



PEOPLE'S MENTAL HEALTH REPORT



**A CROWDFUNDED,
CROWDSOURCED
STORY-BASED
REPORT**

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from ActionStation.

ActionStation
people powered change 

CONTENTS

1	Foreword
2	Executive Summary
6	Robbie's story
7	Why a People's Mental Health Review
8	Kyle and Mike's story
8	What is the People's Mental Health Review?
9	Terms of Reference
9	Whose stories are not here
10	Whose stories are here
10	Background and context to this review
10	New Zealand mental health services by the numbers
10	Previous Reviews of Mental Health in New Zealand
11	What do the stories tell us?
13	Access and wait times
13	Suicide
14	Underfunding
14	Need for more treatment options
15	People who work in mental health under strain
16	Entrenched problems including compulsion
17	Respect and dignity
19	Culturally appropriate care
19	Compulsion, seclusion, capacity and human rights
20	Trauma and social and economic stress
21	Trauma
21	Sexual and family violence
22	Colonisation
22	Whānau and family
23	Post Natal Depression
24	Children
24	Lack of oversight
25	Police filling in
25	Prisons /Corrections
26	What needs to change?
26	Recommendations from the Review
27	Notes on Methodology
28	

FOREWORD

Until 25 or so years back thousands of people resided, often involuntarily, in large custodial psychiatric hospitals. An official Ministry of Health report in 1986 referred to them as Dickensian, overly using drug therapies, seclusion and restraint. It concluded that most patients would not be there if community services and supports were available. A number of official inquiries and reviews conducted around that time reached similar conclusions and recommended major reforms in mental health care.

Today the Dickensian monstrosities have gone. Mental health is more out in the open. There is a wide spectrum of care and support is provided by general hospitals, clinics and community services. Many people are doing good things and making a positive difference – mental health service users/survivors, family members and workers in DHBs, primary care and other health and social services. I have no doubt that vastly more people are receiving appropriate care than in the past. I also see increasing gaps, if not chasms, in service provision. Ministry officials have, uncharacteristically, publicly noted marked increases in demand and heavy strain. Unions and staff have commented similarly. There are ongoing references by coroners and the media to serious service shortfalls and breakdowns. There are disconnects between primary and secondary care, with people experiencing severe mental health issues having major physical health problems and greatly reduced life expectancy. People with common anxiety, affective and substance use concerns are often unable to access appropriate and timely treatment and support. This is unacceptable.

Factors outside the health system – housing, poverty, unemployment, discrimination, erosion of human capital, isolation and loneliness – are also affecting health and wellbeing. These factors also require attention, in their own right and in relation to health and social services.

This report, the *People's Mental Health Review*, collates direct accounts of the lives and experiences of a wide spectrum of New Zealanders. I commend those who initiated it and contributed. It adds weight to the call for a formal review or inquiry into our mental health services. The issues and concerns today seem similar to those that led to the Mason Inquiry a generation ago. It is again time to take stock, obtain an accurate overview of what we are doing well and where we are falling down, and chart a better way forward.



Professor Max Abbott CNZM

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EXECUTIVE SUMMARY

Why a People's Mental Health Review:

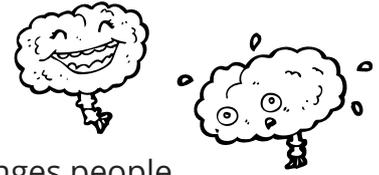
ActionStation's first campaign on mental health was in response to the announcement in February 2016 that \$140 million was being cut from funding for mental health services across the country. ActionStation members responded with a campaign focused on cuts to mental health funding in Canterbury. Within weeks the Government backtracked, restoring \$20 million in funding to mental health services in Canterbury. After that hopeful win, members of the ActionStation community wanted to do more. They wanted to help tackle the problem nationally. So when Kyle MacDonald and Mike King came to us with a proposal to conduct the *People's Mental Health Review*, we said yes. Kyle and Mike were hearing the same story over and over again: a story of frustration at being unable to access mental health services; a story of despair and hopelessness; and on occasion a story of tragedy. So they teamed up with ActionStation to do what the Government would not do; give space to the stories of what was really going on, and going wrong, in our mental health services.

What is a People's Mental Health Review:

The *People's Mental Health Review* is a grassroots initiative, crowdfunded by members of the ActionStation community and supported largely by the efforts of volunteers. The Review consisted of an open call to people who had experience with New Zealand's mental health system to share their stories. We invited people to submit their stories online, with the option to be anonymous, and welcomed stories in various formats. The Review received more than 500 stories. Of those stories 276 came from people with experience of using or trying to access mental health services, 78 stories from people who work in mental health services, and 154 from people whose family members either used or worked in mental health services.



KEY THEMES BY THE NUMBERS OF STORIES



Positive vs. negative experiences

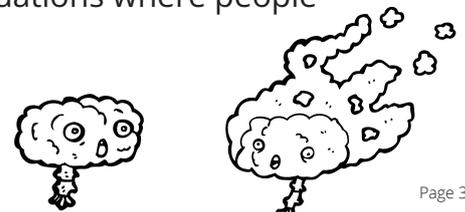
- 464 of the stories (93%) focused mostly on problems and challenges people experienced either using or working in mental health services.
- 36 stories (7%) were about positive experiences that people had while using or working in mental health services, this includes stories that were mixed but contained explicitly positive elements.



Thematic analysis

- 179 of the stories submitted (36%) were about problems accessing mental health services including long wait times, and needing to be in crisis to get access.
- 112 of the stories (23%) were about strain on workers, and other negative impacts of an overstretched and under-resourced mental health system.
- 102 of the stories (21%) described trauma, including physical and sexual violence, most often as a cause of mental distress, sometimes as a result of trying to access mental health care. Of these, 30 stories were specifically about sexual violence.
- 94 of the stories (19%) were about children and young people, many of these were submitted by adults whose experience with mental health services started when they were young.
- 94 of the stories (19%) were about suicide, including attempted suicide and stories submitted by friends or family members of people who died by suicide.
- 85 of the stories (17%) were about the lack of respect, dignity, choice and control accorded to people using mental health services.
- 78 stories (16%) were specifically about people who work in mental health services
- 69 of the stories (14%) were about medication, mostly about the negative side effects of psychiatric drugs, and the lack of choice for other treatment options.
- 60 of the stories (12%) were about the economic, social and cultural factors that affect mental health and well-being, the specific issues that came up include work stress, housing problems, discrimination and bullying.
- 52 stories (11%) were explicitly about the cost of accessing health services being a barrier, often these were stories where people didn't meet the threshold for publicly funded mental health services, but couldn't afford private therapy.
- 30 stories (6%) were about compulsory treatment.
- 25 stories (5%) were about the involvement of police in situations where people were experiencing mental distress.

Note that some stories mentioned multiple themes (e.g. people identified problems with access and trauma) so the percentages add up to greater than 100%.



THE KEY THEMES IN THE REPORT INCLUDE:



Access and wait times: Many people have had difficulty accessing appropriate and timely mental health services, and in particular, many people faced long wait times to access publicly funded treatments. In a number of stories, people expressed concern that they couldn't get the help they needed until their health had deteriorated to the point of crisis. As a result, people observed, resources that could be more constructively used for community-based early intervention are absorbed by expensive and, in too many cases, ineffective crisis management.



