

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

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

"There needs to be an improved overarching strategy put in place to provide education for the community at large on the various different ways that mental illness can present - such as schizophrenia, bipolar disorder and personality disorder to name a few, rather than only focussing on anxiety and depression as the main areas of focus. Whilst the awareness of anxiety and depression has improved across the board in the last 5-10 years, and the stigma has most definitely reduced, this has not changed for those suffering other types of mental illness. For those that suffer from these conditions, it is often a long, bumpy and lonely road for them, punctuated with intermittent service delivery and a lack of consistency in delivery. For a person of sound mind, they will often have feelings of self doubt, lack of assurance, questioning themselves, being worried about what others think, issues with body image etc. For someone with mental illness, these feelings can be more profound, because the people around you often don't understand what you're going through, or unusual behaviours, perhaps they will perceive it as 'weird'. Maintaining a good support network of people who will love and support you and stand by your side in tough times is all the more difficult because of somewhat unpredictable behaviours in those with mental illness, often of a non rational nature. I watched my older brother's friendship group slowly disappear as his behaviours became more and more difficult to cope with due to his diagnosis of schizophrenia, and it was heartbreaking to watch. He remains profoundly unwell, and he has no friends. Not one. One can only imagine the inner turmoil this creates for him in day to day life. 'R u ok' day and other such campaigns whilst valuable, feels token-istic in many respects. As a society we need to learn to accept those with mental illness in their entirety, and not treat these people as weird or different when things get uncomfortable or you don't know what to say or do. There needs to be significantly more resourcing, and education from the ground up in schools, work organisations, universities to train our community in how we can help people who are suffering, particularly in a psychotic or paranoid episode for example - based on evidence based practice. We need to get to a place with treating mental illness where we manage as we do for other chronic illness. If you have a hypoglycaemic attack as a diabetic, a loved one or friend will give you fast acting sugars to assist you and prevent harm or risk to your health. We need to find ways to do this for mental illness - where people feel comfortable responding to unusual behaviours or episodes and want to help and know what to do and who to call to keep you safe, not walk away because it's too hard or uncomfortable to deal with. "

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?

"To be quite honest, there is very little that is working well currently in the mental health system from what I have witnessed. We have huge numbers of mentally unwell people homeless on the streets of Melbourne, many of whom are refusing accommodation, not making good choices for themselves and their mental illness is a huge part of this poor decision making. There are limited

to no resources put into mental health across the state, to enable any real change in the lived experience for patients. My brother was what was at the time described as a 'difficult, rebellious teenager'. His behaviour worsened as he got older, leading to him begging my Mum and Dad to let him leave school at the end of Year 11 to go up north to NSW and stay with family there because he was having such a hard time at school. From here he began taking drugs, got in with the wrong crowd, and his life took a downward spiral from then onwards. We found out many years later that he had been seeing the school counsellor regularly during high school, and my parents were at no stage made aware of this. Whilst confidentiality is of course of paramount importance, improved information sharing for minors would have alerted my Mum and Dad to the potential risks of him developing mental illness much earlier, and early intervention could have prevented what ensued to become a chronic mental illness. Education for families about mental illness is extremely important - this is an area that needs a huge focus. My parents didn't know how to cope. My brother was the eldest and they were pretty strict with Rob (my brother) - as parents often are with their first child. Rob is now 37, so it was also a different era of parenting. It was a tougher approach and this didn't work for Rob. Teachers did their best but were less understanding, and less aware of the signs. We wondered if he suffered significant trauma or abuse at his first high school - a catholic boys school in Ballarat, and whether this affected the course of events for Rob leading to his mental illness. What we witnessed was a boy who was struggling, crying out for help, acting out and making life very difficult for our family unit and causing enormous stress for my Mum and Dad, yet no one seemed to know what to do. Services were not put in place early - Rob wasn't referred to see a GP about his mental health, nor did he see a Psychologist at that time. There weren't school social workers then as there are in schools now who often do family therapy or maintain a connection with students who need extra support. As a family we had no support, and as a result of this consistent stress in all our lives, my other two brothers and I were affected in different ways. We all took our own role - and this has created the initial imprint for the people we are today. Had Rob and my parents and our family had access to early intervention services, things might have ended up very differently for Rob. There wasn't the understanding or comprehensive, holistic care of what mental illness is - there was SO much stigma then, none of us wanted anyone to know. The more society talk about mental illness and become comfortable with it, and once the government recognise and invest in it properly, only then will we see true change. "

