From the Perspective of a Family Member – The Challenges of Dealing with the Victorian Mental Health System

I would like to share the story of the challenges my mother and myself had when trying to seek treatment through Area Mental Health Services for my brother. At the time he was 18 years old and experiencing a first episode of psychosis, with co-occurring substance use disorder.

My mother took my brother to the emergency room many times over a period of months, she estimates that there were around 20 visits to E.D across 2 different cities. I would like to emphasise that my brother was going willingly and was open to receiving help as he was experiencing symptoms that were distressing to him. They were repeatedly turned away, being told that the symptoms were 'just the drugs', and/or, my mother was advised that her parenting needed to be stricter, as though that would somehow fix the psychosis. Regardless of what the origins of the symptoms were, the fact was that they were occurring, and were causing a risk of harm to himself. He became reckless, seemingly unaware of his actions or the danger of the risks he was taking. He expressed a lot of strange ideas to his friends and got into a lot of arguments. As a result, nearly all his friends turned their backs on him and did not understand why he was suddenly like a different person. He would tell us later that he had been hearing voices, seeing things, but had found this difficult to articulate at the time as it had seemed very real. He was only admitted to hospital after several significant overdoses and other disasters.

I remember trying to speak with a clinician from the youth early psychosis program and explain that we needed help for my brother because his behaviour had changed completely and he was not the person we knew. I gave some examples, such as the fact he has never been an aggressive person, and on a particular occasion, he became afraid of me due to paranoia, and responded by being threatening me with a butter knife. This person on the other end of the phone appeared not to want to listen to me, and tried to tell me that my brother has probably changed to become a violent person now, due to having been attacked by another relative in the few months prior, who was also using substances. I feel this explanation was a bizarre and illogical one, and essentially what it meant was this, that 'I don't have time to speak to you, your relative isn't sick enough to warrant help, and so whatever is going on with him is some other problem that has nothing to do with me.'

It is unbelievable that someone can be open to getting support, asking for help, be a risk to themselves, and their family is asking for help, and yet, they are still turned away. Even though people may meet the criteria for needing mental health care, they can still be turned away. This doesn't happen with to anywhere near as many people who present to services with physical health issues. It was only after significant damage was done in several aspects of my brother's life and he became a lot more unwell that he was considered sick enough to warrant help. The system could be improved significantly by doctors and clinicians listening to families/carers when they seek help. This is part of standard practice and families/carers

have a right to be heard, to receive information and support under the Mental Health Act, and yet there rights are only upheld and respected sporadically.

I think this kind of response is firstly indicative of a severe lack of resources being allocated to mental health care compared to physical health care, which is much worse in regional areas like This results in decisions about whether a person will be provided services being based on what resources are available and not about whether a person needs help. Secondly, it is indicative of some issues with the culture of mental health services, a culture that can be discriminatory again people with a dual diagnosis of mental illness and addiction. I work in public mental health myself now, predominantly supporting families and carers, and have heard many similar stories to my own. A common theme is that families take their loved one to get help because they are experiencing symptoms of mental illness (usually psychosis and mood instability) for an extended period of time, not just while using substances. However, when the family and consumer come into contact with mental health services, the symptoms of mental illness are dismissed and blamed on the person because of their drug use. It is common knowledge that mental illness and addiction are not mutually exclusive, and mental health workers should know this better than anyone.

It is important to note that this culture problem is much more pronounced in emergency departments compared to inpatient psychiatric wards and community mental health teams. It is not unanimous among every worker, there are many clinicians who are knowledgeable and sensitive. But when this prejudice does occur, it can have serious consequences for the person and their family. Consequences that are preventable.

The deeper message of these incidents, I believe, is that our government does not care about people with mental illness, or their families and carers. They don't see it as worthwhile to provide better training, education and support for the people working in mental health services, and for the general public who continue to have harmful misconceptions about people with mental illness and/or addiction. Our leaders don't see it as worthwhile to provide adequate resources to the system which could to enable workers to offer support to people when they need it, rather than having to turn them away, sometimes without a meaningful alternative, because there simply aren't enough resources to go around.

It is very important to note that significant financial resources are also needed for early intervention and support. Of course hospital is not the only or the ideal intervention for mental health crises. If people are better able to access various supports earlier on in their experience of mental ill health, then they would be much less likely to reach crisis point that requires hospital admission to contain. There would be less suicides and deaths by misadventure. But preventative and early intervention supports are often expensive and/or difficult to access, with criteria that keep many people out and long waiting lists. Our system is a reactive one, and this is producing poor outcomes.

The NDIS has made this problem significantly worse by removing all the funding that non-government mental health organisations (such as Mind Australia and Neami) had to provide support to people with mental illness, and redirecting these funds to the NDIS, which does

not adequately serve mental health clients. In fact, the majority of our public mental health consumers, often with severe and enduring mental illness, are being rejected by the NDIS! All funding that was cut must be reinstated and increased, so that community programs for people with mental illness can grow. These funding changes have been devastating for families and carers as well, as the programs that used to support them in their caring roles have also been cut back significantly as they don't fit neatly into an NDIS package and therefore are no longer funded. This funding must be reinstated.

On the note of family and carers, some ways to better support them and their needs would be increasing the financial support available to them. Accessing carers payments through Centrelink must be made less difficult. Currently the criteria are so tight it is close to impossible to access benefits, and carers (who are mostly women and often have to reduce or stop paid work) suffer financially and struggle to make ends meet. Increasing funding for and accessibility of low cost family counselling, respite, and peer run carer education programs (these should focus on understanding and responding effectively to mental illness in a loved one, teaching carers to look after their own wellbeing, and setting boundaries). Increasing the amount of affordable and public housing could also be of benefit both consumers and carers, by helping consumers to gain independence, and carers to support their loved ones while still being able to live their own life.

In summary, increasing public education, early intervention, increased carer support, psychosocial support services to engage people in their communities, better training for mental health workers, and better resourcing for public community mental health clinics and inpatient psychiatric units could improve the mental health of Victorians.