

Supporting Document

■■■■ ■■■■

I care for my 45 year old son who has been involved with the mental health system since he was 19.

My son was a functioning, thriving individual before he experienced his first psychotic breakdown while he was at work one day. They took him to the local hospital to get help and they just gave him medication. Soon after, he went overseas. During this time he stopped taking his medication. When he came home he went to university and this triggered a relapse.

The initial psychiatrist he had seen had left so we went through the private system. This psychiatrist was not great, I was not happy with him but we couldn't find another one. He began relapsing and wouldn't take his medication so we ended up back in the public system. We became entrenched in the public system, but didn't have the supports available.

This was really the beginning of the end of my son's life.

Eventually my son became so unwell he required police escort to ■■■■■ Hospital.

When he came out it was as though he had been chemically lobotomised.

I asked for a review, to at least give him a chance. The case manager, who had been a part of the discharge team at his initial admission told me "we have failed your son. What you have to ensure now is that he never ever has another psychotic breakdown."

I have never forgotten these words. For the past 25 years, that is exactly what I have been doing. It is not right how heavily the mental health system relies on family.

Despite, giving all my energy into keeping my son out of hospital, including giving up my fulltime job, he has had two more admissions.

I was told it was up to me, not the mental health system to keep him well, to provide him with the care he needs. When he was admitted again I felt the weight of the case manager's words. I felt stigmatised, I felt as though I had failed. It is wrong to place this pressure on families.

Having dealt with the fragmented public system for a long time now, I am a bit cynical about this Royal Commission process. However, I want you, the commission to understand what our experience has been and what needs to change.

I am a person who works hard to acknowledge the positives when they occur. Out of the 20 plus case managers my son has had, 4 of them were great. You remember the good ones, as well as the truly terrible ones. The ones that I remember had a good understanding of mental illness and a very compassionate approach in their role as mental health workers.

Other positives have been:

- There was one worker who made an impression on me when they took the time to speak with me about the impacts of my son's mental illness. She was only around for a year, but she was the first person who

acknowledged these impacts and helped me to understand that it was okay to change the expectations I had for my son in the lead up to his 30th birthday. From this I knew she understood and was truly there for him.

- Although CATT were less than ideal in some instances, the police demonstrated some level of sensitivity. However, it did depend on the individual police person, even during the same admission. Some were kind and others automatically classed him as less than or inferior due to his mental illness. As such they treated him differently than the officers who were understanding, kind and compassionate when dealing with my son.
- The support offered by the mobile support team (MST) was great. When my son was receiving support from them for 6 months he did really well and it meant I was able to just be his mother, but unfortunately they would not continue to support him after this.
- We had one worker who worked from a family inclusive approach, she would call me once a month to check in on me. In 25 years I've never had anyone do that again, but it was such a good support and relief for that year she was around.
- My son found a great support worker who really supported him to engage in other activities and pursue his interests and develop social outlets. While he had this support my son would say things like he would say things like "I'm so glad I'm doing this, I've wanted to do this since I was younger and I don't feel like I'm good for nothing now". Engaging in outlets outside the mental health system meant he was there with other musicians and he had a purpose.

Some of the key issues I wish to highlight to the commission are:

No continuity of care

My son experienced relapses after being admitted, discharged and referred to several different services. He was taken off his community treatment order (CTO) and put on a clinical medication trial, however he wasn't use to taking medication and there was no support put in place to monitor this. I asked his case manager to take on this role but he said he would not do anything without a legal obligation (CTO). He then received 6 months of support from MST but it was only available for this short period. My son very quickly relapsed once back in community care, which led to hospital admissions, police involvement and him being evicted from his flat. After this, I wrote a complaint letter to the community care team and he was then transferred to ██████ MST. It was great when he was supported by MST again, but we shouldn't have had to go round in circles to make it happen.

Since then, my son has had to move from the ██████ to ██████ area due to precarious housing issues. When he moved, he lost his regular support. It was replaced with 1 visit a week with no medication review. It was not long before he was moved to community care without notifying me. When I contacted the consultant I was assured he would not lose supports, however when I spoke with his case manager I was told his support would now be reduced to once every 3 weeks as they were working towards discharge. I tried to fight this, but the staff just kept turning over. I kept asking, and they kept reassuring me he would get fortnightly support, but it never happened.

I have been told on more than one occasion that if I let him go and allow him to deteriorate enough that he has another breakdown that he'll get the support he needs. It is a scary to think this is the reality of our mental health system.

Now, my son likes his case manager, but he is so unreliable that my son has begun to disengage. It is often a random amount of time that passes before the case manager shows up again, sometimes it's a week, some times a month. As a result, my son has gradually stopped all his social activities and isolated himself.

Community treatment orders: CTO's have become like a treatment model and a weapon to use against the person. If there is no CTO in place, there is no collaborative practice or any attempt at treatment. CTO's shouldn't be the only way to get consistent care.

Impact of care on our relationship

When my son was on the clinical trial it became my role to monitor his medication compliance as there was no worker willing to take on this role without a CTO in place. Having to monitor him created significant conflict in our relationship. Once my son was back under the care of MST again, it was such a relief. I did not have to continue the role of medication monitoring and I was able to be a mother again.

However, once he was moved to the [REDACTED] mental health service and they began to reduce his support, so it all fell back to me. He had built up some other small outlets in his life but apart from that it was all on me. There is no one else.

I am treated like a neurotic mother, but I have to be to ensure he gets the care he needs because no one else does. I don't want to have to. I'd rather take a step back but I can't because the support isn't there.

