Submission No 94

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

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Submission for the inquiry into “Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales”

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Background

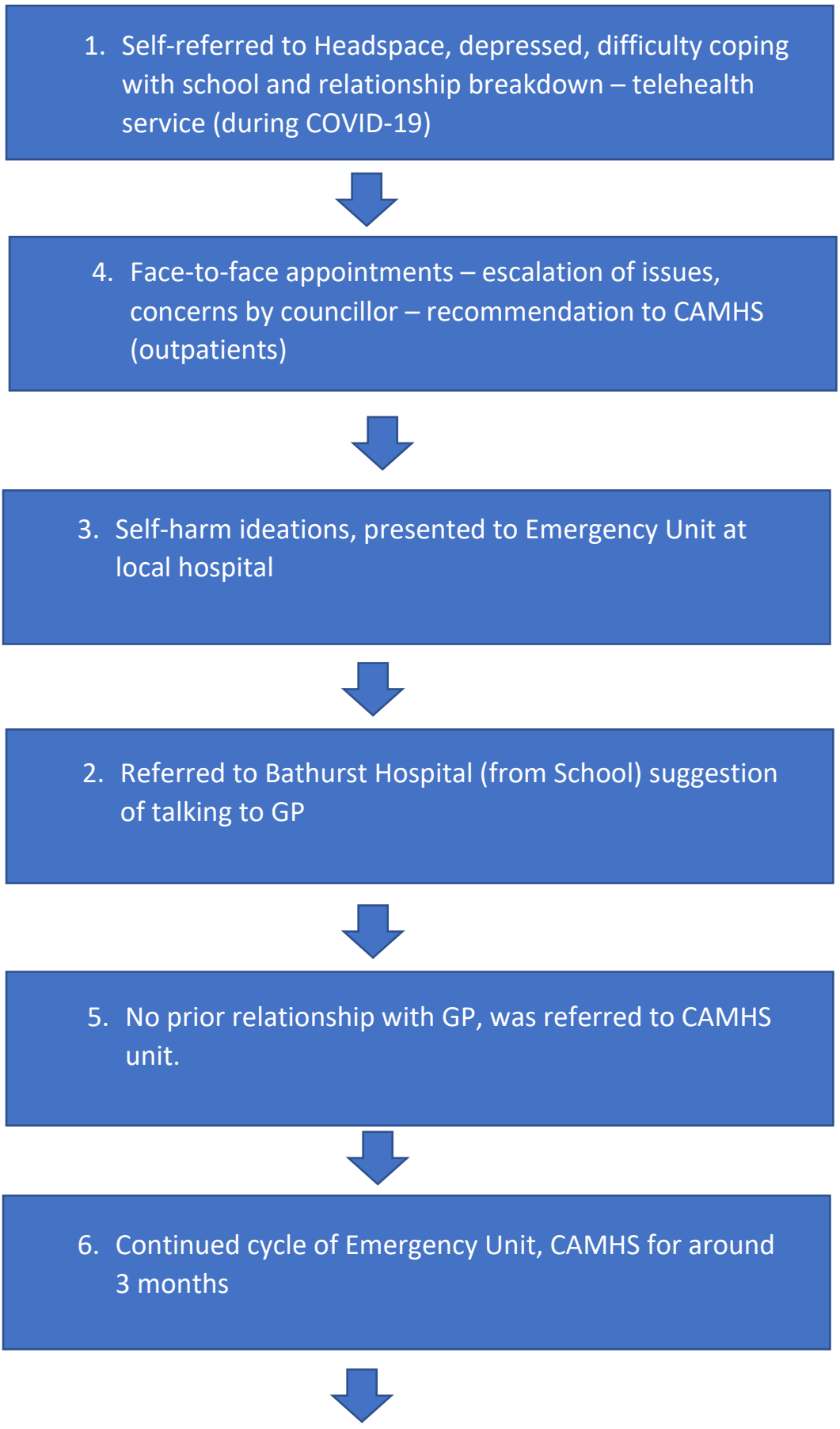
Over a 10-month period my child was using a range of mental health services. My teenager was 17 almost 18 by the time most of the services were accessed, which presented several unique challenges including the usual regional access issues. My child was studying for the HSC in a pandemic.

Services and timeline

Services used:

- Headspace - telehealth
- Headspace - Face-to-face appointments
- CAMHS (outpatients)
- Emergency Unit at local hospital
- Emergency Unit Bathurst Hospital (from School)
- GP
- CAMHS inpatient unit
- CAMHS outpatient
- GP

Timeline:


1. Self-referred to Headspace, depressed, difficulty coping with school and relationship breakdown – telehealth service (during COVID-19)
4. Face-to-face appointments – escalation of issues, concerns by councillor – recommendation to CAMHS (outpatients)
3. Self-harm ideations, presented to Emergency Unit at local hospital
2. Referred to Bathurst Hospital (from School) suggestion of talking to GP
5. No prior relationship with GP, was referred to CAMHS unit.
6. Continued cycle of Emergency Unit, CAMHS for around 3 months

7. Referred to CAMHS inpatient unit following our plea for some form of change. Agreed to voluntary admittance.

8. Overnight – changed to involuntary patient due to request to leave and concerns for his safety

9. Released from inpatient after 1 week as mostly day patient.

10. CAMHS outpatient – with instruction from inpatient to review medication, conduct ASD assessment, regular visits with psychologist, and diagnosis of ADHD. (Note this was the first time any diagnosis was shared with carers or patient).

