

ROYAL COMMISSION SUBMISSION – [REDACTED]

I would like to be considered to give evidence as I believe I have a wide variety of experiences, concerns and ideas about mental health services in Victoria. I attended the [REDACTED] consultation but feel I have so much more to contribute.

About Me

I am a 30 year old Latinx (LGBTIQ+) woman that has spent just over 10 years in the mental health system, both as a voluntary and involuntary client. I have been a service user of youth services ([REDACTED]), 3 adult area mental health services ([REDACTED]) and have had over 60 inpatient admissions in 6 adult inpatient units, 1 youth inpatient unit, and 1 specialist adult inpatient unit.

I have also received services from community mental health services such as NEAMI, have been to 3 PARCS (rejected from 2), and am now struggling to find adequate supports on the NDIS. I also have current and past experience being a client of Spectrum. And have used IMHA, MHLC and MHCC services.

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RESTRAINT AND SECLUSION

Seclusion and restraint are a breach of our human rights. Why should any human being, let alone someone who is unwell, be tied to a bed or thrown into a room for hours. It is dehumanising, humiliating and traumatic. I have lost count of the number of times that these measures have been taken on me (never as a last resort). There is no need for these measures to exist in today's society. The following are the most traumatic memories that have stuck with me, that I will never forget:

Seclusion

- When at [REDACTED] I was told that I had to give up my bed and go into high dependency to make room for another incoming patient. I refused as it seemed absurd and unfair. I wasn't unwell enough to be in high dependency, nor did I feel safe in there. As I refused to leave my room, a code grey was called. Security along with nurses dragged me into high dependency and threw me straight into seclusion. Being thrown is not an exaggeration. When thrown on the bed my head smashed against the wall, and then they proceeded to pull my pants down to inject me. They ran out and closed the door. I couldn't believe what had just happened, that I could be treated this way. They were supposed to be helping me. I couldn't bear to live in a world when the people helping me treated me this way. I decided I would end my life the only way I could then think of in a seclusion room: ripping up and stuffing the paper bed pan down my throat so I could choke to death. When the nurses caught on, I was released from seclusion. But the damage had been done.
- Due to the lack of youth beds I was admitted to the adult psychiatric ward in [REDACTED]. I cannot recall what led to the seclusion, but I know it was a first as opposed to a last resort. I was dragged into high dependency and straight into the seclusion by security members and nursing staff. After everything was removed from the room, they proceeded to remove all of my clothes. Being a small young woman, and having this done to me by men was beyond traumatic. I do not feel safe around men now, and being in a room alone with them has become my biggest fear. I was left in that room for hours. With no one to talk things through with. Checks were occasionally made through a small window, but they never stayed long enough to even hear my request for a blanket. I was violated, cold, and terrified. They experience of being stripped and left in that cold room, have stayed with me to this day. This needs to stop.
- I have been diagnosed with many mental illnesses, anorexia nervosa being one of them. During a general adult psychiatric admission, I was secluded for reasons I cannot recall. However, there is no logical reason that can justify throwing a small woman with a BMI of approximately 14 into a seclusion room. In such a fragile state I could not have been such a danger to myself or others to require seclusion. It was further distressing as I was locked in that room with toast and Milo. I am aware we are required food when secluded. But to lock up a person with anorexia, who believed and was fearful of gaining weight by being in the proximity of food. It was torture. I was so distressed I even remember asking them I would stay in seclusion if they would just remove the food. But as per usual, I was ignored and left there for hours.

Restraints

- A few years ago, I was restrained in the emergency department at [REDACTED] hospital. I had been transported by the police in the back of a divvy van at the request of the CAT team. She had refused to take me herself despite the police saying I was not a danger to others. As soon as the divvy van doors opened when I arrived at the hospital I was grabbed by security and nursing staff and restrained onto a trolley in what they call the behaviour room. I struggled with them to avoid being restrained. But they overpowered me and injected me. I woke to nursing staff taking my top off as they said they had to perform an ECG as they had overmedicated me. Waking up to someone taking your clothes off is terrifying. I was almost thankful that I passed out again moments after. I woke again 2 hours later and asked if the restraints could be removed. I was told no. Despite being so sedated, calm, and with no intention of running I was left tied to the bed for a total of 7 hours. I was never moved positions or allowed to go to the bathroom. I ended up with muscle bruising from being placed in the same awkward position for so long. My life saver was the compassionate nurse who eventually untied me, without asking the doctor. I did not run, try to kill myself, or hurt anyone. I just sat there until the next day when I could see the psychiatrist. He sent me home. After all that ordeal I received absolutely no help. It was not a last resort. It was their first resort. It is the only 'treatment' I received.

