

Royal Commission into Victoria's Mental Health Service SUB. 3000.0001.0466

Supporting Document

My Story

We have 4 children, all adopted from overseas, from Bangladesh and Sri Lanka. Our second child, a son, is 38 years old now.

He was 8 weeks old when he came home in 1981. Our other children also were very young when they we adopted them: when we adopted our eldest in 1979, she was almost 3yrs old, then 2 more children from Sri Lanka in 1983. One of our other children has had difficulties with mental health issues, and from soon after her second year university was estranged from most of the family up until recently. She has been diagnosed with schizophrenia and has been an inpatient at the [REDACTED] hospital.

This submission is the story of our second child. He started some weird behaviour when he was 18 years old. He had had a somewhat difficult time at school, and he was sniffing paint etc. He didn't complete Yr 12. He had been a popular and happy child until he was 13 or 14, but he suffered from chronic juvenile arthritis. The medication he was prescribed didn't take away the pain – unknown to us, he discovered cannabis did, so he started taking cannabis on a regular basis. He was stealing and exhibited other untoward behaviours, and due to some threatening behaviour was placed on an intervention order. Soon after he was admitted to [REDACTED], and became part of the EPPIC programme. For almost 3 months he was an inpatient, and, other than frequently absconding and returning home, he was an easy and compliant patient. He was on an extremely high dose of CLOZAPINE. 750mg is supposed to be the maximum daily dose but he was initially placed on up to 900mg, before he was dropped back over some years to 300mg.

[REDACTED] clinic supervised him well. On Clozapine he progressively got better - from involvement in support groups, to some supported employment, Certificate courses, and peaking at a casual job at a recycling centre, where he was usually rostered 5 days a week. He enjoyed working and would get himself up at 6:30 am, make his bed, and ride off to work on one of his two motorbikes. Besides motorbike and car licences, he also held a forklift licence. He had good friends, a good social life, a couple of hobbies, was earning good money, and saving well, despite spending plenty. And above all, he had the love, respect and support of all his family. This was 20 years ago. A message to the Commission - between 20 and 10 years ago there was a system which worked and *things were better*.

Then in 2010, our son stopped taking his regular Clozapine medication, since he believed he no longer needed it as he was doing so well. To this point, he had been a gentle loving person who hadn't touched drugs, or been in trouble with the law for over 10 years – but all that was about to change. He was still attending Broadmeadows clinic He was sequentially tried on a number of other medications. None of these over the past 9 years has worked as well as Clozapine did, and for most of this time he has been on a depot injection, as he cannot be relied on to take oral meds In the past 9 years as a result of psychotic episodes and sometimes violence, he has had 13 hospitalisations – ranging in duration from 2 nights to 3 weeks. Many of these have had a police involvement. On two occasions, he went voluntarily to ED because he thought he wasn't very well and at one stage had himself admitted to PARC.

Since 2010 our son has had multiple court appearances; for stealing, for assault, for criminal damage, for driving without a licence, and has been on intervention orders five times (including currently). He stole a truck and drove unlicensed to Strathbogie. After charging him and repossessing the truck, the police released him and a relative took him to Seymour station so he could return to Melbourne.

About 2011 VCAT appointed a financial administrator for our son – initially it was me, but after about 4 years I passed it to State Trustees as it was causing too many problems between us. This financial arrangement causes much angst, and resultant anger, in our son, but he is currently not capable of managing his own money or affairs, and the financial administration remaining with State Trustees is the most appropriate solution.

He remains off Clozapine, and uses drugs, and for the last 12 months has purposely engaged less and less with his mental health team, and is adamant that he doesn't need a support worker. He is not currently on a CTO, this is despite his doctors arguing that he should be kept on one. The Mental Health Tribunal is useless in my opinion – it repeatedly ignores the doctors' recommendations, restricting the CTOs to shorter and shorter periods until it is revoked. At the Tribunal, he is able to present reasonably well, and they cannot see how sick he is. When on a CTO he is generally better, more engaging and compliant – the threat of involuntary hospitalisation is very effective. We have avoided all of his Mental Health Tribunal Hearings for the last few years, because of the conflict it can bring, and the resentment. At the hearings, you cannot say things in front of the one you wish to protect. It would be much better if the Tribunal could hear from families separately and not reveal what is said, which causes distress and disrupts relationships. The Tribunal is a very biased entity – it cares only for the rights of the client – the rights of family, carers and others are ignored.