Need for more treatment options: Many people said they didn't have appropriate treatment options. Specifically, people expressed concern about the harmful impact of an over-reliance on medication, partly due to a lack of resources for a wider range of treatments, including a full range of talking therapies, accessing peer support, or simply having someone who could take the time to listen.



People who work in mental health under strain: Both service users and mental health workers described an under-resourced, over-worked and stressed mental health workforce. This has resulted in negative impacts on the health and wellbeing of people working within the system as well as on the service they are able to provide to people seeking their support.



Entrenched problems including compulsion: Essential mental health services need an urgent increase in funding and a review of where those funds are spent. But money won't fix everything. The stories in this review show there are entrenched problems in the ways we think about and respond to people experiencing mental distress in this country. People described being treated in ways that were dismissive, dehumanising and punitive, and felt they had no say or power over their own treatment. New Zealand also continues to have a high rate of compulsory treatment orders, a concern which has been raised by human rights bodies repeatedly in the past.



Social and economic stress: Mental health and wellbeing in New Zealand is undermined by many social and economic factors that operate outside the mental health system. This includes the ongoing impacts of colonisation, and the damaging effects of all forms of discrimination and violence, including the high levels of domestic and sexual violence in our country. Mental wellbeing is also negatively affected by financial stressors including job insecurity, low-wage work and the lack of affordable housing.



Lack of oversight: Some of the stories in this report raise very serious issues, and the people who submitted those stories describe how very hard it is for individuals to take on the challenge of holding the mental health system to account. This highlights the impact of losing the independent monitoring and oversight that was previously provided by the Mental Health Commission



THE RECOMMENDATIONS FROM THE REVIEW:



- **An urgent funding increase** for mental health services for acute and community based mental health services nationally. This requires a focus on increasing community based service access and treatment choices for people using mental health services to provide interventions early. It is also essential to support the people who work in mental health services, by easing workload pressures and enabling them to offer the services and support people want and need.



- **Fully independent oversight** of the mental health system in line with minimum obligations set out in the Convention on the Rights of Persons with Disabilities. This could be in the form of restoring the Mental Health Commission, the creation of an independent Disability Commission, or the inclusion of dedicated Mental Health Commissioners under the current Human Rights Commission. These would include clearly designated roles for those with lived experience.



- **An urgent independent inquiry** into the structure and provision of mental health services in New Zealand. The terms of this inquiry should be informed by New Zealand's obligations under the Convention on the Rights of People with Disabilities and the need to provide for healthy families and healthy communities, and should allow for the increasing numbers of people seeking support from mental health services. We also recommend that **a Royal Commission of Inquiry be carried out into the long-term and entrenched problems** highlighted by this review.



- **A national education programme** to support all New Zealanders to understand what mental health is, and what mental health services provide, that operates in the education system and wider society. This will ensure that the work of change is understood by all New Zealanders so people with lived experience are included by our society rather than having to endure prejudice and discrimination.

ROBBIE'S STORY

When I went to university my student debt started to pile up. The contact time with teaching staff was reduced until office hours with our tutor were one half hour per week. My anxiety became a mild depression.

In November 2016, two years after graduating from university, I was thinking about suicide and worried I might take action. I googled mental health support services and texted the Depression Helpline at 4202. They suggested I get support from a counsellor I could talk to in person.

I considered going to Evolve, who provide free counselling for people 24 and under, but they were only in a position to take on clients in desperate need of support. I spent \$50 to visit my GP, which was a lot of money for me at the time. He wrote me a prescription for Escitalopram, and recommended I go to the Wellington Anxiety Specialists. Unfortunately, it turned out that the Karori Medical Centre was no longer affiliated with the Wellington Anxiety Specialists, so I couldn't be referred to them directly. I visited my doctor for another \$50, and he filled out a form to help me get financial support from WINZ.

I visited WINZ for the first time that November. It turned out my doctor had filled out the wrong form. Unbeknownst to me, I was also eligible for other financial support because of my low income. I was given a large number of forms to fill out, and asked to provide a lot of supporting evidence. It seemed unlikely to me that a person with depression would make it through the paperwork.

I don't get letters - I get emails, which made it difficult to prove my address. I don't own a printer, so I made regular visits to my parents' house to use theirs. I was lucky to have a passport and driver's license, because I needed two forms of identification. My boss had accidentally stopped sending me my payslips, which was another obstacle. I had letters signed by landlords and flatmates. I visited the Wellington Anxiety Specialists for the second time; they signed a document to confirm that they would offer me support. I visited my GP for the third time, for another \$50, this time to have him fill out the correct form. He was away at the time. I had fifteen minutes to convince a new doctor that I was at risk of killing myself.

Escitalopram can increase anxiety when you first start taking it, and by February 2017 I had still not successfully received counselling. I had an emotional breakdown, and I cried in my room. I made a noose and rested my head in the loop. I let the weight of my head pull the noose tighter. I found it comforting to think that there was a way out. There was a moment of stillness, and I thought of my family. I didn't want them to find me there. I took my head out of the loop and called my friend. The next week my parents found a way to pay for counselling. They couldn't afford it, but they reached into their overdraft.

Last week [in late March] the money from WINZ came through"

- Robbie Nicol, 25/03/2017

WHY A PEOPLE'S MENTAL HEALTH REVIEW?

ActionStation's first campaign on mental health was started in response to the announcement in February 2016 that \$140 million was being cut from funding for mental health services across the country. Of most urgent concern to ActionStation members were cuts to funding for mental health services in Canterbury, where many people are still experiencing mental distress in the wake of years of earthquakes.

In response to these cuts 15,000 ActionStation members signed a petition calling for the restoration of funding to CDHB for mental health services and hundreds of people from all over the country emailed the Minister of Health. ActionStation members also chipped in to fund a video about a young man in Christchurch who had experienced significant mental distress during and in the years following the earthquakes. Within weeks of the campaign launching, the Government announced a backdown on these cuts, and an extra \$20 million in new funding for mental health services in Canterbury over three years.

The success of this campaign, confirmed by mental health service providers in Canterbury who told us they believed funding wouldn't have been restored without the efforts of ActionStation members, inspired us to do more. So when Kyle MacDonald and Mike King came to ActionStation with the idea of a *'People's Mental Health Review'* we knew we were ready to make it happen.

It was time to stop asking for a review, and start doing it ourselves.

This review was an extremely ambitious project for a small, crowd-funded campaigning community. It has involved many hours of work for our team of staff and volunteers. Our co-director Laura O'Connell Rapira worked with Kyle and Mike to design the review process and get the word out around the country, resulting in more than 500 submissions all of which were carefully collated by research intern Alex Davis. Every one of those submission was then read, more than once, analysed and coded by our co-director Marianne Elliott, and volunteer researcher Ann Cloet, both of whom also conducted a number of in-depth interviews with people who were happy to provide more context to the stories they had submitted. Additional research support was provided by ActionStation volunteer Lou Hutchison. We also contracted PhD candidate Jonathan Beazer to carry out an independent audit of our data analysis. This report was written by Marianne, with editorial input from Ann Cloet and Kyle MacDonald. All of which is only possible because members of the ActionStation community chip in to fund this work.

Our hope is that the courage of the 500 people who submitted their stories to this process will be rewarded by seeing their concerns taken seriously, along with their hopes and recommendations for a better future for mental health services in New Zealand.