Service Evaluation – Carer's view

Name of Service	Worked Well	Room for improvement
Headspace	Appointments available – short wait, around 2-4 weeks	No real communication between Headspace and CAMHS – relied on pre-existing relationships (if they existed)
CAMHS (outpatient)	Local	Staff overworked, shortage of appointments, poor communication with each other, carers, patient, other services
Emergency Dept	Easy to access	Long wait times – anything up to 8hrs (usually late night, early morning), no communication with other services, including CAMHS – although I believe notes were shared.
Telehealth Services	Ease of access – a television was brought into the room.	No understanding of the patient. Often, we were dealing with different staff each time. They would talk to my son, tell me how lovely he was, and then send him home again to continue the cycle.
GP	Potential to have good pre-existing relationship – good knowledge of the patient and carers	Lack of confidence with adolescents – referred to pediatric psychologist/psychiatrist.
CAMHS (inpatient)	Local, nursing staff overall were very friendly, especially for the patient.	Lack of communication with patient, carers, other services, lack of staff (especially during school holidays) (Although this may be out of scope for this inquiry – please consider the fact that there is a close relationship with outpatients to maintain the treatment – this did not work well in this instance because of the lack of consistency and resources for the outpatient's team).
CAMHS (outpatient)	Local	No communication with inpatient service. Were

		unable to deliver on the release notes. No ASD assessment, no psychologist (had just gotten married and was not replaced), no medication review, no real knowledge of the patient, no communication.
Psychiatrist – ADHD (17 turning 18 – too young for adult psychiatrist, too old for pediatric psychiatrist)	Could prescribe ADHD medication started during inpatient stay.	Unable to get in to either local, regional, or Sydney. Clinic run by VMO does not know the patient and incorrect information was given.

Outcomes

Positives:

- Created a good relationship with our GP- able to discuss issues and know that both carers and patient were being heard. This was very much lacking with use of CAMHS outpatients.

- Eventually – got a formal diagnosis of ASD, ADHD and Anxiety and Depression. This was shorter than many people experience, but took:
    - an inpatient stay, which was traumatic for both patient and family.
    - a formal complaint to the local hospital.

- My son did Completed the HSC and got into University using the "Spotlight" program.

Negatives:

- Carer's family now has two others using psychological services,
    - one with a diagnosis of anxiety and depression,
    - the other with a diagnosis of Post Traumatic Stress Disorder (as a direct result of the events of my son's experiences).

- My son is now reluctant to access services due to his very poor experience with the previously mentioned services.

Key Learnings and suggestions

Communication is key!

Communication with patients and carers should be frequent, including what is clear and what is still not clear, but what is current thinking. We were told that the diagnosis for Autism was not clear and there were concerns about sharing this until they were sure. In the meantime, we were told nothing

– either patient or carer. All we knew was that our son would turn up for an appointment, he would talk to his caseworker, and then he would go away with no appreciable difference. We would continue to go through the local hospital, or he would continue his self-harm ideations.

It is important to recognise that especially with the CAMHS unit, they need to be the key to other services. We were constantly being directed to use a private psychologist or psychiatrist, but no recommendations or referrals were given. We were unable to get an appointment for our son for a paediatric psychiatrist. No psychiatrist would take him on, as he was still not yet 18, but the paediatric psychiatrists were reluctant to take him on due to how close to 18 he was.

Listen and Hear

After we made the complaint, my son was given the opportunity to talk to the director of the CAMHS unit in Orange. He shared that his greatest frustration and disappointment was that he felt that he was not heard.

As a carer our concerns were often dismissed or minimised. We were also constantly being asked to share family history, even between the inpatient and the outpatient units.

Keep the expectations real!

Recognise that this is a scary experience for the patient and their families. The patient particularly is in a vulnerable state. Share information, give as much information as possible, even if the staff are time poor. The more information possible allows everyone to have an idea of what to expect.

Recognise that this is going to affect everyone, especially other family members and carers. We were offered counselling sessions, but by that stage we had no confidence in any service associated with CAMHS.

Training of students

I was asked to attend a lecture for students at Macquarie University, to give a carer's perspective in a regional area. The students were given broad generalisations – people from country areas are less likely to attend services, due to lack of privacy as everyone knows everyone else, men are less likely to get help, farming issues etc. it is very important not to paint all rural, remote, and regional communities as the same, or indeed their populations. Each person, regardless of where they should be seen as an individual and taken individually.

Conclusions

After having one person in our family experience mental health issues, and due to the poor access, overworked staff, lack of communication between services, we now have most of the family experiencing mental health issues.

Having more mental health professionals, as this does include mental health nursing staff, whom we found the most helpful, closer communications with services, it could potentially reduce the cost of those accessing services.