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

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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"I think this question is peripheral to the urgent issue of chronic under resourcing of the mental health care system. It also is a longer term issue that is intertwined with cultural norms. Our approach needs to be much broader than 'mental health literacy'. I would address this by encouraging people to be more inclusive, kind and compassionate to each other in general. "

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?
"I received no meaningful, helpful preventative care. Numerous times actually I've been turned away by practitioners or services that either deemed my symptoms to not be serious enough or the service lacked the resources to respond. Prevention All three of my psychotic episodes were preventable. In the lead up to each episode I displayed insight and help seeking behaviours including: 1) seeing a psychologist, GP and asking for a referral to a psychiatrist in the lead up to my first psychotic episode. There was a 28 day waiting period to see the psychiatrist 2) calling the [redacted] CAT team myself 11 times before my second episode. The CAT team did not visit me to undertake an assessment until my parents called them 3) admitting myself to the [redacted] Clinic for treatment 7 days before I was sectioned for a third time. The [redacted] Clinic was negligent in not correctly assessing my condition or providing treatment for mania during my 7 day stay. Solutions The psychologist and GP should have had the training to recognise that my presentation was an emergency and organised an urgent psychiatric referral. The CAT team should have assessed me and linked me to effective treatment. Safety and Quality at private mental health facilities Before my third psychotic episode, I admitted myself for treatment to the [redacted] Clinic. The [redacted] Clinic discharged me into the community against my repeated requests to stay, and two days later I was sectioned at the RMH for a two week period for a psychotic episode. "

What is already working well and what can be done better to prevent suicide?
"Some individual practitioners, usually in private practice, are exemplary. They are, however, often inaccessible due to private billing with unaffordable gap fees, and have long waiting periods. I was lucky to find the treating doctor that I have. She's saved my life dozens of times through compassionate, evidence-based care. What I also find helpful is services like the Victorian suicide helpline and the suicide callback service. Mental health legal services and advocacy services are also life-saving and need to be better resourced. In terms of what can be done better, first of all mental health services need to be safe and not re-traumatising. My three compulsory admissions for psychotic episodes were actively harmful, caused intense suicidal ideation related to being assaulted by male patients during the admissions, and in significant ways, were more challenging to recover from than my mental health conditions. Currently sexual harassment and assault is a live risk and daily reality in mental health services across Victoria. For me, this significantly

contributes to my ongoing desire to end my life. What has contributed to my suicidality more generally is feeling that my mental health conditions prevent me from caring for myself, contributing to my community and living a life that I find meaningful in spite of my challenges. I have recently become an NDIS participant for my psychosocial disability and this has been life-changing. It means that I'll be able to change my sheets and eat vegetables all the time, not just when I'm well. It means someone can help me organise paying my rent and limit spending if I'm manic. It gives me unprecedented stability and safety in terms of being able to meet my basic needs. The Mental Health Legal Centre saved my life. A lawyer worked with me at length to develop my advance directive and she has also supported me to make sure clinicians abide by it. Before that, I felt completely disempowered I had no say in what I had to put into my body; the medications I had to take; the treatment I had to comply with. Having previously been raped, the mental health system was retraumatising I was saying no, and other people kept doing things to my body without my consent. As a young woman, the physical side effects of psychotic drugs were devastating, as was the intensive chemical restraint. "

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.

"Mental health is intrinsically linked to every aspect of life housing, employment, family, community, physical health, finances, friendships, environment. Climate change negatively impacts mental health, as does not having a walkable community or access to a local park. Political issues like detaining asylum seekers impacts mental health. Australian culture is racist, homophobic and bigoted, which is hugely detrimental to everyone's wellbeing. Violence against women is extremely prevalent. Personally, family violence and sexual assault were significant triggers for my first psychotic episode. I have talked in responses to other questions about prohibitive expense, excessive waiting periods, etc. About a year ago I was experiencing a severe episode of depression and needed to organise a respite admission in a private hospital. I had had a few appointments with a psychiatrist that admitted to the hospital I wanted to go to, and she had said she would be happy to admit me if the need arose. When I called her office during my acute episode, she was on several weeks leave and had no locum to cover her. I went back to my GP, who suggested that I call all of the doctors who admitted to that hospital to find one who would be available. This was at a point where I couldn't check my voicemails, open my mail or cook a simple meal I was cripplingly depressed. My GP needed the funding and resources to organise calling around for me. That psychiatrist in the private hospital should have had a duty of care to have a locum cover her leave. I could have fallen through the cracks. "

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

"I had my first psychotic episode at a point in my life when I was studying a masters degree and had not been in full time employment while studying. I had a low income and no savings. After my first episode, I was unable to work and was receiving Newstart sickness benefit. I could not afford to pay for essentials like rent and food, let alone pay the expensive gap fees involved in the life-saving, intensive treatment I needed. If I hadn't had a family member to loan me money to access treatment, there is a high chance I would be dead. The treatment I needed three weekly sessions of psychotherapy for several months was not available through the public mental health system. From a policy perspective, address the social determinants of health. Being from a wealthier family

saved my life. "

What are the needs of family members and carers and what can be done better to support them?
"As a concerned friend I called a mental health triage service to let them know that my friend a current client of that service - had attempted suicide through strangulation, to the point of passing out. At that point I was the only person she had shared that information with. The triage service was dismissive, rude and unhelpful. The triage needed to listen, take the issue seriously, and take appropriate action to care for my friend's mental health. "