KYLE AND MIKE'S STORY

I deal in stories. When people come to see a therapist, the first thing they do is tell you their story, the events of their life, the plot and narrative of their current struggles. It is the most human need, to speak out loud and have another hear, believe and talk with us. Mike King and I wanted to conduct the *People's Mental Health Review* because in our work we were beginning to hear the same story. It was a story of frustration at being unable to access Mental Health services; a story of despair and hopelessness; and on occasion a story of tragedy.

In the face of the Government's refusal to engage with the idea that our country's Public Mental Health Services were in trouble, we decided to team up with ActionStation, and hold our own review.

And so, the People's Mental Health Review was born.

So with a team of effectively four people, some volunteers and no budget we were able to collect over 500 submissions, receive the official endorsement of the Public Service Association, the New Zealand Nurses Organisation, the New Zealand Association of Counsellors and the Drug and Alcohol Practitioners' Association Aotearoa–New Zealand – along with many individual professionals who not only supported the review, but made their own submissions.

Most importantly though, we have been able to stop talking about numbers, and start talking about people's experiences.

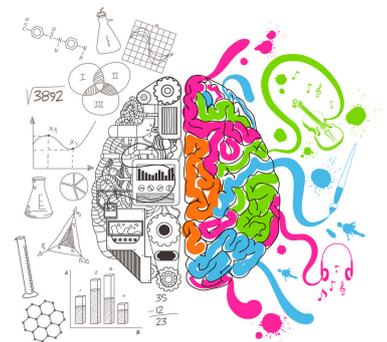
We can fix this, but we need to start listening, and we need to act. We hope this is a start.

- Kyle MacDonald, *People's Mental Health Review*

WHAT IS THE PEOPLE'S MENTAL HEALTH REVIEW?

The *People's Mental Health Review* was an open call to the public to share their stories. We invited people to submit their stories online, with the option to remain anonymous. We are not suggesting that these stories represent the full range of experiences of people who have used or worked in mental health services in New Zealand. Nor do we claim that the stories can be interpreted quantitatively, to make claims about how many people in New Zealand have had these different types of experiences.

We do, however, note that the themes which emerge from the more than 500 stories submitted to this review are consistent with previous reviews of mental health in New Zealand, and we do know that they reflect the experiences of many people working in and using mental health services in our country.



TERMS OF REFERENCE

The terms of reference for the *People's Mental Health Review* were intentionally broad, and designed to allow anyone involved with mental health in New Zealand – from mental health professionals to those with either personal or family experience of the system – to tell their story.

The aim was to develop a full picture of how the system is performing now: the good, the bad, and everything in between, and we encouraged anyone with a story that would help illustrate this to take part.

The review was founded on the belief that those we don't need more statistics – instead, stories will help personalise the problems within the system, galvanise popular support and force the Government to take notice. And, hopefully, provoke a Royal Commission of Inquiry or a Ministerial Inquiry into New Zealand's Public Mental Health System.

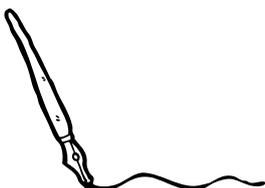
Because sharing personal stories about mental health can be tough, the review was designed to allow those taking part to remain anonymous if they want, and the majority of people did.

WHOSE STORIES ARE NOT HERE

There are some obvious gaps in the stories. Some are unsurprising, and reflect the barriers some people face in telling their stories. For example we got very few stories from people with experience of mental health services in prison, or from young children. We did, however, get stories from people about their experiences as children, and from the parents of young children. Other gaps may reflect the limits of an online submission process. For example, we received fewer stories from older New Zealanders than demographics suggest we could expect.

We were also contacted by some people who wanted to tell their stories but were unable to do so, either because of suppression orders in place during a coroner's inquest, or because they had signed non-disclosure clauses as part of settlement agreements. Their stories are not reflected in this report.

Perhaps most importantly, we acknowledge that people who have had negative experiences of mental health services may be more likely to be motivated to submit their stories to a review like this. Even so, thirty six people submitted stories of either partially or largely positive experiences accessing or working in mental health services, and others made it clear that some aspects of their experience had been positive.



STORIES CREATE EMPATHY AND EMPATHY HELPS DRIVE CHANGE

WHOSE STORIES ARE HERE

When we launched the review, we called for stories from three groups of people:

- People with personal experience of using - or trying to use - public mental health services;
- People who had a family member who had used public mental health services, and
- People who worked in the public mental health system.

Not everyone indicated which of these groups they fell into but of those that did:

- 276 stories were by people who have used or tried to use public mental health services.
- 78 stories were by people who work or have worked in public mental health services.
- 154 stories were by people whose family member has used mental health services.

Other common reasons given for submitting included:

- Work in primary health care
- Work in community organisations including Lifeline
- Work in alcohol and drug rehabilitation
- Work in or use private mental health services

* Note that some people selected more than one of these categories, e.g. they were someone who worked in the mental health system and they also had a family member who had used mental health services.



BACKGROUND AND CONTEXT TO THIS REVIEW

In his 2015 annual report, the Director of Mental Health Services Dr John Crawshaw reported that “a record number of people accessed specialist mental health and addiction services” and that, as a result, “services are experiencing increasing pressure.”

He also reported that mental health outcomes continue to be inequitable in New Zealand, listing Māori, Pacific peoples, people with disabilities and refugees as groups that disproportionately experience mental health issues. Māori are also over-represented under the Mental Health Act. He also acknowledged that New Zealanders with moderate mental health needs, who do not meet the threshold for specialist care, are not having their needs met.

New Zealand mental health services by the numbers

In 2015, specialist mental health or addiction services engaged with 162,223 people (3.5 percent of the New Zealand population), an increase from 143,060 people in 2011.

In 2013 a total of 513 people died by suicide in New Zealand. Provisional figures for 2015-16 show 579 people died from suicide.

In 2015, 91 percent of specialist service users accessed only community mental health services, less than 1 percent accessed only inpatient services and the remaining 9 percent accessed a mixture of inpatient and community services.

Previous Reviews of Mental Health in New Zealand

In 1998 the Mental Health Commission published *Blueprint for Mental Health Services in New Zealand: How Things Need To Be*. The Blueprint emphasised:

- The need for a recovery approach in the delivery of services.
- The importance of meeting the needs of Māori and Pacific people.
- The needs of families of people with mental illness.
- The need for people to be able to move easily from one service to another.
- The importance of respect for the rights and recognition of equality.

In 2012, in its final report, the Mental Health Commission published an update on the Blueprint in which found that “support for people with complex and enduring mental health and addiction problems and their family and whānau has come a long way.” However, “we need to greatly expand access to services ... and will know we are being successful” if, amongst other things:

- No one who seeks help waits for help.
- Support for infants and mothers, children and youth has increased significantly.
- Support for populations who experience inequality of outcomes has improved.

As you'll see in this report, the stories submitted to the *People's Mental Health Review* help to show how far we still have to go on this journey.

WHAT DO THE STORIES TELL US?

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The stories submitted to this review revealed some recurring problems in our mental health system. The next section of this report will illustrate those themes using short extracts from many stories. This approach has the advantage of giving voice to a large number of the people who submitted to the review. But that comes at the expense of seeing the full story of each person's experience and the ways in which each of the themes highlighted in this report overlap and interact with each other.

So, first, a story.

