Submission No 84

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

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

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Dear Amanda Cohan, MP LC,

I would like to address several items listed under the terms of reference, through the lens of being a carer for my daughter. My experience relates to care under Royal North Shore Hospital's (RNSH) Early Intervention Service, Lower North Shore Community Mental Health Team between October 2021, and May 2022.

has an intellectual disability, and I have been her advocate at various times throughout her life. More recently after our experience in the public mental health system, we decided to wait for 12 days for a bed to become available in a private psychiatric hospital. is currently in hospital receiving treatment for psychosis.

I expressed my concerns about care several times over several months between 2021 and 2022. I raised concerns about the care via formal feedback (carer feedback survey in December 2021) and also informally on a number of occasions (e.g., on 26 April 2022 in a psychiatric review with Dr). I also wrote to Deb Wilcox as the Chief Executive Officer (CEO) of RNSH.

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

I'm a Social Worker with experience across mental health services over 30 years. I had difficulty navigating Community Mental Health Services and found the experience extremely challenging.

Medical model

I was shocked to find that our experience was of a medical model and not a holistic approach. I raised concerns with staff from the Community Mental Health Team on several occasions. While I understand that there is a need for anti-psychotic medication and a medical model does need to be applied, I found the approach was purely a medical model. At one stage there was talk about Case Worker meeting in a non-clinical environment such as a park or her home, and yet this option was never followed through. has only ever been seen in a clinical setting. I only ever observed a Westernised medical model.

I found a recovery model was not considered at all. At home, we supported the development of a recovery plan by helping develop a wellness plan based on her strengths and goals. decided to focus on exercise, eating well, seeing her friends, going to see her horse, journaling, completing artwork which she loves and rebuilding her functional skills with the Occupational Therapist. created a vision board with goals such as going back to work and completing a horse handling course, and she also put together a weekly routine on a whiteboard with personal goals. kept a wellness journal and documented how she was feeling.

The Community Mental Health Team assessment of did not seem to incorporate her support systems (e.g., family and friends) and strengths. I found the service lacking in being person-centred (e.g., not involving in the development of her own care plan. Instead, her family had to initiate this. I was very surprised by the lack of a holistic approach to care.

When was engaged with the service, we attended every appointment. My husband and I accompanied her to every session, and this included sitting in the waiting room, and seeing the psychiatrist or Case Manager at the end of the visit. would see the staff in private for most of the session as we felt this was more empowering for her.

We have been rock and support system, and this has resulted in the entire family supporting when she is acute (e.g., highly delusional, paranoid, agitated, hearing voices, and very distressed due to the hallucinations). I found the involvement of family in any care planning was limited.

It is critical that where families can be a support, they are involved. We have essentially been able to monitor, provide practical support, personal care, medication and care.

Lack of empathy

younger sister was in year 12, and it was a stressful year for her sibling. The stress on the family was immense with us trying to work, study and support mental health. sister witnessed very frightening and unusual behaviours (e.g., thinking her eyeballs are being scraped out, that someone is going to cut her limbs off with an axe, that she is being raped and sexually assaulted).

In seven months, only once were we asked about how the family was coping. There seemed to be a lack of empathy among the staff and lack of recognition of the impact on the wider family. Only once were asked how the family was coping on Christmas Eve in 2021. It was the first and only time, anyone had thought to ask. At the end of our experience, we were offered a Carer Gateway brochure with no explanation. I was shocked at the lack of care for the 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

Lack of continuity of care

We experienced a lack of continuity of service, and this resulted in a range of views about diagnosis. We didn't see the same registrar more than once and the sessions were 30 minutes in length every two weeks. While different opinions can be helpful, we experienced vast differences in views and opinions about mental illness and her care plan amongst the registrars. For example, Dr. did not think that going back to her workplace would be helpful for her and that the workplace could be triggering. In contrast, Dr. recommended go back to work as he thought this would be highly beneficial.

The female consultant psychiatrist (name unknown) told that she has Schizophrenia when we attended the clinic in late November 2021. In the meeting, she also abruptly told me to be quiet on a couple of occasions. She was extremely blunt in her approach.

Other psychiatrists maintained that had a delirium due to a urinary tract infection and this is the cause for the psychiatric symptoms. condition was termed 'pseudo psychosis' or 'episodic psychosis'. Dr wrote to employer, Jigsaw on the 14 April 2022, stating, 'we do not regard as having schizophrenia', and he spoke about experiencing psychosis. We have witnessed firsthand varying opinions on condition.

