

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

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

"Calling out and correcting the use/media representation of negative stereotypes of persons with mental illness and the use of words which are incorrectly assigned to things which negatively reinforce mental illness eg the constant use of schizophrenic to describe an activity or process which has no bearing on mental illness. Presentation of mental illness in a more sociocultural context -this is something that can happen to anyone and doesn't just happen to people with drug, alcohol, poor socioeconomic backgrounds etc. "

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?

"Nothing is working well. The system is overloaded, there is not enough support for either the person with mental illness or their carer support person/network. The mental health system is punitive, discriminatory, difficult to access and is not integrated with other important disciplines like drug and alcohol, housing, psychological support, peer support etc."

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

N/A

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.

"What makes it hard -the list is endless but some primary points are: Discrimination, stigma, lack of access to in-patient care before the person is psychotic, integrated health care services, lack of trained staff which is more encompassing of other disciplines, medically dominated psychiatric services, lack of community support and services, funding models which are out-dated, lack of evaluation of funded agencies that are commissioned to provide a service, poor or limited step down facilities etc. What can be done to improve this: improve access points listen to carers when they say the person is de-compensating, spiralling out of control provide better intake services without the pressure to clear beds and send the person out without the necessary supports in place. Integrate the service provision across boundaries, recognise that persons with mental illness often have a dual diagnosis, make the service provision opportunities more transparent, teach mental health workers that the response to an alcohol problem for someone with a mental illness can not be brushed off with the easy out response of 'until they recognise they have a problem there is nothing we can do' "

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

N/A

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

"The needs are huge. It would be a relief to be able to hand over some of the responsibility of managing affairs, day to day crisis to the people tasked and paid to deal with these issues but they all throw their hands up in the air and say that does not fall within my mandate. How often do you have to say "'I can't do this anymore' and be ignored or be offered the pat standard expressions of sympathy without any actual action. The provision of more support workers, peer or otherwise to support the client and liaise with case managers to deal with these issues would go a long way to supporting carers"

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

Proper vetted educational facilities to train workers that are comprehensive and include more than just the medical model of care.

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?

"There are no opportunities. Centrelink is punitive, restrictive in their requirement, offer no flexibility and the staff have limited understanding of mental illness and the ramifications of living with mental illness. There are simply no job opportunities for people with serious mental illness, no training opportunities that are flexible enough to be started and then stopped then re-started as required. Even volunteer opportunities are limited -when you can be fired/asked not to come back to a volunteer position because you asked people for cigarettes and that was seen as damaging to the brand then there are serious issues. Early intervention and appropriate care would assist in diminishing the opportunities to participate."

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?

"A holistic wrap around service that concentrates on good care, early intervention, provision of integrated services, housing and job opportunities, drug and alcohol support services, increased staffing and provision of more beds, step up and step down facilities."

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

improve mental health education integration of services eg drug and alcohol with mental health services evaluate service provision and focus on improvements look at housing models which provide a supportive holistic service eg the haven and look at adapting services which currently provide poor service to encompass some of those support systems

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

attachment provided

Attachment to formal submission to Victorian Mental Health Commission

While I have attempted to provide some information to the questions for the formal submission I felt that I needed to add some context to my story as a carer to substantiate and air my concerns about the mental health system in Victoria. It is difficult to try to provide an overview of the complex, complicated journey of navigating the mental health system without actually writing a thesis. So I have chosen to provide a brief summary and focused on areas for improvement by giving examples of unacceptable provision of services on a range of issues.

I am the primary carer for my adult daughter who over the course of the last 20 plus years has been a client of both the private and public mental health care system. She was a high-functioning young adult, albeit one with anxiety issues that became obsessive compulsive. Our journey began with the private psychiatric system during her teenage years and can only be described as fraught, dominated by psychiatrists and psychologists whose first action was to require payment, whose entire focus was on dissecting family histories with a view to blaming the parents and blended family dynamics, or overstepping their professional boundaries and arranging appointments without parental approval but still expecting payment. We persisted as we thought we might actually come across someone who would provide some assistance in just managing day to day interactions and coping mechanisms which did not eventuate.

With the last visit to a private psychiatrist she recommended that a hospital admission was required as my daughter was hallucinating and delusional. The doctor did nothing to facilitate this admission and it was left up to me to pressure for the admission. They kept her for 2 days and sent her home with no medication, follow up or support. A month later, having been absent from home for that time, she returned, disheveled, crying, delusional, hallucinating and afraid. I called the CAT team and there began our descent into the hell of the public mental health system.

