submitters described a dismissive attitude from some health professionals towards a variety of alternative treatment options (that is, natural, spiritual remedies) and the service user is subsequently discouraged from pursuing these other approaches.

A few submitters indicate that consent for ongoing intervention after a period of compulsory intervention is not sought. Also, service user requests from health professionals are not always being adhered to (who to inform, requests for information, provider preference etc.). Submitters reported the feeling of a large burden, and constant concern for the safety and wellbeing of the service user and other members of the family, yet are unable to improve the situation as it is not compulsory. These same submitters described how mental health professionals avoid these complex scenarios and prefer to leave the choice up to the service user.

**Lack of early intervention services.** Most submitters described unmet need within early intervention services. This is discussed in more detail in section **3.1: Access**. However, it is worth noting that submitters wanted better access to existing early intervention services, but also reported a need for new, or improved services. Many of the comments regarding new or improved early intervention services are described in section **3.1.4**.

If looking at the services in the period after prevention, but before mental health services are typically accessed, then there is room to describe the service gap that submitters reported regarding 'early intervention' services. They described missed opportunities to look at the person's context under a health lens (rather than a criminal lens for instance), and to receive lower levels of support much earlier on. Submitters reported that the current mental health system is not able to meet the need when it first becomes apparent, when either identified by the individual themselves, or others around them. A person's need for early intervention might not reach the threshold to warrant a visit to the GP or to seek counselling, but instead, submitters described a gap in low level intervention that support and guide people through difficult or stressful periods and reduce their risk of their mental health deteriorating.

The range of lower-level services described by submitters is vast and varied, but includes:

- counselling for people undergoing periods of high stress (that is, separation, the loss of a loved one, job loss)
- family support for day-to-day tasks (that is, cooking, transport, child-care)
- safe and supportive short-term accommodation facilities to reduce stress levels
- involvement in targeted community groups and activities to connect with others
- support groups or individuals to talk to.

There is currently no preemptive care provided in the community, it needs to escalate to a point of crisis before support is provided (service user)

**A rush to get people out of inpatient care.** Submitters occasionally identified that there was underlying pressure to discharge service users from inpatient care. Once the height of the crisis was over, both service users and family were discharged, despite them feeling unprepared and in some cases, unsafe.

When [an] inpatient I lived in constant fear of my bed being needed for someone else to the detriment of my mental health as I felt I needed to act up/self-harm in order to be deemed worthy enough to be there (which in itself is clearly not a sign of a healthy state of mind) (service user)

**Lack of culturally appropriate care.** Some service users wanted interventions to be provided by people from their own culture to enhance the cultural understanding and appropriateness. This came out mostly from Māori perspectives (identified earlier), but a few Pacific peoples and Asian submitters described a lack of mental health workers from their own culture.

If [service user] was housed within a culturally appropriate and supported living environment the necessity for him to continue with his medication may be significantly reduced (NGO provider)

**Type of treatment ineffective or causing harm.** As a treatment intervention, there were few submitters who supported seclusion. Comments were made about the anxiety-provoking nature of its use, lack of therapeutic value, and seclusion rooms being poorly setup: see section **2.7 Rights and legislation**.

However, inpatient social isolation was not limited to seclusion. A few submitters described inpatient experiences that left them feeling isolated, with minimal people interaction. It was inferred that having few opportunities to engage with others hindered service user progress towards reconnecting socially.

Caller also notes that when she went to visit her son in inpatient mental health services, all she saw was a bunch of very lonely people (furthering the knowledge that family/friends/support people are not involved in the care) (family member)

## FOCUS ON SCHIZOPHRENIA

Service users told of facing stigma and discrimination due to their diagnosis in areas of education, housing, and employment. Some submitters could not live independently but were still expected to. The physical health of individuals was often overlooked, and rates of smoking were high. Some highlighted how schizophrenia intersects with other addictions and mental health challenges.

How can someone with chronic paranoid schizophrenia on a cocktail of anti-psychotic medications not meet criteria to sit under a [mental health] service? (service user)

Support and treatment were difficult to access and uncoordinated. Once in care, service users spoke of being discharged too early and readmitted soon after. Submitters told of antipsychotic medication being administered, often without review or accountability, producing harmful side-effects. Submitters noted some effective medication is restricted or prohibited in New Zealand.

Families and whānau of those with schizophrenia spoke of persistently jumping over hurdles to get help for their loved ones, or lacking the right information or service to help. Parents growing older worried what would happen to their adult child when they were no longer able to care for them.

providers need to listen to and communicate with families of mental health patients. We know them. We can see when they are getting better and when they aren't ... we should be listened [to] and believed (family member)

Recommendations for what could be better included:

- Increase community-based support over inpatient care, including a team of support workers, occupational therapists, peer groups, day programmes, cognitive behavioural therapy, and weekly follow ups – people with schizophrenia need a place in the community
- Listen to families and whānau who provide care and recognise them as having valuable insight into the needs and behaviours of their loved one
- Place more emphasis on therapeutic, holistic, recovery-based intervention and psychological support over the prescription of antipsychotic medications
- Look to overseas models of care for schizophrenia and psychosis
- Raise public awareness of schizophrenia and develop education programmes
- Invest in accommodation options and employment support that provides meaningful work
- Look into evidence-based alternative treatments.

My [family member] has a lot to offer. He's smart, creative, loving. He just needs a little bit more support than others at times. He needs the dignity of a liveable level of welfare, and a safe place to live while he gets on his feet. He needs a community mental-health team that-involves his family as a core member of the clinical team. And if he's ever in hospital, he needs the full range of therapeutic support - not just drugs - so he leaves stronger than when he went in (family member)

### *Poor use and monitoring of medication*

**Medication is overused as a treatment option.** Almost all of the submitters who commented on the use of medication as an intervention described it as overused. The perspectives regarding medication are mostly concerning situations where GP and psychiatry and inpatient mental health services were accessed. These include:

- medication seen as the **first** option before other interventions are tried
- medication seen as the **only** option provided
- medication too frequently prescribed throughout the period of mental illness.

Caller has found that some GPs will jump straight to offering medication before offering counselling support. It feels like GP's do not know what they are doing and just go down the list of medications on offer until they find the right one (service user)

**Inappropriate prescription of medication.** Once a decision has been made to prescribe medication, many submitters still present numerous issues regarding the appropriateness of the eventual prescription. This includes:

- the type of medication selected
- lack of consideration or knowledge of drug interactions and side-effects
- trialling too many drugs at once or over time
- not enough consideration given towards the risks of dependency
- the strength of the dose is too strong.

Medication is too strong and causing wife to be quite spaced out as well as difficulty in standing (family member)

**Lack of monitoring and review of medication.** Many submitters identified the lack of medication reviews, or even regular monitoring of medications. Submitters described a lack of medical practitioner emphasis on these important activities. In addition, on the occasions when a medication review is arranged, submitters described how there were problems of long delays (can be months) to see a reviewer, or too costly if done privately.

Medications are not being monitored and reviewed. Callers wife was taking lithium for treatment of bipolar for many years. Caller describes that there would be a frequent cycle of wife becoming toxic due to the lithium so she would be taken off of the medication. Being off of the medication would then result in a manic episode and so she would be put back on the lithium. This cycle happened for many years and it was too late when the medication was carefully considered and changed (family member)

**A lack of information provided about medication interventions.** This deficit includes:

- lack of information about potential and likely side effects and consequences
- expected timing, duration and treatment course
- risks of dependency and process to wean-off effectively.

Caller can not recall a time where a psychiatrist adequately explained the side effects of the medication he was to take (service user)

### *Negative attitudes or response by the mental health workers*

**Not being taken seriously.** Submitters alarmingly described many instances when service users or families have reached out for support, and their requests were perceived as not being taken seriously. People were actively discouraged from accessing specific lines of support, even when regarding suicidal ideation. This perception not only occurred when trying to access services, but also while receiving services and afterwards. Submitters described how they felt judged, that their needs were not severe enough, and told they can manage by themselves.

When caller had contact with the crisis services at the hospital, it feel that no one took him seriously and that they worked to deter him from accessing further treatment. They would cite the long waiting times or that they didn't think he sounded that bad. Other strategies frequently told to caller when he was in crisis was "Go for a walk", "have a nice shower", "get a good sleep" (service user)

**Hiding the truth to protect loved ones.** There have been a few concerns raised by submitters that disclosing the full truth around a situation may negatively impact the service user or their family. Parents fear their children will be taken away (that is, if someone in the family is an addict), or there is a chance of a criminal conviction if the family report incidents of physical abuse during a mental health crisis. As a result, submitters allude to the fact that they hide some facts to protect the service user and family unit.

**'One size fits all' and labelling.** There is a perception from some submitters that service users are not truly being listened to, but only categorised for a generic treatment approach. They described how their individual circumstances and wider issues were not considered. Instead they described a sense that some mental health workers try to 'put you into a box' and provide an overly simplistic, and possibly detrimental, label so that it is easier to treat the service user with the same approach as the 'others'.

### *Deficiency in providing information and receiving feedback*

**Difficulty finding the right information.** From what services and supports are available (and what's involved), how to access them, how others can be involved, what helps, hinders mental health and addiction, what the plan and pathway look like, to side-effects, medication risks, drug interactions, and weaning-off guidance.

#### **Health professionals find it difficult to navigate the system.**

Caller's [age] son involved with the mental health services for many years. Caller felt that he fell through the cracks in each part of the system and this resulted in his death by suicide. There is no set referral system in place. Health professionals are not clear of each service available. For example, caller took son to the GP who referred to DHB mental health services. On meeting with the psychiatrist from DHB mental health, son was then referred back to GP (bereaved family member)

**Short GP assessments do not provide enough information.** For those service users reaching out for understanding, diagnosis, and help – there was consistent feedback that the standard (and sometimes even extended) GP session is not long enough. This leaves a large void of information.

**Lack of information for whānau and family.** What's going on? What can they do to support? How to identify risks? What should they do when?

**Feedback about service experience and improvement not actively encouraged.** A few submitters would have liked an easier opportunity to provide feedback about their service experience for the sake of improvement. In many cases, the main method of an organisation receiving service user and family feedback appears to be via written complaints, and not always actively sought by staff.

#### *System is underfunded and under-resourced*

Many submitters identified a key causal factor that contributes to many of the issues faced by the mental health and addiction services. This is so prominent and regularly mentioned by submitters that this sentiment pervades almost all of the themes and topic areas. Both continuity of care and the negative perceptions of mental health service workers are affected by the lack of services and resources available to provide for service users in need. The demand appears to outstrip the supply, and has contributed to large service gaps, and poor service experience.

The mental health and addictions system is woefully underfunded, crisis-led and seems to chew up and spit out not only the patients, but the providers... Just not enough resources. Our mental health teams are stretched to their limits and it is having a major impact on patients, their families, their employers. It can't go on like this, there needs to be more funding for support services (professional organisation)

### 3.2.4 **What could be better?**

This section describes the most commonly described themes by submitters that relate to intervention, treatment and support. While there is an inevitable grey area between service and system level changes, this section does not describe the more expansive all-of-system changes, which are described in a later section.

#### **Improve current services**

##### *Better services for Māori*

**Kaupapa Māori and Whānau Ora models of care to become embedded within mental health and addiction services across New Zealand.** In order to better meet the needs of Māori, there is widespread support from Māori submitters for Kaupapa Māori and Whānau Ora models of care. The key features Māori submitters frequently referenced included the wider aspects of Te Ao Māori, recognition of spirituality needs, and considering whānau as a collective and at the centre of all services. Other prominent features include placing great importance on maintaining strong positive connections to whānau, hapū and iwi, and to wider communities. Taking a strengths-based (rather than deficit-based) approach supports an individual's identity, mana, and self-determination. Addressing the social determinants and contextual influential risk factors for mental health and addiction are considered part of a successful Māori focused Whānau Ora approach.

**Placing emphasis on the connection and involvement of whānau and wider supports to move beyond individualistic approaches** is important for most Māori submitters. This

enables a more collaborative approach to address the important contextual whānau and socioeconomic factors which influence tāngata whaiora.

Whānau, hapū and iwi have an important role in helping to shape the ways in which communities and services address and provide for people experiencing mental illness or addiction issues. As well as supporting Māori who use these services. It is therefore important that these issues are not only looked at in terms of the individuals, but also the wider social impacts as well (Māori NGO provider)

**Key features of a better service for Māori** were identified by several Māori submitters, which included:

- Māori services have more time to engage tāngata whaiora and whānau, and provide a greater range of support that is not typically funded (that is, kai, transport, navigation)
- anyone seeking help should not be turned away, and there is no wrong door to enter services
- pathways and scope of services primarily cater for a whānau perspective
- the delivery of Māori services by Māori, across community-based, primary care, secondary care and tertiary services
- the training of skilled Māori workers takes time and investment, and should be a priority for the government.

#### *Increase resources to reduce wait and cost*

This was one of the most frequently reported service issues, and was the most frequently mentioned solution to improve the current state of these services in New Zealand. The demand for additional 'resources' were usually referring to two factors: more mental health and addiction workers and more funding to deliver these services.

**Better resourced existing services.** Many submitters wanted faster and affordable (typically free) access to the existing mental health and addiction services. Submitters wanted greater availability to both health and non-health professionals.

**Redistribute resources towards community services.** While most submitters described a need for more funding, some thought that spending more is not the only solution.

Open Dialogue, which is the model used in a Finnish DHB, has the best long-term outcomes for psychosis in the developed world and runs at 1/3 cost of the psychiatric model. What is needed is not more money, but less money spent more wisely (health professional with lived experience)

Some submitters suggested redistributing resources and funding (gradually) away from inpatient and secondary services, and into primary care and community groups. Submitters suggested that this approach would facilitate support for greater numbers of service users and families, earlier, with smaller wait-lists and at no additional overall cost to society. Many of these services are described in the next section.

There is increasing evidence that treatment for dementia is in the social rather than the medical realm. Yet much of the funding goes to medical interventions. Supporting people to remain [in] the community is a lot cheaper and more socially beneficial, but the majority of the health dollars are taken up in acute and residential care (NGO)

**Address the co-ordination and navigation of numerous community services.** Some of the more common solutions to this were:

- establish a national entity responsible for the delivery of all mental health and addiction services across New Zealand and ensure adequate geographical coverage
- have a regional entity provide a co-ordination function across all regional services and support
- enhance collaborative models and mechanisms across existing organisations to better identify need and co-ordinate services.

#### *Improve the standards and quality of services*

Some submissions call for improvements to the standard and quality of existing services. This was referring to either how an organisation operates and provides a service, or the competencies of the providers.

Some submitters suggested that organisations providing mental health services should be compelled to meet appropriate sector standards (that is, Home and Community Support Sector Standards). They believed that this process would lead to organisations that are managed more effectively with appropriate policies and processes in place. A few submitters wanted clear and defined practice guidelines across all organisations that underpin their obligations to show respect and legal responsibility in respect to a duty of care.

Submitters had diverging perspectives on how the workforce within community-based organisations should be made up. A few submitters thought that organisations who worked within mental health should be required to employ or have supervision from qualified and registered health professionals (that is, nurses, social workers) who meet their professional standards and have gone through more intensive training. The contrary perspective was also evident, where a few submitters suggested that the workforce be de-professionalised. They wanted a focus on ‘people-smart, not book-smart’, where services were provided by people with high empathy and caring natures.

#### *Training and development for mental health and non-mental health workforce*

(See sections **5.1: Funding and commissioning** and **5.3: Workforce**.)

The skills, training and experience of the mental health workforce was consistently identified by most submitters as of high importance. However, another large number of non-mental health workers are likely to have regular contact with, or be at risk of developing, mental health or addiction problems. Many submitters recognised a lot of opportunity exists to increase the capability of these workforces to more promptly and effectively manage mental health.

**Develop the existing mental health workforce.** Almost all submitters who commented on the existing mental health workforce wanted them to deliver high quality services,

sustainably, in a manner that caters for the unique needs of each service user. Developing and maintaining competence across an ever-increasing number of service user and family needs is difficult. However, submitters identified four key areas of focus:

- increased cultural competence, particularly for Māori
- knowledge, respect for, and application of models of health and wellbeing that extend beyond traditional biomedical models – particularly Whānau Ora
- greater awareness of the scopes, foci, and strengths of other health professions, services, and supports to enable and promote better integration of services
- the delivery of more person-centred care, including working more closely with families and whānau.

In addition to these, submitters occasionally suggested two other areas, namely:

- better training on tools and methodologies to screen for various risks (that is, drug dependency)
- empathy and people relational skills.

**Develop the general health workforce.** Many submitters recommended additional support and training to increase the mental health competency of those who work in jobs that are likely to have contact with people at risk. This includes people working within education, police, midwives, Plunket, community groups, and other health professionals who do not work specifically within mental health (that is, psychotherapists).

**More Māori mental health professionals.** As described previously, Māori and non-Māori submitters alike recognise the value and importance of having more Māori mental health workers. While upskilling of non-Māori workforce is widely encouraged and considered to be important, there are additional service user and whānau benefits when a Māori health professional is involved. The use of Māori language, a deeper understanding of the tāngata whaiora's wider social context (including barriers and effective approaches to overcome them), experience with Kaupapa Māori approaches is typically stronger and more effective when provided directly from a Māori.

### *Continuity of care*

As described previously, there are some submitters who wanted better continuity of care, by minimising wait times to access a service, improving follow-up, or providing new services that meet the unmet need. Most of these submitters described how the greatest opportunity lies at periods of transition out of a service.

In particular, discharge from hospital is a crucial and vulnerable time, where service users and their families described a need to immediately get support, if not prior to discharge. Outside of providing quality community-based follow-up, other examples of suggested services include navigation support, social work services, talking therapies, and regular GP monitoring. These post-discharge services are typically described as non-existent or inadequate in most regions today.

A few submitters suggested that longer access to services (particularly inpatient and free counselling) would ensure that people are ready to take the next steps, rather than feel that they have been forced to end therapy prematurely.

### *Inpatient improvements*

A few submitters indicated that improvements could be made within existing hospital inpatient environments. Separate wards for people with more complex mental illnesses who demonstrate more extreme negative behaviours was suggested. The reason for this was because the submitters felt that in their own vulnerable state, that exposure to these behaviours was not creating a healing environment and was detrimental to their recovery. Similarly, separation of male and female wards would make a few submitters feel less threatened (there were intimidating, and disturbing behaviours cited) and create a more therapeutic environment.

A few submitters also requested the total removal (or at least significant reduction) of isolation interventions, and compulsory treatment.

### **Fix service gaps**

#### *Services in local communities*

There was overwhelming support from submitters to see greater emphasis on the delivery of mental health and addiction services within local communities. There was a great desire to engage service users earlier, reduce hospital admissions, make services more accessible and affordable, and deliver a wider range of holistic support for those in need (including family and support people) all within their own area.

Submitters described the social, financial, and health benefits of service users receiving support in their homes or local centres and recommended that the service delivery model should change to reflect this.

**Embedding multidisciplinary mental health teams within schools and primary care settings** was recommended by many submitters. Submitters wanted children to have easy access to high quality, professional and holistic assessment, information and resources, guidance and navigation support, connection with other community services that could help, and social and/or talking therapies delivered on-site.

Similarly, the same recommendations were also suggested for adults, and primary care or other community centres were often cited as the most appropriate location to house such services. The broad consensus is that services such as these would prevent most of the more significant or severe mental illness – and subsequently reduce the need for higher levels of care.

A Mental health trained nurse in all primary health-care organisations eg GP surgeries, as a first point of call for concerned people or their families. Good referrals to support agencies for further advice and information (family advocate)

**Establish short-term facilities that provide shelter and support for times of significant distress.** There are many submitters who described situations where the service user was very distressed, felt unable to cope at home, and had been turned away from the hospital. Submitters often noted the need for short-term facilities with beds that can accommodate those in distress and provide a ‘safe haven’ until they are ready to return home. The facilities would be able to provide 24/7 access to professional and empathetic mental health workers during these periods of distress and crisis.

The service facilitates connection with other community-based services to provide additional support based on the service user and their family's situation. Submitters also commented that these services could be used to support transition from hospital inpatient care back to home.

**Establish medium to long-term residential and support facilities for those with greater need.** For those service users with longer-term or greater support needs, many submitters considered that community-based medium to long-term residential support facilities would fill a wide service gap. There were a range of different needs and individuals that these services would cater for, and there may be multiple configurations of facilities like this. For instance, those with mental illness or addictions who are under the Department of Corrections (but could potentially be outside prison), may have a need for support and accommodation to transition back into the community.

Other service users with complex diagnoses or multiple presentations might need support for longer periods. Another situation proposed was supported living arrangements where small numbers of service users live together with support to begin gradual participation back in day-to-day activities that regain their independence.

**'One-stop-shop' to provide integrated services.** Many submitters envisioned a 'one-stop-shop' located within communities where people could go to access a range of different services to maintain, or restore, wellbeing including:

- information and guidance
- culturally led support
- assessment and diagnosis
- holistic treatment, intervention and support
- referral and access to any other beneficial services
- group and peer support.

**Community outreach services.** Structured and on-call mental health and addiction services delivered to where the service user/family is was supported by many submitters. In the home, the Marae, or other appropriate locations locally, submitters requested that these services be continued and expanded to be more readily available. After hours support, particularly in more remote areas was occasionally requested by submitters. However, when coming to someone's home or local meeting point, a few submitters requested that the services remain more inconspicuous, such as arriving in non-branded cars.

Every door IS the right door when providers engage with whānau, and unlike [that which] whai ora have experienced with mainstream services, Kaupapa [Māori] service staff work outside normal 'office' hours, within their communities and in whānau homes (Māori NGO collating views of Māori NGO providers, kaimahi, tāngata whaiora, and whānau)

**Provide wellness and early intervention services.** The provision of services to keep people healthy and well have been revealed previously, but are frequently mentioned by submitters. With regard to what type of wellbeing services could be provided for those who suspect, recognise, or are diagnosed with mental illness there were many suggestions. The most common suggestions include:

- physical fitness and health (that is, a ‘green’ prescription)
- Whānau Ora approaches
- simple screening tools available to those in contact with susceptible or at-risk people (that is, midwives and police)
- spiritual services and discussion
- talking therapy during times of stress (job loss, relationship breakdown, loss)
- practical tools, support and advice to tackle key causes of situational stress (that is, financial planning, employment services, accommodation)
- services that engage people in activities that promote the formation of social connections
- group and peer support to help support people through challenges (that is, Alcoholics Anonymous).

**Respite for families and carers.** Many submitters identified the constant strain and demand on families and carers of those with mental illness or addiction problems. The care and guardianship role can be relentless and stressful, and submitters place great value on the roles they perform. It is perceived that supporting people in a safe and comfortable home environment leads to better recovery, outcomes, and places less burden on the mental health services. However, the families and carers need time and space to ‘rest’ and ‘recharge’ and having more available respite care is deemed important to make the situation more sustainable.

#### *Person-centred and family and whānau-centred approaches*

Many submitters believed that the current services could benefit by taking a more person-centred approach. While in some cases there was demonstration of exceptional person-centred approaches, service users and mental health workers alike described that there was plenty of room to improve.

There were a few transformational approaches suggested that were designed to deliver a system-wide approach to person-centred care, but these larger ideas are covered in the sections addressing ‘system’ rather than service changes. Submitters appear to have a few different perspectives of what the defining characteristics of person-centred services are. However, there is mostly significant overlap and factors in common are highlighted here.

- Family/whānau are included with the service user as the focal point of all support and services. They are considered as one.
- The service user understands what they are going through, and are informed of the possible options to support them
- The autonomy and involvement of the service user to plan and choose the approach or intervention, and informed consent is provided
- There is consideration of the service-user’s wider context during assessment and intervention, where not only the symptoms, but the causes are addressed
- Support is flexible and meets the holistic needs of the individual and their family, including cultural and spiritual needs. This support helps them overcome the obstacles to wellbeing.

- Those involved show high levels of empathy and respect for service users, whānau, and carers.
- Organisational systems and process barriers are removed, the focus is on making it easy for the service-users. There are no barriers to access.
- When help is sought, responses are rapid, high quality, and effective.
- Support is provided in the place where it is best for the service-user.

**Involved in planning and decision-making.** Many submitters indicated that families and whānau should also be more involved in planning and decision-making. While in some cases there are dysfunctional family units, most submitters believed this should be occurring as the standard practice.

Families must be more involved in the decision making and treatment of their loved ones (bereaved family member)

Another essential aspect of a whānau centred approach is growing the capacity and capability of whānau to make decisions for themselves and plan for their future, thus is orientated to whānau aspirations rather than deficits (Māori NGO provider)

Some submitters wanted the service users themselves to be more in control of the decisions made around intervention options and planning. They should be more informed and supported to make the right decision for them. Informed consent was identified as lacking in a few submissions, as was the issue of compulsory treatment.

Not just one thing works, and every person is different, we need to learn to adapt to the needs of the patient on a case by case basis. The patient needs to make the decisions of their own personal recovery.. ongoing support is needed (service user)

**Provide support directly to the family.** As indicated previously, many submitters felt that the family/whānau themselves needed support focused directly towards them, not just the service user. Information, education, and coaching to better understand what is going on, how they can best support, and what to do during periods of increased distress were frequently requested. However, other commonly described supports were child-care, transportation, supervision, social activities, grocery shopping, financial advice or assistance, respite care, counselling for family members, and having support groups or people to talk to. Postvention suicide support to families, schools, teams and wider groups is also supported.

**More informed – self-help and general information.** Some service-user submitters wanted better access to information that they could use independently. They wanted to access better online or physical resources to help them understand:

- more about their mental health condition including triggers, and self-management strategies
- who might be able to provide help and how to access it
- what treatment and intervention options are available
- more about medications, risks or side-effects, and weaning.

### *Services that provide low-level early information and navigation*

Providing low-intensity services that can be accessed easily and early was a common theme across submitters. Particularly services which provide the service user and their family with information and navigation support, delivered by a 'caring' individual or group. Many submitters identified this as a service gap, but there were instances of groups who provided these types of services, but these were not co-ordinated across multiple regions, or had minimal capacity and funding to reach an entire community.

The trigger to access these services was described by submitters as one of three main situations.

- The individual reaches out for help and information.
- A friend, colleague, family member or community member identifies possible need.
- A mental health or addiction diagnosis has been given or referral via a mental health worker.

### *Alternative primary care services*

The role of primary care in mental health was mentioned often by submitters. The future role of primary care, and specifically general practice, in the pathway of mental illness and addiction is not entirely decisive in the eyes of submitters. This is because submitters identified many different solutions to overcome the current challenges of mental health and addiction within primary care.

There was, however, strong support for a shift away from the harder-to-access and more centralised specialist services, towards localised primary care and community-based support. It was regularly highlighted by submitters that there could (and should) be better integration and co-ordination between primary care and the community groups to tackle mental health and addiction.

**Two options for general practice.** Analysis of most submitter's responses on this topic highlighted two major themes (with some overlap), both of which necessitate change from the status quo.

The first option was general practice retains and strengthens its position as the main pathway to access mental health and addiction services with extended session durations, more frequent monitoring, reduced use of medication, greater access and referral to more holistic approaches and interventions, lower wait times, and much lower costs are all regularly recommended changes to make this pathway more effective.

The second option was general practice gives more responsibility to other mental health workers. The most common themes included within this scenario are:

- embedding mental health teams within primary care settings (that is, occupational therapists, social workers, psychologists, counsellors, mental health nurses)
- earlier and direct access to funded low-intensity community-based services (that is, Māori services, navigational support, support groups, peer support, counselling)
- community-based organisations referring directly into higher levels of care (that is, psychology and psychiatry)

- pharmacists playing a role in the prescription and ongoing monitoring of some medications (such as suboxone and methadone).

**Stepped care model.** Submitters wanted service users and tāngata whaiora to have their needs met earlier, and receive more complete and culturally appropriate care, within the community, with reduced need to escalate to specialist care. A stepped care model was cited regularly by health professionals.

Collaboration by primary health organisations and district health boards to implement the stepped care model ... this approach involves:

- Using the least intrusive treatment required to meet the presenting need
- Making available interventions with differing levels of intensity
- Matching people's needs to the level of intensity of the intervention
- Entry and exit at any point
- Using robust tools to routinely collect outcomes data to support people's journey into, through and out of services
- Having clear referral pathways between different levels of intervention
- Supporting self-care as an important aspect of managing demand across primary, community and specialist care settings (professional organisation)

The main differences across submitters seem to be with 'who' is providing 'which' components of care, and 'how' these are accessed and funded. Submitters clearly wanted services in the community, at the time they need it, at low/no cost, and they wanted better integration across general practice, mental health workers, and community groups. This can be achieved by enabling GPs to do more, enabling other groups to do more instead of GPs, or enabling both.

**Improving primary care services.** Other themes regarding primary care identified by some submitters were:

- more free counselling sessions available when referred from primary care (currently seen as inadequate)
- to address cost some submitters wanted free GP visits for all mental health patients
- better guidelines to support health professionals with the process of diagnosis (a few comments mentioned that service users mostly come to primary care with a self-diagnosis)
- more frequent medication reviews
- easier to navigate mental health referral pathways from primary care (particularly into alternatives to specialist care)
- joint assessments with other mental health workers to improve integration and cohesiveness
- gain more relevant information within the 15-minute GP appointment by having the patient complete, before their appointment, a comprehensive online assessment

that includes questions about diet, exercise, and more to provide a broader picture than what the GP can cover in 15 minutes

- addiction services embedded within primary care.

**Other service considerations.** A wide range of other services recommendations from submitters involved more fundamental and system-wide changes. These are described in chapter 5: System design and implementation, and include topics such as Open Dialogue, recovery-oriented care and implementation of a National Suicide Prevention Centre.

**Better data capture and sharing.** It was identified by a few submitters that New Zealand and the mental health and addiction system needed to improve the way it captures and uses health information. They described the value in having good data to better understand the current situation while also enabling more informed future-focused initiatives and solutions to target the areas in most need. This is covered more fully in section **5.2: Monitoring, data and evaluation**.

**Improved prescribing and monitoring of medication.** Perceptions of over-medicalised treatment approaches were prominent in many submissions. To replace this, some submitters suggested more holistic person-centred approaches, and a change of messaging delivered from health professionals about the use of medication. Describing medication as just one of the options within the ‘toolbox’, and that other approaches should be tried first, will help reduce perceptions that medication will ‘fix’ them. If GPs were more aware of the mental health services, and these were better integrated with primary care – then alternative options may also be more used.

**Other suggested changes** include more frequent and accessible medication reviews, lower doses of medication, better information about side-effects and weaning, and enabling Pharmacists to prescribe and monitor service users on particular longer-term medication (methadone and suboxone).

## SUBMITTERS' FOCUS ON INTERNATIONAL INITIATIVES

The following is a sample of some of the international initiatives that were mentioned positively within submissions.

**Scandinavia** (including Sweden, Norway, Finland, and Denmark): These countries are noted as having social policies that are child and family-centric; asserting addiction as a health issue and implementing harm reduction models; alcohol availability is regulated through restricted off-licence hours; a commitment toward integrated and rehabilitative care for those in corrections contexts.

The Open Dialogue approach developed in **Finland** – an innovative collaborative approach to treatment whereby professionals, families, the service user, and other key members of their social network all work together to understand the crisis and find a way forward through discussions and home meetings. Medication is used where necessary, but is not considered the primary method of treatment.

**Australia**: a mental health funding model that largely removes the barrier of cost in accessing services, enabling better utilisation of psychologists and talking therapies.

**Portugal**: positive approach to decriminalisation and drug recovery - personal use of illicit substances was no longer a crime and substance users were given easy access and encouraged into treatment resulting in decreased drug-related harm and increased help seeking.

**Iceland**: innovative youth substance approach focusing on creating opportunities for youth to 'feel good' without taking drugs, and included providing government sponsored (free) recreational and after school activities for young people (organised sport, art, music, dance, other community activities), as well as more parental involvement. Iceland has moved from highest to lowest in EU for drug related harm among youth

**Canada**: as a means of reducing homelessness, look to Canada's 'Housing First' approach that aims to assist those who are homeless into permanent housing; The Nova Scotia 'Bloom Programme' – a partnership between mental health and pharmacies that provides medication therapy management, navigation of the system, referral, and education and resources.

**Scotland**: the use of brief interventions for alcohol that is delivered within primary, crisis, and antenatal settings, as well as alcohol regulations; particularly setting of minimum pricing for alcohol; Scotland's example to enshrine a mother's entitlement to a specialised mother and baby unit during inpatient care within its Mental Health Act; the Scottish Mental Health Arts Festival.

**Alaska**: The re-design of an indigenous health model, such as the Nuka system of care – a system built upon a partnership between the Southcentral Foundation and the Alaskan Native people, providing a broad, integrated approach to care and wellbeing, including access to traditional Native healing.

### 3.3 Integration of services

#### 3.3.1 Overview

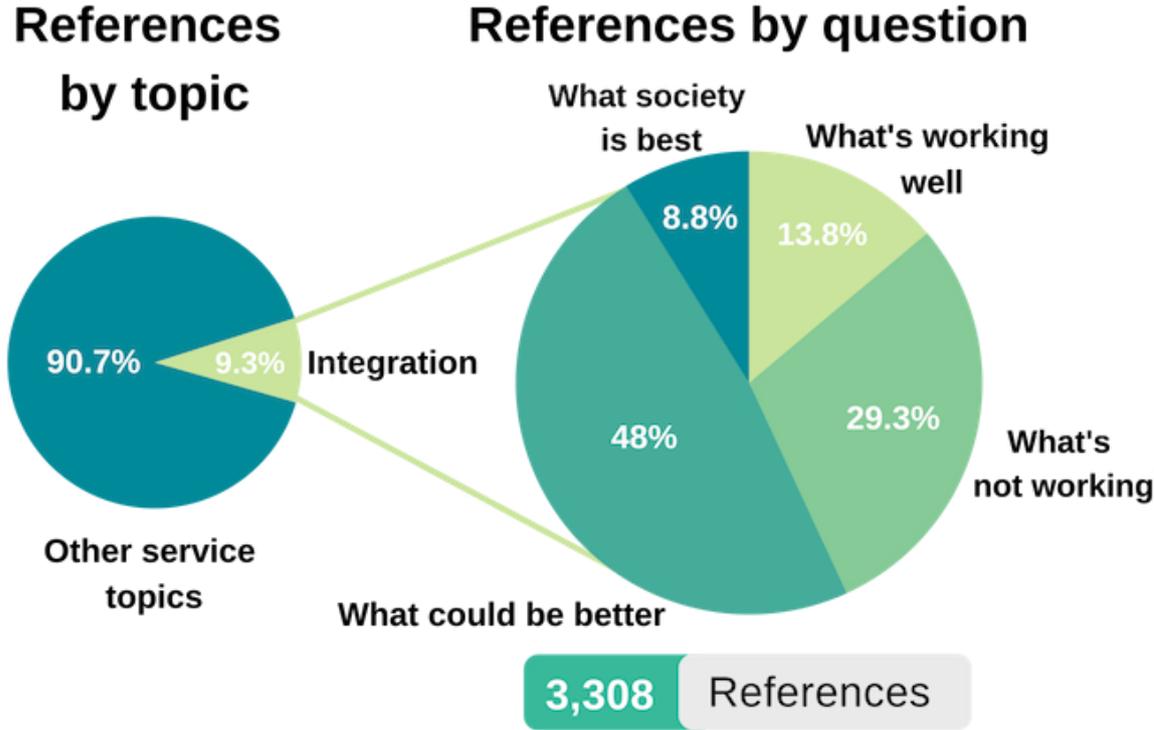
This section presents an overview of responses from submissions related to the integration of services. The concept of integration is wide and has meant different things to different submitters. Submitters often used the word 'integration', but the context in which they used it varies and so 'integration' contained several different elements.

At a system level for integration, see also sections **2.2: Leadership for change** and **2.5: Social determinants**.

Submitters made 3,308 references about integration of services.

Of the comments about integration of services, just under half (48%) focused on what could be better, 29.3% focused on what's not working, 13.8% focused on what's working well, and 8.8% focused on what society is best (see Figure 3.4).

FIGURE 3.4: SUMMARY OF RESPONSES ABOUT INTEGRATION OF SERVICES



As an overview, submitters described the most common elements of integration as:

- **comprehensive** – the delivery of more than one function or service often described as ‘wrap-around’, ‘end-to-end’ and ‘joined up’, and that usually consist of close working relationships, multidisciplinary teams and multi-organisation teams
- **holistic** – the services address a wide range of needs that are not only within the narrower scope of ‘mental health and addiction’; in particular, considers Māori frameworks of wellbeing and addresses contributing causal factors such as social determinants
- **co-ordinated** – assessment, planning and delivery functions are organised, collaborative, and consider the views and inputs across more than one group or individual, and there are high levels of communication with responsiveness
- **continuous** – there are no undesirable service gaps or waiting, and transition between services is cohesive and seamless
- **person-centred and goal-oriented** – shared goals across different services where all involved are trying to achieve what is important for the service user or tāngata whaiora, which is in contrast to narrow and predetermined service goals and outcomes
- **co-designed and collaborative** – planning and intervention is centred on the individual and their family and whānau, but also includes and draws on the wisdom and expertise of others who can add value in this process
- **empowering** – the individual and their family and whānau take responsibility for decisions and are supported and empowered to make them
- **integrated health information** – technology and systems that support efficient and effective information capture and sharing, which allows appropriate access to the right information for those who need it, with the individual’s informed consent
- **led by systems thinking** – where experiences, information and learning can be captured, analysed and shared to inform future service and system improvements.

**KEY THEMES FROM SUBMISSIONS FOR INTEGRATION OF SERVICES INCLUDE:**

**3.3.2 What's working well?**

- integrated Māori approach
- building diverse and multidisciplinary teams
- relationships across organisations
- it's all under one roof

**3.3.3 What isn't working well?**

- current pathway is based on traditional medical models
- poor integration impacts on outcomes for Māori
- current structures not designed for integration
- funding divides, does not integrate services
- poor continuity and transition across services

**3.3.4 What could be better?**

- integrated and collaborative Māori services
- structural and organisational change
- person-centred goals and support
- look at specific integration opportunities

### 3.3.2 What's working well?

In some areas, submitters indicated that elements of integration are working quite well. Internal integration, external integration and access at one physical location are described below.

#### Integrated Māori approach

Integration of services and support is working well in certain areas according to some Māori submitters, albeit frequently under-funded. Key characteristics described by Māori submitters include where:

- whānau and the wider community work together to lead the approach
- communication and co-ordination occur between Māori-focused services and mainstream services, particularly primary care and NGOs
- workers across different agencies and organisations work together to identify and meet the needs of tāngata whaiora and whānau
- navigation and continuity of services is provided seamlessly, particularly at points of transition
- services are targeted across the entire spectrum of age.

Communities are working because they are committed to doing so: the commitment of the community is probably 80% of it working. What is working in the community? It's community that's working in the community (kaimahi Māori)

What's working well? Whānau in [location] are working with government agencies—"it's working together that helps" (Māori volunteer)

[Organisation] has been going for over 28 years in the community. Their approach should be recognized as an example of what's working: Client and community led approach – outcomes are not based on the services provided; it's about who provides them and how. So our services are often designed from the ground up by clients and we use feedback that supports the journey and changes regularly to know what works – fit for each individual client. [Organisation] contracts is 'tick box' and we do that but we also see gaps and take risks and incorporate what our people want then try and grow it led by whānau (kaimahi Māori)

They have a solid Māori provider there with Whānau Ora navigator—the providers are working together, and the Māori provider is larger and better funded than the hospital. Took a long time to work together but in a good space now. Looking at single point of entry—triage to GP practice owned by Māori provider. Coordination around accessing services; hospital and council-based website facilitates this. Developing maternity hubs, etc. Rural areas have some idea of what services are but get lost in the DHB side of things (kaimahi Māori)

### **Building diverse and multidisciplinary teams to meet wider needs**

Some submitters spoke of good examples where organisations are building internal teams with broader skills and experience. These multidisciplinary teams were regarded as setting themselves up to better understand, co-ordinate and meet the diverse needs of service users, tāngata whaiora and whānau. Submitters found it beneficial that these organisations and teams recruit or upskill themselves to deliver more holistic services.

[Organisation] has been operational in [region] for eighteen years... and provides a HUB range of wrap around services for the benefit of local community e.g. Addiction and Problem Gambling Counselling, Advocacy, Disability Support, Stop Smoking, Community Nursing and a very low-cost GP service... This enables a wraparound service method and leads to reduced barriers to engagement... and treatment by providing strong internal service 'cross pollinated' approaches. An example of this is collaborative work between our addiction service to G.P consultation. This provides robust/ timely, and clinical collaboration for shared client aspirations and wellbeing (Māori NGO providers)

Continuity of care provided by psychiatrists across inpatients and community settings enhances the therapeutic relationship and reduces the need for service users to tell their story over and over again (DHB)

### **Relationships across organisations**

A few submitters described how relationships and collaborations have sometimes been formed across two or more groups and organisations which has lead to better experiences

and outcomes. Having people who can navigate, guide and communicate with others was regarded as important for those in times of distress. Submitters noted that integration across organisations increases overall awareness and knowledge of a wider range of services and supports available, and can facilitate direct access to them.

General practice [name] and liaison works very well. Face to face psychiatrist and GP meetings occur on a weekly basis. This has had favourable outcomes for whānau. Included in this relationship is access to alternative interventions such as equine therapy. The effectiveness for Māori with moderate mental health issues has very positive with a significant reduction in re-presentations to General Practice (NGO provider)

Some DHB's have an Oranga Tamariki liaison person. When this relationship works well, this is an invaluable resource and link between services (professional organisation)

One of the real strengths of the [DHB mental health service] is the relationships between the specialist services and non-government organisation (NGO) and Iwi providers (DHB)

### **It's all under one roof**

Submitters described a few examples of facilities that act as a 'one-stop-shop' for some service users and tāngata whaiora. By providing a range of different services and support within one location, service users and mental health workers feel that integration more readily.

We are lucky to have three Youth One Stop Shop primary health services for young people in our area and we have good working partnerships with these organisations. They provide invaluable and very popular service with a mix of health and social service interventions for young people, many of whom experience significant mental health and substance mis-use issues. Working more closely with these organisations over the past few years has been beneficial to us, our service users and reportedly to them (DHB)

Ease of access to our Mental Health and Addiction services and access to all services under one roof - effective management of Dual Diagnoses patients (mental disorder + substance addiction) (DHB)

### **3.3.3 What isn't working well?**

As indicated above, there are some good examples of integration making positive differences to service users, tāngata whaiora and whānau. Unfortunately, this is not often the case. Many service users and their families can point to numerous examples where there has been poor cohesion, communication, and fragmentation during their service experience. Occasionally, with severe consequences.

### **Current pathway is based on traditional medical models that are not working**

Submitters frequently indicated that the traditional medicalised 'treatment' pathway is ineffective, costly, and no longer meeting the needs of society – particularly with regard to mental wellbeing. The usual route of going to a GP, obtaining a diagnosis, being prescribed 'treatment', then reviewing again in a couple of weeks was regarded by submitters as not fit

for purpose for mental health and addiction. This same model also engages specialists with a narrower scope and even higher levels of training and experience when more advanced diagnoses or treatments are required. Service users described how the gap between specialist reviews and treatment can be even larger.

Improve integration between community services, primary care, and secondary care. GPs struggle to get people seen in secondary care; can't get the advice they need and it's hard to hold a suicidal patient in front of them... People with long term severe mental illness need regular good health checks; some people do fall through the cracks so we need to build that integration. Health professional body (health professional)

The same submitters, plus some health and non-health organisations, said that this model has not kept pace with the changing needs of society. For mental wellbeing in particular, the traditional model's ability to prevent and manage distress and addiction was considered inadequate by itself. Now, more holistic approaches are sought but the sector remains predominantly fragmented. Despite best intentions and efforts to address this, submitters described how integration between holistic wellbeing approaches and traditional models remains haphazard. Fragmentation exists across many holistic services, and similarly, across the traditional services (that is, between primary and specialised services). Even submitters who work within mental health or addiction found it difficult to navigate. As a result, many service users, tāngata whaiora, and whānau submitters described significant service gaps and confusion about how to find and receive the right support.

GP, pharmacist and specialist are not part of a joined-up service... Systemic barriers related to complexity and fragmentation – consumers expected to travel around to different sites – e.g. travel across town to DHB, travel for a blood test, wait for results (professional organisation)

### **Poor integration impacts on outcomes for Māori**

The seamless delivery of integrated services for Māori has numerous challenges, many of which were identified by Māori submitters, including:

- poor continuity of care, particularly around discharge and service transition points
- lack of mainstream provider understanding of Whānau Ora and appropriate cultural responses to Māori, which leads to lack of involvement of more appropriate cultural services and support mechanisms
- Māori have a higher prevalence of mental health and addiction problems, but streaming Māori into criminal justice pathways, rather than treatment and rehabilitation pathways exacerbates these issues; also, integration between these systems is poor
- lack of a consistent and integrated approach to tackle the wider socioeconomic situations tāngata whaiora are in hampers the long-term effectiveness of all interventions
- lack of funding for holistic Māori services and support is a barrier to the right services being provided for Māori.

Client of community mental health was abandoned after coming off the ward; staff members did not have understanding to work with Māori and beliefs and culture; relied on meds to shut her up and there were no options for how she could grow or get referrals for other services (tangata whaiora)

The links between services are currently missing, subsequently whānau are not provided with the supported needed. Many of the services tend to criminalise mental health and addiction problems, care and protection; youth justice residences and prisons become default holding pllor those with arguably the most considerable mental health and addiction issues (Māori health leaders and colleagues)

[The trust] has committed itself to transforming itself into an integrated whānau ora provider but we are disappointed at the slow embrace within government to transform its purchasing recognising whānau to not live in silos – especially Mental Health and Addictions whānau who invariably have – health; budgeting; social; housing; justice; education and employment issues at the same time that require attention (Māori NGO provider)

### **Current structures not designed for integration**

Many health and community organisations described a continual struggle to provide more integrated and connected services. Some submitters identified likely causes for this difficulty. As described previously, submitters indicated that services need to be responsive, culturally appropriate, holistic, accessible, and affordable. Many submitters pointed to inadequate governance, accountability and funding to reduce the impact of mental health and addiction on New Zealand. The need to address social determinants and causal factors means that the responsibility for improving the wellbeing of New Zealanders sits across multiple sectors, such as the housing, health, education, social, corrections and economic sectors. Submitters described how this lack of system-level integration makes it exceedingly difficult for the right combination of necessary services to integrate beneath it.

Caller has concerns about ACC [Accident Compensation Corporation] who rely on experts from their agency to determine whether a death was a suicide. Caller queries what was the point of having a coroners inquest if ACC is not going to use this information in their determination of outcome (bereaved family member)

There is a lot of time used up in handover: referral, assessment, multi-disciplinary teams etc.—spend a lot of time pushing back on referral rather than solving the problem. Time wasted at every step in the system, need to reframe the system to use that time efficiently and increase safety (health professional)

Submitters described too many competing priorities, service constraints, competition for resources and workforce, and a lack of clear leadership or co-ordination to be able to more effectively integrate services. Funding for joint sessions is not well supported or encouraged in current mental health service contracts or across different services. Service integration is easily dropped from priorities, particularly as it normally requires significant effort to plan strategic and operational activities together. The appetite and timing for change must be ‘just-right’ across each participating organisation, and this seems rarely the case.

## Funding in a way that divides rather than integrate services

Typically, submitters described that the organisations working in the mental health and addiction sector receive funding for delivering an agreed set of core services within a defined scope. Key performance indicators and measures of inputs and outcomes are used to monitor performance, which can affect future funding. Most organisations reported consistently high demand and stretched staff and despite a general desire to deliver more holistic and integrated services, as soon as pressure comes on (to meet demand using the same resources) services then:

- narrow the scope of support (to only core activities – less holistic)
- reduce the numbers of people who enter the service (that is, introducing/increasing thresholds or only accepting certain cultures)
- reduce time working with each service user (reducing effectiveness)
- reduce time communicating and collaborating with other team members and organisations to cope with workload

There was a lack of follow up support regarding his mental health because it was seen that it was the alcohol that was causing his issues and behaviour. He fell into the 'grey' area of their admission criteria (family member)

Lack of service integration as can't access mental health services because of addiction issues (family advisor)

We have 22 contracts and all of which are audited differently. We only have 15 mins to see whānau and we need to make capacity to get people seen (kaimahi Māori)

When organisations pull-back on services, access, and communication it leaves service users, tāngata whaiora, and whānau more likely to experience a service gap and/or fragmentation. A few organisations who accepted people that were turned away from other organisations spoke of this leading to sentiments of irritation, and on rare occasions, mistrust towards organisations.

Same with mental health partners—people are dumped at our door while they're taking off (kaimahi Māori)

A few submitters mentioned that they were seeking resources to sustain, grow, or initiate services in an area which they noted creates a degree of competition between organisations for the limited pool of funding available.

The professional scope of many health professionals is defined by professional bodies and is linked to training organisations. A few submitters noted a lack of education and exposure to integrated concepts during professional training programmes. Holistic Māori approaches and working closely with family and whānau would be two examples. As each profession attempts to define itself uniquely, often highlighting points of difference – it can lead to minimal overlap in skill-sets, or even understanding, of other professional scopes of practice. This is problematic when trying to integrate services.

Lack of awareness about Alcohol and Drug issues by mental health team in [emergency department] (family advisor)

Historical divide between mental health services and other health services—it's an psychologist ethics issues re: privacy and not trusting other professionals to deal with it (health professional)

Lastly, many submitters highlighted how information management also causes divisions across the mental health sector and others involved. Different practice management systems, privacy concerns and practices, explicit and implicit 'rules' that constrain activities (that is, who can refer to who), and heavy administrative requirements (which may be different for different groups), are all barriers identified by submitters that must be overcome to integrate effectively. Mental health and physical health records are kept separately, and this can undermine integration and compromise care.