It is two years since symptoms commenced and now we have an opinion on diagnosis including a combination Schizophrenia and Bi-polar - Schizoaffective Disorder.

While I acknowledge that Royal North Shore Hospital is a teaching hospital and there is a rotation of registrars, in seven months, we managed to see at least a dozen different psychiatrists from the time was admitted into the hospital on the 31 October 2021.

The exception was that we were able to see Dr. twice. Another factor influencing poor continuity of care is that staff on the LNS Community Mental Health Team seem to work part-time. I am not sure why this is the case (e.g., whether it is budget-related or to enable flexibility of hours for staff). I will say that having a part-time workforce does not work for clients and impacts patient care and client outcomes. We experienced Case Managers working only two days per week which makes it difficult for communication and follow-up. For instance, staff struggle to check emails, and staff cannot follow up and action items. In 6 months, we had four different Case Managers.

I was shocked that General Practitioner (GP) had not received any communication about condition between December 2021 and May 2022. An agreement had been made with Dr in November 2021, that GP of over 20 years, was instrumental in her ongoing care. On May 3, 2022, GP said he was “shocked and surprised to see in the mental state that she was in”, and he said “he assumed must have been well as he had not heard from the Community Mental Health Team since December 2021.”

I alerted the Case Manager of this issue on May 4, 2022, and she eventually followed up with our GP. I also requested a letter for NDIS review. This was requested verbally and in writing via email to on the 20 April 2022. Dr was to write a letter advising of mental illness and the impact. The request was never actioned. It was highlighted as urgent and critical. NDIS review period passed, and her NDIS plan remains the same as the previous year, despite the impact of her mental illness on her functioning.

Lack of resources

Many of the staff are well meaning and well intentioned, however there is a lack of resources. Community Mental Health teams are not able to meet the demand. There are limited resources and nil support for families when their loved ones are acutely unwell. The after-hours number is useful, however a short phone call does not decrease and de-escalate the situation at home, when your child is screaming the neighbourhood down in distress. I have been told unless is hurting herself or others, there is basically no help available. I was advised by a Case Manager to take back to the Emergency Department if I become very concerned.

Basically, unless your child is bleeding to death or has overdosed, there is no help available. Families are left on their own to manage challenging situations. I have had periods where I have not slept for several days at a time due to distress and inability to sleep during the night. We have essentially all been on alert and have had to keep our eyes and ears open throughout the night to ensure that does not self-harm or do something extreme to hurt herself. At times wakes up early hours of the morning screaming the house down and we are frantically trying to calm her down. It is any wonder that carers have very poor mental and physical health.

This situation has not changed. More recently we have coped for several weeks with experiencing psychosis and we had to manage the situation at home. We made a decision not to take to the Emergency Department after our last experience which was Anzac Day 2022.

On the Anzac Day Public Holiday (April 25, 2022), I rang the Community Mental Health Team a couple of times in distress. had found a box of Panadol and was planning to take the entire box. I effectively intervened just before she began to swallow the tablets. A couple of weeks before this, had been found using a knife on her arm. I removed all sharp objects and medications in the house. I rang again in the early hours on the 26 April as not one had returned my calls. When I rang again, I was provided with the opportunity for an urgent psychiatric review.

We presented for the psychiatric review at 11 am that same morning (26 April) with Dr was acute and extremely frightened that her family would be harmed and that she would also harm herself. I witnessed scratching up her arms while we were sitting in the waiting area. It was recommended that we have admitted to the psychiatric emergency care ward. I was then accompanied to the Emergency Department by staff from the Community Mental Health Team.

and I stood most of the time over 10 hours as there were no seats in Emergency. I understand that patients with physical life-threatening illnesses need to be prioritised. However, I was disgusted at the lack of empathy and understanding of the staff in Emergency regarding psychosis.

was in a state of psychosis the entire time and she was not only hearing intimidating and loud screaming voices, but she was also seeing people who were not there. was also having a physical response with the continuous jolting of her head, flicking of her hands, throwing her arms up, and punching in the air. I explained to the triage nurse that was in psychosis and a heightened agitated state. I also explained this to Dr when he physically examined . I was surprised when my GP told me that the hospital had screened for drugs and useless things such as pregnancy when had a blood test. GP said the pathology results were useless. We had waited for hours, both of us in distressed states, for no purpose.

