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

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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
I think there have been some good moves towards this in the media already. \the more media awareness the better.

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?
Please see my submission

What is already working well and what can be done better to prevent suicide?
"More easily acceesible support and outreach workers, able to support at short notice. CAT team in our area has been useless for this. The Suicide Line is good."

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 think there needs to be more case management of people with complex health needs. That has been available to us through NDIS and Youth Projects but not everyone has those services. Patients need some one to advocate on their behalf.

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 mainly lack of funding, and social disadvantage in some areas."

What are the needs of family members and carers and what can be done better to support them?
"Family members need to be included in discussions around the patient's case, as Families are the ones who often have to support the patient. "

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?
"There needs to be a lot more support and opportunities in this area but I think it goes hand in hand with suitable housing. An all round model such has been tried in some other countries looks very good, ie a residential model with supports on side and linked to other services, such as

Frontyard have just opened for young people."

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?
N/A

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?
N/A

Submission to the Royal Commission into Victoria's Mental Health System

From [redacted]

Background

My son aged 22 has suffered from psychosis/schizophrenia and depression since he was about 15 years old. He was diagnosed with schizophrenia at 16. He has had epilepsy since he was 6 years old. He also has addiction problems which have been from the age of about 15.
So my son has multiple problems to do with his brain and his mental health, and these problems affect each other in complex ways.

Hospital treatment and community mental health services

Our son's interactions with the mental health services have been very mixed. I believe that though there are many excellent individuals working in the service, it is very underfunded and under resourced, and therefore cannot perform to the actual needs of patients

Our son's first contact was. with CAMHS at the [redacted] Hospital and overall I would say we were very happy with both their inpatient and outpatient services, the only complain t I had was that a psychiatrist changed his medication without consulting us, but we gave that feed back at the time and it wars explained to us.

When our son transferred to the adult mental health system, his outreach workers from NAMHS St Preston were still very professional and helpful, but I would like to say that the clinic at [redacted] is a very depressing place to visit and needs to be upgraded so that it's more welcoming and calm to visit. Our son did not like going there and he has since disengaged with that service altogether . He prefers to visit his GP to talk about his health.

Our son has had several admissions to the [redacted] Psych. Ward. They have mostly been quite short stays of a few days. We found the psychiatrists to be very good on the whole, but overworked and difficult to get hold of when you ring up. We visited regularly and observed. That the nursing staff are constantly changing so that it's difficult to get continuity of asking how a patient is doing. The staff tend to stay behind the glass of the nurses station a lot, and it can be difficult for patients and visitors to speak to someone. I've seen patients been ignored by the staff when they're repeatedly asking for help. The actual environment of the psych ward is really stark and depressing, with hardly anything to do in the common areas. For example there are garden beds in the courtyards which are very neglected and no body seems to be using. That could be a good activity for some patients. The safely of the patients is not guaranteed in the common areas because there are not enough staff keeping an eye on things. Our son felt threatened by other patients as an 18 year old. I think there should be a young people's section for perhaps 18-23 year olds.
Our son was sometimes held in the emergency department for a day or two before a bed was available in the ward. This is obviously not good enough for someone suffering with psychosis.

The following is what we have seen happen several times when our son has been admitted with a psychosis. He has been given strong tranquillising drugs to calm him down, but then sent home after a couple of days without having his psychotic illness addressEd. There has been little time or resources to look at his underlying problems or history and he is discharged still very ill for follow up in the community, which he doesn't engage with. It is very much a "band aid" approach.

The worst experience we had with an inpatient stay was one New Year when he was admitted with a psychosis. They were obviously understaffed. We had a call from our son one afternoon about 3 days after he was admitted to say he was in the hospital and needed us to pick him up. There had been no call from the hospital to tell us this. He was very stressed because the ward had lost his phone and he had to ask to borrow someone's phone to call us.

By the time we got to the hospital I found him slumped over a table in the café. It was difficult to wake him. He was very disoriented and ended up hitting my husband when he got into our car. We had. To ask hospital security to help us get him back to emergency where he saw a psychiatrist. She said he was highly delusional and definitely should not have been discharged.
The ward had given him sedative medication and discharged him whilst affected by that medication, with no phone, and no means to get home. This I think was absolutely appalling and shows no duty of care. I had to go back to the ward on his behalf to retrieve his mobile phone which in fact they had locked away, but they had told my son he must have lost it.
I subsequently put in a complaint to the [redacted] hospital but I never heard back from them.
That has been our worst experience with the hospital system to date, and has made our son and us have very low confidence in the idea of another hospital admission.

The whole situation of sufficient follow up for patients when they leave hospital is woeful. Our son is fortunate that we would always make sure he had somewhere to stay. A person he met in hospital ended up at our house one day because she had been discharged with no where to go. This is totally unacceptable. There should be temporary accommodation provided for all mental health patients when they leave hospital, if they need it, and with support available.

