

The social and economic benefits of improving mental health

We have spent the past 8 years dealing with the mental health system in Canberra with little or no help provided by any service.

Background

Our son was born with an intellectual disability and at the age of 2 was diagnosed with significant ADHD and Autism. Recently he has also been diagnosed with generalised anxiety disorder, panic attacks and auditory hallucinations.

During his school life he was either in special unit in a mainstream school (for primary years) and a special school for his high school years.

At the age of 16 he started to exhibit some major challenges which often resulted in being transported to the mental health unit at the Canberra hospital. Sometimes this was in the back of police paddy wagons while other times being transported by ambulance or by us his parents. He was exhibiting highly agitated behaviour that just seemed to come out of nowhere and without any warning. When these episodes happened at home he would threaten to kill us and go searching for a knife or some other sort of weapon but he would also call the police once he found what he was looking for saying 'I don't want to kill my parents but I have to'.

This agitated, erratic, aggressive behaviour also happened at school where he was often restrained by staff before the police or ambulance could arrive. It was clear that he was having psychotic episodes and sometime this behaviour could happen several times a day.

This behaviour continued until recently when at age 24 the right medication was finally found that as he puts it 'stopped the voices'.

Our journey through the mental health system

When our son started to exhibit these psychotic behaviours he was seeing a Visiting Medical Officer (VMO) from Sydney through the then Dual Disability service which was part of ACT Governments Disability ACT services. The issue with this service was that you only got to see the VMO, who I might add was a psychiatrist, once every 3 months unless you contacted the office to request an extra visit. Sometimes we were told that he was too busy even after the schools deputy principal wrote letting them know of the erratic behaviours and the concerns they had in managing it and us providing evidence of him being transported to the mental health unit (MHU) at Canberra hospital. When we did see the VMO more often than not we were made to feel like it was us that had the problem and that we were not good enough parents. The VMO never talked to our son directly and at one point told him to 'grow up and stop the behaviours'.

After this we tried desperately to access a private psychiatrist in Canberra but were turned away by all. Some stating that they didn't specialise in disabilities/mental health while others just said flatty no we don't have any vacancies.

We felt stuck in a system that wasn't supporting our son, his family or his school. We were all trying to manage the best we could without any professional help. I had contacted many mental health services during this time only to be told again we can't help you because we don't deal with people who have an intellectual disability and mental health issues.

There were times when our son was taken to the MHU at the Canberra hospital twice a day in the back of a police paddy wagon only to be dosed up with a sedative and sent back home within 3 hours. Because of the frequency of presentations at the MHU the police suggested we develop a multi-agency response plan (MARP) so that the police or ambulance when called would know be able to respond in the same way. This MARP plan gave a profile of our son and what to do when he presented highly agitated. While in essence this was a great idea in realistic terms it did not work. For the police it did not work until we physically showed them a copy of the plan as it was not flagged against his name in the system as it was intended. For the ambulance it also did not work because our son worked out what he needed to say to them to get them to come for example he had chest pain. When you say this the ambulance has to react immediately and anything we tried to add was ignored as they were bound by protocol. Apart from school and a couple of times at home our son was the one who always rang emergency services.

Over the next 5 years each time we presented to hospital a different medication was prescribed to our son. He was always given Seroquel to sedate him but after 3 hours we were sent home with a different script. None of the medications prescribe actually helped with his psychotic episodes. There was no consistency in who he saw at the MHU and in the scripts we were provided. In essence no-one other than us his parents kept an eye on medications prescribed. To many times we were given scripts for medications like Risperdal that we knew made no difference, they had been prescribed by the VMO previously, but were ignored when we voiced these concerns. To make matters worse not once were we ever given any information or offered referrals to community mental health programs.

There were many times over these years where the staff in the MHU decided he should stay the night in the mental health ward as the Seroquel wasn't having the desired affect after an hour. On several of these instances we were told by the treating psychiatrist at the unit that it would probably be a good idea to admit him into the psychiatric ward but was hesitant to do so as they said they could not guarantee his safety because of his dual diagnosis (disability with mental health). We were told that even with a 24 hour carer they thought he was to vulnerable and could potentially be in danger. We were also told that staff did not have the training to cope with patients with dual disabilities. The clanger is then they said it was our choice to either take him home and try and cope and hope no-one got hurt or admitted him into an environment where they didn't think he would be safe! Obviously this left us with no choice but to take him home and wait on tender hooks until the next episode and pray we could get assistance from the police before he could carry out any of his threats.

As you can imagine this put an enormous stress on us his parents and impacted on every aspect of our lives including our jobs, seeing our friends, visiting other members of the family or going out into the community. Thankfully we are strong people and my husband and I made a pact that we would not deal with any of our son's episodes alone we would both do it together. Also thankfully we both had very understanding employers who were amazing when we would get a phone call from support workers saying he was being transported again and we would have to just up and leave our respective workplaces.

Throughout this period we were also in contact with the ACT mental health crisis team who actually made matters worse. They suggested our son could contact them if he was in crisis but when he did was told unless he calmed down they wouldn't talk to him. Consequently he refused to ring any help line from that point onwards.

Throughout this period we also tried to see many psychologists to assist our son to deal with his 'voices' but we told more times than not that there wasn't anything they could do for him due to his intellectual disability. We had one psychologist after 6 months ring to say she couldn't cope with his session anymore and left it at that.

During this time we also approached the only private psychiatric hospital in Canberra to see if they could assist but were told that it wasn't a secure facility and that he could leave at any time and that the staff were not trained in Autism or Intellectual disabilities so they felt it wasn't appropriate that he be admitted.

Throughout this period we found the police to be the most helpful but they also had their hands tied with what they could do.

After coping with this for 5 years we had had enough of the disjointed system in Canberra so felt compelled to look interstate and after doing some research found a private psychiatrist in Sydney who we now have been seeing for the past 3 years. He has been like a breath of fresh air and after trials of different medication finally found one that as our son puts it 'switched off his voices'. We were going up to Sydney on a fortnightly bases which was very expensive let alone having to continually take time off from our jobs but was totally worth it. We now see our sons psychiatrist on a monthly basis as he still suffers from major generalised anxiety and panic attacks but as stated it seems we now have 'voices' under control. Our son has also built up a tremendous rapport with his psychiatrist and does not stress when we are due to see him again. We do not see any psychologists as I still cannot find anyone that understands his dual diagnosis.

In conclusion

We feel we have been discriminated against because our son has a dual diagnosis. He is not the only person in Canberra who has a dual diagnosis who would have the same issues as ours of not being able to access mental health services because of their diagnosis/condition.

We would like to see the whole mental health system overhauled particularly around people who have a dual diagnosis. Staff in any mental health service in hospital settings and in the community should have training and be able to deal with anyone who presents with mental health issues regardless of any other abilities or disabilities.

The failings of the system has put enormous pressure on our son, ourselves as his carers and our respective families that really should never happen in this day and age. I also believe too much is left to the police to have to deal with because of the broken system and those like our son who falls through the cracks because he has more than one issue/disability.

A way of addressing the shortage of psychiatrists in Canberra the capital of Australia also needs to be considered and again perhaps some training around disabilities should also be part of their ongoing registration.

Private and public psychiatric hospitals should have measures in place to accept anyone who is mentally unwell and not be able to shun those away because it's too difficult or they don't have adequate training.