While siting for hours, had decided that she would not be admitted to hospital because she was fearful of “being locked up indefinitely”. The Community Mental Health after-hours staff, while well-intended, had told her that the psychiatric ward was a “scary place”, “intimidating” and “over whelming”. We had previously phoned the after-hours team on a couple of occasions when was highly agitated. had convinced herself that the hospital was unsafe.

workplace wanted guidance on how to best support her in the workplace before she could return. The manager at Jigsaw requested a phone call with the Case Manager. A message was sent to the Case Manager about this on January 12 2022, and it took over a month to action. Numerous text messages and emails were made from employer, and finally went back to work briefly at the end of February. The Case Manager’s intentions were in the right place, however, her work hours prevented her from following through.

(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

I frequently raised concerns about the team's lack of skills and experience in supporting people with a disability. For example, staff from the Community Mental Health after-hours team asked if she had been drinking or using drugs because they couldn't understand she has a disability that impacts her speech. This was raised on different occasions and was again raised on the 26 of April 2022 with staff. In response, staff provided two names of external psychiatrists that specialise in developmental disability. At the time I contacted ten private psychiatrists with developmental disability experience, and there were long wait lists into 2023 with books closed. I felt this was a very inappropriate solution, to refer to out other private psychiatrists.

After being on a wait list for 14 months, we finally have access to a Neuropsychiatrist specialist in developmental disability.

(j) any other related matter.

In terms of the Community Mental Health Team following the Australian Clinical Guideline for Early Psychosis, I would like to point out a few observations:

1.2.1 Access to Care: Mental health services should provide education about early intervention to families. This includes information about psychosis.

The term psychosis was never used in relation to condition apart from one time when Dr indicated has episodic psychosis. I was frequently told that had a delirium that was temporary. There was one exception to this advice. Dr told that she possibly had Schizophrenia back in November 2021.

2.2.5.1 Risk assessment should be undertaken. This should include depressive symptoms and suicidal intent.

experienced suicidal ideation and self-harm behaviour over several months. This was reported to the Community Mental Health on several occasions. I also reported having to remove all knives and medications from the house. Despite this, risk was never taken seriously, and I was left to manage safety on my own.

3.1.1 The possibility of psychotic disorder should be considered for anyone who is experiencing functional decline.

I had reported observations about functional decline on numerous occasions, both over the phone with the after-hours team and in person when attending appointments at RNSH. I kept a diary on what I was observing and shared this with the Case Manager.

Research even supports the fact that people with an intellectual disability with a psychotic disorder experience even more impact on their functional abilities (Kendall & Owen, 2015). Yet, the team considered experienced no functional decline. I expressed concern about deterioration in functioning. I had to step in more as primary carer could not leave her alone. I was unable to socialise became very isolated isolated due to my caring role.

3.2.1.3 All young people should be seen at least twice weekly in the acute phase by the acute treating team, case manager or doctor.

3.2.14 All Families should be seen or contacted at least weekly in the acute phase by the acute treating team or case manager.

was extremely unwell and acute between mid-March 2022 until the end of May 2022. I had no support from the Community Mental Health Team and had to manage independently at home. I had little contact from the team, despite requesting a review of in a phone call with the Case Manager at 9:30 am on April 27, 2022. I pleaded for the team to review after we had presented to the Emergency Department the day before.

had decided she would not be admitted to the PEC. I supported this decision and I had hoped perhaps a bed in a private hospital with a young adult ward would be less confronting for I was very distressed about acute state and having to manage at home on my own, after her refusal to be admitted to any hospital. I had very little support and despite my requests, the team would not review clinical care. I then decided to move to private psychiatric services due to the events on the 26 and 27 April 2022. I felt extremely let down by the public mental health system and had no choice but to move to private services.

3.3.9.1 The needs of individual family members should be recognised and addressed (where appropriate) at all stages of a person's recovery.

As pointed out, I was only ever asked once by a staff member how the family was coping. There was not discussion of family involvement, no family conference and no evidence of a recovery plan or alternative holistic support for Our family needs were never considered. We were never provided with any emotional support or tools to help us cope.