STORY FROM SOMEONE WHO WISHED TO REMAIN ANONYMOUS

"It's been 10 years since I first used mental health services. 10 years, three involuntary admissions, one stint in respite, more doctors than I can remember.

Some doctors were great. They believed what I told them about my illness, they went out of their way to help me, they were kind and compassionate.

Others were just mediocre. Seeing them was a waste of time since they couldn't or wouldn't do anything. Some were awful. One literally told me she wasn't going to give me what I knew were my rights when she committed me. Instead she had the police handcuff me and cart me to a locked ward in the back of a police car. I kept asking the cops why it was a crime to be sad. Another told me she could tell how depressed I was by my cheekbones, not anything I told her.

During the first stay in hospital more than one nurse sat me down and asked me if I was faking being crazy to write a story for the newspaper or for research with the university, saying outright that I wasn't sick enough to be there. I attempted suicide three days later and all of a sudden they didn't want to let me go home, but for some reason they did anyway. "You'll be back here by this time tomorrow" one nurse said. I think I stayed alive just to spite that woman.

I got better, but it seems the system got worse. Now they'd never put me in hospital, the system has always been an ambulance at the bottom of the cliff, but now the cliff is higher and the ambulance has three flat tyres. You have to be really fucked up to get any help.

When my GP said last year that I needed to see community mental health because she couldn't manage my medications, fair enough, as she's not a psychiatrist and I take some uncommon drugs, I learned that now nurses do "screening calls" to decide if you're sick enough to see a psychiatrist, or if your GP can handle you. I wasn't sick, so I was handed back to my GP. Despite the entire reason for my referral being that my GP couldn't handle my needs, and she knew it.

Another piece of ridiculousness came just last week. I have ADHD, and take Concerta and Ritalin. The MoH says that to be prescribed stimulants you need to have a special authority number. And you have to get that number from a psychiatrist, every two years, because apparently the MoH thinks ADHD can just magically evaporate over that time.

My number had run out. I would need to see a psychiatrist to get another one, so I asked to be referred to one. The nurse at my GP's office said it wasn't worth it, ADHB does not give psychiatrist appointments just to get special authority numbers. So one branch of the system says I have to see a psychiatrist to get medication, and another says that being able to get medication isn't worth taking up one of their appointments.

The nurse said the only way to get the special authority number was to see a private psychiatrist. If I didn't have \$400 to pay for an appointment in the private system? Well, I was shit outta luck then. The public system doesn't care that I can't function, do my job, or be a productive member of society. They don't have the resources to actually give a shit anymore.

I've promised friends that if things get really bad, I will call the crisis team. But I'm not sure I can keep that promise, because I know what a crisis is to the system, and unless I'm actually putting the rope round my neck, I'm not having one.

The mental health system, for better or worse, has kept me alive. Without it I wouldn't be here. But it doesn't offer much in the way of hope.

I guess the budget doesn't stretch to hope."

ACCESS AND WAIT TIMES

One of the major themes in the stories is problems related to accessing mental health care - especially timely access and early access before a situation has escalated to a serious or even crisis situation. Approximately a third of the stories (179) were about access. Of that 179, 84 stories specifically expressed concern or commented on excessive wait times, while 14 talked about the need for early intervention.

"The system talks about early intervention, but it doesn't deliver this. A person has to be severely unwell before action is taken."

A lot of people expressed confusion and even despair at the lack of services available to people experiencing mental distress who were not yet in the grip of a life-threatening crisis.

"Since October I've had four doctor appointments—in the the first two I was essentially (and once, literally) told "chin up" after tearfully conveying to them my depression and anxiety and desire to not exist. The third was supposed to be a huge win—I was referred to a local mental health services clinic to assess whether I could get public health support. After two weeks of no follow-up, and ringing daily to hear back from them, it turned out my information hadn't been taken anywhere. So I emailed my GP in desperation. Finally, it was taken higher up and the results came back immediately: they didn't think I fit the criteria to get public funding. I sobbed on the phone to my GP, feeling incredibly helpless. I'd waited so long. I was told that this appointment was what I had to wait for, to keep my chin up for. And then nothing."

One person described this as the 'grey zone' and wondered how many people were lost in it.

"Less than a month ago I experienced an anxiety attack that worsened and started taking me down, very suddenly and quickly. I don't qualify for the services because I'm not a physical risk to myself or others. Not yet. But maybe prolonged lack of services allows mental health to decline to the point I am considered dangerous enough to see someone. In the meantime, I struggle through in a grey-zone of "too healthy to get free services, but too sick and unemployed to afford private services." I wonder just how large this grey zone of "lost" people is?

But the strain is not only on services that would support early intervention, the stories submitted to this review also described a lack of resources for crisis response, including a lack of trained staff and beds to provide appropriate care for people who are at risk of suicide.

"There are no early intervention services. At the same time there is not enough capacity in the crisis centres, both when it comes to trained staff and the number of beds. People in crisis who are suicidal get seen by a nurse, sent home with no follow up. When new people need a bed a nurse will often be the one to sign out another patient. In the regular health system it is a doctor who signs patients out. The first 24 hours after being discharged after a suicide attempt are crucial yet people get sent out on their own without making sure they are supported."

SUICIDE

Unsurprisingly, given New Zealand's suicide rates, 94 of the stories submitted were about suicide, including attempted suicides. According to the Office of the Director of Mental Health's most recent annual report, suicide accounts for a third of all deaths in those aged 15-24 and New Zealand's youth suicide rate is the highest in the OECD - double that of Australia.

Many of the stories about suicide were submitted by family members of people who had died by suicide. A common theme in those stories was a profound frustration at feeling shut out of the care for their family member. Families said they were not consulted or kept informed, and some felt largely unsupported in very difficult times.

"I lost a daughter in 2002 to suicide. She had tried to get help for many years and was 38 when she died. It was very difficult to understand what was the problem until after her death, as being an adult no one helped her family by explaining what her difficulties were. What I find very hard now is to hear stories that indicate families are still not included enough in the team to support someone with mental health problems, when the person wants that to happen. This doesn't happen when a family member has a physical illness."

"[My past fiancée] drowned in 2001. When he had appointments with his psychiatrist they would only see him once a month for about 20 minutes and would use this short visit as a basis for ascertaining whether his medications were appropriate. They never asked me how he was and I saw him every day and could have given them information that was highly relevant. I felt frustrated at being locked out of this process and I felt they should include partners in the assessment process."

UNDERFUNDING

Another major theme of the stories is underfunding, 97 stories talked about underfunded services. Some of the most positive stories submitted to the review, nonetheless expressed real concern that underfunding of mental health services meant that people working in those services were both overworked and underpaid.

"Without the mental health services I received I have no idea where I would be today. They were incredibly supportive and open minded and helped me become a productive member of society again after a full on breakdown and manic episode. My experience of mental health services in New Zealand was fantastic. They were stretched in terms of resources but they did the best they could and in the end, for me, they did fantastically."

Mental health in New Zealand has always been underfunded and the skilled professionals who work in the mental health sector always underpaid. Mental health services in this country need a financial shot in the arm to prepare for an uncertain future and the growing number of people experiencing acute problems. More resources are needed for our health and support workers"

Another problem identified in a number of stories was the reduction in amount of publicly-funded therapeutic treatments. Several stories were about a reduction in the number of funded therapy sessions available and how that had undermined their ability to build trust with a therapist.

