Submission No 18

INQUIRY INTO EQUITY, ACCESSIBILITY AND APPROPRIATE DELIVERY OF OUTPATIENT AND COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH WALES

Name: Name suppressed

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To whom it may concern

Submission to Inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

Context

I am the informal carer for patient XX. I came to know him as a homeless 20 year old in 2020 when my son became friends with him. At the time I met him he had been evicted from a youth refuge and was couch surfing. He has been diagnosed with schizophrenia and complex trauma. He has no birth parents, has a history of abuse and neglect in the foster care, and has spent time in multiple homeless refuges. He now lives in social housing.

The situation – engaging with community mental health

I am writing this submission due to my deep disappointment in a mental health system that has utterly failed XX.

At the time that I met him in 2020, he was on a Compulsory treatment order under Camperdown community mental health. He evaded compliance constantly and he received no care or coordination and no linkage to any other support services.

He relocated to St George Community Mental Health when he entered public housing in that location. Once again, he did not comply with his CTO – he advised me that the medication side effects were intolerable. To my knowledge, at no time did anyone try and review this with him, and he continued to evade.

With XX's consent, I requested that St George liaise with me to support him, however I felt that they treated me with disregard and did not see the value of engaging with the only person that XX had in his life for support – they did not proactively engage with me. Due to his repeated non-compliance with the CTO and non-engagement with the service, they discharged him without his understanding of this and without active referrals to any other services. I complained about his discharge as the case coordinator who discharged him had lied to him – she had advised that if he attended an appointment she would assist with a WDO, he attended with this expectation, but instead when he turned up, she discharged him. I lodged a complaint with the Manager, I received a phone call from the Manager who verbally advised me that I was correct that he had been inappropriately discharged. However no apology was received and he was not provided with any follow up service.

Some months following discharge, XX suffered a psychotic relapse – he was delusional, paranoid, hearing voices, threatening harm to himself and others. He was involved in an assault and charged, but on bail.

During this time, I rang St George mental health crisis line multiple times a day for multiple weeks, requesting assistance. No assistance of any usefulness was provided. On one occasion when XX armed himself with a knife, I called 000. Some hours later, by which time I had removed the knife and he was calm, 8 police officers arrived. I felt that they were unhelpful and rough in their manner and that they escalated XX by the way in which they treated him. They eventually left at my request. About 6 hours later an ambulance arrived (this was during COVID peak). They didn't want to take XX to hospital as he had fallen asleep but I insisted due to his psychosis as I knew when he woke up, things would be bad again. They took him to RPA hospital, where he was left unattended in emergency and he walked out and started wandering the streets. He called me and I picked him up.

Some days later, he placed himself in harm by scaling up a two story house in the rain and breaking into a house of a neighbour. I phoned St George again and they finally agreed to admit him. They advised me to take him to St George Hospital emergency which I did. He sat there for 7 hours with no assistance. I sat with him to keep him calm. Eventually he was admitted.

After discharge from hospital, back on medication but with adjusted dose, he was back on the books of St George Community Mental Health. This time I doubled down on my effort to get them to involve me in a care plan – with variable success. There were promises of support, but no follow through, and also what I consider to be blaming of XX for non-engagement. However my view is that the health professionals should be the experts in working out how to engage with the patient.

As XX was struggling to get or sustain any work, I requested St George to support with access to Disability Support Pension. The doctor at St George refused, stating that 'we don't believe in DSP, we believe in recovery'. I agreed that recovery is a better option and asked what support was going to be provided to support recovery. No information was ever forthcoming and no support ever provided. Again, I complained but was told again 'we don't believe in DSP'. I consider this to be an abuse of XX's right to access a payment to which he was entitled based on his condition.

So to access DSP, I supported XX to get his medical records from the hospital as evidence of his diagnosis and I submitted the Centrelink application myself and was eventually successful after 8 months.

Likewise, I requested St George to support XX to access NDIS. While they verbally agreed, they never progressed any of the documentation – they did absolutely nothing to assist, claiming that it was too hard due to his non-engagement. I repeatedly told them that if they liaised with me, I could support his engagement. However this did not occur.

During this time I lodged multiple complaints – I occasionally got a phone call with sympathetic platitudes, but I never got a response in writing and I never got any action.

Hence I commenced the NDIS application myself with the support of a friend who is an OT.

During this time, I was also pursuing a referral to HASI (support service) which I was successful in gaining for him through Mission Australia.

Soon after this, XX was relocated by public housing to Marrickville and he was transferred from St George to Marrickville Community Mental Health.

Marrickville Community Mental Health could not have been more different from St George. They took 100% care and effort to get to know XX, to understand his issues, to support him with treatment and they assisted with finalising NDIS paperwork. They only discharged him once he was stable and in receipt of support from HASI and NDIS.

At no time did I need to chase them – the wonderful care coordinator was proactive in following up and made sure that I was fully aware and involved in supporting XX. She absolutely saw the value in involving me as XX's carer and ensuring we worked as a team in his best interests. I cannot praise her enough.

XX is now clinically stable though remains functionally chaotic and unable to gain or sustain employment or education.

I would like to comment on some of the terms of reference

a)equity of access to outpatient mental health services

The difference between St George and Marrickville community mental health was unbelievable. I fund St George to be unhelpful, unprofessional and dismissive. XX had no trust in them and

frequently said this to me. This was the main reason that he 'didn't engage' yet St George used his 'non-engagement' as their reason for not providing service to him.