MORE SUPPORTS FOR EATING DISORDERS

I wanted help for my anorexia when I had a BMI of 14. I had my GP's continually sending referrals to the Royal Melbourne Hospital's eating disorder unit. I was happy to be an outpatient. Yet I wasn't even offered an assessment or put on a wait list. It was not until a year later (I am persistent) that a new registrar decided to accept the referral and I was assessed. Within a few weeks I had to be hospitalised. It turns out the previous registrar had known me from my time at [REDACTED] and believed I did not have anorexia, but was just 'being borderline'.

There are 3 public specialised adult eating disorder units, and the waitlists are ridiculously long. For an illness that can potentially kill us, we are made to wait until we get so sick, that we end up in a medical ward with no mental health support or expertise. If we are lucky a transfer will then happen to an eating disorder unit. The alternative outcome is often death.

As I write this, I have a blood sugar level of 2 and an iron level of 3.4. Yet I am not medically unstable and therefore am made to wait until I get worse for a bed.

As I am already linked to one of these hospitals as an outpatient, so it is easier for me to get treatment than those who are not. I would hate to think how much others are struggling.

The inpatient units are far from perfect. More psychology and groups are needed, nasogastric feeds, food and pills are not enough. Nevertheless, we need more services in this area. It would be great to see some attention given to such a vulnerable group of people.

ACCESS

There are many difficulties in accessing various mental health services in Victoria.

- CENTRAL ACCESS POINT

There is currently no central access point to triage and receive mental health services.

If a person has never been involved with mental health supports, it is difficult to know where to turn when a person or their loved one becomes unwell. Helplines that currently exist are not helpful as they are very specific.

Eg if you call beyond blue and do not suffer from anxiety or depression, they will not be able to refer you to an appropriate place.

It is difficult to determine where to go and what type of assistance is required, particularly when the average GP does not have much knowledge about mental health, let alone the types of services that are available. In fact, the regular psychologist they may refer you to often won't know what else is available once the 10 sessions are up.

An experience that stayed with me at the consultations was of a woman who spoke about losing her sister because she just did not know what to do. It was a first presentation of psychosis. She took her sister to the GP, called numerous helplines, even showed up on the doorstep of a private clinic asking for help. No assistance was given, and her sister ended up taking her life. – This need not have happened, and demonstrates a need for a central access point where people can get informed information.

- THE GAP: 10 SESSIONS & PUBLIC/ACUTE SERVICES

10 sessions of psychology are not enough for a lot of people. Particularly since it takes a while to find a good fit that you can trust and open to. Currently when the 10 sessions are over there is nothing else a person can access. You need to wait another year, or until you are unwell enough to be taken on by the public mental health system or end up in hospital.

There is a need for either more than 10 sessions. Or services that can offer support in the interim.

- ISSUES WITH PSYCHOLOGIST ACCESS

Psychologists are under no obligation to take a person on as a client. It took me years to find a psychologist that was willing to take me on as I am considered 'too high risk' and 'too complex'. My diagnoses and history often concern psychologists as they fear that I may just die. But if I'm denied help, am I not more likely to die?

For this reason, I am forced to be case managed by public area mental health services. Which are not all that helpful and have caused me much iatrogenic harm.

- PUBLIC SERVICES

Adult public mental health services differ from catchment areas. They often operate on different models and provide varying degrees of treatment.

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Of the 3 services that I have been to, I have never been offered psychological help at all. You go to see your case manager, go to the doctor for some pills and that is it. There is no 'treatment'. Aside from depression and anxiety, none of my diagnosis can be treated with medication. Such a service is futile, but I have no choice to attend. There is nothing else available for a person on the pension or low income with significant mental illness.

It would be great to see more therapy in ALL area mental health services.

Psychology, groups, art therapy, peer support – anything that can actually help a person whose diagnosis are not treatable by medication, or medication alone.

This contrasts to my experience at [REDACTED] however as every assigned case manager also was qualified to provide therapy. I was able to access two rounds of ACT whilst receiving usual case management services and medication. This model would be very welcome in the adult system.

