

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?

"I think having role models in the community prepared to talk about their battles with mental health has been a wonderful step. We need more of this. Community education is vital. I think this needs to extend beyond the personal recounts to simply say this is a medical problem, a chemical imbalance if you like. Yes the personal ramifications are huge but I think taking some of the emotion out of it and simply stating the facts is equally important. People understand a broken arm or a heart attack. They have little understanding an injured brain and this feeds fear and discrimination. I think education of employers is equally important. People with mental illness face a huge stigma when applying for jobs. My husband has a great resume but had a mental health breakdown five years ago and has been unable to get work ever since. "

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?

"There seems to be little on offer regarding early treatment and support. I know my husband saw many psychologists and psychiatrists in the early days of his illness. And he received almost as many different diagnoses and scripts. There appears to be little sharing of information between the medical profession. Each time he would have to retell his story, from his childhood onwards. Each time there would be questions about his parents, his marriage, his work. A more coordinated approach would be helpful and progress things further and earlier. I think parents and teachers being aware of possible symptoms is helpful and I think more psychologists should be employed in schools to help deal with the epidemic of anxiety there. Aside from the individual impacts, this is only going to impact society as the students graduate. Teachers need to be focussed on curriculum needs and should not have to cope with the burden of increasing mental health issues amongst their students. They are not trained to deal with this. There is no support for families, during these early stages or any other time, in trying to deal with one family member's mental illness or the impact on the family unit. Making psychologists more affordable would certainly help people get professional support in the early stages of mental health problems. The mental health plan provided by the GP is not enough. At most, it will help with 10 visits in a year. That's less than one a month and not nearly enough to help someone with growing or persistent problems. After that, we pay for individual consultations which are \$260 or more for a one hour visit. This is unaffordable for the average worker, even worse if you are unemployed. "

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

"In my experience, calling 000 and asking for the police is the only reliable action. I don't know if this is really their job. I have tried calling the CAT team to help my husband many times. Firstly their number (we're in the inner west) is impossible to find. Last month, in frustration I called a private mental health hospital to ask if they had the number for our local CAT team and even they couldn't find another number other than the one I had which just kept ringing, unanswered. Then I

tried the local police station. No answer. Finally I tried 000. This was about 2.45pm on a weekday. The lovely operator said they would send police out to check and let me know. But hours when past and I didnt know what was happening and I didn't feel I should call 000 just to check on progress. Finally I received a phone call from the local policeman after 11pm. My husband hadn't been around earlier and so they had returned to check on him that evening. The police were wonderful, however that was over eight hours of anxiety for the family, with no support."

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.

"The number for the CAT team is almost impossible to find, and then when you do find it, no one answers. There is no support for families. And no linking mental health services for carers. There is also a total lack of support for people once they leave hospital after a major depressive illness. My husband has been admitted into a private psychiatric hospital many times. He has stayed many weeks at a time. Each time he enters in poor health, sometimes via the emergency unit of a public hospital, and he is in there for a long time, sometimes starting in their ICU. But when he is released from hospital, there are no follow up services. The only option was a one day a week program which he tried after several releases. My understanding is that the program was OK, if repetitive, but the other clients had different issues. Many were single, younger and on Worker's Comp. There was no shared problems with an older married unemployed father and my husband felt out of place. This lack of services post-hospital caused severe problems. The only follow up were appointments with the psychiatrist when what was needed was help adjusting to family life after long stints in hospital and help finding a job. He did see a private psychologist for a while but did not find this helpful. There needs to be a link with employment services to help people get back to work. There was no such service. Centrelink needs to be involved here. [REDACTED] tried to access Centrelink's disability employment service (or whatever it's called) but was knocked back because he was not receiving Centrelink payments. The reason he did not qualify for Newstart payments was that I was on the princely sum of \$70,000 and so we were over the threshold. Ironically, now we have separated as a consequence of his ongoing illness, he now receives Newstart, rental assistance and is with Centrelink's job service (with no luck so far). From an outside perspective, this is costing the government more money in the long run because of the lack of support initially. Not to mention the cost on the broken family. There also needs to be help for people to re-adjust to community and family life after weeks in hospital with a mental illness, for example a social worker or a transitional program. Coming home to family life after hospital was always a shock [REDACTED] even though he was delighted to be home. I think an intermediary step, where people can live independently but with a carer and professionals nearby is a vital step that is missing to help with the readjustment process. Instead [REDACTED] would go downhill, go into hospital, come out in a better state than he went in and then go downhill again. Sometimes it was weeks between re-admissions, sometimes it was months. And the only person monitoring his progress was me - his wife, a mother of two teenagers and a full time worker. I tried many support services and they all agreed such a program would be useful, but was not existent. I did find one attached to a hospital but was told it was only for that hospital's patients. Another professional told me it was fully of former/current drug users and would not be appropriate. There was a high risk that [REDACTED] would become homeless during this process. If I ever tried a community group for help, we were a long way down the list even for people to visit us because he had a home and he had a family. Now he doesnt. And I wonder if support earlier could have prevented this awful situation from happening. Instead, the family is broken, our marriage is broken and we are going backwards financially paying a mortgage on the family home and rent on a unit for [REDACTED] to live in. All on my

