

# 2019 Submission - Royal Commission into Victoria's Mental Health System

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## Name

Ms [REDACTED]

### **What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?**

"The more people who speak openly, the better. Sportspeople, politicians & celebrities are being increasingly open but it needs to happen more. Instead of "taking time off due to mental health issues", they could provide more specific information so that mental health is no longer surrounded in a fog of mystery. Eg Neal Danaher is very open about MND. Arthur Sinodinos was open about prostate cancer. There are countless examples where specific diagnoses are provided. So, "xxx sportsperson has to take time out of the game due to suffering from depression and anxiety" would be more helpful. Or, "xxx politician needs to take sick leave in order to treat schizophrenia". As families, we also need to be more open. I always compare my reaction (and the community's reaction) to the situation if my son had cancer instead of a severe psychiatric condition. There would've been queues of people visiting him in hospital and we would've received community support. But there has been a deafening silence (with the occasional exception)."

### **What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?**

"Headspace is a wonderful service. When our son was 20 and suffered first episode psychosis, Headspace saved us. We had no experience of mental illness and had no idea of what to do. Headspace provided an accessible, non-judgemental, team service. The office is new and fresh which is important. It gives us the message that in this place, mental illness is important and worth investing public funds in. The staff have been caring, warm and professional. Our input as parents has always been encouraged and valued. The involvement of a drug & alcohol counsellor was crucial and probably should have occurred sooner. The provision of a family support counsellor has been so important. Knowing that she is available at the end of a phone, is crucial. We do not feel alone. Ways to improve Headspace: 1. Increased staff. Mostly the appointments have occurred quickly after an episode or request but not always. Last year, our son had taken himself off antipsychotic medication and reacted badly to the new one. I requested an urgent medical review. Due to the unavailability of a doctor, we waited approx 10 days. We understand that they had to prioritise their cases and make difficult judgements. But on day 9, our son suffered a major psychotic episode and then spent the next 6-7 months in the [REDACTED] Psych Ward. His illness progressed to a much more severe & treatment resistant form. He still hasn't come home and his chances of recovery are now very slim. I weep as I type because we will never know whether the slide into a more severe form of psychosis/ schizoaffective disorder could have been prevented if he was seen sooner. 2. Increased continuity of staff: We have seen more psychiatry consultants and even more registrars than you've had hot dinners! After about 18 months and numerous registrars, we requested that our son have consistency through a consultant. This provided continuity for a while but there is churn amongst the consultants as well. At one stage, we lost our consultant and original case manager at the same time. I acknowledge that doctor education is

necessary but turnover of registrars is too high both at Headspace and in the acute setting. We have got to the stage where we do not bother to form a relationship with the registrars and yet it's the registrars who do more of the communications with the family. The current system does not serve the needs of the young people with severe mental illness. Each time a new registrar commences, we lose weeks as they require time to get to know our son. I believe that the situation is different to physical health problems where registrars can probably look at objective data and understand the patients' needs more quickly. The above applies to the [REDACTED] Hospital acute ward also.

1. Lack of staff The nurses are incredible human beings who do one of the most difficult jobs imaginable. They face risks to their personal safety while carrying heavy workloads. Almost universally, they do so with patience and respect for the patients. They are professional, knowledgeable, observant and caring. However, there are gaps in the service. Unbeknown to us, our son spent about 1,400 dollars on twice daily food delivery. He avoided washing for days /weeks because nursing staff lacked the time required to gently persuade him into the shower or monitor whether he had showered or not. He thought he had lost belongings for weeks when in fact they were in his locker or in a bag in his room. He was too unwell and disorganised to remember where the items were. We did not have access to his room (which is sensible) but it meant that he relied on staff to follow things up and they didn't have time to do so. After a few readmissions, we reminded staff to conduct drug screening urine tests. The sooner the test is conducted after admission, the more accurate the results. Recently, there was a 5 day delay rendering the test results meaningless.

2. Lack of continuity of staff Registrars Our son was discharged from the [REDACTED] psych ward two days after Christmas. He had been there since November 15. The registrar commenced on the ward and made an assessment based on our son's apparent increased level of self care. I tried to explain that his father and sister had washed and groomed him on Christmas day. I questioned my son's readiness for discharge to PARC where he has to live, cook, shop and care for himself. My views were disregarded. The short stay at PARC was an utter disaster and his condition deteriorated until he was readmitted to the [REDACTED]. He was in the [REDACTED] for many months after this so the opinion that he was ready for discharge was obviously flawed. We felt that our son was simply discharged to free up beds and this put him at unnecessary risk. There has been a high turnover of other allied health professionals including social workers and Occupational Therapists. At each family meeting, there would be more new faces. It seems there are challenges in staff retention in mental health. The paradox here is that we are regularly told that health professionals form their view on our son over a period of time, and yet churn means that the this process is repeated again and again."

