

NEW ZEALAND 2018



CHANGING MINDS SUBMISSION

THE VOICES OF PEOPLE WITH LIVED EXPERIENCE AND THEIR WHANAU
MENTAL HEALTH AND ADDICTION INQUIRY PANEL

People have Value



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

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Introduction from Changing Minds

Tēnā koutou katoa, talofa lava, and greetings to you all,

Firstly, I would like to thank the 760 people with lived experience and their whānau who trusted us with their stories and believed we could make their voices heard better than through an individual submission. We concentrate on your voices in the following pages.

Secondly, I would like to thank the hundreds of others and their well thought through ideas about “what’s working” and “what you’d like to see”. Our whole team listened and contributed to these ideas in meetings, received letters from you, and heard brave korero in the Inquiry Hui we attended across the country, these have informed our “Appendix of Other Ideas” at the end of this document.

Finally, I would like to acknowledge The Panel and the inquiry secretariat for the compassion, diligence, commitment and humility they have shown to what must be an exhausting process, and personally to the patience and extra time they have afforded us to get such an important piece of work as this compiled.

The team at Changing Minds have taken on the challenge of contributing to this once-in-a-generation opportunity with gusto, committing to our promise of being a national, strategic voice of lived-experience by not just saying what “we” think, but listening, collecting, collating and distilling voices from across Aotearoa who will be most affected by the recommendations you make. Our commitment is evident in the fact that we were not funded or resourced to write it but did it anyway.

At the time of writing, the Changing Minds team has had the opportunity of meeting with the panel to ask questions, listen and learn as well as contributing to collaborative submissions on no less than 26 occasions.

This report begins by discussing the themes that emerged from our community survey. The broad recommendations at the end of this come directly from this data, and are not tainted by what “we” think in order to protect the integrity of the analysis. The list of “*things that will make a difference*” are attached separately from the report in the appendix, as these recommendations did not come from an analysis of the data. This list is a combination of what we know and think, as

'Changing Minds', as well as what we believe will work from the hundreds of people we've had the pleasure of engaging with over time – together, these separate parts present a lot to think about!

The purpose of our submission was always to make the panel's job easier to make bold decisions, and, to support the mana of Dean Rangihuna who is the lone voice of lived-experience on the panel – Dean, may these voices give you the strength to make a difference.

Whilst the report may seem long, it is far from boring. Michelle Atkinson has worked tirelessly (and sleeplessly) to capture the richness of the challenges and solutions that were gifted to us, and we owe her enormous thanks. I encourage you to read every word, as each page holds new learnings, and plenty of ah-ha moments that not only help to build empathy but give us insights into a potentially exciting future.

We are poised on the brink of a new paradigm, where New Zealand could lead the way for other countries. For the first time in history, people with historically diametrically opposed world views (consumers, communities, services, clinicians and government) are united in our need for something different, so take a risk, be bold, we're all there behind you. And remember;

“Every new thinker is at first condemned by those for whom change is far more terrifying”
- the Alienist

Kia Kaha, Kia Maia, Kia Manawanui.

TAIMI ALLAN

Chief Executive Officer

Changing Minds

June 2018

Note from the Author

This paper presents a thematic analysis of the responses to a survey from 760 members of the New Zealand public as a submission to the Mental Health Inquiry, 2018.

I would like to acknowledge and thank every person and whānau who gave their time and experiences toward this. I have carefully read everything you each have written. Thank you for gifting us your thoughts, stories, triumphs, and incredible losses. They are personal and invaluable, and we do not take them lightly.

We have used a thematic analysis approach. This brings out the overall themes and trends, which have been independently peer reviewed.

It is very rare to get such a large number of respondents to a survey like this, which is what makes it such an important opportunity to understand and represent the experiences of New Zealanders. Here are some statistics to give you an idea of the size of the data.

There are **127,000 words** of responses to just the last four open-ended questions (where most of the qualitative data is) – more than a doctoral thesis.

After removing codes relating to specific services and demographics, there are **4326 extracts** listed under codes totalling at least 200,000 words.

These codes were summarised into bullet points, some of which had an accompanying quote from an extract. This list is **22,500 words** long.

This conveys the magnitude of the contributions.

I encourage you to continue to raise your voices to make change – we need to hear from you.

Ngā mihi nui,
Michelle Atkinson



MANAAKITANGA

THEME 1



Peers, Whānau, Staff and Services.

Showing respect, generosity and care for others

HONOURING DIVERSITY

THEME 2



Clinical, Cultural, A Life worth Living & Choice.

Seeing people for who they are, & what they need.

A BETTER WORKFORCE

THEME 3



Creating a caring society through developing a

diverse, skilled, resourced and valued workforce

STRUCTURE & FUNDING

THEME 4



A whole of government approach to

better services, access, equity, and fair-funding.

RECOMMENDATIONS

THEME 5



A system that supports equity and choice

for individuals, whānau and communities

Results

The results of thematically analysing the survey data are an overarching philosophy of a Caring Society with four main themes: Manaakitanga, Honouring Diversity, A Caring Society – Workforce, and A Caring Society – Systems and Funding. Each theme has several subthemes and builds on the content from previous themes.

Overarching Philosophy: A Caring Society

The four themes combined illustrate a picture of a caring society that truly values people and their whānau. This includes whole-of-government policy; how mental health and addictions services are structured, funded, and staffed; the options and choices available clinically and non-clinically; how people are supported to connect with one another; and how people's contact with support services leave them feeling cared for, and like help is at hand.

In the words of a survey respondent,

“Be kind to one another.”



MANAAKITANGA



PEERS & COMMUNITY

“There's simply nothing like being supported by someone who has ‘been there’.”



WHĀNAU

“If I didn't have a solid support network in my two closest friends I wouldn't have survived”



CARING STAFF

“The good ones genuinely care about what is going on in your life.”



CARING SERVICES

“If you can get the wraparound services, this makes all the difference”

Theme One: Manaakitanga

Manaakitanga is 'the process of showing respect, generosity and care for others'¹. In this analysis it refers to a caring attitude held by people and the systems they work in, and fosters a sense of being cared for, belonging, and hope. There are four subthemes: Feeling cared for by staff; Feeling cared for by services; Le va – Whānau; and Le va – Peers and communities.

Subtheme One : Le va – Peers and communities

'Le va' is a Sāmoan term for a concept in Pasifika cultures that "is the space between, the between-ness, not empty space, not space that separates but space that relates, that holds separate entities and things together in the unity – in all, the space that is context, giving meaning to things."²

Engaging with peers communities is the final subtheme of Manaakitanga. Being part of a community is a core part of feeling a sense of connectedness and belonging that cannot be replicated by a service. One respondent wrote:

"In [the] last year [I] had PSW & CSW support. I know they were trying to be helpful, but they couldn't fulfil my need for friendship and human connection."

The points below describe the themes identified throughout survey data that contribute to this.

Community groups. Connecting with members of respondents' wider communities was reported as very important, including becoming involved in hobby groups and community initiatives.

¹ Maoridictionary.co.nz

² [http://moh.govt.nz/moh.nsf/Files/fono---2009/\\$file/monique---faleafa.pdf](http://moh.govt.nz/moh.nsf/Files/fono---2009/$file/monique---faleafa.pdf)

Community peer support groups. The desire for organised support groups was very commonly mentioned, particularly among respondents who had had low access to services. Most did not know of any support groups, although a few participated in online communities. Respondents reported that organised support groups were initiated and run by community members, not any sort of services:

“There are normal people/community groups who are doing more for us than government services.”

Other peer community connections. Respondents also described the value in meeting other people who had experienced distress in their communities, outside of organised support groups. Connecting with people in the same situation generated a sense of camaraderie and determination to go on. One respondent wrote of the impact of meeting other people experiencing distress:

“So much hope knowing so many people who were recovering and understood.”

Another respondent described a turning point in their recovery:

“Meeting stroppy people who refused to lie back and let the illness or system pin them down changed my life FOREVER. Being told I mattered... and that life WOULD be GREAT again changed my options from death by suicide to life by enjoyment and connection.”

Addictions peer groups. Twelve Step peer groups aimed at recovery from addictions such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) were commonly mentioned as having been accessed by respondents experiencing addiction, with many commenting on their value. A respondent wrote:

“AA, NA and Al 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.”

Peer support workers. Staff with lived experience working in peer roles were reported as an important part of recovery. A respondent wrote:

“There's simply nothing like being supported by someone who has ‘been there’.”

Peer support was seen by respondents as something distinct to other forms of support from services, and that could not be replaced with another type of support. Peer support workers offer a particularly valuable therapeutic relationship. According to one respondent:

“Peer support were approachable and sympathetic when I needed support. Peer support were also non-judgmental and effective with advice I could implement to make my own experience more manageable. Peer support took the time to listen and involved me in my own health, like I was still worthwhile and helped me to own my experiences.”

True peers. There was a desire to see demographic specific peer support, such as peer support workers who are also Māori, young, autistic, or LGBTQ.

Peer clinicians. Two respondents mentioned 'peer clinicians' – peers who were also health professionals and applied both lenses. One respondent commented:

“My Autistic counsellor - she can explain things to me in a way I can understand, and she has a good idea of what I'm going through, having been there herself.”

