

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

SUB: 0002.0029.0413

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

N/A

**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?**

N/A

**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.**

N/A

**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?**

"My own experience is as parent to an adolescent suffering from schizophrenia. It is an horrific illness and has hauled the entire family down with it. He has had seven admissions in two years; he has no insight and almost total noncompliance. As I write we believe he is becoming unwell and again and we are preparing as best we can for an eight admission. Families need help in understanding what is going on. They need their own advocate to help them navigate through the system. And they need to be heard, to have an active voice in the treatment plan. Families need to be given help to understand the implications of their child's diagnosis and what treatment will involve. Our child was 16 when diagnosed and first admitted to an AIPU and has had many admissions in the two years since. We had almost no understanding of how services worked or the terminology they used. We didn't understand why our child's inpatient team took the approach they did; it was often difficult to access them and we didn't know how the system worked. Families should be given a briefing - for example, when our child asked us if we would approve leave, we had no idea what he was talking about. When a staff member informed us that he had been placed in the ICA overnight, we didn't know that was part of the facility or what it meant. Having somebody that you love develop schizophrenia means that the person you knew has gone, most probably forever. We see remnants and traces but we don't know what will come back. Neither us as parents nor his siblings was ever offered counselling or therapy or even anything to help us

manage the difficulties of living with him through relapse and recovery (over, and over, and over again). During his last admission, which was in the adult system, we had a call from a carer support worker and once we were emailed some weblinks of various groups. None of these seemed to offer any programs that could help us to continue functioning as a family, to understand his illness and experience or to support him towards recovery. Nobody ever took the time to help us navigate what might be out there. I found a family therapy service which had little practical benefit. I undertook personal therapy to the extent Medicare would offset the costs. We had little help from the AIPU in planning for discharge or in support after discharge - the approach was that the wards would hand him (and us) over to the community based team and there was no discharge plan that was communicated to us or enforced with him. For example, his strong wish in the first year of his illness was to return to school and resume his previous life. There was no staging, he simply left the ward, spent about a week at home and went back to school after eight to twelve weeks as an inpatient. We had one or two visits from a CAT team to see if he was taking medication (they didn't detect the noncompliance) and then it was entirely up to his Early Psychosis Team caseworker to suggest strategies and interventions. I asked for support from the AIPU education officer and was told that because my child had been discharged, he was not eligible for assistance. Although his admissions were very lengthy, I'm not aware of any preparation or planning work directly between the education officer and my son before discharge, and there was certainly none with us or the school. The advice boiled down to "'don't let him take on too much and keep an eye of him if his academic performance deteriorates'". After his last admission a social worker helped him locate a SRS. We didn't know social work support was available and we were not put in contact with one ourselves at any time. We didn't know how long the SRS would be available, who was funding it, what was offered. Perhaps particularly with adolescents and young patients, there seems to be little or no thought given to preparing for discharge or post-discharge support. The ward focussed on getting his medication right and keeping him contained until he was safe enough to return home. He was handed off between the AIPU and the community team and although after one or two admissions it seemed obvious he was a frequent flier, there was no follow up from the acute team. He was being shuttled between two teams. We had strange comments such as a adult ward nurse telling us that his caseworker, not us, should be the one taking him round to check out PARC and the SRS. For young patients, parents need to be consulted and involved in treatment decisions. Carers need to be heard. Especially once he was being treated on an adult ward, we found it extremely difficult to talk to his treating team or have any visibility of his treatment. It took heroic efforts to be heard. In one instance, within a week of admission we were told they were planning to prepare him for discharge. At that time we had had only one or two short conversations with his psychiatrist and he had not had the same nurses twice. He was going to be discharged because he was masking his symptoms extremely well. I had been calling and leaving messages with his psychiatrist, because my son was disclosing to me the delusions and hallucinations that he wouldn't mention in front of any clinical staff. I got a voicemail back that they didn't need to talk to me because they'd already spoken (very briefly as it turned out) to my husband. I had to get his caseworker to communicate to the ward about how very concerned we were and that he could not possibly come home in his current condition. We had to fight, very hard, to keep him in hospital. He was eighteen. We had to repeat ourselves over and over on each new shift; we'd ask nurses to record the self-harming we saw and then the next nurse would say nothing had been written down and they couldn't see anything themselves. In the end I had to trick my son into showing his hand to a nurse so that they could see the religious symbols he'd carved into himself with a razor blade. Nobody on staff had noticed them and none of them had listened to me. "

