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 approach this submission from several spaces. My mother was diagnosed with Schizophrenia when I was fifteen years old and I have overseen her treatment over the last twenty years. It is largely what I have grown up making sense of. I am also a Social Worker in the Out of Home Care sector, a Yoga Teacher and Life coach, which influence my perspectives in different ways.   When I was younger, I was very resistant to telling anyone about my mother's mental illness as I felt that it would label her, myself and my family as ""defective"" in some way. I feared both that people would think that I too must have a mental health issue, and I was very fearful that I may come to experience life as my mother does, especially when I became a mother myself. As an adolescent, I only understood mental health issues from what I had learned at school through my Psychology and Health and Human Development classes. Being an adolescent is tricky enough, without having a family that is going through mass upheaval, largely as a result of one parent experiencing significant mental distress. Growing up in our family, we were taught to keep family issues very quiet and to portray a glossy image to the outside world. While I knew from eight years of age that my mother was in some way ""different"" to other mother's, and I began to act as a parent for myself, there certainly was no way that I would have ever mentioned this to anyone. Despite my mother's mental health issues, we were always very well taken care of in terms of being well fed, lunches packed, well dressed, we did the extracurricular activities and kept on top of our school work. It took closer inspection to notice any signs of issues within our family.... however they were definitely there. So, to notice that things were not as ""spot on"" as they could be at home, would be for our schools to really pay attention to our more subtle behaviour. Which I don't feel that they always did. And I always did my very best to appear ""normal"" and to contain a lot of my emotions and anything which may be suggestive. I was a ""quiet"" child and seen as being ""very easy"", so no one bothered to question further. My brother on the other hand experienced more distruption and therefore drew more attention than me. Given all of this, as a 34 year old woman, I have done an immense amount of work on myself in order to be able to express myself fluently, to feel like it is very ok to be honest with my thoughts, feelings and emotions and to not feel like I have to fit into some one else's version of what is ok. At times this has meant that I have stepped away from my family in order to focus on building my own life. This is because when I was younger I felt a lot of anger and unresolved emotions in relation to my family situation, and I felt that connecting with my family was very triggering and disrupted the progress that I was making in building a life for myself, as a young adult. This also meant that I worked incredibly hard with little family support through these early years. This is something I also see often in the young people I now work with. At this time, I found that the response from others was largely that ""You should see your mother"", which I often felt undermined my own experience of having a whole range of feelings and emotions of my own in relation to that. I also received a lot of pressure being my mother's daughter in relation to the ""expectation"" that a daughter should support her unwell mother. This was further amplified by the public system, who have put a lot of pressure on a family, who have spent at least the last

twenty years at breaking point, largely due to the ripple affects of my mother's mental health issues. There is much about my mother's treatment through the mental health system that I have not raised a light on that should have occurred at the time that these incidents occurred. This is my opportunity to due so, now that I am in a much stronger place to do so and I now am building a much better relationship with my family. At the point that I am at now, I often find that while I more openly share about my mother and her illness, I still do not feel that many people really understand or know how to respond. Some people feel awkward and want the conversation topic changed. Others minimise both the illness and mine and my mother's experience. I feel that this is because we seem to now exist in a society where a lot of people experience anxiety and depression, a lot of people are familiar with visiting Psychologists, and so people just seem to presume that my mother's condition is just a part of how society is. Given all of this, I feel that the following needs to occur: - Better awareness of schools in picking up on subtle signs of stress/disturbance in children and having greater assistance available earlier - Much better awareness of Schizophrenia as well as other more common mental health conditions - Much better support and assistance for children and young adults who experience parental mental health issues, because while not all children/young people need to enter OOHC, this stuff DOES affect their perception of themselves. What assisted both my brother and I was having two Aunts and a grandmother who each in their own way provided care, role modelling and showed us different ways of living life - Giving those living with mental health issues the best opportunity to live in the community and normality, both with those who also have mental health issues and those who don't"

