Submission No 81

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

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My name is Patsy Fokes and I have two sons, both with complex Mental Health issues that require my daily support, both have NDIS support packages which are self-managed. One son is actively engaged with Coffs Harbour Mental Health currently, the other son has numerous diagnoses but is not actively involved with Mental Health services, due to the severity of his condition.

Issues I have faced over the last six years in my attempts to gain adequate support for myself and my son, who is diagnosed with Treatment Resistant Schizophrenia and currently engaged with Mental Health Services, have been frustrating to say the least and led me to the point of burnout and breakdown.

I would like to make this submission, based on my personal experience and the experiences of my son, who is not able to make a submission in his own right due to Anosognosia.

My hope in making this submission is, this inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales, NSW Service delivery leads to a stringent review that will result in better outcomes for all.

Terms of reference

a. Equity of access to outpatient mental health services

Outpatient services in Coffs Harbour are inadequate, they are unresponsive in the times when they are most needed, to avert escalating risk.

Coffs Harbour Mental Health lacks equitable access to skilled resources, staff are not well trained in up-to-date education and are limited by high caseloads and low-level senior support, this makes service delivery not only inequitable but ineffective.

Equitable access for parents and carers is non-existent, at no point have I felt valued by Mental Health, in fact I have experienced increased risk of harm to myself because of Mental Health staff pre-fixing statements with “Your mother said…” even when they have been alerted to the increased risk this causes for me.

Equitable access to Mental Health for those who have coexisting substance use disorders, finds those with co-existing disorders are marginalised and discriminated against. Many a time have me and other parents in the community have presented at the hospital emergency, because of no ability to access Outpatient Mental Health support, only to be turned away, after waiting hours, with statements like “sorry we cannot help” or “there is nothing we can do”. This is appalling for a community in crisis with Mental Health and Substance statistics on the rise.

My son is unable to access an appropriate Psychiatrist that adequately meets his needs**,** in the last 24 months he has been assigned 4 different Psychiatrists, the latest is the only Psychiatrist he has seen twice, and the only Psychiatrist who he has begun to build a relationship with. Unfortunately, we were advised at our last meeting my son would be assigned another new Psychiatrist before his next review, we still do not know who this will be.

Due to issues with Psychiatrists ability to be 'professional' and respect my son's reality, (documented later in the submission) I have attempted to complain but our complaints about my son's experiences with Psychiatrists have not been heard.

There has been no equitable access to the complaints process. The complaint made was not reviewed in any way, rather my son was requested to attend an appointment with the Head Psychiatrist for the service, this meeting had absolutely nothing to do with support for my son, it was very abusive and non-productive. Hence the complaints went no further, as he did not acknowledge any ground for complaint, and in reply, blamed myself as his mother, my son and the Private Therapist Coach I work with as being the problem. This could not be taken further as there was no information provided to me as to the next steps in the process.

I have sought Private Psychiatrist engagement in the community at this time, at exorbitant cost, one session was had, and the Private Psychiatrist advised she was unable to meet the needs of my son moving forward.

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

As a carer and family member the navigation of services is difficult and often 'road-blocked'. Trying to gain access to help and support to avert crisis is non-existent, the best is leaving a message for his Case Worker, whose time is stretched, he does his best. Responses to messages to contact are often excessively time delayed due to the unreasonable expectations of Mental Health on Case Workers, their high Caseloads and expectations on time spent with each patient. Other contacts appear to not be interested in finding any support for myself, to help reduce escalation.

I am totally reliant on my Private Therapist / Coach to guide me and advise., thus enabling me to support my son in the reduction of risk, safety planning and guidance re his ongoing needs to ensure stability. This service I should not have to pay for, this service should be provided by Government Mental Health Services

This is unacceptable, as without the ability to have a Private Therapist / Coach I would be on my own experiencing the frustration and desperation I see on others who are trying to adequately gain support for themselves and their children.

The issue of adequate support for parents or siblings who are primary caregivers needs to be addressed, I am very active in the community supporting advocacy and engaging with other community services and have found most community services, their desire to provide positive help and support is far greater that than Community Mental Health's desire or ability to provide that support.