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
"I've witnessed a lot of compassion fatigue and burnout among mental health practitioners. I've encountered staff that are rude, dismissive, cold, infantilising or actually just ignore me. This behaviour has occurred regularly, including when I've been sectioned and completely dependent on these staff to meet my basic needs and keep me safe. This seems to be related to a number of factors including high workload, long hours, understaffing, poor support for work-life balance and flexible work practices, lack of supervision and emotional support, inadequate reflective practice and training. It also seems that some practitioners don't hold values that align with being an effective mental health professional, for example stigmatising some mental health conditions like borderline personality disorder. All mental health practitioners fundamentally must prioritise building a positive and therapeutic rapport with the people they are caring for. The most effective approaches I've encountered are trauma-informed care and open-dialogue accompanied by attitudes of humility and respect. Practice that is based on mutual trust and respect I think will be more satisfying for mental health professionals and will help improve retention in the sector. Peer support work requires positive organisational culture and a lack of stigma about mental health conditions. Many mental health practitioners I've met don't take peer support workers seriously or consider them to be making a valuable contribution, however informal peer support through my networks has often been the only thing that has kept me alive. "

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?
"I think in a lot of instances this is not about what people living with mental illness need to do, but what the community as a whole needs to do to be more open, inclusive and accepting, as well as valuing of diversity. I have a litany of severe mental health conditions, as well as being an NDIS participant for a psychosocial disability, and I work as a senior policy officer. I worked incredibly hard to get to this point. On a daily basis at work I might feel enraged, terrified, suicidal and elated. What makes me able to deal with that is a supportive team and a positive workplace culture. The people around me don't necessarily need to know what I'm going through, but it does go a long way if we treat each other with kindness and respect, even in stressful situations, because we don't know what we each are going through. "

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?
"The mental health system should be trauma informed and safe. There should be 'hospital in the home' mental health support programs for acute conditions that provide 24/7 nursing on call, daily

doctor visits, delivered meals and cleaning. This intervention would support people to stay at home and involve their family and natural supports while they recover. At scale it would be cheaper than hospital. Open dialogue should be standard practice. Peer support and peer respite should be prevalent. Peer respite should involve access to home-like environments that are calm and containing, with peer workers present and access to clinical support if needed and desired. People living with mental health conditions also need significant support to maintain and improve their physical health. Psychotropic medications often have devastating metabolic impacts including extreme weight gain. This continues to affect me personally and I struggle to cobble together the resources to look after my physical health and counter the impacts of treatment. Personally I choose to take medication however there is merit in voluntary service models such as those in Norway that give people the option of inpatient treatment without medication. There are several reasons I think this idea has merit: 1) in a democratic society, medicine should not be authoritative, and at this stage psychiatry as a discipline is in the early stages of understanding the human brain and mind e.g. few psychiatric conditions have definitive biomarkers; psychiatric diagnoses are still often designed by consensus and regularly change 2) this option would support human rights 3) this option would reduce suicide in some instances because coercion is profoundly disempowering and can lead to despair and lack of hope Voluntary and non-pharmaceutical treatment facilities could serve a range of functions such as providing a place for people to titrate medication, be safe and contained during acute episodes that they do not wish to treat pharmaceutically, and engage in intensive non-pharmacological treatments. It also happens that when people have autonomy, build trust and are free from coercion, they then make the choice themselves to use medical treatments. It gives people choice and the dignity of risk. These units would be different from a PARC in that they could accommodate people with more acute conditions. The units could be supported by medical treatment where needed to manage risk and prevent violence. They could be staffed by practitioners with an interest in this area providing services such as trauma informed care, peer support, open dialogue and techniques used through the hearing voices movement. "

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

"Take immediate action to prevent sexual harassment and assault in public inpatient units, particularly locked wards. Safety 1) Sexual harassment and assault In all three of my compulsory admissions to locked wards in public hospitals I experienced sexual harassment and assault from male patients. I have written about these events in detail initially in correspondence with the Mental Health Complaints Commissioner, and then to the Minister for Mental Health. No resolution resulting in adequate safety was reached. This will remain a safety issue as long as there is no way of separating men and women in high dependency areas. Earlier in my life, a man raped me. When I am psychotic I am vulnerable and often reliving this assault. Being around physically intimidating and verbally aggressive men is re-traumatising even without the live risk of assault, which is unfortunately real and present. 2) Impact risk to life I live with several chronic severe mental health conditions, including a psychotic condition. It is likely that I will need inpatient care periodically for the remainder of my life, despite outpatient psychiatric treatment. At this point I do not consider public inpatient units to be an option. If I am relapsing into a psychotic episode, I have plans to end my life in preference to another admission to a public locked ward. 3) Solutions Women only high dependency wards need to be available, in addition to continuing sexual safety improvements to open wards. Female staff need to be available in high dependency at all times, and at night in open wards. Reducing seclusion and restraint In all of my compulsory admissions I was restrained, and in two admissions I was secluded as a way of protecting me from the

dangerous behaviour of other male patients. During my first admission, I was masochistic and provoked staff into restraining me as a way of hurting myself. Seclusion and restraint were incredibly counterproductive and damaging for me. I think they could have been prevented if the environment had been calming, if I had not been left alone, and if a compassionate practitioner had built rapport with me. "

Is there anything else you would like to share with the Royal Commission?
"At present I consider that the public mental health system is not a safe or effective option for me if and when I experience another acute psychotic episode. My life depends on change. Environment - Emergency treatment Unless serious physical injury or illness is present, an emergency department is an inappropriate place for a person experiencing a mental health crisis. The treatment environment needs to be calming, quiet, with low lighting or natural light, and private. The environment significantly influences a person's mental state and the extent to which a treating team can build rapport to assist diagnosis and treatment. "