

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

SUB.0002.0032.0126

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

"Fix the mental health system,"

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?

Peer support and other forms of consumer participation and leadership are working well but need to be further built upon and supported. What can be done better - see attachments.

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

Fix the mental health system. Believe people when they say they are suicidal - don't turn them away. Don't discharge people when they report that they are still suicidal and are begging for a longer admission.

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.

Fix the system. See attachments.

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

See attachments.

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

N/A

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

"As a consumer peer support worker, I believe our value to both consumers and the services we work for lies in our empathy and identification with consumers. Therefore, our jobs will become much more bearable when consumers themselves are treated with greater dignity, respect and compassion; when their human rights are enacted; and when justice is a guiding principle in the mental health services and the system. Peer support workers also need to be paid a wage that we can live on. To risk sounding arrogant, many of the consumer peer support workers I work alongside are more skilled and provide a higher standard of support than our much better paid clinician colleagues. Speaking personally, I love my job wholeheartedly and it is the best thing that's ever happened to me. It redeems the worst of the pain I have experienced and puts it to a higher purpose. However, I am now being forced to apply for other jobs because I cannot survive

on this wage and that threatens my own mental and physical health. I have come to believe over the last two years that I've been in this role that this is a system that works for no one. Least of all consumers. Clinicians who come into the system with a heartfelt wish to heal and bring positive change end up with a near unbearable amount of 'moral discomfort', and heartbroken. I believe that compulsory treatment, robbing consumers of the 'flight' option in our 'fight or flight' response, causes many of the problems that it is supposed to remedy. The system does not work for nurses on Intensive Care Areas / High Dependency Units. It doesn't work for doctors who are too busy to help in the way they would like to. It doesn't work for allied health professionals who are sidelined and marginalised by the dominance of the the medical model, and undervalued. I believe that when the system works for consumers, it will work for everyone else. This is how to retain the mental health workers, including peer support workers. For this to happen, my personal belief is that we have to act in accordance with the slogan of the disability and consumer movements, a core value of peer support: "'Nothing about us without us.' The ideal way to have begun this positive change, from the outset of the Royal Commission, would have been to appoint at least one person with lived experience of mental distress as a Commissioner."

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?

"As above: 'I have come to believe over the last two years that I've been in [the role of consumer peer support worker] that this is a system that works for no one. Least of all consumers. Clinicians who come into the system with a heartfelt wish to heal and bring positive change end up with a near unbearable amount of 'moral discomfort', and heartbroken. I believe that compulsory treatment, robbing consumers of the 'flight' option in our 'fight or flight' response, causes many of the problems that it is supposed to remedy. The system does not work for nurses on Intensive Care Areas / High Dependency Units who are assaulted by consumers or uncomfortable about depriving people of liberty. It doesn't work for doctors who are too busy to help in the ways they would like to, or frustrated by the lack of necessary funding. It doesn't work for allied health professionals who are sidelined and marginalised by the dominance of the the medical model, and undervalued. I believe that when the system works for consumers, it will work for everyone else. This is how to retain the mental health workers, including peer support workers. For this to happen, my personal belief is that we have to act in accordance with the slogan of the disability and consumer movements, a core value of peer support: "'Nothing about us without us.' The ideal way to have begun this positive change, from the outset of the Royal Commission, would have been to appoint at least one person with lived experience of mental distress as a Commissioner."

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

N/A

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

"Please see attachments. I believe that positive and necessary change is possible. But that will only happen when consumers are involved in our own treatment, when we are respected and

treated with compassion, when our human rights are deemed as important as everyone else's, and when we are able to participate in every level of decision making and service planning and delivery, not just in a tokenistic, tick-box fashion, but authentically. I believe healing occurs when we are empowered to find and use our own language for our experiences, make our own meaning, be the authority on our own lives and experiences, and when we are given the dignity of choice. Thank you for taking the time to read my submission."

Victorian Royal Commission into Mental Health

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Treatment of consumers with BPD

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

I was diagnosed with schizophrenia at the age of 22, a diagnosis which was then changed to schizoaffective disorder. This was the only diagnosis I knew of for around fifteen years, in which time I worked hard on my recovery. I was told at the end of this time that I had made a full recovery. Although I felt confused about this, I also felt exceedingly proud. A year or two later I was subsequently diagnosed with Borderline Personality Disorder. I read the list of symptoms, the misinformation, judgement and blame that abounds on BPD online, and my pride turned to shame. I also noticed my treatment by mental health professionals changed markedly. My experience has been that mental health service providers often seem to think they know everything they need to know about me before I even open my mouth. When I do speak, everything I say is interpreted through the lens of what people think they know about BPD: they believe that I am attention-seeking, manipulative, needy, dependent, bitchy, and likely to ask for more support than I actually need. When I say I am in distress or in crisis, I am therefore not to be believed.

