

ADVICE TO THE COMMISSIONER FOR MENTAL HEALTH

Family Narratives – Getting the right supports for a young person with mental health and co-occurring challenges

June 2021

BACKGROUND

In keeping with the Mental Health Advisory Council's (Council) value of hearing from the most unheard voices and given the current focus on improving responses for young people in the mental health system, the Council invited a number of family members of young people who have experienced mental health challenges, many with co-occurring issues, to the May 2021 Council meeting. The intention was to listen to their experiences and suggestions for improved service responses. The young people at the centre of concern range from 13 to 20 years old. They include young people with a range of co-occurring conditions including Attention Deficit Hyperactivity Disorder (ADHD), neurodiversity, suicidality and alcohol and other drug use. Some young people are part of the LGBTIQ community.

While this Advice is lengthier than what the Council generally prefers to provide, the intent is to provide direct narrative from the family members, for which they have given permission. In this way, their voices are heard and recorded.

Lack of effective services for young people with co-occurring neurodiversity

A number of the young people at the centre of concern have diagnoses of autism. Family members reported that they found it particularly difficult to find services which would accept referrals, let alone access to appropriate treatment and support.

"I got a referral link to CAMHS [Child and Adolescent Mental Health Service] and my paediatrician had told us that it would be unlikely that we would get support through there because of his autism diagnosis, which actually shocked me. I couldn't believe that was a thing. We had a phone call, it took months and months to get into the program, and I told them what I had been told and I asked if it was true that this would be an issue. It was unanimously a yes, it is going to be an issue going through CAMHS with an autism diagnosis. I asked CAMHS if it would be an issue and they said yes, it would be".

"CAMHS through the whole thing kept saying that if it touches onto autism, then we're out.

I kept saying I don't want you to do the assessment, I've got this whole pathway coming for the assessment. I want you to help the fact that my kid can't stay alive".

A number of family members reported misdiagnosis of young people with autism with a diagnosis of Borderline Personality Disorder (BPD). The recommended treatment for BPD is often group therapy which is particularly difficult for young people with autism.



Impact on the whole family

The family members spoke of the heightened, ongoing distress and anxiety experienced by other family members, including siblings and grandparents, as a result of the stress of repeatedly and often unsuccessfully trying to get the supports the young person needed. Extended family members were often actively involved in supporting the young person to access treatment, care and support and also stepped in to prevent further harm when ineffective discharges from care were made. This all takes a significant toll which is congruent with evidence around the caring experience.

“Just recently, we had a grandchild attempt to take her own life. She was taken to hospital and basically told, “Go home until we find you a spot in a mental health unit in one of the other hospitals”. If it wasn't for her sister who's only 24, I think our granddaughter would be dead by now because she had to advocate to keep ringing and ringing. They lost the referral. It was just disastrous and if it wasn't for her sister keeping her alive, I don't think she'd be here today.”

“So, it's a long road and it takes time and sometimes we just don't have time. That's the thing, months of no treatment and no action, it's a long time for a family to try to support an individual. I think that's the thing, you feel isolated and it's hard going”.

Some family members also spoke of the stigma and discrimination they experienced as a family member of a young person with alcohol and other drug issues.

Lack of inclusivity and diversity

Family members reported that practitioners undertaking assessments rarely recorded an accurate or comprehensive family history. This meant that the needs of other family members managing mental health or other conditions were not identified or taken into account when organising treatment, support and care for the young person. One family reported the lack of account taken of their father's experiences of PTSD sustained while a veteran and the impact that increased distress within the family had on his mental health. For families with members in the LGBTIQ community, this was a particularly important consideration given the existing higher rate of mental distress and self-harm already experienced by people in these communities.

Culturally secure approaches were not often experienced.

Services which offer access to learned and lived experience

Family members spoke of the value of receiving education and support from a range of practitioners and peer workers. Peer workers with similar experiences were helpful in supporting family members to develop more effective responses and find more effective pathways where such existed.

“Hopefully lived experience, or that knowledge partnership between lived and learned experience, between people who get it. How much of my helpline phone call am I trying to get you to understand where I'm even at before you might help me? Which phone line do I call?”.

RECOMMENDATIONS

Given the above, the following recommendations were offered by the family members:

- Services, clinicians and practitioners need to listen to families and adopt a family-inclusive approach to assessment, treatment, care and support;

“Ask us and trust us, we're not actually hanging out in emergency rooms for fun. People weren't listening, people weren't even asking about family history. People were assuming it was behaviour or choice”.