teacher's income. The only services that did link, linked to our disadvantage. One day [REDACTED] called the CAT team because he wasn't well. After the CAT team arrived, they told me they would have to contact the Department of Human Services because there were children here while [REDACTED] was self-harming (the children had no idea). We got a follow up letter from ChildFirst (which I didn't open because the envelope identified the sender as MacKillop Family Services and I assumed it was a letter from a charity group asking for donations). Apparently they called me but didn't leave a message so I didn't know. Then they called [REDACTED] was an inpatient at a psychiatric hospital at this stage and this call understandably distressed him further. Why would you do that to someone who is already identified as fragile? As a result, [REDACTED] has declared he will never ring one of these help services again. This is not a good outcome. I understand they were doing their job, and they were nice, however when I called them it was both humiliating and distressing to hear their perspective and have to justify that things were OK. My daughter and I are both seeing a psychologist privately. They said they had tried to trace my daughter through her school. After I explained our situation, and that I didn't want follow up services they now offered because it wasn't necessary, I had to wait for some time before I was informed our case was closed. This was an anxiety producing episode which only added to our stress and distress at what was already a tense time. This was the last straw in our marriage and we separated after this. Even now I resent that we were placed on a file. Before this I had spent hours ringing different organisations trying unsuccessfully to get help for him. When I asked for help from my husband's hospital, I was told there was nothing available. The public system seems to offer better follow up. [REDACTED] has also been admitted to Western General Hospital a few times. There are follow ups, however unfortunately the staff never seem to have a good level of English so communication is poor and it seems pointless. Building rapport is vital in this situation."

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

I imagine poor education and/or employment opportunities. People need a purpose in life. And possibly lack of access to mental health services.

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

"We need to be supported, valued, kept in the loop, offered advice and hope for the future. We found there was absolutely no support for us, and I did ask about it. We need psychological and emotional support, financial support and advice. Importantly I think a caseworker to coordinate and advise of various necessary services, and to call in an emergency, would be incredibly useful. It is very lonely and isolating being a carer. You hear of these caseworkers being available for some people who have cancer. I would argue that it is equally important in cases of severe mental health issues. Financial support. There was no financial support because I was earning a princely sum of \$70,000 as a teacher. We have gone, and continue to go, backwards financially. This is not good for anyone's mental health. If it wasn't for my pensioner father, I would have had to take my daughter out of her Catholic school because we can't afford the fees. Now we are paying rent for [REDACTED] and a mortgage for us. [REDACTED] now receives Newstart but it doesn't even cover the rent on his modest studio apartment. Emergency services. We have had to call the CAT team, the ambulance and the police several times. My son had to come home from school to find his father passed out or in a depressive episode. Sometimes I sent my kids to the neighbours when the ambulance came so they wouldn't have to witness their father being taken away. There needs to be a better system than this. Mental Health Rebate. I have had to pay a fortune in private

psychology fees for my daughter and I. The mental health rebate does not cover enough sessions to be really worthwhile. Ten sessions are not enough. After 20 years of marriage, my husband and I ended up separating because that was the best solution for the whole family. It wasn't fair on anyone and we are all suffering. We do not have any extended family so the burden as carer fell on me. I feel we as a family were offered no support. "

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

I imagine better pay and conditions would be vital. And good professional development programs.