Service induced trauma

My son has experienced psychiatric service induced trauma. This trauma relates to overt trauma caused by forced and insensitive practice with regard to hospital admissions and stays in general. This has occurred through allowing my son to relapse over and over without adequate care or support. In addition to experiencing forced sedation and seclusion during hospital stays. He has also, at times, experienced bullying from CATT.

As mentioned a reluctance to engage with my son and use the easiest option for the nursing staff. Trauma also has occurred over longer periods with polarisation of patient and worker. I think I mentioned the class divisions that occur within the mental health system. This has been a continual and sustained undermining of my son so that this long drawn out stigma has become internalised and a very passive position taken as a result of being treated as if he was worth less in the community and within the relationship between himself and practitioner.

This has not been the case with all of the relationships between my son and treating staff but the majority. This may manifest in how he has been related to or just not turning up to scheduled visits and no call to let him know.

One consultant described my son as "institutionalised", which is distressing to hear but from his traumatic experiences with hospital admissions and transportation, I can understand this.

Service provider relationship & engagement

There are some people who are willing to make the effort to work from a social relational approach, but very few workers make the effort to engage with my son and encourage him to pursue interests or be social.

The personal relationship between individual service provider and my son has been critical in allowing him to develop the confidence to branch out into the world and begin doing things with other people. He currently has a case manager/OT who he likes and I see some opportunity there. I am hopeful that this opportunity won't be lost as with the previous case manager at [REDACTED] who often did not show up, and as a result caused my son to distrust and withdraw back into himself. My son has lost a great deal of confidence since moving to his current clinic due a greatly reduced service.

Medical restraint as the 1st response

My son has been medically restrained several times as an inpatient. During one stay I had requested they did not inject him with a particular medication as I had seen research that said it can precipitate heart attacks. I wanted them to at least try talking to him before sedating him, but they didn't listen. I found out they gave him 3 of these injections over a short period, when they had to call me in to explain that the last time they injected him he had heart trouble. Following this they had to withdraw all medication as his body was in a fragile state. Without medication, the management strategy was engagement and talking with my son. With this simple strategy they were able to keep him stable. Why couldn't they have taken this approach from the start? Medical restraint should be the absolute last resort.

Clinical services perceiving the NDIS as a replacement

Many people feel that the inclusion of mental health or psychosocial disability was a mistake as it has impacted on the existing long-term psychosocial services. However, the NDIS has been more beneficial to my son than these services have been. If the clinical services were to do even an adequate job, then my son would be more likely to engage with services funded by the NDIS. Currently, he has an NDIS plan with activities outlined but the clinical services have not provided him with enough support for him to be well enough to engage with his planned activities. Though, even with his reluctance to engage he is still better off under the NDIS and potentially far better off than with what the traditional psychosocial services have offered him during the past 25 years.

That is apart from the [REDACTED] [REDACTED] where my son use to attend group art activities, which has now been defunded. [REDACTED] [REDACTED] was an amazing initiative that will never be an option again, which is perhaps an indication of how services are driven by motives other than the social model. NDIS seems to be used as an excuse for organisations to avoid offering supports they don't want to e.g. group activities.

Additionally, there is this underlying threat that you are going to be discharged, as clinical mental health services seem to assume that once you are on the NDIS they can phase out their supports and discharge them from clinical services. They fails to recognise that some people need ongoing, continuous mental health support.

Impact on myself as a "carer"

I have had to continually advocate to a less than receptive service. I have had to take on more and more responsibility with regard to medication monitoring and I am currently providing 99% of my son's human interaction!

Like many "carers" I have developed my own mental health condition. After 4 years of engagement with the public mental health service in order to get adequate supports for my son, I found that the frustration and stress were so overwhelming that I left my full time job which I had been doing for more than 10 years. Since then I have sought work with less hours and more flexibility. This has been the case for the past 20 years.

I have been diagnosed with various conditions such as depression, anxiety and most traumatic stress which precipitated my need to withdraw from full time work.

We have no family support and I have been my son's main support since his father and I divorced. I use to engage in other carer groups through MIND, but they have all been cut back significantly. It is difficult to find other supports, my long-term friends just don't get it, and those who do, who I have met through carers groups, don't know my son, so it can be very isolating.

I'm at the point now where I just think, what happens when I die? No one is going to check in on him, monitor his medication. I'll be relying on the mental health service to do it, and they haven't shown to be very reliable.

My son has a very tenuous service delivery and he has as much as that because I keep fighting for it. I'm in my mid 60's now and I'm exhausted.

My recommendations to the Royal Commission are:

- **Inclusive, collaborative family practice:** This should be coming from the mental health services, without family's having to chase it up. It is disempowering and invalidating to continually call. You feel as though you become a problem, rather than a part of the treatment team. I would like to feel we are working collaboratively in the best interests of my son
- **Proper engagement:** We need proper engagement with family and with the consumer so they feel confident and supported.

- **Acknowledgement of enduring mental illness:** For those on the NDIS there should be an acknowledgement that the person has an enduring psychosocial disability and as such clinical services need to be continually involved to ensure stability and continuity of care.
- **Duty of care to all:** Just because some people, like my son, did not get the early intervention they needed, does not mean the system is excused from caring for them now. The system has a duty of care to support them now.
- **Destigmatising practice across systems:** People are automatically treated differently than workers because all anybody sees is the label 'mental illness'. We need a system and service providers who see those with mental illness as people; people with strengths who are worthwhile to engage with.