When we are unwell we do not need the stress of managing referrals, assessments, and engagement with different agencies without someone there to assist us to do so (service user)

we don't even get told (at school) if our students are at risk. Quite a few students self-harm and attempt to jump off the roof. When mental health workers go into the school they don't communicate with the school around high risk and the school doesn't find out until it's too late and they have to deal with that (Māori contributor)

### **Poor continuity and transition across services**

Reflecting common service themes identified previously, many submitters frequently described a lack of continuity and poor transition across services. Starting from awareness and prevention, many submitters stated that there are missed opportunities for an integrated response when recognising warning signs and risks early. Submitters found it difficult to connect those in need with those who can meet that need when the mental health system is too complex, difficult to navigate, and contains so many different organisations.

Community services: there are different contracts with different NGOs and it takes time to navigate those; the NGOs come and go. Quite difficult for [alcohol and other drug] service and also re: shared care—aren't together within the practice. The system doesn't work together as a whole (health professional)

The difficulty co-ordinating the right early intervention support before needing to visit a GP highlights many failings of service integration. Addressing social determinants also may require the services of multiple agencies and organisations. Some submitters noted that many needs are often going unidentified as each organisation and worker are capturing only what information they need to perform their own part, and within their own scope. Similarly, getting the right wrap-around support once diagnosed or in states of moderate distress or addiction was regarded as problematic. Submitters described poor communication and transition between services, and information was not shared effectively which often resulted in the service user having to tell their story more than once.

Caller does not feel that there is interaction and handing over of knowledge between the services. Caller gives the example of Doctor, Ambulance, Police all being involved with son and no information was shared between each (family member)

Many submitters commented that there does not appear to be much shared planning across services and supports, follow-up or provision of relevant updates. 'Who' provides 'what' type of support during periods of wait was also considered haphazard or not clearly known by most submitters, who also often cited being turned away from services during acute distress which leaves the service user not knowing where else to turn.

Caller feels that she and her husband were let down each time they went to reach out for help and that when it all started to go wrong, all of the doors were shut (family member)

[Contributor] said "we need to work with mental health team and navigators" but [the client] said the navigator was taken away and mental health services told her to stand on her own two feet. [Contributor] recently tried to meet up with client's new mental health nurse but nurse said this was not a recovery model and client needed to learn to be independent (NGO)

Submitters frequently cited a key integration failure at the point of discharge from inpatient care. While some submitters acknowledged that they were discharged with a plan, there was minimal/no support to follow-up and support its achievement. A lack of good handover to another service, joint sessions, and/or responsibility to provide consistent support throughout an entire period of distress contributes to a fragmented experience and service gaps.

Unmet need for support to transition out of acute mental health care (government agency)

### **3.3.4 What could be better?**

Services must be coordinated and integrated to meet the full range of social, psychological and physical care needs of individuals with mental health problems. The structure and organisation of mental health services should facilitate and encourage continuity of care. Seamless mental health services should be available in a continuum stretching from the community at large to primary care and specialist mental health services (mental health professional)

Submitters who have commented on integration have almost always expressed the need for more integrated services. Integrated services are described as potentially providing numerous benefits to service users, tāngata whaiora, family and whānau. These benefits include a reduction of service gaps, better use of the capacity and capabilities of the wider workforce, reduced wait, ability to provide support earlier, preventing worsening, reduced cost, and more-effective and long-lasting interventions.

Submitters explained that integration needs to occur both horizontally (across different functions) and vertically (across different steps or stages). For integration to make a tangible difference for the individual and family or whānau, it needs to happen with the people who they are in direct contact with and across those in other organisations and agencies who are (or should be) also working directly with them. This is considered service-level integration. However, as described previously, for service-level integration to occur there needs to be good system-level integration. The majority of submitters recommended significant system-level changes to improve integration and unlock the integrative potential (and removal of

barriers) within the services. While briefly acknowledged in this topic, most system-level recommendations are discussed in chapters **2: System and society** and **5: System design and implementation**.

### **Integrated and collaborative Māori services**

Māori submitters highlighted that integrated service opportunities for Māori predominantly exist in several forms. There was major support for integrated and collaborative approaches across all organisations, groups, and whānau, including:

- access to (and delivery of) local Māori services (delivered by Māori) that take a Kaupapa Māori and Whānau Ora approach, with access to integrated Māori services using three possible approaches (from least to most integrated):
  - Māori services can be accessed instead of mainstream services (least integrated)
  - Māori services can be accessed in addition to mainstream services
  - Māori services are integrated within and as part of new mainstream services (most integrated)
- better awareness and capability within mainstream service providers and services to deliver more integrated and holistic approaches with much wider types of support than is currently provided that also addresses social determinants
- use of Māori navigator roles to support the holistic needs of the tāngata whaiora and whānau
- better connection and links formed across communities, services and agencies to easily involve all who should be involved, and supporting the ‘every door is the right door’ concept
- different options for tāngata whaiora and whānau, letting Māori determine which is the right path.

Solutions are about collective impact and people collaborating to work together to make change. We work with other NGOs and PHOs around the wellbeing of our people, we’re not siloed. Any door is the right door and it has to be for our whānau and we adapt to do what’s right for our whānau. Services should be in the community—we need to bring the people, not the voice of services or DHB or ministry—the people know what is right and how they can maintain their wellbeing (kaimahi Māori)

Our staff have found that often it is not just mental health conditions that one is dealing with, but often the client has other coexisting conditions. Therefore, they often need help to address the other medical issues that can have an impact on their mental health as well (Māori NGO provider)

The Whānau ora approach actively facilitates every door is the right door when Whānau knock. Utilising the collective resources of organisations to support the aspirations of Whānau is pivotal to supporting a wellbeing pathway. Therefore, an analysis of access pathways, eligibility criteria, service scopes and purchase units must be considered from a Whānau access perspective, rather than an agency efficiency lens (Māori NGO provider)

Any changes must be whānau centred, that the voice of Māori kaimahi in the field, of whānau and tāngata whaiora be enhanced to enhance the cultural capability of mainstream services. We advocate for localised solutions including recognising the essential role that individual and whānau agency is to the successful prevention and healing of tāngata whaiora (Māori NGO providers)

Choice for Māori to pick a path through the services that best suits them – from acute three streams – general rehab, male only, and kaupapa (kaimahi Māori)

## **Structural and organisational change**

To meet the diverse needs of individuals, submitters frequently requested more comprehensive and holistic services are delivered. The need to reduce fragmentation and silos is commonly described and submitters wanted to be able to easily access a range of different options seamlessly. Commonly suggested structural approaches to achieve this typically involved consolidation of the number of service organisations, but broadening the scope of services provided to include Māori wellbeing models, and preventative services (that is, social determinants, wellness and early intervention). Examples included amalgamation of:

- many of the NGOs, community organisations and groups
- primary care and NGOs, community organisations and groups
- primary care and secondary care
- all the mental health and addiction services (including NGOs, primary care and secondary care)

Joined Up Services – The journeys people follow through life should be paved with services that work together with few gaps and high levels of cohesion to improve outcomes. In practical terms this means that services that must work together, to support/provide self-care, primary care, secondary care, mental health and physical health care need to be managed, planned and funded together in ways that do not create barriers or silos (health professional)

How we fund services also needs to be revised with more focus on collaborative funding models with a move away from the competitive RFP model. We need to foster a ‘co-built’ approach that requires providers and services to pool and share resources to achieve a common objective (NGO provider)

Submitters occasionally stressed that consolidation and amalgamation would improve the co-ordination and cohesion of supports, promote greater learning across disciplines, and increase efficiencies (that is, reduced information technology costs and reduced efforts to govern each independent organisation) and reduce overheads.

However, some submitters recommended that integration could be improved by:

- co-locating different organisations and services in one premises
- taking innovative collaborative approaches to share funding across different organisations and forming multi-organisational teams

- co-ordinating joint community outreach services across different organisations
- allowing for direct referral into appropriate service without gatekeeping.

High levels of need often cluster in a small proportion of the community and typically needs will arise in a number of settings simultaneously, it is vital to not address these one at a time or leave major needs unmet. So when an individual comes to the attention of one service the wider needs must be considered (health professional)

Have access to a comprehensive range of community-based services and supports (Mental health sector leaders)

Adapt models of care to work across disciplines and organisations (mental health professional)

These changes would likely require significant time, effort and cost to align aspirations, and collaborate closely to co-design the solutions. However, many submitters regarded these integrative steps as fundamental to a better mental health system.

## FOCUS ON BIPOLAR DISORDER

Submissions received from those with lived experience of bipolar disorder, or their family and whānau, shared experiences of heartache and frustration. Inconsistent staffing and a lack of access or continuity of care were challenging. Poor communication between professionals was also highlighted. Many spoke of suicide attempts or losing their loved one to suicide. Co-occurring issues with alcohol and other drugs were also common and sometimes described as self-medication.

After 12 years of issues including suicide attempts, reaching out to mental health services several times a year, not once was I seen by a psychiatrist even though I had a pattern of behaviour that clearly pointed at bipolar (service user)

Suggestions of what could be better included the following.

- Increase access to support and treatment other than medication, including support groups, psychotherapy, mindfulness, cognitive behavioural therapy, micronutrients, and residential facilities with wrap-around care
- Dialectical Behaviour Therapy was regarded as particularly effective and recommended that it become more available; including employing more staff trained in dialectical behaviour therapy.
- Carefully support those who want to reduce their medication, providing the necessary education and therapeutic services for effective management of withdrawal symptoms.
- Include the perspectives, concerns and input of family and whānau members. Ensure they are listened to, supported when caring for a loved one, and provided education about bipolar.
- Include peer support during psychological evaluations and appoints “because there is a big difference between a psychiatrist with a script pad and a person who’s been taking the meds and knows what actually works.” (service user with Bipolar)
- Train and educate staff in care for people with bipolar, to be non-judgemental, and to use reflective practice to improve and learn from mistakes. Ensure service users have the same psychiatrist for at least one year.
- Seclusion for acute relapses of bipolar can be effective and necessary in minimising harm to self and others, so long as it is implemented with proper attention to rights and respect for the person.
- Increase widespread education about bipolar, and provide service users with more information about the side effects of medication.

I wish people would use their words carefully ... the girl is psychotic, the guy is just crazy, they must be bipolar. words hurt we are not all psychopathic horrible humans. we are gentle, kind, loving, we are mums and dads and siblings, we are aunties and uncles and grandparents. we are not murderers or something to be scared of (service user with Bipolar)

The hopelessness of it, if you are told you have this illness for life it doesn’t offer hope for people. There is hope and there are good outcomes, people should be told that (service user with Bipolar)

## **Co-ordinate and communicate to improve cohesion and continuity**

Submitters often described how factors that enable robust planning, co-ordination, and communication are extremely valuable for good outcomes. Outside the structural changes discussed above, supporting technology and processes featured regularly. However, even more importantly, submitters cited that investing enough time and fostering the right relationships are critical. However, many described that these are some of the first elements of a service to deteriorate when under pressure. Informing and involving the right people during planning, decisions and the provision of support is difficult and takes time. Submission from family and whānau described wanting more information and more involvement, while other providers of support and services should also be consulted. Many submitters called for more emphasis, guidance, expectation and funding to do this better. Submitters highlighted how awareness of the various services and supports available is integral for this, and simple mechanisms to engage their help would be beneficial.

I find the fact that my GP, psychologist and psychiatrist all working together, i.e keeping each other informed as to whats going on has been very helpful. In terms of my addiction its been good to have everyone in the loop (service user)

A more collaborative culture between service workers, clinicians/professionals and between professional groups, departments and organisations (NGO provider)

Consistent identification of all the wider holistic needs as early as possible was regarded by submitters as important to build and co-ordinate a multidisciplinary team around the individual, family, and whānau. Submitters wanted those involved in their care to be able to easily navigate and contact others who can help yet minimise the number of times someone is required to tell their story. Submitters wanted mental health workers to use consistent tools and processes to capture and share information, and to collaborate as part of a team – even if they are from different organisations.

More integrated health Care providers such as 'Whaiora' as developed and proposed by Mason Durie. I have seen this work exceptionally well. All health, mother and child needs and social services were under one roof. The high level of co-ordination and co-operation prevented those in need from slipping through the cracks. The only thing missing was a Mental Health professional. Whats more it was affordable, easily accessed and had simple out reach support clinics in the center of state housing/high beneficiary areas (mental health professional)

Establish protocols for interprofessional cooperation and communication- encourage, support, and fund multidisciplinary teams instead of competitive funding models (professional organisation)

Mental health and addiction workers, plus health professionals described integrated efforts consistently hampered by inefficient, burdensome, or inaccessible health information systems and policies. One approach suggested by a few health professionals to tackle this is to integrate physical health and mental health records. Another is more supportive central policies to access and share information in a timely manner, with clear guidance for organisations on how to best use and share mental health information. Investment into

New Zealand-wide information technology systems to store and manage health data was suggested by some submitters as an important step to enable integration.

No individual receives advantages by fragmenting their health information. There is a particular tendency to isolate mental health information from physical health information to the detriment of both mental health and physical health. It is vital that as mental health services develop their information systems they plan for health records to be integrated with other health records (health professional)

...supported by a technological system that allowed all users of health services to be able to access and add to our own file (consumer leaders with lived experience)

### **Person-centred goals and support**

Most submitters wanted support and services to be focused on, and built around, the individual, family and whānau. Their needs determine the make-up of the wider team, and the person (with guidance of whānau) has the final decision. The wider support team need to ensure that they are providing enough information, education and array of intervention options to support appropriate person-centred goal setting. The team also must facilitate access to any others who can help realise these goals. In addition, all involved should be aware of, and working towards, the same goals using one co-ordinated plan. It is in this way that many submitters believed that the individual, their family and whānau feel more empowered and responsible for their own success.

We most definitely need a less medicalised approach and a client co-designed and community-led solutions. We need greater emphasis on peer support. Less diagnosis labelling and more love. A shift of power from medical professionals imposing solutions to solutions co-designed by the person in mental distress (individual with lived experience)

A range of treatment options are made available... What works for one person may not work for another. Our treatment options need to be flexible enough to meet the needs of differing individuals, families and communities (NGO provider)

The majority of submitters wanted to be able to get this high-standard of holistic and person-centred support locally and affordably. This is particularly challenging in more remote and rural regions, and to efficiently provide this service diversity near the service user requires greater amounts of co-ordination and planning. A few services users stated that community outreach services, joint sessions and travel planning may add complexity – but are cited as important. A few submitters suggested that provider or community hubs could be used as a one-stop-shop for mental health services.

Consider development of hubs where people can meet and run support groups (DHB)

Better, integrated discharge planning, communication and support to all affected/involved (NGO provider)

## Look at specific integration opportunities

Alongside these broader themes, primary care and mental health workers had a variety of ideas to enhance service integration in more specific contexts, as follows.

- Integration of mental health teams (that is, occupational therapists, nurses, psychologists, counsellors, social workers) within primary care.
- Better integration across addiction and mental health services, that supports the concept that someone may have either or both needs. This interaction between these two services needs to be smoother with appropriate handover and transition.
- Community-based 'one-stop-shops' for all NGOs, community groups and organisations, and health professionals working within mental health and addiction.
- Inclusion of multidisciplinary mental health teams within schools (that is, social workers, counsellors, nurses) to promote awareness, access and early intervention.
- Mental health teams embedded within emergency departments to more appropriately meet the needs of those in distress or crisis.
- Person having integration opportunities to help them re-integrate into families and communities. These include short to medium-term residential mental health facilities and mental health teams to support the reintegration of prisoners back into the community. Similarly, support for those discharged from being hospital inpatients following periods of acute need or crisis.
- Integrating supported employment services into mainstream mental health and addiction services for those who would benefit from it. Inclusion of, and incentives for employers to support this integration back into the community as valued and contributing members of society could proactively address many causal factors.
- Integrating peer support and those with lived experience into mainstream teams and approaches.
- Integrating representatives from different agencies (that is, the Ministry of Social Development (Work and Income), ACC, Oranga Tamariki across themselves and/or into health organisations (that is, DHBs, primary care) to promote better co-ordination and access across several wider needs.

[Service users and tāngata whaiora] are enabled to reconnect with themselves, their whānau and valued roles in their communities (Mental health sector leaders)

[An NGO and DHB] collaborative innovation has successfully trialled an alternative model of active client oversight using a nurse practitioner role; this role works closely with both the client and the NGO community support worker to provide secondary mental health services as necessary. Both the nurse practitioner and the community support worker work at the top of their scope to provide responsive and holistic services to the client (DHB provider)

Dual [alcohol and other drug] and mental health services as often people are pushed from one to the other when in fact they need both at the same time (family member)

Integrate the various social and community services in the mental health and addiction sector with a view of implementing a life-course approach (academic)

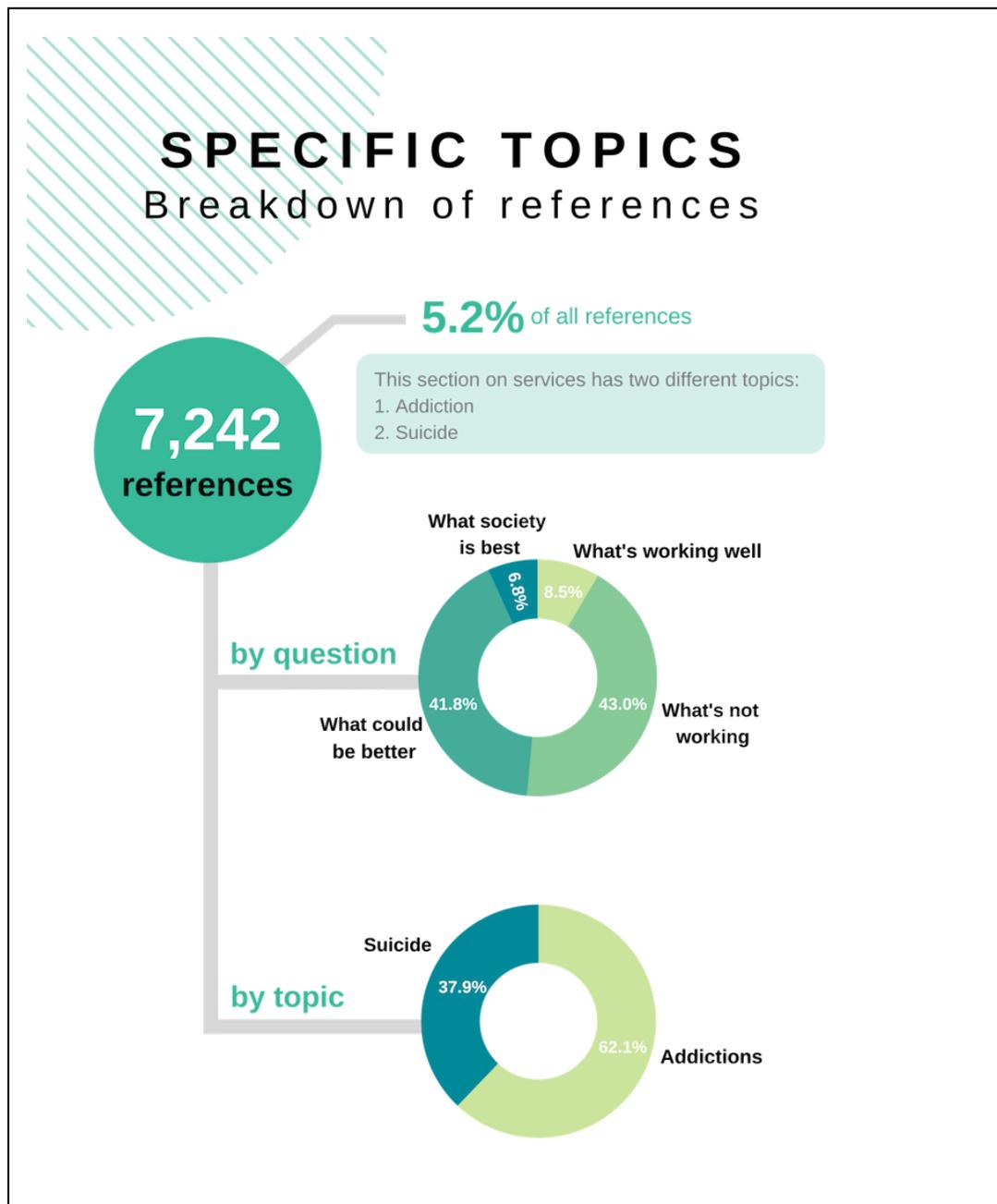
## 4 SPECIFIC TOPICS

This chapter presents an overview of responses from submissions on addictions and suicide (and self-harm).

These two topics are discussed in separate sections as they have unique features and significant impact on individuals, families and whānau, communities and society as a whole. Addiction is discussed in section 4.1 and suicide in section 4.2.

Submitters made 7,242 references about this topic, which accounts for about 5.2% of comments made to the Inquiry overall.

FIGURE 4.1: SUMMARY OF RESPONSES ABOUT SPECIFIC TOPICS – ADDICTION AND SUICIDE



## 4.1 Addiction

### 4.1.1 Overview

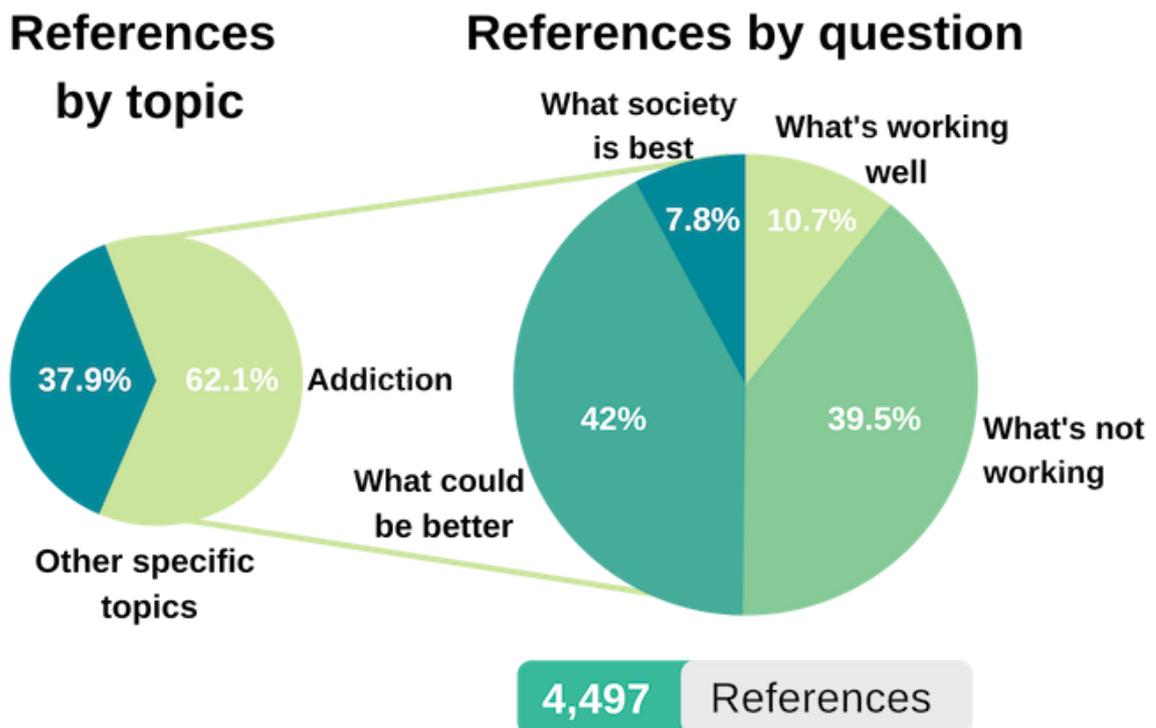
This section presents an overview of responses from submissions related to addiction.

There was a strong consensus across addiction-focused submissions that the causes of addiction were rooted in trauma, poverty, and dislocation. Many submitters agreed that a relationship existed between addiction and mental health challenges. However, addiction was seen as the ‘poor cousin’ of mental health funding. Submissions from those working in the addictions sector frequently commented that the demand for detox, rehabilitation, other treatment and support was far outstripping availability and resources due to issues they identified with funding, workforce and commissioning models.

Many Māori service providers noted that alcohol and other drug issues disproportionately impacted on their whānau. And that service providers were hampered by resources and operating in a system that was fundamentally not recognising tino rangatiratanga. Many regions were suffering from the impact of “P”, synthetic cannabis and opioids. However, they had minimal to no local treatment options particularly whānau-centred, local kaupapa Māori services. Families and whānau were also struggling to find appropriate help and information to support their own loss, grief and challenges as they care for their own children with addiction challenges, or Mokopuna of family members with addiction.

Submitters made 4,497 references about addictions. Most comments focused on alcohol, methamphetamines, opioids and synthetic cannabis. Some submissions were concerned about tobacco and gambling and to a much lesser degree other behavioural addiction (for example, internet and sex addiction).

FIGURE 4.2: SUMMARY OF RESPONSES ABOUT ADDICTION



## KEY THEMES FROM SUBMISSIONS FOR ADDICTION

### **4.1.2 What's working well?**

- variety of timely, accessible services
- support from family and whānau
- some innovative approaches in corrections

### **4.1.3 What isn't working well?**

- Stigma and fear
- Emphasis on incarceration not rehabilitation
- Cultural norms
- Lack of immediate, integrated access and treatment
- Workforce under pressure
- Alcohol-related addiction
- Methamphetamine and other addictions

### **4.1.4 What could be better?**

- Tackle social determinants and system wide response
- Responsive accessible service options
- Focus on harm minimisation
- Campaign to reduce stigma
- Decriminalisation
- Increase needle exchanges
- Workforce, funding and other supports
- Alcohol reform required
- Better monitoring or prescription drugs

#### 4.1.2 What's working well?

Less than one-third of references relating specifically to addictions spoke of what was working well. Services and treatment options that were highly regarded by some submitters focused on the need to address social determinants, connectedness, identity and belonging, as well as providing easy access, treatment options, peer support and client input.

##### A range of timely, accessible services

Service users and tangata whaiora, and their families and whānau, identified the types of services that worked well for them – typically revolving around access and options - including:

- Early intervention and prompt access to treatment
- Maintaining treatment across an adequate time period to avoid relapse, “Research clearly shows that it takes over two years to establish neurological stability and the beginnings of emotional recovery” (NGO provider)
- Abstinence programmes, self-help and working the 12-steps: community-based, peer run, and open to anyone who recognises the need to address their addictions, in a supportive and structured environment.
- Harm minimisation and reduction programmes: includes residential, day-based, needle exchange, and group therapy
- Kaupapa Māori and whānau centred models of care using Māori oranga workforce located within the community, applying matauranga Māori and addressing whānau concerns
- Particular day-stay clinics, day treatment programmes located in regional areas.
- Residential therapeutic-based models. Many submitters appreciated the treatment they received in now-closed services (e.g. Queen Mary Hanmer Springs)
- Rehabilitation centres with pre and post services to ensure good transition
- In-home detox and rehabilitation services - including mandatory drug testing for in-home probation rehabilitation
- Group therapy options, particularly when led by peer workforce
- Support services and groups targeting different populations including families of those with addictions, grandparents supporting grandchildren, men's groups, those impacted by methamphetamines, and parents with addictions, youth services, and population specific. Includes support, education, advocacy, counselling and connections as well as therapeutic options.
- Private rehabilitation services for those that can afford them
- Integrated primary and secondary services that, in the words of one service user, keeps “everyone in the loop minimising my chances to abuse the system” (service user).
- Individual GPs who work hard to get their clients into treatment
- Opioid Substitution Treatment services

- In-patient services when provided (although minimal number of beds available) - particularly strong positive response in some regions
- Medically assisted detox programmes where available
- Relapse programmes – in residential home, in home, in the community
- Volunteer organisations that have grown around the country to tackle what is seen as common community problems of methamphetamine and synthetic cannabis
- Support for complex or co-morbid conditions, for example addiction and mental health challenges; addiction and homelessness; addressing social determinants, health and nutrition: all of which impact on early stages of recovery as well as continuation of recovery during treatment. Self-referred or family referred help to integrated mental health services.
- Trauma informed care that acknowledges “the root of problems of individuals so they recognise they started from an uneven playing field and so deserve (self) compassion” (individual service provider).
- Integrated cross-sector community-developed programmes using police, health and other sectors to target methamphetamines and create pathways for users to receive treatment
- Brief intervention – the ability to engage with non-judgemental support for those submitters who needed support, advice or think about addiction.
- Some screening and mobile health tools (to enhance self-management and greater population reach). Awareness raising websites and public health initiatives that target specific addiction groups in various languages (usually community based).
- Stepped care approaches that offer a range of interventions matched to individual needs – using case managers to coordinate interventions and referrals.

**Collaboration and cross-sector approaches.** Many submissions from non-governmental organisation (NGO) service providers recognised that collaboration and integrated approaches were needed to tackle underlying social drivers of addiction. Those services that focused on holistic approaches to addiction, with single point entry, strong liaison across addiction and other sector workforces, and good communication were seen as positive examples.

What works well also, and this is a factor of the personal relationships established between services, especially other NGO services, is the ability to access a number of other avenues for assistance for clients. This includes some assistance in housing, budget advice, advocacy with [the Ministry of Social Development and Accident Compensation Corporation] services, vocational assistance, primary health care, and probation services. None of these flow out of the funding or support from the [Ministry of Health]; they are a feature of the desire of agencies to work together for the best outcomes for clients (NGO providers)

There was strong support across Māori submissions for Mā Māori Mō Māori (By Māori for Māori) and the need to truly enable Māori communities to be empowered in their ability to provide tikanga-based addiction support for whānau. One addiction specialist noted that to be tikanga-led and guided by kaumātua was their strength, bringing the clinical and Māori

world views together, and reconnecting with ‘what it means to be Māori and their identity’ – this was essential to healing for tāngata whaiora and their whānau.

Submissions from single point-of-entry alcohol and other drug services noted the strong collaboration between addiction NGO providers, peer support, and clinical staff as key to successful service provision. Community pharmacy submissions also noted that, given their role with those with addictions and substitute treatments, they were increasingly seeing the importance of being linked in to other health providing teams.

In their submissions, many district health boards (DHBs) said relationships with NGOs and specialist addiction services were essential, citing their perceptions of what is working well in terms of strong relationships with some NGOs, and a diverse, well trained workforce. Some community service submissions mentioned pilot programmes that focused on pregnancy, parenting, and integrated youth services. Some DHB submitters also noted collaboration between rural hospitals and mental health and addiction services has led to some innovative solutions to combat distance.

Some service providers had employed a consumer advisor to ensure they were responsive to the people who accessed their services. The more successful consumer advisors used multiple strategies for engaging with service users and tāngata whaiora of addiction services, and incorporate this feedback into their service design focusing on truly client-led service design.

From a Pacific submitter perspective, successful addictions services needed single point of entry, the acknowledgement of family and religion, and client led services. A well-qualified, engaging Pacific workforce was key to their service delivery – noting breadth of age, gender, and inclusion of kaumātua as essential.

**Compassionate skilled workforce and other supports.** Including non-judgmental, safe, kind and supportive space with access to knowledge and experience of peer supporters (those with lived experience of being an addict) in recovery.

If you really want to educate people, to help our people, go to those who have walked through hell and survived. Your Education means nothing nor your degrees, without experienced people who have experienced the true depth of mental illness. You keep asking what you can do then talk to us  
AND LISTEN (tangata whaiora)

The ability to enter a space that is non-judgmental, safe, kind and supportive was key for some submitters’ experience. There was strong praise for the skill, knowledge, and experience of peer supporters (those with lived experience of being an addict, now recovered). This was important across a spectrum of addiction services including support while waiting for detox or rehabilitation, creating trusting relationships through rehabilitation and withdrawal, as well as providing meaningful work for those recovering from addiction challenges,

Many clients comment that they would value peer support relationships to continue through treatment with them, just so they can have some external support from a person who isn’t part of the treatment programme who is encouraging them and assisting them to make sense of what is happening for them during treatment (consumer group)

Some submitters with lived experience noted that they have had good support from the courts or police. However, as one collective addressing AOD support in their district noted it is “usually due to personal attitudes and approaches of individuals working within the Justice sector, or alternative approaches being piloted such as the Drug Court in Auckland and Waitakere courts” (Addiction sector grouping).

From a service provider perspective a workforce that catered for diverse clientele was appreciated, and community health workers and Kaiāwhina “are appreciated by whānau and families of people experiencing mental health and/or addiction issues as it alleviates strain on whānau” (Māori NGO).

**Good collaboration between researchers and policy makers**, particularly in the field of tobacco control. A few organisations noted their robust data sets enabled a good view of the sector (in their field) and strong ability to understand what is happening at a local and national level (for example, those involved in Opioid Substitution Treatment).

### **Support from family and whānau**

A few submitters noted that due to lack of services they had to rely on their family and whānau to support their withdrawal. While this was appreciated, they recognised the unfairness of putting their family through the stress of detox.

For other submitters who had lived experience of addiction the reconnection with cultural identity was evident in their recovery,

Going back to tikanga and hanging out with bros who are into the reo have pushed him into his culture. Proud to be who he is and to get the service (individual with lived experience of addiction)

### **Some innovative approaches in Corrections**

**Programmes that work well with prisons and the community.** Although it was widely noted in submissions that the criminal justice system should not be the default setting for addictions and other drugs treatment, there was acknowledgement of programmes that currently work well both within prison and the community. Therapeutic community models provided within a few prisons offer alternative drug and alcohol treatment programmes that are supported by multidisciplinary staff, and collaboration with NGOs within prisons to enhance effectiveness. Typically there is a strong tikanga Māori component to these programmes, and occasionally a good after-care programme to help transition.

A few submissions directly from those in prison noted their appreciation of being able to access the drug treatment unit, or similar, including behaviour therapy and education, noting a “positive and pro-social” environment:

The realisation that the current way of dealing with mental health and addiction is not working. The time I have spent in the DTU unit has given me the opportunity to address my addiction and offending in a positive and pro-social environment (prisoner)

**Strong support for the AOD Treatment Courts and their alternative to jail** for those seeking treatment. Many submitters hoped for an expansion of the project, given its success rate and alternate pathway for those in prison (on AOD related offences).

This reflects the calls for addiction to be treated as a health issue, not a criminal issue (noted in section 4.1.4: **What could be better?**).

### 4.1.3 What isn't working well?

As indicated, submitters noted some good examples of innovative, committed and integrated addiction services and peer support that made positive differences to the lives of service users, tāngata whaiora and their whānau. However, many things were not working well – including a lack of detox and rehabilitation, lack of integrated services (pre and post detox or rehabilitation and co-existing challenges), and limited support for families and communities. Many service providers noted that although demand was increasing, funding and commissioning limitations impacted services and workforce.

Many submitters including service users, tāngata whaiora, service providers, kaimahi, researchers and addiction specialists recognised the role of social determinants, stigma, discrimination, and cultural norms in addiction. Most wanted addiction to be met with a health response, not a criminal justice response.

Many submitters noted the impacts of inequity and social determinants:

... all childhoods are not created equal... We have empathy for a child born in difficult situation, then as a society, compassion fades as they grow up and we change our tune to 'it's their choice' we shun them in prison  
(service providers)

### Stigma and fear

**Stigma of addiction** was noted by many submitters as a barrier to seeking help. Some submitters said the success of *Like Minds, Like Mine* for mental health needs to be replicated for addiction. Service providers noted that stigma remained a significant barrier to help-seeking behaviour,

The general experience of people struggling with addictions is that they feel like they are a 'bad' person for the life choices that they have made. There is little interest in the client's background and journey up to this point and a lack of recognition of the trauma that a large number of people with addictions have experienced. This often reinforces that they have somehow done something wrong or that they are someone wrong. There is a sense of strong judgements and stigma. These feelings of stigma and discrimination seriously impact a person's ability to ask for help (consumer group)

Some submitters noted the lack of action at a Government level regarding stigma of addiction.

A few submitters noted the negative impact of shame on help-seeking, for example submitters noted this was common in Asian and Pacific communities (also emphasising gambling as well as AOD), and other culturally and linguistically diverse communities.

Stigma was also described by some submitters as a consequence of convictions associated with addiction, and the subsequent loss of employment and difficulties finding work.

With a good degree and a criminal conviction it will be very difficult for [family member with with addiction lived experience] to regain a respectable position in society... It is a shame that this is the consequence for someone

**Fear of children being taken.** This was a concern among some tāngata whaiora and their whānau in accessing help for addictions,

Once a whānau loses a child to the Ministry, it's devastating. If there's no-one to intervene at that point they go down path of drugs/meth – end up in addiction ... What about the mothers – taken away their identity and no services. Addicted then in mental health system then when that doesn't work – last port of call is jail. Wahine Māori have increased in jail – something is not working. But what WAS working was Māori Rehab (kaimahi Māori)

### **Emphasis on incarceration rather than rehabilitation**

The emphasis on incarceration rather than rehabilitation was a strong theme across submissions relating to addictions,

We incarcerate rather than rehabilitate. I know people who have kicked lifelong addictions in less than 6 months given the appropriate, in patient care, support and resources. They paid for this out of their own pocket at a cost of more than \$10,000. Where are our services for those who cannot afford private treatment? (youth voice)

This fight on drugs is insane. We should be banning alcohol if we were so concerned (service provider with lived experience)

Lack of rehabilitation in prison, coupled with the criminalisation of addiction, has resulted in imbalanced emphasis on paying for punishment rather than rehabilitation or prevention.

This is also true of criminal justice interventions whereby a great deal of resource is expended to incarcerate and punish and comparatively less to train, treat and rehabilitate. We argue that viewing these underlying disparities through a health and social justice lens will allow us to effectively treat the underlying conditions that exacerbate substance dependence thereby reducing recidivism altering the trajectories for those who would otherwise repeatedly offend and experience repeat custodial sentences (DHB)

### **Cultural norms**

**Societal attitudes towards alcohol.** Many submitters – particularly service providers and academics, but also family and whānau, and service users and tāngata whaiora – noted a cultural tolerance for alcohol, and the negative impact this was having on communities. It was raised that harmful behaviours such as heavy alcohol consumption, or binge drinking, are widely socially acceptable.

As a society we drink too much, our children are exposed to drinking from an early age (service user)

Alcohol culture in New Zealand; it is socially acceptable to drink too much, often. People want to be socially accepted so it's almost encouraged (service user)

Alcohol is the most highly normalised recreational drug in New Zealand, and is costing the country billions of dollars in harm (academics)

### **Lack of immediate, integrated access and treatment options to meet demand**

Most submissions from current or past submitters with addictions, and family and whānau noted the lack of immediate, integrated access and options (from harm reduction to abstinence-based services). This included detox, rehabilitation, inpatient beds, respite, family and whānau treatment options, kaupapa Māori options, local treatment options, mother and child treatment options, and not meeting the “criteria” for help. Lack of integrated services, and post-rehab disconnection often resulted in many people falling through the gaps, or relapsing. Delays in treatment meant those reaching out for help often changed their minds or were less able to receive help. Many submitters noted the devastation that waitlists, and lack of access have on their ability to detox and rehabilitate.

even for those who are wishing to rehabilitate, the wait list for services may be months and months – this young man was recommended to keep drinking until there was a space available (bereaved family member)

looked into going to rehab twice however was told there were no spaces available throughout the country. He has not followed up again with the idea of rehab and has continued to drink (individual with lived experience)

### **Rural and regional areas with high addiction issues and lack of services and resources.**

Regional areas with high “P” addiction and synthetic cannabis have one to zero beds for rehab or detox, no specialist services, long waiting lists, no or limited youth services, insufficient cross-sector support services, high unemployment rates and high costs of travel and accommodation to access services. In many areas, whānau and family are going to prison when they should be going to rehabilitation.

When the whaiora falls over the whaiora is blamed and not the model. Why don't we match the client with the right service? Why aren't Māori who have the worst statistics, matched with a Kaupapa Māori Service? It is the continuation and investment in Western Models when it comes to mental health and addiction which are not working (Māori NGO providers)

**Variability with accessing help through primary care.** This was noted by former and current service users with addiction. Some people noted it was expensive (“If I only had \$50, will I go to the doctor or score?”) or feelings of powerlessness (“why would I admit illegal drug use to someone (GP) in position of power?”) (consumer advisor with lived experience). Others preferred their relationship with their GP but were required to change due to funding cuts.

**Self-medicating to deal with trauma and anxiety.** Many submissions, particularly from submitters identifying as having Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, or trauma, noted the role of alcohol and other drugs in self-medicating.

I am a meth addict and I self-medicate my borderline personality disorder, anxiety and [post-traumatic stress disorder] brought on by childhood trauma ... if I didn't use meth I would not be able to get out of bed in the morning (service user)

most young people who become hooked on meth are self medicating for other conditions: most commonly ADHD, but also depression, post traumatic stress disorder or the effects of emotional and social dislocation (individual with lived experience of addiction)

Lack of recognition of the role of trauma in addiction was noted across submissions. With limited support available in the form of talking and other intensive therapies.

**No recognition of impact when no access to local services.** For those in regional and rural centres, as well as families, there was the struggle to access local care or family-centred care.

some woman who have entered detox have not stayed because it is a struggle for them and their children to be away from each other (service user)

Other service users (mostly without children) found that moving away from their local community was better for their health and recovery as it placed them in a different peer group (one not associated with, or encouraging of, their addiction). However, social support services fail to recognise this in terms of financial support and relocation.

**No recognition of impact on family and whānau involvement and care.** Many families and whānau told their story of struggling to sustain themselves as well as their family or whānau member with addiction. Lack of support, information, and respite was draining their own mental health and wellbeing, as well as impacting on them financially, socially, and emotionally. Many submitters noted the scarcity of support for themselves in terms of counselling, engagement, communication, and help. As one whānau member explained,

We were never given any type of support in dealing with a person with addiction and mental health issues in our home (family member)

**Loved ones ending up in prison due to lack of access to treatment options.** Lack of options and access for many families and whānau often ended with the imprisonment of their loved one on drug related charges, with many noting the cost of this compared with the cost of rehabilitation and prevention.

Caller tried to get support for his brother who was having issues with alcohol and depression... the government will be spending millions of dollars to keep his brother in prison where this money could have been better spent in supporting his brother to get well (family member)

Lack of integrated care from prison into the community resulted in a revolving door for many of those with addiction challenges.

**Limited resourcing severely affects service provision.** Addiction service providers recognised their limited resourcing was severely impacting on service provision, wait lists, workforce planning, professional development, and sustained co-operation and integration with other services. Reflecting the impact this has on service users, one submission noted,

Families have to wait months to get into detox and some (for obvious reasons) lose motivation to detox while awaiting a bed (DHB)

**Addiction services subsumed by mental health.** There was frustration from service providers, particularly community-based and NGO (funded by DHBs or otherwise), that

addiction was ‘tacked on to’ mental health “with little or no recognition of its specific needs” (DHB consumer group),

This melding of two models makes it difficult at times to decipher what is intended: with mental health dominating it can be impossible to know whether addictions is implicitly included or explicitly excluded – and often nobody has an answer because the nuances of the addictions aspect have not been considered – and that is because there is often no one with in-depth addictions knowledge and experience involved in these processes and making these decisions (like the Inquiry panel) (DHB consumer group)

**Primary care appointment times insufficient for screening or brief interventions.** Primary care providers noted that even though they are often well placed to do brief interventions or addictions screening, the standard 15-minute appointment is insufficient. Primary care providers also noted that their referrals for addiction services were often declined.

**Lack of choice between abstinence and harm minimisation treatment models.** Some service providers noted that harm minimisation was preferable for their clients, and that sometimes treatment options were abstinence-only models. They noted that in many cases, socio-economic advantage buffeted some issues with addiction.

**Falling between the cracks of addiction services and mental health services.** The complexity between mental health and addiction was noted by many submitters including the relationship between mental health challenges and self-medication, and vice versa. However, many addiction specialists and services noted that addiction is often an add-on to mental health services, and that when alcohol and other drugs is involved often the mental health team will not attend.

There was also complexity in treatment models – with addiction sometimes viewed as solely a mental health challenge – therefore, “pushing people into a box they don’t fit” (addiction support worker) or a grey area between addiction and mental health creating lack of follow up and support (and often leaving those with addictions to fall between the cracks).

**Lack of resources for prison and community sentencing programmes.** Many meeting and written submissions opposed the criminalisation of addictions, and trauma, and noted the predominance of Māori in prison due to social determinants including colonisation, systemic discrimination, institutional racism and trauma. Two examples are:

- a general lack of support and funding for the prison population, which as one service provider who works in prison noted,

There is not nearly enough resources to cope with the demand in prisons for support with mental health and addiction. Nearly every participant in the [programme] I facilitate has been affected ... most people ... want more support (service provider to prison populations)

- lack of resourcing impacting on effective community sentencing.

While Corrections can refer people to programmes, an insufficient number of placements impacts compliance with this condition. This means that people are sometimes recalled to prison in circumstances where better access to services may provide some assistance, and potentially avoid the recall (government agency)

**Accessibility of treatment for co-existing conditions.** For example, some submitters noted that programmes such as methadone replacement were only available if you entered prison with this in place.

Lack of integration back into the community was also a concern. This includes housing, employment, continuing rehabilitation and support upon exiting the prison system.

**Services failing to meet more complex needs.** Many submitters noted that the growth in methamphetamines and synthetic cannabis, coupled with co-existing physical and mental health challenges, are creating complex needs within the community. There are also growing complexities for certain populations. For example, older people with both alcohol and other drugs addiction and mental health challenges, with some service providers reporting inadequate care opportunities for complex needs of older populations. Homeless populations and youth with co-existing challenges were also seen as vulnerable to alcohol and other drugs.

**Insufficient funding.** Funding was a significant issue across most service provider and organisational submissions regarding addiction. This included funding structure and commissioning models, competitive mode of funding, variability across DHBs in approach to addiction, no national co-ordination and lack of continuity.

### **Workforce under pressure**

**Difficulty recruiting and retaining staff.** Many service providers noted that recruitment and retention was increasingly difficult given increasing workloads, safety issues, complexity of alcohol and other drugs, and lack of job security due to funding and contracting arrangements. Acuity on the wards was seen to be rising as was violence against staff. Also impacting this was poorly designed units, high nurse to patient ratios, unsafe skill mixes and at times a coercive environment. In rural areas this is exacerbated by lack of beds, and nurses having to go into homes to administer help. Other issues were:

- a lack of Māori workforce in some regions, including kaumātua and kuia, Māori whai manaaki, and Māori alcohol and other drugs specialists
- rural areas finding it difficult to recruit specialists and generalists having to be across everything
- workforce lacking diversity and cultural understanding, which is particularly relevant for culturally and linguistically diverse populations, Rainbow communities and older people services
- specialist training, such as specialist GP in addictions, is yet to be recognised and financially compensated
- workforce issues are heightened by funding models that impact on recruitment and retention but also cross-agency co-operation, which is particularly relevant for alcohol and other drugs where,

drug related harm is a complex problem that requires a joined-up approach and the sharing of information between multiple agencies (DHB)

**Low number of consumer and peer roles.** Some submitters noted funding for consumer and peer roles has not grown in alcohol and other drugs services and roles are poorly applied across New Zealand. It was noted by some submitters that there are few or sporadic

dedicated consumer advisory, consultancy and advocacy roles in the addictions sector. As noted by one submitter, the addictions speciality is often forced on to mental health consumer roles.

**Family and whānau experience lack of compassion and indifference from workforce.**

Compassionate, caring and exceptionally trained staff across the alcohol and other drugs spectrum were essential for family and whānau, but often this was lacking from some alcohol and other drugs and broader health staff.

Recently while meeting with my son's [alcohol and other drug] worker and my son was expressing his desire to kill himself the worker closed his diary and said "there is no point me putting hours of work into helping you (making a referral to rehab that my son had requested) if you are going to do that so I won't bother" (family member)

**Substance Addiction (Compulsory Assessment and Treatment) Act 2017.** Comments from submitters about this Act included raising concerns about holding locations (for example, police cells and other inappropriate areas), rights of staff, time frames, and the role of brain injury. The lack of resources and treatment availability to implement this Act was noted.

### Alcohol-related addiction

**Alcohol as a drug of choice.** Submitters spoke of the relationship between mental health and alcohol from both directions: of mental health challenges as contributing to alcohol use and of alcohol use as contributing to mental health challenges. One submission, reflecting the view of many, commented on the ease of masking their underlying problems with alcohol due to the normalisation of consumption within the submitter's family environment.

My drug of choice was alcohol, which was socialized in my whānau ... it was a socially acceptable [way] to reduce my anxiety and pass as normal (service user)

**Failing to address the harmful use of alcohol.** Harmful or hazardous alcohol use was discussed as being linked with:

- violence and aggression (including domestic, physical and sexual violence)

As far as I am aware, alcohol is still the biggest problem drug when it comes to family violence (mental health professional)

- crime and illegal activity
- financial harm and homelessness
- road accidents

**Other issues** raised by submitters regarding the harmful use of alcohol are as follows.

- Alcohol-related dementia. Some submissions noted the rise in alcohol-related dementia and that hazardous alcohol use "has been found to be the strongest modifiable risk factor for the onset of dementia" (government agency).<sup>10</sup>

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<sup>10</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

- Link between alcohol and suicide. Many submissions spoke about the link between alcohol and suicide, stating concerns about the involvement of alcohol in a high number of suicides in Aotearoa New Zealand.

Approximately one-third of all people who committed suicide were found to have high blood alcohol levels (addictions professional) <sup>11</sup>

- Violence and inter-partner violence.

In our area, we have a major problem with excess alcohol usage associated with domestic violence. We'd love to be able to screen more for domestic violence, but the time required can be excessive in a busy clinic plus the pathways for help are not robust enough (professional organisation)

**Current alcohol laws are ineffective.** Many submissions raised concerns with current policies and regulations regarding alcohol, stating that, "legislation remains ineffective" (service provider). The issues that were raised as not working well included:

- widespread availability of alcohol: the ease of access from supermarkets and the high number of alcohol outlets, particularly in areas of higher economic deprivation

Every supermarket sells alcohol and is stones throw away from liquor store.  
Alcohol is too available (service provider)

- price of alcohol is too low: alcohol is cheap and affordable
- pro-drinking messages and other alcohol advertising and sponsorship, particularly in relation to sports events: alcohol is heavily promoted in a positive light
- purchasing age of alcohol: the lowered drinking age was linked to harmful behaviour in young people
- communities are not sufficiently involved, or their views not reflected, in Local Alcohol Policies
- alcohol policies and regulations are not based on evidence
- lack of zero tolerance towards drink-driving.

