

Supporting Document to the Royal Commission into Victoria's Mental Health System

I am 79 years old, and dealing with the mental health system is like banging your head against a brick wall.

My son was a successful skier, in world cup contention.

One Christmas Eve in the early 90's, my son was severely bashed, and descended into a deep depression. He was then diagnosed with schizophrenia.

My husband and I tried many avenues to assist him, but it was rarely forthcoming, and we were left to battle on our own. As each year went on, we got more stressed, as we were unable to get the help we needed.

Just writing this makes me feel rather overcome with stress, anger and sadness.

During the early years he added alcohol and drugs to help him cope with his life. He now is very reliant on them.

As his parents, and now as a single carer since 2006, I was rarely listened to or informed what was being decided by the mental health system - the exception being when he was in the

Although, it was at this time that the ██████ administered electric shock treatment (ECT). We were not consulted over this decision. And, it has been detrimental to his short term memory. It's been extremely difficult to determine exactly what treatment he's receiving.

The other challenge has been around the continuity of his care. Too many times medical professionals have asked the wrong questions, or not known how to ask the right questions, and it's meant that we have found it more difficult to get him the care that he needed.

We have also found considerable challenges in getting my son into decent accommodation. At some times, he's been discharged into apartments with no services. Often, the properties he was placed in were not appropriate for someone who needs care. At one point, he was discharged to an empty unit with no connected furniture or services, on very short notice. My daughter and I were required to drop everything and do everything necessary to get furniture and services.

I have also found it difficult to get the care that I needed. I have spent a huge amount of time and energy trying to stop myself from having a breakdown. The system has failed me too.

In 2009, my son returned to his home district. Living in a rural area, with minimal support, has been very difficult. The distance from services has created many sleepless nights, and a deep concern for my son's future.

I have lost count of the times my son was discharged from hospital without talking to me first. When this occurred, he and I would be left in a vulnerable position, and I would be left to pick up the pieces. Often, there would be no follow up from the hospital, apart from an appointment in a fortnight, or a month, with his Community Mental Health worker with no contact in between.

One of the hardest things about being a mental health carer has been the stigma you feel as a result of interactions with the mental health profession.

Some of the comments that have been made to my family and I include:

- "We don't look on him as a priority as he has you". I've lost count how many times I have approached the Community Mental Health area with pleas for help from them in finding a way to make my son less dependent on me. They state that they don't prioritise him, as I'm always there, but statements like this are not helpful to me, or my mental health, and only add to my despair.
- "Well you will live in the back of beyond." When queried re no help available when it was needed. On one occasion during an intense period, after seeing his community mental health worker in the morning, it was decided that he needed to be admitted in the afternoon. It took police and ambulance hours to arrive, despite being 3-5min away. When they finally did arrive, they decided my son wasn't a priority. The stress this placed on those around my son at this point was immense. We were regularly required to transport him to the hospital while he was in a very florid mental state being aggressive, paranoid and delusional, and the distance was over 100kms.
- "You will have to ask your son's permission" was the regular response to concerns around his treatment. The complaint related to the hospital's decision to discharge my son to a friend who had arrived for a visit without notifying anyone in the family.
- My attempted complaint led to a meeting with the Carer Consultant in the unit, and it was held in the patients / consumers art room, with the door open, and as it was their space, people just wandered in and out regardless. With no attempt to find a private space, it left me so stressed I spent the next few days crying, as nothing was resolved. Just more roadblocks.
- The interactions with his community mental health worker feels too transactional. Many, many times, I have pleaded with his Community Mental Health worker to not let my son run the appointment time they have with him, so as to help him to be more understanding and responsible for what is going on in his life, but it's so much easier for

them to just spend 5 minutes with him, give him his injection, and his fortnightly appointment card.

- The carers allowance is too small, and too difficult to obtain. After many years of applying for a carer's allowance, it was finally granted to me for a few years. Then he moved out for a while, and although I was still having constant daily contact, I lost the allowance, and since then the support has been very little, or non-existent.
- For a short while I attended a carer Group run by [REDACTED]. It was very nice to feel validated as a carer, even for that short while. However, it was defunded, when the NDIS came in.
- Visits to the Emergency Departments can be extremely distressing. Often, you wait for hours in a room packed full of people, while your loved one becomes increasingly more agitated, paranoid, and anxious - only to be sent home with a Panadol.
- If on his own in the Emergency Department, my son would often be given a ticket at 5.30AM when the trams started up, and told to go to his worker at 9AM, leaving us to organise his mental state, and a visit to his caseworker, often ending up in him being admitted into the unit.
- Other times, the doctor would deem him well enough to go home, leaving me to be completely responsible for his paranoia and aggression, placing me in a vulnerable situation.

My life has literally been in a state of depression so much, that at times it would be easier to simply not be on earth. This is not an option, but sounds easier than constantly dealing with my lot.

The amount of times I have asked for help and been rejected would leave anyone in despair.

I am totally and utterly at the end of my tether so at 79 my fervent hope is that someone is ultimately going to listen to me, and others like me.

Writing it down doesn't do it justice.

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

Organisation Name

N/A

Name

[REDACTED]

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?

N/A

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?

N/A

Thinking about what Victoria's 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 Victoria's mental health system and

support improvements to last?