Peer workforce professional development. As with other types of support, respondents reported mixed experiences with peer support workers. One respondent suggested keys to successful peer workforce development and acknowledged the complexity of the role:

“Peer support workers must be trained and supervised well. Peer supports must also be paid well - it's a highly sophisticated role that requires on-going negotiation of boundaries and power relations in nuanced ways (that a psychiatrist would struggle to do well), as well as a massive heart.”

Subtheme Two : Le va – Whānau

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. One respondent wrote:

“Addiction is also a family disease; this has been passed down from generation to generation.”

Whānau are heavily affected by their loved one's distress in both emotional and practical ways.

However, the close relationships that cause whānau to be affected by distress are the same relationships that help their loved ones through. A third person wrote:

“If I didn't have a solid support network in my two closest friends I wouldn't have survived it and I, without a doubt, would have become another statistic.”

The two points discussed below are how services partner with whānau, and how they support whānau in their wellbeing.

i. Partnering with whānau

Respondents commented on the importance of the inclusion and partnership between mental health and addiction services, and the whānau of the person accessing them. This inclusion and partnership is context-specific: some people choose to have people closely involved, others not; some consider their blood relatives their whānau, while for others it may be their friends. The following points summarise respondent comments on whānau participation.

Thoughtful and inclusive. Respondents described how partnership with whānau must be thoughtful and actively inclusive in order to be meaningful. While context-specific, this may include well-facilitated whānau meetings where everybody can be heard in a safe environment, effective communication between services and whānau, and giving whānau a 'toolbox' of skills to support their loved one. One respondent wrote:

“Shared meetings [are] hugely beneficial as long as people can speak freely, have a genuine exchange of ideas and views, and not be led through a purely medical-based review... Families need to know what to DO. To feel you are part of a team is very encouraging. My experience has been of this style of keyworking

(great) and the opposite where it's like squeezing blood out of a stone to get meaningful contact (dreadful)."

Transitions and changes. Meaningful partnership also means working with whānau as the person receiving support transitions through services or life circumstances.

Therapeutic relationship. As discussed in subtheme one, respondents identified the therapeutic relationship as extremely important. This applies equally to whānau, and strongly influenced their experiences. Some parents spoke of feeling supported and empowered, while others felt blamed for their child's distress:

"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."

Treating the whole whānau. Respondents spoke of the benefit of treating the whole whānau, as opposed to the individual. Responses included a desire for more programmes that take this approach and ideas for a whole whānau retreat or respite. Some respondents reported that their experiences with child and adolescent mental health services (CAMHS) had been excellent in this regard. One wrote:

"CAMHS were great as they included the entire family."

ii. Supporting whānau

The importance of support for support people was a strong theme across the dataset. Whānau experience a high level of stress and distress when supporting their loved one, which can affect many facets of their lives.

According to respondents, whānau often deal with crisis alone when services are unresponsive. A number told of trying to keep a whānau member with suicidal thoughts safe after crisis services had declined help. Other whānau who accessed services were in the difficult position of requesting that their loved one be put under the Mental Health Act. One respondent wrote of the stress and fear when whānau are unsupported during crisis:

“I have heard horror stories of people being sent [home to whānau] with absolutely no safety/relapse plans within 24 hours after a suicide attempt.”

Another whānau support person commented:

“I feel completely alone.”

Respondents identified the following points as important when supporting whānau. **Connecting with their loved one.** When whānau do not have strong relationships with their wider community, or are unsure how to help or approach their loved one experiencing distress, they want support to rebuild these relationships.

Whānau peer support. Some whānau respondents commented very positively on the difference that whānau peer support had made, while others wrote that they would like to connect with other families in their situation. A longstanding group led by a community member appeared frequently in the data as an essential support. A respondent praised a group for the whānau of people experiencing addiction:

“The facilitators often have recovered from a personal crisis and by sharing stories with other members of the groups, everyone learns something about our own circumstances.”

The camaraderie of meeting people in the same position, and the hope in hearing from people who have recovered, had a significant impact on respondents.

Education and support. Another theme from whānau is the value of being educated and upskilled in their loved one's experiences, and how to support them. Many whānau expressed a desire for this as it had not been offered – despite a long journey with services, for some. Others considered the skills and perspectives they had been taught invaluable. Organisations that specifically support whānau members with resources, information, and support groups were frequently mentioned. Additionally, a Dialectical Behavioural Therapy (DBT) group for whānau was considered as a key component of their loved one's survival and recovery.

Respite. Whānau described the importance of respite. Those whose loved ones had accessed it described it as crucial:

“Respite has been a godsend – having somewhere to send him so I can hang on to sanity really makes a difference.”

However, many were unable to access respite in any form:

“Respite is needed for families of children battling eating disorders, it is an exhausting journey.”

Support for children. Support for children affected by whānau distress was identified by respondents.

Suicide postvention. Whānau who have lost a loved one to suicide need more support, and for longer.

Subtheme Three: Feeling cared for by staff

A strong theme across the survey data was the importance of feeling cared for and helped when reaching out for help. One of the two main components that determine respondents' experiences is personal interactions with healthcare staff.

Many respondents had some engagement with services including primary mental health, community mental health services, outpatient addictions services, cultural services, NGOs, residential services, respite, and inpatient units.

Respondents' interactions with staff had a significant impact on whether they felt cared for, listened to, and respected. It also strongly influenced their sense of hope and whether or not they would engage with services (mental health or otherwise) again in the future.

All respondents who had 'asked for help' had experienced at least brief contact with one or more professionals in a service (primary, secondary, tertiary, NGOs, helplines, etc). There were a variety of experiences, however, dismissiveness or rudeness within these brief conversations created a barrier to asking for help again. We refer to an ongoing relationship with a mental health or addictions professional as a 'therapeutic relationship'. According to respondents with ongoing contact, the quality of the therapeutic relationship made the biggest impact on their wellbeing (for better or worse) when compared to other facets of the service.

One respondent described the long-term effect of hurtful comments from a staff member:

“The invalidation and hurt that statements like that caused have stuck with me even a decade on.”

Survey respondents also described how a stigmatising attitude caused by one staff member's opinion, or by a commonly stigmatised diagnosis or behaviour, resulted in

a service- or organisation-wide stigma that preceded them and affected all of their care. One wrote:

“Once you are labelled as a ‘self-harmer’ or ‘pill popper’ it is an ongoing issue that’s stuck, but when people are desperate they do desperate things... understand [that] when someone is asking for help who doesn’t often ask, then they need help.”

Correspondingly, good therapeutic relationships were considered extremely valuable:

“The good ones spent time with you and genuinely care about what is going on in your life. You can have a good laugh or a good cry with them and they can handle it. They treat you like a person not a nutter!”

Subtheme Four: Feeling cared for by services

Similarly to their interactions with staff, respondents’ contact with services created a ‘relationship’ of sorts which strongly influenced whether they felt they were cared for, whether help was available, and their sense of hope. Services that were responsive and flexible had a very positive impact, while those whose criteria or capacity were not responsive to people’s needs had a detrimental effect.

There are a number of contributors to how services and systems responded (or failed to respond) to requests for support, which are broken down below.

i. Mental health and addictions services

Lack of information: People are not aware that support exists.

Navigating the system: Navigating entry into services and knowing where to ask for support was reported as being very difficult by respondents. Primary and specialist staff also struggled with navigating complex mental health services.

Waiting times. Respondents commonly reported being placed on long waiting lists for all services – primary care, secondary care, tertiary care, NGOs, respite, rehabilitation, and specific therapies. One respondent wrote:

“Psychology has a wait list. That is not therapeutic.”

Respondents who had experienced waiting list for addictions services reported that the slow response missed the window of opportunity for change readiness:

“Long gap of many months between treatment at [addictions rehabilitation] and entry to [long term mental health rehabilitation] led to relapse/loss of motivation and loss of opportunity for treatment.”

Service criteria. Many respondents did not meet criteria to access any services beyond six sessions with a psychologist in primary care, despite reporting ongoing distress. One respondent wrote:

“It’s awful to watch your whānau get worse and worse before they ‘qualify’ for an appropriate level of care.”

Another respondent wrote about access to support:

“Nothing at all for last five years. Been told I’m in the too hard basket and I’m not crazy enough.”

Unaffordability. Those who were not eligible for publicly funded support frequently attempted to access private care. Some respondents found this useful, however for others, financial constraints meant starting counselling or therapy and having to stop; spending all savings on psychological interventions; being unable to access private care at all; or having funding through Accident Compensation Corporation (ACC) cut. Some respondents were unable to afford to access their general practitioner (GP) for an initial consultation.

The right type of care. When accessing services, specific therapies such as DBT or specialist care such as for eating disorders are not available. Under the community mental health episodic care model, long-term psychotherapy is also not available, though it may be indicated for some conditions such as borderline personality disorder.

Respite. Many respondents wrote about needing a break – somewhere safe to go for a few days, both in the context of crisis and 'moderate' distress. One respondent summed it up, wanting:

“A safe place to go.”