"In my first counselling session I was told "the number of sessions we are able to give you has just gone down to four so we will skip the initial stuff". I didn't go back because I felt unable to discuss these issues without forming any kind of connection to the person who was dealing with me - she wasn't bad, just overworked. I felt like a nuisance in a way and as though I should be able to figure it out myself. What we seem to lack is someone who will take the time to sit down with you and just listen. I still don't really know what to do - but I am trying to grapple with things myself as best I can. I don't want to get to a crisis point, I hope I don't. I don't trust this broken system for myself, and I definitely don't trust this for others...not one bit. "

Related to underfunding, many people said that cost was a major barrier to accessing private mental health services, often the only option available to people who understood that they were "not sick enough" to access publicly funded services.

NEED FOR MORE TREATMENT OPTIONS

Many people said they didn't have appropriate treatment options. Specifically, people expressed concern about the harmful impact of an over-reliance on medication, in the absence of a range of other treatment options.

"The system we have gives very few alternatives to work with, and there are so many alternatives that could be offered."

People working in mental health services expressed frustration that they weren't able to provide the services that people want and need.

"The service we are providing is not service user focused, not tailored to the needs of individuals, rather it is the service user and their whanau [sic] who are "massaged" into the resources we have to hand, resulting in poor treatment options, early discharges, in-complete treatment plans and the inevitability of a quick return to acute hospitalisation for many, many individuals."

69 (14%) stories focused on issues related to prescribed medication, either expressing frustration that they were not able to choose other forms of treatment, or concern about the negative impacts that some psychiatric medications had on their quality of life, physical and mental health and life expectancy.

"These drugs have so many negative side effects, including killing my community up to twenty five years earlier than the general population, that all the recent research and recommendations say that they should only ever be used for a short term to manage a crisis. If they have been prescribed for any length of time these drugs can be next to impossible to

stop taking. I have experienced excruciating withdrawal effects for years as a result of withdrawing from taking neuroleptics, those drugs that are marketed as the 'antidotes' to psychosis."

Similar concerns were expressed by people who work in mental health services.

"Every week I get calls and emails from people desperately wanting help but wanting to try therapies or treatments that don't involve medication. They're told that by not accepting drug therapy they are "not bad enough" to enter the mental health system. Many of these people end up in crisis further down the track. If we could only offer funded choices in early intervention we wouldn't have to wait for crisis intervention. The irony is it would be a lot cheaper and less taking on overstretched inpatient beds and emergency services."

What people say they want is a genuine choice of treatment. In order for that to be possible, a wider range of treatments needed to be publicly funded and available, including a full range of talking therapies, and peer support.

"We need a system that is preventative, one that works with people to support them as and when bad things happen. And we need multiple ways a person can be supported so that people can choose the options that work for them. When we have this we will be growing the wellbeing of everyone in our communities, and giving everyone the opportunity to make the choices they need to make in order to live their best lives."

Some people said what they really wanted was simply someone who could take the time to listen, and many people said that they wanted mental health professionals to listen to them with

"It's actually pretty simple. Talk less, listen more. Don't listen to answer—listen to understand. You have two ears and one mouth—even your own physical body since birth has afforded you a clue that shutting up rather than talking might just be more beneficial."

PEOPLE WHO WORK IN MENTAL HEALTH UNDER STRAIN

Both service users and mental health workers described an under-resourced, over-worked and stressed mental health workforce. This has resulted in negative impacts on the health and wellbeing of people working within the system as well as on the service they are able to provide to people seeking their support.

"Staffing is DANGEROUSLY flawed. We are constantly being asked to work the double shift, come in on our days off, we can not even utilise our annual leave to recuperate and rest because of staff shortages. These shortages have been identified YEARS ago! Yet the service is stretched, inadequate and waiting for the inevitable to occur, another major incident."

People working in mental health services also described how underfunding and other problems in the system make it very hard to deliver quality services and care, which in turn causes them to feel deeply dissatisfied, and in some cases overwhelmed.

"I have worked in community mental health services for 5 years. I love my job so much and get to support the most amazing and resilient people. However with each week I grow increasingly frustrated. The DHB continues to make changes with a significant lack of funding and true understanding of what our community needs. From entry point to services where a person may see up to three doctors and several mental health professionals before they are allocated a regular care team, an inpatient unit that requires a person to be at their very worst point and of some risk to themselves or others before an admission is even considered and then spits them out too soon, residential services I would never send a family member to, and community clinicians with caseloads of 40 just trying to get through each day. I go home feeling I have let someone and their family down, because there is not enough of me to go around or the system has simply failed yet again. Despite all of this I see wonderful individuals give it their best and all each day to support others to recover. They remain passionate despite unmanageable workloads. I have seen tears from teammates before who at times are just overwhelmed."

A lack of resources, and the resulting overwork and stress is also having a negative impact on the mental and physical health and wellbeing of people working in the mental health system.

"I'm a former mental health administrator. One month out from my eight-year anniversary in the role, I had to resign due to depression; my job was identified as my main stressor. I know of a few mental health clinicians who have also had to leave the work because of their own mental health issues – mainly from inpatient services."

Several stories reported that experienced people were leaving their jobs in mental health services because of stress, and a frustration at being unable to do a good job.

"Out of an experienced Crisis Assessment and Treatment Team, only two staff are remaining. The rest have left or are in the process of leaving, because of the deplorable way it has all been managed. The service is losing years of experience. I do not like working in a service where people have to wait hours to be seen."

People who have used mental health services also made a point of recognising the dedicated and hardworking people who persist despite the challenges of underfunding and other systemic problems:

"I'm grateful for the good people in the broken system, who talk to me in caring voices till their fifteen minutes are up."

"The people I have worked with in mental health services have invariably been amazing. I got on with some of them better than others, but they were all fantastic, thoughtful and caring people."

Overall, the stories submitted by people working in mental health services paint a picture of people who though still passionate about their work and committed to doing better for the people who they are there to serve, are feeling increasingly helpless and desperate for change.

"We get a lot criticism and complaints but it is often out of our control. The service has crumbled, and with the current restructure, local services are in absolute crisis. Management are not listening. Whenever I hear of a special incident or sudden death, I ask myself why I continue to do this job. However it is because of my passion for the work – I have still got a bit of fight or hope that management may start listening. I fully support the need for a national inquiry into mental health services."

ENTRENCHED PROBLEMS INCLUDING COMPULSION

The stories in this review show there are entrenched problems in the ways we think about and respond to people experiencing mental distress in this country.

Respect and dignity

People described being treated in ways that were dismissive, dehumanising and punitive, and felt they had no say or power over their own treatment. At the heart of many of the stories in this review was a simple request to be treated with dignity respect, and as a person of value.

"So, what I am trying to say is that, I am worth it. People who are mentally unwell are worth the time and money our healthcare system spends on them. Recovery is possible - even if not complete - but, it does take a lot of work and commitment. From ourselves, and from our healthcare system."

Many people (85 stories) wrote about feeling undermined and diminished by their encounters with mental health services. People experiencing a crisis feel they are not being heard. They experience a total loss of agency, and a disregard of their capacity to reflect on and make sound decisions about their own. Medical staff do not have the time to properly listen to or assess their needs. Nor do they usually have anywhere to refer them to.

