

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

SUB. 0002.0028.0437

Name

[REDACTED]

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

"I am a mother and carer to a son, 23 yo who has a diagnosis of Schizophrenia. When our son was initially diagnosed at 16 yo with a psychotic depression / first episode psychosis we were in a state of shock and grief/ denial. My husband and i were both working as mental health professionals in the service he received treatment. I will never forget how i felt walking away and leaving my young son on an adult mental health ward as there were no youth specific beds available. He later told me that he thought he had gone to hell. We felt completely powerless and that his care was completely out of our hands, and in fact i was asked by a psychiatrist what we had done that had contributed to his mental state. No body asked us how are son was, or how we were. Your Family and friends do not understand or know how to respond to mental illness , there is a lot of stigma and limited knowledge, understanding. And honestly until someone has has their lives touched by mental illness you can not understand. My hope is that other mothers will never have to endure knowing their beloved child, who you have given life too wants to end their life as they can no longer endure the torment. Lack of education and understanding is what breeds stigma. Certain diagnosis like Schizophrenia particularly are viewed negatively as there is little public education . The system currently is not strength focused but illness focused. Our wards also contribute to the stigma (i speak from personal experience at [REDACTED] and [REDACTED] wards) are dark depressing ,over crowded spaces that are in desperate need of renovation, light and redesign. Patients do not feel safe or that they are are place to recover. I believe that wards being as they are in this current states only add to this discrimination and stigma towards Mental illness.

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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?

"We are very lucky to have been linked into Headspace and i can not speak highly enough about their service and particular the [REDACTED] program at [REDACTED]. My son feels well supported there and has amazing clinicians who care for him. The peer , lived experience workforce there makes a huge difference and has had a positive impact and connection with my son. The lived experience workforce model has had a very positive impact in services and the understanding and connection and rapport that develops through shared life experience is just amazing and very effective. Early treatment and support will be sort by individuals when a service is welcoming and inclusive and when spaces are appealing and feel safe. If you do not feel that a ward is going to be safe why would you want to go there ? I've worked in mental health for over 10 years with many many clients. A consumer will not seek help if they do not have relationship and connection with their workers. Or if they are fearful of being put in hospital in a ward where they do not feel safe or supported. Shared overcrowded wards with consumers of many ages and complexity and chronicity will never make anybody ever want to seek help if this is the only option. The lack of youth or women only beds in Victoria are also a huge problem. My son during his first admission

experienced a sexual assault that he refused to report due to embarrassment and fear of reprisal and a fire on the ward when a patient in the room next door set fire to a mattress. "

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

"I believe the Headspace model works extremely well. For us this model has lowered his suicidal ideation. My son feeling supported and making contact with his clinicians when he feels unsafe has lowered his risk and desire to end his life. I believe we need models like this for the adult community. The PARC model is extremely effective, as often a step up from the community to some support, where a consumer feels welcome and safe can be the difference needed, it doesn't always have to be a hospital admission. Peer workforce and presence in ED departments could also make a huge difference. Better follow up on discharge from hospital also . "

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.

"Loneliness and isolation only worsen stigma and negative symptoms. We need to treat Mental illness holistically by looking at the whole person- not just an illness. Everybody needs to feel a purpose and be connected. We all need to build on our strengths and seek support for what we struggle with. A mental illness diagnosis does not change our basic human needs and rights. When a service is stretched, when they are not welcoming, when waits are long and not even a glass of water is offered, when case managers have no capacity to make anything other than limited contact and there is no relationship, when consumers are lost to follow up or wait weeks and weeks to be seen, when workers change constantly and you have to tell your story over and over again, when you don't get called back or feel listened to or able to input into your own treatment - why would you willingly go?"

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

I think lack of service in regional areas is a contributing factor.

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

"Families and carers need to be welcomed and included in discussions and treatment planning for best outcomes and whole family recovery. Mental illness doesn't just happen to the individual but the ripples affect us all and trauma is often vicarious. If a service can offer specific carer support (practical and emotional)and help to educate and equip those who support and care for the consumer we can achieve so much more for that individual. With everyone working together for the best outcomes. Carers need to be heard , to be able to freely give and receive information. Also if services are non inclusive they miss out on vital information and expertise about the consumer from those who know them best. "

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

The mental health workforce and particularly the lived experience peer work force need more ongoing training and supervision opportunities. More carer peer worker training is needed as much that is currently offered is consumer peer worker focused. Pay awards need to be addressed as

the majority of these roles are part time and low paid.

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?

"Closing the day programs, drop in centers (like IMPACT in Oakleigh) in Victoria a number of years ago has had a disastrous ripple effect and nothing has replaced them. A lot of these programs were what kept individuals well in the community- routine, purpose, structure, friendships, new activities to learn together ect. Consumers have struggled with loneliness and isolation ever since. We need more of these programs and a headspace model for adults. A lot of consumers have common needs and issues with socialization and day programs really helped with these, NDIS has not been rolled out or implemented successfully, we have waited more than 6 months for our first meeting for support coordination. There is strength in peers and leaning together, NDIS is an individual package."

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?

"We need to focus on a recovery model that is person centered not a illness led and crisis model that is under funded, unsatisfactory and unsafe. We need more youth and women specific beds in Victoria. We need wards that are spaces that focus on and lend themselves to individual recovery. Bright and pleasant places with outdoor areas that can be accessed. "

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

"Rethink, restructure, redesign and rebuild. we need to involve consumers and carers in this discussion."

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

I was previously a mental health support worker and i now am employed as a carer peer worker and carer consultant as i desire to use what i have gone through to help others. Having a child diagnosed and become a part of the mental health system has honestly been the hardest thing i have ever endured and the grief at times is just crippling. Being at times excluded from treatment planning and decision making and having critical health information about him withheld from us (when he was under 18 mind you) has made this even harder. Seeing my young son hurt in this system has been heart breaking and we need change. We need all consumers to be safe. I was previously a mental health support worker and i now am employed as a carer peer worker and carer consultant as i desire to use what i have gone through to help others. We need a system that is better for all.