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

"Ongoing support is needed for long term sufferers of mental health - the stop gap system that currently is in place is completely inadequate. Improved access and funding for psychological services is required to ease the cost burden for patients - this is a huge barrier for many to accessing continuity of services. For those at suicide risk, regular check in phone calls from professionals to risk screen would be of huge benefit - a major issue with the mental health system at large is lack of continuity of supports. Significantly increased resourcing for CAT teams so they can triage and respond appropriately - far more staff are needed all over the state - this is of utmost priority to keep people safe. Dedicated mental health specialist staff so these patients who are deemed high risk avoid having to access the emergency department - there is a lot of stigma in these wards from overworked staff and repeat offender patients - stigma in these areas can be hugely disrespectful to patients. Dedicated short stay specialist mental health areas of hospitals would be a way to manage this - where patients are admitted for up to 48 hours for medical assessments and services put in place by trained mental health staff."

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.

"Stigma - feeling like you don't fit in and that there is something wrong with you. Lack of education opportunities and access to services - particularly in rural and regional areas. Lack of society education in understanding and accepting mental illness. The lack of government concern or investment in mental health to date (royal commission aside). A lack of continuity of services - this is where the mental health system is in complete disarray. The services are limited at best and severely under-resourced, and for services that are put in place for people, there are time limited, staff changeover is frequent, and there is a disconnectedness. People with mental illness don't want to be repeating their story over and over trying to build a connection with a therapist. In addition accessing psychology services is often out of reach due to cost - mental health and low income are linked - this needs to be rectified immediately. The control of mental health services needs to be controlled more centrally across the state rather than attaching it to certain health services - the technology of various health services do not talk to each other, and so getting an accurate history of inpatient admissions and interaction with the healthcare system is extremely difficult. An online portal that patients could opt into to access services or connect with professionals would be better - where health services could register admissions, and link the patient in with services, but where the patient could request support also when it is needed. The patients need to have agency over their own care also. Case management - this needs a huge overhaul. A centralised system is key for this, again something that sits above the health services so caseloads can be maintained, as mental health patients will naturally swing in and out of the system. There needs to be ongoing care for these chronic conditions, and if a patient is deemed well enough to be discarded from case management, ensuring they know how they can reinstate or interact with the health care system to get support when they need it. More support groups - both for families and patients. More allied health services - my brother lives in an acute secure psychiatric inpatient unit and he has done for many years. There is NO social worker, no psychologist, no occupational therapist, basically no services at all. It is absolutely disgraceful - all inpatient and outpatient psych services need to be funded for this sort of allied health intervention permanently for multi disciplinary management. "

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

"- poor educational status: poor education links to lack of employment opportunities and an increased risk of experiencing mental health issues - lack of access to integrated support services, particularly in rural communities. - stigma associated with gay/lesbian/queer communities - we know that children who fit into these groups have a higher risk of suicide due to discrimination and not feeling ok with who they are - sexual abuse victims - victims of trauma - lack of community understanding - poor management and lack of understanding in schools - this is a key area for early intervention "

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

"Families need to be provided with increased supports - via support groups, but also having access to family counselling and independent psychology services. Both my younger brothers were extremely traumatised by some of the behaviours they witnessed due to Rob's deteriorating mental health, and for my youngest brother this caused some significant issues with anxiety that

he still has to self manage today. Putting in place supports for families is key to prevent other members of the family suffering secondary trauma and increased risk of their own mental health issues. Family therapy - I truly believe this would have been of huge benefit for our family. We weren't good at talking then - we were all just trying to keep our head above water, but what we really needed was to unpack the issues, to hear what each member of the family needed, and learn how we could support each other. "

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

"Significant improvements in funding and remuneration for mental health workers. Putting in place staff supports - access to debriefing, regular reflective practice and professional development to ensure they are up to date with evidence based practice. Improved infrastructure for staff - the mental health wards are often barely fit for purpose - without even staff tea rooms where they can have time out to recharge. Working in mental health can be a draining and more high risk area. Staff need to be provided the utmost support to do their jobs properly , and feel they are part of a team, that their work and role is valued and that the executives of hospital and senior government decision makers are invested, and really care. When was the last time you saw an announcement or public government media event held at a mental health facility? NEVER. Because its not sexy for image. Mental health has been kicked to the side for too long and it needs to change immediately. Case conferences and mental health teams need to be put in place - where staff meet once a week : medical, nursing and allied health to discuss health plans for patients and how goals will be met, what barriers exist etc. This needs to be a team approach. "

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?