"There have been several times where I have reached out to the mental health team because of my increasing suicidal ideation and risk in acting on those thoughts. The first time I got turned away, because they did not believe I was a risk. But would I have asked for help if I didn't truly believe I was a risk to myself? Do you know how hard it is when you're in that position to actually ask for help and then to be dismissed because they don't think you're at risk?"

The stories submitted to this review reveal that not everyone seeking mental health care in New Zealand is currently being treated with the kind of respect.

"I was seeking professional support and services that would help me and my baby have a well pregnancy and journey into motherhood. Instead I was met with an interrogative assessment process that left me feeling bullied and coerced. My voice and experience were not valued."

Culturally appropriate care

As well as general respect for people experiencing mental distress, some stories in this review highlighted the specific need for our mental health services to respect people's cultural norms and practices as they relate to mental health and wellbeing. It is particularly important that people working in mental health services in New Zealand understand and respect tikanga Māori, as this story from Egan Bidois illustrates:

"If I had been listened to, then the hospital staff would have realised that what they were viewing as extreme decompensation was actually me fighting for my sanity. That those 'wild gesticulations and violent screaming' was me performing haka/traditional Māori dance to centre myself through condensing, consolidating and then calming the waves of wairua/spiritual energy flowing over and through me. That those 'repetitive mutterings' were me reciting karakia/prayer to keep myself safe within those experiences.

If I had been listened to. If I had been understood. If my whakapapa/direct ancestry had been taken into account. If I had been supported by a fellow Māori they would have realised that I am not simply that Westernised clinical term 'Schizophrenic'. Rather I was born a slightly different breed, another term, another 'title' or 'tag' if you will. Matakite."

The need for mental health services that are consistent with tikanga and kaupapa Māori has been recognised for many years, thanks to the work of leaders like Sir Mason Durie and Marama Parore, the CEO of Te Rau Matatini. Te Rau Matatini provides a strategic focus for Māori mental health and well-being that is underpinned by Māori workforce development, education, clinical and cultural capability and capacity for the advancement of indigenous health and wellbeing.

COMPULSION, SECLUSION, CAPACITY AND HUMAN RIGHTS

Thirty of the stories submitted to this review raised concerns about compulsory treatment, and the practice of seclusion. This is unsurprising, given that New Zealand's mental health services use among the highest rates of legal coercion in the developed world, a concern which has been raised by human rights bodies repeatedly in the past.

"When I refused to take my medication, no one asked me why and I didn't tell anyone either. In the end I was put in the locked unit and injected. While there is a place for medication and it helped me, in my experience it is not the most effective way for treating mental illness. People going through mental ill health also need a lot of listening to, compassion and affirmation. It is also important for people to understand that people suffering from psychosis are still aware and have insight even if it doesn't seem that way at the time."

In 2004, the New Zealand Human Rights Commission published *Human Rights in New Zealand Today / Ngā Tika Tangata O Te Motu*, a comprehensive review of the state of human rights at the time. The report identified two critical human rights issues in mental health clinical practice:

- The inappropriate use of seclusion, and
- The tension between compulsory treatment and the rights to refuse treatment, to make an informed choice and to give informed consent.

In 2005, in the *Mana ki te Tangata / The New Zealand Action Plan for Human Rights*, the Commission pointed out that improvements in mental health service infrastructure and clinical practice would be key to minimising the use of seclusion and addressing issues of competency and capacity.

In 2010, the Human Rights Commission updated *Human Rights in New Zealand Today / Ngā Tika Tangata O Te Motu*, and recommended, as the top priority for action in relation to the right to health, that the Mental Health (Compulsory Assessment and Treatment) Act 1992 be amended to better reflect the concept of capacity in line with international standards.

"The issue of capacity and the tension between compulsory treatment and the right to refuse mental health treatment, to make an informed choice and give informed consent have been raised by mental-health service users on many occasions.

There is now a series of cases in like-minded jurisdictions on this topic which have changed the way in which capacity is viewed internationally, and which indicate that simply because a person is defined as mentally disordered, it does not necessarily follow that they have lost the ability to consent to treatment.

The Convention on the Rights of People with Disabilities, with its emphasis on individual capacity, has also shaped thinking in this area. While the Director of Mental Health has acknowledged that the discussion on capacity is in its infancy in New Zealand, he has also noted that "future revisions of mental health law will need to be consistent with recent international and domestic human rights developments".

Some of the specific concerns raised about compulsory treatment in the stories include a sense of having lost control over one's own life, and the way that diminishes identity and self-esteem, both of which are crucial for mental well-being. Another recurring concern was how difficult it can be to end compulsory treatment, and the problem of placing the onus on patients rather than on medical professionals.

Another concern raised was the risk of DHBs using coercion as a defensive reaction to high profile cases of tragedies involving a mental health patient.

"When these events are reported they tend to be sensationalised, they tend to be interpreted as catastrophic failure of systems, that clinicians are incompetent. The result [is for] many clinicians to take a much more conservative and much more defensive approach."

Some people had positive experiences of compulsory treatment – and proposed ways to offer safe, monitored spaces for people experiencing an acute mental health crisis to recover.

"In the forensic hospital ICU I was taken off my medications and started on another and am a different girl. ... We do need a community based lock up facility for people to go to when they are seriously acutely unwell where they can recover holistically. It would be lovely to have therapy provided like making meals or tending to horses. Just a place which is 24/7 monitored and a lockup but not a prison, more like a home hospital. As an alternative. With people with lived experience of surviving mental health crises and getting back on track, to show there is hope. "

TRAUMA AND SOCIAL AND ECONOMIC STRESS

Mental health and wellbeing in New Zealand is undermined by many social and economic factors that operate outside the mental health system. This includes the ongoing impacts of colonisation, and the damaging effects of all forms of discrimination and violence, including the high levels of domestic and sexual violence in our country. Mental wellbeing is also negatively affected by financial stressors including job insecurity, low-wage work and the lack of affordable housing.

Trauma

Trauma was a feature of 102 (21%) of the stories, with traumatic experiences often being described as a factor that contributed to mental distress and the need for mental health services. Some stories described trauma experienced in the process of accessing mental health services. Sexual violence was specifically mentioned in 30 stories, but many people used more general terms like 'violent' or 'abusive' childhood, which could cover a range of different forms of trauma.

"I grew up in an unsafe, and unsupported family that thrived on adults drinking heavily, verbal abuse, neglect and an inability to love. Sadly I would say, a typical NZ story."

"I grew up in an abusive family where I endured sexual, physical & emotional abuse for 18 years."

Other forms of trauma that appeared in several stories include having a parent or other family member die by suicide or violent crime, being the victim of a violent crime, and having a head injury or other injury.

"I was in my first year of University when depression hit me like a truck after a traumatic brain injury. My life changed forever."

A recurring theme in these stories was the sense that people's traumatic experiences were not properly taken into account in the process of diagnosing or treating their mental distress.

Sexual and family violence

New Zealand has high rates of sexual and family violence, so it comes as no surprise that we received many stories describing the mental distress experienced by people who have survived sexual or family violence.

Other stories suggest that even when women explicitly describe their mental distress as stemming from an experience of trauma, including sexual assault, they may not find the support and understanding they need to heal and recover.

"Nearly 12 years ago I was a volunteer firefighter. I was assaulted and raped by one of the officers who was in charge of my crew and training most of us young members. I demanded help and support for myself and crew mates. They phoned the CAT team and I was taken by the police, locked in a police cell and transferred up to the hospital psychological ward. I did what I was told, I was compliant but heartbroken to be treated so badly for having nightmares and flashbacks because of the community service I had done."