Many acknowledged the lack of Government action on alcohol advertising standards, and the "missed legislative opportunities" (DHB) from the lack of substantial implementation of the recommendations from the 2010 Law Commission report *Alcohol in Our Lives: Curbing the harm*.

### **Addiction to prescription drugs**

Some submissions focused on the harm and complexity of prescription drugs with the medicalised approach of some primary care and specialist services adding to addiction challenges. Some doctors were seen as too quick to prescribe and many submitters described becoming addicted to benzodiazepine and other iatrogenic drugs. Some submitters noted the lack of monitoring.

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<sup>11</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

Many Mums experience self-harm and depression. Spoke about having an addiction to prescription medication being seen as better than being addicted to other drugs (those you choose yourself); addiction to prescribed medication actually helps you fit the criteria (kaimahi Māori)

**Lack of information about drugs and their side-effects** was seen as not only detrimental but a breach of the Treaty of Waitangi and informed choice.

**The interface between chronic pain (for example, arthritis) and addiction to prescription medication** was noted in some submissions, with better pain management and integration of care required.

**The role of social determinants and adverse life experiences** was noted in regards to dependence on opioids (both prescription or otherwise).

### **Methamphetamine and other addictions**

#### **Scarcity of detox, rehabilitation and treatment options for methamphetamine addiction.**

The rise of methamphetamines – particularly in rural and regional areas – and scarcity of detox, rehabilitation and treatment options was noted across many submissions. Service providers see multiple complex problems relating to methamphetamine, including the impacts of abuse, poverty, damage to family and whānau, and community. There are limited meth specific services across the country – and communities have created their own alternatives but are desperate for options, access, and services.

Addiction to meth is ripping apart our communities and creating a generation of children who cannot engage in normal society due to behavioral problems (individual submitter)

**Growing number of deaths from synthetic cannabis.** Synthetics are on the rise and, due to cost and availability, are replacing cannabis and other more expensive options. Growing number of deaths attributed to synthetic cannabis and limited detox and rehabilitation services.

Harms caused by synthetic cannabinoids have resulted in needless fatalities and this is underpinned by the growing black market for synthetic substances containing toxic substances such as industrial solvents (addiction sector grouping)

synthetics are brutal and will kill our communities (service provider with lived experience)

**Self-medicating with cannabis and understanding harm.** There were variable views within submissions relating to cannabis – with some people noting its use in treating pain and injury, and others recognising that cannabis users have difficulty identifying as having addiction challenges.

My son was not a mindless druggie that smoked weed for the hell of it. Marijuana was medicine for him after he received multiple head injuries through rugby and falling out of a tree at school (whānau Māori)

There was also some sense that using cannabis was normalised as a recreational drug and dangers of addiction were overlooked (including psychosis and impact on brain development).

**Inadequacy of the national drug policy.** Some submitters called for a review of the National Drug Policy (and failure to continue the reporting system for tackling methamphetamine), with some submissions noting that the drug early warning system has yet to be implemented. They urged continued support of the harm minimisation approach. There was annoyance at the ‘knee jerk’ reaction of the Government toward meth in houses, which was seen as costly and stigmatising, contributing little to the reduction of addictions.

**Lack of services to help gambling addiction.** Although not part of the Inquiry’s focus, gambling concern was prevalent in some submissions particularly relating to internet gambling, accessibility of gambling, and lack of services to support and help gambling. Several gambling specific services noted that gambling is addiction by design, and gambling behaviour is normalised with social determinants of poverty leading into gambling. Some leaders were more concerned about their youth, for example, Pacific youth leaders and lack of education in schools in relation to gambling harm. Also noted was the impact of gambling addiction on family and community, violence and other mental health challenges.

### FOCUS ON GAMBLING ADDICTION

Gambling addiction was seen as an issue by some submitters. Submitters were concerned about the harms caused by gambling, including the impacts on families and whānau and the community. There was concern about the availability of gambling, including online gambling and instant play gambling.

Many submitters noted that gambling was a contributor to suicide. Some submitters noted that becoming addicted to gambling was linked to some forms of violence, trauma and distress in the same way as other addictions were.

Submitters were also concerned about the lack of support available to those that became addicted to gambling, as well as a lack of education and support to help prevent people becoming addicted.

[Family member] discovered with online gambling addiction issue. Online gambling issue not widely enough promoted by schools, GP, media and community as an issue. [Alcohol and other drugs] is talked about but gambling is hidden. [Family member] also had issue that he was [adult age] but because of privacy act it was hard to get him help ... Being told he wasn't top 3% of [mental health] people in [city] was really poor and made family feel bad. Wrong that people can run up debt really wrong for people with gambling issues. Bad money lenders exist and family couldn't access information because of privacy (family member)

Some submitters noted that the rates of gambling were troubling for Pacific, Asian and Māori communities in particular. This concern was often linked to issues around social determinants, poverty, and the likelihood of experiencing harm from gambling addictions.

Suggestions for what could be better, included:

- more controls on gambling - some submitters supported initiatives to control the 'liberal markets' that have limited controls over gambling and gambling advertising in New Zealand such as by blocking online gambling sites, banning gambling advertising and banning pokies (or reducing their availability)
- education about gambling addiction and online gambling to help to prevent addiction occurring – a few submitters noted that more education may help to reduce the stigma of addiction and increase people seeking support
- more support, especially free support, available to those that were addicted, or at risk of being addicted, to gambling
- address bad money lenders – particularly those targeting poorer communities
- address other social determinants, including isolation and loneliness that can contribute to various addictions including gambling.

#### 4.1.4 What could be better?

It was acknowledged across submissions relating to addictions that alcohol and other drugs challenges do not exist in isolation.

As such any approaches need to be innovative, immediately accessible, and provide options across the population with strong leadership and cross-sector collaboration. Services need to be embedded in a system that recognises Māori rangatiratanga and whānau-centred approaches to healing and wellbeing, that provides population diverse options, and is adequately funded, with a trained cross-cultural workforce.

Many submissions called for early intervention, cross-sector approaches, a stronger emphasis on trauma and initiatives that address the root causes of addiction,

A new model of care needs to look at each person with addictions as a competent, valued person who is currently struggling and vulnerable... We acknowledge that there is a medical aspect to managing addictions in the same way that there is a medical component of mental illness, however there are also social, practical, and emotional components of addictions that need to be well supported if we are wanting people to live well in their communities (DHB consumer group)

Most submissions focusing on addiction called for more funding, and access to detox and rehabilitation service when and where the person with addiction challenges requires it – for submitters, this meant: rural and regional expansion of services, a variety of options, diverse workforce reflecting communities, and the ability for localised responses to specific addiction challenges.

#### Tackle social determinants and system-wide response

Many submissions called for an understanding of social determinants in treatment as well as a change in societal attitude.

Someone with an addiction is left to their own devices often in a cold house, with no power, no food, no furniture, no transport, isolated and broken family relationships. If New Zealand truly cared about all of our citizens we would not think it is OK for anyone to live like this. Yes they may have made choices that left them in this situation, but no-one can heal and learn to value and love themselves enough to make good choices, whilst living in these situations ... A new model of care needs to look at each person with addictions as a competent, valued person who is currently struggling and vulnerable. Instead of making their life harder (to encourage them to make different choices), we should offer the support and encouragement that they need to be able to move to a place of wellbeing and health and able to make better choices. This support shouldn't have conditions attached to it (DHB consumer group)

For many Māori submitters understanding the historical and intergenerational trauma, impacts of colonisation, and systemic discrimination was essential to understand addiction. There was acknowledgement from both Māori and non-Māori that the rights of whānau to live a quality of life under Te Tiriti o Waitangi must be upheld. Any solutions have to recognise that convictions for alcohol and other drugs are unevenly distributed across

society with more Māori incarcerated for alcohol and other drug-related offending, as well as lower socioeconomic population.

As noted in one submission (reflecting on methamphetamine and drug response hui), “the ‘P’ phenomenon was seen as a response to wider environmental adversity and led to advocacy for an approach where cultural enrichment, whānau integrity, iwi leadership and other preventative measures were supported” (DHB).

Pacific submitters called for integrated approaches to addiction, recognising the impact of intergenerational distress,

The very human and personal nature of distress is intertwined with the essential human need to connect with others, meaning that whānau and communities are at the core of the matter. Distress is often bound up in intergenerational trauma (NGO provider)

Other ways to target social determinants were variable and broad.

- Some submitters noted the role of trauma in addiction and the need to address the underlying pain (through access to therapy, rehabilitation, dialectical behaviour therapy, cognitive behavioural therapy).
- Kaupapa Māori and Whānau Ora approaches to health and wellbeing across the population were preferred. Whānau centred approaches that involved the entire whānau in the journey of recovery, and the increased role of kaumātua and kuia within addiction services.
- Early interventions in childhood starting with increased wrap-around services for maternal health care, maternal alcohol and other drug support, family-based addiction treatment
- Early intervention in treatment particularly for co-existing challenges (such as Autism Spectrum Disorder), physical challenges, pain management, mental health and addiction.
- Developing the community as an “oasis of natural supports” in the treatment protocol – before during and after treatment.
- Social programmes that encourage employment in regional areas.
- Innovative and collaborative approaches so “that clients can easily attend the groups (both pre and post treatment) that best meet their individual needs” (DHB consumer group). Greater flexibility and collaboration enables individualised packages of support and treatment.
- Keeping students in school was a protective factor recommended by some submitters, noting that this includes drug education within supportive health approach in schools, and minimising school exclusion for drug related issues unless all other avenues have been exhausted.
- Safe and supported school environments were seen as essential particularly for vulnerable groups including acceptance of gender diversity.

## Responsive accessible service options

Innovative ways to decrease waitlists and increase alternative options were suggested or are being trialled. The importance of peer workforce across alcohol and other drugs, and the role of the consumer voice in creating services for addiction support was widely supported. Both ideas for what could be better and current practices that are working included the following.

- Pre-treatment recovery support services to enhance readiness and reduce attrition from waitlists including respite services, community support workers
- Increase group therapy.
- Affordable access to GPs and counselling.
- Increase brief intervention approaches.
- Effective use of data to target particular areas or groups with intervention, screening and prevention.
- Flexibility of treatment options to meet individual, family and community needs – including opening times (beyond 9-5), location of services (marae, school, workplace and so on).
- More diverse means of reaching people, for example, walk-in shop fronts where advice and information is easily available and people are supported to access whatever is appropriate for their particular needs; the use of digital apps and websites and social media; community-based support networks, drop-in centres, whatever it takes to meet people's needs.
- Places in the community where people can find support and relax.
- Connect those in rehab,
  - to the real community ... and that this is individualised ... yoga, gym groups, bone-carving etc that provide support for people's wellbeing rather than just treatment focused groups (DHB consumer group)
- Community support and structured programmes for those that are in the community with limited supervision and support.
- Individualised treatment transition co-ordinator - from detox or rehabilitation or prison – not simply health related – recognising that post treatment is just as critical as treatment, particularly for some addictions such as methamphetamines and risk of relapse.
- Easier access for NGOs into secondary services if required.
- Increased regional and rural services,
  - We would have a Rehab centre for AOD that was kaupapa Māori based, and tikanga based. We would have kaupapa Māori and tikanga based residential respite located in the bush. Because going away to Rehab is a barrier for some of our whānau. So in an ideal world they would not have to go away to [city] or to the [organisation] service (kaimahi Māori)
- Increase options for seeking help for addiction,

People living with addiction may not seek assistance from their GP due to cost and access issues. We contend that other social services – such as Plunket, the Police, Housing New Zealand and Ministry of Social Development that come into regular contact with the consumer – need to increase their capability around identifying and referring those living with addiction to appropriate services (professional organisation)

### **Campaign to reduce stigma, increase health promotion and wellbeing**

Many submitters called for health promotion or campaigns that reduce stigma, and challenge current attitudes towards addiction – enabling employers, community groups and wider whānau members to provide understanding and support particularly during treatment. The Government needs to be involved in this campaign and many suggestions to roll out an addiction campaign similar to *Like Minds Like Mine* – and for it to be culturally specific to Māori, Pacific, and Asian communities as well as wider community.

Education in schools was seen as important in teaching youth about alcohol and other drugs, and the impact of addictions – both alcohol and other drugs and gambling. Similarly, school was seen as an intervention point in terms of protective factors (keeping people in school), and education (good education and emotional health literacy), and providing well trained support staff such as mental health and addiction counsellors or nurses (see section **2.6 Wellbeing, health promotion and awareness raising**).

### **Focus on harm minimisation**

Some submitters argued that the abstinence paradigm did not work for all people who experienced addiction. Where abstinence-based programmes were rejected, submitters advocated for, and commented on the value of, alternative harm reduction approaches.

Harm minimisation was an important approach that many submitters recommended. This required greater investment and workforce, and a co-ordinated approach to harm reduction initiatives.

Many submitters noted the need for a framework that “meets the needs along the whole continuum, from the person who needs some information through to the ‘I can’t do this anymore, life’s fallen apart, I’ve lost everything’” (DHB consumer group). This would include the following.

- Pre-treatment recovery support services (to improve retention and readiness). Many submissions noted the importance of peer support during this stage.
- Respite care for people with alcohol and drug problems especially those looking for a safe and supportive environment prior to entering community based or residential treatment.
- Respite care for family and whānau looking after their family member.
- Wet houses where prescribed limits of alcohol are allowed and monitored.
- A continuum of care for those exiting the prison system, rehabilitation services, and detox.

- Purpose-built treatment plans will be necessary given the variety of challenges, co-existing challenges, and service user needs across alcohol and other drugs. Includes cultural and gender identity supports.

## **Decriminalisation and legalisation**

Many submitters commented on the inadequacy of the current approach of criminalisation of drug use in New Zealand, and instead called for the decriminalisation of drugs for personal and medicinal use. Some submitters pointed to the Portuguese approach (see page **173**) of decriminalisation.

The continued criminalisation of drug use has contributed to New Zealand having one of the highest rates of imprisonment, and there is reasonable consensus internationally that the ‘War on Drugs’ is a losing battle which results in significant harm but no increase in treatment for those with substance use disorders (professional organisation)

We would like to see a society that ... adopts the Portugal model where drug use is decriminalised and regulated, where people have easy access to treatment and uptake of treatment has increased, new HIV diagnoses decreased, drug related deaths decreased, drug use among adolescents (13-15 yrs) and "problematic" users declined, and drug-related criminal justice workloads decreased (consumer leaders with lived experience)

A few submitters emphasised the option of decriminalisation, but not legalisation, of drugs such as cannabis. Submitters commented that a decriminalisation approach can have positive public and health benefits, particularly increased access to treatment and support for those with addiction challenges. As one academic noted,

Decriminalisation when implemented effectively does appear to direct more people who use drugs problematically into treatment, reduce criminal justice costs, improve public health outcomes, and shield many drug users from the devastating impact of a criminal conviction. Decriminalisation when coupled with investment in harm reduction, and health and social services, can have an extremely positive effect on both individuals who use drugs and society as a whole. Even if a state is unable to invest in these services, decriminalisation removes the harms a criminal conviction can bring, such as reducing people's education, housing and employment opportunities, and in some cases the right to vote (academic).

We need to decriminalise and regulate—New Zealand may not be ready to legalise (NGO provider)

Those in favour of decriminalisation or legalisation of drugs (particularly cannabis) for personal and medicinal use often spoke of the benefit of tax revenue that can be gathered through regulation. It was proposed that this revenue could then be directed into mental health and addiction rehabilitation treatment, as well as public health, prevention, or harm reduction programmes.

A few mentioned how legalisation had the potential to “take drugs out of the hands of gangs” (service user). Others recommended legalisation of cannabis “so that the other drugs aren’t the easiest to get” (service user). Submitters regarded these “other drugs” as illicit drugs such as methamphetamine.

On the other hand, a few submitters noted particular concerns with cannabis use as a cause of impairment in cognitive functioning for adolescents, and as an increased risk of psychosis and other harms. For these reasons, submitters who raised these concerns recommended that cannabis not be legalised.

Aotearoa should not legalise cannabis as it significantly changes people's minds long term (service provider)

A few submitters recognised that changes to the current approach drug legislation would be a challenge, with one government agency noting that,

a proposal to decriminalise currently illicit drugs is politically highly fraught and may attract condemnation on philosophical grounds, moral grounds, economic grounds, and religious grounds, and on the basis of simple prejudice. However, drug use is currently not under any effective control and the cost to individuals, family/whānau, and society is enormous and growing. If we take a public-health approach to what is a public-health problem, we will benefit from exploring and implementing better ways to spend money and, even more importantly, better ways to promote the wellbeing of individuals, whānau, and the wider society (government agency)

### **Increase needle exchanges**

Some submissions noted that the needle exchange was doing a good job at taking care of people with addictions while educating them and others around treatment and other options. Its peer workforce was trusted by service users. There were calls to expand the needle exchange programme to cater to other populations.

Needle exchange outlets and capabilities need to be maximized. Rural outlets are limited and the range of funded products varies throughout the country with the user having to pay (professional organisation)

There were some calls for the provision of needle exchange in prison.

### **Workforce, funding and other supports**

Some submissions commented that the addictions workforce needed to be committed, skilled, highly trained and empathetic across addiction services, including:

- **Compassionate and empathetic staff needed.** Calls for staff who had genuine care and empathy for responding to those with addiction challenges and who were sincere and compassionate.
- **Analysis of workforce and resources.** Addiction workforce agencies deliver a pipeline analysis of workforce and alternative resources utilised given the scarcity of specialists (such as nurse practitioners, specialists, alcohol and other drug workforce).
- **More mātauranga Māori specialists.** Many Māori submitters called for mātauranga and alcohol and other drug specialists – both under the Māori and mainstream medical systems. As one submitter with lived experience of addictions noted, “Our Matua is a rock, we are like paua sticking to him. I have a whānau now not in addiction” (tangata whaiora).

- **Peer support roles and strong consumer involvement.** Continued consumer involvement was important in designing and supporting treatment.
- **Increase specialist workforce** and advanced roles to meet needs including recognising GPs and nurses who specialise in addiction. Increase addiction psychiatrists and psychologists, and improve pipeline from university.
- **Increase training.** Many submitters wanted more training for cognitive behavioural therapy, dialectical behaviour therapy, basic counselling for staff, and basic addiction education for non-addiction staff.
- **Increase diversity of workforce.** Including access for migrants to culturally appropriate care providers, or detox and rehabilitation where Rainbow populations feel safe and supported.
- **Strong leadership.** Many organisations noted the need for national level addictions leadership, and government policy direction.

There was a strong call from some submission for an increase in funding across addictions, including:

- **Stronger focus on collaborative funding.** A change to the current competitive funding model which will then enable people to access as much support as they feel they need and will encourage services to actively support clients to attend other providers' services and programmes.
- **Proceeds of crime.** Some cross-sector initiatives and addiction services supported the move to access resources from the 'Proceeds of Crime' for community groups that are working in the field of harm prevention.
- **Properly fund underfunded services.** From community pharmacy to detox and rehabilitation there is a need for adequate funding to meet demand.
- **Expand the funding and development** options for residential rehabilitation centres so they include and support medication-assisted treatment such as Opioid Substitution Treatment.
- **Recognise and invest** in the connection between adverse childhood events (ACEs) such as complex interpersonal trauma and addictions.
- **Increase funding** specifically for youth addiction, education and treatment including adequate funding models for one-stop-shops and youth-centred addiction treatment.

## **Alcohol reform is required**

**Alcohol law reform, policies and regulations.** The majority of submitters that specifically discussed alcohol recommended that the focus be towards prevention by making changes to a variety of policies and regulations on alcohol. Of these submissions, a combination of the following recommendations featured.

- increase the price of alcohol, increase excise tax, set a minimum unit pricing of alcohol (although a few submissions disagreed with this)
- reduce the visibility and availability of alcohol, including reducing the density of liquor outlets, removing alcohol from supermarkets and corner shops, and limiting trading hours

- increase the purchasing and drinking age (most commonly recommended was 20 years)
- reduce or prohibit alcohol advertising and sponsorship, including alcohol-free sports events
- enable greater community influence or involvement in the development and implementation of local alcohol policies, particularly local licencing decisions
- ensure that those with commercial or other vested interests in the alcohol industry do not hold power over development and implementation of alcohol policies

Due to an obvious conflict of interest, the alcohol industry must be precluded from having any place at the table in policy development (professional organisation)

- acknowledge alcohol as a drug, use clear phrasing in health publications that asserts alcohol as a drug (that is, 'alcohol and other drugs' rather than 'alcohol or drugs') – and increase health campaigns that demonstrate harm
- introduce zero tolerance for drink-driving across all ages
- introduce tougher penalties for those breaking the law around sale of alcohol (only a few submissions argued that alcohol should be banned or made illegal)
- implement fully recommendations of the 2010 Law Commission report on the review of the regulatory framework for the sale and supply of liquor (*Alcohol in Our Lives: Curbing the harm*)
- make sure public health approaches to alcohol understand the links between substance abuse and suicide and that these recommendations are included in suicide prevention strategies
- improve education around alcohol, particularly for young people and rangatahi, and shift the drinking culture, including using:
  - advertising (particularly with sporting events) and public promotion to educate on how to use alcohol safely and awareness of the harms of unsafe alcohol use
  - education programmes in schools
  - warning labels on alcohol products alerting consumers to the harms associated with alcohol consumption, particularly during pregnancy

**Education and social change.** A small number of submitters commented that social determinant factors have a greater impact on mental health and addiction than alcohol itself. Targeted education and social change programmes that look to shift the current culture by encouraging safe and positive drinking practices were recommended as a more effective prevention route than changes to alcohol policies and regulations.

Some vied for greater education around alcohol, particularly for young people and rangatahi, and an emphasis on normalising responsible alcohol use.

Smarter and safer drinking culture, in particular, better and increased self-control over unsafe drinking practices (rangatahi voice)

We need to change the way we drink alcohol in this country and that again starts with teaching young people and their parents about how to do this (service user)

I think assisting young people to develop a health relationship with products such as alcohol through the reduction [in] a binge drinking culture would be helpful in establishing a safe way to drink (service user)

### **Better monitoring of prescription drugs**

Some submissions called for better monitoring of prescribers and recipients on an electronic database. The legal supply of addictive substances was noted and a few submitters called for prohibition of over-the-counter availability of opioids.

Some submitters noted that certain populations - including the older population - were developing addictions to prescription drugs: often prescribed for short term use they become necessary for sleep. A better approach was noted to teach sleep hygiene and other skills.

## 4.2 Suicide

### 4.2.1 Overview

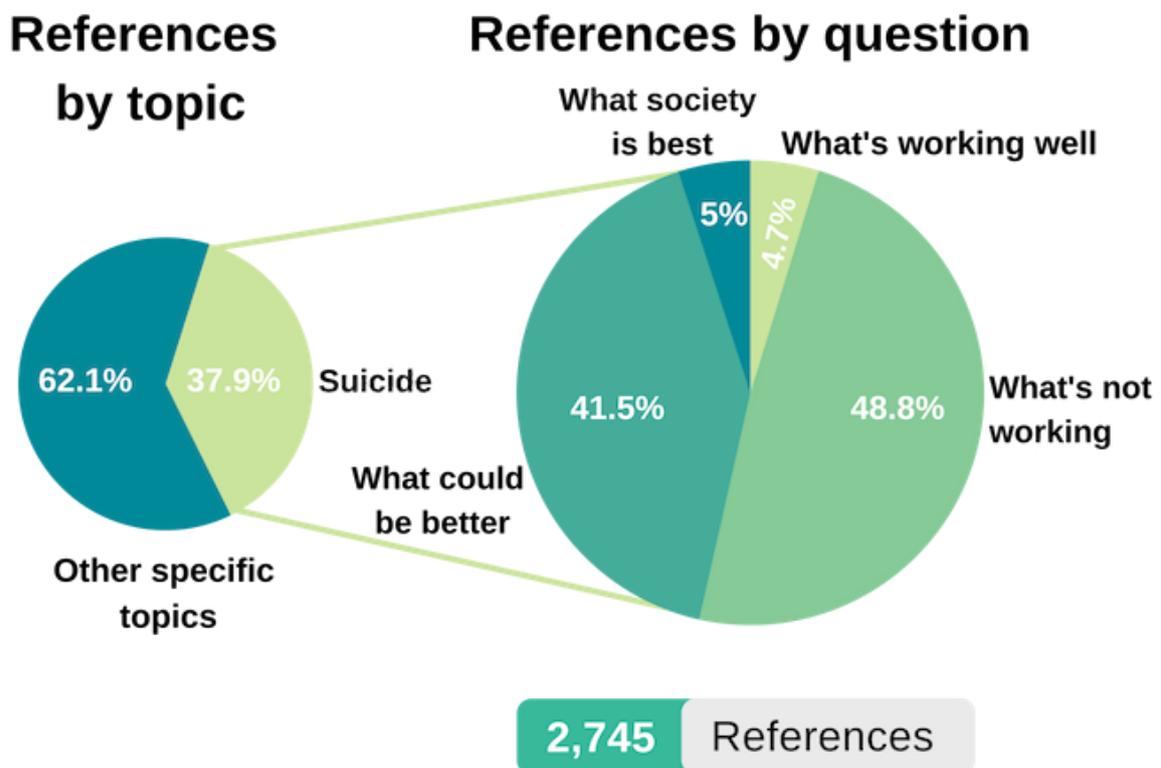
This section presents an overview of responses from submissions about suicide (and self harm where this was appropriate to group together).

Suicide has an overwhelming impact on family, whānau and friends across Aotearoa New Zealand. Hundreds of submitters told their story of personal loss and grief, and its impact on themselves, their family and their communities. Often these stories told of the struggle to find appropriate support, solutions and information, and a mental health system that was unable and sometimes unwilling to meet the needs of their loved one. Stories also offered solutions and hope for change, so that another family would not have to suffer what they suffered.

This section presents an overview of submissions, both personal and from organisations, service providers, iwi and researchers that talked about suicide and self-harm. Self-harm is often linked to suicide, but non-suicidal self-harm was also raised as a distinct issue by some submitters. Where relevant, the two terms will be used to indicate that the section refers to both. Some sections refer only to suicide, especially those focusing on suicide prevention strategies, but this is only because of how the submission was framed.

Submitters made 2,745 references about suicide.

FIGURE 4.3: SUMMARY OF RESPONSES MADE ABOUT SUICIDE



## KEY THEMES FROM SUBMISSIONS FOR SUICIDE

### **4.2.2 What's working well?**

- Prevention Services
- Postvention support working well in some areas, where it is available
- Crisis or emergency response for suicidal individuals
- Emergency response – waive privacy
- Integrated Services and working together
- Wrap around care
- Community led support and interventions
- Respite care
- Peer support
- Good therapists
- Other approaches that are working well

### **4.2.3 What isn't working well?**

- Negative rates for different populations
- Long-term causes of (or contributors to) suicide
- Situational distress and crisis (not long term)
- Contributors to youth suicides
- Media reports of suicide and social media discussion about suicide
- Lack of access to services
- Negative staff attitudes
- Family and whānau exclusion
- Mental health drugs leading to suicidal thoughts and suicide ideation
- Police inappropriate first responders
- Lack of data collection and sharing

### **4.2.4 What could be better?**

- Address long-term or underlying causes of suicide
- Make structural changes and leadership changes to prevent people from taking their own lives
- Improve the workforce
- Implement better support and treatment
- Make improvements to support or interventions
- Do more research and collect more statistics

## 4.2.2 What's working well

### Prevention services

Many submitters provided examples of prevention and early intervention services that were working well.

- Suicide prevention: support and training to upskill the workforce (for example, work to upskill GPs, the work of Suicide Prevention Officers, upskilling education staff, and community upskilling for people in the community that are likely to interact with suicidal individuals).
- Early intervention where they were available (a few submitters noted that some schools have early intervention support available through guidance councillors or similar roles that children and youth can access).
- Prevention – online, telehealth services, or e-services (some submitters provided examples of online, telehelp and e-services that were working well, such as online suicide prevention networks, online tools, various telephone helplines).
- Prevention – targeting at risk groups (A few submitters discussed interventions that were working well that used data or other information to identify and target at risk groups with awareness raising and other early interventions)

### Postvention support working well in some cases, where it is available

Some submitters commented on postvention support services that were working well. These included a range of services, often delivered in the community, that provided support to friends, family and whānau of those that have suicided. It was noted that these services were important due to the higher risk for those who have attempted suicide.

Postvention support that were seen as person-, family- and whānau-centred were viewed positively by submitters, including helping bereaved family and whānau to navigate the types of support they may require after a suicide. Services that helped to network bereaved individuals, families, whānau with others that were experiencing, or had experienced, similar loss was seen as positive, and an important part of effective postvention support.

A few submitters commented about Dialectical Behaviour Therapy (DBT) and other counselling, especially when the support was available for free to the bereaved.

### Crisis or emergency response for suicidal individuals

There were some discussions about positive experiences with crisis and emergency response from those that had personal experience with it, as well as those whose family, friend or whānau had accessed it. In these cases, the service users described immediate response to suicidal events that were available quickly, with good staff helping them. One service user commented that,

I found the crisis team were fantastic when I was taken down to be assessed when I felt suicidal and was planning to kill myself (service user)

Another service user noted that,

As someone who went through three suicidal incidents in 2017 I can say that crisis incidents work well for those facing suicidal ideation. The support, phone lines and team are there, and easy to access. However it is obvious they are overloaded (service user)

Another service user noted that them being suicidal meant that they received support quickly,

I got mental health help within a couple of weeks of reaching out to my GP. The only reason I got help so quickly is because I was SUICIDAL and have attempted suicide before. Although I am so grateful that I got help so quickly, I also know that if I didn't say I was suicidal I would probably still be waiting months later (service user)

A grandparent of a service user reported,

I had the experience of visiting my grandson in hospital after he attempted suicide. The crisis team visited him while in hospital and follow up with the out-patient service was good with no delay (family member)

A few service users, or family, friends or whānau of service users commented that ambulance and police had performed well in the circumstances when called upon to provide emergency response to self-harm or suicide events, even when noting that dedicated mental health response may have been more appropriate.

A parent of a service user commented about what was working well, saying,

Crisis response when a person is physically at risk and needs to be kept safe. When my... [family member] attempted suicide twice in a month, the ... ambulance, the... Hospital Psych team and Adult Mental Health Unit provided fast response and kept her from harming herself further. The degree of real caring exhibited by many of the mental health professionals we encountered (family member)

Service providers also discussed aspects of emergency response that were working well, including responses from ambulance services, police and DHB crisis teams. For example, one provider commented on steps to improve competency of ambulance staff when responding to self-harm or attempted suicide call outs. A DHB noted that it had structured its services to be able to provide emergency services.

Clinicians on the urgent roster will cancel other appointments to see an urgent assessment. An urgent assessment is considered risk to self /others. All urgent assessments are seen with a carer/family member and any plan is made with the carer/family input. While all endeavours are made to include the young person in plans if there is a risk of suicide decisions are sometimes made for the young person rather than with (DHB)

### **Emergency response – waive privacy**

A few submitters talked about specific times when providers had waived privacy considerations to provide the support that was needed at the time, including contacting family members against the wishes of the service user (which was seen as a positive by the submitter). A few providers similarly talked about how they waive privacy considerations when someone's life is at risk from suicide. One of these providers noted that sometimes

they get it wrong, but whānau don't mind the call because they are happy that the provider cares about people.

### **Integrated services and working together**

Several submitters commented on specific examples of where agencies and providers were working together to provide better, integrated services for those that were at risk of self-harm or suicide. These examples were generally of DHBs working with NGO providers, effective integration between GPs and specialist services, or school services and other providers. For example, one NGO provider spoke of a suicide prevention coalition that included the DHB, national NGO providers, national telehealth lines, national consumer support groups, and locally contracted providers that worked to implement a local action plan. A DHB both commented on their work with a national NGO to develop and implement a local action plan that brought together local networks to work together. Another DHB discussed an initiative where agencies collaborated to provide evidence-based dialectical behaviour therapy support into schools.

A Māori provider commented on a hui that brought together Māori providers to form a rōpū to reduce Māori suicide rates in their region. The provider noted that, even with no specific funding, they came together each month to learn from each other and focus on health promotion, prevention, capacity and capability, workforce development, and key campaigns (Māori NGO provider).

A Pacific contributor spoke of a collaboration between providers, and the Ministry of Education to address issues of contagion in schools after a suicide. They noted that the collaboration worked because they left individual performance indicators at the door to do the right thing.

A government agency discussed a range of partnerships and relationships that were working well to support children and young people. For example, they noted that they worked regional youth justice teams to support staff to manage young people with difficult behaviour, especially around suicide and self-harm.

Specifically, for postvention support, there was discussion from some submitters about collaboration between providers to provide more effective postvention support. One DHB commented,

Suicide prevention and postvention is an area of focus with a whole of system governance structure that includes Police, Community and Public Health and ... Chief of Psychiatry. There is also an Action Group with broad membership and a Suicide Prevention Coordinator role is being established in the PHO (DHB)

### **Wrap-around care**

Some submitters provided examples of specific instances of wrap-around or holistic care that they or their friend or family member received while they were at risk of self-harm or suicide. One submitter noted,

All consumers and their family-whānau who survive a suicide attempt are assessed by [mental health] Services, and provided with a special information pack containing information for them and their family-whānau about how to support themselves and each other, support agencies and programmes available in the region, and contact details for these (DHB consumer advisory group)

One submitter, the parent of a daughter that was a service user of a residential programme with wrap-around care/therapy, commented that they “seem to have the best outcomes” (family member). This family member also valued the fact that the staff at the facility employed ‘a different approach’ and “rather than put our daughter in a stitch gown when she was looking for ligatures, they merely removed the ligatures and watched her”.

Another parent commented,

What worked well was once our GP had diagnosed my daughter with depression he linked me immediately to the [Child and Adolescent Mental Health Services]. I learnt quickly all the parts that made up the support network and my daughters school was also well informed about where I could go for help (family member)

Another submitter commented,

In particular my experience of [organisation], which provides support for friends and family members with suicidal loved ones, has been amazing. I believe their one stop shop model, providing a key worker ... who can advocate on your behalf and link you into a range of services to meet your specific needs, is hugely beneficial; as I always struggled to know where to go about various things and access resources (service user)

A service user commented that they were helped by accessing community support, such as swimming, gym, yoga, dietary classes, and joining the local library. They added that different organisations, including those outside of mental health, working together was important to improving mental health.

### **Community-led support and interventions**

Some submitters noted that support and interventions that were working well were those that were delivered by and in the community. Features of these programmes normally included bringing together different agencies to work together towards a common goal without being “bogged down with red tape and politics” (Pacific contributor).

One submitter noted that community approaches work because they are,

Community driven... without the often political ideologies that hinder ‘authentic’ community driven approaches... [the] approaches mentioned are CLOSE to the ground - grass roots. They have a heart, passion and desire to see our Pasifika and Māori communities transform themselves, be self-determining and build on each others strengths as a collective. They work well because ‘real’ people with ‘real time’ responses act immediately without hidden agendas of securing funding to mobilise their kaupapa. They just ‘DO’ (Pacific contributor)

Another submitter added that independent community led solutions work well because “there are little to no systemic constraints, taking away from the core purpose and focused too heavily on processes” (service provider with lived experience).

### **Respite care**

Several submitters commented that respite care was working well for them or their friends, family or whānau. Submitters noted that respite care was working well because it provided a safe space for service users that may be at risk of self-harm or suicide, as well as providing respite for their friends, family and whānau who are caring for them.

One submitter stated that respite had been used at times where her daughter’s suicidal ideation had escalated, and she found that this was a safe space for her daughter to spend time and receive the necessary support.

Speaking about respite, a submitter noted,

It was a saviour on numerous occasions for both patient and family. Ideally there would be a similar facility in every health area (family member)

In the words of one submitter involved in mental health and suicide support, respite worked well because,

it takes the individual away from their stressor, takes them away from their family who may bear the stressor or contribute to it, relieves them of all responsibilities to cook and transport costs and accommodation food and shelter are free (advocate)

Another submitter talked about a friend who took her own life who had benefited from female-only respite,

She found a female only respite that she loved, because there were no males there and because she developed a good relationship with the two women who ran it. Most of the respite where there were male clients she found scary (bereaved friend)

### **Peer support**

Several submitters commented that peer support services were working well. This included service users being supported by peers who had similar experiences that they could relate to, as well as bereaved friends, family and friends of those that had suicided who received support from peers that had similar experiences as them.

For example, one service user commented that support from a service that utilises the peer support model has prevented them from becoming a suicide statistic. Another noted,

Peer support works - with a well-managed group people can learn to understand the complexity of their loss and learn valuable skills on recovery from others (academic)

I am a survivor of having actioned suicide ... what has now made me strong today in 2018 has been peer support people with lived experience and peer programs (service user)

Another commented that peer support works because,

These are people with real experiences and real passion to, not fix, but prevent mental illness. Govt agencies are unable to take action until it's too late (service provider with lived experience)

They [services] work well because the people are committed, they care and frequently they have been addicts and victims themselves (service user)

Bereaved friends, family and whānau of those that had suicided also reported that peer support groups worked well for them. One submitter noted,

I think providing support from those bereaved by suicide is working well. I have been supported by Victim Support and also a free counselling service in my city (bereaved family member)

## Good therapists

Several submitters noted that specific therapists, GPs, counsellors or other workforce that had worked well for them as service users.

I have bi polar. I have made several suicide attempts. I also have a family, pets, I got a degree while sick and I hold down a full time job. It's hard. I consider myself lucky because my GP is an absolute gem. I also have a great psychiatrist and case manager at specialist mental health services (service user)

At times, especially after my worst crisis, I found a clinical psychologist absolutely invaluable. He listened, helped me identify what had caused my suicidal meltdown, taught me about self-compassion, gave me a lot of material to read and provided tools I still use, four years on. I would say, that this type of talk therapy is useful for anybody, but especially those in extreme mental distress (service user)

## Other approaches that are working well

**Education, awareness raising and mindfulness.** Many submitters talked about education and awareness raising initiatives already in place as working well. There were many general comments about awareness initiatives working well that helped to normalise mental health issues around self-harm and suicide. A few submitters discussed DHB services, such as suicide prevention co-ordinators, that were working well to educate and improve awareness, but most submissions talked about national awareness campaigns and helplines that they saw as positive.

There is so much out there about accessing help for people struggling with low mood, depression or suicidal thoughts, this is great to get contacts etc out there (service provider)

I think there's increase in public awareness of mental health through various campaigns. Especially in regards to depression and suicidal thoughts. I've seen TV ads and website ads about identifying some symptoms and where to go for help. Also whenever there's a news article about suicide there is a lifeline number and suicide hotline number. So the topic of mental health is more out in the open and less stigmatised in some ways (service user)

Many submitters talked about initiatives aimed at children that helped to raise their awareness about self-harm and suicide constructively.

Working well - That people are talking about mental health issues because more people are affected by this and talking about their problems openly - having high profile people admit they are depressed or suicidal makes young people aware they are not alone (individual with lived experience)

Talking about suicide was also seen by some submissions to be breaking down stigma.

Experiencing and being part of a growing movement of people working to break down the stigma and silencing of mental health and suicide (individual with lived experience)

**Building resilience or development of mental wellbeing in children.** Many submitters talked about education initiatives that promoted resilience and wellbeing development in children to protect against “behaviours known to be associated with increased risk of suicide, for example, depression, alcohol misuse, delinquency” (individual submitter).

For some submitters, building resilience included developing greater connection with culture. One Māori provider spoke about cultural wellness and connection and the impacts of this on confidence and resilience of children. That provider spoke about wānanga with kids 13 and up about suicide as part of other activities to nurture hearts and minds of tamariki and rangatahi.

Several submitters discussed a current approach taken to connection in a range of ways that help to develop mental wellbeing and protect against self-harm and suicide.

1) Connect – relationships based on love make us feel valued and develop our self-worth. 2) Strong Families – families can give us a sense of self and support during tough times. 3) Talk – talking helps us process thoughts and feelings and reach out for help when we need it 4) Cultural identity – evidence shows for Pasifika young people that the stronger the cultural identity the stronger their mental wellbeing 5) Spirituality – connecting with God or something bigger than ourselves supports purpose and meaning in life (Pacific NGO providers)

Several submitters talked about emotional regulation and mindfulness as tools that were working well. For example, one programme was discussed that took youth and worked with them to understand wellbeing and mindfulness who went on to become a leader in his school community and learned to self-regulate emotion.

Programmes in schools to teach safety, emotional regulation (suicide prevention) and avoiding addiction works for children and youth (service provider)

**By Māori, for Māori.** Some submitters commented on wellbeing promotion and suicide prevention initiatives that used Kaupapa Māori approaches.

Additionally, whānau have voiced an appreciation for services delivered ‘for Māori by Māori’, underpinned by Māori cultural values i.e. ka nohi ki te ka nohi (face to face), and linking to community services using whakapapa as a method ... These initiatives work well for those impacted by methamphetamine and suicide; the ‘hard-to-reach’ populations. Given that [alcohol and other drugs] services are limited in [region] where the impacts of methamphetamine is rife, this initiative works well for the whole community (Māori NGO provider)

The best thing about this [suicide intervention and prevention] course was it was not your typical system based, educational institutional learning environment, nor was it based on these principles & values. It was from a Māori perspective, from Māori views, philosophies, principles & tikanga. It was addressing underlying root causes & based on trauma & damage, as opposed to just post-vention & being the ambulance at the bottom of the hill. This for me helped to confirm & validate for me everything I had already learned through my own personal experience through a life of depression, anxiety & suicidal tendency, ideation & survived attempts and my own journey of self-healing. and I guess the governments contribution to this is the funding to the personal training institute that is allowing this to happen (service user)

Some Māori submissions spoke positively about Tūramarama ki te Ora, National Māori Strategy for Addressing Suicide Tūramarama Declaration.

Similarly, for a few Pacific submissions that commented on what was working well, having a provider that understands your background was important.

I think [organisation] works well because again, they have a team of experienced practitioners who are conversant with Pasifika values and approaches from a cultural competence lens. They too have important networks within the Existing strategies that are working well (service user)

### 4.2.3 What isn't working well?

#### Negative rates for different populations

Several submissions commented on the negative suicide rates in New Zealand, including for:

- Māori and Pacific peoples (particularly of a certain age and/or those living in areas of high socioeconomic deprivation)
- mental health service users and those admitted to hospital for intentional self-harm
- migrants and people from refugee backgrounds
- Rainbow communities
- elderly people
- people serving custodial sentences
- rural communities and farmers
- military personnel and first responder personnel
- disabled people

- children aged up to 14.

Another commented that,

A now well-known fact is that New Zealand has the highest rate of youth suicide in the OECD. As well as for Māori, suicide rates have also increased for Pasifika youth and those with lower socio-economic status. New Zealand's high youth suicide rates are very distressing (professional organisation)

Several submitters commented on negative self-harm and suicide statistics for Rainbow (LGBTIQA+) individuals.

Rainbow (sex characteristic, sexuality and gender diverse) communities and people have the same inherent potential to flourish and thrive as other New Zealanders, but currently experience higher rates of poor mental health and addiction issues including suicidal behaviour, depression and anxiety, eating disorders, substance misuse and isolation due to experiences of social exclusion and discrimination (Rainbow sector grouping)

### Long-term causes of (or contributors to) suicide

Many submitters commented on a wide range of factors that were grouped as long-term causes of suicide. The main long-term causes of suicide raised by submitters were as follows.

**Lack of focus on addressing underlying causes.** The most significant barrier to improving our poor statistics around suicide and mental health in general is the “focus on the symptoms of mental health difficulties, rather than the underlying cause” (professional organisation).

**Alcohol.** A large number of submitters commented on alcohol and New Zealand's drinking culture as having a negative impact on self-harm and suicide.

In New Zealand, alcohol is present in almost two-thirds of all suicides – but in some age groups it can be present in up to 79% of cases. Approximately one-third of all people who committed suicide were found to have high blood alcohol levels. This was especially so among males.

Hazardous alcohol use directly affects the mental health of the drinker by:

- causing depression
- leading to suicidal thoughts, increase impulsivity, and decrease inhibitions to complete suicide
- exacerbating existing mental health problems and increase relapse (addictions professional)<sup>12</sup>

**Our culture** – “drugs are very common place, everyone drinks, we're drinking at 14 and it's normal. New Zealand has the highest rate of teen suicide – with high alcohol rates.” (DHB staff)

**Family violence.** Several submissions drew attention to suicide amongst young people, the links between suicide and family violence, and the links between suicide, and maternal mental health and addiction challenges

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<sup>12</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

**Trauma.** Several submitters commented on trauma and its impact on suicide.

Adolescents with greater exposure to adverse childhood experience and trauma, violence, neglect, and care and protection need emotional support to buffer the effects of post-traumatic stress disorder (government agency)

Underlying causes of mental distress, illness and suicide are often put in the 'too hard' basket. But unless we address these we have no hope of stemming the epidemic we are currently facing., There are issues such as bullying, relationship break ups, and trauma that are all contributors to people experiencing mental distress. They are issues that are difficult to deal with but for a person with support, resilience and hope they are far more likely to be overcome (bereaved family member)

**Colonisation.** Colonisation and its impacts were referred to by several Māori submitters. One told the story of the intergenerational trauma experienced by her whānau as a result of colonisation; that trauma then being internalised so that hatred for all things Māori, including themselves, grew.

the echoes of this hate infestation continue to resound through our personal and collective hearts and minds ... [It] cripples us with shame and self-doubt. It smothers our potentials for wholeness. I believe this is the rotten colonially induced hate-filled core from which the voice of much of the suicides of our young Māori people arises (whānau Māori)

**Sexual abuse and sexual assault.** A large number of submissions discussed the impacts of sexual abuse and sexual assault and its contribution to self-harm and suicide.

[My friend] disclosed to me that she suffered sexual abuse as a child. This was so traumatic that she had never told me about it until she disclosed it to a therapist... at the time she started discussing it in therapy she started to have psychotic episodes. I had known her then for almost [passage of time] and I had never known her to have any psychosis (bereaved friend)

**Problem gambling.** Problem gambling was referred to by a few submitters as a contributor to self-harm and suicide.

Huge correlation between gambling and domestic violence/ suicide. There are too many pokie machines and grog shops in places where people are most vulnerable (NGO staff members)

**Online, screen time and use of technology.** A few submissions commented on time spent online, including cyber-bullying, as a contributor to self-harm and suicide.

There is robust research showing a negative correlation between the use of technology in young people and their mood and increasing anxiety levels. Viewing over 2 hours per day of social media is not a good thing (mental health professional)

**Link between attention of government agencies and police and suicide.** Several submissions talked about the link between individuals being in contact with government agencies (including Oranga Tamaki and New Zealand Police) and later suicide.

Frontline services (first responder agencies such as police, Child, Youth and Family, social support services, hospitals and other health services) appeared to have had significant involvement at various points in time during the lives of those who died by suicide... Many of those in the subgroups who died by suicide were known to a number of government agencies. Over 40 percent of men of working age who died by suicide had come to the attention of police for an alleged offence in the 10 years prior to death and half of these men committed an offence the year before they died (government agency)

### **Situational distress and crisis (not long term)**

Situational distress and crisis, in the absence of long-term mental health challenges, was identified by some submitters as a contributor to suicide that is not widely recognised in current policy or practice. One submitter from an NGO provider noted,

We are concerned that prevailing methodologies and priorities are still over-estimating the correlation between inherent or long-term mental health issues, and under-estimating the importance of situational distress and crisis, as a contributor to suicidal behaviours (NGO provider)

The submitter added that situational distress triggers can be different for men and women.

Situational drivers impact both men and women ... (e.g. relationship breakdown, loss of a child or close family member, loss of status or reputation, experience of another suicide, addiction). However, there are many triggers ... which are more likely to impact men or impact them more severely (e.g. loss of employment, sustained unemployment, greater levels of risk-taking behaviour and resulting adverse consequences, business failure, facing criminal charges or being convicted of a crime, etc). It is important to acknowledge that there are also situational distress triggers which are more likely to impact women, particularly being the victim of abuse, violence, or other crime (NGO provider)

Related to situation distress, some commentators noted that suicide isn't always caused by mental illness.

Many suicides occur as a result of situational distress, such as relationship difficulties, social isolation or job loss as opposed to mental illness. Often suicide prevention strategies lead through to mental health specialists for diagnosis and treatment. While this approach may help people who have a mental illness, it is of limited use to people at risk of situational suicide.[organisation] believes that the Inquiry needs to consider actions such as providing support services for those experiencing situational distress such as relationship breakups and suffering from alcohol or drug harm. Currently many secondary providers need to provide support services out of hours because the community and primary services are under resourced to respond especially during after hours (DHB)

### **Contributors to youth suicides**

Although the factors identified above might also be present in youth suicides, particular trends can be observed specific to youth suicide. These include:

- multiple problems and stressors within the family-including parental separation, difficult relationships with step-parents, difficult or non-existent relationships with biological parents, lack of parental control, a high level of responsibility for younger siblings, domestic violence and abuse (including verbal and/or emotional abuse)
- alcohol and other drug use and abuse
- social deprivation
- negative and destructive social media communications
- bullying
- suicide and suicide attempts being a presence in their lives
- truancy
- disciplinary problems at school
- youth offending
- sexual abuse and assault
- roaming at night
- self-harm (including cutting).

### **Media reports of suicide and social media discussion about suicide**

There was discussion from some submitters about the media reporting of suicide, and whether the current media guidelines are still relevant.

Some submitters noted that social media has changed how news is disseminated, and that the discussions about suicide are already happening on social media, meaning there is less ability to monitor and shape the conversation about suicide.