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

Capacity is a major issue; you cannot gain access to Outpatient Mental Health services unless in crisis, the number of people needing service far outweighs the states and communities ability to provide service .

Two issues are key to this

1. **Access to skilled Case Workers in a timely manner**, currently access for my son to his case worker is sporadic to say the least, there is no continuity in intervention or ability to grow and learn for my son due to this.

2. **There are not enough key Mental health staff to meet need,** just having more feet on the ground is not the answer, capacity is not about space it is about adequately trained and adequately resourced staff

When considering capacity, I believe NSW Mental Health need to look at models where those who know the client best, the family and carers, are 'intentionally' educated in risk reduction, safety planning and finding day to day support in a more informal way through outpatient services,

I would suggest a more collaborative approach across the community as a whole and more specific identification of models and practices that cater for this type of intervention.

d. integration between physical and mental health services, and between mental health services and providers

Coffs Harbour talk the talk about being 'collaborative', they however do not walk the walk, it is easier to quote 'Confidentiality', 'Patient Rights' etc rather than do the work to facilitate good quality service delivery through collaboration with patients, carers, other providers etc.

Implementation of a 'Single Case Planning Model', where all who are involved in a patient's care, including patients, family and carers, work together in a collaborative way (the team).

The goal is one nominated 'lead agency', most likely Mental Health Services, and 'one collaborative case plan'. Case plans are developed with the input of all members of 'the team', meetings are held regularly to review and provide ongoing updates to the plan, and to incorporate not just a medical perspective, rather a whole of well-being perspective, through Physical, Psychological, Social and Spiritual growth.

A major advantage of this model is a reduction in duplication of services, different services and providers not 'working blind', unaware of what others are doing and an overall reduction in need for professional services, as patients, families and carers are all on the same page, with their knowledge and input acknowledged and valued.

The biggest limitation to this type of model is when attempting to get this model working for my son, I experienced Professionals who are passive in the unwillingness to work together, the fear of putting their funding at risk, the fear of 'professional criticism', and the fear of needing to be accountable, are what I have noticed other professionals are limited by, this does not reflect what is best for the patient, their carers and family.

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

In the last 24 months my son has been allocated 5 different Psychiatrists, there is no continuity service or of relationship, these things are important to be able to plan and for my son to have a level of connection and trust.

Psychiatrist appointments are sporadic with the time between appointments being way outside his Treatment Plan, "must attend Psychiatrist reviews at least every 3 months". He recently went over 6 months without seeing a psychiatrist, this was as a result of Outpatient Mental Health either cancelling or not having an appropriate Psychiatrist available.

Being allocated different Psychiatrists, has been detrimental to my sons ongoing Mental health, it is very difficult for him when each appointment starts with the basic assessment questions, like he has never been a part of the service and there has been no prior preparation for the appointment, reading historical notes.

Psychiatrists are not available to answer questions of parents / carers due to time and the allocation of 15minutes per appointment does not adequately meet anyone's needs.

My son's GP is a big support for my son and me as he does make the time to be available.

Families would benefit from a dedicated Family / Patient Liaison worker, who is a skilled clinician / case worker and who has a realistic case load to be able to provide meaningful support, as a first-person contact. This would benefit families, carers and patients and would likely reduce the need for crisis intervention.

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

My son is currently on a Community Treatment Order (CTO), he has been on this order for several years now, his CTO is valuable in him maintaining a medication regime that benefits his wellbeing at this time but does not always reflect my son's updated needs.

Mental Health fails in their liaison with Carer / Patient and orders are not realistic. Coffs Harbour Mental Health are unable to meet the treatment plan associated with the order, regarding their service delivery requirements, the

" The Coffs Harbour District Hospital Outpatient Services will support, monitor and educate in relation to his mental illness, current treatment, medications and rehabilitation needs by providing written and verbal information

The mental health case manager will coordinate the effective implementation of the CTO by liaising with , his nominated carer Patsy, his treating psychiatrist and the treating team

The Coffs Harbour District Hospital Outpatient Services will assist in identifying and planning treatment and service options to address identified rehabilitation and recovery needs

The Coffs Harbour District Hospital Outpatient Services will support, monitor and encourage to monitor and address his physical health needs through his identified local General Practitioner".