The main point that I would like to make is that I feel we had not been heard. I should not have been forced into seeking private psychiatry services, and we should have been able to rely upon the public mental health system. I found it interesting to read the National Carer Survey. I am not surprised that carers feel their needs are not heard in a community mental health care setting. Only one in three carers reported receiving adequate information and half of carers agreed that supports were inadequate (Carers NSW 2020, p. 28). The survey results are worth visiting - Carers NSW (2020). 2020 National Carer Survey: Summary report. Available online at: http://www.carersnsw.org.au/research/survey

3.3.9.4 The treating clinician should assist the family by providing information about psychotic disorders (including the recovery process) by helping the family, where necessary, develop skills in problem solving and enhanced coping strategies.

treatment involved medication (Olanzapine), and there was never a discussion of the side effects. Apparently, Olanzapine is the drug of choice as it is cheaper under the PBS scheme. had terrible side effects including weight gain of 10 kilos in a matter of weeks.

was not provided with a recovery focused model of care during her engagement with the service.

I am hopeful that you will genuinely hear my concerns and that cultural change will take place regarding how Community Mental Health Teams work with and supports families and carers in the future.

The Community Mental Health Team have an ethical responsibility to ‘do no harm’. I found that deteriorated under the care of the Community Mental Health Team. As a family we hit rock bottom in treatment, and care and the public mental health system let us down. The status of mental health profoundly impacted her quality of life and her relationships, her ability to hold down her job, and her goals to go back to study horse care. As a family, we were all saddened and frustrated by the poor quality of care that received.

I am happy to discuss this further, and I have been reflecting upon solutions given the issues are largely systemic.

Regards,

Sharon Grocott

Recommendations for submission: Inquiry into and report on the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales.

The following recommendations are based on experience of being a carer of a beautiful and remarkable twenty-five (25) year-old young woman with a complex mental illness.

1. Continuity of care & choice

Under the public system, there are workforce issues including a high turnover of staff and this impacts the continuity of care. In teaching hospitals such as Royal North Shore Hospital (RNSH), it is not uncommon to see a different psychiatrist each time and to have to repeat your story. The Community Mental Health teams are under resourced. The staff are well intentioned, but they do not have capacity to meet the needs of patients due to part-time hours, high caseloads, and the high turnover. The experience of having four (4) different Case Managers in four months in the Community Mental Health Team is unsatisfactory.

The private system is also challenging in terms of gaining access to mental health specialists including psychiatrists and psychologists. For example, I found it almost impossible to find a psychiatrist with developmental disability knowledge and a psychologist with a specialisation in psychosis and cognitive behavioural therapy. The choices are very limited in Sydney, yet alone in regional areas.

There are limited specialists and very long waiting lists of 18 months + due to the shortage of psychiatrists and psychologists. We have experienced three (3) different psychiatrists in the private system in eighteen (18) months due to the challenge in finding a specialist with psychosis and development disability knowledge.

Recommendations

a) Improve staffing levels and resources in community mental health centres.
b) Address shortages of psychiatrists and psychologists with incentives and through promoting career opportunities and educational pathways.
c) Provide training and financial incentives for psychiatrists to increase specialist knowledge to work with diverse groups (e.g., disability, LGBTQ+, etc).

2. Cost barriers

Although a Federal government issue, the States need to advocate. The costs under the Better Access initiative through Medicare are prohibitive with only ten (10) sessions with a Mental Health Care Plan. Particularly in the case of conditions such as Schizophrenia, the number of sessions is inadequate.

The cost of a GP long consultation is too expensive and even obtaining a Mental Health Plan in the first place is prohibitive. We have spent thousands of dollars - our savings for retirement - on my daughter’s treatment. The prohibitive costs then impact the public system as more people become acutely unwell due to the lack of access to early intervention. Conditions then become more serious and take longer for people to recover with higher rates of hospitalisations. It is a vicious circle which could be prevented if the system keeps people out of hospital through affordable access to adequate treatment in the first place.

Recommendations

a) NSW Government to advocate that the cost of mental health care is impacting access to treatment. Advocate that the cap of ten sessions will leave many people not seeking adequate treatment.
b) Advocate the Better Access scheme and number of sessions should be based on the complexity and impact of a person’s mental illness on their life.