One of the hardest parts of my job is supporting people who are treated in this exact way by the service I work for. Consumers with BPD on our ward can be observed saying that they fear they will kill themselves when they are discharged, and then can be observed being discharged minutes later without any support. I have seen terrified consumers self-harm as they are being escorted from the ward by security in an attempt to stay in an environment that is safer than their own lives and homes. In one instance, a consumer I care for deeply presented to ED with plans to commit suicide, and was sent home rather than being admitted to our ward, due to the belief that those with BPD should be kept off acute units. I called every colleague I could think of, trying to voice my concern that she was in real danger. She called me an hour or two after being discharged from ED to tell me she had taken an overdose. I called an ambulance. This consumer had had the diagnosis of a psychotic illness for more than thirty years and been treated with relative compassion by our service. This incident was the second time she had sought support and safety after having a BPD diagnosis tacked on to her file.

My understanding is that the rate of BPD diagnosis is ever increasing. This kind of callous treatment is going to be experienced by more and more people unless something is done.

I recently asked a clinician specialising in BPD why efforts are made to keep consumers such as myself off wards, even when we are terrified that we will take our own lives. We had been speaking about the discrimination and prejudice of mental health professionals towards those labelled with BPD. I asked, 'Is it because they think we're dependent and if they let us in, we'll never leave?' I had just read the treatment guidelines on BPD and the reason for this recommendation was never specified. He replied, 'No it's because of everything you just said. Wards are horrible places. They make people with BPD feel worse about themselves.'

Those of us labelled with BPD know how we will be treated in hospital. When we seek help in the face of this, it's because we feel profoundly unsafe and vulnerable to self-harm and suicide. This specialist clinician's argument is thoroughly circular. The reason wards are so difficult for us is

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because clinicians treat us as though we shouldn't be there; as though we're exaggerating our distress and 'malingering', rather than being in real and significant emotional pain. If wards are difficult for us, services and service providers need to improve their practice and treat us with respect and compassion, not kick us out.

Victorian Royal Commission into Mental Health

Dual Diagnosis

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

One of the most frustrating recurring stories I witness in my work as a peer support worker on an inpatient unit is the complete lack of overlap between mental health and AOD services. Due to this oversight in our system, consumers with dual diagnosis are slipping through the cracks every day of the week. They are discharged from our unit with no support for addiction struggles and sometimes without adequate accommodation. They end up back on the unit swiftly, and frequently. These are people who are often talented, intelligent, witty, kind, and with boundless potential, and their lives are being wasted and sometimes lost. They live with immense suffering, and the merry-go-round they find themselves on robs them of hope and self-belief. They give up on themselves, and clinicians give up on them. This is a crime. I do not understand how this can be so hard to fix.

Victorian Royal Commission into Mental Health

The dominance of the medical model

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

I imagine that much will be said about the effects of the dominance of the medical model of mental illness in the course of the Royal Commission. I'll limit my comments to two themes.

Scientific and medical language purports to be neutral; about unbiased observation, free from value judgements. Having been an inpatient in the public mental health system many times over twenty years, I have often, on wards, picked up a sense that I was being judged, treated with suspicion, not believed, certainly not 'heard' or 'seen' as the person I really am. But this was an intangible feeling, not something I could put my finger on. I oftentimes concluded that it was my own mental distress, a distortion in thinking, that led me to feel this way. Now that I work on an inpatient unit, I have access to consumer files and to the notes written by clinicians. I have seen with crystal clarity that the judgement, condemnation, suspicion, and dismissal I experienced was very real, written into my notes and into my history, to forever influence how I was seen and treated with each subsequent contact with the system. This discovery was both validating and terrifying. When consumers are admitted to inpatient units, we are raw, and profoundly vulnerable to the people charged with our care. There is nothing neutral about psychiatric language. The tone of it is often actively hostile, even hateful. For mental health systems and services to improve, this use of language, and the attitudes it is imbued with, must change.

I have also found the dominance of the medical model confronting when consumers have trusted me to support them in hearings of the Mental Health Tribunal. It seems obvious to me that a human being's mental and emotional wellbeing comprises many factors, including social, spiritual and political dimensions of a life, not to mention the primacy of trauma. However, in mental health tribunals, a person's freedoms, human rights, and ultimately their ability to feel human, are determined according to medicine alone. No other factor seems to be considered. The narrow-mindedness, short-sightedness, of this is remarkable. I perhaps naively thought that the community member of each tribunal panel would contribute to the consideration of other components of human wellbeing. This has not been the case in my experience.