COMMUNITY MENTAL HEALTH & NDIS

What helped me the most out of all the services I have accessed was my time with NEAMI. I had a community mental health worker who worked with me as a person. My diagnoses were secondary to the person I am and the person I want to become. She helped me access the community when I was socially isolated, assisted me with managing the stresses of uni, and encouraged me to reach my goals. I achieved a lot with her and since I lost her to the NDIS my positivity towards a better life, what some term recovery, has gone.

Similarly I have found when PARCS are paired with a good community mental health service, my stays there have been very beneficial to remind me that I am not my illness, that I have strengths, and I can achieve great things. All whilst having the clinical aspect on site if need. I feel this is a better alternative to hospital for me and it would be great if there were more of them.

I have been on the NDIS for just over a year now and have found it really difficult to find a support worker that is qualified to deal with my mental health issues. I have spent so much of my funding going through workers that have just made me feel worse.

A lot of the great workers from community mental health services that existed prior to NDIS are unable to continue working as support workers. Two of mine left mental health all together as there just weren't any appropriate jobs. Or they became support coordinators because their organisations no longer offered support workers.

I would suggest that more is invested into the quality of mental health support workers available through the NDIS, but also re-establish them for people who are not eligible for the NDIS. They could for example, be re-established as they were and be NDIS providers. That way both the community and those with NDIS plans can access great supports in the community.

ACCOUNTABILITY WHEN BREACHING THE MENTAL HEALTH ACT

There is no accountability when clinicians breach the Mental Health Act, and this needs to change. They can restrain a person longer than allowed. Prevent a voluntary patient from leaving a ward, and

force medication upon people without even telling them what it is (to name a few). I believe that when breaches of the Mental Health Act occur, clinicians and services need to be held accountable.

Eg When I was restrained for 7 hours despite also being heavily medicated, a clear breach of the Act, my only recourse was to complain to the MHCC. This complaint was made almost two years ago and the report has not yet been finalised. However, the MHCC only has the power to make recommendations. Services and clinicians are literally getting away with inhumane acts that go against the powers given to them by the legislation, yet there are no repercussions. There is not even a requirement that they comply with the recommendations. They may be audited, but what happens when they don't comply?

LEGAL PROTECTIONS FOR INPATIENTS

From my experience, having over 60 inpatient admissions in the last 10 years it angers me that patients lose all their legal rights once admitted to an inpatient unit. Patients suffer violence from not only other patients, but also staff. Yet nothing is done.

Although we have a right to call the police from the inpatient unit, they never take a call from a psych ward seriously.

When assaulted by other inpatients, the staff always respond with 'they are unwell, they don't know what they are doing'. This is not satisfactory, particularly since more often than not they do know what they are doing, and if they don't staff should be taking greater care of those patients.

Being an inpatient should not deprive us of the legal rights and protections that we have when we are in the community. Particularly if we are voluntary patients.

- **LEGAL PROTECTIONS FOR STAFF**

Staff often choose to exercise their legal rights and can do so freely. At times I would say they go as far as to abuse their power in enforcing such rights. If these remedies are available to them, they should be available to us.

- My life was almost ruined by a nurse who took unwarranted legal action against me. She claimed, 11 months after the fact, that I had tried to strangle her and caused her physical harm. I NEVER did this. Nor was it physically possible as I am quite a small person who at the time could not even stand for long periods of time due to my anorexia. I did not have the energy to strangle anyone, let alone a large woman twice my height.

Having to go to the police station to make a statement was terrifying and significantly worsened my mental health to the point of developing bulimia and needing to be hospitalised due to concerns for my heart. There was not enough evidence to take it to court and the police officer found the allegations to be ridiculous. The charges were dismissed.

Months later there was more evidence that allowed the matter to go to court. The evidence being supporting letters from other staff members who claimed they weren't in the room at the time, but medicated me afterwards.

Not only did I not do this, as a law student this could significantly ruin my career. Having no money for legal representation the duty lawyer said that although there was not enough evidence for the nurse to succeed, they could not represent me so it was best to ask for a diversion.

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How is this just? How is it that a nurse can put me through this turmoil for nothing, yet when I am restrained for 7 hours, beaten or masturbated on, I have no legal avenues to pursue?

