

2019 Submission - Royal Commission into Victoria's Mental Health System

Organisation Name

N/A

Name

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What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

My main experience of stigma has been from health professionals. I feel like educating health professionals on different mental illness is very important. As a nurse myself I know that the mental health component of the bachelor of nursing is extremely limited and there is little to no acknowledgement that people with mental illness will be treated on medical wards as well because people with mental illness are not immune to physical illness.

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

"I feel like the advance statements are working well - they just need to become legally binding to force health professionals into taking the whole statement seriously, not just cherry picking what they want to do out of it and then turning it around to say that you said you wanted x treatment. So much can be done better - the mental health system needs to be better staffed, especially in the community because once you've been inpatient, going home is just the start of getting well not the end. In my experience I would go home, have no support, relapse, get readmitted, go back home, have no support, get readmitted....and so on. There also needs to be much better support for people with eating disorders, because currently the wait lists for specialist units in Victoria (of which there are 2 if you don't have private health insurance) are completely blown out and people are forced to deteriorate to even be eligible for treatment in the first place."

What is already working well and what can be done better to prevent suicide?

"Again, professional education is the key. It almost becomes like a challenge when a health professional says to you "'I'm not worried about going to the coroner's court because I know you're not serious about killing yourself'". The crisis team/triage teams need to be less intimidating to contact. At the moment they're so overwhelmed with people who have enduring and serious mental illness that if you call and say you're suicidal and just need to chat to make a safety plan or whatever they pretty much laugh at you."

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

"I think factors like unemployment and disengagement from the community make good mental health hard. It might sound strange, but in my opinion, disability pension makes people mentally worse because they don't have to try and support themselves anymore. I say this as a person who has spent from 2012 on DSP and I am grateful for it as it allowed me to afford health insurance. But I feel like there should be some kind of requirement to volunteer, or work a few hours a week or something, just so people aren't sitting at home wallowing about how crappy their lives are and how things don't seem to be getting better. It's easy to fall into the trap of feeling more disabled

than you are, and that you can't make a contribution to society because you're on welfare. "

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

"I would consider the eating disorders population to be a community and I feel like the health outcomes are poor because of the lack of treatment available to people with eating disorders. There are few day programs, mostly for people under the age of 26 - people don't just magically recover once they turn 26. Services are directed towards younger people, and it's very hard as an adult who still struggles with an eating disorder to feel like recovery is possible or that you're not alone. I think this is what drives a lot of people to suicide."

What are the needs of family members and carers and what can be done better to support them?

Not applicable to me.

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

"Better ratios in mental health, more further education opportunities (doing a masters in mental health nursing is expensive!), regular debriefing."

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

"Victoria's mental health system should consider community care a priority. It's much better to be treated in the community than in a hospital where you're away from your family and friends and community. In the case of eating disorders, if you're from anywhere but Melbourne, you're also going to have the added trauma of being taken hours away for treatment, often involuntarily. There needs to be better access to psychologists, and day therapy programs. The 10 visits with a psychologist funded through medicare are only really designed for people with a mild mental illness. If you have trauma, or a complex mental illness like an eating disorder or a personality disorder 10 sessions is, pardon my language, going to do jack shit. If you're really struggling with your mental illness, it's highly, highly unlikely that you're going to be able to work enough to pay for a psychologist. Inpatient stays need to be more holistic - rather than doing nothing all day and getting drugged or sedated everytime you're upset, they need to use other therapeutic methods to try and de-escalate the situation. It would be helpful if allied health professionals were also available on the weekends as people aren't only struggling between 9am and 5pm Monday to Friday. Nurses need to be better educated on how to sit with people's distress rather than running for sedating medications. There need to be more eating disorder services which offer psychiatrist, psychologist, dietitian, exercise physiologist, GP and day program services. Funding for these programs need to be beyond the age of 26 and not tied in with headspace."

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?

"It really comes down to funding and education. Education for health professionals - those training and those currently practicing. Funding needs to be improved to improve accessibility and not wait until people are critically unwell or have attempted suicide to get help. There needs to be greater accessibility to services which advocate for the rights of consumers who are inpatient. There needs to be a big focus on staff working with mental health consumers to have training in de-escalation techniques, not only safe restraint techniques. If restrictive interventions have to be used, the patient needs to have a debrief with an appropriately trained staff member after the event. Doctors need to be more transparent with the side effects of treatments, even if a patient is involuntary. Advance statements need to be legally binding so that the treating team doesn't ""cherry pick"" parts of the advance statement. The patient needs to be considered a part of the ""treating team"" and regular case conferences involving the patient need to be held for patients with severe and enduring mental illness. The service needs to have a review committee and review every single incident of restraint and seclusion and the results of these reviews needs to be publicly accessible. There needs to be better training for patients who are under the mental health act, but being held on medical wards, not psychiatric wards. "

Is there anything else you would like to share with the Royal Commission?

"Eating disorders have the highest mortality rate of any mental illness. Despite this, there are 37 public beds across the entire country and public programs have extensive waiting times, leaving patients to deteriorate before they are eligible for the intensive treatment that is needed. If someone becomes medically unwell, they're often stuck on a medical ward with staff who have the attitude that they've done this to themselves and it's just a spoilt little white girl who went on a diet gone wrong. There needs to be more transparency around seclusion and restraint stats in the state and the hospitals with the highest rates need to be investigated and held accountable for changing their practices."