Then having nurses wake me all night caused me to become anxious and have panic attacks and insomnia. I felt like was unsafe there had no privacy or autonomy. Support and being believed and listened too would have helped me. I was diagnosed with PTSD and have been treating myself to stop having flashbacks and panic attacks."

One of the most alarming stories in the review was from a woman who was raped while in a psychiatric ward, supposedly receiving treatment for mental distress which had at least partly been caused by an earlier rape.

"I went through a rape case this year after a patient raped me. Even though two senior staff came to my aid it was brushed under the rug. However four years later I was supported to formally lay a complaint with police who took it very seriously and after a thorough investigation charged him and put him before the courts.

I was raped when I was 12. I never told anyone until I was broken at 18 in a psych unit. Then years later for it to happen again in a hospital receiving treatment stemming from the first incident, witnessed but not believed by the staff working with me. Nothing done it was dealt with in such an appalling way and has been so detrimental."

Given the high rates of sexual violence in New Zealand, our mental health services must be resourced and designed to provide safe and appropriate support to people who have experienced sexual violence.

Lou's story illustrates how we are currently failing to deliver that, and suggests how we could do better.

"When I finally found the courage to ask for help as an adult woman to address childhood sexual abuse I thought I was walking into a stage in my life where my hope would be restored and I would be provided with the skills to regain control over my life.

What I discovered was a journey into never ending diagnoses, medications, symptoms, behaviours and treatment approaches which never addressed what the root cause was in my life, trauma. At the request of my doctor, I was sent to a psychiatrist. The symptoms of my "breakdown" were discussed and my inability to sleep, never was I questioned about my history of sexual assault. I was placed on a common antidepressant and sent on my way. Adult psychiatry does not inquire into, see signs of or understand sexual trauma.

The last 10 years of my life has seen me on a never ending merry-go-round. To be pushed from pillar to post, treated as someone who had some sort of "brain disease", not as someone who was profoundly hurt and traumatized by defining incidents in my childhood.

Healing people doesn't come from a pill out of a bottle, it comes from deep individual healing work, dealing to unique individual trauma and intergenerational trauma. Healing comes from being in a protected environment which nurtures and provides the means and opportunities to thrive and flourish and lead lives of wholeness, experiencing true happiness and joy with those treasured around you."

Colonisation

When we talk about trauma in Aotearoa New Zealand, we can't overlook the violence and trauma of our colonial history. Whilst very few of the stories submitted to the review referred to our colonial history explicitly, the traces of that history show up in many of the stories. This could, and should, be a topic of its own review. For now it's important to note that the roots of much of the trauma and violence described in these stories can be traced to the violence perpetrated against tangata whenua in Aotearoa, and that healing those historical wounds will require an ongoing willingness to face painful truths and account for harm done.

"Ehara taku toa i te toa takitahi—engari he toa takitini ke!

Essentially I never stand alone. The person you see, or support, or uplift, or judge, or diminish is never just me. Never just one. What you do to me, you do to my entire ancestry. For I am just one of the most recent physical embodiments of them. A singular link in a timeless chain. The countless warriors, chiefs, healers and helpers, cooks and cleaners, everyone."

Whānau and family

One critical aspect of social context for many people who submitted their stories was the support, or lack of support, which they had from their families. Sarah Gordon's story shows how powerful family support can be, and what a positive impact it can have on someone's life.

"I was diagnosed when I was 17, and put in a mental health hospital. I was there six months before I was discharged back into the care of my family, with the advice that a return to university would not be wise and that independent living would not be an option for me. My parents were not compliant with that advice, and they facilitated and paid for mental health support to enable me to go back to university.

I managed to complete a bachelor of science, a law degree, a masters of bioethics and health law and a PhD in psychological medicine. But more important than any of that, I don't live independently, I live with my husband and two children. And I work for the department of psychological medicine, University of Otago. I use my personal experience of mental illness to inform mental health research and teaching.

My positive outcomes are about the support that I received right from when I was first diagnosed. My family's expectations about who I was and what I was capable of never changed. Their perspective was that given the impact of my illness I'd just need a bit more support to realise my dreams and aspirations. People need to know that recovery is not only possible, it is probable but it is dependent on the right attitudes and the right support."

Many stories described much less supportive family relationships, and some illustrated how easy it can be for people who are going through a crisis on their own to either be dismissed or simply fall through the cracks.

Post Natal Depression

Research indicates around 15 percent of mothers will suffer from postnatal depression – up to 9,000 cases a year in New Zealand alone – making it a serious public health issue that affects mothers, children, partners and wider whānau. So it is not surprising that many of the stories submitted to the review were from women who had experience severe mental distress during pregnancy or after the birth of their babies.

“After having my first baby I visited my doctor for help with depression. With no family in NZ I was experiencing extreme lows and I needed help. My baby was 9 months old and I was told by a doctor that there was no help for mums with kids over 9 months old. Other than alerting an acute mental health team (which would take weeks to engage and which sounded both scary and serious), there was no help for me. With no income and feelings of despair, I had no-one to help me.”

The recurring theme of these stories, as with many other stories, was of the struggle to access timely, accessible and appropriate mental health services. Barriers included long wait times, geographic isolation, or a lack of options that were suitable for mother and baby.

“My only choice was to commit myself into a psychiatric hospital and my son could be placed into care. That was not what I needed, when I felt as though I was failing the one job I had, failing the small person who I loved more than anything else, I did not need to be locked up. ... It blows me away that when doing everything you are told to do when you are not coping, talking to someone, seeing a GP, asking for help - only to be told there is no help, or that help is four weeks away. We need to put more resources into supporting people towards wellness, not removing them.”

Children

94 stories (20%) were about children or young people, this includes stories submitted by adults about their experiences with mental health services when they were children or young people and stories submitted by parents about their children. These stories echoed the themes of the rest of the submissions. Parents expressed fear and sadness at the deteriorating health of their children while they waited to access mental health services.

“My story is about my 12 yr old son, who is still waiting to be seen by a CAF Rural Counsellor after the process started 5 months ago. I want my son to be happy and enjoy his childhood. The services available are just not there when you really need them due to the huge waiting lists, lack of funding, lack of services in general. We are very lucky that my son can talk to us about how he's feeling as I am sure if he couldn't talk to us, we would be in a much more serious place. He has said on more than one occasion that “I don't want to be here anymore mum”. My heart aches every time he says this.”

Some parents wrote with gratitude about the wonderful care their children received from some mental health professionals, and frustration at being ignored or dismissed by others. Many stories came from young people whose first contact with mental health services happened while they were still children, and some of them explained the challenges they experienced when they needed to transition from specialist services for children and youth, to the adult mental health services, some feeling they got lost between those two services along the way.

Another theme in the stories from and about children was the potential role of schools as a place for more education about mental health, and mental health services. Many of the children whose stories were submitted to this review were in school when they first experienced mental distress, and they think they would have benefited from more education on the topic at school.

LACK OF OVERSIGHT

Some of the stories in this report raise very serious issues, and the people who submitted those stories describe how very hard it is for individuals to take on the challenge of holding the mental health system to account.