Our son has had the most benefit from an outreach type of support and still works with two outreach workers who meet him once a week. This however is though NDIS and another organisation called Youth Projects. Our son does not currently engage with the mental health system at all. There needs to be a lot more outreach work funded, as many psychiatric patients do not feel comfortable in a hospital or clinic sort of setting. It would al so be great to have more peer support funding as that is something our son found very good, but it was only funded for a certain number of meetings.

CAT team and emergency services

I would like to say that the CAT tam is so under resourced in our area [redacted] that it is more or less useless. Numerous times I have called them on evenings and weekends because our son was unwell and we needed help. Firstly, there can be a very long wait time
Until they answer, secondly they will not come out to you if the patients is possibly aggressive or it is drug related.
Once my son did talk to them on the phone about feeling suicidal and all they could suggest was to go to the nearest hospital emergency department. Near to useless.

We have found that we have had to call the ambulance and police in a situation where our son is very unwell with psychosis. We have found the police to be excellent in handing these situations, but in my view it shouldn't be their job to be the first point of call for mental health emergencies. They have several times taken our son to hospitals or escorted him in an ambulance.
The best option to attend our home has been a combined team of one police officer and one mental health nurse, which has been an excellent solution and we think there shouldn't be more expansion of that sort of team, especially for drug induced psychosis situations, or situations where there is a risk of violence.

Housing options for those with Mental Illness

In short, there needs to be MUCH more funding for housing solutions for those with mental illness, for our son, he was in a situation of being homeless unless we provided housing for him. He does not have the capacity to navigate housing waiting lists, although we have made sure he is on them, the wait time is really long. He would not be able to cope with a share house due to his paranoia and other symptoms, he finds it really difficult to be around other people. There needs to be a lot more dedicated housing with comprehensive support on site, like the new model just opened by Frontyard in Melbourne, which sounds fantastic.

Young people with mental illness are incredibly vulnerable if not supported with good housing.

Drug and alcohol issues combined with mental illness

This is a very difficult issue which has affected our son, He uses drugs to try and alleviate the voices in his head and the the sever depression he experiences, However the drugs tend to induce psychosis. He is trapped in a vicious cycle, he needs expert treatment to tackle this whole situation in an integrated way. I know there are some dual diagnosis treatments available in Melbourne, but there needs to be a lot more and I think long term residential. This type of treatment might be provided out of town with a good environment rather than a hospital like environment, which for many people with mental illness, has very bad connotations.

The issue of whether some dual diagnosis treatment should be mandatory is something which does need to be looked at in my view. It is a very serious thing to take away someone's liberty, but if the person is so unwell that they or other people could be in danger, and this is particularly caused by their drug use, I personally think that some mandatory long term treatment should be available in certain circumstances. Such treatment could be mandated by courts as an alternative to just sending them to a custodial sentence in jail. This is really as an alternative to the person ending up in the criminal justice system which is not the right place for someone who is very unwell. A lot of mentally ill people end up in jail because it seems the only alternative that our society can offer them at the moment when their behaviour becomes anti social. This is very sad and we should be able to do better as a society. We also need to make sure that violent behaviour by those who are very unwell or drug affected, can be picked up as a risk before someone gets hurt or killed.

NO smoking in public hospitals

Since the no smoking rule came in in hospitals, this has created a huge amount of stress for patients and staff in the psych wards. Many psych. patients do rely on smoking as crutch, our son is one of them and when told not to smoke in the wards it has caused a lot of conflict. Some staff turn a blind eye and others say no, which infuriates him. The staff are in very difficult position trying to enforce the no smoking rule. If it's not consistent, this makes matters much worse. Some staff have told us unofficially that they would rather have smoking allowed. Often patients are pressuring their visitors to bring in smoking supplies unofficially to the wards, which puts families under a lot of pressure as well. Our son basically ends up asking for leave and spending most of his time at the front of the hospital outside, where people are smoking even though there's a sign saying No Smoking! This is not the best place for him to be therapeutically, and he was robbed on one occasion while sitting there. Because of the no smoking rule our son has found it impossible to consider going into various long term treatment units, which means he is less likely to seek treatment when he desperately needs it.

I personally think that smoking should be allowed in an allocated courtyard at psych wards, for those who smoke. It is often the only social thing the patients have to do.

Mental illness and other health conditions
As our son suffers from epilepsy as well as mental illness, we spend a lot of time and fort trying to liaise between these two specialities. It seems very difficult to get the two types of doctors to speak to each other, unless in a hospital stay.
I would like to see better coordination between different parts of the health service , with some kind of management of the patients as a whole. Although this is a gps role to some extend, the Gp doesn't usually arrange for specialists to speak to each other, and some people with mental illness don't see a go regularly anyway, I have found that I have had to do a lot of work to try and ensure that psychiatrist and neurology and our sons other services actually know what each other is doing. This adds a lot of stress to an already stressed parent and is not a good system for the wellbeing of the patient, who will rarely be able to do this for themselves.

Please contact me if you would like any more details on any of the issues I've written about. I am happy to be involved at any stage.

Thank you,

[redacted]