This is a difficult area, but statistics indicate that shutting down the reporting of suicide has not worked. With social media usage growing exponentially the need for accurate and timely reporting is more needed than ever. While suicide clusters are a clear concern, much of the discussion and news is underground and therefore unable to be challenged (service user)

Some other submitters took an alternative view, that the strict legislation and guidelines around speaking publicly about suicide prevented having better conversations about suicide, thus helping to prevent further suicides.

REPEAL THE ARCHAIC LAWS THAT MAKE PUBLICLY SPEAKING ABOUT SUICIDE A CRIME. This simple legislative exercise will likely be the easiest, cheapest and most far-reaching recommendation that I will make... What these laws actually do is create fear about talking about suicide at all to avoid breaking the law. They transform suicide into a taboo subject (family member)

### **Lack of access to services**

Many submitters reported barriers associated with access to services when either they or their friend, family or whānau was suicidal or self-harming. These barriers are

interconnected and combine to create a system that is a significant barrier to suicide prevention. The most commonly reported themes included:

- a lack of services
- a lack of culturally appropriate services
- a lack of youth appropriate services
- a lack of talking therapies and diverse modalities
- a lack of staffing, funding and resourcing
- narrow eligibility criteria
- negative staff attitudes
- front-line workers' limited knowledge of suicidality
- distressed people not being taken seriously
- family and whānau concerns not being listened to
- long waiting lists.

A few submitters made a distinction between self-harm and suicide, where someone can be self-harming but not suicidal.

**Lack of staff.** Many submitters commented on the failure of the system to ensure a large enough and well trained enough workforce to meet demand on services. Service users and suicide bereaved, as well as staff providing or working in services, commented on this topic. One submitter who lost a son to suicide commented on a range of workforce issues.

Our [family member] died in 2015 while in the legal care of the ... DHB in the midst of this growing crisis. It was our experience that all of the services we engaged with were overstretched, under-resourced, lacked leadership and qualified staff, had an antiquated model of care, and a culture of defensiveness and butt covering (bereaved family member)

Many submitters addressed the impacts of staff shortages on people who are in crisis.

[There is] not enough staff – thin on the ground – support therefore not ongoing. e.g. someone at risk of suicide but no one could come from [crisis team] to help with a stressful crisis situation as only one staff member on and couldn't come alone. e.g. people lost/forgotten by providers – file on someone's desk for 7 months before called to say can't help because 'too hard basket' (family member)

Many submitters reported that staff working in DHBs and NGOs were stretched to capacity and that this impacted on staff wellbeing.

I work as a front line clinician in [region] Emergency Department. I have performed thousands of assessments of suicidal people. Our service is massively under resourced and the stress of work affects the Mental Health of our ... team ... Trying to get a sensible response to this situation with DHB managers is like herding cats. The response to requesting extra staff is actually to be given more work to do (health professional)

Another submitter commented that we need to look at the “suicide stats amongst doctors and clinicians themselves, the whakamā” (NGO staff members). One submitter with experience of working in the mental health sector commented,

I was worked very hard despite my mental health beginning to decline. There is also a strange judgment around professionals who become unwell—it’s not talked about a lot. I was left suicidal one Friday afternoon after work, I was ready to end my life. If I hadn’t seen someone I know I would have killed myself that evening. We need other people who believe in us to recover (support worker with lived experience)

Other examples,

If staff are well-trained and looked after, then patients will get the benefits from that. Under-funding, under-staffing are NOT good reasons for poor patient treatment or outcomes. This has to be a priority. No different to having informed educated staff working with cancer patients (former health professional with lived experience)

**Lack of access and lack of beds.** A large number of submitters spoke about the experience of contacting services and not receiving an appropriate response anywhere in the system. This was often linked to comments about the services not having enough staff and not having enough funding.

I contacted emergency mental health team six times and emergency department twice and police once — wasn’t enough for mental health team to listen and I attempted suicide after. Shouldn’t come to that point to be taken seriously. Would have helped to have gone into a safe place or unit for a few days until I calmed down. Crisis admission for 48 hours does help me and they should have known that. Could be in community if I was well supported—I got into a deep hole and it was extremely difficult to get help. Earlier community respite would have been beneficial but by the time they got to me I was in crisis (service user)

Several submissions to the Inquiry panel referred to whānau or family members who were denied hospital support because of a lack of beds.

Brother was asked to stay at home because of a bed shortage in the ward and he tried to cut his wrists. He rung up to tell ward he wanted to hang himself (health professional with lived experience)

[Crisis team] said there were no beds; she made a suicide attempt with overdose—it shouldn’t take that to be kept safe (service user)

**Lack of access – not considered serious enough.** Many submitters talked about issues with people being turned away from services because they weren’t considered to be serious enough risk. For individuals that were trying to access services, there were many stories about them being turned away from services:

I have been under mental health care for the past 18 months. I do not have a psychiatrist and am on a second key worker as first one burnt out and was no effective in job. I have not heard from my key worker for six weeks while being depressed and suicidal. I am told I am resilient and high functioning, which makes me feel guilty for asking for help because there are so many more so worse off than me (service user)

For many submitters that had lost friends, family, or whānau to suicide, there were many stories about their loved one not being able to access services that may have helped them.

Some submitters commented that the issue of high thresholds and being turned away was worse in rural areas, with less services available and less capacity where there were services.

A few submitters talked specifically about prisoners not being able to access services because they weren't serious enough. A government agency noted,

The management of prisoners who do not meet the criteria for admission to mental health facilities, or who are waitlisted, is an ongoing problem. Some prisoners spend long periods in an intervention and support unit due to a risk of self-harm, including suicidal ideation or have frequent admissions to enable them to be safely managed, which many not be the most appropriate way of managing their care (government agency)

**Lack of access to appropriate services.** Many submitters addressed a lack of access to services as part of their discussion about effective services. This primarily reflected issues to do with a lack of talking therapies and included:

- a lack of diverse therapy services
- the short duration of subsidised talking therapy (for example a four-session maximum)
- the cost of talking therapy
- therapists leaving and not being replaced
- time taken to replace talking therapists
- having to retell painful information
- having to develop a new therapeutic relationship.

Many individual submitters and groups that addressed suicide called for access to a diverse array of quality therapies. Some submitters highlighted the need for women-only services to ensure women's safety.

Free or low cost counselling needs to be made more readily available to people experiencing mental health issues... there is a very big need for women-only hospital wards and women-only respite in every part of the country (bereaved friend)

**Lack of access – referrals, falling through the gaps, and lack of integration.** Transitions between services were also identified as an area where people who are suicidal 'fall through the gaps'. While this was sometimes related to access issues, it also related to shifting service type (for example, maternal mental health to community mental health; child and youth services to adult services) and shifting catchments (for example, central Auckland to south Auckland).

It is frequently observed in mortality reviews that a young person with co-morbidities of mental health and addiction disorders, that the person is ineffectively transferred between Mental Health and Community Drug and Alcohol services, each claiming that the other needs to be addressed before being applicable for treatment through the relevant service. Frequently resulting in the young person falling through the gaps as the service often declines the referral or fails to engage the youth in a timely manner (DHB)

Māori submitters also reported issues with assessments and referrals not being handled well, leading to people falling through the gaps.

**Lack of access to appropriate services for postvention support.** Access to appropriate postvention services was also raised in the context of stigma that affects families, whānau and friends' help seeking following a suicide. Because many suicide bereaved people conceptualised their experience of loss as sadness and grief, they did not seek support from 'mental' health services as these services were not regarded as relevant. One suicide bereaved whānau member spoke of never thinking to contact mental health services for postvention support for themselves because "we are not 'mental', we are sad and grieving. So why would you go to mental health?" (bereaved whānau Māori).

Submitters addressed many shortcomings of current suicide postvention services. Key themes identified included:

- inappropriate services
- a lack of culturally relevant services
- a lack of age-relevant services
- inconsistent service provision
- a lack of seamless service provision across catchments (e.g. the death of a loved one in one region and trying to access services in another)
- culturally offensive practices relating to the deceased individual's body, including access to the body
- ineffectual and inconsistent assessment of suicidality (linked to being unable to access service due to not meeting the specified threshold).

A lack of a culturally sensitive approach to suicide postvention support was raised in some submissions. One suicide bereaved submitter commented on a lack of understanding and barriers associated with access to deceased whānau.

Cop said, "You only got 5 mins", then said, "I've done my job" and then left ... No support for the whānau was put in place including no concern or help with where they could stay or who would next be in touch with them (bereaved whānau Māori)

A lack of follow-up with suicide bereaved families and whānau by services was reported in several face-to-face oral submissions to the panel. Some felt it was left to them to seek out answers and support following their suicide losses and whilst dealing with intense grief. This was perceived as unreasonable. Coroners were also reported as being too slow at contacting families and whānau after suicides.

They shouldn't have to do the follow up to get answers (bereaved whānau Māori)

**Lack of access – cost of accessing services.** Some submitters commented on the cost of accessing services through GPs, and the cost of accessing private therapy or counselling when they were not able to have publicly funded care.

I am currently doing three reports to the coroner for patients who have committed suicide in the past month. This is more than I have done in the previous 20 years in practice. These patients could not afford to see us, and we do not have enough doctors to see everyone who needs us (professional organisation)

### **Negative staff attitudes**

Many submitters often reported disrespectful, demeaning and offensive comments and interactions from staff working in health and other services. For some, the lack of empathy they experienced from health professionals was considered a factor in eventual suicides.

Talked about trying to keep 'seeking help for our son' but finding a 'lack of empathy' from services: 'The GP just didn't seem to care' (bereaved family member)

Talked about the failure of [government agency] to recognise and properly respond to her [family member's] suicidal intent prior to his death. While at [government agency] he was crying saying he wanted to die while the [government staff member] was saying, "I don't care about that, I care about you not causing more trouble in my society" (bereaved whānau Māori)

Some submitters added that staff they or their friend, family or whānau dealt with while self-harming or suicidal did not listen to their concerns or dismissed them. One 0800 number submitter noted that they experienced demeaning communication from services. For a few submitters, this was extended to staff on telehealth support lines, reporting after calling a helpline they would overdose because it was such an unhelpful experience and made them feel worse than when they called.

### **Family and whānau exclusion**

Many families and whānau reported in submissions that they had been actively excluded by staff in services and not consulted about discharge plans for their family and whānau member. Some submissions identified this exclusion as a significant factor in the suicides of their loved ones. One submission to the panel from the parent of a service-user who died by suicide, stated their son was dead because "they weren't listened to over five years of hell" (bereaved family member) by continually dismissive staff.

Other parents told similar stories of being denied information about their adult children when those children were inpatients of DHB mental health services. Parents spoke of receiving texts from their son from inside the unit asking them to come and get him, but being blocked by mental health professionals from doing so. Instead they were told their son did not want to see them and were denied any information about his wellbeing.

They lied that our son didn't want to see us. Initially the unit would not give any information at all to us over the phone: They said they couldn't confirm he's there but we could (their son was texting them) and were told "even if you do come you won't be allowed in" (bereaved whānau Māori)

Some Māori submitters named this Western approach to support being provided to an individual independently of the whānau as a contributor to their whānau members' suicides.

Family meant everything to him. He always rang, always came home. If we were allowed to be involved [in his counselling] this could've been a different story (bereaved whānau Māori)

Some submissions from parents of service users noted that their adult child had not wanted parent/s involved, adding that the Privacy Act was a barrier to ensuring a loved one was cared for, supported, and prevented from dying.

Unknown to me as he didn't talk to me, I didn't know how bad he was. He lived in [city] and was taken to emergency psych services by a friend of his. If I have known that I would have gone and got him or advocated for him or looked after him and maybe he wouldn't have killed himself. I will never know now if this would have helped prevent his death and I will go to my grave of not knowing. However the staff in that Mental Health team misunderstood the Privacy Act and didn't inform me. However it was very clear that he was a danger to himself (bereaved family member)

Other families and whānau said that without their support, the loved one would have died a lot sooner than occurred. Some families and whānau wanted information and support to enable a better understanding of mental health and addiction challenges and suicidality.

I always felt like I was being blamed for daughter's mental distress. The ones who come to A&E after suicide attempts... look and behave as if... there's nothing that can or will be done to help you as a whānau (family member)

One submitter reported being turned away when trying to visit a relation.

I once tried to visit my mentally unwell cousin in [the inpatient unit] but the front staff would not let me in to see him. In the interim [a staff member] was able to have my cousin released ... without our knowledge or reintegrating support, and within a week my cousin had committed suicide (family member)

Although families and whānau often commented that they were excluded from services, people with lived experience of suicidality did not tend to raise this issue.

### **Mental health drugs leading to suicidal thoughts and suicide ideation**

Many submitters commented negatively about the impacts of medication given to service users as part of their treatment on suicide. There were two main themes from submissions: that the medication itself led to suicidal thoughts, and that there was often insufficient planning in place to keep people safe when they were coming off their medication.

Doctors should be more aware of drug interaction as these drugs tend to lead to suicidal thoughts and plans. Patients who are on multiple drugs should be under appropriate mental health (individual submitter)

### **Police inappropriate first responders**

Several submitters highlighted the role that the New Zealand Police has adopted in the absence of mental health services being available to respond to people who are suicidal. One submitter commented that, "Police have found themselves becoming default frontline mental health workers" (NGO provider).

Some submitters commented on the need for appropriate police training to understand how to work appropriately with people who are suicidal. One person reported that they just been released from the mental health system after three suicide attempts and noted that the police and emergency department staff did not know how to deal with them. They said, “I was thrown around and treated like a criminal” (service user).

### **Lack of data collection and sharing**

Some submitters noted there was a lack of useful information available about suicide and self-harm statistics. Several submitters noted that suicide and self-harm data exists, but is often outdated, and suicides are not collated in a dataset despite the coroner investigating each suicide in depth.

In terms of data collection from coronial processes, a few submissions noted that the current database does not provide detailed enough information on social demographics and other information to enable themes to be identified.

Without a database that captures such issues it is difficult to confidently identify themes (government agency)

Some submitters noted that the information that is collected during coroners’ inquiries is not readily shared, even with those working in suicide prevention.

During a coroner’s inquiry into the death of a person in whom suicide is suspected, a wealth of important source information is collected. This data is currently not easily available to assist those working in the field of suicide prevention (government agency)

## **4.2.4 What could be better?**

### **Address long-term or underlying causes of suicide**

**Shift away from the medical model and greater community connectedness.** Many submitters called for a shift away from the ‘medical model’ where patients are given prescription medication instead of being supported holistically to flourish. Many submissions recommended that preventing suicide was linked to creating a greater wellbeing focus with greater connection between people and their communities.

We would have a nurturing society with greater empathy towards those suffering from mental health illnesses. Make sure that there is a priority of funding to support all services for families, consumers and communities, that people would be adequately loved and supported by society, so that hopelessness would be eradicated and thus the appalling suicide rates (service user)

Many submitters commented on both the need to shift away from the medical model and clinical interventions to support that was more tailored to an individual’s circumstances.

Rather than needing clinical intervention involving pharmacology or psychotherapy, many may need practical support dependent upon the situation they are facing. Service delivery methods may need to be more tailored to the fact that men are less likely to seek help than women, even where they are more likely to face distress. An example of this in a success model is [organisation] whose support workers can go onto farms and talk about anxiety and distress but also talk about farming (NGO provider)

Even in terms of making changes to the medical 'system', there were many calls for greater investment in earlier support, such as through primary health providers and community providers.

This model should be a family-based (broadest interpretation of family) model – purely strength-based approach. None of the indicators in the primary care model which is piloting in [city] are negative indicators. Suicide is not going to be solved by more Doctors and Nurses. We need to build from the other end (Pacific professional organisation)

**Address alcohol.** Many submitters commented on the link between alcohol and suicide, calling for greater acknowledgement of the link between alcohol and suicide. Some submitters noted that alcohol is both a contributor to suicide in its own right, but also causes or reinforced other social determinants that contribute to suicide such as domestic violence.

Understanding the link between suicide and substance use should be included in suicide prevention strategies. People who misuse alcohol and other substances are more likely to suicide. Substance use, especially alcohol is associated with increased rates of violence, often to intimate family members. Research indicates that people exposed to domestic violence have a greater risk of suiciding. Public health initiatives targeted at reducing suicide must be cognisant of the role substance use plays in increasing the risk of suicide, both with the person living with addiction and those close family members who may be indirectly harmed by their substance misuse (professional organisation)

There were calls from many submitters to limit the access to alcohol through a range of measures such as making changes to current alcohol policies and regulations. For more information on these specific recommendations, see section **4.1.4: What could be better?**

**Address social determinants.** Many submitters commented on the need to address social determinants as underlying contributors to New Zealand's suicide rates.

A few submitters commented on the difference between risk factors for non-Māori, Māori, and other populations.

Evidence all around the world has shown that for indigenous populations, there are some risk factors (and thus protective factors) for suicide (and mental illness) that are different from the dominant population. Because New Zealand's programmes have focussed on reducing 'pakeha' risk factors, it is not surprising that suicide prevention and mental health promotion programmes have not met all the needs of Pasifika families (Pacific NGO providers)

Many submitters that discussed social determinants noted that resolving the underlying causes of these issues would be complex.

Actions to address these factors will be complex, multi-faceted, and require strong commitment and a long-term view (government agency)<sup>13</sup>

**More wellbeing promotion and prevention.** Many submitters talked about the need to reprioritise how we invest in suicide prevention to focus on prevention to give people the tools to deal with distress and not reach crisis. For many of these submissions, there was a call to invest in prevention but also to improve services for those that are in distress.

Fences are typically cheaper, however both must be strong and well resourced. The fence is generally cheaper though harder to conceptualise, and requires a long term view to approaches and costing. We must make the effort if we are to turn around our terrible suicide rate and worsening addiction epidemic (individual with lived experience)

Other health promotion approaches to suicide prevention suggested by submitters include:

- ridding Aotearoa New Zealand of the attitude of needing to ‘just harden up’ – especially important in farming communities who think someone is ‘soft’ when they need support
- delivering suicide prevention or leadership programmes that build healthy networks throughout communities between adolescents, parents and teachers
- delivering programmes that address the language we use and explore the safe usage of concepts like depression, suicide, anxiety, addiction, mental health and mental illness.

One submitter provided a list of examples of programmes to improve mental wellbeing that captured the approach mirrored by many submitters, including:

- Anti-racism or Treaty of Waitangi as a subject/module/credits in the classroom at every year to illuminate the truth and understanding about New Zealand's history, and strengthen bi-culturalism and race relations,
- Anti-bullying or relationship building programmes to develop respect and trust in self and others,
- Suicide prevention or leadership programmes that build healthy networks throughout communities between adolescents, parents and teachers,
- Programmes that can be implemented to address the language we use and explore the safe usage of concept– like depression, suicide, anxiety, addiction, mental health and mental illness to name a few,
- Programmes that teach self-love and self-worth,
- Programmes that support communities to foster their ethnic-cultural identity,
- Programmes that can be implemented like “a toolkit to survive - skills for life” such as healthy ways to express emotion,
- Programmes that develop community leaders,
- Programmes within the education system that tap into childrens learning styles to achieve greater learning outcomes,

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<sup>13</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

- Programmes that support young people to keep busy after school,
- Programmes that provide rehabilitation to persons addicted to illegal drugs rounded with whānau ora navigators to work with their whānau to strengthen and provide the supportive environment for the persons to return to,
- Programmes that give persons fresh starts in life,
- Programmes that support rongoa Māori,
- Programmes that lift whānau out of poverty,
- More yoga, tai chi and meditation programmes,
- More funding for official websites promoting mental health wellness, information about mental health and where to find support,
- More funding for access to mental health services in the community,
- More funding to develop evidence-based Māori healing programmes,
- More funding to support Māori into tertiary education,
- More funding for whānau, hapū and iwi driven initiatives that already work such as kapahaka and sports that Māori naturally strive in, and
- More ring-fenced funding for whānau, hapū and iwi driven initiatives to meet equitable outcomes (whānau Māori)

**Shift in how we talk about mental health and suicide.** Many submitters commented on the need to shift the language of suicide. Submissions commented on changing the conversation about suicide and how we raise awareness of suicidal thoughts, as well as changing the conversation for how we talk about suicide after it has happened.

Reframe our language to continue to address the stigma and discrimination in our society (bereaved family member)

Major concern in the bigger picture is the need to change our language starting at the top - the words we use can either bring us together and 'in' or separate us from others and/or reinforce behaviours and our ideas we hold about ourselves consequently impacting on our own and others mental health (service provider with lived experience)

Regarding conversations around prevention and awareness raising, there was a broad call to reduce the stigma around suicide and suicidal thoughts to make it easier for people to talk about their feelings. There was also a call to shift away from the use of language such as 'harden up' when someone spoke about their mental health, especially in the rural community where people are considered soft if they ask for help.

There needs to be a rethink about how people who want to suicide are treated. What is being done currently is not reducing the numbers of completed suicides (consumer leaders)

A caring, supportive, whānau based society where all differences are the norm. Where everyone accepts that mental health issues, suicidal thoughts and addictions are a health issue not a belief they need to 'toughen up, get on with it, move on or accept it' (family member)

Some submitters recommended changing how services are designed, such as greater use of co-design and trauma-informed care, to change how people are supported once they were in services.

Trauma Informed Care is a an empowering and positive process that allows the vulnerable person to re-take charge of their life and understand that they are not to 'blame' for how they feel and think. It is understandable that they think of suicide as an option when they have been exposed to trauma or neglect earlier in their lives and don't have sufficient tools (mental health professional)

Regarding language after a suicide, there were calls from some submissions to change the narrative to stop blaming friends, family and whānau for the suicide of people close to them. For example, one submitter recommended that "being more open about suicide as a society and trying to change the culture of fear and blaming could be really helpful" (health professional). This was linked to recommendations about more education about the impact of suicide on bereaved families and the types of support they may require.

**More education and health literacy.** Many submissions called for more education about self-harm and suicide. This included education for children and youth, but also for all New Zealanders around the causes, effects and impacts of suicide and how it can be prevented.

Increasing mental health and suicide prevention literacy is very important, and it needs to be occurring at national level as well as community level. At a community level, it needs to take the form and language of the community themselves and occur at a pace that is tolerable (DHB)

Submissions contained many ideas for what could be included in this education, but some of the common themes were better education around:

- self-harm awareness
- suicide and suicide ideation awareness
- mood disorders
- alcohol and other drug use
- warning signs around suicide
- underage sex
- how to open up or share with others
- how to manage stress, anxiety and depression.

For many submitters, improving the health literacy of everyone around self-harm and suicide would help people to recognise when they or others required support, and to provide them with basic tools to provide a first level of support. Other submitters added that improved health literacy would help to remove stigma around self-harm and suicide, including stigma for those bereaved by the suicide of friends, families or loved ones.

Other submitters called for more specific education campaigns, especially for children.

It is recommended that a youth wellbeing program is incorporated as part of the Health Curriculum focusing on students aged 11yrs and upwards. The content of such a programme would include; keeping well, maintaining wellbeing, and supporting peers to be well. Teach skills dealing with difficult times, Anti-bullying/violence programmes, online safety/wellbeing, relationship skills and addressing conflict/resolution. The program should focus on developing awareness of youth depression and suicide, recognizing the signs of suicide and the various resources that are available to youth who are considering suicide. Young people who subsequently die have significantly higher rates of disengagement from the school system than the normal youth population. Any stand down, suspension or exclusion from school is a red flag for a high risk of adverse outcomes and should trigger supportive interventions (DHB)

Other examples included education about the effects of self-harm and suicide attempts. One submitter added that there was a need for education about the damage that a suicide attempt can cause even when the individual doesn't necessarily expect it to be successful but more a 'cry for help' (for example, liver damage from overdose attempt, or brain damage from hanging attempt).

As we open conversations about suicide, about how to seek help, about how to talk to each other, perhaps we might consider discussing the physical health effects of such self-harm. Obviously, this discussion needs to be very careful about not explaining how to successfully commit suicide, but I believe there are benefits in explaining how much harm you can cause yourself (service user)

**Teaching personal coping mechanisms.** Some submitters talked about teaching people personal techniques to safely deal with distress and control their emotions. Many of these submitters specifically called for teaching of mindfulness as a way to help people to better handle their emotions and prevent them from reaching a crisis point where they may harm or kill themselves.

I believe a culture of talking and wellness starts with education at school with simple things like mindfulness and emotional intelligence being taught (rangatahi Māori)

Wellbeing programmes and/or Mindfulness as part of the school curriculum. Education for those who have loved ones who might be sliding towards depression or suicide (what to look for, how to engage to help the person). The further into the tunnel you go the darker it is and the harder it can be to find your way out (service user)

## **Make structural changes and leadership changes to prevent people from taking their own lives**

**Many submitters called for more leadership at a national level.** This took on a range of formats, but included:

- appointment of a Minister responsible for Suicide Prevention
- establishment of a Wellbeing Ministry

- an independent centre for suicide prevention and postvention that provides strategy and leadership, shares best practice and evidence-based information, leads the field and builds knowledge
- independent Māori leadership to drive improvements in Māori health outcomes.

**Need for alignment between providers and other agencies.** Many submitters commented on the need for better alignment between providers and government agencies to provide better, continuous care that did not let people fall through the gaps. A few submitters specifically discussed the complexity of the responses required to put effective suicide prevention systems in place.

For example, one government agency recommended comprehensive cross-government and cross-agency, intersectoral system responses to suicide prevention and postvention that address many of the systemic issues raised in submissions to this Inquiry. This includes the need for greater intersectoral collaboration and information sharing, especially in relation to New Zealand Police, Ministry of Justice, Department of Corrections, and Oranga Tamariki.

Another agency similarly recommended,

future suicide prevention activities should aim to approach the issue through concerted action across all social sectors - not solely within health (government agency)

It was also submitted that there needs to be “a whole of government approach to suicide prevention (justice, health, housing, welfare, corrections)” (consumer leaders).

Services need to respond to people’s distress in the moderate space to address the huge gap. People who suicide are usually known to other sectors such as Justice, Oranga Tamariki. System collaboration needed (NGO provider)

Some Māori submissions noted that the approach to preventing suicide in Māori populations needs to take a broader approach to embed wellbeing strategies in all services.

Reducing suicide should not be a focus of specific services but should be an outcome of **wellbeing strategies in all services**. Schools, all health care services including service for older people, community and inpatient services, rural and urban services, prisons, local authorities need to work together towards the same thing. The message should be about everyone’s life having worth [Emphasis added] (Māori NGO provider)

**Suicide reduction targets.** Some submitters commented on the difficulty in setting targets for suicide prevention. For example, some submitters stated that the ‘zero suicide’ target was named as unrealistic and prompting idealistic interventions. However, other submitters supported the introduction of the zero suicide target.

Resource and co-ordinate national suicide prevention programme involving whole of community response for zero suicide (DHB)

Instead of a zero suicide target, several submissions called for a range of other suicide prevention targets that were more realistic instead of aspirational.

[Organisation] strongly recommend setting suicide reduction targets, these targets should be achievable and not aspirational, with the aim of encouraging government organisations, PHO's, NGO's and the local community to work to collaboratively on the shared goals that are time-specific and measurable to achieve better outcomes for our local communities and young people (DHB)

We need clear targets and intervention based on solid research not waffle. NZ has weak suicide prevention targets (addictions professional)

We recommend that mental health targets are developed, particularly for suicide and self-harm (family member)<sup>14</sup>

[Organisation] recommends that mental health targets are developed, particularly for suicide and self-harm. They need to be outcomes focused and supported by qualitative and quantitative analysis (professional organisation)

Related to the issue of targets, a few submitters commented that suicide prevention cannot be measured in data as there is no certainty of output, noting that you cannot accurately record how many suicides you have prevented if they have not happened.

**Suicide prevention strategy.** Many submitters were concerned at the current situation around the development and implementation of a suicide prevention strategy. Many submitters called for a new suicide prevention strategy to replace the existing strategy, others called for the better implementation of the current strategy, and others called for a strategy to be created (without mentioning any existing strategies).

Continued development of the [Ministry of Health] Suicide prevention strategy will support implementation of common practices nationally, with local enhancements to reflect the local population needs (DHB)

Several submissions were concerned at the lack of a current strategy for suicide prevention, while others were concerned that the current strategy or strategies were flawed.

Abandon the current draft suicide prevention strategy (2016/2017) and develop a new Strategy; the current draft can most usefully be regarded as a summary representation of the community consultation conducted in 2016 in preparation for a new Strategy. A revised Strategy based on evidence rather than community consultation (but taking account of community consultation) is needed to capture public confidence that the Ministry of Health is addressing suicide prevention adequately (DHB)

Some submitters addressed the importance of having a national suicide prevention strategy but noted shortcomings of the current strategy that it does not adequately encapsulate Māori and Pacific world views, approaches and responses. Some submitters commented that *Tūramarama ke ti Ora: National Māori Strategy for Addressing Suicide* was more culturally appropriate and supported it being implemented as a priority. Likewise, some submitters commented positively about Waka Hourua, the Māori and Pacific suicide prevention programme and outcomes framework.

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<sup>14</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

Prioritising Māori suicide prevention approaches. Māori are disproportionality represented in suicide statistics. Suicide prevention efforts need to be derived from culturally driven knowledge and solutions and the Tūramarama ke te Ora Māori Suicide Strategy 2017-2022 is a culmination of this. Priority needs to be given to the enactment of the strategy (NGO provider)

The solutions to Pasifika mental health and suicide issues lie within Pasifika communities. These local solutions are only effective if supported by top down structures such as effective policy, research, and legislation. New Zealand is now at a turning point to integrate both community-based solutions with effective systems and structures. Countries around the world would follow New Zealand's leadership if we were to integrate top down and bottom-up collaborative efforts (Pacific NGO providers)

There were calls from some submitters for there to be more specific strategies and approaches to improve suicide prevention activities in some other groups, such as Asian peoples, Rainbow (LGBTIQ+) communities, Pacific peoples and older people. This was either expressed as having a specific strategy for that population or by identifying that group as a priority population in other strategies.

The rainbow population should be a named priority in all national and regional mental health and addictions policies, given its high rates of distress, addiction and suicidality, and specific risk factors that require targeted responses. Currently, rainbow issues are absent, invisible or inadequately addressed in mental health and addictions policy, and in other national policy areas that contribute to mental health (Rainbow sector grouping)

Suicide prevention planning and service provision to include Asian/MELAA [Middle Eastern, Latin American and African] and refugee groups specifically, as most of them are migrants with many challenges faced by them such as language, culture, religion, employment, education, housing, income and physical/mental trauma (before or during the migration, particularly for people with refugee background) (DHB)

Recognise positives from the suicide strategy – but also its limitations, we have already recognised we need a framework and that we need to work collectively. Then our solutions to improve collaboration, collective action, funding and increased focus on wider causes in a collective (NGO consumer group)

## **Improve the workforce**

**Specialist workforce available to provide assistance to people in crisis.** Many submitters called for improvements to be made to the workforce in terms of both quantity and quality. There were many submissions that noted that the workforce needed to grow to be able to meet the demand for services to prevent people from taking their own lives due to services not being available when they needed them.

There were calls from some submitters for a larger specialist, dedicated mental health workforce to provide support to people that are suicidal. There should be a well-trained expert workforce who can be mobilised in an emergency.

More specialist people need to be readily available to assist suicidal people seeking help. We hear from time to time of suicidal people seeking help but being turned away often because of staff shortages. The results are often drastic (professional organisation)

There were also calls from many submitters for a better-trained workforce that could provide more dedicated support. For example, there were calls from some submissions for more workers to be available that were trained in dialectical behavioural therapy to make this kind of support more accessible.

**Peer workforce.** Many service users and tāngata whaiora recommended the expansion and development of peer workforces to appropriately respond to people experiencing suicidality. While peer support was widely recommended, submitters called for better training and investment in the peer workforce.

we believe it would help in the short term to provide more peer-led and peer-delivered services. There is a big gap between the support that the average person in their community can offer someone in distress, and what the crisis team at the hospital does. We need to fill that gap with a range of options, and to upskill the general public about how to have those conversations with someone in distress (NGO provider)

Ideally the peer workforce would be an integral and important part of that work force and have the same or similar experience, training and access to supervision as everyone else (consumer leaders)

**Need for more representative workforce.** Some submissions called for a more culturally representative workforce that would be able to provide culturally appropriate responses to people in crisis.

We need to invest in educating and training more Māori, pasifika and other main ethnic MH workers. We must utilise the authentic and trusted voices of peers (leaders and across the spectrum) including those of lived experience to devise and operationalise our MHS strategies. We dont have to re-invent the wheel (service user)

Build and support Asian capacity in the education, health and police sectors and in the wider justice and social sectors. All services need to have a culturally competent workforce. Greater focus and care needs to be taken in identifying and supporting people in distress, as soon as possible (DHB)

**Better support, training and integration of GPs (primary care).** GPs were seen by many submitters as the primary service that most New Zealander's accessed when in distress. Many submitters reported that they had received poor support from their GP, and recommended that improvements to how GPs were trained and equipped to deal with mental distress were made.

## **Implement better support and treatment**

**More support more quickly.** In terms of improving service delivery for support for people that are self-harming or at risk of suicide, the majority of the submissions called for greater access to services earlier. Many submitters were concerned about people being turned away when they needed support, and many of these submitters called for more staff, beds, and resources to ensure that these people seeking support are able to be accommodated.

In my ideal New Zealand upon going to ... Hospital I'd be immediately taken to a monitored waiting room for those at risk of harm to themselves. I would see a mental health nurse, doctor, just anyone with the qualification to triage mental health. I might then wait for a bit for a crisis team or on call psychologist. Then together we'd work out the best and most safest plan for me. Which I believe would be: medication, around the clock observation, rest and counselling. Just 5 days, somewhere away from home, with qualified mental health professionals. What a world that would be (youth service user)

For children especially, many submitters recommended greater emphasis on putting appropriate resources in place to provide support before they reach crisis point.

A society that provides more support before a crisis, particularly for young people. This can be incorporated into school's curriculums, alongside physical and sexual wellbeing (bereaved family member)

**Need for earlier support (before they are suicidal).** Many submitters talked about the need for people to have access to support before they reach crisis point and become suicidal. Many submitters talked about either themselves or others being turned away from services because they weren't serious enough, and these submitters commonly recommended greater availability of services to those that don't meet the current definitions.

For some of these submitters, this could take the form of community interventions, or better education to allow friends, family and whānau to provide early support.

If people can get community help and professional counselling before they get to the acute suicidal stage, and receive well monitored secure unit help if this stage is reached, with ongoing help once released without big wads of pills, it would avert many tragedies (individual with lived experience)

Long waiting times for services was seen as contributing to worsening mental health of individuals, increasing the likelihood that they self-harmed or suicided.

Our staff have commented upon the long wait lists their clients are facing when reaching out to different providers. When dealing with addiction and mental health challenges, long-term waiting for support exasperates the need and can drive a rapid decline of client wellbeing. It is in these instances where individuals can feel most at-risk, heightening their chances of self-harm and suicide. More available services with a faster response to the needs of the community is essential to ensure minimal harm upon the individual and whānau (NGO provider)

Suicide is an outcome of a collection of missed opportunities. Ensure services are in place to support people when they need it (DHB)

A few submitters commented on the need for more services for rural populations to help ensure that people get the help they need when they need it.

In rural areas, people may not be able to be seen for weeks, meaning that they reach crisis point before any help is available (NGO provider)

**Better integration of services and need for wraparound care.** Several submitters commented on the need for better wrap-around care, that tried to address more than the immediate circumstances of the self-harm or suicide attempt.

I would ensure that a formalised protocol involving a social worker is undertaken by every person who is seen by emergency or medical services for self harm or suicide (health professional with lived experience)

[Organisation] recommend the development of wrap-around services that are able to provide support and treat complex comorbidities that involve alcohol and/or drug dependences and challenging mental health disorders. These services should provide access in a timely manner, provide a key-worker, be culturally responsive as well as be developmentally appropriate. ... recommend all services should form a continuous chain of care; any 'referral' from one service to another, the last engaged service should remaining responsible until the next service picks up the care responsibility (DHB)

**Educate society and people at large to be able to provide better support to prevent people from taking their own lives.** Alongside interventions from professionals, there were many calls from submissions for education and awareness campaigns that taught people how to recognise when they or others might be at risk of self-harm or suicide, and to teach skills for how to engage with those that might need support. Some submitters also added that this education should include improved awareness of what services were available to support those that might need it.

A society that takes an active role in responding to people in need. It's everyone's responsibility to identify and help those in need. This requires a society that believes help is available when needed, knows where to get the help, and has confidence that support will be given if it's asked for. Suicidal thoughts and impulses should be taken seriously as an indication that a person needs help. Even if we think they wouldn't actually go through with it, we should take the statement seriously as a request for help. If we are serious about reducing our suicide rate we need to take action, not wait and see or fail to take people seriously. We should all be aware of those among us who might be struggling and how and where to find help for them (service user)

Māori submitters in particular commented that the best approach to preventing suicide was by empowering communities and whānau to be able to respond to the needs of their own people to prevent suicide. For some Māori submitters, there was distrust of the mainstream mental health services so they tried to access resources within their own communities rather than engage with services.

Whānau believe that strong whānau connections and healthy relationships with each other can prevent suicide. In particular, they believe that strong connections can help whānau to maintain their cultural knowledge, expand their social networks, grow their self-confidence, and improve their mental wellbeing (Māori NGO provider)

For some Māori submitters, there was a need for mental health services but they should be supported by a better resourced community that could provide support alongside the professional services.

An adequately funded, highly trained, proactive Mental Health and Addiction sector that incorporates alternative forms of therapy and takes a strength-based approach wherever possible will be a step in the right direction. Alongside this needs to be a greater push to upskill the community in gatekeeper training, in terms of identifying distress and having the confidence to provide support until a professional can be engaged. This will ensure that people are always able to be linked in with someone who can help when they need it, whether that be their neighbour or their doctor (Māori NGO provider)

**Provide holistic support and shift away from using medication.** There was a call from a few submissions to provide more holistic care that did not rely on medication to prevent people from taking their own lives. It was noted by some submitters that moving away from the medical model to a system that attempted to treat the whole person rather than their symptoms would be more resource intensive, and would require a longer-term view of treatment beyond short term management of symptoms.

Increase the emphasis on problem formulation and long-term management in mental health clinician training expand focus beyond medication and behavioural compliance (government agency)

Early intervention and competent, holistic support is the key. We all have a role to play in reducing our abhorrent suicide rate in this country. It will be no easy task and it will not come cheap; but the greater cost of doing nothing is unimaginable (family member)

Medication was seen by some submitters to treat the symptoms rather than the illness.

Medication should not be the go-to as for some people it just dulls the pain and doesn't treat the illness - much like a painkiller (service user)

**Need for dedicated suicide prevention and postvention support roles.** There were calls from some submitters for more resources for dedicated suicide prevention and postvention support roles to enable cross-sector engagement. Other submitters noted that a dedicated position might allow for more pro-active 'wellbeing' engagement with individuals instead of only reacting to those in crisis.

We think the appointment of a suicide pre and post vention coordinator is essential and that consideration to specialist mental health nurses in partnership with practice nurses running 'warrant of fitness' whole of health checks would support the early identification of risks related to mental health and addictions and suicide (DHB)

Others saw the postvention or suicide prevention co-ordinator role as a key role to facilitate interagency engagement, improvement and action from a societal perspective.

**Access to appropriate services and support – culturally appropriate.** Many Māori submitters commented on the need to fund, design and provide services that meet the needs of Māori as the current Western model was not working well for them. Many submitters, including Māori and non-Māori, pointed to the high suicide rate for Māori (particularly young, rural Māori Males), with many adding that this discrepancy is unjust and must be addressed.

In terms of improving services to help to prevent suicide for Māori, the strongest theme was for more services to be provided by Māori for Māori, based on tikanga Māori and Te Ao Māori. There was a clear call from some submitters for these services to be led, funded and provided by and for Māori instead of being attached to mainstream services.

In term of Māori, start again have resources developed appropriate to Māori, not just translated but designed to fit a Māori world view, have services that engaged at every level eg individual, whānau, Hapu and iwi, for those impacted by suicide coordinated approaches with first responders, health and justice and coroners not offering victim support or Māori wardens this just aggravates the situation and whānau disengage (whānau Māori)

Our whānau contact me on Facebook, walking on the street, on the marae. I say call 1737 or mental health service. They say no they want to talk to you, I say why, they say you're Māori. We want Māori to talk to us (kaimahi Māori)

A few Pacific submitters discussed the need to change how support for Pacific peoples is funded, designed and provided. There were strong calls from a few submitters to shift the focus towards prevention rather than treatment.

Prevention is the most effective intervention – yet our current mental health system continues to over-invest in crisis and secondary services and continues to construct buildings in hospital settings for mental health 'beds'.

For Pasifika, this would mean:

- a) grow the capacity and capability of people in communities to prevent suicide, recognise mental distress, and know where to get the right help, through education, information and training.
- b) Focus most effort on Pasifika children and young people (in the context of family). The Pacific population has the highest rate of children and young people of any ethnic group in–New Zealand, with over half of the pacific population aged under 24 years old.
- c) Invest in growing Pasifika leadership and clinical workforce to influence outcomes in mental health, addiction and preventing suicide.
- d) Include Pacific ethnicity measures in all mental health and suicide data gathering and analysis. For suicide data, focus on attempts, not just deaths - suicide attempts are a true measure of the wellbeing and hopelessness of a nation, and 100% preventable (Pacific NGO providers)

In terms of how to improve wellbeing for Pacific peoples:

We believe that game changers for Pasifika wellbeing are:

- Mental health literacy in schools led by mental health and culturally competent experts (not school teachers) would be an effective upstream intervention (including anti-bullying, alcohol and other drugs harm reduction).

- Use technology to reach youth and care for their wellbeing.
- Access to parenting and healthy relationship education focussed on behaviour change
- Education programmes incorporating cultural identity to strengthen self-worth (Pacific NGO providers)

Other groups who were not receiving appropriate services or suicide prevention initiatives, in particular:

- **Rainbow communities**

While a significant amount of research exists about rainbow populations, mental health, addictions and suicide, more is needed. In particular, evidence is lacking about older rainbow people, intersex, trans and gender-diverse people, Takatāpui and Pacific rainbow populations, the experiences of people from recent immigrant cultures, the impacts of religious and cultural values on rainbow mental health, and the impact of marginalisation within rainbow community spaces for rainbow Māori, Pacific, disabled and other minority groups (Rainbow sector grouping)

- **Older people**

The government could improve the health outcomes of this very at risk group of older people by investing in clinical research to develop and test novel clinical pathways to help older people who have made a suicide attempt. These novel clinical pathways include individual and group psychological treatment using the framework of problem solving therapy, cognitive behavioural therapy and interpersonal therapy... and psychosocial group therapy to improve loneliness and enhance social connectedness (professional organisation)

- **Deaf community**

Ideally, it would be best to establish Specialist National Deaf Mental Health advisory or task force group that would be able build foundations, principles and values that would support positive mental wellbeing for all the Deaf Community in New Zealanders and how we can provide the best [to] assist those who need help. The group would be able to develop Aotearoa, promote positive mental [wellbeing], and prevent, [identify] and respond to mental health and addiction challenges, including suicide (advocate)

There needs to be resources in NZSL about suicide and how to prevent this so that Deaf people know what to do (Deaf service user)

**Access to services and support – postvention.** Many submitters talked about the lack of support of any kind that was available to them after the suicide of a loved one. Other submitters commented on the lack of *appropriate* support available after the suicide of a loved one. For example, one submitter noted that they needed more time to tell their story than the service was able to provide.

Many submitters said that there is need for appropriate postvention support “when you consider that those most at risk after a suicide are those closest to the person or those directly affected” (NGO provider). The same submitter noted that providing better

postvention support would help to reduce the overall impact on the already stretched mental health system as it would help to keep their people out of crisis and being suicidal themselves.

Postvention needs to sit alongside prevention and be resourced and supported to ensure those affected can function and survive (NGO provider)

Postvention follow up for families following a suicide i.e. whatever timeframe is needed by the family/whānau not just post serious incident review (DHB staff)

### **Access to services and support – suicide survivors and service users.**

Increase support for those people who have unsuccessfully attempted suicide (NGO provider)

The feedback that [organisation] receives from callers is that many people are still suicidal when they are sent home and follow up should be in place over a period of time (NGO provider)

### **Make improvements to support or interventions**

**Co-design and lived experience.** Many submitters called for greater input from service users into the design of services, both for services and support for those in distress as well as postvention support for bereaved friends, family and whānau.

I believe that using the experiences of people who, like myself, have attempted suicide and fortunately survived, and later addressed the issue should be explored. We have a view that cannot be replicated via study, or by professionally treating the distressed. Our experience should not be ignored simply because we have had mental health issues in our lives (service user)

**Better screening and assessment by suitability.** Many submitters called for improvements in how staff made their initial assessments of those in distress and at risk of self-harm or suicide. Several comments were made about the need for these assessments to be performed by specialist staff that understood the risks of turning people away (this was closely linked to comments about there needing to be enough staff, services and beds to provide support to those that are assessed as need it).

[Organisation] strongly recommend that full psycho-social health assessments such as the HEADSS [home, education/employment, peer group activities, drugs, sexuality, and suicide/depression] assessment should be performed by staff skilled in their use, as screening and detection tools. These skilled youth providers need to have a comprehensive understanding of when to preserve confidentiality and when they are obliged to share information (DHB)

**Better inclusion of family, friends and whānau in treatment or support.** For example, one parent strongly advocated for improved consultation with families and whānau, stating that it's not enough to have a policy of consultation but that consultation must be real.

Many submitters commented on being left out of treatment decisions of friends, family and whānau that were self-harming or suicidal, and some of these recommended that services

should more explicitly look to include them in treatment decisions. Family and whānau inclusion covered a range of areas, including notifying parents/family/whānau when someone was in treatment or in danger of harming themselves, allowing family/whānau to be included in decisions about the care of the service users, and inclusion of the family and whānau in discussions about how to support the individual once they are released from care.

Family inclusion and support on how to support those with Mental Health issues needs to be focussed on. As a parent who has had a [family member] diagnosed at the end of last year with severe depression and suicidality I found I wasn't given any direction on how to support my child through the journey to recovery (family member)

### **Do more research and collect more statistics**

**More research on – suicidality and self-harm.** Many submitters commented on the need for more and better information on suicide and self-harm. It was noted that it is difficult to measure suicide but that we needed more data on self-harm and suicide. An example of what type of data should be collected on suicide and self-harm was set out by one submitter:

How many suicidal people have identifiable stressors, and how are these grouped? I believe that statistics on the following groups could/should be collated.

- self-harm and suicidal behaviour from people in inpatient and outpatient care
- self-harm and suicidal behaviour from people not known to mental health services
- self-harm and suicidal behaviour from people who have experienced sexual or childhood abuse
- self-harm and suicidal behaviour grouped for unemployment, volunteer work, part-time and fulltime employment
- self-harm and suicidal behaviour grouped for income bands, either using income tax bands or some other socio-economic ranking system
- methods used for suicide (both unsuccessful and successful) in order to identify dangerous areas in a community (I am not suggesting that this information be publicly disseminated) (service user)

If we are going to be honest and transparent in discussing suicidal behaviour, statistics need to be publicised on a regular basis, perhaps quarterly or half-yearly. The statistics should reveal true numbers of suicide and self-harm (service user)

Some submitters specifically called for better data on Māori, Pacific and high-risk populations such as Rainbow (LGBTIQ+) communities and older people.

Include Pacific ethnicity measures in all mental health and suicide data gathering and analysis. For suicide data, focus on attempts, not just deaths - suicide attempts are a true measure of the wellbeing and hopelessness of a nation, and 100% preventable (Pacific NGO providers)

Some submitters noted that we needed more rigorous data collection to drive improvements in suicide prevention services.

To support the work of such a centre and local initiatives, we also need urgent work to ensure data collection on suicide deaths and attempts is accurately and consistently recorded and analysed nation-wide, along with in-depth qualitative analysis of the complex drivers of New Zealand suicides (DHB)

A few submitters commented that there needs to be more data collection around postvention support services to illustrate whether it is effective and should receive further funding.

Currently, there are very few DHB's that appropriately resource suicide prevention and postvention efforts. The majority of prevention work is undertaken by passionate individuals' on-top of their workload and is done without the organisational resource support. The drawback of this current arrangement means that there are no resources focused on data-collection or analysis of the postvention efforts. Without reporting systems in place, it is difficult for these individuals/small groups to put together a business case for funding of such efforts (DHB)

In addition to more data collection, there were calls from some submitters for more funding for research into suicide in New Zealand. Some submitters called for more research on mental health and addiction issues, suicide prevention and 'What can be done for people' – such as psychological therapies and local clinical research into mental health interventions – in the New Zealand context, were recommended. Several submitters noted that the workforce required to perform this research would need to be developed.

There is a need to build workforce capacity for suicide prevention including research capacity, and a cadre of people trained and experienced in programme implementation and evaluation. There is a need for an academic unit which can provide leadership in suicide research and education, provide undergraduate and postgraduate education, deliver suicide education to health, educational and social service providers, and be a resource which can disseminate information (DHB)

For Māori submitters, some noted that research into what works for Māori needs to be done by Māori researchers who understand the cultural background.

**Improve coroner processes.** Many submitters commented that the coroner process needs to be improved by speeding up the process, improving the types of information collected, and improving the sharing of information collected through the investigation.

Coroners and family, friends and whānau of those that had suicided all recommended allowing for greater involvement of family and whānau in the coronial process.

The coronial process needs an immediate and comprehensive review and whānau need to be formally included in the design and conducting of that review (bereaved family member)

Some submitters wanted greater involvement of friends and whānau to assist them in their grieving process, as they reported that being shut out of the coroner process was not helpful for postvention support. Others commented specifically that greater inclusion of family,

friends and whānau would provide better information about the background and emotional state of the person that suicided to allow for better identification of contributors and causes of each suicide. These submitters indicated that better processes for each suicide would help to design education, support and services that would help to prevent other suicides.