- Adopt an increased focus on and availability of a range of therapies, as distinct from medication;
- Implement and monitor strategies to reduce stigma and discrimination particularly for families where there are co-occurring alcohol and other drug issues;



- Development of services, including an emergency helpline, where staff have an understanding of autism, ADHD and mental health, rather than having these conditions treated as separate issues by separate agencies. This could also mean having one core worker who would co-ordinate the services needed by the whole family. This would also potentially enable data to be collected about what outcomes are actually realised. At the moment, there is minimal data available on what the outcomes of referrals are which means that people fall into the gaps if the referral is lost, not accepted, inappropriate or if there is no effective follow-up. There was significant appreciation when a practitioner was encountered who took on the service navigation and referral role effectively.

“We got referred to the Midland family service and we had one case worker who then directed us through different services. And she followed us through the whole way. And that was really great because it was one person, she knew our family. Then I didn't have to repeat this story. That was really important as well and she got us referrals into counselling services for my younger son to help him and support him through this journey as well and even for myself, so I think that was really good”.

- Access to consumer and family-carer peer support workers;

“We were 3 months in before I found out that some of the ways I was responding was actually hindering her, not helping, and only because MIFWA's [Mental Illness Fellowship of Western Australia] Building a Future course connected me with people with lived experience who said, you know what? Just validate. Stop trying to convince her that her view of the world is wrong, even if you have like factual evidence that she is wrong, just validate and if nothing else, you can say, “I know”, because you're not saying she's right, you're just going, “I know”. Of course, you know. She feels trapped. No one had helped me know how to help her”.

“Can I just say, all I wanted was someone to take me and give me a cup of tea. Take me for a cup of tea when they were pumping my daughter's stomach because she'd overdosed”.

- Improve training and supervision of clinicians and other practitioners, to work effectively with young people with mental health challenges and neurodiversity;


“So, they've actually found her what we call the Unicorn, which is an autistic clinical psychologist with experience also working with autism and at the very first appointment, we walked in, she said: ‘Now tell me about the environment. What's working for you? What's not working for you. Here's how I speak, what do you need?’ We did what I consider a working together agreement and she got it. The difference when we can work with people who get it, it's amazing”.

“I don't need services that help my kids or me with our disabilities, but I need services who know how to work with us because of our disability”.

- Access to family-inclusive practice and appropriate family therapy models and practices. It may well be the case that other family members are also experiencing mental health challenges or life struggles. The family therapy offered needs to take this into account and above all, ensure that it is practiced in ways that maximise whole-of-family safety;

“None of us were safe to be at family therapy (with CAMHS). We had one appointment that was just even myself and my husband and it got quite emotive, and then they went cool, bye see you next week. I went home in a very emotional and unsafe situation and at that point I was working full-time and everyone had to just not talk to each other until I got home. I'd get home, and everyone was in their own cave”.

- Continuity of care is critical to minimize the retelling of traumatic experiences and to allow trusting relationships to be developed;



“My daughter had finally found a psychologist who was helpful with a youth focus and then she went into a private clinic where the youth focused psychologist wasn't allowed to speak with her anymore, so she lost the one person and private clinics don't do one-on-one so all they do is medication and grouping. So sure, she was in a theoretically safe environment that wasn't actually, but also, she had nothing to help her anymore. So, continuity of care across environments so we don't just keep losing our services. When we finally do find someone, and I love the idea of the separate service, but I want all services to be able to do it”.

- School counsellors and nurses need to be a more integrated and readily available support for young people who may hesitate to access external services. Initiatives within schools which support young people with mental health and other challenges should also be identified and expanded to ensure access post transition from school; and

“Baldivis School, they were amazing, and it was actually a youth support worker from Rockingham City Council that was engaging with Baldivis School and the amazing work this young girl did with my grandchild, was incredible. But, then my grandchild, got that unwell that she couldn't go to school anymore, so she lost all of that. She lost all of that hard work of that youth worker and you know things went really, really downhill whereas when she was engaging with this youth worker things were much better, yeah, and they were wonderful.”

- Services need to have clear, accessible and responsive feedback mechanisms.

“I'm going to name because it's positive. Rockingham Hospital, so when my daughter was transferred to a community service and we had some concerns and we had a formal complaint process. One of the things that they've come back to let us know that they're changing is that they are introducing two peer support work positions to be with families, both inpatient and outpatient through the whole journey”.

The Council supports the above recommendations. It also recommends prioritising the implementation of the establishment of a specialised state-wide service to meet the needs of people with co-occurring mental illness and intellectual, cognitive or developmental disability (including autism spectrum), as in the Western Australian Mental Health, Alcohol and Other Drug Services Plan Update 2018 – 2025, p70.

Sincerely



Margaret Doherty

CHAIR

Mental Health Advisory Council

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