Victorian Royal Commission into Mental Health

Use of induced coma to control behaviour

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

Recently in my capacity as peer support worker, I supported a consumer who was brought to our ward and placed under the Mental Health Act. She was described by clinicians as manic. Her treating team believed she needed ECT in order to recover. She did not agree, and did not wish to receive ECT, having found it extraordinarily distressing previously. She described it as a 'barbaric practice'. Clinicians believed her behaviour to be dangerous to their safety, although I cannot comment on how accurate this account was. She was taken to the Intensive Care Unit of the hospital for co-occurring medical problems and was placed under mechanical restraint (manacled to a bed) on and off for 4-6 weeks. For much of that time, she was also placed in an induced coma, partially to manage her behaviour. (Her terror and distress at being manacled to a bed was causing her to react in understandable ways). One clinician in a leadership position on the mental health ward where I work confided in me 'We were lucky this time because the medical issues gave us an excuse to sedate her so much [to the point of unconsciousness].'

This consumer is still, months later, grappling with the loss of several weeks of her life, and probably will be for years to come. I can only imagine how terrifying it must be to have your very consciousness taken from you against your will.

I visited this consumer regularly during her time in ICU. When she was awake, we had many intelligent, funny and warm conversations together. We were able to laugh together and cry together. Remarkably, when I raised the issue of how hard it must be for her to have friends and supporters like myself come and visit without freeing her from her restraints, the consumer was more concerned for me and my keeping my job than she was for herself, in spite of her extreme distress. This is a woman of integrity, reason, insight, wisdom, intelligence and great care for others. We had a connection; she knew and trusted me, and knew that I would listen and could in part understand what she was going through. I believe that the majority of the behaviour clinicians objected to in her was caused in the most part by the system itself; by 'care' that is actually indifferent or hostile; by interaction with staff who lack empathy and who cannot or will not give beautiful people like this the simple benefit of the doubt.

This consumer has given me her consent to tell her story in my submission.

Victorian Royal Commission into Mental Health

Family violence and carers' rights

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

Roughly a year ago I met a female consumer on the ward where I work in my capacity as peer support worker. For the purposes of this submission I will refer to her as Lisa. The story Lisa told me was that she had been in an abusive marriage for some years and had moved out from the home she had shared with her husband and children at least a year prior to her admission. (Lisa had not sought to divorce her husband due to a fear he would harm her children). On a trip back to the family home to see her children, she had become distressed when she was locked out of the house. Her abusive husband had called an ambulance and lied, saying that she had threatened to commit suicide, when in fact what she had said was that she was afraid her husband would kill her. She was forcibly brought to our ward, placed under mechanical restraint and injected with a sedative. When she woke the next morning, she was sat down and told by her treating psychiatrist that she suffered from Bipolar Disorder. She was in her fifties at this stage and had never been observed to have either a depressive or manic episode previously. The doctor had not spoken to her for more than a few minutes when he informed her, in a dismissive way, of her diagnosis. Lisa never claimed that her husband had physically abused her, although she feared that the abuse would escalate to include this. Her doctor on the ward was heard to say, when asked about the abuse 'That's just her way of framing what's going on.'

During her stay in hospital, Lisa's husband called the ward many times, sometimes more than once a day, demanding information on her condition and treatment, and presented to the ward to see her against her wishes and the advice of staff. When she was discharged, I supported Lisa by providing post-discharge peer support. She was at first discharged to our area's Prevention and Recovery Care (PARC) facility and then became a client of the service's team for consumers who are homeless or at risk of becoming homeless. Throughout this time, her husband continued to harass her treating teams, stating that they were not doing their jobs. His opinion was that if they had been effectively performing their jobs, Lisa would be well again, and the evidence of this would be that she would return to their marriage.

During the period when I was supporting Lisa, I discovered that her abusive husband had been offered, and was receiving, carer peer support. I was shocked, and questioned this. I was told at first that the abuse was 'alleged abuse' and had not been proven. When I then questioned this person's actual status as a carer (he had not been living with the consumer for over a year, and was not supporting her financially or in any other sense), I was later told that he was co-parenting children with the consumer, and could therefore be said to be indirectly supporting her. When Lisa and I spoke to an IMHA advocate about the situation, we were asked how much time Lisa was able to spend with her children. When she heard that Lisa was only spending around an hour per week or even per fortnight with her children, this advocate argued that this did not constitute co-parenting. IMHA were ultimately unable to assist in Lisa's situation, however, given that she was no longer under an Order at this time, and it had been more than 28 days since her discharge from the ward.