### **What is already working well and what can be done better to prevent suicide?**

"Suicide risk has not been an issue for us so far. It seems that in the High Dependency Unit at the [REDACTED], there are suicide prevention protocols in place which are strictly adhered to."

### **What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.**

"There are gaps in the system: Headspace is great but is only available for young adults. We are apprehensive about what will happen after our son outgrows Headspace. There is also a gap in services for the severely mentally ill where they cannot be cared for in the community by Headspace-type services. Their behaviour becomes too difficult or dangerous to manage at home. So, they are set up for failure. We wait until they get sick enough to be admitted to an acute setting and we hope that they don't do damage to themselves or others on the way down. It seems since

the institutions closed in the 1980s, a gap has remained for people who are not well enough to care for them selves or make good decisions. Our son is fortunate to have a place in a supported accommodation with 24 hour monitoring and medication supervision. Medical support is provided. But he has been yo-yoing between the [REDACTED] facility and the [REDACTED] acute setting. He stabilises in hospital so he is discharged. Then he has the freedom to come and go at [REDACTED]. It appears that he is accessing cannabis which worsens his mental state and then he returns to the [REDACTED]. It seems that there needs to be a facility where he is locked up but is a more normal environment with supports to encourage independent living and recovery until the patient has sufficient insight to not engage in risk-taking behaviour. We have learned that even with all the goodwill in the world, we cannot rely on the mental health services. As parents, we have learned that we need to be assertive and to advocate for our son. He was in the [REDACTED] for months in a holding pattern with no planned change to the treatment. It was not until we made a fuss, that our son attracted the attention of the experienced consultant and a new treatment plan was instigated. All the services that are part of [REDACTED] Care are connected electronically and organisationally. However, we have observed that we can never rely on any staff member to have read our son's file or be familiar with previous treatments. At Headspace and at the [REDACTED], there were family meetings where professionals were asking us about which meds he had been on previously when the history was recorded in his file. It seems that agencies only have the time to deal with what's in front of them rather than read through the histories. We were grateful to a particularly compassionate registrar at the [REDACTED] who took the time to comb through our son's entire psychiatric history of more than 2 years to formulate a summary of medications."

### **What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?**

"Some areas of Victoria don't have access to Headspace. Apparently, in the growth corridors, there are waiting lists which is entirely in appropriate. "

### **What are the needs of family members and carers and what can be done better to support them?**

" Three out of four members of our family are sick/disabled. My daughter and myself suffer from a complex physical illness which leaves me bedbound most of the time. My husband is a carer for three people. Yet, we don't qualify for any support. I don't have any family in Melbourne. [REDACTED] Carer services kindly organised some short term support to ease the stress on my husband. 12 x 2 hours of cleaning & meal preparation made a world of difference but it was discontinued at the end of financial year. Some domestic support would help! Headspace provides a family counsellor who does home visits which is brilliant."

### **What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

Maybe pay them more and make their jobs less stressful and better resourced? Something has to be done to reduce the churn in the mental health workforce. Having to start over with new staff repeatedly is inefficient and less effective and discouraging.

### **What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?**

" So far, we have observed our son temporarily recover sufficiently to resume socialising and

some study. However, each recovery phase has been followed by another psychotic episode which have left him more seriously ill. He is only 22 years old but his chances of normal economic and social participation seem remote. If he does become well enough in the future to work, it would need to be in a supported and undemanding environment. Unfortunately, the unskilled jobs are disappearing."

**Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

" A whole layer of service provision in the mid level between Headspace community care and hospital acute care. Perhaps we still need institutions with transparency and oversight that are not institution-like. [REDACTED] in [REDACTED] is a wonderful facility. But for those who are not yet well enough for freedom to wander the streets, maybe a step-up facility that is otherwise similar. The village of units is very normal and non-institutional. The staff seem skilled and available. We hear of instances like our son where their future is to be either in hospital, on the streets, or in prison. Having prison as the last refuge of the mentally ill is not just expensive, but arguably barbaric."

**What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

Increase funding for mental health.

**Is there anything else you would like to share with the Royal Commission?**

N/A