Marrickville was amazing. Access to a decent service should not be a lottery ticket of where you live. Services should be accountable to a standard. St George is not.

Additionally, the only reason I got XX access to HASI is because of a personal connection I had with someone who helped me get the referral sorted. Access to services should not rely on personal connection. This is hugely unfair.

Additionally, XX had multiple encounters with homeless services, yet none of them was successful in linking him with appropriate mental health support.

(b) navigation of outpatient and community mental health services from the perspectives of patients and carers

As you would glean from my story above, it has been a long hard road to getting XX access to services and the only reason I was able to navigate as well as I could was because I have previously worked in a govt department involved in funding housing and homelessness services and I had a good understanding of how to navigate and advocate and personal connections with people who helped me. Most people would not be able to do this. Without me supporting XX, I believe that he would now be either dead or in prison (he has had multiple encounters with the justice system before I met him and during his psychotic breakdown).

(c) capacity of State and other community mental health services, including in rural, regional and remote New South Wales

As per my story above, the difference between community mental health services is significant. One had no care or accountability (in my view), the other was amazing.
I am aware that St George had staffing issues, but in my view they also clearly had a very deficient management and quality assurance approach. The fact that I never got any response in writing to any of my complaints is one very obvious sign of a system that is not accountable.

They really did not seem to have sufficient attention to my concern that XX was expressing suicidal thoughts and was also arming himself with a knife and a threat to others over a period of many weeks – it is a miracle that no one got hurt and that he did not throw himself under a train as he expressed he wanted to.

Also at St George, the psychiatrist seem to change frequently and there was lack of continuity of care. Appointments were usually 15 mins, the doctors appeared unengaged and uninterested on the whole, and XX found the encounters dehumanising and he didn't like to engage, but they blamed him for not engaging when he missed appointments. Additionally, the psychiatrists appeared to lack skill in understanding what was going on. I sat in some appointments and I heard XX tell them whatever he thought they wanted to hear, which was very far from the truth of what was going on. When I tried to provide some clarifying information, I felt disregarded. This was not the case at Marrickville where my opinion and information was welcomed.

(d) integration between physical and mental health services, and between mental health services and providers

Marrickville Community mental health did a great job of linking XX with a GP and OT. I am not aware of other integration issues.

(e) appropriate and efficient allocation of mental health care workers, including psychiatrists, nurses, psychologists, GPs, counsellors, social workers, allied health professionals and peer workers

As above, I have commented on psychiatrists at St George.

Also at St George, in the almost 2 years of being associated with that service, XX was not actively provided with any access to any GP, counsellor, social worker or allied health professional.

When he moved to Marrickville this changed. They supported him to access a GP and an OT, and they offered to link him with a psychologist which he said he wanted but he did not end up engaging.

XX did not encounter peer workers in any of these services.

The case workers provided by HASI have been the main support for XX. These have also been variable. The first one was good, but when he was on leave, the replacement was uninterested and unprofessional and XX disengaged. XX had to relocate from Mission Australia HASI to Flourish HASI when he moved from Arncliffe to Marrickville. There was a 6 month delay by Flourish in accepting the referral. When they finally appointed a case worker, she was great, but after 2 months she left, The next case worker did not know how to develop rapport or trust with XX and appeared uninterested in doing so, and I asked for another and he was provided with a new one who is currently working well.

(f) the use of Community Treatment Orders under the Mental Health Act 2007

As above in my description of XX's story he was on a CTO when I met him but he refused to comply due to side effects. At no time, to my knowledge, did any doctor discuss with him the reasons for refusing to comply or what modifications could be made to the medication to mitigate side effects. Rather, Camperdown and St George both threatened to send the police to enforce compliance. This meant that XX did not trust either of them and did not engage well. They consistently blamed him for lack of engagement.

Once XX got back on medication after his breakdown, and it was adjusted to a different dose to the CTO to mitigate side effects, he was happy to comply. He now remains on medication and is clinically stable. The HASI worker makes sure he gets to the appointment monthly for his injection and there is no resistance from him in doing so.

(g) benefits and risks of online and telehealth services

XX has occasionally had telehealth appointments during Covid – these have worked well.

I see no risk in these if the patient is clinically stable, and they offer a real alternative for people who can't travel to a service.

(h) accessibility and cultural safety of mental health services for First Nations people, culturally and linguistically diverse (CALD), LGBTQIA+ people, young people, and people with disability

XX was born overseas – whether or not his race is a factor in the truly terrible experiences he has had with mental health services and the police, I do not know, however it would not surprise me given the racism in our society and unconscious and conscious bias from health care professionals.

He is also young – he is now 23. He is immature and lacking the ability to make good decisions for himself - in part due to his age and in part due to his complex trauma history and absence of parenting. He relies on me for guidance as the only consistent adult in his life. The services he has encountered have not been able to understand the degree to which he requires functional support and guidance and have made incorrect assumptions about his capacity to follow through on actions.

(i) alternatives to police for emergency responses to people experiencing acute mental distress, psychosis, delirium, dementia or intoxication in the community, including but not limited to Police, Ambulance, Clinical, Early, Response (PACER)

I do not know what alternatives exist, but when 8 police officers came to my house when I called 000 during XX's psychosis, they appeared to have no knowledge or training in mental health and treated XX like a criminal rather than like a person who needed help. It was horrendous. I lodged a complaint with police which was dismissed. Their view is that they responded appropriately.

I would be happy to provide any further information on this submission.