Lisa's homelessness team (a part of the service I work for) had commenced applications for public and community housing on her behalf. She was waiting for this housing to come through so that she could then have partial custody of her children, as she was living in a boarding house that was not suitable to having children visit.

Lisa contacted me, extremely distressed, when she was informed by her treating clinician on the homelessness team, that a meeting was to take place between Lisa, her husband, the treating clinician, and the psychiatrist. Lisa stated that she did not consent to this meeting taking place. It was never made 100% clear to Lisa how this meeting was supposed to benefit her, and she was anxious that information about her mental health and treatment would be shared with her husband. Any explicit account of the purpose for the meeting seemed to be about arriving at some kind of agreement between parties about how they would all communicate. Lisa was told that she had no say in the matter, and needed to just accept that the meeting would take place and prepare for it. Clinicians on the team would allow her to have a support person present, so she asked me to attend with her.

In the time between being informed of the meeting and it taking place, Lisa and I tried every avenue for self-advocacy that we could think of to stop the meeting from happening. IMHA could not intervene for the reasons given above. The Mental Health Complaints Commissioner would seemingly only be able to accept a complaint after the fact. The Mental Health Legal Centre never answered their phone. The Office of the Public Advocate also said they couldn't help. VMIAC could do nothing. Lisa's access to her children was being held in the hands of the team demanding this meeting take place. This was clearly a case of coercion. The afternoon before the meeting was to take place, I went to see a senior decision maker in my own organisation. This also got us nowhere.

When the meeting came around, it turned out that only very perfunctory information was shared with Lisa's abusive ex-partner. It is my belief that the primary reason for this meeting was to stop this man from making multiple harassing calls to the service each week, sometimes each day. It had nothing to do with providing service, or aiding the recovery or wellbeing, of Lisa.

In trying to appease Lisa's husband so that he would later cooperate, the meeting began with the psychiatrist asking for his account of the whole situation. He spoke for more than twenty minutes, describing Lisa as mentally ill, not to be believed or trusted, a danger to her children. He described her as being voluntarily homeless, and stated that she was to blame for her situation. At no point was he asked to stop speaking, even though the two clinicians present could clearly see the distress this was causing Lisa. After twenty or thirty minutes, Lisa became so upset that we left the meeting. We had been promised that it would be a short meeting. An hour and a half later, we received a phone call from the treating clinician to say that the meeting had finally finished. She would come and debrief us. Before she could get there, however, Lisa's husband exited the building and chased us both up the street into a café bathroom. When the treating clinician arrived, we were both shaken. She told us that she was a 'glass half full person' and believed something good would come of the meeting. I asked her what resolution had been arrived at, and the clinician replied that Lisa's husband had been given her manager's phone number to call when he had questions. Lisa's husband already had the phone number of a manager more senior than this. I expressed my opinion that this was no resolution at all, certainly not for the consumer supposed to be served by our organisation. The clinician said to Lisa, 'at least our working relationship won't be affected by this anymore, because he won't be bothering me.'

6-12 months on, Lisa has moved house and been referred to a different Area Mental Health Service. Her new clinician believes she never had Bipolar Disorder, but rather is showing a proportionate

response to trauma. She is being weaned off the mood stabiliser that has caused her disabling side effects for over a year. Lisa states that the trauma caused to her by her interaction with the public mental health system has done her as much, if not more, damage than the trauma she experienced with her husband and in her childhood combined.

This story highlights many problems in the mental health system.

Under the Mental Health Act, carers have rights to information about a consumer's condition and treatment, and the right to be involved in treatment decisions. However, under the Act, a carer is defined *by the carer*, not by the consumer. Where the definition of a carer is mentioned, we are referred to the Carer Recognition Act. While I can see that many consumers live with family members who they may have fractured relationships with, but who nevertheless need to know details like when a consumer is to be discharged etc, this leaves the door wide open for family members who are abusive now, or who have abused consumers in their childhood, to be afforded rights that put consumers in direct danger, both physically and emotionally. In some instances, this could be a matter of life and death. (In the case of expected discharge dates, this is information that is rarely shared to the same degree with the consumers themselves).

When I have raised this concern on the acute unit I work at, I have been told that treating teams only share information with families and carers when they have a consumer's consent. However, IMHA report that this is the single most common complaint made to them about the practices on our ward. Long-estranged ex-spouses and other family members who have no caring role whatsoever are contacted and given information when consumers have expressly asked for this not to happen.

