

Supporting Document

My daughter, was diagnosed with a serious mental illness in 2002. Since then I have been supporting her to navigate both the private and public mental health system in Victoria. My daughter has been compliant with medication and is a non-drinker, smoker and her mental health issues are not drug related. My daughter is the youngest of 5 children and I have been her sole carer throughout the 17 years of her illness, as her dad remained in the background until his death a few years ago.

We have had several terrible experiences in the public sector, including my daughter being discharged from a 28 day hospital admission to a women's refuge, where I was unable to make contact with her. Since this first hospital admission my daughter has had further hospital admissions – some longer than others. She has stayed at PARC, has experienced being discharged to high security accommodation services and she has come into contact with CATT and community outreach services several times.

These experiences did not leave us with great confidence in the resources available nor the prioritising of continuity of care in the public mental system.

As such, we decided to go through the private system to receive better continuity of care. However, I have been extremely dissatisfied with the number of clinicians available and the quality of those who are available.

My daughter was without a psychiatrist since March of this year until just two weeks ago, after she ceased sessions with an unethical clinician who appeared to be taking advantage of her vulnerability. Since then my daughter has lost her stability and become unwell for the first time in 4 years. She had been volunteering and was really enjoying engaging with people, but she has been unable to return to her volunteering role. We know that she becomes unwell very fast so I called the CATT and she is now back being treated in the fragmented public system.

When my daughter is well she is an extremely engaging and articulate person. When she is unwell, like this last time, it like she goes back 22 years to when her paranoia and delusions first begun.

Informed by my experience caring for my daughter, these are the key issues I wish to raise to the attention of the Royal Commission:

Waiting times: The waiting times for both the private and public system are far too long, especially for those like my daughter who become unwell quickly.

Private system:

Private is for "easy street" - Limited options of psychiatrists who treat complex mental illness: We are currently up to referral number 12 to find my daughter an appropriate psychiatrist. Five of those we contacted said they did not treat patients with schizophrenia. Six others we contacted said they had no space, and would not take new patients. You would think going through the private system would mean greater access to specialist support but it has not. My daughter did have a good psychiatrist for a short time but unfortunately he moved on to a new role. Since September 2018 my daughter has been without adequate support from a psychiatrist. There was one clinician who took on this role but he was extremely unprofessional and my daughter had to discontinue any sessions with him. It should not be so hard to find a good, reliable psychiatrist, especially when we are paying and going through the private system.

Unethical clinicians: My daughter was transferred to another clinician's patient list after her initial psychiatrist changed roles. This clinician seemed to become quite fixated on why my daughter was not dating or in a relationship. He felt, despite her vulnerability in the recent years, that she should be 'putting herself out there

more'. He spoke to her about other patient's experiences of getting married young and how it was good for them. I found these comments extremely inappropriate. He then went further to tell my daughter that he would not continue to see her as regularly as she liked, and would only bulk bill her sessions, if she fulfilled his 'set tasks' which included her pursuing dating and relationships with people. At this point my daughter decided she did not want to see him anymore as he made her uncomfortable. As a result she has been without a psychiatrist since March this year.

Public system:

Under resourced CATTs: CATTs take too long to respond when you call for assistance. I have waited over 3 hours for someone to arrive when my daughter was psychotic. When they do arrive, they often just say "there's nothing we can do" and they call the police to take her to the hospital. There have been times when they told me they couldn't take her to hospital because my daughter could sue them for taking her when she is not on a community treatment order. My other daughter said "what about my mum?" as she lives with me. They just said "there's no beds".

Hospitals not communicating with family: There have been other times when we called CATT and they waited out the front when we had called, only for my daughter to run past them and into the streets. She was missing all day until at 10pm I rang [REDACTED] where they told me she had been there since 5pm after being hit by a car. When I complained about them failing to notify me, her next of kin, they said "we were just about to give you call, don't come in tonight, come tomorrow".

Staff turnover & lack of permanent staff: The continuing change of staff in the public system, especially the 6 month rotations, is extremely disruptive for consumers and family, as it negatively impacts their continuity of care. We need more permanent staff.

Inappropriate discharge: People, such as my daughter are being discharged before they are ready, while they are still unwell and unstable because there are not enough beds available. This puts unfair pressure on family who end up being put in unsafe situations. My daughter becomes another person when she is really unwell and I fear for my life when this happens.

Carer & family supports being defunded: There were some great initiatives, such as MIND Carers respite camps and social support groups closing down. We rely on these types of programs to have a break, to get information and support. It is not fair to remove them.

There have been some good experiences.

After the CATT visited but did not hospitalise my daughter they put her on medication and then visited regularly for the next few weeks to check in on her. This worked really well, especially as one of the nurses agreed for me to call her at the end of each day to check in and I was able to give her advice on how to best support my daughter.

A great psychiatrist once said to me "you must do nice things", I've always remembered that. I don't look too far ahead, I try to live in each day as it comes.

To the Royal Commission I make the following recommendations:

- **Create a safe haven** in the community so that people feel supported and safe when discharged. This includes adequate supervision to keep them stable and to assist recovery. When my daughter becomes sick, I think, where can I go? Where can I run? There should be a safe haven for family to.
- **Better, safer housing.** Public housing is rife with drugs, it is not a safe place for recovery. We need to give people the best chance at recovery and that includes safe housing.
- **We need proper discharge processes,** which ensure family, carers and/or next of kin are ALWAYS notified and that there is a treatment plan in place and someone to oversee it when the person is discharged. We need

processes that hold services accountable when this does not occur to ensure that duty of care is always honoured.

- **Provide avenues to be connected to their community**, to be able to gain normality in their lives, be it through work, volunteering, hobbies, social outlets. Whatever it is we should be providing avenues for people to pursue interests and find purpose in their lives, however great or small that may be.
- **We need processes to hold unethical professionals accountable.** These processes need to be accessible to family so we can ensure our family members are not being taken advantage of, and so that unethical or inappropriate staff cannot continue to harm others. We need to be able to do this safely, without fear of backlash that may impact the treatment of my daughter.

First priority in our mental health system should be to get people well, there's no point in having the other things until we can get them well.

Families want a normality to our lives as well, we need time and space to be able to the things we enjoy, to have a break.

My daughter is very proactive with her care and since not having a regular psychiatrist, she has asked her GP if she can visit him every fortnight just so she has someone to talk to. It is great that she is able to do this, but we need proper supports available so my daughter can access the care she needs and feel connected to services and her community.