Severity criteria. Respondents described the unexpected effect on their distress of having to meet a severity threshold to access compassionate support. One person wrote of their reaction to the prospect of being discharged too early from an inpatient unit due to bed pressure:

“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).”

Another respondent described how they were invalidated and denied care until they were totally unable to regulate their emotions:

“My overall experience of services thus far has confused me; it seems when I am invested and trying to do the right I treated as if I’m not. I am treated better and given more options when in a state of tantrum and presenting badly. Has been a horrifying roller coaster of mixed messages, at a time of mental instability.”

It may be easy for the reader to demonise these honest respondents. However, distress arises from a complex range of factors and often traumatic experiences, and a service that exists to improve wellbeing should not be exacerbating distress by rationing care.

Consistency. Turnover in services result in disrupted therapeutic relationships. A respondent reported:

“People kept leaving and I have abandonment issues.”

Post discharge. Respondents who accessed services reported being unable to access further help once receiving their ‘entitlement’, difficulty re-entering secondary services, having no follow up plan, and being discharged before they were ready.

Crisis. Lack of responsiveness from crisis services was mentioned by a large number of respondents and caused significant distress. Respondents expected that upon calling the crisis team, the phone would be answered by a staff member who would have the time and resource to talk them through the situation and offer appropriate support if needed, such as coaching whānau members, visiting at home, or organising respite care.

Some respondents spoke of being negatively affected by having to leave a message and waiting to be called back, asking whether they had engaged in coping mechanisms, and being told that they were not severe enough for any help – as well as some explicitly dismissive comments by staff.

Models that stigmatise. Some respondents reported stigmatising behaviour in response to particular diagnoses (such as borderline personality disorder), presentations to services (such as suicide attempts), or levels of engaging with services. One respondent wrote:

“I would get told off in programs for not doing my homework etc. And I wasn't doing my homework BECAUSE I WAS TRYING TO KEEP MYSELF ALIVE. And I don't think the clinicians heard or understood that. And then I got labelled as 'non-compliant'.”

Violence. Some respondents reported being severely traumatised in response to violence experienced accessing services. Each of these stories related to tertiary care, or the process of being placed under the Mental Health Act.

Addictions support while in recovery. There are no formal services available to support people who are in recovery from addictions – they can only receive support after relapsing. One respondent reported:

“I'm in recovery from addiction and current [alcohol and other drug] services do not provide support for people when they are not living in the problem.”

Practical considerations. Respondents reported that barriers to access include service location, parking, transport, and appointment times.

ii. Social determinants

Relationships with services and the sense of being cared for was also heavily reliant on whether respondents were supported in other areas of their lives. One respondent wrote:

“Mental health recovery involves every part of us and our environments.”

The following points relate to these determinants of health.

Life circumstances influence mental health, and vice versa. Respondents wrote that aspects of their lives such as financial situation, housing, and employment determined their mental health status. One reported:

“Being mentally ill and living in a rental situation rather than supported accommodation means being unable to have enough money to eat or dress properly.”

Integrated public services. According to respondents, it is extremely difficult to access support for health determinants such as employment, education, housing, physical health services, and financial support. Services are not integrated and poorly coordinated, which can have a particularly severe impact on people who are very vulnerable. One respondent wrote:

“My sister was discharged from the mental health service and left to her own devices and as she was unable to cope [it] resulted in her living in squalor.”

Wraparound support. Those who could access comprehensive wraparound support reported it as being very positive for their wellbeing. One respondent wrote:

“If you can get the wraparound services for a person who has developed a major mental health disorder this makes all the difference. It closes the gaps.”

Justice. Respondents observed the relationship between poor mental health and addictions, involvement in criminal justice, and the lack of services provided to prisoners – reflecting a lack of compassion in the system. One respondent wrote:

“These people are not criminals - they have sad pasts and deserve help.”

Just as feeling uncared for by staff has had a long term effect on respondents, so has feeling uncared for by services, including affecting their long term behaviour. A parent wrote:

“The journey with mental health [services] has been a nightmare. I will not be going there ever again with any member of my family – it is not safe.”



HONOURING DIVERSITY



SPECIALTY CARE

“Services... can be put together to create a treatment pathway that is unique and creative to each person seeking help.”



CULTURALLY RESPONSIVE

“Listening is so important, it was so awesome that they looked for solutions that really took into account us and our culture.”



A LIFE WORTH LIVING

“I saw there was more to life than my struggle and that gave me a reason to keep fighting”



MEANINGFUL CHOICE

“I was given considerable freedom to implement my recovery goals”

Theme Two: Honouring Diversity

The theme of Honouring Diversity is seeing and acknowledging people for who they are, meeting them where they are at, partnering with them in a meaningful way, and supporting them to engage with the options they choose.

In the words of a respondent:

“Weave the kete with many strands - applicable to each age or stage.”

There are four subthemes: Clinical services; Culturally responsive supports; A life worth living; and Meaningful choice.

Subtheme One: Specialty Care - Clinical services

This subtheme addresses suitability of clinical services to individuals and whānau. It is divided into two parts: having accessible, appropriately skilled clinical care available; and providing a range of clinical options to choose from.

i. The right clinical services and expertise

A theme throughout the dataset was the importance of having the right specialist services and expertise and was particularly important to those respondents who had had difficulty accessing this. The type of expertise fell into the following categories.

Condition-specific interventions. Respondents wrote of the difficulty accessing appropriate clinical care for certain conditions, and the toll associated with this. Support for people who experience emotional dysregulation and symptoms of borderline personality disorder was commonly mentioned as both extremely important and almost always unavailable, including Dialectic Behavioural Therapy (DBT) and long term talking therapy. A parent wrote:

“[DBT] has been life-saving for my daughter. More access to DBT programmes and long term psychotherapy would save lives.”

The most commonly mentioned was the difficulty accessing any specialist expertise or interventions for people with eating disorders. This included appropriate outpatient care, day programmes, and inpatient care.

Care tailored to mothers and infants was also reported as needed but hard to access.

Workforce capability for common diversities. Respondents reported that the workforce as a whole needs to be able to respond more appropriately to facets of individuals that may be different from the norm, and that may or may not affect their distress or addiction. One example given was the ability to appropriately engage with people who are LGBTQ (in particular transgender or gender diverse):

“Many doctors and staff have been bad about my sexuality and gender, it makes it hard for me to talk openly about things with them.”

Another example was working with people with autism. Respondents noted that every staff member did not need to be an expert in all diversities, but did need to have a basic understanding and know how to respond and engage appropriately.

Accessible and integrated support from other professionals. Respondents identified that disabilities and physical health conditions prevented people from receiving clinical care due to a lack of available or integrated support from other professions. This included people with communication difficulties:

“In one case, until a patient was able to talk, he couldn't be assessed. It was an impossible catch 22. No one could secure a speech therapy consult. And assessment is impossible without speech.”

ii. **A range of clinical and other support options to choose from**

Across the dataset, respondents reported that they wanted more choice in the clinical care they can access. One wrote:

“Services... can be put together to create a treatment pathway that is unique and creative to each person seeking help.”

Comments fell into the following domains:

Approach and philosophy. Respondents want to be able to choose the philosophical approach to their care, particularly when engaging in programmes and groups. For example, one respondent found it difficult to engage with addiction peer groups offered to them as they took a harm reduction approach, which was triggering to the respondent (who was taking an abstinence-based approach).

Therapeutic interventions. Respondents want access to therapeutic interventions or talking therapies. Those who had low access to services made a consistent plea to simply have someone to talk to (which they identified as currently unavailable). Those who have had access to services expressed a desire to be able to choose from a range of therapeutic interventions beyond what is standardly offered, including DBT and Eye Movement Desensitisation and Reprocessing (EMDR).

Levels of intensity of support. According to respondents, there should be more levels of intensity of support available, and access to them should not be rigidly determined by service criteria. One respondent said:

“I don't want to go to hospital, but one hour of therapy a week IS NOT ENOUGH.”

Available support should include drop-in centres, day programmes, and more intensive therapy. The ability to access respite, a retreat, or take some time out was

consistently mentioned across the dataset, including the ability to access respite before reaching crisis. Respondents who had already had access to respite also considered it essential.

Medication. Respondents held a wide range of philosophies and experiences to medications and medical interventions. These range from wanting support to withdraw from medication or remain medication-free, to more follow-up regarding medication prescribed, to be able to try more medication options, to wanting access to ECT for treatment-resistant depression. Some respondents were also concerned about the physical health effects of some medications. The common thread between these diverse positions is access, when desired, to a skilled psychiatrist or general practitioner who will work in partnership.

Choice of staff. Respondents would like to be able to change the professional they are working with, or to choose a professional from a team or service. Some respondents observed that while the former is currently theoretically possible, it is not necessarily easy to accomplish.

Professions. Professionals from a variety of disciplines should be accessible including occupational therapists, nutritionists/dieticians, psychotherapists, psychologists, and physical health professionals. There should be good access to peer support including peer support workers and peer support groups.

Determinants. Coordinated, integrated, effective support for social determinants should be readily available. This includes support with or into education or employment, help obtaining financial entitlements, coordinated physical healthcare, and assistance to access suitable housing including supported accommodation.

