

My Story

Without me, my son would not be here. I am sure that there are lots of people in this situation.

Our initial experience of the emergency room at our local regional hospital was disgraceful—that is the only word for it.

My son initially had a sudden onset of his symptoms when he was aged 25. When he was first admitted he was asked question after question, to the point where he was getting very frustrated and upset. After that the questioner went away and another person came in who asked more questions. This happened again and this time by a psychiatrist on call who asked the same questions that had already been asked. Then they put an assessment order on him and theoretically he was detained. You can imagine how both my son and I felt after this experience. **Neither then nor since has anyone been able to give my son a formal diagnosis of his condition. My son seems to have been put in the “too hard basket”. His condition is complicated but why can’t somebody at least diagnose it and provide support.**

My son presents as a calm, thoughtful and intelligent person, however he has been unable to work since he was 25. He is now 31 and he has been living mostly with me since then. Sometime after his initial episode he was admitted to a residential program and he did quite well and even started to improve. We were both happy with this when the psychiatrist in charge of the facility told my son that he could no longer stay there and that he had one hour to pack up and leave to move to a totally different facility. When my son asked why and what he “had done wrong”, the psychiatrist simply said, “I have made my decision.” I was shocked by the arrogant way the psychiatrist was speaking to me and my son. I was not consulted before this decision was made.

That is a key part of the problem. As my son’s carer I am almost never consulted by psychologists, psychiatrists, and support providers. Most of the time my opinion is ignored. My son lives with me, so I have more contact and knowledge of his behaviour and condition than anybody else. I should be consulted more as his illness is quite complex. His diagnosis changed depending on who was treating him.

Housing is a big problem. My son lived in a residential unit. He was in a unit by himself and actually coped OK with support. But he could only stay 28 days. Then he was sent home and connected to an independent service provider. He was given a case manager. He has lived with me since then. The service provider told us that because my son had no police record, was not violent, not using drugs and not homeless that he was very low on their list of priorities, so they were not going to help

him! Except from a couple of text messages and letters in the mail from the case manager. **To this day the service provider has not contacted my son about any possible treatment and support. They have never even invited him to come in and see them or to do a home visit.**

My son consulted a psychologist for 10 visits using his Mental Health Plan. The psychologist was not interested in anything that I had to say on the first visit and was quite rude. But she continued to see him nine more times and then told him that she could not help him. 10 sessions on a Mental Health Plan are not sufficient for a person with complex mental health issues.

Because of my son's complex mental illness, he became "too hard" to treat in the public health system. They did not know what to do with him and it was suggested that we should try a private clinic instead. He did end up accessing a private clinic a few hours' drive away in Melbourne, but he didn't cope well and subsequently came back to live with me. Following this, he continued to skype with a clinician from the private service, but this meant he was unable to access any local public services because they would not support someone accessing both systems. How is this fair?

We got some help and support through "Partners in Recovery" and they helped us access NDIS, but I hear that Partners is going to have its funding cut. So, to sum up our experience, **I am disappointed that my son's case is considered too hard and complex and I am the one left trying to deal with and cope with the situation.** Currently, my son is not allowed to use his core support NDIS funding for additional psychology sessions that could be life changing. With his complex needs, to see a psychologist more often would take the pressure off me because at the moment I have to deal with everything. He needs specific psychological support because his illness is so complex.

To the Royal Commission, I would say that in the Victorian regions, **there needs to be safe, secure, dignified housing** where people can live independently yet in a supported environment for longer term residence. Not just 28 days. Bendigo is a big region; it needs some kind of centralised regional mental health hub that is suitable for people with complex needs. Support needs to be available on a continual basis with a Case Manager working with the Carer as well when returning home. The support should not stop when leaving residences.

Support the carers. They are doing the bulk of the work treating and looking after patients with acute conditions. Instead of treating them rudely and as irrelevant or interfering, take them into account and listen to their opinions. **Carers should be included in a hell of a lot more of the whole process.** Caring for my son has a huge impact on me and my mental and physical health, and it is constant, 24 hours a day, 7 days a week. The only way I get a break is actually going away, but my son can only deal with me being away for a week at most.

There needs to be more continuity of provider staff at all levels. There is a constant change in staff, and this is highly distressing to patients who have to start all over again with their case managers, nurses, psychologists, and psychiatrists. Also, the levels of empathy, knowledge and ability in the providers varies greatly.

Home visits from providers would allow clinicians to form a better relationship and understanding with my son because he gets anxious when attending appointments and therefore, they do not get to know the real him. Some people should get out of their comfort zones and be more flexible about this.