Corinda Taylor started Life Matters Suicide Prevention Trust, after the suicide of her 20-year-old son, Ross, in 2013. As well as setting up the trust, Corinda has pursued a formal complaint about her son's experience in the mental health system, and started a petition calling for a review of the mental health system. As a result, Corinda has become someone who other people ask for help, including help complaining about their experience with mental health services. The most common problem people bring to Corinda is that it is very hard for people with mental health issues to get their complaint accepted.

"Most complaints get thrown out by District Health Boards. If they do make it to the Health and Disability Commission, only about 4% get investigated. The District Health Boards are so preoccupied with protecting themselves that they no longer protect the patient."

This highlights the impact of losing the independent monitoring and oversight that was previously provided by the Mental Health Commission.

Police filling in

Because of the strain on the system police are responding to people experiencing mental distress, or extreme states. Police responded to just over 18,000 calls coded as "threatens/attempts suicide" across the country in 2015-16, up from 14,000 in 2012-13.

Senior Sergeant Matthew Morris, Project Manager Mental Health Team, NZ Police confirmed that police currently attend on average 90 mental health related events every 24 hours.

Prisons /Corrections

We know that many people are using mental health services in prison. In June 2016, Corrections received \$14 million to buy its own mental health services, over the next two years, with \$10m set aside to contract mental health workers and clinicians to help offenders in prison and in the community. However, we got very few stories from people with experience of using mental health services while in prison. This is not surprising, given the limits of this review and the constraints on people in prison, but it does highlight the need for dedicated reviews of the experiences of people using and working in mental health services in our prisons.

The Office of the Ombudsman does have the power to conduct self-initiated investigations into matters relating to mental health in prisons, and recently conducted an investigation into prisoner health services generally. In February 2017, the Chief Ombudsman released a report finding the use of restraints in prison, specifically in relation to prisoners experiencing mental distress, was in breach of the United Nations Convention Against Torture. The report highlighted the case of one self-harming prisoner in Auckland who was restrained on a tie-down bed for 16 hours a day over 37 consecutive nights, after he was refused a transfer to the Mason Clinic, a forensic psychiatric facility.

WHAT NEEDS TO CHANGE?

"I don't want sympathy. I want money and for this to get sorted so that I can get the medication and ongoing psychiatric care I need to live my life. I don't want sympathy, I want the system to change so that people with mental health issues—all people, children, LGBTQ peoples, Maori [sic], Pasifika, the elderly, people with no money, people on working holiday visas, famous people, immigrants, students, women, men, people who are a Venn Diagram of two or more of these, have NO barriers to getting the health they need. I don't want anyone to have to live like I'm living."

The people who submitted stories to this review made a wide range of recommendations for change, some of the recurring themes in those recommendations include:

- Urgently increase funding to mental health services.
- Conduct a national review of mental health services.
- Provide a wider range of treatment options including a full range of talking therapies, and peer support - both of which people had found to be useful and therapeutic.
- Treat people using mental health services with respect, acknowledging their experience and expertise in their own mental health, and their capacity to make good choices about their treatment.
- Involve families more in the care and support of people experiencing mental distress, and help families to give the kind of support that is needed.

Some of the solutions to the problems highlighted in these stories lie outside of the mental health system, and require proactive changes to social policy in other sectors. These would include greater protection for workers, to remove the stress of insecure and low wage work, and reduce workplace bullying. Another significant source of mental distress for people was the struggle to find safe and affordable housing. This challenge was often exacerbated by discrimination and stigmatisation against people with experience of mental illness, but in some cases a lack of secure housing was one of the stressors that led to mental distress in the first place.

The stories in this review also reinforce the devastating impact that domestic and family violence, and sexual violence, have on mental health and well-being in our country. While efforts to reduce the prevalence of family and sexual violence in New Zealand reach well beyond the mental health sector, this review did also reveal some changes that need to be made to how our mental health services to meet the needs of people who have experienced trauma of this kind. This includes the need to allow time for people to build trust with mental health professionals, understandably more of a challenge for people whose safety has been violated by people who they should have been able to trust.

RECOMMENDATIONS FROM THE REVIEW

- **An urgent funding increase for mental health services** for acute and community based mental health services nationally. This requires a focus on increasing community based service access and treatment choices for people using mental health services to provide interventions early. It is also essential to support the people who work in mental health services, by easing workload pressures and enabling them to offer the services and support people want and need.
- **Fully independent oversight of the mental health system** in line with minimum obligations set out in the Convention on the Rights of Persons with Disabilities. This could be in the form of restoring the Mental Health Commission, the creation of an independent Disability Commission, or the inclusion of dedicated Mental Health Commissioners under the current Human Rights Commission. These would include clearly designated roles for those with lived experience.
- **An urgent independent inquiry** into the structure and provision of mental health services in New Zealand. The terms of this inquiry should be informed by New Zealand's obligations under the Convention on the Rights of People with Disabilities and the need to provide for healthy families and healthy communities, and should allow for the increasing numbers of people seeking support from mental health services. We also recommend that **a Royal Commission of Inquiry be carried out into the long-term and entrenched problems** highlighted by this review.
- **A national education programme** to support all New Zealanders to understand what mental health is, and what mental health services provide, that operates in the education system and wider society. This will ensure that the work of change is understood by all New Zealanders so people with lived experience are included by our society rather than having to endure prejudice and discrimination.

NOTES ON METHODOLOGY



Methodology

The analysis of the stories submitted to the review involved three phases:

- A manual analysis of all the stories to identify common themes and develop of a set of thematic keywords;
- A keyword search using Nvivo software to establish how often each theme appeared in the stories;
- Another manual analysis of the stories (by two different researchers) to check the results of the Nvivo analysis.

As well as revealing the key themes of the stories, this analysis showed up some gaps in the stories. In response, we proactively solicited stories from underrepresented groups and experiences. Where those stories were hard to find, we looked for existing research into e.g. the experience of people in places of detention.

At the same time, certain stories were identified as being illustrative of the experiences described by many others and we asked those people for the chance to interview them in more detail. Some of them agreed to be named and have their stories featured in this report.

Researchers and authors

This report was written by ActionStation's Marianne Elliott and Ann Cloet with research assistance from ActionStation volunteers Lou Hutchison and Alex Davis. An independent audit of the data analysis was provided by researcher Jonathan Beazer. The report was designed by Laura O'Connell Rapira from ActionStation.

References

For a full list of references, please visit www.peoplesmentalhealthreport.org.nz

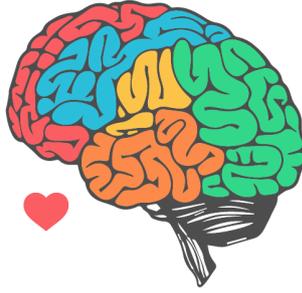
ActionStation

ActionStation is the new vehicle for people who believe in a fair and flourishing New Zealand. Since launching in June 2014 we have grown to a community of more than 150,000 people who act together, in new ways and in real time, to create what we cannot achieve on our own: a society, economy and democracy that serves all of us – everyday people and the planet we love.

Who funded the review?

The People's Review is a fully independent, crowdsourced project. It has been funded by donations to the campaign, via ActionStation.

The Review was endorsed by the Public Service Association, the New Zealand Nurses Organisation, the Drug and Alcohol Practitioners Association Aotearoa and the New Zealand Association of Counsellors but they have provided no funding or support beyond encouraging participation.



PEOPLE'S MENTAL HEALTH REPORT

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