3. Access to medications & information

The Medicare Benefits Schedule (MBS) and the way that medications are costed does not make any sense. My daughter can only access certain medications under the MBS if she has a formal diagnosis of Schizophrenia. For example, Rexulti (brexpiprozole) is a prescription antipsychotic medication used in the treatment of major depressive disorder, schizophrenia, and agitation associated with dementia due to Alzheimer’s disease.

We discovered that she needs a formal diagnosis of Schizophrenia, or we will have to pay the full cost. Others with a diagnosis of depression do not have access to the same medication at the reduced price. The cost is $148.50 per month. No doubt, many people are not seeking treatment due to the costs of the medications. The costs are high even with the MBS, particularly when on various treatments. Many medications are not covered under the MBS, and we are paying huge costs for medications such as Melatonin ($60.00+ per month).

I was told by a staff member in the Community Mental Health Team, that “Olanzapine is always prescribed as it is the cheapest under the MBS despite all the terrible side effects.” The public system seems to be prescribing medications based on lower cost and not considering the impact on patients.

Recommendations

a) Although a Federal government issue, the NSW Government needs to lobby about the equity of the MBS system because this will have a flow on effect on people needing hospitalisation. In other words, if people are not taking medication due to cost, their symptoms can very quickly become unmanageable.

The other issue is that consumers and carers are not made aware of the side effects of the medications. My daughter experienced a range of terrible debilitating side effects such as excessive weight gain and feeling suicidal which was the result of medication such as Olanzapine and Rexulti. The side effects should be discussed before the medication is prescribed. I was savvy enough to seek out the information from our pharmacist. I also found the GP did not really understand the various anti-psychotic medications and the side effects. Although a great GP, this information does not seem to be readily available to GPs.

Recommendations

a) Training is need for health professionals (e.g., GPs) on the side effects of medications and for psychiatrists on the importance of disclosing information about side effects to patients and if appropriate to carers.

4. Alternatives to Emergency Departments: Safe Haven

There should be alternatives to Emergency Departments for people with an acute mental illness. More recently, rather than going to the Emergency Department, we made the decision to support my daughter at home despite her being acutely unwell. The decision was made knowing that we would sit in Emergency for 10+ hours. Instead, we managed acute psychosis at home for several weeks and we waited for a private psychiatric hospital bed for two weeks. We chose to do this, based on our previous experiences of the Emergency Department and public hospital system.

It is perplexing that we do not have Safe Havens that operate 24/7 funded across every region in NSW. We need alternatives to Emergency Departments that are peer and clinician led. The alternative of sitting in Emergency for hours on end or phoning the after-hours mental health team is not good enough.

The Safe Haven initiative provides a calm, culturally sensitive and non-clinical alternative to hospital emergency departments, for people experiencing distress or suicidal thoughts. We should have access to a Safe Haven in Northern Sydney. At present, my family have no alternative but to manage acute mental illness on our own.

For further information:

Safe Haven - Towards Zero Suicides (nsw.gov.au)

If we do need to go to Emergency, people in significant distress due to their mental illness should have a separate space and calming environment. It is not a good situation when you must stand in Emergency for several hours with no seats available with people bleeding, crying in pain, coming in with broken limbs, etc and your daughter is pacing up and down, having visual and auditory hallucinations and very distressed.

Training is also needed for hospital staff in Emergency. I was very surprised that staff did not seem to understand psychosis.

Recommendations

a) Safe Havens to be funded 24/7 in every region in NSW.
b) Separate waiting areas to Emergency also to be made available for people with acute mental health.
c) Additional training for Emergency staff on mental illness and the different conditions including psychosis.

5. Access to Inpatient Care

There are not many alternatives to public adult mental health wards. Access to private inpatient services is very costly and I recently discovered it is approximately $16,000 per week with an excess charged if covered by private health. My daughter is vulnerable due to her intellectual disability, and I do not feel the public unit is a safe environment for her. In fact, in the past it has been said by the staff at Royal North Shore Hospital that the Psychiatric Emergency Care Unit (PEC) is a safer place for her to stay in comparison to the adult psychiatric ward in Royal North Shore Hospital.

There are not many options available. Recently, we were fortunate to get my daughter into a private psychiatric hospital. The quality of care has been very good. We have been told that she "slipped through the cracks as the hospital would not normally take someone with such complex mental health issues." As for the future, we are very concerned about what will happen when she needs another admission. We had a twelve (12) day wait for a hospital bed recently, and I have had friends share that they have been in Emergency with acute mental illness for three (3) days due to the bed shortages.