The Chief Psychiatrist on the Tribunal and other members are not active in, when advised of breaches in Coffs Harbour Mental Health accountabilities, accepting feedback from family and other professionals and they are not active in following up their (the tribunal members) requests of Coffs Harbour Mental Health, when requesting the service work more collaboratively, the service says we do and we will, but there is no independent follow up outside the hearing.

When the Tribunal was advised by a professional my son suffers Anosognosia, the Head Psychiatrist indicated he was familiar with the conditions, and then totally ignored the ineffectiveness of the treatment plan in stating "to educate in relation to his mental illness, current treatment, medications and rehabilitation needs", for someone who does not recognise himself as 'sick' it is impossible for these strategies to work.

g. benefits and risks of online and telehealth services

Online telehealth services are great in my experience, my son and I have experienced provision of service delivery via Zoom and tele health. My son and I undergo regular connection in this way with outside professionals, where these professionals are open to it and in our case we have experienced nothing but positive outcomes in this method of service delivery.

The biggest plus for online / telehealth service is it enables access to skilled professionals located anywhere in the country. Reviews and meetings, case work and therapeutic intervention can all be provided in the safety and comfort of your own home.

Cost of travel, easing of travel times and associated issues re parking all are eliminated.

For my son, Community Mental Health buildings and the environment are huge trauma triggers for him, he does not feel 'in control' of his abilities to seek safety if he needs. At several psychiatrist meetings he has had in person, he has faced being abused by the psychiatrist through their sarcastic remarks such as "one day we hope you will grow up and recognise you will need medication for the rest of your life", or another "this person/voice is not real to me, I can't see them", "you will never get out of the system until you accept you have Schizophrenia", make this environment incredible unsafe. When triggered through this my son cannot get up and leave if he needs to maintain safety, everything is locked, he is a prisoner in his meetings.

My son has Anosognosia, something Coffs Harbour and other Mental Health professionals fail to identify, fail to acknowledge, and fail to know how to work with. My experience is an experienced clinician such as my Private Therapist / Coach, working via Zoom with my son, has been able to make great inroads with helping him move forward in reducing his dependence on substances.

I have positive experiences in online learning with undertaking sessions and online learning modules to support me in creating positive change for my son through using the LEAP Model of intervention, something the professional I work with, believes all professionals should know how to use, as it is simply the basics of good patient / professional relationship building.

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

Unable to comment

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)

Currently there are no alternatives, and asking old sets of eyes to be creative in new ways is an impossible task. Community, including family, others experiencing the same issues and patients (when not in crisis) are the best options for coming up with alternatives.

This does require expanded thinking and an openness for a different approach, passing the power back to the community, providing adequate professional facilitation from an experienced facilitator (Collective Impact experienced) and support for the community to provide a safe alternative and safe plan that would best work for them and other services.

j. any other related matter.

Outpatient Community Mental Health and all Mental Health Services would benefit from integrating into their policies, procedures, ongoing professional development two models

1. Single Case Planning

2. Collective Impact

Both these models place the patient, and their families as a key component of effective Mental health and service delivery intervention. The current ways of working are referred to as 'Evidence Based', we are kidding ourselves we are doing a good job and the models we use work for the majority, they may work for the minority who usually are less severe in nature.

As a mother and a primary carer, I have been forced to do in-depth research to find a better way, I am lucky to have found a professional who understands the value of family and the values of community in this journey, this has made a huge difference for me and my sons. Not all families can access research or employ private professionals. The NSW Government will benefit when they recognise there are more beneficial ways to spend mental health dollars that will gain better outcomes for all.

Outpatient Mental Health needs to be able to provide the same type of patient intervention, the same type of family support and the same type of clinical reflection that I get by employing a Private Therapist / Coach.

I would be more than happy to be a part of any ongoing dialogue around this issue as would my Private Therapist / Coach. I believe getting the same old heads around a table trying to improve a system that doesn't work is insane, you are only ever going to get the same old understanding just with a different name, nothing changes.