Alternative Healing. Some respondents would like support to access cultural/spiritual healing (such as mirimiri and rongoa) and alternative healing therapies (such as other natural medicines).

Timing. People should be able to choose to engage with services when it is right for them. They should neither be left waiting a long time for help, nor be denied access to a programme because they have turned it down or left it before. A respondent described it as:

“Working at each person's pace and ability to change and allowing return to services for follow up.”

Subtheme Two: Culturally responsive supports

Respondents identified the value of supports that are culturally responsive including kaupapa Māori services, and Pasifika-led services. Youth services are also included in this section to ensure culturally responsive services are available for this population group.

i. Kaupapa Māori

The value of kaupapa Māori services was a strong theme amongst feedback for cultural services. The following are commonly occurring and salient points in the data.

Respondents emphasised the value of kaupapa Māori services being widespread and accessible, with one suggesting a Māori mental health and addictions services in every main centre. Māori service models are founded on Māori philosophy. This is captured in the following quote:

“Empower the person rather than victimising them. Using the holistic approach attempts to engage whānau in a real way which does not relinquish their responsibility to their loved one. This will require a more in depth three party consultation i.e. whānau, services [and] tāngata whaiora to source the root of the issues to attempt to find healing in a real way...”

The depth of wairua, hinengaro, whānau, and tinana is much more than the one word... When the depth of these words [is] really understood than we may find a way forward for our people."

By Māori, for Māori. Respondents highlighted the importance of services that are truly led by Māori and the important role that they play.

"Pākehā never worked for me because they are directive in their approach and they don't get me. As much as they like to think they do, they never ever will – the quicker the professionals understand this concept, Māori stats may go down. Māori for Māori."

One person also identified the Māori community as a source of innovation and leadership – not only for Māori, but also Pākehā.

Children and whānau. Respondents described what a Māori approach to children and whānau should encompass. One wrote:

"There is such a need for tamariki/rangatahi to be treated for behavioural and disconnectedness by Māori for Māori, a whānau collective model."

Another respondent suggested a rangatahi residential addictions service with the best programmes and clinicians, and coordinated by Māori, for Māori:

"Māori would have far more positive outcomes being at the helm of these programmes..."

because they have everything else to make a child better except funding.”

Integrated approach. Some respondents emphasised the need for an approach that integrates kaupapa Māori and the best elements from other models of care. One wrote:

“A tikanga based response working from a Māori methodological framework which incorporates the latest advances in neuropathy and psychiatry has not yet been given a chance.”

A Māori model works for everyone. Respondents identified that the inherent nature of a kaupapa Māori approach is therapeutic and healing for all people, regardless of culture or ethnicity. One respondent summed this up:

“These models benefit many consumers regardless of how they identify culturally – not because these practices are ‘Māori’ or ‘Pasifika’, but because they uniquely encompass holistic wellbeing and empathetic care.”

Another non-Māori respondent wrote of their positive experience accessing a kaupapa Māori service:

“Although it was a totally different culture and I felt way out of my comfort zone walking in, they embraced me as without blinking an eye. Respect was what I needed and received. I went there inside a dark cloud, and now helping those in that cloud. “

ii. Across cultural services

All comments made about Pasifika cultural services were broad and applicable to any cultural service. Consequently, they are not in a separate section but are included here with other comments that could apply to any cultural service. There was also a low number of Pasifika respondents, limiting the feedback. In addition to the Pasifika responses, comments about Māori services that can apply more broadly are also included here.

The points below describe the important role that cultural services play, and essential components within them.

Equity. Peoples from non-Pākehā³ cultures frequently have poorer health outcomes and access to services. Respondents identified the role that culturally specific services can play in improving equity. One wrote:

“Mental health services should also be more considerate [and] structured around Tikanga Māori. It should make [an] effort to represent and assist minority groups who are disproportionately affected by mental health issues.”

Stigma within a culture. Respondents identified that cultural services were able to challenge stigma around mental health in a culturally specific and responsive way.

The importance of language. Language is valuable – including Te Reo, Pasifika languages, and NZ Sign Language. Respondents would ideally like to work with a staff member who speaks their language. However, they also identified that a minimum standard would be immediate and ongoing access to an interpreter for

³ We acknowledge that some people don't like the term pākehā. We use it as this is how many respondents self-identified.

those who do not speak English. One person wrote about the added difficulty of a language barrier when supporting his friend who is Deaf and wanting to access comprehensive support:

“[I am] supporting a Deaf Māori male... needing full access with NZ Sign Language, on top of his current mental health issues, addiction issues... Many local and national-wide addiction services are not able to support his severe needs.”

Cultural competency. The cultural competency of staff working general services was also considered important. One respondent shared a positive experience with a staff member of a general service who was able to partner with them and understand what was important, including their culture:

“Listening is so important, and it was so awesome that they did that and that they looked for solutions that really took into account us and our culture.”

A third respondent identified an opportunity for change – all aspects of cultural considerations in services need to be meaningful:

“Real and substantial considerations of the place of wairua is required, not just lip service.”

Individuality. Respondents stated the importance of not assuming the personal significance or engagement of a person with a culture, and to acknowledge that many people come from more than one culture. A Pasifika respondent described a situation where they experienced more partnership and a better therapeutic relationship with a Pākehā clinician than a Pasifika one.

Cultural services face similar challenges to other services. Issues described in previous sections also apply to cultural services including quality and difficulty

accessing appropriate and coordinated clinical, social determinant, and other support services. Respondents had a range of experiences.

iii. Youth services

Support for young people was a strong theme across both respondents who were young, and those who were not. A higher proportion of young people who responded had had limited access to services when compared to adult and older adult respondents. The following cover the main points in the data. Some are specific to adolescents and young adults, while others are also relevant to children.

Definition of 'youth'. Young and adult respondents described the difficulty of youth-specific services often ending at the age of 18 and considered this inappropriate, particularly in light of brain development continuing until the age of 25.

Youth-specific services. Young people and adults identified the importance of youth-specific support services with a holistic model that is appropriate to this unique stage of life. Many respondents considered youth services to be much more comprehensive, holistic, and supportive than adult services, and identified that losing that support when discharged to adult services was very difficult. Additionally, some young adults discharged from youth services were unable to access adult services due to service criteria. One young person wrote:

“There needs to be more services [for] young adults because this is a very common time for people to be going through mental health issues and there is a serious lack in services when you transition from being a child.”

Another young person commented on the importance of a youth-specific service model (such as a youth development approach) in developing a therapeutic relationship:

“Being able to feel validated and seeing that you're not alone in what you're dealing with can have an enormously positive effect on someone's mental health and having age appropriate services would facilitate this.”

A holistic, responsive approach that works in partnership with the young person and includes whānau and other areas of their life (such as school) was identified as important for young people. A number of respondents had had positive experiences in this respect, both with child and adolescent mental health services, and with youth health organisations.

Early intervention. Supporting young people early in their lives and when they are first starting to experience distress was a consistent theme among respondents. An easily accessible, youth-specific, preventative and universal approach was favoured including upskilling teachers to recognise distress and resiliency programmes in schools.

Peers. Young people wrote of the value in getting to know other young people who understood them.

Intersectional identity. Young respondents commented on the importance of the facets of their identities and wrote that these were often not recognised as only age was focussed on. They asked for support that is appropriate and tailored to who they are as a whole person. Different aspects named by respondents include being Māori, LGBTQIA+, and autistic.

Changing the future. Respondents described the roles of families, communities, and wider society in improving young people's wellbeing. They wrote of changing societal attitudes to distress, teaching resilience and self-acceptance, taking a holistic approach, and supporting families to bring up their children in less stressful environments.

Young people want similar things to adults. Most of what young respondents named as important was the same as other respondents. They want someone to talk to; someone to care about them; to be taken seriously; and hope. Their distress is as complex and human as that of adults. A respondent wrote:

“Young people... have underlying psychosocial and existential issues such as being socially isolated and lacking direction, meaning, and hope, but are referred for being depressed, anxious, or suicidal.”

Youth services face similar problems to other services. Like other respondents, young people had mixed experiences with youth-specific services including those described under Theme One. These include difficulty accessing appropriate and coordinated clinical, social determinant, and other support services.

Subtheme Three: A life worth living

A third strong theme across the dataset is the importance of the things we do to make life worth living. These are the mechanisms by which we form the close connections described in Theme One, generating a sense of hope. One respondent wrote:

“I was also blessed to attend a programme that showed me a larger view of life; so often in my journey, I didn't know what I was fighting for because I had never had it. I remember one-day going horse riding and seeing a glimpse of a life I didn't know existed. I saw there was more to life than my struggle, and that gave me a reason to keep fighting.”

The topics that respondents mentioned and their assessments of them reveal the significance of these activities, which are generally referred to as similarly important to access to excellent clinical services. This is highlighted throughout the points below.

Service- and community-led pursuits. The activities identified by respondents include both those organised by mental health and addictions services, and those that occur in the wider community (such as social sports groups).

Structure. Most of these pursuits can occur in a variety of contexts. Respondents suggested hubs, regular programmes, groups, day programmes, and retreats.