Recommendations

a) There needs to be more alternative access to care within the community including mobile acute mental health teams that can support people to remain out of the hospital system.

6. Carer supports including NDIS

I found the Community Mental Health Team (public system) seemed unwilling to coordinate with the NDIS. Perhaps it was more the lack of understanding of the NDIS system. It has been two years since my daughter become seriously unwell and we have not had a change in her NDIS package.

The psychiatrists do not seem to understand how the NDIS works and even people within the NDIS system do not understand. For example, recently we appointed a Support Co-ordinator under the NDIS plan for my daughter. The co-ordinator was convinced that we just need an official diagnosis from the psychiatrist, while the Local Area Coordinator at Uniting was convinced this is incorrect and we need a functional assessment.

Staff at the Community Mental Health Team were unsure, and despite repeated requests for a letter outlining my daughter's condition, we didn't receive anything in writing. There seemed to be misunderstanding of how the Case Managers in the Community Mental Health Team can co-ordinate care with the NDIS support coordinators.

Recommendations

a) There needs to be further training for professionals operating in the mental health system on how the NDIS system works.

7. Family and carer inclusion

The staff in the Community Mental Health Team at RNSH did not ask about how my family was coping until 6 months after my daughter had commenced service. Finally, the Carer Gateway brochure was provided, and the question was asked "how was the family coping."

There was little interest in carer and family inclusion. This included the impact on my other daughter who was studying her HSC. There needs to be training on how to involve family and carers. We can monitor our loved one's mental health, provide practical support, assist with medications and receiving treatment, and of course provide emotional support. In some instances, family involvement is not always a positive thing, but in many situations the family or kin offer a safety net and support for their loved one with a mental illness.

The Open Dialogue Centre training would be very beneficial for professionals working across the mental health system. Open Dialogue employs principles that see every person as an active participant in their own care, with a social network which may include invited family, friends, carers, and supporters, in a setting where they feel safe and acknowledged. Open Dialogue enables people to navigate support without being locked into a defined treatment pathway. The training for mental health professionals across the public system would be invaluable.

For information:

About – Open Dialogue Centre

Carers also require training, for example on psychosis and how to support a loved one experiencing acute psychosis. Suicide prevention training tailored more towards carers would also be beneficial. My partner has no clinical background and yet he has had to step into being a 24/7 carer, leaving his employment and caring for his daughter who has been suicidal, self-harming and acutely unwell.

Recommendations

a) Training for professionals in the mental health system on how to be family and carer inclusive.
b) Appropriate training for carers on how to support a loved one who is suicidal, self-harming and in psychosis.

8. Integrated & holistic care

I have struggled to see an approach through our experience of the public mental health system, that is person centred. Instead, I have observed a medical model which was a ‘one size fits all’ approach. If a person is different due to disability, cultural background, LGBTQ+, Aboriginal or Torres Strait Islander, the mental health system is not individualised. The treatments and approaches are not adaptive and flexible.

We talk about person centred but the approach is the opposite, just like we talk about recovery and yet the treatment plans are only medical based. If peer workers were utlised more, perhaps this would change the culture and create a shift in the paradigm that currently exists – that of a *Western Medical Model.*

Training also needs to target GPs. My daughter’s GP is wonderful and very engaged in her care plan. However, many GPs need more training on understanding different mental illnesses and conditions. There also needs to be work around understanding psychosis.

I found that I lost trust in the system, and still today have little faith in the ability of the system to provide a holistic approach that is recovery orientated.

In the case of my daughter having Schizophrenia and an intellectual disability, I am told that there is little known on the effects that anti-psychotic medications will have on a person with an intellectual disability. Little is known about how the condition will impact functionality. It has essentially been like an experiment, with five different anti-psychotic drugs being trialled, each having debilitating side effects due to the sensitivity of having an intellectual disability.

More research is required and new therapeutic approaches to supporting diverse populations such as people with intellectual disabilities.

Recommendations

a) Workforce development is needed to upskill professionals to be able to work with diverse needs of individuals and families.
b) GPs need more training on mental health conditions.
c) Research and new therapeutic approaches need to be developed to support the needs of diverse populations.