There were calls from other submitters to shift to a more in-depth, interview or investigation process that aims to better understand the “specific emotional/personality make-up, and external factors, leading to any suicide death” (government agency).

A few submitters noted that improving the coronial process would require additional workforce as a more in-depth investigation process would take significantly longer than the current process.

A few submitters commented on the need for cultural sensitivity when investigating non-Pākehā suicides. An alternative approach to coroner’s investigations was set out by one submitter who noted,

An alternative approach to the investigation of self-inflicted deaths requires substantive, face to face engagement with families so that they fully understand the purpose and potential outcomes of the inquiry, which, with their engagement, puts the death of their loved one into its multi-factorial context, and may include the making of comments or recommendations to reduce the risk of future suicides in their family or community...

This process breaks the traditional mould of suicide investigation, and is predicated on the premise that the most effective solutions-based recommendations to lower suicide risk should be developed with and targeted at the families and communities who have suffered the loss of a loved one by suicide. To do this, the deceased’s life and experiences within his/her family and community must be thoroughly investigated and understood; it is only by embarking on and completing this alternative investigation process that the coroner can speak for the dead to protect the living (commentator)

**Focus in-depth coronial processes on high-risk populations.** A few submitters called for changes to the coronial processes to enable a more in-depth investigation of suicide deaths that could create better understandings of the circumstances around each suicide.

It is proposed that a coroner be seconded to focus solely on investigating identified suicides in this way for a two or three-year pilot period. The identified suicides may include all suicides of a particular high-risk group (for example young Māori, or young persons of Pacific Islands’ descent) . At the conclusion of the trial period the benefits and pitfalls of the approach could be evaluated and further decisions made as to its use (government agency)

To improve information collection and sharing, some submitters recommended adopting the approach taken to suicide data collection in Victoria, Australia where additional information about the suicide is collected, compared to the current processes in New Zealand.

## 5 SYSTEM DESIGN AND IMPLEMENTATION

This chapter presents an overview of submissions that referred to system design and implementation.

System design includes workforce, funding, commissioning, monitoring, data and evaluation. Most submitters, including workforce organisations, service providers, service users, Iwi, tāngata whaiora, researcher, consumer advocates had much to say about workforce, as the front line of mental health and addiction, recognising that workforce is affected by what sort of society is best for mental health, leadership and commission structures, community needs and current service provision. Workforce is intimately tied to funding and commissioning, and monitoring and accountability.

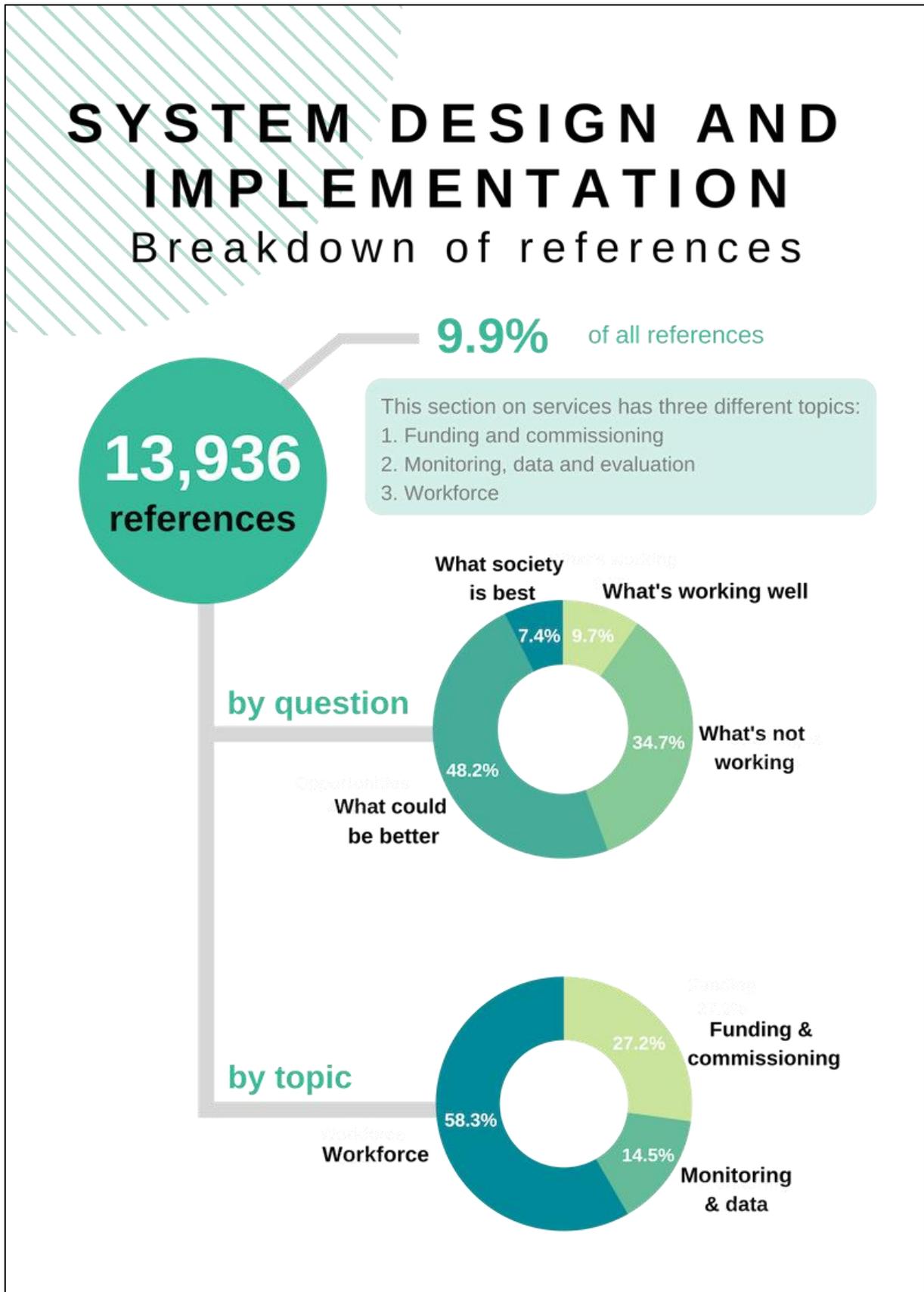
Submitters made 16,199 references about this topic, which accounts for about 11.5% of comments made to the Inquiry overall (see Figure 5.1.)

### TOPICS

The sections in this chapter summarise the responses into three topics.

- **Section 5.1: Funding and commissioning:** Restrictive and competitive funding and commissioning models are not enabling service providers, particularly non-governmental organisations and community providers, to deliver quality, holistic, culturally appropriate and locally available services. Funding needs to increase but requires sector transformation to enable innovative and flexible funding across community, primary and secondary services.
- **Section 5.2: Monitoring, data and evaluation:** Submitters wanted better monitoring and accountability of services, more effective data integration and evaluation models that reflected diversity of approaches.
- **Section 5.3: Workforce:** The mental health and addiction workforce, although highly dedicated, is working under immense pressure with high caseloads, limited resources, and within a system that lacks integration and coherence. Workforce needs to be driven by leadership but requires significant funding and increase in both the diversity and quantity of specialists, GPs, mental health and addiction nurses, addiction specialists, peer support workers, and kaimahi including kaumātua.

FIGURE 5.1: SUMMARY OF RESPONSES TO SYSTEM DESIGN AND IMPLEMENTATION



## 5.1 Funding and commissioning

### 5.1.1 Overview

This section presents an overview of responses from submissions to funding and contracting (that is, commissioning). In general, submissions focused on broad funding and contracting issues rather than specific solutions. Funding is a significant concern to both individuals and service providers at all levels, from governance and independence of commissioning, the types of contracts given to providers, through to the systems in place to monitor service delivery.

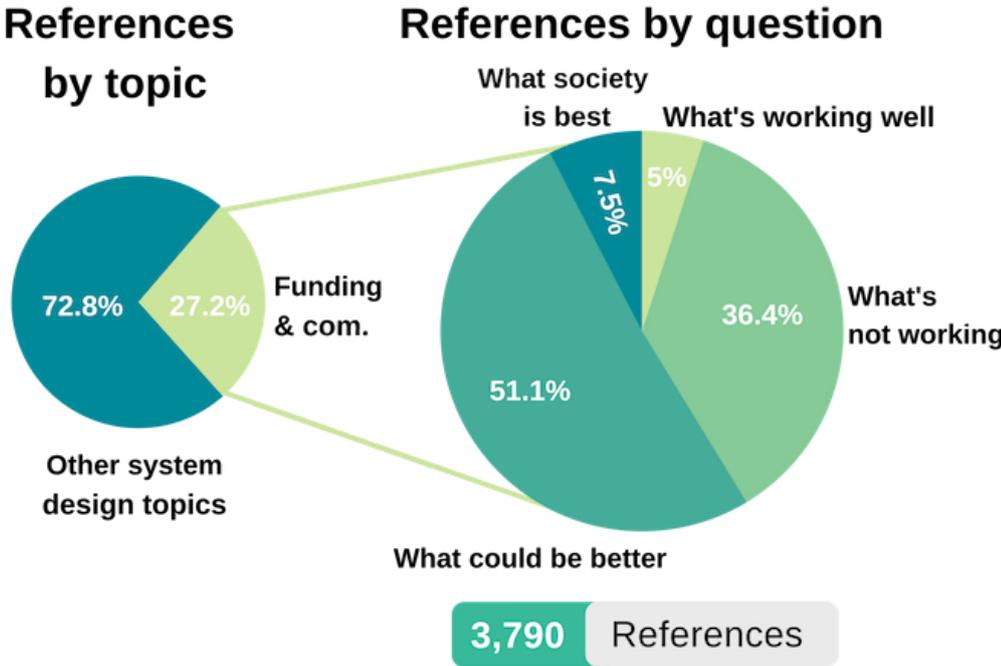
For individual users funding impacts their ability either directly or indirectly to access the system and receive effective, integrated services. For service providers it impacts delivery and design of timely, efficient services, treatments and outcomes for users. There is also the significant cost to workforce efficiency in terms of time required to source and secure funding – particularly for community organisations. These issues are closely linked to the issues raised later in this section about monitoring and accountability for service delivery.

At the broadest level, there was a clear view from submitters that there was a lack of investment in mental health and addictions. The underinvestment ranged from the view about lack of investment in housing and other social determinants; to lack of funding for research and evaluation; to lack of investment in providing specific types of services/support/interventions; and lastly to lack of investment in specific services.

See also section **2.2: Leadership for change**.

Submitters made 3,790 references about this topic (see Figure 5.2).

FIGURE 5.2: SUMMARY OF RESPONSES RECEIVED ABOUT FUNDING AND COMMISSIONING



## KEY THEMES FROM SUBMISSIONS FOR FUNDING AND COMMISSIONING

### 5.1.2 What's working well?

- Funding models that work

### 5.1.3 What isn't working well?

- Lack of independence between commissioning and delivery
- The current system doesn't address root causes of distress
- Competitive funding model is not working well
- Lack of flexibility for alternative approaches and services

### 5.1.4 What could be better?

- Shift in focus for funding and contracting
- Need for change in who commissions services
- Independence of commissioning and delivery
- Māori self-determination
- Pacific perspectives

## 5.1.2 What's working well?

### Funding models that work

There were very few submissions that commented on aspects of funding and commissioning that were working well. The types of things that were working well were where:

- Long term funding of services allowed for certainty
- Flexible funding allowed for services to meet the diverse needs of their populations

A few submitters noted specifically that the Whānau Ora commissioning model was working well, noting that progress has already been made on creating effective commissioning functions through Whānau Ora. For example, one submitter noted that a commissioning model used for Whānau Ora included:

- a whānau-centric approach
- incorporates the Te Tiriti o Waitangi and in particular upholds the rights of Māori to be self-determining

- is ecosystem-focused allowing resources to be more effectively allocated to the frontline
- values effective systems
- expertise lead which acknowledges the ability to draw on global Indigenous best practice
- builds the capacity of both providers and whānau
- outcome-driven; and
- promotes active and responsive governance which ensures transparency, accountability and independence, while demonstrating an inclusive, community focused decision-making process (NGO)

### 5.1.3 What isn't working well?

#### **Lack of independence between commissioning and delivery**

Many submitters stated that the current approach of having DHBs as the primary commissioners of services was not working well. There was a call from many submitters, especially NGO providers, to address the funder-provider split that currently means the “DHB provider arm...gate keeps access to many NGO services and support” (Pacific NGO providers). Many submitters commented on issues with DHBs acting in the role of both provider and commissioner of services, noting that this created power imbalances between the DHB and NGOs that created difficulties for NGOs to remain sustainable.

There is the disparity in funding levels for the same purchase unit codes between DHBs and NGOs. The DHBs fund their own services at higher FTE rates than they fund NGOs for staff doing the same work. The length of contracts providers have with funders also makes it difficult to ensure organisational sustainability and effective strategic planning. Some contracts with DHBs and Corrections are rolled over on an annual basis while a few are offered on a one-off basis for a year and sometimes less (National sector grouping)

#### **The current system doesn't address root causes of distress**

Funding and contracting was seen by many submitters to be piecemeal, too short to deliver long term service and workforce solutions, the wrong model, and a strain on staff resources. Submitters reported that the short-term funding approach was constraining the types of services that could be delivered, and increasing uncertainty for NGOs.

Many submitters also commented that funding systems do not focus enough on social determinants. In addition, the siloed approach to funding for services prevents services from attempting to address or mitigate the impact of social determinants on mental health and addictions. Submitters noted that funding initiatives that try to address more root causes of mental health and addictions challenges requires long term, cross sector and ongoing solutions particularly in light of early intervention research, and the positive correlation between early life hardship, deprivation and family violence and lifecourse mental distress/illness.

There was concern from many submitters from government, DHBs, NGO providers and others at the lack of early intervention and focus on children/youth even when this had been shown to be effective and good value for money.

The issue of short term, overly-focused funding models was also seen by some submitters to create issues around comorbidity. Submitters commented that some users fall through the system due to comorbidity and lack of clarity as to who pays (ACC/disability/aged care) as the funding systems are too narrow. For example, some submitters noted that Foetal Alcohol Spectrum Disorder does not presently meet the criteria for either disability or mental health services as they are not funded.

### **Competitive funding model is not working well**

A large number of submissions commented that a funding system driven by a competitive model had negative impacts on service integration and effectiveness including staff recruitment and retention, supply of services, access to service, innovation, culturally appropriate care models, and use of resources. There was a general consensus from submitters that there was fragmented funding (especially from DHBs to NGOs) and inefficient use of skilled workforce in securing funding.

There is also a trend for funders to create a competitive “market” amongst mental health and addictions service providers, resulting in an environment which focuses on retaining contracts instead of ensuring clients are receiving the best care. Funders need to think of alternative ways to encourage providers to provide the best possible service other than financial gain or loss through contracts, illness should not be seen as a “market” (Māori NGO provider)

One NGO provider noted that ‘organisations need to be sustainable and this should be assisted by funders where possible. Where there is a profit or surplus this can be reinvested back into services / the community where the provider is a not for profit organisation.’ They added that “removing competition, as much as possible, and encouraging collaboration between service providers would create a much healthier and positive environment. This can only be good for the communities and individuals who use those services” (NGO provider).

Highly skilled clinical staff need to be able to deliver effective care to service users rather than being involved in constant negotiation to secure funding to enable programme continuity (Professional organisation)

Collaboration between organisations is hindered by the need to compete for the same funding. There needs to be more incentive for organisations and services to work together (service provider with lived experience)

### **Lack of flexibility for alternative approaches and services**

A number of submitters commented that the current approach to commissioning and monitoring services prioritised short term measures, such as requiring services to see a set number of people, rather than focusing on whether the service was effective for the individual. These submitters considered that the current system was not well suited to providing more people-centred approaches to support.

It was noted that there is currently a “lack of commitment and support in Kaupapa Māori health services by funders and planners, of doubt amongst health professionals and health services of their value and capability” (Māori health leaders and colleagues). Other submitters noted that control over what is funded sits with mainstream leaders and decision makers, which results in a system that does not allow for enough flexibility to provide alternative types of services that submitters called for. For example, some Pacific submitters noted that the funding system did not allow for long-term implementation of services that would be effective for supporting Pacific people due to the short term focus of the contracts.

Submitters also discussed the narrow types of service that were funded but solutions often require broader interventions outside of psychology. There was frustration expressed by many submitters in terms of the difficulty of holistic service provision under the current system. For example, one NGO provider discussed the adoption of an approach that allowed for funding to be used by the provider as needed to fund the type of services an individual might require, such as paying for a peer support worker instead of a clinician.

Submissions from organisations providing services to diverse and refugee populations all agreed that that current funding model is based on a western medical model of intervention.

Psychiatric and psychological one to one interventions are inadequate to meet the psychosocial needs of people from refugee backgrounds. Funding needs to include the provision of social workers, body therapists, family services, parenting and community programmes (Refugee NGO provider)

#### **5.1.4 What could be better?**

##### **Shift in focus for funding and contracting**

A number of submissions recommended shifting to a system that worked across traditionally separate sectors, such as the health, social and justice sectors, to create a system where “population wellbeing, distress and addiction are a multi-sector responsibility and not primarily a health one.” (Mental health sector leaders) One of these submissions recommended the following set of planning and funding priorities:

- trial the removal of mental health and addiction funding from the DHBs with a view to localised multi-sector pooling of all planning and funding functions within the next decade
- set up district or regional governance of planning and funding led by people with lived experience, whānau, Social Development, Health, Education, Housing, Corrections, ACC and others
- Māori design and deliver services for Māori
- equitably plan and fund all the Big Community responses with flexible and individualised funding models
- use incentives and accountability levers for providers to achieve improved social, education, employment, financial, housing, personal, health and mortality outcomes for people with distress and addiction, with an emphasis on outcomes for Māori

- test and scale up Indigenous, national and international promising and evidence-based practices that enhance Big Community (Mental health sector leaders).

A few submitters called for a fundamental change in how taxpayer funds are allocated for service delivery (for example, calling for the creation of a new Vote: Wellness), that would remove structural barriers between services and allow for more holistic approaches to be funded.

### **Need for change in who commissions services**

There were calls from a range of submitters for significant changes to the current funding model of the DHB commissioning services in their own regions. There was a strong view that the current funding and commissioning system was too disjointed, too time-consuming, too short-sighted, lacked transparency, lacked independence, and didn't allow for innovation and culturally appropriate ways of working.

A few submitters commented on the need to give consumers a stronger, more explicit voice in decisions about funding and leadership, recommending that:

Transformational options for devolution of service development and commissioning, funding, service delivery and general oversight mechanisms to consumer led agencies should be explored, in consultation with service users and other stakeholders. A brave and significant paradigm shift is required to maximise the input of consumers at every level of the system and to ensure a move away from token and piecemeal consultation with input being “tacked on” to existing outdated funding and delivery mechanisms. A completely new, consumer centred, model is required (government agency)

### **Independence of commissioning and delivery**

Some submitters called for ‘independence in commissioning and service’ and noted that this is “paramount to supporting transformational change and shifting the current inequity in the power paradigm” (Pacific NGO providers), including making more rationalised decisions about what government services are contracted out.

### **Māori self-determination**

Submissions from Iwi and Māori organisations recommended the establishment of independent leadership organisations that would promote Māori self-determined commissioning and funding structures. Tangata whenua submitters commented that Māori leadership and self-determination, including greater involvement in funding, was required to implement a broad conceptualisation of wellbeing, a focus on whānau wellbeing, and the requisite policy, systems and structures needed to deliver services and supports in ways that align with Te Ao Māori.

A group of Māori health leaders and colleagues emphasised that independent Māori oversight is implicit to Māori health leadership, policy and decision making, role sharing with Māori, and Māori service provision to Māori. Other Māori submitters recommended the adoption of similar approaches that allowed for greater independence for Māori to fund and provide services that provide wrap-around care for tangata whenua, such as an independent

commission, a Te Tiriti o Waitangi partnership authority, Waiora Commission, or other national entity with a Whānau Ora framework operating alongside Māori self-determined commissioning and funding structures.

For example, a Kaupapa Māori organisation, reflecting the feedback from many Māori organisations, recommended a joined up approach to service provision which required “removing the barriers between agencies and services to allow ease of access and fluidity of support based on Whānau need” (Māori NGO provider). They noted that working in this way would require a whānau outcomes focus; not an agency outputs focus, and recommended establishing a community commissioning framework to implement the integrated support needed to meet the needs of tāngata whaiora and whānau.

One collective Māori submission commented that,

models for assignment of funding for service users will enable access to proven evidence-based interventions (including cultural interventions) to drive consistency and adherence to accepted standards of quality. In this regard, a model of managed care oriented purely towards driving quality (with a lesser impetus for cost control) should be explored (Māori health leaders and colleagues)

### **Pacific perspectives**

A few Pacific submissions similarly called for a shift with regard to funding approaches. One Pacific organisation outlined key features of leadership important to Pacific people, such as being grounded in a cultural context and cultural leadership, being family centred and driven, and having the ability to gather data and evidence using Pacific methodologies. Further discussion of a Pacific Whānau Ora Commissioning Agency approach was regarded as central to future leadership.

Other submitters suggested that giving more control over direction and commissioning would allow for Pacific populations to help their own people more effectively.

We are happy to fix ourselves, just need opportunity ... Don't have a system run for exceptions ... (we need) Purchasing power with flexibility for specific services for our people; more power to get what you need for your people (Pacific health professional)

One Pacific group recommended the implementation of independent Pacific mental health commissioning, noting that mainstream is not serving them well and they could do it better. To achieve this, the submitters recommended removing commissioning power out of 20 DHBs and the Ministry of Health and replacing it with a different mechanism. Another Pacific group recommended establishing a Pacific Mental Health commissioning agency that would allow for solutions to be placed in the hands of Pacific people, with flexible contracting models that would allow for everyone to work across traditional silos.

## 5.2 Monitoring, data and evaluation

### 5.2.1 Overview

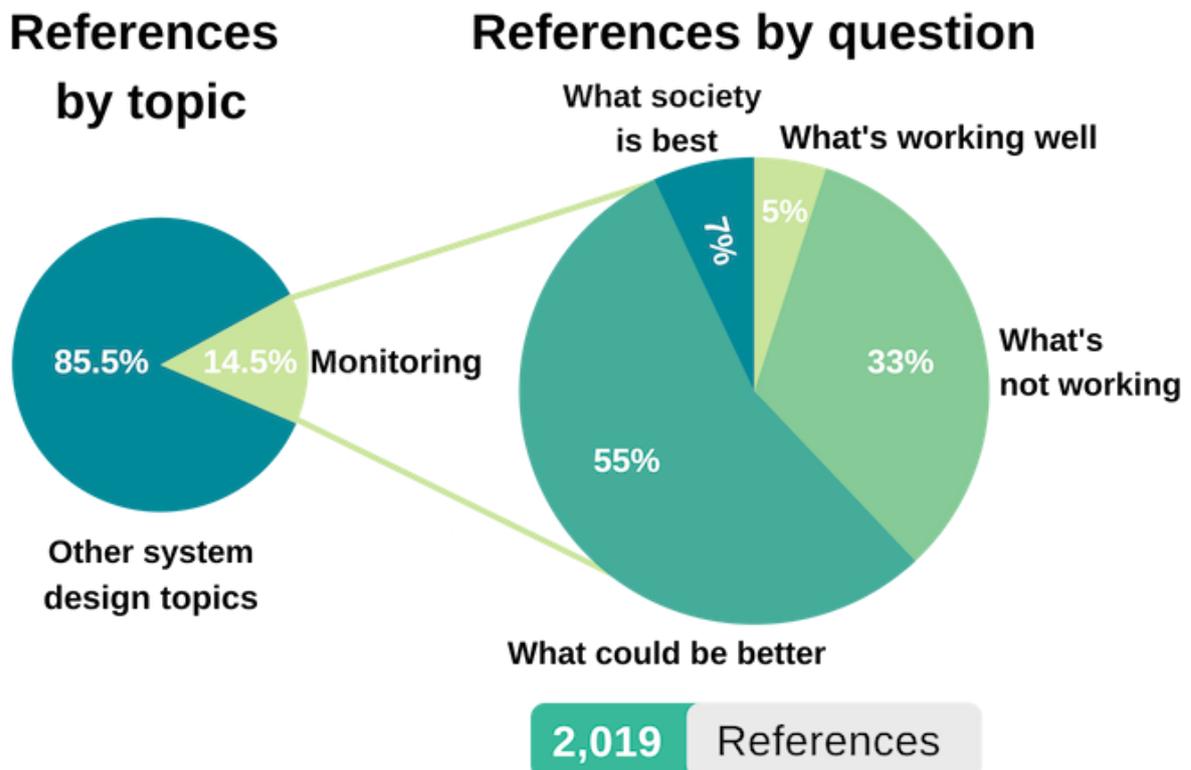
This section presents an overview of responses from submissions about monitoring, data and evaluation. It is broken into four interlinked areas that deal with different aspects of what submitters told the Inquiry, namely:

- monitoring of services, providers, and of effectiveness including accountability (who is responsible for service delivery, as well as accountability for progress toward goals and targets) and the complaints process (the process for service users and tāngata whaiora to raise concerns about treatment or decisions by service providers)
- data sharing (collection and sharing of information about service users or tāngata whaiora, particularly between service providers)
- data collection about populations (statistics and prevalence information)
- research and evaluation (including pure research, research on populations, and evaluation of what works).

These issues are closely linked, as submitters often spoke about the effect of monitoring and what that meant for funding and contracting of services, as well as their views on how to set up a better system to drive the funding and commissioning across mental health and addictions.

Submitters made 2,019 references about this topic (see Figure 5.3).

FIGURE 5.3: SUMMARY OF RESPONSES ABOUT MONITORING, DATA AND EVALUATION



**KEY THEMES FROM SUBMISSIONS FOR MONITORING, DATA AND EVALUATION**

**5.2.2 What's working well?**

- Monitoring
- Research and evaluation
- Data integration/sharing

**5.2.3 What isn't working well?**

- Monitoring has deficiencies
- Data collection and sharing is inefficient or non-existent.
- Lack of funding for research and need for more research

**5.2.4 What could be better?**

- Improved monitoring approach focusing on outcomes and targets
- Investment in research and evaluation
- Better information sharing (about service users and tāngata whaiora)

## 5.2.2 What's working well?

### Monitoring

There were relatively few examples provided by submitters about what was working well for monitoring.

**Monitoring to support ongoing performance.** Some submitters provided specific examples of data analysis within specific services that they saw as working well. Examples included the use of appropriate performance indicator reporting to support ongoing improved performance. A submitter also noted that the incorporation of rating scores such as Kessler-10 and Patient-Health-Questionnaire-9 into the practice management system improved treatment monitoring.

**Whānau ora approaches to monitoring for outcomes.** Some submissions commented on positive examples of monitoring that allowed for greater flexibility and innovation (such as those that use a Whānau Ora commissioning scheme). One Māori organisation that was already using a commissioning for outcomes model noted that it has marked “a deliberate shift away from the traditional practice of measuring outputs to tracking whānau outcomes, ensuring working towards what matters essentially” (Māori NGO provider).

### Research and evaluation

**Research that guides service design.** A few submitters commented generally that there was some useful research being undertaken in New Zealand universities. There were few specific examples of research that was working well, such as reference to Te Rau Hinengaro (which was seen as useful and still being used to drive service design), Youth 2000, and the New Zealand Health Survey. Regional specific surveys were also viewed positively by a few submitters, such as the Canterbury Wellbeing Survey.

**Funding requirements that require evaluation.** Submitters raised other examples, such as Fit for the Future, which required evaluation as part of the funding arrangements as effective.

### Data integration/sharing

**Electronic referral systems that allows for service users to be transferred easily between providers.** One example of this was a service that provides the opportunity for collaborative solutions between providers using video links from personal and other devices that improve communication, efficiency, planning and productivity.

**Enhanced integrated care across services.** Submitters commented positively about initiatives to improve electronic client pathways shared across DHBs, enabling clinicians to have prompt access to client information. Data sharing also assisted in identifying clinical gaps. Submitters commented that DHBs had set up the ability to share successful projects with other DHBs.

**Investment in ensuring all mental health data is in a data warehouse** along with a reporting platform. One NGO service has developed its own software to monitor progress while also tracking other relevant information such as demographics.

**Service users self-monitoring their progress.** A few submitters commented positively about the use of mobile eHealth tools that were designed to support services users and tāngata whaiora to engage with treatment services, understand care plans and self-monitor their own progress.

**Collecting feedback from service users.** For example, Mārama real-time feedback was referred to positively, as were approaches that allowed for the inclusion of service user feedback in evaluations, and the use of focus and listening groups.

Submitters noted that requiring consumer feedback as part of monitoring and evaluation was effective as it helped to inform policy and audits of the specialist Mental Health, Addictions and Intellectual Disability Services.

Consumer led organisations and the involvement of consumer feedback has been useful in the improvement of services. This supports the current trends of trauma informed care and de-stigmatisation for the people we work with (individual with lived experience)

### 5.2.3 What isn't working well?

#### Monitoring has deficiencies

##### *Deficiencies in monitoring approach*

**Lack of effective monitoring.** Submitters were concerned about the lack of measurement and monitoring of mental health and addiction services as it reflected limited knowledge about what was working.

**Monitoring the wrong things.** The current system doesn't measure everything that is important, and sometimes what is measured is misleading. Some submitters commented that DHB performance measures were driving adverse behaviours. Several submitters raised issues with how GPs were monitored, noting that their funding and monitoring requirements provide little incentive for preventative care and the focus on reducing appointment times is detracting from attending to the person's wellbeing, and ensuring tāngata whaiora remained well.

Reporting required as part of funding contracts do not reflect outcomes. Many submitters raised concerns that "the quality of data and the input and output measures do not reflect outcomes for Whaiora and their family/Whānau" (NGO provider).

As Māori providers we are always stretching the contracts to fit the people which means that we are always having to consider how we can best serve our people's needs, whilst still maintaining our accountability to our funders. This is difficult, because the system expects key performance indicators that are often funder-focused (Māori provider)

**Mismatch between measures and culturally appropriate interventions.** The issue of using performance indicators for reporting was raised in particular by Māori submitters, who commented that the information that is reported about people does not reflect the community and are normally set in agreement with the people they are reporting on. Submitters noted that the current monitoring framework was biased against non-Western clinical interventions as it struggled to measure broader outcomes form culturally

appropriate interventions, such as the telling of stories, despite the evidence that it is an effective therapy.

Lack of flexibility and innovation that was allowed for in current reporting systems.

The current PRIMHD [pronounced 'primed' – Programme for the Integration of Mental Health Data] national data collection system requires services to conform to PRIMHD parameters and is unable to accommodate flexible/innovative/real world clinical service delivery (NGO provider)

**Lack of consistency in data collected across government agencies.** Some submitters noted the difference between DHB and government data on services and that data gathered by consumer organisations due to the difference in questions being asked, with information from consumer groups showing a more negative view of services than official government statistics. Related to this, some submissions commented on the lack of service user input into the design and monitoring of services. They also noted the benefits of including the consumer voice more centrally in service design and delivery, as well as in decisions on monitoring and reporting, to get a more effective service that meets the needs of service users and tāngata whaiora.

**Impact of too much monitoring on service delivery.** Many submitters that were staff from NGO providers and DHBs raised concerns with the amount of reporting and monitoring they were required to complete. One submitter that worked at a Kaupapa Māori service estimated that 70% of her time was spent documenting key performance indicators in front of her computer instead of helping whānau (kaimahi Māori).

Submissions from service users often reflected similar themes about their experiences with service providers that appeared to spend more time writing up notes than spending time with them.

As a patient, I saw staff spending hours writing up patient notes. I was baffled as to what they would write about me each shift, because staff seldom had a meaningful conversation with patients (service user)

#### *Accountability (and monitoring) for progress*

**Lack of accountability for mental health staff,** particularly in a medicalised model of care. These submitters stated that staff misused power and their position to maintain their roles, whilst families lacked legal support and were unable to afford full participation in, or the completion of, the complaints process. Most submissions on the issue of accountability were concerned about decisions made in services for certain treatments, especially compulsory treatment orders.

Where is the accountability of every person & every service to doing their job, and well? (individual with lived experience)

**Lack of tracking progress or implementation status of mental health and addictions strategies.** Some submitters from a wide range of backgrounds, discussed the lack of tracking progress or implementation of mental health and addiction strategies. For example, one government agency commented that there is “prevalence of broad mental health strategies that lack any mechanism for tracking and measuring progress of implementation” (government agency).

**Lack of tracking towards the goal of reducing health disparities.** Some Māori and Pacific submitters noted that there was a lack of overall accountability for how well (or not) government agencies were tracking towards the goal of reducing health disparities between different groups as well as greater accountability for achieving those targets. Several Māori submitters commented that DHBs need to be measured against how well they are reducing Māori health disparity, and that the Ministry of Health should likewise be held to account for improving Māori health.

**Lack of monitoring of other government agencies.** Some submitters also commented on the lack of monitoring of other government agencies, particularly ACC and the Ministry of Social Development (Work and Income), and the impacts that had on mental health and addictions

**Complaints process is slow, ineffective and traumatic.** The complaints process was seen by many submitters as the main method to hold people to account. However, many submitters said that their experience with complaint processes within mental health and addiction services were long and drawn-out, and traumatic. Providing feedback was often associated with fear of not being heard.

DHBs have best lawyers representing them and most people don't (family member)

#### **Data collection and sharing is inefficient or non-existent.**

**Lack of data sharing between providers about service users and tāngata whaiora.** Many submitters from all backgrounds reported that there were issues with sharing information between:

- primary services (mainly GPs) and specialist mental health services (in both directions)
- different arms of the same organisation (such as between a hospital and a mental health unit within the same DHB)
- DHBs (especially when shifting regions, or where services are provided in multiple DHBs)
- NGOs and DHB services (in both directions)
- pharmacies and other parts of the mental health system.

Archaic communication, booking, record keeping systems mean that information is not available when it should be and is frequently incorrect. Family/patient meetings are not documented and shared. Patient plans are not plans, please refer to MH patient plans overseas with goals, tracking against those goals and regular review and communication meetings (family member)

**Over-collection of data placing strain on services and taking up clinical time.** Several submissions described the immense reporting and administration requirements of mental health and addiction services, which they saw as a strain on services that took up clinical time. These submissions reported that the shift to digital records means that clinicians are expected to document and re-document information multiple times despite little evidence of reducing risk or improving the treatment. Particular strain was reported by Kaupapa Māori providers who said they are generally small charitable organisations with limited resources.

Some submitters, especially those providing mental health and addiction services at DHBs and NGOs, reported technology and software as being outdated and cumbersome; whilst others found adjusting to new/updated computer programmes time-consuming.

### *Population data*

**Lack of information about prevalence data.** Many submitters noted that there was a lack of information about prevalence of mental health and addictions. Some submitters commented that there hadn't been a nationwide prevalence study since 2006, which they said was an issue as the information was now out of date. It was noted that this study was the 'gold standard' in prevalence information and was still being used in service planning despite evidence suggesting that the demand for specialist mental health and addiction services was increasing from 2.3% to 3.6% of the population. Many submitters called for better national data on key populations.

**Poor information on Māori.** A large number of submissions reported that, despite vast documentation efforts intended to support better resource allocation decisions, good mental health and addiction data is lacking. Many submitters discussed the lack of mental health and addiction information available about Māori, but particularly the lack of information about Māori collected in a way that is culturally appropriate (using Te Ao Māori as the basis for identification of measures, and collection of information in culturally appropriate ways).

**Poor information on some topics, and other population groups.** Other submitters identified populations that had limited mental health and addiction data available, including:

- Pacific peoples
- Rainbow (LGBTIQ+) communities (including submitters noting the lack of information available about gender and that the last census did not include specific questions regarding these populations, which makes collecting information about these populations even harder)
- veterans
- other ethnic minorities – especially on ethnicity, language spoken and immigration status – is not available
- disabled people
- people with eating disorders
- suicide and self-harm (although several submitters noted that suicide and self-harm data exists, but is often outdated, and suicides are not collated in a dataset despite the coroner investigating each suicide in depth)
- older people (especially related to lack of information on dementia, noting that there is no national data collection on dementia)
- children (especially those under five)
- maternity (pregnant women and new mothers)
- rural people (the census is not working well for rural populations as it has an assumption that everyone has access to information technology).

It is difficult to address a problem in the absence of data (NGO provider)

The most recent nationwide prevalence study of mental illness was completed in 2006, and did not collect data on Asian populations. Population mental health data needs to be updated and information collected on different Asian ethnicities, preferably the three largest groups (who have very different cultural backgrounds and demographics) to inform funding and service design to better meet the needs of Asian patients and their families (DHB)

### **Lack of funding for research and need for more research**

There was a broad call from many submitters about the need for more research. Research was viewed as having “revolutionary potential” (academic). Research on mental health and addiction issues, suicide prevention and ‘What can be done for people’ – such as psychological therapies and local clinical research into mental health interventions – in the New Zealand context, were recommended. Increased knowledge, awareness and better treatment was hoped to result from targeted research on population groups such as refugees, people living in rural areas, veterans, children, those at risk of perinatal depression, and those under forensic services.

#### **5.2.4 What could be better?**

##### **Improved monitoring approach focusing on outcomes and targets**

**National consistency in monitoring.** Some submitters called for ‘a nationally agreed set of service specifications to check that we have a consistent and robust service across the country’ or variations of national reporting. These submitters stated that this national monitoring would give a better picture of how services were operating.

**Improving monitoring for and about Kaupapa Māori services.** Many Māori submitters were concerned that the current system of measuring outputs and key performance indicators does not always work well for Kaupapa Māori approaches to supporting tāngata whaiora and their whānau. One Māori submitter commented that Māori ways of working require longer time to “build trust and connection with whānau over time” (Māori NGO provider).

**Measuring outcomes instead of outputs.** This often included broader views around measuring wellbeing and social determinants such as housing, reducing health disparities between populations, and measuring outcomes that were relevant to service users and tāngata whaiora and their families and whānau instead of what was important for providers.

It will be recognized that effective support requires addressing all the areas where people are facing difficulties. Treatment and support for mental health and addiction will no longer be able to focus on only managing the presenting issue. Success will be judged on how well people are able to live life, not on the disappearance of symptoms or an ability to hold a conversation. Ensuring that people are adequately housed, have access to finance and immediate practical needs, are able to connect with others, have their cultural and spiritual needs met, and can make plans and set goals for the future will be the key measures through which success is established. It will no longer be acceptable to deny responsibility for helping people to achieve these and simply move people on (NGO collating views of service users)

**Mental health targets, especially for suicide, youth suicide and self-harm.** Some submitters called for mental health targets, especially for suicide, youth suicide and self-harm. Some submitters commented on the difficulty in setting targets for suicide prevention. For example, some submitters stated that the ‘zero suicide’ target was named as unrealistic and prompting idealistic interventions. A few submitters commented that suicide prevention cannot be measured in data as there is no certainty of output, noting that you cannot accurately record how many suicides you have prevented if they have not happened.

**Realistic and evidence-informed targets.** Submitters said that targets need to be realistic and evidence-informed, clinically relevant and not gathered “at the expense of ‘time to care’ or as a burden to clients” (NGO provider). Outcome data needs to include “Head and the Heart (empirical and anecdotal) data” (DHB) and consider cultural aspects, for example those specific to Pacific peoples.

**Use the United Nations Sustainable Development Goals.** A few submitters referred to the United Nations Sustainable Development Goals, noting that the 17 goals cover determinants of health and wellbeing both for individuals and populations. Submitters noted that the Sustainable Development Goals agenda prioritises the collection of high-quality data, disaggregated by vulnerable groups, to ensure that progress towards implementation is accurately tracked and monitored.

### **Investment in research and evaluation**

**Need for independent research and evaluation body.** In terms of improving evaluation, DHB managers commented that setting up an independent commissioning and evaluation body for mental health could be useful.

**Need for culturally inclusive research and evaluation.** Several Māori organisation submitters commented on the need for a separate Māori research, evaluation and monitoring body that would a focus on Māori best practice models of mental health care, integrating the Māori world view with contemporary psychiatry and exploring new models of Māori mental health and addictions care. For example there was discussion of the need for more kaupapa Māori research instead of having more Pākehā researching Māori. Likewise, some Pacific submissions discussed the need for Pacific-focused research into what works based on Pacific views and Pacific ways of working.

**Research on effectiveness of services.** Some submitters noted that the lack of evaluation of how well services were working meant that poorly performing services continued to be funded.

**Improved application of research.** Several submissions discussed the need to improve how mental health and addiction services implement evidence from research and evaluations into actual practice. Some submissions discussed the need for more researchers that can provide input into public discussions about effectiveness of treatments.

**Incorporate lived experience and indigenous knowledge.** A few submitters commented on the need to incorporate both lived experience and indigenous knowledge bases into decisions about how we use research.

This should adopt the same principles used in ‘co-design’ ie the use of evidence from the scientific literature, in combination with our indigenous knowledge base (I), and evidence from those with lived experience. Evidence and experience should be given equal weighting. The credibility gained from use of the growing evidence base would give any such organisation’s recommendations the necessary weight (mental health professional)

**Take a broader approach to applying evidence and research.** An NGO provider commented on the need to take a broader approach to applying evidence and research, including the community situation into account.

An over-reliance on ‘evidence-based’ approaches where the evidence-base is narrowly interpreted. Whilst rigour and evidence is of course important, there are many complex and localised settings in which there is no existing evidence-based and the rigorous approach would be to work carefully alongside communities and young people to develop an understanding of what is needed and what works best. We need room for a broader and more contextualised interpretation of the evidence-base and the capacity to build practice-based evidence when working within complex settings like youth mental health (individual submitter)

**A separate mental health research stream.** Some submitters argued for a separate mental health research stream, yet others determined that a national strategy for research on mental health and addiction was needed.

**Need for new research into emerging issues.** A few submitters discussed the need for more research into new areas of potential harm. For example, one provider described the need for more research into the potential impacts of online gambling for youth.

### **Better information sharing (about service users and tāngata whaiora)**

**Real time data accessible by all relevant service providers.** Many submitters called for patient data to be available in real time, and accessible by all relevant service providers across any service they access. Other submitters noted that there needs to be protections on this kind of data sharing, however, as individual privacy and personal information always requires protection during data collection and analysis, ensuring people are not deterred from seeking help for mental health and addiction challenges for fear of personal details being shared unnecessarily.

**Regional or national patient information system that all relevant providers could access.** Large, interconnected high quality datasets were viewed as a priority. Some submitters commented on the need for interconnected datasets from a range of areas to gain a multidimensional understanding of wellbeing, with one submitter describing this as intelligent infrastructure with joined datasets.

**One joined-up information system.** One collective submission recommended,

a reset of the primary healthcare system for Māori that improves integrated service delivery with an aligned funding model. That includes one plan for one whānau and one IT system across multiple providers supported by a range of approaches to allow providers to partner and share resources (Māori health leaders and colleagues)

**Improved aggregate data about populations to inform service design and delivery.** There was a clear call from submitters for improved aggregate data to inform service design and delivery, as well as to allow for progress to be measured.

There is a need for standardized national data sets to inform funding and planning for health care delivery, including mental health and addiction related care, and coordinated, longitudinal reporting. Improved data and analysis would strengthen decisions about priorities for demand management and opportunities for strengthened care (professional organisation)

## 5.3 Workforce

### 5.3.1 Overview

This section presents an overview of responses from submissions related to workforce. The Inquiry heard from a wide range of submitters regarding workforce – including those who are in the mental health and addiction workforce, organisations leading and developing the workforce, and from service users, tāngata whaiora, family, whānau, consumer groups and advocacy groups who are interacting with the workforce.

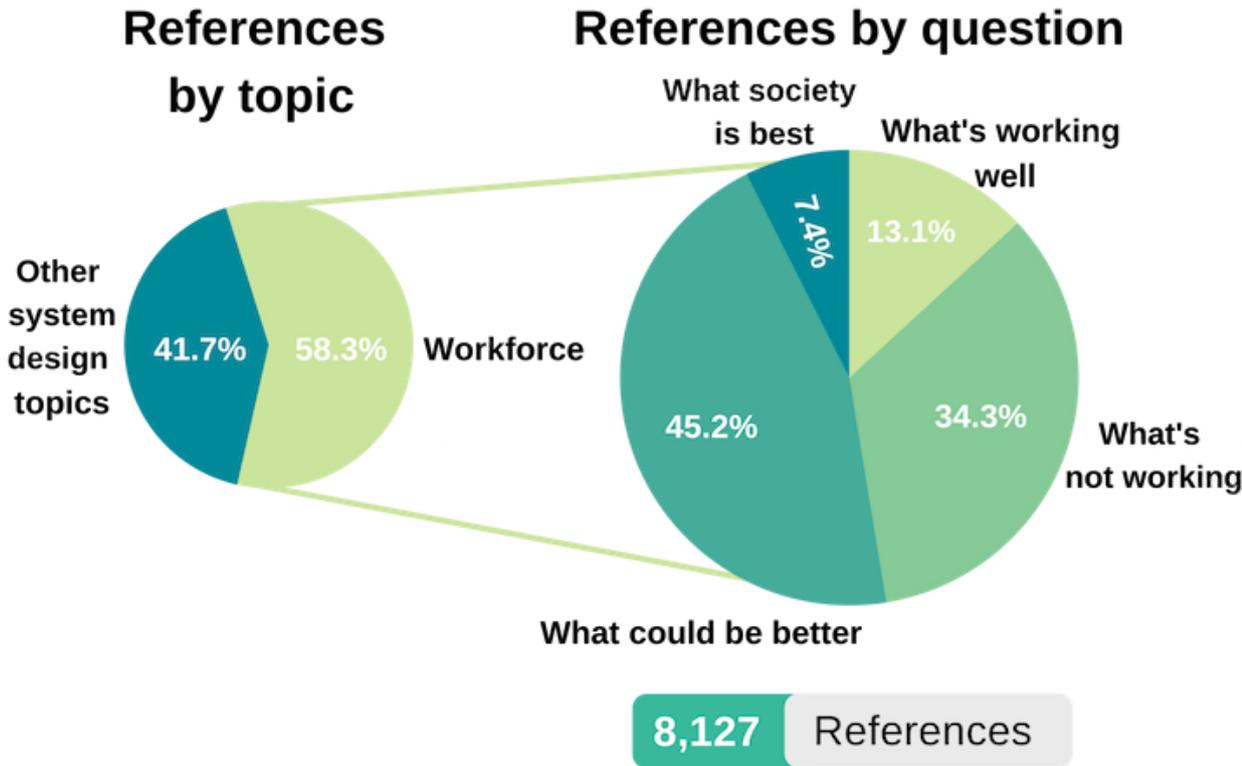
It was clear from submissions that the mental health and addiction workforce is working under extreme pressure. This pressure includes time, workloads, workplace safety, pay inequities, disparate funding models impacting job security, burnout, limited options for professional development and stress. Many staff working in mental health and addiction carry a burden of care and responsibility for the people they see, and feel overwhelmed by the need in society and lack of access and options to help.

For service users, their families and whānau there were many instances where staff have changed lives, showed compassion, helped them through crises or where they felt genuine aroha. However, there were also stories of being met with indifference, disrespect and discrimination – being turned away – many times with disastrous consequences.

Workforce pressures resulted from a complex system of funding, commissioning, forward planning, world view, leadership and lack of cohesive system-wide access and options.

Submitters made 8,127 references about this topic (see Figure 5.4).

FIGURE 5.4: SUMMARY OF RESPONSES ABOUT WORKFORCE



## KEY THEMES FROM SUBMISSIONS FOR WORKFORCE

### **5.2.2 What's working well?**

- Dedication and diversity
- Workforce that responds to needs of culturally diverse populations
- Education and training

### **5.2.3 What isn't working well?**

- Limited capability and cultural competence in mental health workforce
- Unsafe, under-resourced workplaces in mental health and addiction services
- General health and education workers do not understand mental health
- Long wait times and inadequate response
- Limited ability to plan and implement change

### **5.2.4 What could be better?**

- Increase Māori workforce
- Increase Pacific workforce
- Increase capability and competence to work with diverse populations
- Improve workplaces with workforce support and more staff
- Increase mental health knowledge and skills across the system
- Improve workforce response to mental health and addiction needs

### 5.3.2 What's working well?

#### Dedication and diversity

Some submitters acknowledged the compassion, dedication and professionalism of individual mental health or addiction workers who cared for them. For many submitters it was the opportunity to express their gratitude for the services they received.

Some submitters noted having a workforce that could respond to the needs of culturally diverse populations was highly valued. This included work within culturally responsive services with Māori, Pacific peoples and Asian people.

A few submitters mentioned the work of individual skilled professionals they had encountered. This included multidisciplinary teams and good coordination between teams.

The range of submitters appreciated individuals in the following services:

- attention deficit hyperactivity disorder services
- mental health inpatient units in DHBs
- community services including home visiting services
- primary health care services
- private practices such as psychologists
- schools
- NGOs
- youth services
- dementia services
- addiction services
- crisis phone services
- refugee services
- deaf counselling services

There are a lot of organisations and individuals doing their best to care for ... people and their whānau and families despite unmanageable and unhealthy workloads (family member)

Secondary services are under enormous pressure, but the quality and commitment of staff does not go unnoticed by their primary care colleagues who are also appreciative of the communication channels for collaborative care and advice (health professional)

#### Workforce that responds to needs of culturally diverse populations

The capability of a workforce that can offer culturally appropriate services was another key theme from submitters. Specific initiatives and services included:

- cultural supervision and support provided by kaumātua
- Māori clinicians who focus on the whole person and their specific needs to achieve goals, and to move to discharge

- Kaupapa Māori workforce who are proficient in Te Ao Māori and who persevere to ensure good quality care that reasserts the mana, tapu and mauri of the tāngata whaiora they service.

The kaupapa Māori workforce are a vital key to the journey of any tāngata whaiora and their whānau (Māori NGO provider)

## Education and training

The value of education and training for those who work in the system was acknowledged. The availability of continuing education programmes that up-skilled the mental health and addiction workforce was valued, in particular the primary mental health nursing credentialing programme; cultural competence programmes; as well as specific training courses.