ENDING THE SEGREGATION BETWEEN AGE GROUPS

I have experienced treatment in both the youth sector and the adult sector, and they are remarkably different. I agree that different age groups have different needs however the foundations of the services available should be the same, and there should be room for smooth transitions between each age range.

As mentioned previously, when I was in [REDACTED] I received ACT treatment from my case manager who was also a clinical psychologist. There were psychosocial and social groups that you could attend to meet others, learn skills, and not feel so isolated. I benefited from attending the choir, art therapy, a pampering group for women, and a general socialising group where we would hang out together and share food and conversation.

As soon as my time was up there was no weaning in process to adult services. I was allocated a case manager and a doctor and that was it. There were no groups, no therapy, just a terrifying inpatient unit attached to the service. I can tell from the 8 years I've spent in adult that adult services are nowhere near as well funded or person centered. There is no hope for the future. It's just a mechanical, attend you appointments here are your pills.

I am not old enough to have experienced the aged sector, but from fellow consumers I have heard that it is even worse. I cannot count the number of times that I have heard people say 'I'm terrified of turning 65, because I know what awaits me'. This is unacceptable. And since we have an increasing aged population, this should be a priority.

GENDER SPECIFIC WARDS & PARCS

There has been much research into gender based violence in inpatient units. And I can say I have also experienced this. I have woken to men stroking my face in my sleep, I have been masturbated on, had a man expose himself to me, have been yelled at when I have not returned a sexual interest, and felt overall intimidation and discomfort.

It is not enough to have female only corridors as most of these only contain a few beds. There are more women in an inpatient unit than there are beds in the locked women's section. And there seems to be no system of prioritisation. For example there have been times when women who are not intimidated by men are given preference over a women who has experienced sexual violence.

Women's wards are necessary not only for safety from men, but also for those with religious beliefs who cannot share a space with them, let alone communal bathrooms.

- **GENDER – LGBTIQ+**
Safety considerations also need to be had for the LGBTIQ+ community. Lesbians being fetishized and gay men being harassed seem to be the obvious issues. However having friends who are also consumers who identify as trans suffer significantly when staff and other patients misgender them or dead name them. People should be referred to by their preferred names and pronouns to avoid unnecessary harm.

DUAL DIAGNOSIS

More dual diagnosis inpatient units and community service should be created. A lot of the time the violence that occurs in inpatient units is due to a patient being on or withdrawing from drugs. These people also need support, however general psychiatric nurses are not equipped to assist these people and those who suffer the consequences are fellow inpatients.

MY DANCE WITH DEATH

I struggled to receive help as a young person because I was too 'high risk' and 'complex'. It wasn't until I had tried everything that I told [REDACTED] that if they didn't take me, I would just end my life because I had sought every avenue and no one would take me. They initially rejected me, but then offered me a reassessment and I was accepted into the service. It saddens me that you have to become so unwell to get help, and even more so, that when you finally do become unwell, if you are too unwell no one will take you.

I have lost count of the number of times I've attempted suicide and ended up in ICU and/or resuscitated. But what has always stuck with me is that when I was with [REDACTED], I was told I would be lucky to make it to 30. This was not encouraging at all. I recently turned 30 and had the biggest celebration because I believed I should be dead, according to the doctors' predictions.

I could ramble forever about all of my attempts. But the point I want to get across is that during all of these attempts, I was under the care of the public mental health system. At times I begged them to help me because deep down I didn't want to die, it was a compulsion. But the help never came.

Most recently I had told my case manager, doctors and psychologist that I wanted to die, I had a plan and explained it to them. They carefully took notes and told me they'd see me next week. No extra supports were offered. So after class one day in March, as I had planned, I took all of the pills and passed out somewhere in the city. All I remember is I was having trouble walking, and a few days later I woke up choking on the intubation tube in ICU. When I was conscious, they sent the mental health team to speak to me. I was still delirious from my medications and cannot for the life of me remember the conversation. But the result was. I was sent home with no follow up. Not even a call from my case manager.

This is the typical reaction to when I present with suicidal intent and ask for help. I am lucky to be alive yes. But it is not thanks the mental health system. It is thanks to emergency services who were lucky enough to be in the right place at the right time.

FINAL THOUGHTS

Please take on board what consumers are saying, we need real reform in this space. These are only some of the issues that require urgent attention, but there are so many more. Again, I would like to be considered to give evidence on any of the abovementioned points or anything you think may be appropriate. The past cannot be undone, but if I can help make things better for the future. It would help me heal and prevent other suffering the same fate.