Our son has always been very good at absconding when an inpatient. Our experience of him being recaptured with police involvement varies from gentle and respectful, to rough and aggressive – probably more of the latter.

On one occasion, whilst we were overseas he was admitted and then absconded. He broke into our house, was picked up, and returned to hospital, where he was given day leave and then promptly absconded again (a common pattern for him). On our return, we became aware of his whereabouts and rang police. Although he had been gone for 2 weeks, and they'd only that afternoon visited the house to check if he'd been there, they said - "*we haven't got enough people to come around*". We said we'd take him to the house, give him a meal and they could pick him up there. An after dinner phone call still resulted in no attendance. Our son took himself to bed, and next morning asked that I take him back to the hospital. As we were about to leave 4 or 5 police arrived, led by a very aggressive and un-empathetic sergeant. It was a very unpleasant situation. After eventual discharge from hospital, he was released into police custody, and after the interview was completed, he was told to *go to Vincentcare, who might find him some place to live* -hey! It doesn't work that way! .

We can't keep doing this. Somewhere in the "system" there has to be some entity responsible the rights and safety of families and other people, in addition to caring for the mentally ill person. We would like to point out to the commission a few of the most distressing circumstances:

- Our son has been discharged to **homelessness** at least 3 times, being told to "*go see Vincentcare*" or, on one occasions, was given a place in a nursing home. When he arrived at the nursing home, he rang home and said "*I'm not staying here*". We ended up having to let him live at our place (rather than be homeless), a situation that ended badly, as expected. Currently, our son has a room 10 x 12 in a rooming house (unregistered). There is nothing in the lounge room, the laundromat is a 1km away. He is there with 3 others. This form of accommodation is totally inappropriate and makes him worse. All of this is because they need the beds in the hospital for those who are even more unwell than the unwell person that they are discharging.
- I have concerns around **Outpatient facilities**. Registrar training appears to be almost the primary function, rather than the welfare of the patient. Every 4-6 months the registrar on the treating team is changed. A mentally ill patient needs to have stability and build a relationship with, and have confidence in the their treating team. The individual team members obviously are dedicated, but when a case manager has about 30 clients, they are obviously overstretched.
The practice of using Catchment Areas is also disruptive to the client. It results in fragmentation. Our son, due to a forced change in his accommodation is now 200 metres inside the [REDACTED] area, and

therefore has to change teams from his current [REDACTED] team. There goes the stability – now to try and get him on-side with a new team. Handover from one team to the other has not been great. 20 years of history, or even the last 5, cannot be absorbed by the new team. As the de facto carer, I now have to try and build a relationship with the new team, who of course need to seek his permission to talk to me. Clinics need to be more collaborative. They could do a much better job of accepting data and information, and they should welcome the partnership with families. At times we feel that our involvement is treated as a nuisance; that when we call it's a case of *"its him again"*. They can be too busy to talk to us, and due to the lack of engagement by our son, and his ability to play the system and present well, he is assessed as not showing sufficient symptoms for greater action other than, *"here's you're depot; come back in 3 weeks"*. I think at times it is futile to try and get anything done.

- **Inpatient Facilities.** Our son has not been an inpatient for 3 years. The units are staffed with people who obviously have a dedication, but I was horrified to hear a nurse who had known our son over many inpatient stays, say to our son, who is only stable on clozapine that *"clozapine is real bad stuff – you won't want to go back on that stuff again"*.
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- **Physical health problems** should be assessed, diagnosed and treated for mental health service clients, by the mental health treating doctor. Advising the client to go and see a GP really doesn't work!
- Our son has been approved for the **NDIS**. He did not understand the process or how the support was meant to work. . I travelled a return trip of 350Km a couple of times to accompany him to meetings. At one it was suggested, *"we can give you money to go away for a few days"* – this was said to someone who can't get out of the room. Another time, *"..you can hire or fire your own support worker."* His response was: *"I don't want to be given all this money; I don't need a support worker; I don't want to have to employ people."* And he refused to sign the documents. Meanwhile, at 71 years old, I remain his de facto support worker. He didn't have much in the way of support before the NDIS, and it was getting worse, but then the NDIS came and now it is at an all-time low.

Our final comment is one that applies to so many families: when we, the carers, die, who will be there for our sons and daughters? This is one of the most important aspects that the commission needs to address, and come up with a implementable recommendation.