Training has improved for Police and Corrections in de-escalation, understanding how to best respond to individual and community needs. Whilst there is significantly more work to be done in this area, changes in training is making a marked difference to how police are now working with individuals, families and communities (submission collating views of lived experience, mental health professionals, and community members)

Greater requirements for a more trained and skilled workforce with professional registration ... has increased capability and credibility (NGO collating views of service users and staff)

### 5.3.3 What isn't working well?

Submitters said that the system was not working well when there was:

- limited capability and cultural competence in the mental health (and addiction) workforce
- unsafe, under-resourced workplaces
- limited mental health (and addiction) knowledge and skills in the general health and education workforce
- long wait times and inadequate response to mental health and addiction needs
- limited ability to forward plan and implement change.

#### Limited capability and cultural competence in mental health workforce

Submitters shared their views about limitations of the current workforce in understanding and working with people from difference cultures. This was particularly the case for Māori and Pacific peoples. Other groups mentioned were Asian people and refugees. The low numbers of people in the health workforce from these ethnic backgrounds, the configuration of services and the limited cultural competence of the workforce were all highlighted.

To understand the beliefs, ideas, and values that influence and inform behaviour and mental well-being, we need to understand the Pasifika indigenous knowledge system these derive from... The mental health system in New Zealand for the most part, is informed by and dominated by secular, scientific and empirical understandings of human behaviour (Pacific NGO providers)

The non-Māori health sector is out of touch with the realities of Māori communities, and the importance of Māori health professionals. This disconnect leads to poor engagement and quality of care for Māori (Māori health leaders and colleagues)

The changing cultural and ethnic diversity of the Auckland population is not adequately represented in the current workforce or in recent candidates who have been recruited. Although there are slightly higher rates of the number of Māori and Pacific clinicians working in mental health compared to general health, there is still room for improvement (DHB)

The current workforce would benefit from enhanced cultural competency, particularly in relation to Māori and Pacific and our increasing Asian population in central Auckland (DHB)

### **Unsafe, under-resourced workplaces in mental health and addiction services**

The impact of not having enough health practitioners and support workers was identified by submitters. In some cases, the relationship between levels of funding for services and pay and conditions of workers were raised as contributing to the situation.

For many services users and their family/whānau the impact on them was an inability to access a service when needed. This was particularly the case when trying to access psychiatrists. Other services that they had difficulty accessing due to a low number of practitioners are:

- child health and adolescent mental health services
- psychogeriatric services
- psychology services (counselling)
- addiction services
- forensic mental health and addiction services
- psychological emergency services
- family therapy and support services
- community support services
- social worker services
- pastoral care.

There is not enough staff on in psych emergency in the hospital. I was once sent to psych emergency by my GP at about 6pm that evening. I left the hospital at midnight having seen NOBODY! I was suicidal (service user)

The Police are attending twice as many mental health callouts as they were 7 years ago. There is clearly a huge area of need and needs a targeted response. They receive very minimal mental health training (2 hours for recruits), and yet can be powerfully helpful, or powerfully damaging when responding to mental health callouts. They generally want to respond well, but they need more training (and probably better systems) to do this (mental health professional)

For the mental health workforce, the impact of not having enough practitioners resulted in:

- significant pressure experienced
- overwork
- high level of stress
- high staff turnover
- lack of experienced staff and short-staffed leading to practising out of scope and clinical ability
- difficulty recruiting new staff.

As a suburban GP of 30 years duration I have found that the amount of time given to mental health care is growing and oddly the backup from specialist services is decreasing. The turnover of staff in this area also means that no one is accountable when things go wrong. We need psychiatrists not managers (professional organisation)

Submitters also raised the issue of mental health and addiction services as unsafe workplaces. The most mentioned issue about safety was about the degree of workplace bullying. The fear of speaking out was also mentioned.

The bullying culture within our DHB from management has impacted on staff being able to provide good care. These are urgent issues if you truly want to improve services and support wellness in the community (health professional)

The issue of unsafe workplaces was also raised in relation to the number of practitioners and first responders who experience serious attacks and assaults in the course of their work.

### **General health and education workers do not understand mental health**

Submitters raised the need for mental health training including crisis training for people in the general health and education workforce. Most submitters considered those working with child and youth to be in most need of mental health training. The following areas were mentioned:

- counsellors in schools
- GP and primary health care
- midwives
- Plunket
- early childhood education
- schools and teachers
- Oranga Tamariki

- social workers
- first responders.

The training of health professionals (outside of dedicated mental health workers) in recognising and managing patients is relatively limited (NGO provider)

### **Long wait times and inadequate response**

Service users and tāngata whaiora highlighted the impact of their experience when the mental health workforce could not respond to their needs. These experiences included:

- long wait times for psychiatrist and psychologist appointments and attention deficit hyperactivity disorder services
- staff without the required skills providing postnatal care, neuropsychology assessments and transgender assessments, and dealing with alcohol and other drug problems
- a sense of a 'tick box' approach to their care
- no early intervention
- medication being offered as the only option
- concern with the dysfunctional way that the services were operating
- stigma towards people with addiction.

I was personally told I would be contacted by a counselling service within two weeks after I had been through a traumatic experience. This was a year ago and I did not hear anything from anyone after that (youth service user)

### **Limited ability to plan and implement change**

Submitters commented on what they saw as deficiencies in the wider system, including the lack of:

- mental health and addiction workforce planning generally and specifically to address diverse consumer base
- infrastructure and ability to implement new national strategies and policy
- ability to share information between services.

My impressions [are] that the level of severity and complexity of cases is increasing along with increasing demand. The resourcing (training, mentoring, funding) for the increased workload has not kept up with this demand (health professional)

#### **5.3.4 What could be better?**

Submitters said there were opportunities to improve the system by:

- increasing capability and competence in the mental health workforce to work with diverse populations
- improving workplaces with workforce support and more staff

- increasing mental health knowledge and skills in both the mental health, the general health and education workforce, and the wider community
- improving response to mental health and addiction needs
- taking a wider systemic view to plan and implement change.

Long term strategies are also needed to address known predictors of poor mental health, well documented by NZ's world leading ... Dunedin multidisciplinary Health and Development study which often shows that we are not addressing the appropriate problems. For instance, "Self-control in childhood is more important than socio-economic status." is a huge concept not yet taken up by Education, Social Welfare or even sporting policies (health professional)

### Increase Māori workforce

Many submitters stressed the need for more kaimahi including kaumātua and tōhunga, Māori clinical specialists, psychologist, psychiatrists and mental health and addiction specialists. This is detailed in section **2.3: Te matapihi ki Te Ao Māori (window to the Māori world)**. This is summarised below.

- Praise for kaimahi who reflected true aroha, manaakitanga, workforce professionalism, and clinical skill. For many Māori submitters, the guidance of kaumātua and respect for their advice and wisdom was essential to healing. Some Māori submitters called for more access to and respect for tōhunga.
- Kaimahi spoke of their high caseloads, underfunding for extra or specialised staff, and, for many, relative job insecurity given the short-term funding structure of many Māori services. Services are often bottlenecked with referrals, delays and lack of access.
- Enabling an appropriately sized and culturally relevant workforce was essential across Māori submissions including appropriately funded roles of kaumātua, kuia, tōhunga, taurawhiri, and the lived experienced of tāngata whaiora (as peer leaders).
- Peer support roles were highly valued as one addiction specialist noted,

The only ones getting through to our people are the ones who have overcome addictions, been through it themselves and now helping in the community (kaimahi Māori)
- There were strong calls from workforce organisations and service providers to increase Māori professional staff, and focus and invest in workforce pipeline to ensure Māori are represented across the health spectrum: specialists, GPs, social workers, nurses and psychologists.
- Several submissions referred to the need for a comprehensive national Māori health workforce development plan if any demonstrable change was to be seen for whānau.

### Increase Pacific workforce

Similarly, there were strong calls to increase the Pacific workforce across populations. This included Pacific leaders across services, more specialists, and integration of Pacific world

views into training, enabling a pipeline from school into workforce through scholarship, and acknowledging the value of peer support workers.

Pacific peer support workers were also under-acknowledged by professional staff. They “have on-going and strong relationships with their clients but their narratives and knowledge about their clients are not considered, particularly by clinical personnel.” (Pacific NGO)

### **Increase capability and competence to work with diverse populations**

Submitters saw opportunities to improve the care of people from diverse populations in three ways.

- Have a more culturally diverse mental health workforce. Particularly Māori, Pacific peoples and Asian peoples. Offer financial incentives for education.
- Increase best practice of the mental health workforce by using cultural wellbeing models such as Te Whare Tapa Whā, and involving national workforce centres in workforce development.
- Offer more tailored support for diverse populations, including:
  - Rainbow communities (LGBTIQ+)
  - Māori
  - Pacific peoples
  - Asian people
  - refugees.

there needs to be a tailored approach to attract more school leavers from Asian ethnicities (especially underrepresented South East Asian and refugee populations) to take up a career in mental health (Asian health professional)

### **Improve workplaces with workforce support and more staff**

Submitters saw opportunities to improve workplaces through recruiting and retaining more staff.

In terms of encouraging recruitment into mental health services submitters suggested:

- allocate more funding to employ staff particularly in community health, respite and residential care and child and adolescent health
- fund internships
- allow more student placements to experience mental health
- employ more new graduates.

To retain staff, making the workplace more attractive was seen as important. In particular:

- address bullying and other in-house issues
- develop a structured career pathway for allied health, peer and family whānau support workers, and nursing workforce
- celebrate and appreciate the team

- provide administrative support to free up clinical time
- pay them well.

Allied health and nursing groups would benefit from improved career structures and pathways, including recognition for developing clinical skills and excellence for career development (DHB)

### **Increase mental health knowledge and skills across the system**

Some submitters noted the need for community-wide mental health and addiction capability. Some suggestions including:

- **Health and wellbeing lens.** Training at all levels of professions and society needs to be broad, must be funded, comprehensive and informed through the lenses of health and wellbeing.
- **Primary health practices.** Offering more mental health assessments and integrating with other community services.
- **Medical professionals.** There needs to be more training for GPs in mental health assessment, and affordable access to therapeutic counselling. This would also reduce demand for crisis interventions in the emergency department.
- **School admin and counsellors.** In the context of bullying, self-harm and eating disorders, intervention would enable the school and counsellor to pick up on behaviour and access help. Including mental health as part of health education provided at schools would contribute to wellbeing in schools. Such programmes may also need to be used with a much younger age group than they are currently.
- **Parents.** Increase Triple P training and other parental courses.
- **Prisons.** Funding access to mindfulness-based courses and trained staff for prisons, schools, mental health services, to work alongside individual therapy.
- **Judges and police.** In the context of skillset, it would be beneficial to upskill police and judges in better understanding addictions and mental health conditions.
- **Employers** would benefit from a greater knowledge of mental health. Compulsory mental health education for all employers (managerial position level) has been suggested in order to inform the decision-makers of the organisations about knowledge of mental illnesses, how to deal with people with mental health issues, what adjustments can be appropriate in helping people's wellbeing.
- **Peer roles.** Training of peer roles and particularly more lived experience roles – consumer peers and whānau peers. A greater recognition of the role that family/whānau play and consideration of the support they need is required. There is a need to build this Peer Workforce.
- **First aid mental health certificate.** “The recently developed First Aid for Mental Health certificate can increase awareness and reduce stigma. Making this education accessible to all teachers would be a good start to increase their awareness and ability to recognise signs of distress” (mental health professional).

- **Social services.** Mandated suicide prevention training for all health and social services providers including primary care providers, with all training provided by accredited and preferred providers.
- There were also a variety of suggestions made for **improving knowledge and skills in the mental health workforce**. These included both service areas and areas for development.
- **Allied health and nursing.** Training and up-skilling in psychological assessments and intervention
- **Te Ao Māori.** Better training around Te Ao Māori, more Māori services and clinicians, including a better understanding of obligations around the Treaty of Waitangi in the context of specialist mental health services.
- **Transgender studies.** Including the provision of healthcare for transgender people is a core curriculum subject for all medical and nursing students and for those training to be counsellors or clinical psychologists.
- **Understanding trauma.** All clinicians need to be trained in mindfulness, strength-based therapy, motivational interviewing and trauma-informed therapy.
- **Internships for rural and provincial workforce development.** Fund internships for rural and provincial areas with accommodation supplements for staff in high decile areas.
- **Attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD).** More education and continuing professional development should be provided to mental health professionals around ADHD and ASD. Many professionals are ignorant of the effects of ADHD and autism on children and do not provide quality support so the child is diagnosed at an early age and steps taken for behavioural management.
- **Cognitive behavioural therapy (CBT) training for key workers** who could become locally trained CBT therapists. CBT groups for anxiety and depression would improve cost-effective delivery of CBT.
- **Talking therapies.** A tiered competency framework for talking therapies and a package of training for all adult community and inpatient staff based on the strengths approach, motivational interviewing, problem solving and cognitive behavioural therapy.

People with mental health issues present in all parts of the health system ([emergency department], inpatient, palliative care, etc). There is also a need to up skill parts of the workforce dealing with older adults who have challenging behaviours, particularly when they require an inpatient stay to address a medical/surgical or rehabilitation need (DHB service users and health professionals)

### **Improve workforce response to mental health and addiction needs**

Submitters saw opportunities to improve how the workforce responds through re-focusing where and how the services were offered. Suggestions included focusing on recovery and rehabilitation and prevention, in preference to relying on medication.

In terms of where services could be offered, more in schools with nurses and counsellors and giving people in the justice system access to mental health services were mentioned.

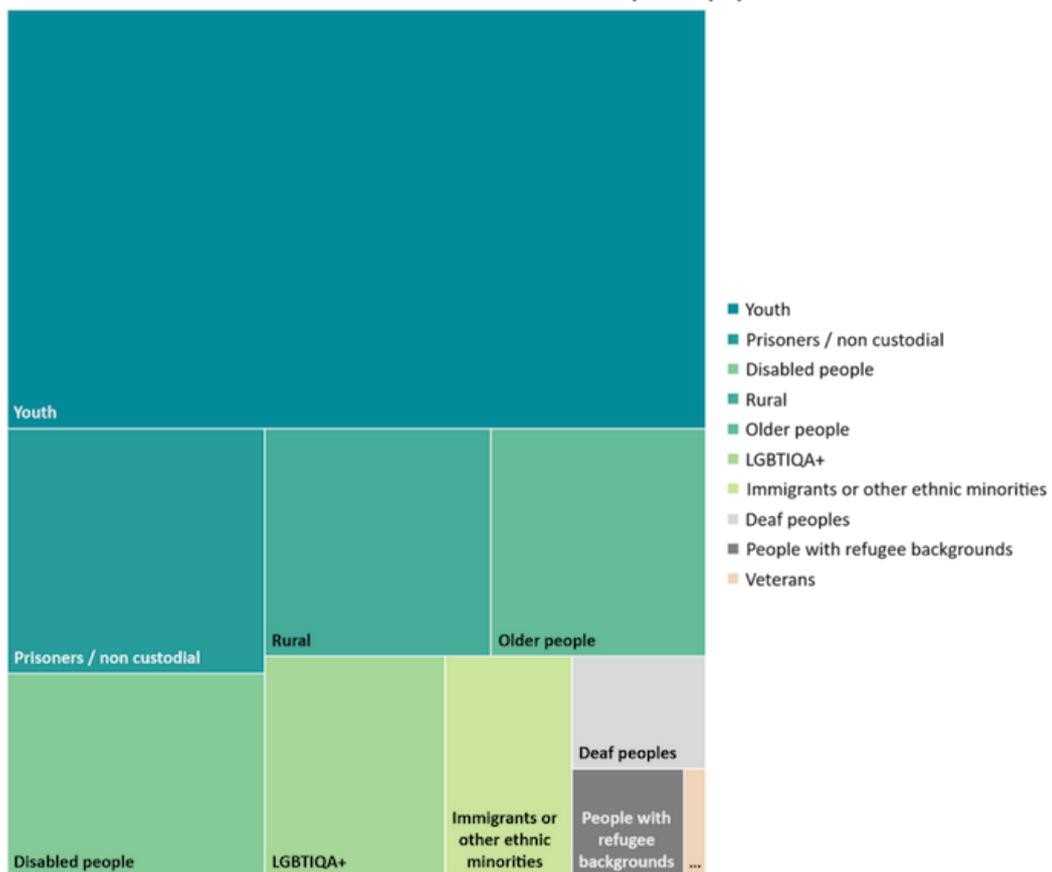
People struggling with mental health should be shown compassion more than anything. We should try and promote the person to be in an environment that makes them feel more settled rather than taking them out of it and locking them up (service user)

## 6 POPULATION OVERVIEW

# SPECIFIC POPULATIONS

Included are summaries of the submissions from 10 identifiable population groups. The relative proportion is shown below

Relative number of references from specific populations



The following population summaries focus on both submitters who identified with particular populations and families, whānau, service providers and organisations who talked about these populations. The sections contain a brief overview from submissions and may deviate from the question 1–3 structure. In addition, much information in this chapter is also incorporated into the preceding chapters.

Please note that information by and about Māori and Pacific peoples is incorporated throughout the document rather than recreated as a population overview in this section. Separate summaries of Māori and Pacific voice from submissions will be available on the Inquiry website in January 2019.

#### TOPICS

The sections in this chapter summarise the responses into topics by population group.

- **Section 6.1: Rangatahi / Youth Voices**
- **Section 6.2: People in prisons**
- **Section 6.3: Disabled people and neurodiverse communities**
- **Section 6.4: People in rural communities**
- **Section 6.5: Older people**
- **Section 6.6: Rainbow communities**
- **Section 6.7: Migrant populations**
- **Section 6.8: Deaf community**
- **Section 6.9: People with refugee backgrounds**
- **Section 6.10: Veteran population**

## 6.1 Rangatahi / Youth Voices

For the purposes of this summary, rangatahi/youth are defined as being aged between 15-24 years – although this can vary. Although there were some submissions from those who self-identified as youth (or identified in their demographic information as such), there were many submitters who spoke about youth – from those involved in youth work, youth mental health and addiction services, specialist youth services, and organisations that champion youth mental health and wellbeing. Many submissions also came from family and whānau speaking of their children or younger relatives or rangatahi in their community, as well as educators and researchers.

Youth were noted as being a priority population group in the Inquiry's Terms of Reference. However, it should be noted that many submissions also focused on a lifecourse continuum of maternity, child and youth (through to adult and older). Summaries of child and maternal submissions are noted throughout the report, particularly within section **2.5: Social determinants**, and a short focus on Postnatal depression on **page 97**.

A society where all children and young people know that there are adults that they can trust and seek help from. If this isn't available in their family, then it's crucial they know that this is available from others. If this is modelled to them from an early age, then hopefully they will carry this on into adulthood. This will help us become a society where we all thrive, and where each person feels supported and understood. To be heard and not Judged, to be given the opportunity to explore the consequences of ones choices, and to feel confident as a child, young person or adult that 'I can make some good choices to be heading in a positive direction' (NGO providers)

### 6.1.1 What is working well?

#### Positive staff experiences

**Positive staff engagement** with those working with youth – many submissions noted the commitment, skill and concern of those who work with youth. Youth also commented on the importance of family, whānau, kaumātua, educators and others in their recovery,

If it wasn't for the kindness and compassion of my teachers I wouldn't be here (youth voice)

#### Options and access

**Talking and other therapies where available** were working well for young people including counselling through secondary schools, mindfulness programmes in secondary schools, specialised therapies, family therapies, and therapies aimed at adolescents with serious conduct challenges. Early intervention therapies were seen to be working well when available (for example, Multi-systemic therapy and Functional Family Therapy). Other forms of communication that enabled youth to talk to someone about their challenges was working well, including 0800 numbers, online forums, e-health tools, and peer groups.

## Targeting stigma and help seeking behaviour

**Growing awareness** of mental health among young people, and reduced stigma in help seeking behaviours (which must be matched by access to services and support) were commented on positively in some submissions. One research group whose focus is on young people noted that there is an increasing awareness among educators (and school leaders) of the importance and need for mental health education, including allocating time and resources. Some educators and schools noted the resources they have allocated to wellbeing, mindfulness, and other positive psychology practise and teachings.

Some organisations commented they used peer support groups to good effect, with one noting,

We offer the chance for young people who identify as peers to get together in safe and supportive environments. This is designed to address stigma and discrimination as well as to work towards earlier intervention in people becoming unwell (NGO providers)

**Youth targeted intervention** particularly for alcohol and other drug challenges with a single point of entry, youth support workers, and youth worker AOD specialists were noted by both service users and providers as important in recovery. Bicultural models of care were also viewed positively.

**One-stop youth shops** were praised by general practitioners, family and whānau, and youth as being accessible, holistic, helpful and non-threatening (however some submitters noted that they are under pressure with funding arrangements).

**Youth developed, youth run** connections and interventions particularly for groups that experience stigma and discrimination, for example, intersex young people, worked well.

One community organisation noted of a survey they ran with the youth in their district,

They told us what life was like for them; they identify that bullying, alcohol, social media issues and mental health are top concerns. Stress is big in their lives. 68% of 16 year olds are stressed all or most of the time. They get good information about alcohol, drugs and sex at school but not about how to use that information and how to apply it to their lives. In response to this, we developed a resilience toolkit that we workshoped with hui and young people and rolled out in schools last year to work in a holistic way to build resilience to build resilient in adults overtime. Programme works in prevention space, which is currently under resourced (youth NGO provider)

## Community responses to suicide

**Some submissions told of excellent NGO and community groups proactively targeting youth in their communities.** For example, one suicide prevention group working with young people in the digital space (Facebook etc.) have been able to connect with and identify at risk youth in their communities and send out response or intervention teams.

**Schools are working with the community** to try and tackle high suicide rates. Some communities report good support from schools to identify at risk students, and try to provide a pathway to services.

## 6.1.2 What is not working well?

### Unacceptably high youth suicide rate

Many submitters noted the high youth suicide rate in New Zealand, with many family and whānau in both written submissions and at community meetings and hui sharing the grief of losing their beloved child or rangatahi in their community. Māori and Pacific populations noted in submissions that their young people were disproportionately impacted by suicide. In addition, Rainbow groups also noted the high rates of mental distress in their communities and high rates of self harm for Rainbow youth.

Many communities found support for prevention and recovery initiatives only in their own resources, or peer programmes, with many calls for better funding and interventions to reduce unacceptable suicide rates. Many family and whānau told stories of trying over and over to access help for their son or daughter but being turned away due to under-staffing, no services or specialists, or not reaching the threshold for help.

A few years ago my [family member] came home from University saying to get an **urgent** appointment to see a counsellor he would need to wait six weeks. Our young people need help. Suicide needs to be brought out into the open and money needs to be spent on better equipping our young people with the skills and knowledge to deal with some of life's increasing pressures [emphasis in original] (health professional with lived experience)

### Under-funded and under-resourced

Some submitters noted that “the prevalence of mild-to-moderate mental health need among young people is high” (academics), but that those youth with moderate to high needs may be underestimated by youth specialist services (typically due to under-resourcing and therefore ever increasing thresholds). As one parent noted,

At times we had some good support but the majority of the time it has been horrible. His illness and addiction are terrible enough to survive but the constant battling services, trying to fill the gaps and access what we need at times of despair is terrible (family member)

Many submitters (both service users and the service providers) noted that youth services (NGOs, DHB funded service providers, specialists, community hubs) are under-funded and under-resourced, particularly when compared to demand. Submissions referred to not only school counsellors, but other services such as one-stop-shops, and CAMHS (Child and Adolescent Mental Health Services), where high thresholds for access meant many young people were being sent back into a system that is unable to support their needs. School counsellors stated they are overwhelmed and overworked with some submissions quoting a 1:400 ratio of counsellor to students.

Some submissions noted the cost and access to helpful therapy for youth is out of reach. For example, dialectical behaviour therapy takes time and is expensive, and although validated is mostly out of reach for those youth who may respond to this treatment.

Some submissions noted that youth research is underfunded, and this is impacting on understanding the nuances of self harm, suicidality, mental health challenges and addiction.

Some submissions from youth spoke of their traumatising treatment due to staffing shortages.

Many submitters noted the lack of coordination between youth and adult services, with many young people falling through the cracks of services at this stage due to lack of continuity.

### **Social and other determinants**

Many submissions focusing on youth noted a significant number of youth were particularly vulnerable to disadvantage at this time of their life due to identity, family situations, and other social determinants. This included the impact of poverty, housing, traumatic events, education, and employment opportunities. Some submissions noted that indigenous youth faced ongoing racist and discriminatory behaviour which continued to perpetuate inequality and injustice.

Some submissions noted that there is also enduring stigma and discrimination toward youth in minority groups such as those with eating disorders, those who have disabilities, and those from migrant or refugee cultures.

Some submitters reported a dearth of gender-affirming mental health support for transgender people of all ages (especially so for children 12 and under who identify as outside of traditional binary gender classification). This type of 'social hardship' was seen to be particularly impactful for youth at this stage of life.

Within the schooling system, many submitters noted the absence of help and specific teaching for young people with learning challenges, ADHD, dyslexia, those with ASD, auditory and visual processing disorders. For some submitters this not only impacted self-esteem and belonging, but ability to complete schooling. As one submitter with both personal and professional experience noted,

My experience has led me to believe that we have made a big mistake in education by not really recognising that this separate group exists. These are not children who just have barriers to learning or low literacy they have specific learning difficulties that are preventing them from accessing the education system (family member and educator)

### **Alcohol and other drugs too acceptable in society**

Although many submissions noted the harm of drug and alcohol abuse (and in the case of alcohol normalisation) for young people, some submissions also called for an increased focus on the cost of drug abuse for family and friends – and the limited progress in terms of government action on the impact of alcohol and other drugs on children and youth.

This was particularly relevant for some submitters in terms of youth suicide and self harm. Many submitters had strong views on the impact of alcohol on youth.

Prevention is key. We need to address underlying, modifiable factors that affect mental health. Evidence shows that when countries take strong action on alcohol, suicides are reduced. In particular, suicide rates among young males significantly decrease (addictions professional)<sup>15</sup>

### **Impact of technology**

Some submitters were concerned about the impacts of gaming, technology, and social media on young people, noting the disruption to sleep, addictive impacts of the internet, online bullying, and social comparison through social media. In addition, the voices of many young people through surveys submitted to the Inquiry noted the increasing pressures on everyday life, the impact of perfectionism and performance, the inability to cope with stresses of life.

### **Impact of addiction**

Many communities noted the impact of unemployment, addiction (particularly methamphetamines, cannabis and synthetic cannabis in addition to alcohol), and the lack of local, youth specific services.

### **Rainbow Youth adversely impacted**

Some submitters noted that physical and verbal violence and bullying of Rainbow people contributed to distress, addiction and suicide, especially for children, youth and young adults. Some talked about the stigma of being queer and/or from the rainbow community and not having staff with whom they could relate.

As a young queer person this is so much harder because I still feel embarrassment over talking about my female ex-partner to these mainly older men and doctors around me (youth service user)

### **Complex needs too difficult for many providers**

Some submitters reported that children, youth (and adults) with multiple disabilities or neurodiverse conditions (as well as mental health and/or addiction challenges) were often regarded as “complex”, as having “high and complex” needs, or “too hard”. Submitters noted that this group often fall between the cracks of disconnected and siloed mental health, disability, addiction, education and justice services.

Many submitters, particularly whānau and family, noted how difficult it was to get into specialist services for their young adult children – particularly for eating disorders, ADHD diagnosis, early intervention into psychosis, and trauma informed counselling.

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<sup>15</sup> Note: this was reiterated by approximately 40 submissions through an NGO form submission

### **6.1.3 What could be better?**

#### **Target prevention and intervention**

Many submitters called for investment in targeted, evidence-based prevention and earlier intervention for youth rather than letting distress escalate. This includes de-stigmatisation of mental health and addiction challenges.

Many submitters called for increased youth funding, more flexible funding options to take into account the transience and diversity of youth populations, and an increase in one-stop-shops across the country.

Many submitters said there was a need for greater restrictions on alcohol and for its normalised prevalence in society to be challenged, and addressed through legislation and advertising restrictions.

Many submitters noted that the government has to get serious about the social determinants of health – particularly the impact of family violence on young people and its associated trauma, poverty, unemployment, and education disrupted by behavioural and neurodiverse challenges.

People & especially younger people seem to be losing hope because they do not have the resources to be able to make choices. The building of resilience in communities, caring and helping each other in community are essential to turning this tide around. The impact of loneliness, bullying, violence, harassment, sexual abuse, unemployment, mental illness especially depression, and the break-up of family relationships all impact on these statistics (support worker with lived experience)

#### **Focus on a healthy education environment**

Many submitters wanted to see significant improvement in anti-bullying and harassment in schools – particularly for Rainbow populations, disabled youth, and neurodiverse youth. However, many submitters were concerned about the impact of bullying on youth mental health and wellbeing outcomes in general, and felt that bullying was not being seriously addressed to the extent that it should.

There is a need for schools at all levels to be able to demonstrate they have strong processes and procedures in place for assisting students who are being bullied, and/or who appear to be suffering emotional and mental distress. In addition, strong disciplinary mechanisms need to be put in place to deal with bullies, and to act as a deterrent to verbal and physical violence and abuse. Greater school involvement in policing cyber bullying involving its students and those from other schools should be encouraged (academic)

Some submitters called for a complete ban of mobile phones in school.

Many submissions called for a focus on the education system to include emotional literacy, mindfulness, health classes and other emotional regulation education into the school curriculum. Some submitters noted the evidence-based outcomes on wellbeing from mindfulness in schools and other emotional literacy programmes. This was noted as being particularly important for rural areas where there may be limited support (including the training of teachers).

Submitters also noted the need for more mental health and other staff within school especially trained to work with youth. The current ratios were not adequate due to high demands on existing school counsellors.

### **Connect rangatahi with their culture and identity**

Both in school and everyday life, some submitters noted the importance of youth connecting to cultural whakapapa for identity and belonging.

Some submitters particularly pertaining to youth noted the need for Whānau Ora models that rest on the premise that “children and adolescents belong in family units and the quality of the relationships by which children are surrounded impact on their wellbeing” (professional organisation)

### **Meeting youth where they are**

Several submissions noted the importance of meeting youth on their terms – this includes expanding GP and primary care services into schools, expanding counselling services, using e-tools and other online tools, and expanding family and early intervention therapies. Some submitters called for an increase in youth respite services, youth hubs within school grounds, and peer support services.

In addition, increased access for mild to moderate distress, and increased subsidised counselling to reduce waitlists.

### **Listen to youth and take their leadership seriously**

Some submissions called for listening to and including youth in conversations – and leadership of issues – and co-designing programmes for youth with youth.

What works? When we are able to nurture in a hapū development way and can rebuild, and work with rangatahi. They give you the most amazing viewpoints of how basic it can be. Talk with kids. Talk about smoking and bullying, then talk about cannabis. They want to ask us questions. We all need to learn leadership around caring for one another (kaimahi Māori)

This includes broadening the type of support that youth need to include talk therapy, nature-based and adventure activities, and family therapy. A few submissions noted the impact of overseas models such as those in Iceland for reducing addictive behaviours and depression.

Some rangatahi called for more mental health and addiction training for staff ( particularly for front line GPs) and the value of peer support groups. They also spoke about help they had received during times of suicidal ideation and self harm, its variability but also the exceptional work and commitment of individual staff. Many spoke of the need for affordable help.

I should not have to pay \$400 a month to see the only effective and supportive practitioner I have met in the ... years that I have been in the mental health system (youth service user)

### **Educate youth on their consumer rights**

Some youth submissions noted their treatment within the residential care system and the powerlessness they felt. Some submitters called for increased accountability and avenues for complaint.

We need to make it easier for our rangatahi to understand their rights as a health consumer and be able to report the abuse they have faced in our health system (youth service user)

### **Increase specialist youth services**

Many submitters – particularly those from youth or their family and whānau - called for more specialist services, adolescent inpatient and day units, youth-focused rehabilitation and detox services, eating disorder services, home-like accommodation for youth with complex needs, and specialist services and workforce dedicated to early intervention in psychosis.

## 6.2 People in prisons

(See also section **4.1: Addiction**.)

### 6.2.1 Overview

The health and wellbeing of people in Aotearoa New Zealand includes those who are in prison. The majority of those people entering or exiting our corrections system and facilities are (or become) inextricably tied to another system – our mental health and addiction system. In particular, submitters described three main areas where justice and mental health intersect:

- entry and preventing entry into the criminal justice system
- the environment and support available inside prison
- transition and re-integration support when exiting prison.

Many service users or tāngata whaiora within prisons, families, whānau, prison and corrections staff, and mental health workers consistently described fragmentation and ineffectiveness where mental health and addiction met.

For many [in prison] their mental health issues will not be diagnosed while they are in prison (government agency)

We are locking up people for a long time without understanding their needs... a lot of us want [to] change and we don't know how (prisoner)

### 6.2.2 What's working well?

#### Alternative drug and alcohol treatment programmes

Therapeutic community models provided within a few prisons offer alternative drug and alcohol treatment programmes that are supported by multidisciplinary staff, and collaboration with non-governmental organisations (NGOs) within prisons to enhance effectiveness. Typically, there was a strong tikanga Māori component to these programmes, and occasionally a good after-care programme to help transition.

A few submissions directly from those in prison noted their appreciation of accessing the drug treatment unit, or similar, including behaviour therapy and education, noting a “positive and pro-social environment” (prisoner) as working well.

#### Alcohol and other drug treatment courts and their alternative to jail

Many submitters wished for an expansion of the Alcohol and Other Drugs Treatment courts given its success rate and choice of alternate pathways for those in prison often due to alcohol and other drugs-related offences. This reflects the calls (noted in section **4.1: Addiction**) for addiction to be treated as a health issue, not a criminal issue.

### 6.2.3 What isn't working well?

#### Entry into criminal and justice system worsens chances of rehabilitation and recovery

Submitters frequently said that people with mental illness or difficulties with substance addiction that are sentenced to prison worsens their chances of rehabilitation and recovery. They are concerned that not enough is done to prevent or reduce entry in prison, even when a 'crime' has been committed. Submitters said that people who use illicit substances become 'criminals' and often enter a pathway that dramatically affects their chances of a positive outcome or recovery in two ways:

- exposure to the wrong environment for recovery

Prevention before detention!! Rehabilitation Centres before more Prisons, as prisons do nothing to help people with Mental Health and Addiction problems (prisoner)

I feel as though putting people with addiction issues [in prison] with a lot of people that are aren't trying to change... is just making it harder for these people to try and change their lives (prisoner)

- gaining 'criminal' status.

**Exposure to the wrong environment for recovery.** Some submitters note that being in prison was the wrong place for those with mental health and addiction challenges, and actually worsened outcomes,

The role of prisons themselves in the development and exacerbation of mental health disorders needs to be thoroughly examined and remediated (government agency)

**Difficulty reintegrating.** For some submitters with family and whānau in prison, as well as organisations that work with prisoners there was consensus that having a criminal record impacted on their ability to reintegrate and get employment, housing and travel,

It's hard for them to find work find homes. Is there support for them when they get out? Can they even get jobs? Can they get a house? I get they have done things wrong, I get they have messed up pretty bad, but why should that hinder them to the point that it is easier for them to be in jail than in our community (family member)

Our [family member] was charged as a direct result of us calling the police. If I had known that he would be charged, I would not have made the call and would have dealt with the matter myself. Whilst he received a rehabilitative sentence (which included drug and alcohol intervention), he now has a criminal conviction which has lifelong implications for him. This will restrict him from travelling overseas and will limit his job opportunities. As a family, we are still picking up the pieces of that one phone call (family member)

Many submitters have many concerns that New Zealand's youth are being involved too early in the corrections system.

**Use and enforcement of bail conditions.** One agency suggested that the current use and enforcement of bail conditions could be “setting young people up to fail” (government agency). Some submitters strongly recommended alternative approaches for youth instead of incarceration, particularly because prison environments promote antisocial behaviour at the time when they need to be learning pro-social behaviours.

### **Mental health and addiction in the prison environment**

The majority of submitters are concerned with three key factors relating to people with mental health and addiction challenges inside prisons.

- The prison environment is not conducive to wellbeing and recovery (described above).
- There is poor access to appropriate services and support.
- The prison processes and environment do not facilitate inclusion and contact with whānau and family.

**Poor access to appropriate services and support:** Forensic mental health resources were also stretched with demand than cannot be met. With extended wait times to access services and infrequent sessions, most submitters believe that most people in prisons do not receive adequate support to manage their mental health and/or addiction challenges effectively. In particular, there was great demand for addiction services.

We don't have enough inpatient beds so that people can get initial treatment. Many are in prison without any treatment (service provider)

Targeted holistic approaches were regularly described as lacking, particularly for Māori and women. When considering the high proportion of Māori prisoners, many Māori submitters describe minimal access to kaupapa Māori approaches and other Tikanga Māori programmes. There was concern about the lack of tikanga training and Kaumātua services and often a general lack of consideration for cultural heritage. However, a few submitters said that where programmes like kappa haka and Māori art design were accessed, there were greater opportunities to connect with their whakapapa and cultural identity.

An environment and model of care that acknowledges and promotes the place of one's culture in healing (DHB)

A few submitters identified that women in prisons have a higher prevalence of mental health challenges and trauma. Women may also struggle to engage with treatment unless they know their loved ones are being cared for. Submitters said that women would benefit from more targeted services to meet their needs.

**Difficulty supporting continued connection with family and whānau.** Some submitters highlighted the difficulties for prisoners and family and whānau to remain connected. This can affect the mental health of those inside prison and also create more difficulties to reintegrate upon release. Factors such as the slow and burdensome processes required for visitors, costs to whānau (that is, travel distance, phone cards, supplementing food with fruit), poor facilities that support whānau visits (that is, family areas), and family not being informed of some events such as the prisoner receiving hospital treatment.

There are not enough pathways for families and whānau to visit their loved ones in prison and not enough is being done to support children with parents in prison (service provider)

For children of people in prison there are two issues. The children themselves are at greater risk of future imprisonment, and the disconnect between the prisoner and children may affect the mental health of both. This scenario is common, with one organisation reporting that “seventy percent of prisoners are parents” (professional organisation). Assessment and holistic support for the needs of children is recommended.

### **Inadequate support for transition and reintegration**

Submitters frequently cited inadequate support for transition out of prison and reintegration back into the community. At a system and societal level, some submitters report a lack of community acceptance and caring for ex-prisoners and as described earlier, there are many additional barriers faced.

If someone commits a crime while being mentally unwell, their criminal conviction becomes a long-term barrier to their employment and wellness (government agency)

Prior to release, some submitters described that not enough is done to prepare families and prisoners for their release. Residential and preparatory facilities within communities are few, making the transition more difficult and leading to an increased chance of reoffending. Alcohol and drug services, self-care, life-skills, and relationship skills are described as beneficial. Better, and more proactive integrated support across agencies was also suggested such as the Ministry of Social Development (Work and Income) and Housing New Zealand.

#### **6.2.4 What could be better?**

##### **New approach to dealing with non-violent crimes driven by mental health or addiction challenges**

Service users, tāngata whaiora, families, whānau, prison and corrections staff, and mental health workers strongly support a change in New Zealand’s entire approach to those committing non-violent crimes when driven by mental health or substance abuse issues.

Most submitters wanted alternative health-focused pathways where rehabilitation and harm-minimisation approaches rather than punishment were the primary objectives. There was strong support to consider these scenarios as public health issues rather than criminal issues and providing those involved with adequate support. They argue that imprisonment is resource intensive and costly with poor long-term outcomes as many prisoners re-offend after their release.

It would be smarter to allow judges to sentence non-violent drug offenders to rehab rather than expose them to further emotional damage and the anti-social influences of prison (prisoner)

**More preventative and early intervention efforts.** Many submitters highlighted the high proportion of Māori prisoners. They recommended that more preventative and early intervention efforts be directed towards addressing social determinants and supporting kaupapa Māori approaches to health and wellbeing. Targeting at-risk groups and communities with information, support and tools – particularly regarding alcohol and other drugs – was suggested to reduce the number of Māori entering prisons.

**Avoid youth exposure to gangs.** Submitters said that a focus on youth avoiding exposure to the wrong environments (prisons and gangs) during the years while their brains are still developing is important. For youth living in, or coming from, difficult or problematic environments, there is a greater chance that they have been exposed to significant trauma. Mental health workers and organisations explained that due to their backgrounds and exposure to trauma, they are less likely to have effective coping strategies and are more likely to be using substances as a coping mechanism. Preventing entry into the criminal and justice systems for youth is likely to require capable, holistic and trauma-informed practice.

I think that if we concentrate on mental health awareness and addiction problems between the ages of 10-16 we will start to reverse the problem Aotearoa has when it comes to mental health and addiction. When my school noticed all the warning signs [in me]... they didn't offer any alternative or help, they kicked me out, adding to the problem (prisoner)

### **Design a more integrated approach**

Submitters also outlined a desire for a more integrated approach, where health, response teams (that is, police, ambulance) and corrections systems work more closely together to ensure that there are appropriate pathways with adequate support.

### **Invest in improvements across the system**

In addition to the opportunities described earlier, submitters also recommended:

- increasing the mental health and addiction awareness and capabilities of prison staff to improve the treatment of prisoners and reduce the discrimination of prisoners with mental health or addiction issues (including cultural competence)
- providing a greater range of holistic services, support and activities within prisons to engage prisoners in meaningful activity – with regular access
- increasing the amount of forensic mental health and addiction professionals and resources working with prisoners to improve access
- improving the numbers and access of Māori wardens to first-time offenders, enabling them to use a whānau approach
- increasing the focus on rehabilitation and treatment, rather than punishment for crime

## 6.3 Disabled people and neurodiverse communities

### 6.3.1 Overview

Submissions concerning disabled people and neurodiverse communities encompassed people across a broad spectrum of impairment and diversity, including autism spectrum disorder (ASD); brain injury; epilepsy; attention deficit hyperactivity disorder (ADHD); foetal alcohol spectrum, including foetal alcohol spectrum disorder (FASD); Tourette syndrome; physical impairment; cerebral palsy; Down syndrome; disruptive behaviour disorders such as Conduct Disorder; dyslexia, dyspraxia and sensory, auditory, and visual processing disorders, and learning disability.

While there was diversity of responses to the Inquiry, predominantly submissions discussed in this section were focused on neuro-disabilities and learning disabilities.

The following overview from submissions were from youth, young adults, and adults who themselves identified as being disabled or neurodiverse, family members with children identified as disabled or neurodiverse, organisations, teachers and others who work with or support disabled or neurodiverse populations, and academics and thought leaders who spoke specifically about these population groups.

An overview of submissions from and regarding Deaf communities is provided in section **6.8: Deaf community**.

### 6.3.2 What's working well?

A limited number of submissions spoke of what was working well for disabled or neurodiverse populations. One survey conducted within the autism community found,

Those who reported positive experiences acknowledged themselves as the few lucky ones who were fortunate enough to get the right supports and services implying that the system is not working well for all (NGO collating views of families of service users)

#### Individualised integrated holistic services

Where it was working well, most submitters described the importance of individualised and context-specific support where professionals had specialty knowledge, and where services were integrated, holistic, and individualised to the person's specific needs. A few spoke of alternative education as working well when the mainstream education system and schooling environment was unable to cater for the needs of these population groups.

Some service users with learning difficulties noted that caring staff members and clear communication was important to them, preferring to be "communicated to in a way I understand and works for me, like easy read or pictures" (service user).

A range of service users also described specific services and support that worked well for them and their particular needs, such as one-on-one therapy and support, peer and group support, community-based creative activities (art therapies, nature-based activities including animal therapy and gardening) and other community-based services that created a safe and inclusive environment.

Homely environments and meaningful and enjoyable activities are important for people with learning disabilities (support worker)

They respect all of us and that's why I'm so happy in that house, they respect our feelings as human beings. I am really happy; I don't feel threatened at all (service user)

Family and whānau members noted support such as residential and respite care as working well as it provided an opportunity for rest from the stress of supporting loved ones with complex needs. Receiving a diagnosis as well as education about a person's needs was also working well to facilitate acceptance of themselves, and for family members to better understand, care for, and relate to their loved one.

Being diagnosed with ADHD has enabled both of these women to make sense of their experiences of being themselves in the present. Most importantly, it has allowed [them] to fully embrace [who] they are and to recognise what they need for mental wellbeing (NGO provider)

### **6.3.3 What isn't working well?**

Many submitters (both service users and organisations) spoke about current challenges for those who identified as disabled or neurodiverse.

#### **Human rights and social determinants**

New Zealand researchers and thought leaders recognised that the basic human rights of disabled and neurodiverse populations are not consistently upheld, and that current mental health and disability legislation is not consistent with the United Nations Convention on the Rights of Persons with Disabilities. Concerns were raised over the continued use of forced treatment, seclusion, and restraint among those with disabilities.

Discrimination against the disabled and neurodiverse was also evident within health and social services, and society at large.

The issues of stigmatisation, prejudice, reduced opportunity, unrealised rights and the interaction of impairment and context are issues experienced by all people with impairments (government agency)

I'm particularly concerned with problems for disabled people who may have a mental illness, such as severe depression. These often result from poverty and the constant exhausting and debilitating struggle to participate in a society which may not be openly hostile but which can be toxic in its exclusion, deep seated and systemic discrimination and inequality (service user with disabilities)

Negative attitudes towards disabled people are widespread (family member of person with ASD)

Submitters highlighted how disabled and neurodiverse people often have co-existing mental health diagnoses. Where multiple disabilities, coupled with other conditions and adverse experiences intersect, outcomes are exponentially worse and contribute to difficulties in areas such as employment, housing, and social isolation. One submitter noted how disabled individuals make up a significant portion of the unemployment rate, and those who have employment earn significantly less than those who are able.

I am a disabled person with a mental health issue on welfare for over a decade, trying to get care so I could return to work, being left destitute and terrorised by housing issues, living environment safety issues, lack of professional care, discrimination, at times highly suicidal and very unwell (service user with disabilities)

There's no help for my wife with mental health issues and epilepsy. Society thinks she cannot be employed (family member)

One submission noted a particular link between sight loss, mental health challenges, and other social issues for Pacific peoples. For this group, sight loss had an impact on job loss, low income levels, poverty, a feeling of being unable to provide for their family, and an inability to fully participate in cultural customs.

Some submitters talked about feeling the need to self-medicate with substances due to their experiences with disabilities or neurodiversity including dealing with failure at school, low self-esteem, and isolation. As one service user wrote,

A lot of individuals with Asperger syndrome will languish in addiction due to the need to self-medicate. Earlier intervention for Asperger syndrome and ADHD will do much to address this (individual with lived experience)

## **Education and school environment**

Many spoke of the current New Zealand education system as “woefully inept at responding appropriately”(NGO collating views of professionals, carers, and people with lived experience) for disabled and neurodiverse populations, noting high levels of low educational achievement among these groups. Some submitters described issues with overstimulating environments, bullying, and teachers who are ill-equipped to effectively manage and address their learning needs.

There is a group that is underserved by our current education model. These are children with dyslexia, dyspraxia, those on the autistic spectrum including those with aspergers, children with ADHD and children with auditory and visual processing disorders (family member)

My son's story is one example of many. There is considerable evidence to show that many young people with dyslexia and ADHD fall through the cracks and leave school without qualifications (family member)

I deal with many parent complaints that children with ASD, ADHD, dyslexia and dyspraxia are inappropriately managed in schools that are struggling to accommodate such students effectively due to insufficient targeted government funding and other support (government agency)

the majority of our teachers are not trained to teach approximately 22% of the students in their classes. This is not fair to teachers or schools and the reason we have a large failure group (family member)

Everyone has different abilities and learns in a variety of ways. This is acknowledged frequently yet we are all forced to learn things in one particular style that suits some people but not everybody. Having students with mixed styles of learning in a classroom creates a strain as all the students have different learning needs that a teacher must try and accommodate to (youth with Aspergers)

## **Accessing services and support**

Widespread concerns were raised with difficulty accessing services and support for either themselves or their family member. Some spoke of access as dependent upon receiving a diagnosis, particularly for ASD or ADHD, yet encountered barriers such as long waitlists, poorly trained staff, and high costs to obtain assessment and identification of diagnosis.

My [family member] never received proper diagnosis for her Aspergers and can't be diagnosed after 18 [years old] under current mental health system. As an adult the only way for her to see a psychiatrist is to pay \$600. In the past we did pay that money and saw a psychiatrist and he said to her that you can't be Aspergers as you are a girl (family member)

While some expressed frustrations over a lack of services for children and youth, it is particularly difficult to access services as an adult. Some submitters reported a lack of sufficient respite care and other community-based support for both the service user and their supporters.

How come someone with an array of disabilities is expected to live in the community without any support? (family member)

Many families need their vulnerable loved ones to be taken under a safe wing so they themselves can catch their breath, and our current mental health system doesn't offer this respite (family member)

Both service providers and service users spoke of rigid eligibility criteria and a lack of co-ordination between disability and mental health services, with service users often relaying stories of being bounced between the two and eventually falling through the cracks.

it took six years to get public mental health services after I got out of that stupid hospital because mental health didn't want to take me because autism and epilepsy, and disability didn't want to take me because major depression and anxiety (service user)

Both [disability and mental health] sectors still maintain an unhealthy fixation on eligibility. This leads either to an unthinking acceptance (thereby missing the significance of the person's dual disability), or a rigid unblinking exclusion (thereby leaving the person with significant unmet need) (NGO providers)

Disability service providers can't provide mental health services and mental health services don't want to know about disability (service user with disabilities)

We are passed from pillar to post by each organisation not wanting to take her on (family member)

One submitter described frustration that, despite being able to access help for addiction problems, the support was not provided in a way that was useful or appropriate,

I am mainly writing this on behalf of the people with learning difficulties suffering drug addiction. The rehabs we have in place in New Zealand are basically all about a writing program. How do I know? Because I have attended 3 different rehabs, completing 2 of them and I suffer from dyslexia. The first time I left after 2 days because there was no way I could do the program without help of a reader/writer, or the use of technology (service user)

### **Knowledge, skills, and attitudes of staff**

Many submitters address the widespread lack of knowledge about disability and neurodiversity across the mental health, education, and other social service systems.