Social groups. Respondents described how important social groups are. One person wrote that they would like their support service to organise a coffee group so they could socialise with other people accessing the service.

Cultural activities. A number of respondents described the fulfilment found in connecting with their culture through activities such as kapa haka, harakeke, carving, and learning or speaking the language. The Māori culture was commonly mentioned by respondents from a range of ethnicities.

Spirituality. Some respondents identified spirituality and spiritual practices as important to their wellbeing. One respondent described what this meant for them:

*“Going back to basics: trust in the self...
connectedness, [and] being contented in your
skin/body.”*

Diet and exercise. These were commonly identified as important to respondents, and are reflected as part of New Zealand's commitment to “Equally Well”. People wrote of their healing journey through food and nutrition. Others identified sports as a valuable part of their recovery:

“Sports and recreation in a safe environment to burn energy.”

Hobbies and interest groups. Other pursuits such as the arts and meeting people with similar interests were also named as beneficial.

Personal development. Some respondents named personal development in the form of education, life skills, wellbeing programmes, and employment opportunities as either something that was a core part of their recovery journey, or something they would like to access.

Nature and animals. These were a very important part of a number of respondents' lives. One wrote:

“I've found nothing helpful except being with nature and having pets (unconditional love). “

Mentoring. Various types of mentoring were named including employment mentoring and wellbeing mentoring.

Holistic, combining lots of aspects. Many survey responses described a combination of the above as ideal for recovery. One respondent painted a picture of their ideal holistic retreat:

“This is set in beautiful tranquil bush so there are plenty of walks to go on, and preferably a beach nearby for swimming, bikes are available... Meditation and yoga classes... Movies... Positive music. Detoxing mineral baths. Good sleep patterns are encouraged. Trained counsellors and psychologists are there for a lot of support and love on teaching on good

values. Forgiveness, gratitude, raising clients' own self-healing and self-esteem levels. The Māori culture is taught and is a huge part of healing for the Māori clients."

Lack of funding for pursuits. After mentioning their significance in recovery, respondents described how their engagement in the above activities was largely dependent on their own abilities and natural supports. Many services were unable to meaningfully remove barriers to community engagement for clients who struggled. Services ran few non-clinical programmes themselves, and those they did run were frequently discontinued due to lack of funding. This respondent described the two things most important to her recovery – intensive engagement with a small, specialist psychotherapy service, and a netball group:

"[Psychotherapy] programme - intensive, was a structure, working closely with therapists and clients, among people with similar struggles to you to feel understood... [and] a netball group run by community team which... has been cancelled. This was such a boost for so many of us socially, physically and mentally."

Subtheme Four: Meaningful choice

The fourth subtheme of Honouring Diversity reflects how the 'choice' that services offer to people must be meaningful, which requires the following:

Information. In order to actually choose to engage with something, people need information about what exists, how to access it, and what it encompasses. This information needs to be delivered in an appropriate way. One respondent wrote:

"Bring it to a level we can understand."

Options must exist. If there is little to nothing to choose from, there is no meaningful choice. The clinical, determinant, cultural, and holistic options described in this Theme cannot be chosen if they are not available.

Access. While services may offer a variety of choices, many people are unable to access them due to service criteria, waiting lists, or other barriers described in Theme One. A respondent described his experience in an inpatient unit:

“I was... given considerable freedom to implement my recovery goals and even though I returned to work, my room was kept available for me until I decided discharge was appropriate.”

Resource. Services that are not properly resourced may be lacking in quality, have high staff turnover, or be unable to remove barriers for people to engage with them (such as support with transport).

Sustainability. Respondents consistently described services that have lost funding and subsequently stopped – particularly those that are not clinical. Meaningful choice assumes that the activity and people someone is engaging with will not be subject to closure.

Integrated care. There are many public services, physical health services, and mental health and addictions services available. Theoretically, many of these are available as choices. However, respondents reported considerable difficulty in navigating these and accessing coordinated care. Service choice implies that the system will function well and deliver these services.

Flexibility. While most services offer some flexibility, service structures also prohibit the range of that flexibility and the choices available. One respondent described a

good experience with choice of appointment times at a community mental health service:

“They're also really flexible with meeting with me outside normal hours because I work full time and it is hard to leave the office.”

Staff. In most mental health and addictions services, clients have the right to request a different professional to work with. However, in practice this choice may not exist, particularly for services that are under pressure.



A CARING WORKFORCE



DEVELOPED

“[recognise] that lived experience is uniquely valuable in areas outside of peer-specific positions”



SKILLED

“Train employees to listen and not to bring their own prejudice”



RESOURCED

“People need to feel they have value, this can be achieved with better client to staff ratios.”



VALUED

“People are precious – staff and clients. Support overworked burnt out staff.”

Theme Three: A Caring Society – Workforce

The Workforce appeared as a strong theme from all groups of respondents. One described its significance:

“People, not [inpatient] walls, save lives.”

This section is divided into four subthemes: Workforce development (including the peer workforce), Skilled, Adequately staffed and resourced, and Valuing staff. Some of the information presented is a summary of content that has been covered in Themes One and Two. Other points are presented for the first time here.

Subtheme One: Workforce development

A sector that embraces manaakitanga and honours diversity requires significant development to the workforce for it to be authentic. This subtheme discusses workforce development, in particular, regarding diversity.

i. Diversity

Diverse disciplines. A workforce consisting of diverse disciplines is needed to provide the wide range of clinical, social determinant, and holistic community services described in Theme Two. This includes existing multi-disciplinary mental health and addictions professionals to provide specialist care and support more generalist health and social staff.

Community-based professions including community support workers (CSWs) and peer support workers (PSWs) would be in higher demand due to an increase in services that address social determinants and access to community activities. Community development activities for wellbeing (such as community support groups or activities) could be better led by non-health or -social sector staff, such as people who are already embedded in their communities. Interpreters are often necessary to increase access for people with English as a second language, and those who are hearing impaired or Deaf. Increased services also require increased administration and support staff.

Diverse people. The importance of therapeutic relationship and diverse services for a diverse population have been discussed in Themes One and Two respectively. Respondents identified that the current workforce lacks diversity and that they would prefer to work with people from a similar background or culture. This requires a workforce that is diverse ethnically, culturally, linguistically, in age, and in other facets of identity – two examples offered by respondents include gender and sexual identity, and autism. One respondent wrote:

“Talking therapy worked for me, but [it would be good] having someone who can understand Māori and can relate to how I am.”

Diverse places. Moving specialist mental health and addictions staff out of hospital buildings and into more local environments is necessary for more holistic, accessible, supportive services. Respondents identified that people who can offer basic support for distress should be in schools, workplaces, primary care, and community venues. They would also be accessible outside of business hours. Mental health and addictions specialists could be located in other government agencies and vice versa to increase access and integrated support to people experiencing distress.

ii. Peer workforce development

As discussed previously, peers were identified as important in survey data. According to one respondent:

“To be able to see a woman who was in recovery was incredibly important to me. I'd never see a person in recovery before. I didn't think it was possible.”

The following points summarise respondent feedback on developing the peer workforce.

Recognising the peer workforce. Some respondents felt that the peer workforce should be acknowledged and recognised more for its contributions. This includes the

value of professionals with lived experience in roles outside of peer support. A respondent wrote:

“There needs to be more recognition for the fact that lived experience is uniquely valuable in areas of mental health outside of peer specific positions, including management, advocacy and clinical roles.”

Growing the peer workforce. As described, many respondents mentioned the value of peers, their desire to meet or work with someone who had personal experience of distress, or the need for support groups.

Respondents who had trained as peer workers also spoke of the positive impact of ‘giving back’ on their recovery. However, it was highlighted that there were a limited number of roles for peer support workers, as well as insufficient positions in other professions that require lived experience as part of the recruitment criteria (such as Consumer Leaders). This was emphasised by one respondent in the following quote:

“People are graduating from [peer support worker] courses full of enthusiasm, only to find that peer support roles are few and far between.”

Another respondent wrote:

“[We] currently have extremely under-funded and over stretched lived experience advisors for systemic service improvement... this sets up the consumer movement again for burn-out and potential failure.”

Diverse peer disciplines. Alongside identifying the need for clinical, social determinant, and holistic services provided by diverse disciplines, respondents commented that peer roles should also be more diverse and should include delivering the afore-mentioned services. The peer workforce should be working in community development, health promotion and early intervention. Various roles and positions were identified such as consumer leadership roles, as clinicians, and facilitating support groups. One respondent also wrote that there are almost no independent peer individual advocates:

“There is currently only one (3FTE) contract across the whole country that funds individual mental health peer advocates (at minimum wage).”

Diverse peers. The importance of a diverse workforce (described above) also applies to the peer workforce. Some respondents wrote that they would prefer to connect to people who were similar to them – the term ‘true peer’ could be applied. One respondent wrote:

“[There should be specific] peer-support groups for youth, mothers and/or elderly people with lived experience of mental distress.”

In addition to the demographics described earlier, peer workers should have diversity of lived experience. This may include the nature of distress (such as psychosis or alcohol dependence), other life experiences (like experiencing homelessness or abuse), or services used (such as accessing an inpatient unit).