"Increased funding for allied health and peer support workers across health networks for mental health units is required - from here these staff can facilitate social connections and opportunities for community engagement. Networking with industry that would be willing to engage people in casual/permanent employment to provide training, with the knowledge that their mental health condition may at times impact on their ability to attend work, and plan for this possibility. Offer targeted training and education programs for people with mental illness to engage in to upskill - with increased flexibility and supported delivery by professionals trained in mental health. More involvement of peer support workers and OT's supporting return to activities of daily living and skills to live independently after periods of acute stay, or where basic ADL skills have regressed. My brother Rob was transferred at various time to a support daily living unit with staff onsite 24/7 to support transition to independent living - Rob was unfortunately never successful with this. Due to lack of funding however , the unit has since been shut down, meaning noone in the local Ballarat area has this opportunity for graded return to independent living. "

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. Immediate increase in funding for mental health infrastructure and training and recruiting of professional staff trained in mental health, with a focus on evidence based practice. 2. Co-design and access for key stake holders ie. families, carers, clients and health professionals within the mental health system itself to advise on policy formation and development for optimal client focused mental health care in the future to ensure place based services are implemented. 3.

Annual accreditation and spot checks of all residential mental health facilities without prior notice to ensure adequate standards are in place to provide client focused care at all times. These include adequate staffing levels, infrastructure improvement and if not why not, adequate levels of hygiene and lifestyle facilities within the unit in general. 4. Improving data collection and setting clear performance KPIs around staffing levels and infrastructure and services provided for patients. Ensure senior executive staff of all health care facilities are accountable for poor outcomes within the mental health unit. 5. Community outreach programs readily available for those with chronic mental illness living within the community to access at will. 6. All residential psychiatric units require the support of allied health staff for client care. A social worker should be permanently assigned to these units as there a range of social supports required by those experiencing recurring bouts of mental illness. 7. The immediate introduction of mental health emergency units whereby clients needs are addressed by professional staff adequately trained in mental health emergency care. This area should be adjacent to but not part of the pre existing emergency units to allow all stake holders within the emergency setting to work and cooperate together to provide optimal care for all. Currently mental health issues within the general hospital emergency setting demand a great deal of staff and security input, this results in distress for all those involved and other families and carers waiting in the main stream emergency setting. 8. Overarching integration of services via an online portal/database that provides a central place to access and locate services around the state, and ensuring this portal is independent of health services for improved patient data. Ensure the ability to link services together, access so that patients and hospitals can interact with it and that patients can also if they need to reach out for support. 9. Case management access - this needs to be put in place for continual care, or ability to access it ongoing, or dip in and out as it is needed. 10. Improved support groups and psychology/support services for families, that includes strategies to assist in caring for a loved one with mental illness to ensure you are providing the best possible environment for them to be able to manage their mental health issues and improving them as much as possible in a supported way. 11. Improved funding to CAT teams so they can support appropriately - to allow the ability for a triage system of support - this could then funnel into emergency mental health units where these staff could work together for improved continuity of care for patients, and an improved experience of the hospital system in general. 12. Offer remuneration to nurses/professional health staff who want to be trained to specialise working in mental health and offer guaranteed employment. "

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

"Consider a mental health tax that is added on to our medicare fees to assist with facilitating ongoing funding for mental health issues. - Audits on what services around the state offer in terms of services, and more importantly what they don't offer is key information that is needed. - Speaking to services around the state - talking to staff as the services vastly differ as to what they offer. Look at where funding is going, and where it isn't - what infrastructure is in place, and is it adequate and fit for purpose? - Continue speak to people living with mental illness. - Speak to the hospitals directly - what would they support and why why/not? - There needs to be a commitment from government to fund mental health ongoing - this is a chronic, systemic issue in huge need of complete reform. - Speak to schools, what are they doing now and what can be done better? - Speak to school kids - get the message out their that mental illness is a health condition, that its ok, that these people need to feel supported, accepted and loved. We need to start from the

ground up. "

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

"Advocacy is so very important for those living with mental illness. My brother now also has a concurrent diagnosis of multiple sclerosis. He has had limited input from Neurology as an acute psychiatric inpatient. Rob can't advocate for himself. If it weren't for him being hugely loved and supported by my parents and our family, I hate to think where he would be now. These patients fall through the cracks all the time because they need support to make the right decisions for themselves and guided through this, They need people around them who are invested in improving their health outcomes, and knowing it will be a long road ahead, and that their will be one step forward and three steps back at times. Their needs to be love, compassion, and real care and understanding for these people. We need to be behind them, rallying for them, not turning our backs and walking away because its all too hard. It's unlikely the status of my brother's mental health will improve, and unfortunately he has lived a live that no one deserves. But for the time he does have left on this earth, however he has to live, I want it to be with dignity and true compassion. Supported with the right type of professionals, and access to all the right services when he needs them most. We need a mental health system that is robust and responsive to the growing needs of our mental health community. I would be happy to be contacted to discuss my submission further. Thank you."