I rue the day that I called but recognize that there were no other options either then or now.

I can only characterize what then followed as a series of mistakes, missed opportunities, mismanagement and misery.

With that first admission to the acute care ward (43 days in total) there was no referral to the first episode psychosis service, no carer support, no provision of options for housing and a pressure to clear the bed. This pressure to clear the bed resulted in an interstate discharge to a family member who had been identified as having abused her. My objections were ignored. She ultimately managed to return of her own accord.

During that year she was admitted 5 times for a total of 200 days, many spent in the high dependency unit, interspersed with numerous episodes of absconding. A back of the envelope calculation of this cost would be approximately \$200,000.00.

Never in that year did anyone accept that there had to be better ways of managing her, improved discharge planning, use of step-down facilities, supported housing options, early intervention strategies, opportunity to access psychological support or anything that even resembled a holistic overall management plan.

The hospital continued to discharge her to inappropriate placements including to a facility that was outside their catchment area with no handover and culminating in the penultimate negligent discharge to a squat on Christmas Eve, after having been hospitalized for a consecutive 75 days. The consultant rang me late afternoon to tell me she had been discharged and when I asked why and where to, he advised 'because she wanted to be discharged' and gave the address which I identified as a squat. He had given no consideration to the fact that she had no money, no ATM card, no sleeping gear and no food, that she was subject to the vagaries of the other itinerants in this

housing situation and this was all occurring during a period where most service providers were closed or on limited staffing.

When I advised him of this, his response was [REDACTED] will follow her up. They did, but they made a point of saying they would not attend the squat unless there was two of them so while it was okay to discharge my vulnerable, fragile daughter to this environment it was not safe for the [REDACTED] staff to attend unless there were two together.

Over the years there have been 17 more admissions, with many of the discharges premature so that she ended up being re-admitted within 1-2 weeks of discharge.

In 2009 she again had multiple admissions for a total of 62 days.

The hospital staff took an inordinate amount of time to recognize that she was good at holding it together to appear stable when she wasn't, to understand that if the door to the open ward was not locked that she would abscond, that she was treatment resistant and non-compliant with oral medication and that they were continually failing in discharging her to inappropriate housing.

The only blessing of the hospital admissions was that I knew where she was.

Not that this actually meant that she was safe for the ward was never really safe. The nurses were rarely on the floor, there were many areas of the outside courtyard which were out of sight line, visitors were rarely supervised or questioned and up until many years later visitors could access the patient rooms quite freely.

During her hospitalizations she was assaulted on several occasions, with one episode where she was being strangled by another patient and was only saved by an agency nurse who actually came out of the office to walk the floor.

She has had her hair cut by a visitor, lost clothing, received visitors from inappropriate people and been rorted for \$1500 by another patient who told her she could rent a room in his apartment but she needed to give him the rent straight away.

He ordered a taxi which took them to her bank whereby the teller handed over the money even though she later admitted she was concerned because of the male dominating the process and the signature was not quite right. They then taxied all over Melbourne while the male bought and used drugs, purchased weighing scales and then finally returned her to the hospital with no money. She was promptly put into the high dependency unit and he was discharged.

When I questioned how this could have occurred, the hospital admitted that the social worker was supposed to have arranged for a VCAT hearing to have her pension controlled by State Trustees but he had not got around to it. With the subsequent hearing the social worker admitted he would rather play in a band than be a social worker, had arranged the appointment over lunch time and made no provision to ensure that she could have a meal before or even on return to the ward and was no support whatever.

Finally in desperation about having a safe place for her to live I went to the federal and state Members of Parliament for her electorate and due to my own connections was able to access the office of the Chief Psychiatrist. All of that effort resulted in her admission to a continuing care unit where she stayed for several years.

During the time at the continuing care unit there was no effort to direct her into alcohol counseling, cognitive behavior sessions, social normative experiences with regard to cooking, budgeting or anything resembling life skills acquisition. The staff's constant refrain was that 'she is very hard to engage' which was compounded by the very clear demarcation of what was deemed non-nursing duties, eg we don't help them with kitchen cleaning despite the fact that this was a perfect opportunity to engage and communicate, there were no requirements for participation in any activities and she was essentially left to her own devices. During this time she moved from being a binge drinker to drinking consistently with resulting injuries occasioned by having been hit by a car, found collapsed in an alcohol coma on the sidewalk and assaulted.