Supporting the peer workforce. Professionals working in peer roles should be supported with supervision, training, a culture that fosters excellence, and fair pay. A respondent observed that low pay for peer professionals works against recovery principles:

“I would like to see staff paid a living wage. People in recovery have oftentimes had to start again from scratch. They need a living wage so they can rebuild their lives, so they have a chance of living a healthy fulfilling life.”

Integrating the peer workforce. Some respondents suggested that peer support workers should be integrated with clinical teams, rather than working separately. One wrote:

“Offer peer support alongside clinical services. Blend peer workers and clinical teams.”

This is congruent with the theme of integrated services and teams that has been described already.

Transforming the peer workforce. A small number of respondents commented on the constituency of and leadership within the peer sector, indicating room for improvement.

Subtheme Two: Skilled

As discussed in previous Themes, a number of respondents had poor experiences with services due to feeling misunderstood or alienated by staff, or not receiving appropriate care. Their recommendations are summarised in the following points.

Universal skills. Universal skills. All professionals working in mental health should have a minimum competency in the following areas: culturally responsive; identity responsive (LGBTQIA+, youth); working with whānau; knowledge of other services; identifying mental and physical health problems requiring referral (metabolic syndrome, reactions to medication); and disability.

A respondent wrote:

“It's not necessary to educate people about every single disability... Train employees to listen and not to bring [in] their own prejudice.”

Specific clinical skills. Respondents from all groups described a lack of access to counselling or talking therapy. However, there was considerable additional feedback from two groups of people with specific diagnoses and their whānau. Firstly, respondents affected by eating disorders commented extensively on the lack of identification, acknowledgement, outpatient care, inpatient care, and whānau support for eating disorders. Secondly, people with a diagnosis of borderline personality disorder or experiencing emotional dysregulation and their whānau also described an inaccessibility to DBT and long-term psychotherapy.

Skills for other professionals. In line with the themes of prevention, early intervention, and integrated determinant and holistic support, respondents wrote that people working in the community (such as teachers) should have a 'basic grasp' of resilience, be able to recognise and respond appropriately to distress, and know who to contact if they are concerned.

Subtheme Three: Adequately staffed and resourced

A significant number of respondents commented on the level of pressure currently experienced by mental health staff and its impact. This included people who identified as mental health and addictions professionals and those who didn't, with the latter group including both those who had accessed services, and those who had not been able to.

Noticeable understaffing was described across primary, secondary, and tertiary mental health care, as well as NGOs. Respondents experienced this through waitlists, early discharge from services, and staff stress levels. In some respects, the level of staffing is not optimal according to the service mode.

One respondent shared an experience of being discharged from an early psychosis intervention service before the two year period (which is part of the service model specifications). In others, low staff numbers in proportion to people seeking help is part of the service design (such as the crisis team, who only assist those triaged as the most at-risk callers).

As established in Theme One (Manaakitanga), feeling cared for is very important to respondents and their wellbeing, and feeling unsupported by staff or a system has adverse impacts beyond the initial discomfort.

A system that embraces manaakitanga needs to ensure that staff have enough time to support those seeking help, as well as a working environment that minimises stress levels which, in turn, increases staff ability to be empathetic and build rapport. Such a system also provides opportunities for staff to reflect, connect with team members, and participate in supervision and professional development. The importance of a number of aspects of holistic support including working with whānau (and some experiences of a lack thereof) are described earlier in this document. One respondent who is a mental health professional wrote the following:

“Clients report they want to include their whānau, but we don't have the space, training, or energy to provide this service.”

Another professional respondent wrote about working in partnership and treating someone as an individual:

“People with a label need to feel they have value, not be boxed up. I think this can be achieved with better client to staff ratios.”

A number of non-professional respondents commented on their positive experiences with better-resourced early psychosis intervention and child and youth services.

High staff stress levels lead to high turnover, a lack of consistency, and a poor therapeutic relationship, described here by one respondent:

“[I was] passed like a parcel from clinician to clinician.”

Resource beyond staff time also affects the workforce. Respondents identified that client experience, and consequently staff job satisfaction, were affected by things such as access to petty cash to provide kai, cars and time to support people in community activities.

A lack of capacity in services, and services to refer to, was also identified as increasing stress on staff, as they are put in the position of turning away people in distress or who may be at risk.

Finally, a lack of time and resource extends to other sectors, such as physical health staff not identifying distress or asking about family violence.

Consequently, increasing staffing and resources in all services was a strong recommendation from respondents.

Subtheme Four: Valuing staff

A lack of adequate staffing and resource leads to the fourth subtheme: Valuing staff. As one respondent commented:

“People are precious – staff and clients. Support overworked burnt out staff.”

The following four points align with manaakitanga and the overarching philosophy of a Caring Society.

Staff wellbeing. Staff are members of our community, and people who also experience distress. Current conditions in services are adversely affecting their wellbeing. One person wrote:

“Good clinicians are leaving because work is affecting their own mental health.”

Safe and supportive workplaces. Workplaces where staff are valued by colleagues and management, where diversity is welcomed, and where bullying is addressed were identified by professional respondents as essential to their own wellbeing.

Pay that values staff. Some professions in mental health and addictions services are particularly poorly paid, such as CSWs and peer workers (formerly mentioned). Additionally, staff in any profession employed by an NGO are consistently paid lower wages than those working for a DHB, even though many NGOs perform distinct work that is not easily replicated. Low pay is demoralising, negatively affects determinants of health, and fails to attract the best employees. One respondent reported:

“Better wages for kaupapa Māori organisations’ workers would be great, when we have to run our business with crumbs it is a joke... We don’t want to leave our organisations to be paid better in mainstream because we make a difference doing the hard yards on the ground, and yet we receive poor wages.”

Job satisfaction. Mental health professionals’ job satisfaction is not only affected by high workloads, difficult workplaces, and low pay, but also tasks that limit the time available to do the work they love. Respondents who are mental health or addictions professionals wrote that they wanted more time to spend with people and build relationships, and that they were overly busy with things such as paperwork, particularly when administration support has been reduced due to budget pressures. They also described the trauma caused by working in services, and the lack of time or support to address that:

“I love working with tāngata whaiora. In the last eight years my caseload has quadrupled... I

have no clients with low risk anymore... the trauma I have witnessed indirectly or indirectly is not addressed or supported by other staff as no one has time to check if their colleagues are ok."



STRUCTURE & FUNDING



SERVICES & ACCESS

“If you were in a crisis they would find the time. They’ll listen, and they will give you the best care possible”



PRIORITISE EQUITY

“We need a service that works with the most vulnerable and advocates for those that do not have a voice.”



WHOLE GOVERNMENT

“recovery isn't an individual goal, it is about recovery of the region, infrastructure, and receiving all kinds of supports”



FAIR FUNDING

“Non clinical needs serious investment and prioritising and funding and support alongside clinical stuff.”

Theme Four: A Caring Society – Structure and Funding

Theme Three discussed the workforce required for a Caring Society. Respondents consistently commented on ways to structure services and the wider sector, as well as funding priorities. This Theme describes the common threads in survey data and summarises the lessons on Structure and Funding from Themes One, Two, and Three for easy reference. It is divided into four subthemes: Services and access, Whole of government approach, Equity, and Funding.

Subtheme One: Services and access

i. **Services available**

“Support options need to be as diverse as the people they're supporting.”

Themes One (Manaakitanga) and Two (Honouring Diversity) describe the services needed to create a caring society. The following is a brief summary:

- A variety of appropriate clinical options including talking therapies, medication, and long-term therapy
- Services across the spectrum of intensity such as peer support, counselling, support workers, peer support groups, specialist outpatient care, respite and retreats, day programmes, inpatient units, and crisis services
- Support with social determinants such as housing, employment, education, and finances
- Holistic and relationship-based activities that make a life worth living, such as coffee groups, culture and spirituality, diet and exercise, and personal development
- Services that take a number of person- and whānau-centred approaches like partnership, trauma-informed care, and working with whānau

- Services that are culturally responsive to Māori, Pasifika peoples, young people, and other groups.

These services should be integrated so that a whānau experiencing distress is provided with high quality, individualised support that helps them meet the goals they have identified.

A number of respondents spoke highly of youth mental health services in this regard. One person wrote:

“When accessing youth services, staff are extremely compassionate; there is a more of a holistic wrap around service for the whole family.”

Another respondent commented about a youth health organisation:

“They could be booked solid for literally months but if you were in a crisis they would find the time - and when they find that time, they won't rush you to get you out the door faster. They'll listen, and they will give you the best care possible without hesitation.”

Excellent youth mental health services may be useful case studies to understand and role model the components of a holistic, whānau-centred service in the New Zealand context.

ii. Access

Along with describing the services present in a caring society, Themes One and Two discuss what access to help would look like, and current barriers. In summary, there should be:

- Universal access to preventive initiatives such as health promotion, community support groups, and resilience programmes in schools

- Universal or very easy access to primary supports or interventions such as initial sessions with a counsellor or peer support worker
- Easy access to more ongoing support involving more expertise
- Services that are responsive to people culturally, age-wise, and identity-wise
- Services that are high quality and accountable
- Services that offer meaningful choice.

