

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

SUB. 0002.0030.0222

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

"I have been a consumer for over 15 years. Over that time, I've had hospital admissions, dozens of trips to the emergency room, and sought support from both public and private clinicians. I've navigated mental health challenges throughout school, various workplaces, and within day to day relationships with the people around me. I agree that we need to improve the Victorian community's understanding of mental illness, but I also recognise that over the past 15 years the place that I've felt the greatest levels of stigma, shame and discrimination has been while seeking support from mental health services. I have often felt pushed away, unheard and at times have been actively shamed and had my diagnosis used as a form of discrimination and as a reason to withhold support. I have at times met some exceptional clinicians who have genuinely listened to me and believed me, but unfortunately my experiences of shame and rejection far outweigh my experiences of empathy and care. The shame I've experienced has at times left me fearful of reaching out for support. Suggestions: -For everyone to feel welcome and heard every time they seek support and for people not to be turned away from services without an adequate plan for what else to do. I feel as though this should be a given, but it's often not a reality within our current system. -I would like to see peer workers in emergency rooms and for enough of them to be employed with enough time and capacity to sit with people in waiting rooms, to have long and genuine conversations, and to support people to better advocate for their needs while they're distressed. I find it really powerful when I can connect with someone who has had similar experiences to my own. -I'd like to see the creation of alternative places for people to seek support when experiencing high levels of distress. ED is often the place where people go for crisis support (particularly after hours), but EDs are cold and sterile and not designed reduce people's distress. "

## **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 don't believe the answer to preventing mental illness' lies within the mental health system. I believe we need to address issues like childhood trauma, family violence, homelessness, the cost of living, social isolation etc. Based on my experiences, as a young person I needed (and often still need): -Support and opportunities to make friends and understand relationships with people my own age -Support to explore my interests and hobbies and better establish my sense of self and where I fit into this world -For there to be more safe spaces to access support online. -To have had access to adequate and ongoing trauma counselling -For my whole family to have received adequate and ongoing therapy -To have had access to at home (or school) intensive support in times of crisis, instead of hospital admissions. These admissions led to months of missed school and further social isolation. "

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

"I don't believe we can prevent suicide' until we're willing to genuinely connect with people who have a lived experience of suicidal thoughts and behaviours, and are willing to learn from their experiences. Based on my experiences of living with suicidal thoughts from 15 years of age and having attempted suicide multiple times, the things that have worked well for me are: -When I have access to shame free conversations with people who believe me, who listen to me, and who don't judge me and my experiences based on a diagnosis I've been given. -Having a stable job where I feel like my work is valuable (and having management that understand that my mental health challenges do not make me any less capable to be at work and perform well at my job.) -When I am supported to connect to myself and the people around me, through things like spoken word poetry nights, gym classes, visiting local cafes, going out for dinner with work mates, being a part of the consumer/lived experience mental health workforce. Often my distress decreases when I feel a sense of connection and belonging (either to myself or to my community). -Having access to an exceptional GP who is kind, understanding of mental health challenges, available for consistent appointment and bulk bills. -Access to peer support. These relationships have helped me reflect deeply upon my experiences, and often help me feel more grounded and able to recognise my ability to grow through my distress. I feel able to speak more freely in these relationships than I've been able to speak in relationships with clinicians, due to their ability to connect with me and my experiences. -The Safe Haven caf (located at [REDACTED] hospital), has felt like a (mostly) shame-free space for me to go when I'm feeling isolated and has at times supported me to stay safe during crises. It's the only service I've ever been to where people have asked me joyfully, Will we see you again tomorrow? It's nice to feel like there's a service that is easily accessible and welcoming. I would love to see these opened at multiple locations throughout Victoria. [REDACTED] Things I would love to have access to: -Peer respites. These operate in various locations throughout the world. Often, they're a space staffed by peer workers (some have clinical staff too but are predominantly peer workers). They're a voluntary respite that people can choose to stay at as an alternative to hospital. When people stay there, they are encouraged to continue to take part in their lives. People can still go to work, or school, or remain connected with community activities. This allows people a safe space to move through their crises, without forcing a disconnect from their community. -Peer-supported Open Dialogue. <https://opendialogue.org.au/principles/> -Peer support groups where we can speak openly about our experiences in a space with others who have had similar experiences. One example is Alternatives to Suicide peer support groups <http://www.westernmassrlc.org/alternatives-to-suicide> -Access to long term therapy with a highly skilled therapist. without needing to navigate long waitlists or pay unaffordable amounts of money. "

**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.**

"?All mental health services, trainings, programs can and should be co-designed alongside consumers (And I mean truly co-designed with consumers being leaders in the process). And all services can and should have consumers in leadership and management positions. -10 mental health care sessions per year is not enough. For some people, 52 sessions per year won't be enough. People should have access to as many medicare funded sessions as they need. -It would be more effective to have mental health services with extended opening hours. With many services only open from 9am 5pm it can be challenging to maintain full time employment (or maintain other commitments such as childcare, school, volunteering etc) while also receiving consistent and adequate support. -Crisis lines (ie. mental health triage) should have the ability to

communicate with people in a similar format to some helplines (ie. phone support, online chat support, online support via skype.) When needing to call triage (or any helpline) I often feel a sense of fear around picking up the phone and calling. This fear can be greatly reduced by having access to online support etc. Having access to alternate forms of -Access to sensory rooms and lounge spaces for those coming to ED with mental health concerns. Being confined to a hospital bed or to a cubicle often limits people's ability to soothe myself and manage distress. -Peer Support workers in every emergency department. These peer workers should be able to offer support to consumers in the waiting room, upon admission into the ED, throughout their time there, and then through their transition into an IPU admission. They should also be able to support to people once they have been discharged from ED. -Increasing capacity of Emergency Mental Health clinicians so they are able to see all consumers in EDs quickly, and more than once over their time there. I have often been in ED for 24+ hrs and only received a 10min conversation with an EMH clinician or sometimes no conversation at all. The times when ED has felt most useful to me has been when I've been able to properly connect with the people who work there. "

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

N/A

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

N/A

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

"Currently Victoria's consumer workforce is growing, but not quickly enough, and often not in ways where strong structures are put in place to be able to support and sustain the growth of this workforce. Focus needs to be put on creating a strong foundation for this workforce, including having access to adequate training (initial training such as Intentional Peer Support, and ongoing professional development) that is relevant to our workforce; adequate supervision, support and reflective spaces; consumer worker leadership positions that can support the growing workforce and provide consumer perspective within executive level of organisations (these leadership positions should not be solo positions and should be backed up with high levels of consumer perspective support and supervision). Peer-led organisations should also be set up that have capacity to offer peer support within the community. These organisation could offer one on one connections, group programs, peer respites etc. Consumer workforce within the public mental health system: ol believe this workforce needs to grow exponentially within our public mental health services. With scope for people to work across peer support, consultancy, co-design, training, service evaluation, research and management roles. At the moment the lived experience voice is not heard well enough within our services. There is often one consumer and/or one carer (and often neither) within committees with 10+ clinical staff members. So many decisions are made about the way services should care for consumers, without any consumers present to address their concerns and to speak about the care that they would like to receive. oThe workforce needs to grow so peer support can become part of the core-business of what our services offer. People should have access to peer support in the community, and in IPU's and residential care facilities. Every consumer should have access to peer support. This is such an integral part of reducing stigma, promoting hope, helping people to better understand and explore

their experiences alongside someone who gets it'. Currently most peer support on offer within the public mental health system is time-limited (often to only a couple of conversations). I'd like to have people (and myself) be able to access peer support for the duration of the time they're linked in with a mental health service. The public mental health system is at times a difficult place for peer workers to work. These roles are at undervalued and misunderstood. At times peer workers are employed with only one or two colleagues from the same discipline (and sometimes they're solo roles). They're at times supervised or managed by people who have little to no understanding of what the role entails or who don't understand peer work values and the framework that these workers are working from. Greater focus needs to be put on the importance for organisations to understand and support these roles, and for there to be people with a lived experience at all levels of the organisation to be able to create adequate support structures and career progression opportunities. "

**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?**

N/A

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

"-I'd like to see the establishment of peer-led organisations, peer respites and peer support groups prioritised. We need alternative support options to become available in addition to the current mental health services in place -We need a complete overhaul of inpatient units (including environment, staffing structure and therapeutic support on offer there). I believe we can co-design better and more therapeutic environments, with adequate levels of person-centred support. Spaces where consumers, carers and clinical staff all feel safe. Spaces where clinicians feel safe to come to work because they're adequately resourced and supported to work within environments which decrease consumers distress rather than increase it. And spaces where consumers feel heard, cared for and empowered as the expert in their own life and experiences. -We need advanced statements to be made legally binding, so that the preferences of consumers have to be heard and adhered to when receiving mental health support. "

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

"Focus resources on supporting and growing Victoria's lived experience workforce. By growing and supporting this workforce you're growing the capacity of lived experience workers to be involved in the co-design of services, and in systemic advocacy and leadership. You would also be growing the capacity of the peer support workforce which is such an important addition to the support that can be offered to consumers and carers throughout the current systems that are in place. In order to prepare for changes within our mental health system I believe that all clinicians and support staff need an increased level of supervision, reflective spaces and mental health support for themselves, Many people are burnt out and traumatised and unable to give additional energy to supporting consumers and their families. Currently risk for burn out is high and can result in less optimal support for consumers. In order to support changes to the current system, we need the current staff to have the ability to reflect and grow and be open to change it's really hard to do all of these things when you're in a state of being overworked and under supported. All organisations should have full time consumer positions within their executive, so they can help

ensure that consumers perspectives are adequately heard. These positions can help drive systemic change from within organisations, and can lead co-design initiatives and other projects that will see long term change established. "

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

"I have a strong believe that any and all mental health services can and should be co-produced alongside consumers. We currently have a mental health system that falls short of meeting the needs of consumers. There are a lot of factors to this, but one small step forward that can be made to make a commitment for all future services to be co-produced. Co-production resource: [https://recoverylibrary.unimelb.edu.au/\\_\\_data/assets/pdf\\_file/0010/2659969/Coproduction\\_putting-principles-into-practice.pdf](https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf) In addition to co-production I also believe that consumers should hold leadership and management roles across all mental health organisations. People with a lived experience bring a particular perspective and set of expertise that is essential in being able to better understand how to establish services that will better meet the needs of service users. "