Centrelink compounded the stress by demanding that she attend scheduled meetings to justify her disability pension. At the end of the first interview the Centrelink staff member was advising her to go looking for a job but cautioned that she shouldn't tell a prospective employer that she had schizophrenia.

This was punitive, discriminatory and risible advice from a government official that undermined my daughter's disability.

The opportunity arose for her to be given a flat in an independent living arrangement on the grounds of a chronic care facility both of which were for clients of a mental health service. There was supposed to be a support service in place to assist in adapting to living independently. This service was essentially non-existent and it was only due to the good graces and concern of the 24/7 staff of the chronic care unit that any support was actually provided.

The state funded service was never held to account for the lack of support. There were a shifting set of rules and regulations e.g. the dictum that the flats are single occupancy and no one else could live with the tenant which changed over time to the premise that anyone was able to co-reside for however long, with no due consideration of increased harm to the tenant or anyone else on the property.

The flats, while looking nice were badly designed in terms of physical safety and security with many design flaws and overall maintenance and repair difficulties.

When my daughter first moved into her flat, which was the first flat accessible from the street, she told me that she didn't know how to respond to the knocks on her door, subsequently she opened the door to everyone. She lived without access to hot water for 6 weeks because she didn't know who to tell (the plumbers had made a mistake). Additionally the funded agency told all the tenants to use the washing machine and drier for the chronic care house with the result that chaos reigned and each tenant had piles of washing and the house staff were furious.

I advocated to the funded agency and the tenants were all subsequently provided with washing machines.

Over the years the situation has deteriorated with tenants, including my daughter, having boyfriends move in on top of them who were/are detrimental to the health and well being of the tenant as well as to everyone else on the property. It is only because my daughter was subject to a serious assault that the partner could be moved out and restricted from accessing the flat. Another female tenant has a live in partner who does not have a mental illness and he is selling drugs, causing havoc and abusing the situation.

The place has become notorious as an easy target for every predator, drug dealer, lost or homeless person to seek to find a place to stay, sell drugs or take advantage.

The housing association has made it very clear that the chronic care staff is to provide no support and they require written complaints by the tenants in order to be able to do anything about the situation where tenants are exposed to harm.

The housing association continues to assert that because the tenants are under the Residential Tenancy Act they can do nothing to alleviate the situation. They also continue to assert that the flats are independent despite the fact that they pay the electricity and that there is only one gas meter for the premises for which they also pay the bill.

A recent letter to my daughter from a collection agency demanding payment or the gas would be cut off resulted in the housing association providing the information that there is only one gas meter and because the gas company needed an address my daughter's flat number was provided. For some reason the housing association had failed to pay for the gas. If I had not followed up on the letter then all of the tenants would have been without gas for their heating and hot water service.

It is paradoxical to claim that these flats are independent and require no support, despite the fact that they are reserved for people with mental illness, the housing association is paying for gas and electricity and the flats are tenanted by vulnerable people who are easily victimized.

Having allowed the situation to become chronically insecure whereby the tenants are targets for predators and drug dealers it appears that nothing can be done. The current housing officer is extremely helpful and aware but is limited by what he can do.

There is a perfect opportunity here to change the situation and provide better support in terms of wrap around services and 24/7 support much like a modified version of The Haven, but who will lead this initiative?

I as a carer could try but my voice is alone in the wilderness and I do not have the time or energy to manage this.

In summary my daughter is now an alcoholic, subject to domestic violence, has had personality damage, lost any sense of social norms, is resistant to any sort of intervention or support, even more difficult to engage with and leads a lifestyle where she is subject to abuse, intimidation and assault. She has not been reviewed by a GP in over 10 years, has chronic cough due to smoking and requires expensive dental remediation. Her friendship circle consists of users, abusers and other people at risk. There will now be no opportunities for change, for a job or career, for stability or long-term happiness.

This was not the life she was meant to have, it is not the life that she wants and it is certainly not the life of her choosing.

I am tired and I want to give up, but if I do there will be no one to stand for her, to advocate on her behalf, to ensure that people try to do the right thing in terms of her treatment and support, to attend to the myriad small crises that arise because of issues with daily life management along with major crises and most importantly to support her and remind her of who she is, that she is important and matters to the people who love her, myself, my husband, her sister and brother.

The mental health system has failed her.