Service users and family members often spoke of staff with poor understanding of disability or neurodiversity. Some described dismissive or discriminatory attitudes as particularly frustrating, resulting in feeling unheard, ignored, and excluded.

My male psychiatrist is paternalistic and doesn't appear to believe in adult ADHD. He does not listen to me and won't change my medication to something that works, and the treatment he has placed me on is clearly not working. He will then tell me medication is not the answer, I need to get better coping mechanisms. I love my ADHD and it's not a matter of coping, it's that I can't fit into the rigid world we live in, there [are] no allowances in life for my 'behaviour' or 'quirks' (service user)

some mental health providers/ professionals are prejudiced to people with disabilities and can assume that mental health issues are just a part of the disability (government agency)

[staff] also appeared to not know what to do with [family member]. Unless they've specialised in autism, it's in the too hard basket. This goes for the nurses as well (family member)

More than one doctor said "we are all on the autism scale somewhere" – um, no we're not. The link between being autistic and certain physical health issues i.e headaches and migraines, anxiety and depression is not being made. Ignorance perhaps? (family member)

One whānau recounted experiences of discrimination, judgemental attitudes, and poor training among specialists when seeking help for ADHD.

Endemic racism in specialists who are far above ADHD families. Structural individualism. No understanding and only judgment of larger Māori families struggling with untreated ADHD as we were. Judgemental about people seeking treatment for familial hereditary ADHD in multiple family members. Specialists untrained in recognising ADHD who will not ako with whānau. Girls and women being missed left right and centre (whānau Māori)

### **Needs of specific groups**

#### **Foetal alcohol spectrum disorder.**

See Focus on foetal alcohol spectrum disorder (FASD) on **page 144**.

**Brain injury.** Brain or head injury was reported within a small number of submissions as a continuing area of serious concern, often missed, under-reported and down-played in

significance. Within these submissions, brain injury was most often spoke of as having resulted from accidents involving vehicles. Submitters reported significant gaps in access to specialist assessment and treatment for this specific group.

Māori service providers mentioned particular concerns with the rates of Māori in prison with diagnosed, or undiagnosed presentations of, mental health issues due to brain injury.

**Prison populations.** A few submissions raised concerns regarding the rates of people with (often undiagnosed) disability or neurodiversity within prisons, particularly ASD, ADHD, foetal alcohol spectrum disorder , and learning disability, and noted that these groups have increased vulnerability within the justice system. One submission noted that a lack of service provision and housing for those with learning disabilities can be the catalyst creating a pathway into prison for this group.

Our prisons are full of people with low literacy and learning difficulties  
(family member and educator)

Submissions called for increased identification of disability and neurodiversity for those in prison, and more supports available to learn about and manage these differences while in prison. This included calls to implement screening of learning disability and foetal alcohol spectrum disorder in prison and in the criminal justice system, and programmes that teach rehabilitation tools for adults with ADHD.

#### 6.3.4 What could be better?

Many submitters called for increased awareness and education of disability and neurodiversity, particularly the recognition of the increased risk of mental health, addiction, and other challenges for these population groups. It was especially important for this risk to be recognised within the education system and school environment.

The presence of disability needs to be recognised as additional risk in the case of mental illness (bereaved family members)

Schools need to be more aware of the mental health of this sector, these are the at-risk students who enter society, with few qualification, very low self-esteem and an inability to communicate appropriately in society because of their learning difficulties (NGO)

#### Adopt a social model of disability with a human rights framework

Thought leaders, NGOs and other service providers called for the adoption of a social model of disability within a human rights framework, and to fully implement and follow the United Nations Convention on the Rights of Persons with Disabilities.

If we could live up to the Conventions we have signed up to as a country, we would be in no doubt that our citizens (and particularly our vulnerable citizens made vulnerable through mental un-wellness, disability or age) would be able to live a long, happy and prosperous life (NGO collating veiws of professionals, carers, and peepole with lived experience)

A few noted the importance of those who are disabled or neurodiverse to be at the centre of decisions made about their care, and to be supported to make choices and have greater autonomy in their lives. Thought leaders and service providers in particular advocated for a

shift to supported decision making, considering this fundamental to the wellbeing of those with disabilities and neurodiversity. Some suggested a need for more support workers, better training, and correct and full implementation of legislation to facilitate supported decision making.

Disabled people have the right to choice and control in the services that support them to live independently and be included in the community (commentator)

We need supported decision making rather than substituted decision making (NGO)

### **Focus on education system and other social determinants**

Changes to the school system included calls for more strengths-based approach to education and learning, where the focus is on “how to unlock their potential instead of expecting them to fit in with the status quo” (service provider for Deaf and disabled people).

We are looking at the symptoms of issues, this is looking at the problem through the wrong lens. We need to allow students in schools who don't ‘fit’ the system ... to be able to thrive in their area of strengths. Our education system strips them of curiosity and disables many of these students by focusing on literacy and numeracy at the expense of their other skills and talents (NGO)

Young people need exposure to strength based narratives of who they are, what makes them different and unique (commentator)

One youth commented that schools could be arranged according to,

Pattern Learning, Visual learning, Verbal learning, and Auditory learning ... [as] most individuals have their strengths in one of these groups ... The idea with [this] system is that the classes are not streamed by abilities as such, but by the style in which they learn best (youth with Aspergers)

One family member of an individual along the autism spectrum described the importance of a school environment crafted to the specific learning needs of this group.

Ideally a school for people with high functioning ASD, so they do not have to endure the subtle toxic bullying and so that they are under teachers who are properly trained to teach them. They need to be with their actual peers in a supportive non-judgemental learning environment that is suited to their brains (family member)

Classroom environments catered to different styles of learning would benefit students with higher needs particularly (youth with Aspergers)

Support to obtain employment and housing was noted as particularly important and beneficial for the wider wellbeing of those with a disability or neurodiversity.

Improving access to housing and employment for disabled people is essential for improving their mental health outcomes. For example questions about a person's disability should come after an employment offer, not before, to reduce this barrier (government agency)

Where is the support to enable autistic people to become productive contributors to society. My daughter is highly intelligent and capable and wants to make a difference – she just needs a pathway to employment (or the voluntary sector) to work with an agency to get her from where she is now to reaching her potential (family member)

What us ASD individuals without intellectual disability need more than anything is employment. We are all desperate to work, but cannot function in most jobs as the difficulty of communication we have invariably alienates us from our colleagues, our sensory problems make many working environments extremely difficult to tolerate- light, noise, smells etc. We are highly intelligent people with an awful lot to offer any workplace, but it seems it is not considered worthwhile to accommodate our differences so that we can provide the workforce with our significant strengths (support worker with lived experience)

### **Prioritise early intervention**

Targeting early identification, assessment and, where applicable, treatment was widely regarded as beneficial or leading to better outcomes, particularly for those with neuro-disabilities. Increased screening for learning disabilities and neurodevelopmental differences were recommended, such as autism screening during child hearing tests and professional screening at kindergarten and primary school. Some recognised that effective early intervention was dependent upon the training of teachers and professionals, access to a variety of treatment options, and continued support for those supporting loved ones.

Early identification and intervention of [foetal alcohol spectrum disorder] can have a more supportive pathway for that child and their whānau (addiction sector grouping)

More investment needs to be made on identifying neuro-disability and related learning, communication behaviour needs as early as possible in a child's life (commentator)

So many families who are able to find success are the ones who get the right intervention early; teachers who understood what ADHD was, health professionals who are interested and engaged and understand the ADHD, quick and effective assessments; multiple treatment options (family member and health professional)

get more resources for the quiet strugglers in school, like kids with dyslexia and dyspraxia and adhd and asd, don't wait till they're throwing chairs at school and their families are falling apart at home, have professionals spend a week at kindy like the hearing nurses do and pick it up early, and then again in primary school (individual submitter)

One NGO stated that evidence-based and evaluated parenting programmes work well for those with disruptive behaviour challenges such as conduct disorder. However, to be more effective, these programmes should be shifted to an early intervention approach rather than targeting families at the extreme end of need.

Service users and tāngata whaiora regarded occupational therapy as beneficial for developing functional and social skills, particularly for those with high functioning autism and ADHD.

## Upskill workforce

Many submitters called for the need to increase training for those who come into contact with disabled or neurodiverse people, including mental health professionals, teachers, police, and social services staff. Service users wanted to be listened to, taken seriously, communicated with clearly, and for mental health professionals to be able to distinguish between features of their disability or neurodiversity and features of their mental health challenge. Service providers called for greater workforce development, particularly around specialist training, to ensure access to professionals with sufficient expertise in learning disabilities and specific neurodiversity. This included increasing capacity for specialist consultants.

We need staff who speak our language and services we can use. Mental health staff with lived experience of mental health who are disabled. We need to be seen and counted (service user with disabilities)

[what] would have helped my daughter when she was at school would have been to have teachers who understood (family member)

One submitter described wanting mental health professionals to understand that those with disability want to live independently but require support to deal with the challenges that arise.

Mental health professionals should be more aware about the barriers and challenges people face ... and the barriers of trying to live everyday lives and how that impacts our mental health (lived experience with disability)

## Improve access, services and Integration

Calls for easier and more equitable access to services and support were frequent. Recommendations included easier access to mental health services, greater availability of advocates who specialise in disability and mental health, more community-based support including day programmes, specialist neurodevelopmental services, wrap-around holistic treatment, and care that was culturally, diagnostically, and age appropriate. Family members noted the need for services to extend past the arbitrary adult cut-off point of 18 years old and continue into adult years as “Autistic children do not disappear when they reach 18” (family member).

It is important that people with disabilities who are experiencing anxiety, low mood, hopelessness, a sense of futility, or suicidal thinking have appropriate, timely and equitable access to mental health assessment and treatment (NGO provider)

Families and whānau also vied for more inclusion of family members in recovery and treatment plans, and greater ‘support for the supporters’, with one family member highlighting the importance of respite care.

RESPIRE care for people with ASD, especially those with mental health involvement ... My son and I NEED rest and breaks from each other, in a safe and supportive appropriate place (family member)

Many submitters called for greater collaboration between disability and mental health services to keep people with dual disabilities from falling through the cracks. Cross-sector collaboration with ministries, such as the Ministry of Justice and Ministry of Education in

particular, were also raised as an important and necessary aspect of keeping disabled and neurodiverse people well. A government agency urged for,

[a] mental health and intellectual disability service system that recognises the need for an integrated social model of care (government agency)

More connection and communication between health, disability, education and social development (submission based on collective views of professionals, carers, and people with lived experience of disability)

## 6.4 People in rural communities

### 6.4.1 Overview

For the purpose of this Inquiry, 'rural' refers to geographical locations in New Zealand that are far away from the three major population centres as well as larger towns. Submitters to the Inquiry identified rurality in a variety of ways, including mentions of "the provinces" or "provincial", "isolated communities", or "small towns". Submitters often referred to a community, town, or region by name, for example, Kaipara, Wairoa or the West Coast, which implied a rural location. Occasionally, submitters would refer to larger geographical areas of New Zealand in the context of rurality, including "up North" or "the Deep South". There were some references to "the rural spread", which often indicated a small population distributed over a relatively large area. These references were all coded as 'rural'.

Some submitters would identify a rural area by name or region in their submissions, without mentioning issues specifically connected to rurality itself. These references to small towns or isolated communities were coded as rural even if the submission spoke about mental health and addictions in a general way.

Farming or farm communities were often mentioned in conjunction with rurality but it is important to note that farming and rurality should not be conflated.

### 6.4.2 What's working well?

#### Locally provided services

Many submitters –tāngata whaiora, service users and service providers--mentioned specific mental health and addiction services that worked well precisely because they were close to home and provided support in their communities. These examples were often referred to as community-based responses that had been created in response to the general lack of services in rural areas.

Access to local counsellors through PHO funded packages of care (POC) - local counsellors work with practices and are easy for patients to access with a valuable understanding of local issues and support services. This works well in some areas, but other areas do not have access due to the large distances involved and the lack of adequately trained staff (rural professional organisation)

In [remote area] we had the wonderful services of a community mental health nurse who would travel down from [larger town] to [remote area] and beyond ([large distance]) seeing first referrals and follow up patients. She also acted as a single point of contact for all mental health referrals, directing them to the appropriate service. Her up-to-date knowledge of the constantly morphing secondary mental health services lead to a smooth process and reduced the frustration of getting patients to see the most appropriate health professional. She also had her hands on the latest iterations of referral form or mode. This is particularly important when rural health services are often being staffed by series of locums or with clinicians who are not necessarily skilled in or attuned to mental health issues (rural NGO provider)

Some submitters identified mental health and addiction support from local GPs as particularly appropriate, as a local provider would understand the special issues a community faced.

### **General rural community support**

A few submitters mentioned local programmes that addressed the social determinants of health such as employment and income.

Working well: a new initiative in [remote area] re: employment—all they do is work with employers in community to find jobs and build employer understanding; good success to get people who had no rehab options into work. Initial screening from social worker, primary care, etc., catching people before crisis and options to give people help and rehabilitate people back to where they want to be. Ability to have a communication infrastructure to let systems talk to each other and to build relationships between services (health professional)

Rural support trusts were also specifically mentioned by some submitters as playing a positive linking role between people living in rural areas and mental health and addiction service providers.

### **Health promotion campaigns**

A moderate number of submitters discussed a decrease in stigma around mental health and addictions attributed to health promotion campaigns directed at rural audiences.

Currently working well for Rural Mental Health is the exposure that it has been given by the media. It is working well by removing some of the stigma of having mental/emotional health issues and making rural communities more aware of the issues that people have that live in our community. It is working well for those of us that work in the field and has provided us some clarity about services that are available to our rural folk (health professional)

### **Close knit community as an enabler of innovative response**

Many submitters referred to the close-knit nature of rural communities in terms of innovative solutions born out of necessity: people create their own services where they are few and far between.

One of the beauties of living in a rural and isolated community is that you do find your own answers, because you can do a lot on the smell of an oily rag – which is what we have been doing (kaimahi Māori)

In [remote area] people who came to the mental health hui were very visible—there was one woman who was the hub of that community: she would give people a feed, talk to them and they'd be fine. That's not primary care but community capability, building up resiliencies in community (DHB staff)

Whānau catching up with each other in the community is a common theme, as well as the community programmes [in remote area]. There's a sparse demographic [in remote area]—to bring our whānau together for those programmes is important, particularly because of distance and rurality (kaimahi Māori)

In [remote area], inter-departmental collaboration and making optimal use of available resources has led to the medical ward at [larger town] hospital providing up to two inpatient beds for respite care use. This has enabled clients to receive respite care in their own community where they can be supported and monitored by clinicians in their home Mental Health team (DHB)

Service providers stressed the potential for increased integration amongst the available services in rural contexts.

A low cost initiative is to continue to do more joining up of services and organisations in rural New Zealand, making the most of what is already there (government agency)

[rural area] is an isolated part of Aotearoa, the attribute that falls from this isolation is the close community working relationships which have formed over years, not always great relationships but certainly known relationships. Knowledge and understanding of Iwi is a strength locally as well. We have very strong support from all of our mental health providers to promote and support wellbeing within our community (DHB)

Rurally I think things are working better than urban communities because we are local we are connected we work collaboratively with other community organisations i.e. GP's Pharmacy schools police corrections MSD and NGO's (service provider)

### **6.4.3 What isn't working?**

#### **Access to services**

Many submissions spoke to the lack of services in rural areas as the key problem for them in terms of mental health and addiction. Submitters mentioned that services for suicide prevention and postvention, rehab and detox, and maternal mental health in particular were missing in rural communities. Submissions from service providers often discussed difficulties around lack of services for their clients and patients.

Teams from [larger city] coming to rural areas such as [rural area]. We have tried to access acute and early intervention services for our people here in [small town] and have been advised that we are outside of the area that these services cover (NGO provider)

My weeks not over yet, tomorrow I'm seeing a young one first thing, whose mum died but there is no grief counselling in rural areas, I'll do it because I can and no one else will, please help us to work holistically and with good resources in our small rural towns (mental health professional)

Rural community doesn't have health services—in [remote area] there's no health services; if you have a heart attack, you die. We need to make rural health urgent because of this situation. All that currently happens is you pray, then dig a hole (Māori contributor)

Some submitters singled out the necessity of leaving the support systems of communities for treatment in larger towns and cities, especially for addiction treatment, as detrimental to wellbeing and recovery for rural people.

Substance Detox options for people close to home are limited in the [geographical location] area with services delivered regionally in [urban centre]. Whilst social detox is available in [larger town] delivered by [treatment facility] this is only available to people who reside in the [larger town] area (DHB)

There is currently a lack of inpatient beds. The nearest inpatient unit is located in [larger town] When people are admitted to the inpatient unit, they are a significant distance away from their supports and community. At times, clients are discharged from the inpatient unit before they seem ready to be, because their beds are needed for other clients to take up (DHB)

A moderate amount of submitters connected lack of services with high suicide rates in rural communities.

3 suicides in last 3 months... causing devastation for small rural communities - real risk of suicide contagion. Postvention interventions (whānau and community) provided by under-resourced local team (NGO provider)

Many submitters also referred to general difficulties associated with living in rural or isolated locations, including high unemployment, lack of housing, and other social problems. These determinants were often mentioned in tandem with low or no availability of mental health and addiction services in rural areas.

Our population is highly deprived. High [alcohol and other drugs] abuse, poverty, family violence. 30%-50% Māori across the whole region. Population is young, many Māori youth. In [remote area] 30% is under 18. There is a hole in the 19-40 age bracket; people leave and return later. Also have over-64 age bracket is also growing. Big hole in working age group. Māori have huge numbers of young people but tapers off for older age Māori. Shrinking population of working-age people. People left find it hard to get jobs. Small population but our geographical spread is a challenge re: access to transport, areas of employment. But there is a strong sense of community—people can unite quite quickly around a common direction. We tend to be familiar with each other (DHB)

High rates of domestic violence and child abuse: 40% of Primary [mental health] referrals involve abuse dynamics. Significant under reporting due to fear, rurality and poor service provision (NGO provider)

No local women's refuge: domestic homicide and several attempted homicides in last 5 years (NGO provider)

There are no afterhours DHB services in [remote area] – we need a crisis afterhours service. We don't have the option of specialists in [remote area]. There is a lack of housing options; no emergency or residential housing for Tāngata Whai Ora (Māori consumer representative)

Changes in farming communities in particular were mentioned as taking their toll on the mental health and wellbeing of rural people.

The idea of a close connected farming community no longer exists. Share Milking has changed the fabric of rural life styles. This week 1 June we will see this demonstrated through 'Gypsy Day'. We are working so hard – wife travel hour and half to get more work while husband stays and works the farm. The idea that farm life is a wonderful place to live and work isn't necessarily so (NGO provider)

Loss of connection; rural scene has changed. Farming pressure and long hours and stresses. We don't have the connection of knowing everyone in smaller district as you'd think (DHB)

## **Workforce problems**

Many submitters identified difficulties around mental health and addiction workforce. The high rate of staff turnover and the use of locum practitioners in particular were seen as poor service.

Services travelling from [urban centre], constant change of service provider/counsellor/GP therefore engagement can be difficult and important information not gathered or consumer having to repeat their experience (rural submitter)

I don't think enough support is being given by government to the rural community. There are a lot of volunteers out there trying to do this with assisting rural people who are finally feeling more able to speak out. However trained staff are needed to visit and assist where volunteers are out of their comfort zone in dealing with an issue which is known from NZ statistics – re increased suicide rate in rural community (rural family member)

Doctors, psychologists, etc., don't engage with consumers or with families—things were the same ten years ago as they are now. Mental health facilities should be therapeutic; there are no facilities for people who are high users. There are no social workers who visit in a rural community, no care plan, no respite. The ward is a holding pen. Crisis team can take over and hour to arrive. Police are the people you ring, not the crisis team (family member)

### **6.4.4 What could be better?**

#### **Increase access to mental health and addiction services.**

The majority of submitters' recommendations centred around increased access to mental health and addiction services by physically locating them in rural communities. This was often mentioned in the context of the need to change district health board (DHB) population-based funding models to better serve rural areas.

Population based funding is a challenge for rural based services. Our geographical spread includes... coast line and... native bush and scrub land. In addition, we have high Māori population... and a high incidence of deprivation, and this widespread deprivation coupled with rural setting impacts on access to health services. Population based formulas do not take in to account these mitigating factors of deprivation and rural-ness. Possible solution: in Australia there are two different funding formulas, one for metropolitan services, and another for rural and remote. Maybe this idea of two different funding and planning environments is a possible solution for New Zealand to adopt also? (Māori NGO provider)

Some submitters suggested that providing rural bonding schemes to mental health and addiction professionals would be a useful way to solve the access problem. A moderate proportion of submitters recommended expanding e-therapies and upskilling rural GPs in mental health treatment.

Our health graduates struggle under high levels of student debt and our rural areas struggle to attract health professionals. Current supported programmes that offer salaried positions in rural areas need to be extended and linked to progressive student debt abatement with longer service. It needs to be recognised that medical students, while having higher absolute debts, pay these off considerably sooner than nursing and allied health professionals, due to their higher earning power, so these schemes need to be extended beyond just doctors. Adequate ongoing training and support needs to be provided for these new graduates (health professional)

The needs of rural communities for high quality care also must be considered, with excellent support from experienced clinicians built in to the system (health professional)

Other approaches for enhancing access to psychological therapies. Technology is a powerful tool that can improve access. Use of e-therapies for people with some mild-moderate MH&A difficulties and other challenges to wellbeing has proved useful, either on its own or as an adjunct to therapy. This may be particularly valuable for those in rural areas or who have other physical/geographic access issues, but is also valuable as a first step for other people (professional organisation)

All primary care providers need expertise in managing mental illness - this is certainly not uniform across rural areas especially in areas where it is hard to recruit GPs and where they are dependent on long-term locums. This may also have an impact on the ability to provide culturally appropriate services. There needs to be easy access to appropriate and relevant education (professional organisation)

## **Social determinants of health**

A moderate number of submitters recommended addressing the social determinants of health in rural areas, both on the service provider and community level.

Regarding the social needs of patients, a huge amount of time is spent by small numbers of clinicians in rural practices in dealing with social issues. Having social work also embedded in rural primary care would have a major impact in ameliorating the social determinants of poor mental health and addiction (rural NGO provider)

This small community experiences the most intense discrimination I have seen. Clients are stood over at the cash machine and their entire benefit is stolen from them. I have seen clients have angry community members move in to their housing NZ homes and pushing them out saying "others need this home more than you do". Even services can appear discriminatory, four years ago I met clients who had not had a second opinion after continuing service for ten years without change, and when we first supported clients to access a second opinion, there was push-back from clinical services suggesting the clients did not deserve or need such a thing. The local police appear to target mental health clients as they are more easy to charge. It is as though the 'Like Minds Like Mine' project has never existed here! We need to do something about this discrimination that is both about mental health and also about people being Māori (Māori NGO provider)

## 6.5 Older people

### 6.5.1 Overview

Older people were categorised as such in multiple ways although Statistics New Zealand define “older people” as 65+.

Occasionally a submitter would self-identify as being “older” or “elderly”, or indicate their age, or talk about what would happen to their children as they “grew older” and were unable to care for them. Some family members would talk about their “elderly parents”. Organisations used the terms aged-care, elder care, elderly or older patients. Some organisations represented “grandparents” or “grey” demographic – without indicating age.

Whānau Māori used terms of respect for elders in their community (although not necessarily “older” in terms of a quantifiable age) – Kaumātua, kuia, koroua, koro. Sometimes this was bracketed by “elderly kuia” or similar. These terms carry status of leadership, cultural authority and mana – and hold a particular active role within the whānau. The health and wellbeing of kaumātua was very often seen to be linked to the health and wellbeing of the whānau.

The mental health and wellbeing of older people was notable in submissions.

Lifting the quality of life for older people not only resides with health professionals but it is the responsibility of our society. We should look more closely at the Māori model that places great mana with their kuia and kaumātua. In western society older people often experience loneliness, isolation, lack of meaningfulness and hopelessness and these factors ultimately impact on their mental wellbeing (professional organisation)

This section looks at both from an elder care perspective but also the role of “older” people in society as noted by submitters.

### 6.5.2 What’s working well?

#### Reducing isolation and challenging stigma

**Services that reduced isolation** included home visits, home-based activities, access to technology, culturally comfortable groups, a wide variety of hobby groups, opportunities to volunteer in schools and community, and free public transport to reduce costs.

**Public health campaigns working well** for older people in terms of seeing mental health challenges in a different light or raising awareness for family members.

#### Choice in access to services and options

**Characteristics of services working well were similar to those mentioned by broader population** and included lower cost or free counselling, length of intervention, holistic bio-psycho-social approach (including free dental services, physical activity in the home), workforce characteristics (experienced caring staff), integrated services, good funding, and enabling older people to maintain autonomy or stay in their home and have appropriate care services.

**Good relationships with other NGOs and multidisciplinary teams.** A few service providers cited a handful of well-integrated services that connected mental health teams with local GP clinics, or multidisciplinary care teams.

**Home-based care.** Many whānau submitters that spoke about their elders expressed both the desire and the privilege of caring for their kaumātua within a home environment.

**Many Māori and Pacific organisations** run specific services for their elderly. These focus on physical, spiritual, mental and social wellbeing.

### Positive workforce and training

**Commitment, care and expertise when dealing with older people service users, respect – including cultural respect – for elders.** Particularly relevant to some submitters were service providers skilled in dealing with co-morbid conditions existing with ageing such as disability, serious mental health challenge, significant physical frailty, and primary dementia (with serious behavioural and psychological symptoms),

There are many staff working in this area that have a longstanding commitment and years devoted to this often marginalised sector of the population ... When fully resourced the Mental Health Service for Older Persons Team are a proactive, highly skilled and cohesive team that make a difference in supporting this client group to remain living in their communities of choice (DHB)

**Real diversity of staff** was particularly important for whānau Māori, particularly important when caring for kaumātua in a community service,

The organisation wanted relationship with the marae so came along to get the tick. One Aunty asked how many Māori working for the kaumātua and they answered none. I went back to school so I could support the kaumātua ... [section re job progression] ... I get the hard baskets, the people who fall through the cracks. I get the phone calls from the GP, we've got nobody to work. I'll work with whatever nationality to navigate the services. On my books – I leave you when I bury you. I get my guidance and boundaries from my Aunties and kaumatua. Still feel like I'm seven still getting told off. Love the guidance from my hapu (kaimahi Māori)

**Programmes and staff training courses targeting specific older people populations.** A few submissions talked about programmes that targeted older Rainbow population, older people with addictions, and older people with neurodiversity,

In aged care settings, staff training is needed to ensure older rainbow people experience safe and inclusive care. One example of a successful initiative in this area is the Silver Rainbow resource kit and training programme (NGO provider)

### Services and advocacy groups operated by “older” people caring for mokopuna and whānau

Role of older people helping younger generations or same-age peers was a strong theme in some submissions, particularly in Māori communities (and Whānau Ora approaches) but also in peer-led charities. In some cases, charities support those grandparents who are caring for

mokopuna, due to parental addiction or mental health challenges. These charities were seen as an invaluable resource.

### 6.5.3 What isn't working well?

#### Lack of respect shown to older people by health system

Many submissions from service users (or their families) noted with sadness the disrespect their older family member was subjected to in the health system.

Overall, however, it was a devastating experience which left us wondering about the values of our society and the rewards meted out to many of our elderly fathers and mothers, faithful workers who have often spent their lives caring and interacting kindly and well with others. It is a most disillusioning and stressful experience (family member)

#### Lack of access and poor co-ordination with other age-related services

There were similar issues with lack of access, service, integrated care and follow-up for older service users as across the general population. However, access and services issues were exacerbated by concerns with age-ism and age-related illness.

**Rise of dementia.** There was significant concern in many submissions from both service users and organisations about dementia – the impact of dementia on mental health, appropriate care and respite, age appropriate services (including early onset dementia), inconsistency between services, and lack of recognition and staffing skills in terms of dementia and other mental health and physical challenges. More importantly, many service users, families and whānau and service organisations noted the lack of consistency, integration and navigation through the “dementia” system, both at a systems and service level.

we've got three non-intersecting circles: one mental health, old age, disability – and dementia falls through the cracks. We're 20 years behind the rest of the mental health sector ... dementia is not to one side ... depression itself is a risk factor for dementia (national representative of seniors)

Lack of services has led to an often default position of restraint and isolation (seclusion) and “can sometimes be a result of society's unwillingness to provide adequate dementia care and resources - People with dementia do not have the legal safeguards of other groups when it comes to seclusion and restraint” (NGO).

**Lack of access to mental health services for older people in aged care.** It was noted by some professional submitters that there was a perception that older people do not present with serious personality disorders is completely false. A few submissions noted the link between depression and moving into rest homes, and an absence of integration with mental health services.

**Isolation of older people.** Isolation was noted in submissions to occur in multiple ways for older people including ill-health, social discrimination, lack of access to transport, closure of community facilities, poverty and costs, and language barriers including New Zealand sign language.

**Moving into aged-care facilities and impact on mental health.** A few submissions noted the link between depression and moving into rest homes, and an absence of integration with mental health services.

The physical health of the person is given priority and mental Health issues are regarded by the [staff] as "something that will lessen with settling in to a new life style" (former NGO staff)

**Impacts of polypharmacy on ageing population.** Concern in a few submissions of the lack of information sharing and integrated services, as well as over-prescription, and the impact of this on the health of an ageing population.

### Lack of support and respite for family and whānau

**Family and whānau supporting older people.** Many submissions noted the importance of caring for their older people or kaumātua. However, it was also noted in many submissions that those caring for family members also need support as there are often higher risks of depression and anxiety, with financial implications and stress.

**Older people supporting children.** Some submitters were ageing family members supporting their adult children. They worried about who will care for their children when they die. This included adult children with neurodiversity, mental health challenges, acute mental health challenges, addictions, and early onset dementia. There is a dearth of appropriate supported living facilities and adult children with unmet needs are being housed in inappropriate facilities including aged-care homes, night shelters, and hospitals.

Caller is 80yo and has had [adult] son living with them for the past 4 years due to addiction and mental health struggles... Caller feels that there are no facilities available to take him and work on 'getting him right'- comments that this is the case since institutions closed and if there are facilities then there is a very long waiting list (family member)

**Older people supporting mokopuna and grandchildren.** Some submitters spoke of their role looking after grandchildren, having to support not only their own children but their distressed grandchildren, with minimal access to services, high financial burdens, minimal respite and no consideration of their own mental health needs.

### Human rights of older people are being denied

**Stigmatising language.** A limited number of submissions questioned the stigmatising language used in aged care. For example, the term "psychogeriatric" to define a person – instead of seeing the person, and Alzheimers and dementia as an illness.

**Older people with dementia and similar conditions having their rights denied.** Lack of beds, lack of standardised care protocols, lack of training and awareness have resulted in many older people with dementia and similar conditions having their rights taken from them. Those without guardianship from family and whānau have no advocacy.

some patients at [DHB ward] wander around all day and are sometimes refused the ability to have a support person with them. Their rights are being denied and the DHBs don't have that right (national representative of seniors)

The Human Rights Commission report, *This is Not My Home*, outlines significant breaches in Human Rights for aged-care residents in terms of restricted or denied movement without authority,

The use of residential care is relatively high in New Zealand compared with some equivalent countries. Many elderly people in ARC facilities, by virtue of their illnesses or disabilities, have no (or very limited) capacity to make their own health care decisions, including where they should reside. In New Zealand law, those without capacity should have a substitute decision-maker who can consent for them, whether for residence or treatments. However, it is well-known in the sector that many such residents in ARC facilities have no such person appointed to make those care decisions for them. The significance of this grows in recognising that many of these people are effectively restricted or detained, in the sense that they are not permitted to leave (government agency)

The report outlines reasons why this is occurring including growing elderly population, more living alone, pressure on beds and time to organise legal authority, lack of appropriate staff knowledge, long delays in family court, financial costs and cultural issues. But highlights in particular, issues for Māori and Pacific families,

Māori and Pacific families rarely appear to have Enduring Powers of Attorney in place. This may be due to factors such as educational or financial disadvantage, but there also appears to be a cultural reluctance to give decision-making authority to a son or daughter, when families believe that power (mana) within the whānau should reside in the older generations (kaumātua and kuia) (government agency)

**Unmet needs for some older people populations.** Some submissions focused on the unique needs of older people with addictions or in prison, particularly men and the inability of current services to meet their needs, and inappropriate aged care services and difficulty in assessment of complex needs.

**Older people rights for LGBTIQ+.** A few submissions noted these rights not being included in mental health and addiction considerations, nor are there opportunities to express their gender in aged care facilities.

Some submitters noted the links between neurological disease (such as Parkinson's disease) and co-existing depression, noting this may be contributing to self-harm or suicide.

Some submissions noted that age cut offs for funding older peoples' services, particularly the drop off of mental health and addiction services for aged residential care.

**Older Deaf people.** One submitter noted older Deaf people in residential homes are isolated and find that the opportunity to get an interpreter is very difficult,

Some interpreters never visit a residential home, maybe the older person wants one interpreter and another one comes in, communications just dies. Older Deaf people rely on lip patterns, lip reading from age 60 upwards; they're not signers, they use gesture and pointing as their main form of communication. We need another Deaf person there to facilitate that communication between the older person and the interpreters (Deaf advocate)

#### 6.5.4 What could be better?

Many submissions focused on the need to shift societal attitudes of ageing,

Of wider consideration is how society and health providers treat older people living with mental health issues, as they experience both the stigma of mental illness and ageism. There must be cultural change, both within society and the health system, to ensure older people with mental illness are treated with dignity, consulted about their preferred treatment and have treatment delivered as close to home as possible. This a public health issue that requires attention (professional organisation)

#### Reduce social isolation and loneliness with a focus on positive ageing

Some submitters focused on positive ageing and the need to shift old fashioned perceptions of older people, and their capabilities in society.

#### Recognise the rights of older people

**Change policy and legislation** in regards to the rights of older people, particularly improving the rights of those in residential aged care. Several key submissions noted the need to focus on legal safeguards, oversight and accountability, reduce barriers to enduring powers of attorney, enhance workforce understanding, and implement supported decision-making framework as a default.

**Review the Protection of Personal and Property Rights Act 1988** to ensure people living with dementia are treated equitably. A few submissions from service organisations concerned with human rights abuses noted,

‘detaining’ people in secure dementia units without sufficient legal documentation to support this decision-making is a breach of international and national human rights legislation (professional organisation)

**Promote person-centred care**, which,

[begins] with a foundation of understanding the person: their life so far, interests achievements and preferences and relationships and continues by using this understanding in working with the person and family to continue to live well (professional organisation)

**Update the Care of Children Act 2004** to include grand-parenting rights of access, recognising the impact on mental health of grandparents being withdrawn from grandchildren.

#### Better access and services for older people

Many submissions reflected access and service solutions that were also prevalent in the general population but with a focus on aged-care, including:

- improve and fund ways to reduce isolation such as providing free transport services, libraries, meeting places for older people – as well as stronger social integration for the older people into the community through volunteer opportunities and so on
- increase integration in facilities and services for older people including respite, supported living, dementia care, and those suffering cognitive decline

- increase access to mental health and addiction support in residential homes and aged care facilities
- increase kaupapa Māori, holistic approaches to aged care focusing on the health of the whānau as a whole, and the health of the marae
- make it easier for older people to navigate the health system
- increase the number of full-time equivalent positions of specialists for older people in the community (including rural communities), including nursing staff, psychologists, support staff (for example, for dementia, complex post-traumatic stress disorder, acute mental health, addiction services, and co-morbidities), and include advanced planning for the ageing population, better data input particularly related to dementia, consistent national strategies
- increase the number of full-time equivalent Māori aged-care staff and specialists and kaumātua positions
- increase the number of full-time equivalent Pacific and ethnic-specific aged-care staff and specialists and reduce cultural and language barriers for specific population groups such as older Asian groups
- funding for individual care packages so service users can determine how best to use money to purchase the services they need
- increase evidence-based training; for example, a few submissions cited training programmes for carers which promotes a person-centred approach and has been very well received by care facilities and community care providers in the region
- work towards appropriate training and care facilities to stop the use of restraints
- improve, within prisons, the management of frail, older prisoners and address the high physical and mental health needs of ageing prisoners
- acknowledge and responding to the high rates of suicide for those over 80.

### **Consistent access and services for age-appropriate dementia care**

Many submissions focused on the need for dementia care that takes into account individual personalities, co-existing conditions, and impacts of depression. There was a high level of concern among service users, family and whānau, and organisations of the impending impact and growth of dementia in New Zealand and the seeming lack of preparedness and appropriate services/support/integration. There was a call for national leadership and prevention strategies. This included calls for the implementation of the New Zealand Framework for Dementia Care. In addition, New Zealand has no formal national data collection on dementia and this was noted as something that needs to be better for planning purposes.

### **Support for family and whānau**

There was a strong call from those supporting family for increased access to services, more options, financial security, financial support, navigation of services, supported living for family in their care, respite services, access to counselling services to help manage their own depression and anxiety.

## Caring for kaumātua

Many Māori submitters spoke specifically about the importance of caring for kaumātua, but some noted generational change could impact responsibilities, and that funding and commissioning models should support this way of caring for elders.

If we could have palliative care out here (on the marae) – it would be better for those receiving care; watching life, their kids, their grandchildren (Māori contributor)

## Increase Community services and integration

Improve positive ageing with a focus on reducing social isolation and loneliness,

Many people will retire from full time employment, and continue to live a productive life for another 20 years plus, thus it is important that opportunities to socialise and remain motivated to seek new challenges are able to be made from a diverse choice of options (mental health professional)

Healthy Ageing Strategy is good but has a gap re: positive ageing mental health model. New Zealand is on the cutting edge of this demographic change—has potential to change the view of what ageing is. Older people are doing amazing things; urges the Panel to think about positive ageing for older people (national representative of seniors)

## Workforce, funding and commissioning

**Importance of kaumātua in Māori specialty services was strongly emphasised** in some submissions. The need for adequate funding and recognition of their role in mental health services was expressed in the following ways.

Reinstate tikanga in practice by having kuia, kaumātua and tōhunga as specialists in Māori health; to guide the tikanga required when engaging with Māori. Nurture and reinstate Māori methodology in practice (kaimahi Māori)

**Real relationships and respect for culture.** Providing service options, funding and opportunities for cultural support both within services and service provision, not just lip service.

**Caring for kaumātua.** Many Māori submissions spoke specifically about the importance of caring for kaumātua. There was acknowledgement that funding and commissioning models should facilitate this support of caring for elders. A few submissions noted that with changing times and impacts on the marae, this way of caring for kaumātua was proving more difficult. Pointedly, some submissions spoke of the lower life span of their communities.

**Skilled workforce.** A few submitters noted it was imperative that students interact with older people during their training, the number of mental health practitioners increased, and there was a skilled workforce supporting people in home and aged care facilities.

**A workforce aware of the rights of older people.** Several key submissions noted the need to change policy and legislation in regards to the rights of older people, particularly improving

the rights of those in residential aged care. These focused on legal safeguards, oversight and accountability, reducing barriers to enduring powers of attorney, enhancing workforce understanding and implement supported decision making framework as a default.

## 6.6 Rainbow communities

### 6.6.1 Overview

This population analysis summarises key themes from submissions from those that identified as being from a group commonly grouped together under the umbrella term ‘Rainbow’ or LGBTIQ+ (lesbian, gay, bisexual, trans, intersex, queer, asexual, and other diverse sexual orientations and gender identities).

One submission described the term ‘Rainbow’,

We are using rainbow as an umbrella term to describe people whose sexual orientation, gender identity, gender expression or sex characteristics differ from majority, binary norms. The rainbow population is large, and its rich diversity is not adequately reflected in terms that define people based on who they are not. However, for the purpose of this submission, the term rainbow describes people who either do not identify as heterosexual, have a gender identity that does not match the sex they were assigned at birth, do not fit typical gender norms, and/or were born with bodies that do not match common biological definitions of male or female. This includes a range of identities and experiences, and encompasses:

- Diverse sexual orientations (identities, behaviours or attractions) other than heterosexual (for example gay, lesbian, bisexual, takatāpui, queer, pansexual, asexual)
- Diverse gender identities or expressions (for example trans, transgender, transsexual, takatāpui, whakawahine, tangata ira tane, ia, fa’afafine, fa’afatama, genderqueer, fakaleiti, leiti, akava’ine, fakafifine, vakasalewa, FtM, MtF, non-binary)
- Diversity of sex characteristics (people born with intersex variations that mean, for example, that their including genitals, gonads or chromosome patterns do not fit typical binary notions of male or female bodies)

Some of these identity terms can encompass diversity of gender, sex characteristics and sexuality in a holistic way that describes more than one aspect of a person’s sense of self (for example takatāpui and queer).

(Rainbow sector grouping)

**Key themes** for Rainbow communities are as follows.

- Rainbow communities are overrepresented in negative mental health and suicide statistics.
- Societal discrimination, stigma, lack of awareness and lack of understanding are key contributors to the negative mental health and suicide statistics.
- There is a massive lack of appropriate services available for Rainbow communities, and discrimination, lack of awareness and lack of understanding by the mental health and addiction workforce are very common. These issues were raised generally across the broader Rainbow communities, with particular emphasis on intersex, transgender and gender-diverse individuals.

- More visibility of Rainbow communities and Rainbow issues at all levels and stages of the policy process and service design process is needed.
- More Rainbow-specific services need to be available, including gender-affirming healthcare.
- Our workforce needs upskilling to better understand Rainbow communities, the issues they may be facing, and how to provide best practice care.
- Much better information, statistics, and research on Rainbow communities is needed to better inform the support and services needed, as well as the effectiveness of what is in place.

## 6.6.2 What's working well?

### Awareness raising

Some submitters saw it as positive that support for Rainbow populations (especially transgender and gender diverse people) was 'on the table' as part of discussions about our mental health system.

We are talking about mental health more as a country—it's not a hush-hush topic anymore and talking helps to bring action. Resources are being created through various orgs for LGBT, Māori, and Pasifika—amazing resources for schools have started coming out as well. There is more literacy around mental health as a stepped thing rather than binary—reaching out more to more communities (youth)

The work to normalize gender and sexual identities is a start however its impact is shallow (educator)

### Access to specific services

Submitters talked about improved access for specific services that were specifically designed with Rainbow service users in mind. These were normally single services, or specific areas or the country where things were working well. In general, services that provided supportive services that were designed to normalise and validate the identity of Rainbow service users that were seeking support were seen as positive.

Participants described mental health professionals as supportive when they had knowledge of the differences between sex, sexuality, and gender, as well as the ways in which identity can impact on mental health (academic)

Rainbow peer support groups were also viewed positively, including online communities using social media, as well as the use of Rainbow liaison workforce when working with Rainbow service users.

The fact that many of the services that were viewed positively were free to access was seen as an important characteristic of the services.

## Training for service providers

A few submitters commented on existing programmes that have been set up to educate and train service providers about best practice approaches to providing support for Rainbow individuals, especially Rainbow children and youth.

One submitter noted that service providers are generally interested in learning “how to do their job more effectively when working with people of diverse sexes, genders, and sexualities” (NGO provider).

In summary, what we have seen working well is the upskilling of staff working in mental health and addiction services (NGO provider)

### 6.6.3 What isn't working well?

#### Discrimination

**Society wide.** Many submitters discussed discrimination against Rainbow individuals and the negative impacts of this discrimination.

Sexual orientation, gender identity or expression and intersex status are not the cause of the elevated risk of mental health problems, addiction and suicidality among the rainbow population. Rather, the increased risk is due to stigma, discrimination, prejudice and exclusion (Rainbow sector grouping)

Submitters spoke about discrimination by society in general and a lack of acceptance,

Our Rainbow communities continue to bear the brunt of hostile environments in relation to home, schools and education, health services, corrections and the justice system. This has resulted in negative health outcomes for many people. A report commissioned and published as part of the Ministry of Health's suicide prevention research fund found that gay, lesbian, bisexual, transgender and intersex people have higher lifetime risk for mental health problems including depression, anxiety, suicide and self-harm, substance misuse and eating disorders (NGO provider)

Some submitters specifically talked about the links between discrimination and suicide.

Transgender issues are not in people's awareness and the profile needs to be raised, as these people who suffer gender dysphoria, are over represented in the suicide statistics. More education, acceptance and resource needs to be put into this area. It looks like it's almost impossible to get subsidised surgery for gender reassignment (individual submitter)

**Discrimination – within health services.** Many submitters also commented on specific discrimination related to the actual interactions with the service providers, but also of discrimination when trying to access medical or mental health services in terms of barriers to access.

Part of this discrimination occurs within health services, with many people reporting that they face barriers to quality healthcare (NGO provider)

These barriers were related to a range of issues, including cost, lack of availability of services based on location, lack of suitability trained professionals (especially related to ability to

access hormone and other gender affirming healthcare), and lack of understanding of how to provide appropriate support.

The services we've dealt with also tended to lack a grounding in intersectional issues and trans-disciplinary care which made finding appropriate support additionally difficult. The psych team at the hospital seemed to want a simple single diagnosis when a combination of illnesses and adverse experiences contributed to the disorder being presented. Services we encountered failed to account for complexities in neurology, learning styles, sexuality and gender identity, or the potential for conflict with the religious or traditionalist character of some services (family member)

### **Lack of understanding of intersex individuals**

Many submitters commented on the lack of understanding about the issues that Rainbow may face and the need for appropriate support, but submitters especially noted the lack of understanding about the complex issues faced by the intersex community. Some submitters commented that this lack of understanding about the intersex community caused trauma for these individuals, which contributed to higher rates of suicide, drug and alcohol abuse, and risk-taking behaviour.

The complex issues faced by the intersex community poorly understood. There is little documentation, collection of information, at any level of the health system (NGO)

Intersex persons trauma and lack of support and understanding has led to higher rates of childhood sexual abuse, violence, development of related mental distress, instances of higher rates of drug and alcohol abuse, risk taking behavior etc meaning many intersex people reach adulthood at a significant disadvantage (NGO)

**Pathologising transgender and gender diversity.** Within the broader discussion about barriers to appropriate services for the Rainbow community, there were comments from some submitters that the way government and the healthcare system are set up means that being intersex or gender diverse requires psychological assessment and a mental health diagnosis.

Since we are encouraging people to not pathologise gender diversity (i.e., don't treat transgender people as if their gender identities are automatically a mental illness or pathology) we do not want to set up a system where transgender becomes just another mental illness. However, we do want transgender people to be able to access mental health services when they need to. Currently, we have a system that prioritises one-off mental health assessments for transgender people when they seek hormone therapy or surgical pathways, but does not provide any ongoing mental health support for people undergoing these processes (NGO provider)

Part of the pathway to receiving gender-affirming hormones or surgery in Aotearoa is to undertake a 'psychiatric assessment'. This generally means that we have to convince a cisgender (not trans) person that we are the gender we say we are. Cisgender people DO NOT know what it is like to be trans and often haven't heard of very basic concepts such as physical vs social dysphoria and nonbinary identity. This often results in trans people lying about their actual experience of gender in order to be seen as Actually Trans by their healthcare professionals. It can also traumatize or retraumatize a patient, especially when they are constantly being told by their psych that they "have to be 100% sure you're Actually what you say you are" in a world where their gender is constantly being questioned anyway (rainbow youth service user)

### **Lack of access to appropriate services**

**Lack of access to gender affirming medical services:** Several submitters discussed the lack of access to medical services, such as hormones and surgery, related to their gender and sex. These submitters noted that there was a lack of qualified mental health professionals that could undertake readiness for treatment assessments, which added to the barriers to accessing these services.

However because i'm transgender I am not eligible for ... this simple procedure I don't fit the box for funding, So essentially I have a physical problem affecting my mental health and the health system will do nothing to help (rainbow service user)

The current barriers for transgender people to access hormones and surgery, based locally on system blocks to endocrinology and lack of availability of psychological assessment capacity. We know that early access to hormones creates better health and well-being outcomes and less pressure on mental health services (DHB)

**Lack of access to appropriate support services:** Many submitters discussed the lack of access to appropriate support and services for Rainbow individuals.

As well as experiencing higher rates of mental health problems and addictions, rainbow people have mixed experiences of support in mental health and addictions services, as well as in other settings and institutions that influence their mental health, especially wider health services including primary care, social services, education and justice settings. These settings may offer unhelpful or unsafe service due to inadequate staff training, inappropriate policy settings, exclusionary environments or lack of availability of appropriate referral pathways (Rainbow sector grouping)

The lack of access included issues such as:

- lack of psychotherapy and counselling set up to provide appropriate support for Rainbow individuals

There is an appalling lack of care available for people who are transgender - lack of psychotherapy, medical and surgical options, as well as more options for general support services throughout life. There are a number of individuals who are adults now that are finally starting to feel safe enough to be their true selves but there is a lack of services for these people, who might have different needs compared to those who are younger (individual submitter)

- lack of gender-affirming medical and surgical options for, in particular, intersex, transgender and gender diverse individuals
- lack of explicitly Rainbow-friendly services

The structural barriers participants identified seem to be a product of an overstretched and underfunded public mental health system, rather than participants' sexualities or gender identities. However, it is likely that difficulties in accessing support are amplified among queer and trans New Zealanders due to the limited number of explicitly rainbow friendly services (academic)

- lack of specialist workforce in rural areas to provide the support required (referred to as a "postcode lottery" of whether services were available in a specific area)

Participants described access to gender affirming healthcare as a "postcode lottery" - the availability and accessibility of gender-affirming healthcare is often dependent on the region in which someone is trying to access care. Participants described the process as drawn out and frustrating, due to funding constraints within the public health system. They noted that there is a shortage of mental health professionals qualified to carry out readiness for treatment assessments, leading to lengthy waiting lists to access care (academic)

Some particular client groups do not have specific services available at all in many localities e.g. those with gender identity issues (rural professional organisation)

- staff discrimination against Rainbow individuals
- lack of professional understanding of Rainbow identities (such as staff not educated on good practice for working with Rainbow individuals, creating negative experiences for service users and deterring them from accessing services)

Asked by a professional if I am 'transgendering', and other uninformed language. My experience has not been understood or validated when talking with care workers so I tend to avoid them as the experience just adds to my stress and is ironically bad for my mental health (rainbow service user)

Mental health professionals should have much more intensive training around trans and queer people. I should not, as a patient/service user, have to educate my therapist on what it means to be trans. I shouldn't feel like I have to blame all my mental health problems on being trans and I shouldn't feel like I have to separate my mental health entirely from my being trans either (rainbow youth service user)

- lack of services to support families and whānau, especially support for families and whānau of intersex individuals

New Zealand has no system for supporting families. This has led to systemic issues that include, attachment related issues with mothers, stress and trauma within the families that compounds as the intersex person grows up (NGO provider)

- lack of integration between mental health services and other support Rainbow individuals may need

As a member of the rainbow community it feels like specific help for the common problems that queer people face and which are often concurrent with mental health issues is lacking (rainbow service user)

- lack of flexibility in how hormones and other medical treatment can be accessed.

For trans services you have to go through CAMHS [Child and Adolescent Mental Health Services] to be referred, but you can only get into CAMHS when in crisis, e.g. a pre-teen wanting puberty blockers cant access them unless they are already in mental health services or are in crisis. So parents are dealing with suicide attempts and eating disorders (rainbow community)

### **Lack of funding, information and data**

**Lack of funding for Rainbow providers and Rainbow support groups.** Many submitters noted that there was a lack of funding for the types of services and support that would be effective for Rainbow people. For example, it was noted there was a lack of clinical pathways for gender diverse children and youth to access the support they require, and that the availability of services was variable around the country. Submitters also noted there was a lack of funding for gender-affirming healthcare and gender-affirming surgery.

Some submitters also reported a lack of funding available for Rainbow community organisations, such as Rainbow peer support and Rainbow consumer advocacy organisations.

Rainbow-led mental health and addictions support services are limited and poorly resourced, due to an almost-complete absence of recognition in national or local health policies of rainbow mental health needs, lack of sustainable funding sources to enable rainbow-specific service provision or collaboration with 'mainstream' organisations, and consequent heavy reliance on volunteers and temporary employment arrangements (Rainbow sector grouping)

**Lack of information and data.** Many submitters commented on the lack of information available about Rainbow communities and the lack of information about mental health, addiction and suicides rates within these communities.

If we are not visible in policy through statistics, then we are not visible. But we are not invisible to each other (rainbow community)

There is a lack of national data regarding the size of transgender populations, but we do have some indications. For example, a nation-wide survey suggests that as many as 4% of young people in NZ identify as transgender or are questioning/unsure of their gender. This survey also discovered that one in five transgender youth had attempted suicide in the last year and nearly 40% of transgender youth were unable to access healthcare when they needed it. That includes mental health support as well as primary care, and also transition related health services (NGO provider)

Some submitters noted that there was less information available about some parts of the Rainbow community,

While a significant amount of research exists about rainbow populations, mental health, addictions and suicide, more is needed. In particular, evidence is lacking about older rainbow people, intersex, trans and gender-diverse people, Takatāpui and Pacific rainbow populations, the experiences of people from recent immigrant cultures, the impacts of religious and cultural values on rainbow mental health, and the impact of marginalisation within rainbow community spaces for rainbow Māori, Pacific, disabled and other minority groups (Rainbow sector grouping)

#### 6.6.4 What could be better?

##### Greater awareness, understanding and tolerance

The most common theme from submissions was to tackle the issues around stigma, intolerance, and lack of understanding of Rainbow communities.

In order to change the public perception about LGBT individuals it is vital to their mental wellbeing that society sees the need to change the way it thinks. This can only be done through an honest retraction by the people who created the problem in the first place - only then will the public's view change - the violence and discrimination cease - the suicides and the murders stop (Rainbow advocate)

**Greater visibility and inclusion of Rainbow communities at all levels.** Many submitters commented on the need for Rainbow communities to be more visible at all levels of policy setting as well as in system and service design.

Change will require well-resourced community leadership, recognition and inclusion of rainbow issues at all levels of policy, specific support responses to address rainbow-specific drivers of distress, training and ongoing professional development for providers of mental health and addictions support, and an ongoing commitment to research and learning (Rainbow sector grouping)

There was a call from some submitters for the broader government and policy settings to be more inclusive of Rainbow people.

For transgender people, Government and local government should have and implement gender inclusive policies, especially in gendered spaces. The human rights act should be changed to make discrimination on grounds of gender identity prohibited. The [Births, Deaths, Marriages, and Relationships Registration Act 1995] should be changed to allow transgender people to change birth certificate gender markers by statutory declaration. They should be granted health care on the basis of self-consent in a primary care setting, not through gatekeepers. This is not hard. Finally, gender reassignment surgery should be careered for in the NZ healthcare system (service user)

This was often coupled with calls for more co-design of services to make them more appropriate for Rainbow service users.

### **Improve services and support**

**Need for more services and support designed for Rainbow communities.** Many submitters called for more services and support to be available for the Rainbow community. This was especially strong in relation to providing services for Rainbow children and youth, as submitters noted that these populations had negative statistics around mental health and suicide.

Submitters noted that transgender and intersex children and youth often needed access to different types of services that often required a more integrated understanding of their situation than just a one-off diagnosis. These submitters made a call for more gender-affirming primary mental health services, more funding for services to support the Rainbow community, including both medical and basic gender affirming healthcare, and a clear pathway to access this healthcare.

There was a call from submitters for DHBs and the Government to recognise the need for the types of services sought by Rainbow communities.

we also note that increasing evidence demonstrates that supportive, gender affirming care for transgender people significantly improves mental health and wellbeing outcomes. It is best practice that gender affirming healthcare is provided by well resourced multidisciplinary teams that include mental health professionals (DHB)

**Need for inclusive and understanding services.** Many submitters commented on the need for mental health, other health services, and other social services (especially the Ministry of Social Development (Work and Income) and ACC) to be more inclusive and understanding of the Rainbow community.

For most of these submitters, improving the professional and cultural competency of staff so they were better prepared to support Rainbow individuals was the most important aspect of this shift. Recommendations related to improving staff competency of service providers included the need for:

- more Rainbow-specific services to meet the needs of these communities
- more Rainbow-specific support, peer support, and consumer advocacy organisations dedicated to supporting Rainbow communities

- ongoing cultural competency training and professional development for all providers across public services and DHBs

Develop inclusive services with confident, competent staff. When people reach for help, services need to help, not add to trauma and discrimination and isolation. Training is ad hoc and limited. Most training doctors get no education on these issues (rainbow community)

We have particularly noticed a need for education about gender diversity. With more and more people of all ages seeking health services as part of their gender transition, or wanting health services that are inclusive and understanding of the health needs of transgender people, it is crucial that health providers receive effective, practical, and evidence-based education about transgender and MVPFAFF [*Mahu, Vakaselewalewa, Palopa, Fa'afafine, Akava'ine, Fakleiti, Fakafifine*] populations (NGO provider)

- recruitment and employment of staff with lived experience of distress and involvement in Rainbow organisations
- more co-designed services so services are set up to be inclusive and respectful of Rainbow communities

Services need to be co-designed from the outset. If the system is respectful of gender and orientation, it would be fine for everyone else too (rainbow community)

- culturally appropriate services

The goal is to offer mental health and addiction services that meet the needs of LGBTTQIA (lesbian, gay, bisexual, transgender, takatapui, queer, intersex, asexual) and MVPFAFF (*mahu, vakasalewalewa, palopa, fakaleiti, aka'vaine, fa'afafine, fiafifine*) people and their whānau (NGO provider)

- a shift away from using gendered pronouns.

There are simple measures that all healthcare providers can undertake when working in any area of health with transgender young people. For example, using identified name and preferred pronouns both in consultations and when writing medical letters. Not using these can lead to a simple healthcare contact triggering gender dysphoria and potentially resulting in a significant negative impact on mental health, including suicidal ideation (DHB)

**Need for more integrated support for the families and whānau of intersex and transgender children and youth.** Some submitters also noted that there was a need for services to support the family and whānau of children that are intersex or transgender. This support was to help the family and whānau provide more support to the child, but also to provide support to the family and whānau themselves.

**Implement a Rainbow liaison workforce.** Many submitters called for the recruitment and resourcing of a dedicated Rainbow liaison or Rainbow co-ordinator workforce. This part of the workforce was seen by submitters to have potential to provide more visibility within services for Rainbow issues, provide a more welcoming and understanding environment for Rainbow service users, and provide leadership around community Rainbow support groups.

Resourcing a network or a group of Rainbow Co-ordinators who can liaise between community groups and the relevant health services is one way to invest in the health of LGBTTTQIA/MVPFAFF people and bring some of the valuable community knowledge into the institutions that are meant to serve us all (NGO provider)

It is clear to us that DHBs need to partner and collaborate more with NGOs who have Rainbow knowledge so that community leadership can form the basis of improving the mental health system. Furthermore, we suggest that the Rainbow population's higher lifetime risk for mental health problems (including depression, anxiety, suicide and self-harm, substance misuse and eating disorders) requires a community development response across the sectors of health, education, justice, and social services (NGO provider)

**Shift in how Rainbow people are understood by the health system.** Many submissions commented on the need for a paradigm shift in terms of how mental health and addiction services approach Rainbow people, from the current approach of pathologising Rainbow people to a system that ensures cultural competence and understanding Rainbow people in a holistic context. Some submissions commented specifically on how decisions are made by and about intersex, trans and gender diverse people, recommending New Zealand follow international best practice towards an informed consent model of care.

### **Need for quicker access to hormone therapy and surgery**

Some submitters commented the need for faster access to gender affirming hormone therapy and surgery. It was noted by these submitters that the physical conditions were affecting their mental health, and in other circumstances there would be funding and support available to make the required treatment accessible.

## 6.7 Migrant populations

### 6.7.1 Overview

Culturally and linguistically diverse groups include those of refugee or migrant backgrounds who are Asian, Middle Eastern, Latin American or African. The Inquiry process was careful to distinguish the needs of migrant groups, and refugee groups.

Although some submissions spoke of migrants and refugees sharing the same sets of needs, others were careful to separate them and distinguish differences. Relatively fewer submissions both from service users, family or service providers focused on migrant population or the refugee population specifically, although several meetings across New Zealand met with either migrant or refugee specific mental health and addiction services.

Identifying submitters as having a migrant or refugee background was not possible unless they specifically self-identified or completed demographic information. As such for some submissions, the context of their background was not as important for them as was the experience with mental health and addiction services. Others were careful to distinguish how their migrant or refugee background shaped their experience.

The migrant and ethnic minority groups referred to in submissions mainly refer to Asian communities, with a few mentions of African and Latin American groups.

One service user (self-identified immigrant) – talked of her own mental health journey but not necessarily relating to be a migrant.

**Key themes** for migrant populations are as follows.

- Language barriers are an important issue for people engaging with services.
- Societal issues such as racism, xenophobia and ignorance negatively impact on people accessing and utilising health services.
- Loneliness and separation from culture impact negatively on mental health.
- The mental health and addiction workforce need to be more ethnically diversity with improved cross-cultural understanding.
- Cultural differences and attitudes about mental health and addiction affect when and if people access services.

### 6.7.2 What's working well?

#### Interventions, treatment and support for migrants

Some submissions noted interventions, treatment and support that have worked well for members of these populations, for example:

- **ethnically diverse mental health and addiction services** with linguistically diverse workforces

- **ethnic-specific peer support groups** that encourage people to come together, such as women's groups, and may discuss mental health (although not directly marketed as being for that purpose)
- **gambling-focused services** that include private practice teams for people whose visa status precludes them from accessing funded health care in New Zealand
- **cross-cultural training** for the mental health and addiction workforce
- **organisations supporting women and diversity** across New Zealand.

### 6.7.3 What isn't working well?

#### Specific social determinants of health for migrant populations

In addition to the common social determinants of health such as access to adequate income, housing, and transport, some submitters or service providers talked about the issues and experiences outlined below.

- **Immigration/visa problems** impacting financial privilege: some migrants are not immediately eligible for funded health care and must pay privately for services.
- **Loneliness and separation from culture:** one submitter noted that many Asian migrants may use gambling as a form of release from stress and to escape failures and other problems in their lives. International students are a particular high-risk group – experiencing loneliness from families and boredom as a trigger to them to take up gambling.
- **Racism, xenophobia, and ignorance** from New Zealanders about nationality, culture, and religion.
- **Concern with migrants who are unable to work,** access suitable employment, or whose partner does not have a working visa, and subsequent isolation.

Women with often highly skilled backgrounds but can't transfer skills to work without English—feel worthless when they can't get self-esteem from jobs (NGO)
- **International students at universities** face specific challenges including cost of tuition, pressure from family to perform, inability to access on campus health services.

#### Access to services offered in first language of migrant populations.

**Language barriers with clinicians and other staff** including lack of translating and interpreting services, and the difficulty with conversations about mental health and addiction (for both service user and interpreter). A few submissions focused on this as a key issue for migrant populations.

Chinese family member says the Chinese interpreters are disadvantaged it is not successful as they do not know or understand mental health systems or illnesses. This is incredibly difficult for all parties involved (individual submitter)

## Cultural differences towards addiction, mental health, and suicide

A few submitters noted it was not language barriers but cultural barriers that created more difficulty accessing counselling services.

Cultural stigma around addiction, mental health challenges, and suicide was noted as leading to late presentation and fear of visa repercussions (therefore, hiding suicide attempts).

As a Chinese GP ... most of the patients I see speak English as a second or third language or minimal English. These patients are of predominantly Chinese heritage and their knowledge, conception, and understanding of mental health is often very different to that of the average NZ European. Like many other non-Western cultures, there is a strong cultural stigma attached to mental health issues which means it is often underreported or ignored for fear of losing face. This provides some challenges in the primary care setting in term of both making a diagnosis and providing help to these patients (Asian health professional)

Regarding the values of the current system, one submitter noted that,

The medical model and western values are a huge barrier. I'm Indian and love "Te Whare Tapa Wha". It makes sense to me, and probably all other folks too. Why is it not a default model? (youth service user)

## Navigating the system to find service and treatment options

Finding the culturally suitable workforce and treatment options and knowing how to access the system was raised by submitters.

GPs are go-to person for Indian populations; there has to be more funding and understanding to link specialist with those GP clinics, otherwise we will carry on with the same thing. Language barrier is huge, often families will depend on one person and on whether they can make appointments (ethnic sector grouping)

### 6.7.4 What could be better?

In addition, a few submissions both from meetings and written submissions noted ideas of how services could be improved.

#### Access to multilingual and culturally competent workforce

**Dedicated, multilingual workforce, particularly in smaller towns and regional areas.** This would include dedicated funding to attract workforce. Similarly, with interpreters. This pipeline should be encouraged with role models from school age onwards including scholarships.

**Better utilisation of the existing Asian work force,** including improved co-ordination and flexibility in utilising the cultural expertise of existing staff.

Chinese people are ashamed re: mental health but increasingly people are self-referring re: depression, anxiety, issues with children. They would like to change and want to get help: they want to find someone who can speak their language (ethnic sector grouping)

Appropriate education from rainbow migrant communities including non-Western approaches to gender and sexuality for all health practitioners. For rainbow migrant population, a few submissions noted approaches to care must consider racism, isolation, immigration issues, and being a minority.

Show particular regard to each culture when handling cases of suicide. In particular, the police and coroner.

### **Access to culturally appropriate services**

**Parenting programmes** and other culturally appropriate services need to be developed or expanded, to provide community-level support as a preventative safety net for new immigrants.

**Increase one stop shop community hubs**—no one presents with just one issue.

Need Whānau Ora approach for Asian communities (ethnic sector grouping)

**Review, modify and extend existing Asian mental health service delivery model** to encourage primary, secondary and tertiary use. Many Asian service users noted they may access services through cultural or community groups, not a GP.

I think more anti-stigma campaigns in ethnic communities would be good. While the suicide rate isn't as high for the community, I feel we present our issues in different ways - family violence in particular. We are also wonderful at hiding stuff (alcoholism, sexual abuse, gambling) (youth service user)

**Focus on Asian people aged 65 and over.** This population is very isolated due to language barriers and transport issues. This population often feels like a 'burden' and that there are fewer people who can share that burden (that is, separation from friends and extended family members and so on).

### **Collect migrant population data**

Increase migrant population data for mental health and addiction to inform funding and better service design.

## 6.8 Deaf community

### 6.8.1 Overview

For the purposes of this Inquiry, Deaf refers to those with partial or complete hearing loss, which may occur at any point of the life course. Many Deaf people in New Zealand speak New Zealand Sign Language (NZSL) as a first or additional language; some Deaf New Zealanders also sign in te reo Māori. Deaf New Zealanders may work with New Zealand Sign language interpreters to communicate with those who do not speak or understand New Zealand Sign language in health and mental health-related contexts such as doctor's visits, counselling sessions, and hospitals.

Many Deaf submitters to the Inquiry identified as members of a distinct Deaf culture different to hearing culture; Deaf cultural identities may also co-exist with other cultural identities such as New Zealander, Māori, Tongan, Rainbow (LGBTIQ+), and so on. Most of the Deaf submitters to the Inquiry did not identify as disabled unless they had a co-occurring disability. As Deaf was most commonly identified as a culture and not a disability the coding distinguished between Deaf and disabled people on a population level. Submissions from Deaf people were self-identified as such. Most submissions pertaining to Deaf people were from Deaf people themselves, those who worked as NZSL interpreters, or who had Deaf family members.

**Key themes** for the Deaf people's population are as follows.

- Access to services, specifically around availability and use of NZSL interpretation in mental health settings. This is the most significant theme for this community. Access to mental health services is incomplete without interpretation.
- Lack of understanding of Deaf culture in mental health and addiction services. This relates to the access to language but also refers to the ability of the hearing workforce to engage with Deaf service users in meaningful, effective and equitable ways.
- The relationship between mental health and access to and participation in Deaf culture and language, particularly around the connections between mental wellbeing and isolation.

### 6.8.2 What's working well?

#### Access to New Zealand Sign Language interpreters in mental health settings

Submitters identified instances when access to interpretation from a trained NZSL interpreter had enabled a Deaf person to use mental health services.

One DHB has set up a video-conferencing so that I can work directly with a Deaf mental health client in another city. This DHB also funds me to travel and work there face to face with him 3x a year. This enables me to talk with the client's family, the mental health nurse and psychiatrist as well. They really appreciate my work with this client as there are no interpreters where he lives and they are limited with how they communicate with them. With the client's permission, I can pass on information to his key worker and mental health team. The client looks forward to the video-conferencing times (mental health professional)

Some mental health providers are actively looking at ways to improve access to mental health services for Deaf people:

Currently [identified DHBs] have established a group called NZ Sign Language (NZSL) in Health task force. The group is trying to find a way how to develop appropriate resource at the [identified DHBs'] Hospitals by providing a NZSL video and website. We believe it is important to provide information that are accessible for the Deaf community. We are currently working and creating a video in NZSL. This would be the most useful and beneficial resource for the Deaf community... There are many Deaf Mental Health (DMH) groups throughout New Zealand... [who] have worked for many years trying to find a way how to support the Deaf people with Mental Health (Deaf advocacy group)

### **Understanding of Deaf culture**

Some submitters referred not only to the access to services that NZSL interpretation allowed, but also to the ability to discuss mental health issues in a culturally appropriate manner:

There are a few Deaf counsellors in NZ that can sign. We don't need to have interpreters with them for counselling. Deaf counsellors already know about Deaf culture so we feel comfortable explaining things with them. They can meet our level of language - adapt to our signing style easily (Deaf older person)

I went to a hearing counsellor with an interpreter years ago. That interpreter already knew about Deaf culture but first of all I had to explain my Deaf identity and culture to the counsellor so that she understood my background and situation from a Deaf perspective. I was able to express myself well by using the interpreter. The counsellor was really interested and asked me lots of questions before she began counselling me (Deaf service user)

### **6.8.3 What isn't working well?**

#### **Barriers to access around lack of New Zealand Sign Language interpretation and lack of understanding of Deaf culture**

While submitters did identify some barriers to access to services that are common across populations, such as lack of income due to underemployment, by far the most common barrier for Deaf communities was around access to NZSL interpretation and a lack of understanding of Deaf culture within mental health and addiction services. Submitters noted

that access to NZSL interpretation is necessary at multiple levels and that lack thereof might negatively impact adequate education about mental health issues, understanding of a mental health diagnosis, choice of treatment options, and the ability to benefit from talk therapy.

Deaf get referred to hearing therapists with no NZSL skills and no deaf awareness – some of them may communicate by pen and paper or even lip reading neither efficient methods, others have interpreter or an extra cost, impacting on the dynamics of client – therapist relationship (Deaf mental health professional)

Interpreters are highly valued and the best can ensure that Deaf get good treatment and therapy and have good understanding of their illness and their options. Interpreters are standing in for the almost complete absence of signing mental health professionals, but even informants who has been in counselling for a number of years with strong interpreter support, believe that this is not sufficient (Deaf mental health professionals)

Communication problems with Deaf clients lead to them being over-sedated or medicated as a convenient way for hearing professionals to deal with them. Discourses of oppression and of "hearing people know best" and ignorance of the system and of health and disability rights prevent Deaf people from speaking out about this (mental health professional)

Deaf submitters also stressed that low or no understanding of Deaf culture is a significant barrier to accessing mental health and addiction services. This was often framed as a workforce issue as well as a service model issue—hearing mental health and addiction workforce were seen as unaware and uneducated in Deaf culture. On the other hand, NZSL interpreters were seen by some submitters as necessary but not sufficient to increase access to mental health services as the interpreters were not trained in mental health. Having to explain Deaf culture to a hearing mental health professional was seen as an access barrier in and of itself.

DHBs do not fund Deaf professionals to work with Deaf clients. While some Deaf clients are happy to work with hearing professionals using NZSL interpreters, many are not and would prefer to have a professional who can sign and understand Deaf culture so that they can start on their intervention or therapy straight away without having to explain Deaf culture. Choice is taken away from the clients when only one service (NZSL interpreters) is funded (health professional)

## **Isolation and discrimination**

Social isolation of Deaf people who are not connected with Deaf communities and Deaf culture was seen as connected to mental distress for Deaf people, as was general discrimination against Deaf people. This discrimination was often mentioned in the context of mental health and addiction service providers. This isolation and discrimination intersected with general lack of access to mental health services, for example in prison and in residential living situations.

Deaf people can struggle within the hearing culture. For those who do not have access to their first language and also cannot access services through their first language (such as New Zealand Sign Language), there is an impact on identity which can lead to an impact on wellbeing (government agency)

Contributor says police are terrible and gets angry at thought of police. When she's gone in for help with mental health she has been mocked for not being able to understand and for being Deaf—people won't write things down and people think she's being stupid. When she goes in for personal stuff it's very difficult (Deaf service user)

Deaf criminals are not offered the same ability to [rehabilitate] in prisons due to lack of NZSL interpreter provision. Therefore our Deaf criminals are released back into the community... more damaged in terms of the mental Health and often unable to recover, often leading to more reoffending or/and severe addiction. If restorative justice is to be an option Deaf criminals need significant support in all areas of social services with understanding of Deaf culture and respect and provision of interpreters (Deaf service user)

#### **6.8.4 What could be better?**

##### **Create a dedicated Deaf mental health service**

Several submitters called for a dedicated Deaf mental health service and suggested using Kaupapa Māori mental health and addiction services as a model for culturally responsive services. Submitters mentioned the importance of Deaf cultural identity to a Deaf mental health service, particularly around Deaf leadership in staff and management. This recommendation for a specialist Deaf mental health service was often mentioned in the context of the closure of such a service in their region, as well as recent shifts in service providers for the mental health needs of Deaf people.

The importance of specialised Deaf Mental Health service was expressed as important by all consumers. The profound reason why this was the case was because the consumers felt more comfortable expressing themselves through NZSL which gave them better access to help. All consumers reported they felt safer using this specialised service compared to a general mental health service because there was a good level of understanding, better collaboration between [community support worker] and service providers and ensuring the Deaf consumer was fully participating in the process. Taking into consideration the limited literacy skills across the Deaf community, the [community support worker] would enable a better individualised approach to understanding the information at hand (Deaf advocacy group)

We would also like to see a nationwide Deaf Mental Health entity established in a suitable location somewhere in New Zealand; one that will be able to meet the needs of Deaf people across the country. This place would also ensure the safety of not only Deaf patients but the general community. There are many available for hearing people but those places are not always necessarily suitable for Deaf people (Deaf health professionals)

In weighing up the costs and benefits of a specialist national Deaf Mental Health Service, the outcomes and benefits for Deaf people receiving culturally and linguistically appropriate services, receiving the correct diagnosis and thus the most appropriate medication and/or treatment, must be considered in the context of the social and mental wellbeing of Deaf people, their families and community (Deaf NGO consumer group)

Since the closure of the specialised Deaf Mental Health service in [city], those interviewed reported feeling left in the dark. They described how the lack of information has left them waiting longer for something that may not come, which caused them to feel significantly disadvantaged (Deaf advocacy group)

### **Increase access to interpretation services and to Deaf mental health professionals**

Many submitters called for increased access to NZSL interpretation for Deaf users of mental health and addiction services. Other submitters identified a gold standard of mental health professionals who were fluent in NZSL and familiar with Deaf culture as preferable to the use of interpretation in mental health contexts.

Evident in every story here, is that Deaf people of all ages, ethnic backgrounds, language preferences and levels of deafness, need culturally driven clinical and community services with a pool of expertise in Deaf Mental Health who have an in-depth understanding of sociolinguistic complexities that Deaf people have. They require a safe space where they can fully express themselves in multiple languages and communication support facilitated so that everyone can access to each other with ease. They should have the opportunity to explore their identity, how that has been formed and shaped from external factors, to reflect on their life experiences and to become conscious of their own attitudes, as part of their Deafhood journey (Deaf mental health professionals)

We need a website that lists all the mental health specialists in various sectors who are fluent in NZSL and has Deaf awareness training to deliver their service in a culturally appropriate manner. Not everyone is comfortable having an Interpreter to translate for them and something can be lost in the translation, certain nuances which isn't a reflection of any NZSL Interpreter's skill, but rather on having a 2nd party to communicate with us (Deaf service user)

### **Upskill the hearing mental health and addiction workforce**

Some submitters called for training and upskilling in Deaf culture and working with Deaf people and NZSL interpreters across the hearing mental health and addiction workforce. This was often framed in terms of cultural competencies.

Create Deaf awareness training re: language and culture for all nurses counsellors, doctors at DHBs (contributor from Deaf community)

Require hearing professionals to work with Deaf professionals to improve support to a fundamental level for Deaf service (contributor from Deaf community)

GPs need deaf awareness, compulsory in training to recognise the linguistic needs of deaf patients then with an interpreter there exist communication barriers. GPs need training to be culturally sensitive, not to misunderstand the patient (Deaf mental health professional)

MH Practitioners – careful not to misdiagnose deaf patients with facial expressions, body language. Part of NZSL, not in an angry state. Need deaf expertise in team (Deaf mental health professional)

Several submitters extended their workforce upskilling recommendations to NZSL interpreters as well, regarding their understanding of mental health issues.

Deaf people don't want interpreters in the room with a counsellor—more people add to stress and anxiety and mental illness. Interpreters need more training re: mental health and mental health staff need more training to work with interpreters. Clinicians are also not trained in knowing how to deal with someone who's deaf – eye contact is important. “Providing an interpreter is a bandaid.” (Deaf mental health professional)

## 6.9 People with refugee backgrounds

### 6.9.1 Overview

People with refugee background are distinct from other migrant or ethnic minority populations (even if they come from the same country of origin or share ethnicity or religion) because of the nature of their arrival in New Zealand. People with refugee backgrounds have different immigration status, and access to funded healthcare and social services.

The refugee voice is rarely heard. It is essential that government agencies have a clear understanding of the differences between a refugee and a migrant and why different approaches need to be applied (NGO providers)

**Key themes** for people with a refugee background are as follows.

- An important issue for refugees is addressing the impact of trauma on their lives.
- New Zealand is ill-equipped to address the impact of trauma with only two services, both Wellington based, available.
- Language barriers are an important issue for people engaging with services.
- Navigating how to access and engage with mental health and addiction services is very difficult.
- Cultural beliefs and attitudes about mental health and addiction affect when and if people access services.

### 6.9.2 What's working well?

#### Community services designed to meet needs of refugees

Very few submission spoke about what was working well for those with refugee backgrounds. Majority of these submitters worked in community services specifically for refugee populations, and spoke of these services as working well for refugee service users.

### 6.9.3 What isn't working well?

#### Specific social determinants of health for migrant populations

In addition to the common social determinants of health such as access to adequate income, housing, and transport, members of these populations also experience the following issues outlined below.

**Trauma is a significant factor.** Many submissions focusing on refugees noted the role of trauma (including post-traumatic stress disorder) being a significant factor in the lives of many people with refugee backgrounds.

Some of our clients have suffered from torture and trauma to a degree that seriously affects their ability to settle, to learn a new language, and to participate in and create a new life for themselves and their families .. These disturbances cause each one of our clients huge stress, and hinder their ability to integrate, learn a new language, and settle in NZ (NGO provider)

Availability of specialist services for trauma therapy and refugees is extremely limited in New Zealand – with only two services available in Wellington.

**Difficulties around resettlement: separation from culture; being far away from family and friends; assimilation into New Zealand culture around laws, and cost of living.** There is a concern around self-harm and interpersonal violence in former refugee youth population.

Came to New Zealand as [child]... with parents and four younger siblings. When arrived stayed here... for six weeks. Bullied in community because I was different, couldn't speak English properly. I wanted to be like other children. [school year] was really tough but wasn't ready for high school where I still got discriminated against. Made me feel like I didn't want to be here – wanted to be in [birth country] where everyone accepts me (youth with lived experience)

### Access to services

The key issues around access to services for members of refugee populations include:

**Language barriers** with clinicians and other staff at services: complexities of multiple languages and dialects, and referrals to culturally competent specialist staff. This is also true for children. The biggest barrier to support children appropriately is accessibility to services and interpreters.

Cultural expectations around mental health challenges, addiction, and suicide.

Mental health is a completely foreign concept to them and to attend service is shameful and can be ostracized and feel like they crazy, western model is not appropriate, talking to stranger about family/personal issues so not common (refugee supporter)

**Complexity and processes of mental health challenges and accessing the system.** A few submissions noted that navigating the health systems was difficult, yet lack of data made it hard to ascertain how difficult the issues were. For example, are people unaware of the services, or simply not seeking them out.

**Trauma that has occurred in the home country cannot be supported in New Zealand.** For example, one submitter told the story of a child raped in their home country but could not get support for that trauma here as it happened “outside New Zealand” (NGO).

#### 6.9.4 What could be better?

Recommendations made about improving treatment and support for refugees:

- provide specialist refugee mental health services

We need specialist mental health services for people from refugee background. Because by virtue of refugee journey most have likely have experienced trauma, separate to migrants as result of experience (refugee supporter)

- better connect primary care and the community
- encourage GPs to connect back to community leaders.

## 6.10 Veteran population

### 6.10.1 Overview

For the purposes of this Inquiry, the term ‘veteran’ refers to those who have attested service in the New Zealand armed services. Relatively few submissions to the Inquiry referred to the veteran population; most of those were from organisations that work with and serve veterans.

**Key themes** for the veteran population are as follows.

- Veterans have a high risk of service-related trauma in addition to other mental health conditions.
- There is a low understanding in the health sector of veteran-specific issues in mental health and addiction.

### 6.10.2 What’s working well?

#### Support from veteran service organisations

The support from organisations that work specifically with veterans was seen to be useful for veterans, both around mental health concerns and other problems.

I am a veteran and [veterans organisation] has been excellent in supporting me with my Major Depressive Disorder. They have ensured that I can access the necessary professionals without financial worry. Unfortunately I had to leave my job and [veterans organisation] have been compensating me (service user)

### 6.10.3 What isn’t working well?

#### Lack of understanding and knowledge around the veteran experience

Veterans were described by a few submitters as being at high risk of service-related trauma, addiction and suicide, and transition to civilian life was cited as a particularly dangerous transition. Submitters discussed the low understanding of these risks and concerns from health professionals, and which was seen as contributing to less effective treatment for mental health issues as their root causes may not be properly identified.

This issue was seen to be compounded by a lack of data around veterans in the health system as veteran status is not collected by the DHBs.

Because of the general lack of knowledge and understanding of service life and its environment traditional mental disorder assessment methods may not identify the root cause of a patient’s problem as being service related. Estimating the number of New Zealand Veterans with a mental disorder is therefore extremely difficult (professional organisation)

Veterans are a product of their environments, and these are as varied and diverse as those individuals who become veterans. Our experience has proven most providers have little knowledge, or understanding of what it means to a veteran (NGO Provider)

## **Stigma**

A few submitters mentioned that stigma around mental health as particularly damaging to veterans. The mentioned the negative effects of stigma on future employment for veterans transitioning into civilian life. Some submitters also mentioned stigma in the context of veterans' own propensity to minimise their own concerns about their mental health and to delay seeking help.

Veterans are often reluctant to acknowledge what could be perceived as weaknesses or problems, so they may not seek early intervention help or treatment. [Veteran organisation] members believe that instances of mental health related issues in veterans are probably significantly higher than those which come to attention. Because of the reluctance of veterans to seek help, their problems sometimes only come to light a long way down the track; and sometimes, sadly, when it is too late to help them, as they have taken their own lives (Veteran sector grouping)

### **6.10.4 What could be better?**

#### **Improve treatment options for veterans**

Many submitters suggested improvements in mental health and addiction treatment for veterans. These included more holistic wrap-around services, early identification and intervention, and preventive programmes (including suicide-specific prevention) aimed specifically at veterans. A few submissions discussed the creation of veteran-specific pathways of care or 'exit packages' after service that would address the known mental health and addiction risks post-service.

Some submissions connected back to the need for better understanding of the veteran experience and improved identification of veterans in the post-military healthcare system.

Above all, [veteran organisation] members advocate a greater understanding amongst New Zealanders in general, and health practitioners in particular, about the impact that service could have on the lives of our veterans and, by extension, their families. We suggest that training in this area should be part of the professional development of general practitioners and others (Veteran sector grouping)

Increase the capacity of our mental health system to better understand and manage Veteran health, including government funded complimentary options that appeal to the military mind-set and culture (professional organisation)



# APPENDICES

## Appendix A: Summary version of the Terms of Reference

The Terms of Reference, issued by the Government, set out the purpose of the Inquiry, which includes:

- hearing the voices of the community, people with lived experience of mental health and addiction challenges, people affected by suicide, and people involved in preventing and responding to mental health and addiction challenges, on New Zealand's current approach to mental health and addiction, and what needs to change;
- reporting on how New Zealand is preventing mental health and addiction challenges and responding to the needs of people with those challenges; and
- recommending specific changes to improve New Zealand's approach to mental health, with a particular focus on equity of access, community confidence in the mental health system and better outcomes, particularly for Māori and other groups with disproportionately poorer outcomes.

Areas the inquiry will focus on include:

- mental health challenges faced by people across the full spectrum from mental distress to enduring psychiatric illness;
- mental health and addiction needs from the perspective of both:
  - preventing mental health and addiction challenges and promoting mental well-being; and
  - identifying and responding to people with mental health and addiction challenges;
- prevention of suicide, as well as support for those close to someone who has taken their own life.

The Inquiry covers the breadth of current New Zealand policies, services, programmes, and interventions (referred to as 'activities' below) in the mental health and addiction area, including:

- activities directly related to mental health and addiction undertaken within the broader health and disability sector (in community, primary and secondary care), as well as other sectors, including: education, social welfare, housing, justice and corrections, disability support, accident compensation and wider workplace relations and safety systems, Māori development, and emergency response systems;
- opportunities to build on the efforts of whānau, communities, employers, people working in mental health and other sectors or organisations to promote mental health;
- activities for key groups: Māori, Pacific peoples, youth, people with disabilities, the Rainbow (LGBTIQ+) communities, the prison population, migrants and refugees, the isolated (including older people), veterans, and rural populations;

- activities in support of families and whānau affected by mental health and addiction (including suicide) of loved ones;
- activities undertaken by, or funded by, government agencies and those undertaken by non—government agencies;
- activities addressing risk factors, which include (but are not limited to):
  - ease of access and cultural attitudes to alcohol (and other drugs);
  - continued dislocation of Māori from their whānau, communities and iwi;
  - increasing dislocation within our ethnic migrant and refugee communities; and
  - a range of social determinants such as poverty; inequality; inequity; lack of affordable housing; low levels of educational achievement; low—paid work; exposure to abuse, neglect, family violence or other trauma; social isolation (particularly in the elderly and rural populations); deprivation persisting across generations; access to welfare, disability support and accident compensation; engagement in the criminal justice system; and discrimination.

Recommendations about what needs to change to refresh and improve mental health and addiction outcomes in Aotearoa

The Terms of Reference require the Inquiry Panel to provide recommendations on some important areas that will determine how New Zealand approaches mental health and addiction in the future, and how support is best provided to those who need it.

The inquiry will make recommendations on the following areas:

- roles and responsibilities of agencies in the health sector, including a re-established Mental Health Commission
- improved co-ordination between the health system and other systems such as education, social, housing, justice, disability support, accident compensation, and emergency response
- the design and delivery of services (for example, kaupapa Māori approaches to mental health) and effective engagement with all relevant stakeholders including mental health service providers, and consumers and their communities and whānau
- governance, leadership and accountability levers to ensure access to an appropriate standard of mental health services across the country
- fiscal approaches, models and funding arrangements
- data collection, programme evaluation and information flows
- the suite of relevant regulatory frameworks, including the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Substance Abuse (Compulsory Assessment and Treatment) Act 2017
- workforce planning, training, support and management
- any other matters that the Inquiry believes are important.



GOVERNMENT INQUIRY INTO

# Mental Health and Addiction

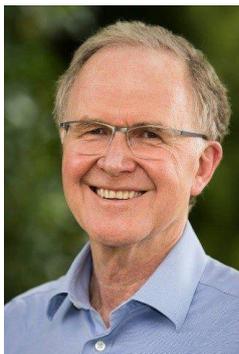
Oranga Tāngata, Oranga Whānau

PUBLIC CONSULTATION ON MENTAL HEALTH AND ADDICTION IN AOTEAROA  
NEW ZEALAND NOW, AND INTO THE FUTURE

A CHANCE TO HAVE YOUR SAY



## INTRODUCTION



*Nau te rourou, naku te rourou, ka ora ai te Iwi*

On 31 January 2018, the Government established an Inquiry into mental health and addiction. The ultimate goal is to improve the mental health and addiction outcomes of New Zealanders. We are a diverse and multicultural panel with a broad range of ethnicities, ages, backgrounds and perspectives.

Our task is wide ranging: we have been asked to look at how mental health is promoted and supported in New Zealand, and how interventions and services could be transformed to respond more effectively to the needs of people experiencing mental health and addiction challenges, including people affected by suicide.

We want to provide a clear direction for the future that generates hope and supports communities, whānau and family, providers and government to take action.

Providing a submission on this consultation document is one way you can contribute to this Inquiry. Our website has more information about other ways you can connect with us: [www.mentalhealth.inquiry.govt.nz](http://www.mentalhealth.inquiry.govt.nz).

### Your views

There are five key questions that we would like to hear your views on. These questions are deliberately broad to ensure that they capture the full range of issues and solutions you may wish to share with us.

Your submission might be very specific, based on your own experiences of mental health or addiction. You might have insights as a service provider or a family member, supporting a person who has experienced mental health or addiction challenges. As well as your personal experiences, you might also have ideas about what improvements could be made across the whole country and the entire system.

Everyone's views are important because they will help us to understand what people around the country think is working well and what needs to improve.

### Tell us what you think

We want to hear what you think, especially what your solutions are to make things better. Your comments and ideas might be about anything you think is relevant, including the role of different sectors — such as education, disability support, social welfare, housing, justice, policing and prisons — and the impact of various risk factors, for example: housing issues, violence, unemployment, social deprivation and poverty.

To help you make your submission, you may want to read a simplified version of our Terms of Reference: <http://www.mentalhealth.inquiry.govt.nz/About-the-Inquiry/Terms-of-Reference>,

Overall, we want to hear your ideas about solutions that might help to:

- build positive mental wellbeing for all New Zealanders
- help people to deal with mental health challenges early (before specialist treatment is required)
- enable people to avoid becoming addicted to something that causes harm
- prevent people from taking their own lives

## *Submissions Report: Government Inquiry into Mental Health and Addiction*

make it easier and faster to identify when someone is facing mental health or addiction challenges and get them help more quickly

improve the quality of the support and interventions given to those who need it, and

any other ideas about how to improve mental health and wellbeing in Aotearoa.

### Your views matter

Every submission is important and all will be read or listened to. When the Inquiry finishes, we will release a report that explains what people told us needs to change and how it should change.

### How your information will be managed

The only people who will have access to your submission will be the Inquiry panel and nominated staff of the Inquiry. It is possible that some content from submissions, such as individual stories and experiences, may be referenced or included in the Inquiry report but identifying information (such as names) will be excluded, and stories and experiences will be kept anonymous where possible.

You can tell us that you would like your submission, or certain parts of it, to be kept confidential so that it won't be used in the report. You can find out more about our management of your submissions during and after the Inquiry here:

<https://mentalhealth.inquiry.govt.nz/consultation-document/legal-information-about-your-submission/>

### You can attach documents to your submission

You can also attach documents to your submission. If you are completing your response online, there is an opportunity to attach anything you want to contribute (except current service complaints which are outside the Terms of Reference). If you are completing a paper version of this document, please attach any additional information to your submission when you send it to us.

### You can provide more detailed comments

You may wish to make more detailed comments about areas such as design and provision of services, how to improve coordination between the health sector and other areas, workforce planning, collection and sharing of information, and funding, governance and accountability. You can include these in your answers, or put them in a separate submission from you or your organisation.

### Conclusion

This Inquiry is a once in a generation opportunity for change. We will be working hard in the time available to gather the best information we can, and your views are part of this.

Your voice is important and will help us set the direction for mental health and addiction in Aotearoa. Thank you in advance for taking the time to complete your submission — we look forward to receiving it.

*Mahi Ngātahi he oranga mō tatou,*

Professor Ron Paterson (Inquiry Chair)

## HOW TO HAVE YOUR SAY ON THE INQUIRY

These questions are a starting point for our discussions. Feel free to answer some or all of the questions, and please raise any other ideas or issues that haven't been covered but you think the Inquiry panel should consider. You can answer our questions online at <https://mentalhealth.inquiry.govt.nz/consultation-document/>. Or you can download a PDF version of this document for completion and send it by email to [mentalhealth@inquiry.govt.nz](mailto:mentalhealth@inquiry.govt.nz) or post to the address below.

**Translated versions** of the document can be found at <https://mentalhealth.inquiry.govt.nz/consultation-document/> :  
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[\www.translatedversions.govt.nz](http://www.translatedversions.govt.nz)

If your preferred language isn't on that list you can call CAB Language Connect (an independent community organisation) on **0800 78 88 77** and someone may be able to assist you. It's free to call to get assistance in the languages they support. See <http://www.cab.org.nz/languageconnect/Pages/home.aspx> for more information and a list of languages.

A video version of the document with **New Zealand Sign Language** interpretation with audio and captions can be found at <https://mentalhealth.inquiry.govt.nz/consultation-document/nzsl/>  
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[\www.translatedversions.govt.nz](http://www.translatedversions.govt.nz)

An **Easy Read** format of the document can be found at <https://mentalhealth.inquiry.govt.nz/consultation-document/have-your-say-easyread/>

A **large text** format of the document can be found at <https://mentalhealth.inquiry.govt.nz/consultation-document/large-text/>

You can also **provide your submission over the phone** if you prefer by **calling** 0800 644 678. Someone will be able to talk to you and write down your ideas about how to improve mental health and addiction in New Zealand between 9:30am and 5:30pm Monday- to Friday.

### **When to send your submission by**

Submissions are due by **5pm, 5 June 2018**.

### **Where to send your submissions**

You can send your submission by email or post.

[mentalhealth@inquiry.govt.nz](mailto:mentalhealth@inquiry.govt.nz)

Mental Health and Addiction Inquiry  
 PO Box 27396  
 Marion Square  
 Wellington 6141.

### **Other ways to contribute to the Inquiry**

The panel will not be able to spend time with everyone, but we will meet with whānau and communities, individuals who access services, providers, representative organisations, advocates, sector groups and experts where we can. If you want to find out more about our meetings around the country and how you can join in, please go to

<https://mentalhealth.inquiry.govt.nz/contact-us/expressions-of-interest/>

You can also get in touch with the Inquiry on our website, email or through social media.

The Inquiry team is always contactable through our email address —

[mentalhealth@inquiry.govt.nz](mailto:mentalhealth@inquiry.govt.nz).

<https://www.facebook.com/MentalHealthInquiryNZ/>

<https://twitter.com/MHInquiryNZ>

## WHAT'S CURRENTLY WORKING WELL?

We know there are concerns with how we view mental health and addictions, promote mental wellbeing, and provide support and services to those who need it. We also know there are some good things already happening that could be supported and expanded. We want to hear about the good things currently happening.

What do you think is currently working well? Why do you think it is working well?  
Who is it working well for?

## WHAT ISN'T WORKING WELL AT THE MOMENT?

We know that some things are not working so well at the moment. We want to hear what you think isn't working well, and where there might be gaps or problems — such as the underlying causes of the problems, unmet needs, the way services and support are delivered, the links between services, and the availability of services and resources.

What mental health and addiction needs are not currently being met? Who isn't receiving the support they need and why? What is not being done now that should be?

## WHAT COULD BE DONE BETTER?

You've told us what you think is working well, and what isn't working well. In this section we want to hear what you think would make the biggest difference to improve and transform mental health and addiction outcomes in New Zealand. This might include your ideas about how to prevent people from developing mental health or addiction problems, as well as ideas about how to improve the support and treatment given to those who need it.

Your ideas might be focused on specific communities or groups of people, or more general views about what could be done better. We want to hear all ideas — big or small, specific or broad, innovative and new, or building on something that is already happening.

What are your ideas about what could be done better or differently to improve mental health and wellbeing in New Zealand? What could be done better or differently to prevent addiction from occurring? What could be done better or differently to

prevent people taking their own lives and support those affected by suicide?  
How could support be better provided to those who need it?

## FROM YOUR POINT OF VIEW, WHAT SORT OF SOCIETY WOULD BE BEST FOR THE MENTAL HEALTH OF ALL OUR PEOPLE?

We want to hear what your ideal, healthy New Zealand would look like. What would be the foundations, principles or values that would support positive mental wellbeing for all New Zealanders, and how we might best assist those who need help.

If you could refresh how the system in Aotearoa promotes positive mental wellbeing, and prevents, identifies and responds to mental health and addiction challenges, including suicide, what would that system look like, how would it be different from what we have today, where would you start, and where would you focus your efforts?

## ANYTHING ELSE YOU WANT TO TELL US

Is there anything else you want the Inquiry to know?

## BEFORE YOU GO...

### About you

Before you finish, please tell us a few things about yourself. This information will help us better understand the information we receive, where the areas of unmet need are, and identify ideas that best fit various groups, because what works well for one group might not work for another.

Is this an individual submission, or a submission on behalf of a group or organisation?

Individual

Organisation

Please state which organisation:

Group

If your submission is on behalf of a group, how many people does it represent?

Please indicate which of the following best represents you. Tick as many as appropriate.

Personal experience of mental health and/or addiction challenges

Family, friend or whānau of someone with mental health and/or addiction challenges

Current/past engagement with mental health or addiction services

Family, friend or whānau of someone with experience of mental health or addiction services

Individual service provider or support worker

Advocate

Service provider organisation

- please specify type of provider (eg, DHB, PHO, primary practice)

Representative or professional organisation

NGO

Researcher, Academic, Commentator

Central or Local Government agency

Interested member of the public

Other (please specify)

**If you are a person who has accessed services either currently or in the past**

Please indicate if you identify with any of the following groups. Tick as many as appropriate.

New Zealand European/Pākehā

Māori

Children

Youth

Pacific peoples

People with disabilities

Deaf

Older people

Immigrant and refugee groups

Veteran

LGBTIQA+

Prison populations

Non—custodial offender

Rural

Other (please specify)

**If you are a provider, representative, or professional organisation**

Please indicate if you provide services specific to any of the following groups. Tick as many as appropriate.

Māori

Children

Youth

Pacific peoples

People with disabilities

Deaf

- Older people
- Immigrant and refugee groups
- Veterans
- LGBTIQA+
- Prison populations
- Non—custodial offenders
- Rural
- Other (please specify)

1. **Sex:**
  - Female
  - Male
  - X (Gender diverse/Indeterminate/Intersex/Unspecified)
  - Prefer not to say

2. **Age:**
  - Under 16
  - 16 — 24
  - 25 — 44
  - 45 — 64
  - 65 — 84
  - 85+
  - Prefer not to say

Are there any parts of your submission that you would like kept confidential?

3. Yes / no (If yes, please clearly indicate in your submission which parts you request be kept confidential (eg, by highlighting confidential sections), and reasons why this is important to you)
4. Please indicate how you would like the confidential parts to be treated.
  - The identified parts of my submission are not to be referenced at all in the Inquiry report
  - The identified parts of my submission can be anonymised and used in the Inquiry report and other Inquiry documentation — for example published as part of an analysis of submissions

The identified parts of my submission should be anonymised before being seen by the panel

For further information about requests for a submission to be kept confidential, please visit the Legal Information about Your Submission webpage at

<https://mentalhealth.inquiry.govt.nz/consultation-document/legal-information-about-your-submission/>

Unless confidentiality is expressly requested, all submissions and evidence may be made publicly available at the discretion of the Inquiry.