I have had an eating disorder since the age of 12. I was formally diagnosed at 14, and not offered any treatment until I was 16 and failing school. At the age of 19 I was hospitalised for the first time, and spent my 20th birthday in hospital. This would mark the beginnings of many, many hospitalisations over the next decade. Over 50 admissions, especially in the last 5 years.

I moved from Sydney to ████████ in Victoria to access comprehensive private treatment for my eating disorder. I was more unwell than the treatment team in the private hospital initially realised and I was quickly transferred to the public system for total food refusal, abnormal blood results, starvation ketoacidosis and severe depression with suicidal ideation.

In the public system I was not appropriately assessed. From a discharge summary from a suicide attempt 10 years earlier, I was given a diagnosis of borderline personality disorder and the hospital could not see past that diagnosis. I was told that my eating disorder was a form of self harm, so while I wasn't cutting myself, I was still self harming in a way. I was repeatedly admitted, refed, discharged home, would deteriorate at home, be sent back to hospital. I was offered case management for a few months, but as I had private health insurance it was deemed that I didn't need case management. Despite the BPD diagnosis and the repeated hospitalisations, I was not offered any form of DBT or schema therapy. I was just told that this was my diagnosis and that was it.

I became catatonic with depression at age 26. I wasn't able to eat, shower, or move. I would literally have to be prompted to go to the toilet. The rest of the time I would lay in bed, staring at a blank wall. I wouldn't sleep, I could barely respond to people. It was during this episode that I was given ECT for the first time. I had a full course and improved significantly. Many nurses commented that this was unusual for a patient with borderline personality disorder to respond so well to ECT. Regardless, my diagnosis would remain BPD. I had several more episodes of severe depression, and was given ECT each time, and it was effective.

Eventually I had a manic episode, one of many I'd had in my life. I was trailed on a mood stabiliser and an antipsychotic and I was well for 12 months, until I was distressed by the weight gain from the medications and stopped them. I made a serious suicide attempt and ended up in a coma once again, in ICU for a week. When I was moved to the medial ward (I hadn't been eating in the time prior to this attempt and was medically unwell) I was treated like a criminal. I was held in my room, unable to leave. I was told "if you step over the threshold of this door, we will strap you to the bed." They were serious. I was shackled to my bed 8 times in 2 weeks, for up to 10 hours at a time. One of the times I was wearing a dress and my dress rode up around my waist and no one bothered to pull it down or cover me with a blanket to preserve my dignity. For the 2 weeks I was there, I was not consistently seen by a dr. At one stage I didn't see a consultant for a week, as he had gone on leave. I was seen by registrars who wouldn't make decisions regarding my care until the consultant came back. I was frequently injected by powerful antipsychotics that would sedate me for days at a time. I was verbally abused by nursing staff who were clearly completely overwhelmed and told many times they couldn't understand why I wasn't in the psychiatric

ward. I was paranoid, depressed and angry. I strongly believe the more you treat a person like an animal, the more they will act like an animal. I was treated like an animal.

I was denied visitors because I “hadn’t behaved well”. My phone calls to IMHA and VMIAC were constantly interrupted by nurses who didn’t think I should be able to make phone calls. I called the consumer liaison frequently, asking to be seen by them and they didn’t come and see me for 10 days. For the first 4 days I wasn’t allowed my clothes or toiletries because I might be an absconding risk if I was allowed my clothes or shoes.

This was on the back of approximately 50 admissions where I had been treated similarly. I feel like my spirit broke over those years. I cannot count the amount of times I have been shackled to trolleys or beds, I often wake up at night feeling like I am back there. I never once received any kind of debriefing for the trauma I have endured in the inpatient facilities of [REDACTED] and Melbourne.

My advance statement was a waste of time. I wish it was legally binding because the doctors literally cherry picked what they wanted to take out of the statement and left the rest or told me I was “too unwell to have made that decision when I wrote the statement”. I was denied my medication for my bipolar, because they couldn’t see past the borderline diagnosis. Even though I don’t meet any criteria for BPD when I am taking the medication.

To add to this story, I am a registered nurse. I was an enrolled nurse for 8 years prior to completing my degree. I have worked at the hospital with the highest rate of restraint in the state [REDACTED] and the hospital with the lowest rate of restraint (Latrobe Regional Hospital). The difference in the facilities is palpable. In my three months at LRH, I have not seen a single patient restrained on a medical ward. This was a multiple times a day occurrence at [REDACTED]. At LRH we are offered de-escalation training before we even start. I never received any such training at [REDACTED].

On medication for bipolar, I am well and stable. It is extremely frustrating that three of my medications (lamotrigine, lurasidone and melatonin) are not available on the PBS for bipolar disorder. If I had a consistent doctor in the public system, I think my bipolar would have been recognised earlier. I think if there was greater education around eating disorders, my symptoms wouldn’t have been dismissed as self harm. I think if I had been able to access comprehensive outpatient treatment, I wouldn’t have required nearly as many admissions, if any. If I had been included in decision making of my care, rather than the paternalistic attitude many of the psychiatrists have, I would have felt included, rather than feeling like the mental health team was working against me. If communication had been better between my public and private treating teams, I would have spent more time out of hospital, rather than in hospital. If staff had been trained in de-escalation rather than seclusion and restraint, I would have had far less traumatic restraints that still impact me today. If I was nurtured as a person, and my ambitions to study and work were taken seriously, I feel like I would have been able to get out of the cycle of repeated admissions much faster, instead of being told “see you again in a few weeks” on discharge. If there had been an appropriate day program for people with eating disorders, I would have avoided a lot of lengthy, expensive hospital admissions.