Submission
No 117

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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I am a 58 year old, queer, Anglo-Australian woman living in Bathurst, NSW. I have been unable to work and receiving disability pension for about 12 years due to my persistent mental illness. I also have hypermobile Ehlers-Danlos Syndrome, ADHD, and autoimmune hypothyroidism, all three of which were diagnosed during my 50s, despite my having clear symptoms of h-EDS and ADHD since early childhood.

These are some of my experiences of outpatient and community mental health care since moving to Bathurst in late 2013.

For context, there are quite a few psychologists, counselling social workers, and other counsellors working in Bathurst in public health and private practice. There is only one psychiatrist in private practice in Bathurst.

In 2015 I was referred by a social worker in community health to see a psychiatrist through community mental health at Bathurst Base Hospital. The nurse who admitted me to community mental health asked me a number of questions about my state of mind, how I spent my days, etc. When I said that I was studying a Cert IV in Mental Health at the local TAFE, the nurse said that it was good that I was making an effort, unlike a family member of his who just sat around all day doing nothing because of depression. That was inappropriate and it distressed me to hear a mental health nurse be so judgemental.

When I saw the psychiatrist, I was very worried that he would either tell me I was being silly and there's nothing wrong with me, or that he'd see how disturbed and full of self-loathing I was and commit me to involuntary hospitalization. I was more afraid of being scheduled, so I tried to appear "normal", didn't say I'd been cutting my skin to externalize the emotional pain I felt, and didn't say that I often wished I could stop existing, and sometimes planned how I could end my life. The psychiatrist noted that I was able to speak coherently, and talked about my hopes of being able to work again some day. He wrote to my GP saying that I was recovering well from depression and would benefit from finding suitable work. If the psych had asked me how I felt about seeing a psychiatrist, and talked with me about the difference between self-injury, suicidal ideation, and actually attempting suicide, I might have been more open about how distressed I often was.

As an outpatient, I attended the day program at Bathurst Hospital Panorama Clinic on & off between 2014 and 2018. The day program had informational and skill-development sessions in a rotating six-week program. I mostly went to sessions co-run by a psychologist and a social worker, who were both good at group facilitation and helping people explore the topics such as distress tolerance, communication, etc. One session I went to was run by a psychiatric nurse, who said that anxiety was a symptom of depression; he didn't acknowledge that people can have an anxiety disorder without being depressed.

Sometime in 2017 my sister (who lives in Darwin, NT) rang an ambulance because she was concerned that I was at risk of seriously harming myself. The ambos who came to my home were fine. One of them didn't interact with me much, the other was very kind and non-judgemental, and she persuaded me to let them take me to Bathurst hospital. At the hospital, I waited in a "safe room" which was empty except for a couple of vinyl covered mattresses on the floor, and a poster high up on one wall. I felt very isolated and scared. I had been feeling anguished and was visibly distressed when the ambulance arrived. By the time the on duty psychiatrist saw me in the safe room (I assume he was a psychiatrist, he said his name, and that he was there to have a chat with me) I was very shut down, really not wanting to be admitted to hospital. I tried to talk normally when the psych asked what had been happening. I said that the state of the world was getting to me – the No campaign about the marriage equality plebiscite was so hostile, and the government and people generally seemed so ready to scapegoat anyone different from themselves. Somehow we got onto the topic of the Conservative government in Britain closing public libraries, and this psychiatrist (who was originally from Britain) said that it was UK Labour's fault too. I can't remember what I said in response, just avoiding disagreement, and he said I was fine to go home. I was not fine, he was not helpful, but I went home and rang my sister.

In the 9 years I've been living in Bathurst I've seen a number of general practitioners at a private practice in town, a couple of whom were also lecturers teaching medical students through a university. All of the GPs I've seen have had a tendency to underestimate my levels of mental distress, because they only saw me when I was able to get myself to an appointment, because I spoke coherently, and because (I now realise) I was unconsciously masking my real feelings and not saying what I really thought, because I was afraid of confrontation.

Only one of the several psychologists, three psychiatrists, several GPs, or two social workers who have seen me (all but the psychiatrists on multiple occasions over the years) have asked me basic questions like how often do I shower, how often do I cook and eat a meal, am I managing simple household tasks like doing laundry, do I have any friends who I can talk to when I'm distressed. Less basic, but relevant for me, it would have helped if someone had asked if the amount of clutter in my home was a problem for my mental health or physical safety.

One time when my then GP was reviewing my mental health plan, she used the K10 to assess me (then a policy of that medical centre). I asked if it would be better to use something like the Depression, Anxiety and Stress Scale, which is for people with ongoing mental health issues, rather than the K10, which is a simplistic diagnostic tool, and she said it was just for the paperwork. I wasn't confident enough to say "I thought it was so you would know how I'm going".

Doctors (and dentists, maybe not covered by the scope of this inquiry, though it includes supervising dentists at the public dental clinic at Bathurst Hospital) have been dismissive of my physical health issues if they know that I have chronic anxiety and depression. Dentists have often dismissed my salicylate sensitivity (confirmed by RPA Allergy Clinic) as anxiety when I say that mint flavouring in fluoride treatment will cause a bad reaction (not anaphylactic, but gastrointestinal symptoms), and doubted me when I told them that I need extra local anaesthetic and I metabolise it quickly (both of which are common in people with Ehlers-Danlos Syndrome, which I have).

It took a couple of years of distinct symptoms of hypothyroidism before one doctor tested for thyroid antibodies and referred me for a thyroid ultrasound, instead of just testing T3, T4, and TSH, and telling me that the numbers were only slightly abnormal, and my fatigue, confusion, constipation, decreased appetite, feeling cold, and occasional weeks of insomnia were caused by my mental illness. The extra tests confirmed that I have autoimmune hypothyroidism. It took another 10 months of asking doctors to treat my symptoms and not just look at the test result numbers to get to an effective dose of thyroxine.

A clinical psychologist who I had psychotherapy with for a couple of years ignored my questions about having an assessment for ADHD and my then GP told me to be guided by my psychologist. After a couple of years of having NDIS support I trusted my own judgement more, and had the mental stamina to search for a psychiatrist who assessed adults, particularly women, for ADHD. After assessing me through a lengthy standardized questionnaire about my behaviours and experiences from childhood until the present, and interviewing my older sister, the psychiatrist diagnosed me with combined type ADHD.