Where clinicians or carer peer support staff assert that abuse of a consumer by a family member is 'alleged but not substantiated', and yet such claims are never actually investigated, this obviously leads to a situation where every single claim of abuse will be described in the same way. Action taken will therefore in many if not all cases reflect that the consumer is effectively not believed. This is compounded by the fact that families and carers are often seen as sane and reasonable, whereas consumers are vulnerable to being perceived as psychotic, or sensationalising situations out of a distorted perception of reality. Again, this is a scenario that can be life-threatening. In actual fact, when psychiatrists suspect that a consumer may be displaying psychotic symptoms, the people they almost always contact to corroborate or disprove the consumer's claims, are family members. They do not always ask for consent before doing so, and share information in the course of this contact. This may place consumers in even greater danger.

As a staff member on an acute inpatient unit, I receive emails about the system's and our service's policies and procedures surrounding family violence. I have noted recently that new policy allows for greater information sharing between services to better protect children in abusive households. It is mind boggling to me that the importance of information-protecting – privacy, confidentiality – for the safety of the consumers we exist to serve, has not been similarly recognised.

Many of the communications I receive state in black and white that family violence and abuse are not always physical in nature. However, the same senior clinicians and administrators who send these communications make decisions every day that reflect a belief that if someone with a diagnosis of mental distress claims they are the victim of non-physical abuse, they are essentially crazy and not to be believed. The hypocrisy of this is staggering.

A poster on the wall of the office that consumer and carer peer support workers share in my workplace states the following:

‘Consumers’ right to privacy is a human right and must be upheld to the fullest extent possible...
Balance the consumer’s right to privacy with the carer’s right to information.’

I do not understand how a human right can be balanced with anything, let alone with something that directly contradicts and compromises it, and may ultimately endanger life. Surely our most fundamental human right is our right to live.

Finally, this is an issue that often speaks to gender inequity, and the intersectionality of the disadvantage experienced by consumers who are also women. At a time when sexual safety on acute units seems to be such a priority, this is alarming. Lisa is now engaging with VMIAC’s Phoenix Project for people made sexually unsafe by mental health services.

Lisa has given me consent to share her story in my submission. She sees it as an important act of advocacy. Lisa has been profoundly damaged by the experience of being disbelieved by those who purported to care for and support her.

Victorian Royal Commission into Mental Health

Legal issues at time of being placed under the Mental Health Act

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

Recently a friend and former colleague of mine called me from a Victorian Emergency Department where he was waiting to be assessed by a psychiatrist. He had been placed under an Assessment Order. At the time of being placed under this order, he had challenged his treating clinician as to whether or not he met the criteria needing to be satisfied for him to be treated involuntarily. He had excellent points. It was his belief, and later mine, that he did not satisfy the criteria. However, in this situation he had no legal recourse to challenge this. He contacted Independent Mental Health Advocacy (IMHA) by telephone but there was nothing they could do to intervene until he had been placed on a Temporary Treatment Order or similar. In that moment, I realised the injustice of this aspect of our system. There needs to be available to consumers legal support at the time of the criteria being weighed. If such support does not exist, the criteria might as well not exist. Clinicians (and police, ambulance officers) can decide the fate, freedom, enactment or violation of human rights, completely arbitrarily, as a matter of opinion, with little or no accountability. If they are to be held to account, it will in every case be after the fact, when damage may have already been done to the consumer.

Victorian Royal Commission into Mental Health

Supported Residential Services

I have been a consumer of mental health services for over 20 years and have been diagnosed with several mental illnesses over this time. I have been working hard on my recovery for my whole adult life. I am currently employed as a consumer peer support worker in the public mental health system. I have many friends who are consumers.

I have several friends living in an SRS in Ballarat. My understanding is that these friends of mine are not under the Mental Health Act, and, legally speaking, are free to come and go as they please during the day. The staff at this SRS limit when my friends come and go, decide which friends they may or may not have contact with, and in some cases determine whether they have any friends outside the SRS at all. My friends' rights are being violated daily. Community Visitors occasionally visit the SRS, but I understand that complaints are not raised because residents are not aware of what their rights are, and do not realise that they are being breached. I have not officially complained out of a concern that residents' lives would be made much more difficult by the people running the facility. Although some staff members working at the SRS are compassionate and flexible, the women who manage it are unskilled, lack compassion, and are either ignorant or do not care about the consumers' legal and human rights. I have been told by respected members of the wider community that the SRS I am speaking of is the best in Ballarat.

My understanding from speaking to other consumers, consumer workers and clinicians is that very poor service provision is the norm in Supported Residential Services in Victoria. Whilst in this case, my concern is with the consumers' freedoms and rights to have friends and leave the facility to have full lives, it is my understanding that in many of these services, consumers' basic needs such as adequate nutrition etc are not being met.