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

Submission: 0002.0028 0716

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

"I think it needs to be treated like any other illness. This includes workplaces and professions not being able to discriminate against people with a mental illness. You don't need to disclose your diabetes, so why disclose a mental illness? I think what has worked in the past is media showing people who have mental health issues but are doing great things with their lives. This however needs to extend beyond depression and anxiety. I know I try to reduce the stigma by being open about what is going on for me, and it has helped the people around me to gain a greater insight. I have also lectured university students in the social work field and I think if helping professions were taught about mental health from the perspective of a person with a lived experience it would really change the way they think and practice in the future."

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?

"As I already have a mental illness it is difficult to think what could prevent it. Most of what led to my conditions were due to things like child abuse, bullying, trauma and iatrogenic harm. So perhaps targeting younger people, ensuring they are in safe environments and learn resilience and healthy coping strategies would be helpful to prevent mental illness. Kidshelpline really helped me when I was younger, but it didn't prevent my mental illness' from developing. "

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

"Having attempted suicide on numerous occasions, I have primarily found contact with Suicide Callback Service to be helpful, as well as having a realistic crisis management plan. Plans that have worked for me in the past include planned admissions to hospital, PARC stays, connecting and being cared for by family and regular contact with my treating team."

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 cannot remember a time when I had good mental health, so it is difficult for me to say. I think consideration needs to be taken into people's cultural beliefs as well. Not all Victorians accept 'mental health' and 'mental illness'. When I was a child I was taken to churches, prayed on, and splashed with holy water! So people may be needing help, can recognise it, but their upbringing or culture makes it unacceptable to seek such help. General Practitioners should be better educated about mental health as they are the gateway to most services initially. Their manner and the way they address concerns may put a person off returning or even seeking another GP. Recently I went to a GP asking for help with my anorexia which was causing physical health problems, she told me to eat a sandwich and let me go home."

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

"I think it's the fact that the services are funded and created by the privileged who have not experienced such hardships as people in some communities. Decisions are made without consultation. I believe that people experiencing poorer mental health outcomes need to be asked what they need, what they would like, and be given the opportunity to co-design services that suit."

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

"As I am not a carer I would not know. But seeing how my mum struggles to care for me, I think psycho education is important. As well as offering them psychological support. I think it's hard for carers sometimes to ask for help because they feel they need to be strong for the person they are caring for."

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

"Better education and training. Adequate support, supervision and respect in the work that they do. With peer support workers generally I feel they need to be respected by others in the field as their own profession. Many are just being hired as tick boxes and aren't allowed to practice from their values and training, but are rather used by services to pick up the slack."

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?

"I don't think there currently are any opportunities. Flexible working hours might help to allow people to get back into work? Socially there needs to be activities, programs, gatherings with support where needed that are low cost or free. I don't participate in a lot of the things I would like to because I just can't afford it."

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?

"I think community mental health services such as NEAMI need to be reinstated so everyone can access positive free/affordable mental health supports. Those who do not qualify for the NDIS have been left with nothing. And those who do qualify, like myself, find it hard to find trained mental health support workers. Seclusion and restraint should be abolished. All age groups should receive the same basic care and funding as others. Youth seems to be getting too much funding, adults get a little less and older people seem to be forgotten. ALL Victorians deserve access to good mental health treatment. Including psychology and community based treatment options. There needs to be consistency within the way area mental health services operate. I have been a client of three and they all seem to have a different model, varying in supports available and varying in the condition and care of their associated inpatient units and PARCs. It should be equal across the board. MORE SPECIALISED EATING DISORDER PROGRAMS & INPATIENT UNITS/BEDS!"

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

This question isn't clear. Being transparent about what the changes will be and supporting people

into the transition would be helpful.

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

"What we have is not working. I had ""early intervention"" at [REDACTED] and 10 years later I am still stuck in the system wondering if I will ever get better. Mental health should be treated like medical health. A large majority of Victorians cannot afford to access good mental health services and are either left to the public system if they are ""lucky"" which is most unhelpful. Or they are left with nothing. No Support. 10 Medicare sessions is not enough and the government should really provide more funding to help more people receive the treatment that they want (there should be choice) and need."