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?

"From my perspective, there are few opportunities, yet this participation would be incredibly beneficial for people living with mental illness and their families. More needs to be done to normalise this illness. People with mental illness, like my husband, can be intelligent, hardworking and productive members of the community. Yet after a breakdown like this, there appears to be no employers willing to take them on. This impacts both their financial and social wellbeing, and is also detrimental to the economy as a whole. Maybe there needs to be incentives for employers to take them on. People need a purpose in life, and this is taken away when there is little access to social and economic activities."

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 quality care should be available for everyone, regardless of income. This includes both psychiatrists and psychologists and more beds in psychiatric hospitals (I have had to stay home from work to monitor my husband while we wait for a bed to become available.) There needs to be more attention paid to early signs of mental illness and consistent follow up care for patients once they are released from hospital. I think there also needs to be an intermediary residential stage between hospital and home to help people adjust and ensure they're ready to go home. There is a vast divide between being ill in a hospital with educated staff dedicated to your care and a family environment at home where everyone needs attention and this can be very hard. This stage needs to include social services and employment services. The impact that the roller coaster of someone living with mental illness has on the entire family has to be better recognised and helped. The above step would be instrumental in this. A case worker for each patient would be a wonderful thing to help both the patient and their family. Once in a private hospital, there is no information about services available in a community. Employment services to help people with mental health should be a priority. There needs to be a recognition that not all mental health patients are the same. A middle aged married father who wants to work to support his family has different needs to a young single woman who is on worker's comp or an old man whose only responsibility is his cat. They may all suffer depression, however their needs and problems need to be recognised individually and not all lumped together. "

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

"I think the education of the public, the education and employment of more professionals in the field and greater research into these illnesses is vital. This all needs to be planned for, and to be

funded. I think recognition of the many issues is vital, as is education. I think the community needs to know mental health is nothing to fear. Nor is it a reason to not employ someone. I think there is far more support for people with broken limbs or with cancer. Much of this is due to public health campaigns and community expectations. Yet the statistics of people suffering mental illness show what a huge problem this really is. I think more educated people are needed in the field, more beds are needed in hospitals and more support workers and services are needed. I think these professionals need to be recognised and well paid to demonstrate their value and attract more people to the field. And I think the Medicare funded rebate needs to be extended to include far more sessions to make it truly useful for people with mental illnesses. "

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

"My husband suffers severe chronic depression (alternately diagnosed as PST, anxiety, bipolar, bipolar fast cycling and more). He has been in and out of a private psychiatric hospital for five years. Before this illness, he was hardworking and successful (he was in the top tax bracket). He had not had a job in five years, at first because he was too ill and more recently because no one is willing to give him a chance. He has lost his job and his career as a result of this illness. Like many people, his identity was closely linked to his work and this has been lost. His illness has greatly impacted his relationship with me and his two teenage children. Aside from the depression, all of this has impacted his self esteem and wellbeing. We have also lost our marriage and our family. And our plans for the future. █████ constant illnesses took a huge toll on the family. Each day became tense for all of us as we waited to see what could come next. I was working full time to support us. Last year my son was studying for VCE and never sure what to expect when he arrived home. This was not fair. This has impacted us as a family and as individuals. Both our present circumstances and our futures have changed, and feel uncertain. We found there were absolutely no services available to us after █████ many hospital stays. There was no help for him in finding services, no help to find employment and no help for the family. I feel let down by the system. Each time █████ was in hospital he would improve, but it was only a bandaid because he would come home and it would all fall apart. Eventually my son or I would have to call the police or ambulance when things had gone too far. There was no one else to help and no other support. Even now █████ lives separately, this has not changed."