As described by one respondent:

“We can't continue to turn away people who are finally asking for help.”

Subtheme Two: Prioritise Equity

Respondents identified the role equity plays in disproportionately impacting some demographics' wellbeing, and that it is a structural issue. Following is a summary on themes from survey data about some groups with inequitable outcomes.

i. People with significant mental health needs

People who are diagnosed with a 'severe, chronic' mental illness have poorer physical health and determinant outcomes than people who are not.

As described in previous themes, things like poor housing, low income, and unemployment were identified as having a significant impact on wellbeing; conversely, poor wellbeing has a significant impact on determinants. Additionally, this population is often on medication that has adverse physical health impacts such as metabolic syndrome. One respondent identified:

“There is an entire population of forgotten people. There are people living in substandard housing, on huge amounts of medication, whose health is not adequately monitored.”

Another respondent described how the more someone is struggling with distress, the less likely they are to be considered a 'good client' or somebody who can be helped, and the less able they are to access appropriate services. They commented:

“We need a service that works with the most vulnerable and impacted by mental ill health, that targets motivation issues, takes into account the negative symptoms and also advocates for those that often do not have a voice of their own. People with serious mental health issues do not fit nicely into NGO services that are target driven and work with people who are 'motivated', can get to services and live close by. It leaves a massive group of people without access to services and no voice to speak up.”

ii. Autism and other neurodevelopmental disabilities.

Some respondents described the inequitable mental health and addictions statuses experienced by people with neurodevelopmental disabilities, and the compounding inequitable and inappropriate access to services (as described in Theme Two).

They discussed professionals' poor understanding of these disabilities and the lack of coordination, or aligning policy, between education and health services. One respondent said:

“Let's help people with Aspergers, [attention deficit disorder,] dyslexia, [autism spectrum disorder,] drug addiction etc instead of punishing them right through the school system with lack of help, then prison later.”

Another person commented on the experiences of people with autism in public services and the criminal justice system:

"I fear I will continue see the extreme suffering and human rights violations that should be completely avoided in such a progressive and forward thinking [place] such as NZ."

iii. Māori

Māori experience significant inequities regarding health and social determinants, and in access to health and other public services.

One respondent wrote about this in relation to the high rate of suicide among young Māori men:

"Please don't let our young Māori men slip through the cracks when multiple [suicide attempts] have been made."

A current aspect of society affecting equity for Māori is systemic racism. A respondent described how hard their brother tried to access services when in crisis; how he was turned away; and how he subsequently overdosed and died. They wrote:

"A big stocky brown male with a drinking issue, single with kids has no chance. The observer will have already made their assumption about him when he walks in the door of the doctors, of WINZ, his kids daycare, supermarkets... it is subtle, but it is everywhere like racism. Our story is bigger than what I write here. This is years of his soul being broken down piece by piece by the 'system'."

A number of respondents described the roots of Māori inequity and systemic racism in colonisation. One wrote:

“The seed was sown two generations back when our people gradually had to unlearn what being Māori meant i.e. loss of language, loss of whenua, loss of identity etc. We are now reaping the fruit of what that means with people not knowing who they are, where they come from and why they should be proud of who they are.”

Explicitly educating the workforce about the history of colonisation in New Zealand and its impacts is one suggestion from a respondent to work towards acknowledgement of the harm done, understanding of how it affects Māori today, and creating culturally responsive services:

“There needs to be programmes educating practitioners about the history of this country for Māori and what happened to their well-being from land confiscation to [being]homeless and in poverty. Those conversations need to be voiced.”

As described in Themes One and Two, respondents consider kaupapa Māori services important for wellbeing and service access. One respondent describes the problem with general services:

“Methodologies that focus purely on Western approaches without meaningful engagement with tikanga-based Māori methodologies and frameworks are doomed to repeat more of the same abysmal outcomes for Maori. Or is this intentional?”

Kaupapa Māori approaches are not just for Māori however, as many respondents identified. One person recommended:

“Multisystemic or wraparound interventions that include whānau, are intensive (low caseloads for practitioners, in client’s home if safe), kaupapa Māori for everyone - holistic view of health [and] prevention measures.”

The nature of the relationship-based, holistic approach benefits people regardless of culture or ethnicity. These respondents’ sentiments are reflected in this analysis which presents strong themes of feeling cared for, connectedness, choice, and holistic community activities.

Subtheme Three: Whole of government approach

A caring society with support for determinants, integrated services, and policies that foster community building requires a whole of government approach. One respondent compared building a society like this to recovering from a natural disaster:

“Having been through a natural disaster myself recently, it is obvious that recovery isn’t an individual goal, it is about recovery of the physical region, infrastructure, and also largely about giving and receiving all kinds of supports, including human connection.”

This is described in two parts: Structure of the mental health and addictions sector, and structure of the wider social sector.

- i. Structure of the mental health and addictions sector

The mental health and addictions sector is complex and fractured. A number of respondents described their difficulties navigating the sector, including finding out what is available, who is eligible, and how to access the service (as described in Themes One and Two). The 760 respondents to the survey also named around 450 distinct services or groups that they had accessed or would like to access, indicating the magnitude of the problem.

A sector with caring systems that are easy to navigate is one that has integrated and coordinated services. There is currently a distinct divide between mental health services and addictions services. There are also separations between each of the services provided by district health boards, non-governmental organisations, primary care practices, and community groups.

The private mental health and addictions sector is possibly removed even further.

The future sector must strike a balance between integrating different types of professionals (described in Theme Three) and maintaining hubs of expertise to foster excellent practice. Possible models to investigate include co-located services and virtual teams (where each team member may be based in their own workplace, but regularly work with the same team of professionals from other workplaces. Mental health specialists will not solely work delivering face-to-face clinical care, but also provide expertise to the wider team. One respondent wrote:

“Specialists [should be] a guiding pillar.”

According to some respondents, the public health sector should also have a degree of oversight of private mental health and addictions services to help navigate choice and ensure quality.

i. Structure of the wider social sector

As discussed in previous themes, integration of services providing support for social determinants was also identified as very important to wellbeing. Although a complex

challenge, a caring society requires public services that are coordinated and easy to navigate, and whose systems work with one another to meaningfully address people's needs.

The coordination of public services will not succeed without supportive policy. Within public services, policy must enable a high standard of service delivery, easy access to entitlements, and flexibility.

More widely, a caring society is one with strong community development to foster relationships and social groups; urban development for good quality housing; and well-developed transport infrastructure to support engagement in and access to services and activities. Employment support is such that parents are able to spend more time supporting their whānau and work more flexible schedules. As one respondent said:

“More needs to be spent on enabling parents to be parents rather than getting them back to work. Someone has to be crazy about a kid for that kid to develop into a healthy adult.”

When a whānau is facing a particular challenge such as someone in distress, it is easy to arrange things in such a way that they can support their loved one.

A whole of government approach also includes aligning the criminal justice system with the principles of a caring society. Respondents identified that a very high proportion of the prison population has mental health or addiction issues that are untreated, that are contributing factors to their offending, and that are part of a personal and intergenerational cycle of disadvantage. One respondent wrote:

*“Mental health patients and addicts should not be locked in prison or have disabling criminal records. It does not work. It makes things worse.
STOP DOING IT.”*

Another commented:

“Treat drug addiction treatment as health issue, not justice issue.”

A third respondent wrote:

“I am dismayed by some of the people I have encountered in prison who very obviously are experiencing treatable mental health issues (e.g. psychosis) but who remain untreated.”

Finally, a fourth reflected on current criminal justice policy, and wrote:

“We have an inherently abusive society that does not address issues that are trauma related with compassion, but with anger and a punitive response.”

Subtheme Four: Fair Funding

These services and systems require funding that supports and enables the goals of a caring society. The key considerations are described below.

i. Funding priorities

There is not enough current investment to fund services, let alone develop them.

One respondent wrote:

“[There are] insufficient mental health services across the board to be adequately responsive to population needs.”

However, respondents also identified that funding alone will not improve wellbeing – what is funded is also crucial. One comment was:

“We must stop thinking that the way things are work and would only work better if there were more of the same. We need to have a complete re-think about our mental health, remove it from the Ministry of Health and locate it under MSD.”

As described in Theme Two, supports for social determinants, and holistic activities that support relationships and a life worth living were very important to respondents' wellbeing; however, these are rarely supported with funding. A respondent wrote:

“Non clinical needs serious investment and prioritising and funding and support alongside clinical stuff.”

Sustainable funding of determinant support and holistic activities was also identified as important, particularly in the light of these services being subjected to cuts due to their non-clinical nature.

One respondent wrote of investing in other public services in a whole of government approach, which would improve wellbeing and lower the costs associated with specialist services:

“It would be better to put the money into affordable, safe and secure housing, and income support set at a level commensurate with a living wage, and with flexibility and abatement rates that allow fluid labour market participation.”

Investing in building communities that celebrate diversity (congruent with Theme Two) was put forward by another respondent as a funding priority:

“Save mental health dollars and lives by nurturing diversity early on.”