"addendum to previous submission, see next field"

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

"Review of the Victorian Mental Health system Things that need to be reviewed by the Royal Commission into Mental Health system in Victoria. The ease that people can get an A.V.O against a person who has mental health issues with no need for an explanation / or the said party being able to dispute what's written about them , due to their mental health state ,this has a profound impact on their mental health status and that of other involved parties E.g other family members ,much more needs t be done to bring the Justice system and police association into line with what should be expected of all services . Psychiatrist more often than not disregard Carers input and only listen to what the consumer has to say ,our son had 9 sessions of shock treatment with no input from his family ,it has affected his short term memory to a great degree and left us very stressed . 1/ The need for the Justice system to be engaged with the mental health system in a more effective way along with all others services such as G,P,s E.D ,s all must be on the same page to make our Mental Health system as effective as possible . Stigmatising and or discriminating against anyone ,stops people from getting the correct treatment I feel that it should be brought into line with all other areas that are already illegal according to the law . Drs have actually diagnosed people with the label you're mentally unstable or explain to the patient that if they prescribe medication it will prohibit their work choices in the future thus the consumers go untreated and maybe escalate into to full blown mental health status and this is disregarding the N.D,I. S recovery model as per the government,s recovery plan ,using early intervention as a very worthwhile tool . The M.H system is in need of a overhaul so as not to do more damage to both Consumers and Carers alike which certainly isn't the case since the introduction of the NDIS which has been an abject failure in many areas ,especially for those who are struggling with a serious long term Psychosocial mental illness , it's the least understood of all the illness,s making it very hard to get a plan that will be able to be successfully negotiated to make a difference in the person,s life . ??To discharge a homeless person into a empty unit on a Wednesday that has no utilities connected ,no furniture or food is with no staff follow up for 2 weeks is tantamount to dereliction of their duty . This happened to my son a few years ago leaving us both very Scarred / stressed . The more you talk and listen to others the scarier the Mental Health system appears ,aided and abetted by our M.H Act . The Mental Health Act gives control to even the most paranoid / delusional consumers leaving the Carers feeling that they are only good to save the Government money by filling in the caring gaps for the service , unless the consumer has agreed to a Advance Statement under the M.H Act in Victoria which gives Carers some rights that allows some input into the treatment of their family member / person that they are caring for , though many M.H Consumers don't wish this to happen. They are changing the meaning of sentences / words / diagnoses to suit their so called push to save the NDIS money such as separating alcohol and drugs from the diagnosis of any Mental issues even if the consumer was diagnosed with schizophrenia at the onset plus wording to describe issues like being put in H.D.U is now called intensive care so as to comply with the units stats on a monthly basis when the consumer is hospitalised. when the community / families report any serious concerns to the police (who more often than not have only limited training in this area) they do a health check only to be confronted by a person who will be able to conform to normality for a fleeting moment as in the case of my son , the police then report all is well, so that's the end of it ?? till next time , They report back to the concerned person leaving the Carers / guardians stressed and feeling like why bother ? , so they leave it ,often to everyone's detriment . when the initial diagnosis is schizophrenia at 19 years old and the promise of early intervention is not forthcoming then being bashed twice in one night

and the police spending many months harassing him to tell them who did it (even though it was well known who the culprit was) ,leading to an escalation of the condition , and to help them to so call function on a day to day basis ,they often turn alcohol and drugs ,this leads to a downwards spiral in their unwellness . Regardless of how unwell a person is the M,H unit can only hold a person up to 48 hrs regardless if they have just attempted Suicide making it imperative that the Act and the Law have to be changed as they have their hands tied in regards to what they can do .when we look at the [REDACTED] ?? went on a rampage and the police had their hands tied waiting for instructions from the top brass . When we hear from the coroner I would hope that things will change for the better . All services should work together in a united front going forward The need for people suffering from ADD or ADHD especially utilising Early intervention with Children diagnosed but left to the families to battle on their own would be a great start , It's not just the families being let down but schools at all levels ,leaving teachers trying to educate the affected children plus keep harmony in the class room , causing all children missing out . These children more often than not struggle with their education as not much support is available to the children who have ADHD,ADD which has a high percentage of them evolving into mental health issues , . It's imperative that ADD and ADHD be treated like other conditions such as Autism ,and be put on the list of mental health illnesses so that parents can apply for the N. D.I.S to assist their abilities in an ongoing way .to the benefit of all concerned. The answer isn't just medication it's counselling at an early age . Too many families are left to deal with so much trauma for years with no help that surely would be a bonus for ALL concerned in our society The application of the NDIS in regards to people who have a diagnosed mental health issue are being treated in an abysmal way which is causing no end of depression to both consumers and Carers alike .I have been seriously depressed trying to negotiate the 2nd plan my son has had approved even if it appears inadequate ,but has some redeeming value to it , finding a plan coordinator to assist the consumer in getting suitable help in areas of need tends to be an impossible task ,this leave the most vulnerable ,hard to help consumers and their Carers totally bereft . This has to change for the better and ASAP Believe me I speak from my heart and I know there are many more consumers , Carers / guardians who are in the same boat .. Regards [REDACTED] . Long time carer of a son with severe psychosocial mental health issues ,and struggling to get support . "