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

N/A

**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?**

"Young mental health patients need better help to recommence education and age-appropriate socialising. There was nothing for our son between specialised outpatient units which seemed to be designed for kids with BPD or school refusal, and simply returning to his mainstream school. Nothing was done to help him gear up to cope with school return, to design programs he could begin while he was on the ward. It was suggested that we take in some of his textbooks so he could do some study once he felt up to it. Nobody worked with his teachers to help them develop a return to study program. It was entirely up to his caseworker to check how he was doing and to try and come up with ways to support him. Post-discharge support needs to be multi-disciplinary and heavily increased. As well as an empathetic, supportive and severely overloaded caseworker it would have helped to have somebody work with him and the school to set up strategies and monitor how he was going. The AIPU actively discouraged the patients from developing friendships. We never understood why; it was simply a thing. Nonetheless, and not surprisingly, our child did connect with several co-patients and kept in touch with them after discharge. Again, all of the focus from his treating team was on managing his medication. Nobody seemed to be working with him to ease him back into the social mainstream, develop strategies to manage anxiety. It was very much "take your meds and you'll be right"."

**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?**

"Young people should not be treated in the adult system. At 18, our son couldn't return to the AIPU any longer. He has found his adult admissions terrifying and we have been very concerned for his welfare. It was much harder for us too; for example, visiting hours were very much restricted and it was very hard to keep in contact with him. Instead of watching movies with kids his age, he was botting smokes off middle-aged men and fending off marriage proposals from thirty year old women. There seemed to be almost no activities. He went to PARC once, but was twenty years younger than everyone else. We had thought that the AIPU focussed heavily on medication. The adult system focussed exclusively on medication. They seemed to have nothing else to offer. We can understand that an AIPU can't accept the risk of an older psychotic teenager. But there needs to be something for the next life stage. An eighteen year old is not a forty year old. We saw his attitudes towards his own illness and to treatment, and most profoundly to hospital, harden after a couple of weeks in the adult ward. Where we saw the AIPU co-patients complain about hospitalisation, but gently support the idea that he'd be better off taking his meds, the older patients reinforced the idea that psychiatric medication causes physical damage and should be avoided at all costs. He came out solidly convinced that he needed to escape from all clinical care. There is no step-down unit for young people. He fled the PARC because the much older, chronically unwell adults living there terrified him. So he came home having undertaken no programs, no post-discharge work and he was expected to simply pick up life again. Our child became unwell at sixteen. Despite seven admissions in the next two years, there was a sharp cutoff: at eighteen, he was treated as an adult. Worse, because he had been supported by the early psychosis unit for two years we were told he had to transition away from them. Evidence

indicates that early intervention should extend for five years and it is commonsense that it's invaluable for a treating team to know somebody's background and history. We have been assured that his case files will be accessible to any service in Victoria in future; but that's it. The system places no value on continuity of care. In what other fields of medicine is a patient given X years to respond, and that's it? Physical illnesses are treated ongoing as they need. The system is not set up for complex, difficult cases. It is a one size fits all model of treatment. Our son had been noncompliant and extremely ill for two years of his short life. But there was no additional support, no increased intervention, nothing. "

### **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?**

"The 2014 changes to the Act and the Mental health Tribunal's current approach have swung the balance on intervention and treatment against best clinical outcomes. A sixteen year old in his first couple of psychotic episodes is not in any position to understand the implications of refusing or avoiding treatment. Our son still has no insight and rejects the notion that he has a mental health condition; he disputes how he has behaved when unwell and does not understand the impact that his behaviour has had on his own health or the safety of other family members. The only times that he has been compliant have been when he has been under a CTO. He is not a middle-aged nor older sufferer who has been overmedicated for decades. He is very young and still has a chance - but the MHT overbore his treating team, handing down a four week order instead of the six months they had been seeking. The Tribunal emphasised his right to minimise treatment, without placing any weight on his inability to make an informed decision. By definition, somebody in the throes of an intense psychotic episode does not have normal cognitive functioning. But he was treated as if he were making a rational decision about his physical health. The Act needs to deal with young people differently and for some conditions, for acute early-onset psychosis, prioritise the patient receiving the treatment with the best possible outcome. It also needs to provide for input from carers and families. Because he was sixteen and refused consent, we were unable to attend the hearing. We had to rely on the treating team relaying our comments and had no opportunity to describe directly what we had seen and how the illness was destroying his life. We had no rights or voice in the process at all. And yet, we are the ones who have to cope within the parameters set by the tribunal. We were the ones who took him home and tried to convince him that the medication would help. None of the members, nor his legal aid lawyer, had to pick up the pieces from the wreckage once the order expired. I didn't see any of them at ED at 3 am trying to stop him from absconding. They haven't had to call 000 to have him sectioned, again; they haven't been spat on or shouted at or threatened; they haven't had to step very quickly between him and other family members. They haven't used up all their leave trying to support him nor lost their jobs when they were wrung dry. They haven't watched him fall apart again, and again, and again. None of this is a factor. They do not have to take direct evidence on what happens when there is ineffective treatment. All they have to do is force the treating team to propose the least restrictive mechanism; and then they can go to the next case. "