Community building was identified as another area that would build caring relationships and resiliency:

“Start now so we can build communities that care enough to prevent situations for their neighbours.”

Respondents described the need to invest in prevention and early intervention while simultaneously funding services for those who did not receive that when they were young. One person wrote:

“It must be 'new money' because the service demand reduction benefits of early interventions... will not pay off for 5 to 20 years. Meanwhile existing services need to cope with people for whom early intervention is already too late.”

ii. **How we fund**

Effective funding models and mechanisms are required in order to foster a funding environment where contracts are delivered in a way that is meaningful to the people they serve. The following were suggested by respondents:

Individualised funding. A model whereby each person is given funding to allocate to the services and professionals they desire – like that used in some parts of the disability sector – was suggested by more than one respondent. This would maximise choice and allow flexibility.

Led by communities. Several respondents commented on the value of funding being handed to the communities they are targeting – such as by Māori, for Māori – instead of being ‘done to’.

NGO contract funding models. A small number of respondents criticised the contracting models used between DHBs and NGOs. One person wrote about the lack of sustainability of NGO services, the resource NGOs must use to reapply for funding, and the intangible elements that contracts do not assess:

“Failure to ‘win’ a contract can result in closure and a service gap whilst the new provider gets up to speed. Institutional knowledge and established relationships are of course lost.”

It is also a model that incentivises competitiveness and low wages, which additionally do not attract the best staff.

“NGOs are pitted against each other in competitive tendering processes which discourages cooperation and I’ve even seen open hostility.”

ACC. Respondents also described their inequitable access to services based on whether or not they were eligible for ACC, which acts as a parallel health service funding mechanism with arguably arbitrary eligibility criteria.

Accountability. A respondent identified the need for increased accountability for all public mental health and addictions services:

“Many more checks and balances should be in place to ensure contracted services are actually being delivered - not always is this the case now, [and] there should be more accountability for places that do not provide contracted services.”

Funding of DHBs. The inflexibility present in some NGO contracts is also reflected in government funding of DHBs, where the majority of the money is mandated toward clinical services. This generates some of the problems mentioned earlier – such as

holistic services and administration staff time being defunded under budget pressure.

A recommendation of how a new structure encompassing these themes in layers from whole government and commissioning to communities is presented by Changing Minds in the Appendices.

Discussion

The four themes of Manaakitanga, Honouring Diversity, A Caring Society – Workforce, and A Caring Society – Systems and Funding capture and discuss the experiences and thoughts of the 760 survey respondents.

Many lessons and recommendations have been included in these themes; consequently, they will not be reiterated here. Instead, this section reflects on the four themes to discuss how the Mental Health Inquiry can learn from the past as it advances New Zealand's mental health and addictions sector forward.

The mental health and addictions sector has periodically undergone reform, with deinstitutionalisation as a recent significant example. More frequently, it adopts new approaches or philosophies such as restraint and seclusion minimisation, trauma-informed care, and the recovery model.

Such reforms, developments, and new perspectives are incredibly important and key contributors to increasingly consistent and quality support for large populations. However, the sector has abandoned some models of care and aspects of value along with them.

While many consider current services to be of superior quality compared to those in 'the bad old days', there are supports that have been highlighted as no longer available that were present 'back then'. Attempting to revisit abandoned models is socially uncomfortable, thereby preventing a non-judgemental, naïve inquiry into recent history; constraining our understanding of the lessons learned; and limiting our ability to avoid past mistakes and best serve our communities.

There are a number of thematic threads throughout the survey data that reflect this. These illustrate the unchanging nature of distress and important things in life, and some similar challenges associated with service provision over the last forty years.

For example, Theme One – Manaakitanga – explores the importance of feeling connected, and of feeling cared for. Subtheme two summarises an enormous volume of survey feedback to briefly describe challenges for people accessing services, and

the harm caused by this. Under the point 'waiting' times, a quote from one respondent is included:

“Long gap of many months between treatment at [addictions rehabilitation] and entry to [long term mental health rehabilitation] led to relapse/loss of motivation and loss of opportunity for treatment.”

There is another topic illustrating perceptions of the past and present that appears among respondent feedback. The violence experienced in services, described in Theme One, may be associated most commonly with mental health institutions, or inpatient units some time ago.

As mentioned above, restraint and seclusion minimisation, trauma-informed care, and the recovery model have since become tenets of modern service provision. However, we also know that people do still experience violence and trauma in services, and when being placed under the Mental Health Act.

When reading stories such as these, it can be tempting to abdicate responsibility to either the police (who are not mental health professionals), or to the victim (as psychosis is easily stigmatised).

Examples of access to residential addiction treatment, meaningful choice, and violence and trauma in services are not intended to argue that previous services were better and safer than current ones. They are only meant to illustrate that our perceptions of the past and present are probably vaguely accurate at best; and that our disinclination to examine mental health and addictions sector history with a curious approach – and current philosophies as a devil's advocate – are doing a disservice to the people we serve.

This comment provides a reminder of the original intent of asylums as place that is peaceful and safe:

“I understand we do not want to return to the negative days of modern asylums, but the original principles of somewhere peaceful and safe makes sense.”

“Somewhere peaceful and safe” reflects a place to live and a safe community to be part of, identified by survey respondents as important – and lacking – in Themes One and Two. The respondent points out the similarities to current day services to the system disbanded by the early 1990s:

“Our current residential services are often mini institutions in disguise.”

However, they still acknowledge that institutions (generally considered far worse than current residential services) did one thing well that is now done poorly. Sector reform at the time either did not adequately see, or plan for, or succeed in addressing the unstable and inadequate housing that is now a key contributor to stress, distress, physical health issues, and inequity.

Comments from other respondents illustrate the unchanging nature of distress, and what matters to people when they are receiving support. One person wrote:

“I have been in and out of secondary mental health services since I was 15 and I am now in my early 60s... I believe the biggest fear for people is the fear of being judged. Whether I am sick or not, my truth is my truth and it is hard to open up and speak when others don't believe you.”

Not only has this held true for the respondent across their lifetime, but validation and therapeutic relationship were the first topics to be discussed under Theme One – Manaakitanga. They then go on to describe their observations on changes in the mental health and addictions sector since the early 1970s:

“I have seen a lot over this time and find there has been some change but a lot of shuffling around calling it something different but really is still the same old.”

The frustration at the Mental Health Inquiry and its consultation process reflects the understanding that the problems and solutions are already known, but change is slow. However, the public is enthusiastic about participating – many respondents expressed gratitude for being able to tell their stories.

As the sector transitions from confirming the issues to moving into action, there is a unique opportunity to engage a much larger and more representative group of people to actively be part of this change.

It is important we value and acknowledge the input so that participants do not feel as though their input has been received but will have little impact on transforming the mental health system. This sentiment was echoed by a number of survey respondents:

I like that you are asking for our input. I only hope that you listen as these questions have been asked before but... nothing has changed."

Limitations

Limitations to this research include survey design (some ambiguous wording of both multi choice and open answer questions, and questions focussed on services), self-selecting respondents, a low number of respondents from some demographics such as Pasifika and older adults, and the size and complexity of the dataset in relation to time and resource.

While this has been subjected to some peer review, it was limited by the short timeframe. This limited time has also reduced the ability to research Māori and Pasifika cultural concepts in-depth; however there is an expectation that the Panel will take leadership from those communities when understanding how the themes may apply.

Conclusion and Principle Recommendations

There is strong agreement on the major issues affecting the wellbeing of New Zealanders in regard to mental health and addictions.

The thematic analysis of the responses from 760 members of the public who completed this survey asserts that it is important that people feel cared for, that they feel connected to one another, and that they are recognised and treated as individuals.

These principles span every aspect of their lives; and it is not only the workforce that contribute to these domains, but also the very large and complex systems they work in.

These findings are congruent with national strategy documents such as Blueprint, Blueprint II, and Rising to the Challenge; with leadership from the peer workforce, Māori, and clinicians; and with formal evidence on the drivers of distress and inequity, the strengths and weaknesses of modern services, and the barriers to service access. The solutions are extremely complex and require sector transformation and reform, rather than gradual adjustments.

Many specific recommendations from respondents have been included within each theme already, and Changing Minds has included a list of smaller, more specific recommendations that fall outside this data in the appendix - "things that will make a difference"

The following 6 recommendations over the page take this complexity into account and are accordingly broad and principle-based:

1. A whole-of-government approach is required to significantly improve the wellbeing of New Zealanders. This includes public services and policies that are intentional and deliberate, and based on good evidence and partnership rather than political agendas, media, or pressure from vocal minorities.
2. Significant investment is required in both initiatives that directly support mental health, and other public services that determine wellbeing.
3. A diverse group of leaders with integrity – including mental health and addictions experts with lived experience, Māori, clinical mental health experts, and social sector experts – are required for this transformation.
4. These leaders must take a bold and critical approach; be constantly willing to learn, question, and challenge; and must draw on the considerable amount of information, expertise, and strategies that already exist.
5. The process must be reflective, evaluative, self-critical, and transparent from the beginning.
6. The focus must always be on valuing people and whānau, and creating a caring society.

He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata.