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?

"Much work has been done with some impact by organisations like Beyond Blue to promote conversations around anxiety, depression and suicide seemingly having a positive impact on stigma and discrimination. Significant effort now needs to focus on the people in our society who have experienced or continue to experience psychosis and live with labels such as Schizophrenia and Bipolar disorder. There continues to be significant misunderstanding of psychosis seemingly everywhere even including health settings. As a result, many people who experience psychosis are mistreated and significantly undervalued with their potential to contribute and achieve fulfilling lives wasted.   Much work needs to be done in many systems (including the health care, housing, education, welfare and judiciary systems) to ensure that individuals basic needs are met providing an environment where people are able to move forward with their goals following periods of psychosis. It important that the general population understand and accept that recovery is possible following psychosis to reduce discrimination, stigma and self-stigma (a consequence of stigma that leads people to isolate themselves in fear of being judged). Currently people are misinformed and believe inaccurate sensationalised information making assumptions that lead to fear and misunderstanding experienced by and directed towards people experiencing psychosis.   People with mental illness are fully aware of the stigma associated with psychosis. They are inaccurately perceived to be unpredictable, incompetent, often violent and difficult to communicate with and as a consequence begin to internalise these myths. As a result people hide their experiences from others as they know that if exposed, more often than not they will not be given the same opportunities as others (eg. Paid and volunteer positions, education, access to insurance, social inclusion in community organisations). Hiding experiences may help in achieving certain goals but in the long run is often detrimental to both the person (denying aspects of themselves) and organisation supporting them due to both parties being denied knowledge and potential support. It is important that it is known widely that people with all types of mental health challenges have the potential to recover from their experiences particularly when they are included in supportive environments and have access to therapies.   I have been extremely fortunate in my recovery to be employed by an organisation for the past 10 years with whom I could openly share my experiences with my colleagues and be supported and welcomed back to the workplace after relapses in my condition. This opportunity has had a significant impact on my mental wellbeing (reducing the need for services), my ability to be independent and provide for my children. I highly doubt that I would be nearly as successful in achieving goals and moving forward if I was required to hide my lived experience from employers for fear of stigma and discrimination. "

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 believe that the recognition of the impact of trauma (particularly childhood trauma) and access to therapies to treat the impact of trauma is helpful in preventing long term mental illness. The

sessions provided by Medicare the Mental Health Care Plans are helpful but as they are limited they are sometimes not enough. Finding the right person offering the right support can take many sessions before any benefits are gained from therapy. Different approaches work for different people and it is important to find a therapist that you can build a positive, trusting relationship with. Depending on the trauma you have experienced and how it has impacted on you, you may need ongoing regular therapy for years which is not readily accessible if you are financially limited. People who go through the public health system have little support to find the right therapy space to explore their trauma. The system is geared towards treating people with medication rather than therapy. Rather than dulling symptoms with medications there should be a shift to supporting people to finding therapy that actually addresses trauma (the cause of many symptoms) and reduces the ongoing need to be medicated.   I have accessed EMDR therapy for the past 10 years over which time I have been hospitalised twice and have become well enough to no longer require taking medication. I now understand how the traumas that I have experienced have impacted my mental health and am aware of what I need to do when I am feeling my mental health is deteriorating. In comparison, during the decade prior, the therapy I tried briefly was ineffective and as a result I was prescribed multiple medications (experiencing many side-effects) and was hospitalised 8 times. My most recent 10 years was far more positive in all aspects of my life importantly including my ability to provide my children with positive experiences impacting on their mental wellbeing.   "

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

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.
"The crisis support offered by the Victorian Mental Health System can be very difficult to access which can lead to traumatic and life changing situations for many. Equally the experience of receiving treatment from the system when vulnerable can also lead to trauma. Both Accessing and Not Accessing support can have a detrimental impact on you depending on your experience. At a recent Consultation for the Royal Commission that I attended, it became clear that many carers are frustrated that their family members aren't able access hospitals when at need. As a consumer I know that when consumers do access the hospital system, experiences in emergency departments and wards can have long lasting negative impacts making consumers very wary of accessing hospital services ever again. What a sad state of affairs when the quality of the system that you have available sets carers against the ones that they are caring for. Carers desperately wanting support from a system that terrifies the people that they love and are trying to help.   I personally have experienced the negatives associated with of both being not admitted and admitted to a hospital when psychotic. On one occasion, my mother requested that the CATT attend her home to assess me as I was psychotic and flighty. They did not offer me any support and later that evening I took off, consequently getting lost, being found and held captive by a stranger and sexually assaulted. Three days later, when I managed to return to my mothers house distressed and even more unwell, the CATT team returned and I was this time admitted to hospital. Despite advising the CATT team of the sexual assault, the hospital I was admitted to failed to detect my subsequent pregnancy, treated me without consideration of my pregnancy and did not provide trauma informed care which was most evident when they put me in seclusion after I reacted to being followed by a man on the ward. I was transferred to another hospital and

discharged with no follow up from the area mental health team in supporting me as I navigated my pregnancy.   The sexual assault that I could have avoided by being hospitalised at the right time has and continues to impact significantly on my life. On the flip side I have also experienced trauma whilst in hospital which also impacted on my mental health significantly. This experience was being physically and chemically restrained in an emergency department. This occurred on an admission a period after I had experienced my sexual assault and after several experiences of seclusion in previous hospitalisations. I mention this as waiting in a clinical cubicle in an emergency department for extended periods of time took me back to memories of seclusion and being held captive. The white walls, bright lights and staff member observing but not communicating led to my delusions and paranoia spiralling into fear. I soon began yelling and as a result two large security guards in uniforms approached the cubicle, further scaring me resulting in me reacting by throwing my mobile phone.The next thing that I remembered was gaining consciousness to discover that I was lying on a bed in different area of the hospital with my hands tied to rails and not being able to move at all or speak. Still delusional I became more scared. I did not know where I was and believed wholeheartedly that I was dying - I was not able to ask any questions and the nurse on the computer at the end of the bed did not communicate anything to me let alone reassure me in any way. I was extremely scared and believed that I would never see my children again. The Nurse at the end of the bed seemed totally oblivious that I may be distressed. Next I recall being assisted into an ambulance shaking uncontrollably, in shock. The paramedics wrapped me in blankets they had warmed as they transferred me to another hospital. I am under no illusion that I was admitted to the ward in a far worse mental and physical condition than when I arrived at Emergency. This is a trauma that is very vivid despite my mental state at the time and continues to feed my fear about accessing any public Mental Health Services in the future. How can a service that is supposed to provide care and treatment allow its patients to experience unnecessary trauma that further impacts on mental health.   It seems to me that at times you are damned if you are admitted into hospital and you are damned if you are not.   It iss easily understood that people go to extremes to avoid hospitals when they have experienced past trauma in a system that is supposed to understand mental health and care - this makes forced admissions difficult for everybody. Most people experiencing mental health issues have a history of trauma and yet the system treats them similarly to the perpetrators that have caused them trauma in the past. Mental Health undoubtedly improves when people are respected, supported and valued and yet the system allows people to be locked up, treated against their will, isolated and physically restrained.   This could be avoided by providing decent environments (preferably natural) staffed by people who understand the value of effective communication and have the time and inclination to interact in a respectful and caring manner. People are dehumanised in in the current system, by the clinical environment, treatments and many staff who don't have the time, skills or inclination to connect with people that they are caring for. I know through my own experience and contact with others that many people have been damaged by the system which would suggest that new options should be available to people. It is very difficult to adjust to hospital settings and then adjust to being back home when discharged. It would be ideal to have more people adequately supported in their home environment or if needed have the option to be supported in a more natural, relaxed environment than what is offered in a hospital. PARCs facilities are one alternative option but there should be more options for people unable to access these facilities.   "

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"When people's basic needs are not met their ability to manage their mental health is

compromised. Not having access to secure housing, healthy food, regular contact with family and friends and an income all impacts on somebodies mental health. Other impacts would be diversity, stigma associated both with mental health and being part of a community that is not well understood (LGBTQI, Refugees, particular CALD groups). Secure housing should be a priority for all people.. Access to good quality food and creating opportunities which enable people to develop supportive social relationships is important in enabling people to feel settled before striving for more challenging goals. "

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?
"The mental health workforce need security in their employment. Constant changes in funding means constant changes in positions and less permanent fixed term employments. Peer Support Workers are invaluable in sharing information about the experience of mental illness and the perspective of the Consumer to other workers. As this is a relatively new profession it seems there is a lack of consistency in rates of pay for peer workers, duties of peer workers, pathways for peer workers and supervision and support available for peer workers. More clarity about what is required to become a peer worker and what the role of peer workers is would be helpful. "

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 have worked with a volunteer program which provided volunteer support for people socially and supported people to then to transition to becoming volunteers. During this time it has become apparent through networking with other agencies that another layer of transitional support is required by many agencies to provide extra support to people with mental health challenges who want to volunteer with them. Although many people would like to volunteer in a variety of roles they often require some initial assistance and some flexibility by agencies to make opportunities accessible. I am sure that this would also be the case in paid work environments in addition to the need that these workplaces having a better understanding of best practices in managing and retaining people who experience mental health challenges.   The constant changes in Community Mental Health funding that I have seen over the years has resulted in many programs being forced to finish up causing people to lose social networks that they had highly valued. Feeling comfortable around peers is so positive for wellbeing and self expression. It takes time to develop levels of comfort and social confidence and it seems that just as people have adapted to forced change, they are required to adapt again. I have seen groups supporting people to socialise dwindle and little evidence that many community groups have developed to become more inclusive."

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?
"1. Remove intake into mental health wards via emergency departments 2. Provide more in home treatment options as an alternative to inpatient admissions 3. Develop alternative settings for treatment - away from a hospital environment - environments with genuine access to activities

(including art, exercise, natural environments, pet therapy - all the good stuff) 4. Shift the focus of care away from clinical support with medications / ECT treatment to access to therapy to address trauma and community based care. 5. Fund more programs that provide opportunities for the development of strong social relationships and access to community events / programs 6. Support and encourage volunteering agencies and workplaces to be more inclusive and apply best practise 7. Educate the community better about all mental health challenges - not just the seemingly most common - they are all interconnected and fluid - why ""normalise"" some diagnoses and not others. I have experienced lots of episodes of psychosis but for most of my life I haven't. Should I continue to live with the stigma associated with only a small part of my life because of peoples lack of understanding?? "

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

Is there anything else you would like to share with the Royal Commission?
Hoping and Wishing that the current system will improve for society's sake!