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?
"For my mother, the things that have and/or do work well include the following: - Access to groups where she feels that she fits in and that offer her a social connection and to learn skills, keep fit etc, such as walking groups, art classes, helping in a soup kitchen, going to church. When my mother is well, she loves being social and getting out and doing things. My mother has lived in SRS's for the last 17 years and these groups are VITAL to keeping her well - At one point my mother was living in a facility where they had four one bedroom units on a black of land, with a nurses station, where she would collect her medication. this worked well for a period of time as my mother loved that she had a greater sense of independence and she could look after herself, cook for herself etc. Given that the thing that my mother has prided herself on more than anything is being a homemaker, so having her own space to tend to made her feel good about herself. Unfortunately this accommodation was a short term assessment facility and my mother was not deemed as being able to sustain living on her own without support, so she returned to SRS's. It would be great to have arrangements like this full time. - On putting this application together I asked my mother her perspectives around her care over the years. My mother is in the best space that I have seen her in a very very long time at the moment. Possibly in the last 20 years. For years she only wanted to live on her own. My mother told me that she now likes living in her current SRS. Things that she said make an SRS good to live in are: good, caring and effective management, lots of outings and activities, clean environment, a good mix of people living in the house and decent healthy meals. These things I feel should be non-negotiable, however over the years my mother has lived in many SRS's that have not met these standards. There have been times where I have demanded that my mother be moved out, when I went to visit her at a home with concrete flooring inside an annex of a house, where my mother's room was a curtain partitioned off section of a room where about six elderly men were sleeping. My mother is ""very lucky"" at the moment to be living in a place where she feels good and these things are met. The

last two years have also been the period of time where my mother's mental health has also been the most stable. - When my mother becomes unwell and goes to hospital (on average a couple of times a year), it seemingly happens very quickly and without a lead up. I feel that SRS's must have some indication that my mother is becoming unwell. I feel that the prevention in keeping my mother out of hospital is a combination between SRS's not always being staffed with those who are well versed at responding quickly, efficiently and being aware, mixed with a hospital system which is crisis driven and will only respond to the most high risk situations at any time. This is a HUGE gap to be responded to, making sure that people are responded to in a timely way to minimise the length of time that recovery takes, or to avoid hospitalisation in a positive way. Rather than just not putting them in hospital as there isn't a bed. In addition, there have been times where my mother has been admitted to hospital because of a medical issue, such as she may have a UTI which has not been treated, or her insulin levels have become unmanageable, and by default this has affected her mental wellbeing. There was one occasion where my mother was in the Intensive Care Unit with a UTI which had not been addressed. - In relation to preventing mental illness, from my own study and research there are many things that can be done. Things such as Yoga, art therapy, outdoor education, music and dance therapy, life skills and empowerment programs are severely undervalued in our community services. Through my work professionally I have watched young adults come leaps and bounds through these kinds of programs, and it is no coincidence that I choose to work in these spaces as much as I can. I can also attest to the immense value of lived experience programs, where those who are in a position to support others through an experience provide. "

What is already working well and what can be done better to prevent suicide?
"My experience with suicide is largely professional, however I do have a fear that one day my mother may be a statistic of this. What I feel can be done to prevent suicide is much greater understanding and awareness of what to look out for, and much better education of the community around how to respond to mental health challenges. I would suggest that often when someone commits suicide, a lot of people around them did not see it coming. We really need to address social isolation and the constructs of society that encourages us to keep our internal battles silent. And on the flip side, know how to respond to someone who has expressed suicidal ideation and where to get support. We need to become more community focussed and to genuinely care for others. Check in on people, and feel ok doing this. There is no ""nosiness"" about it. I always worry when I come across someone who is socially isolated. While people who are socially connected can definitely struggle too, isolation is literally a killer. In addition, as a society, we can offer a lot more to assist people to recover from trauma and other factors that can predispose people to handle challenging times with less resilience."

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.
"Both through dealing with my mother's mental health and through my work, I often do not feel that services link well together at all. There is a lot of double up of services, and also a lot of gaps. There is a lot of staff turnover and workers who are burned out. I know that my mother would not be an easy person to work with, however her situation is not helped when she has a worker who is very clearly frustrated and a bit over working with her. Often what makes the most significant difference in these situations, whether it's mental health, OOHC or any other area of public care is good quality (as per section one, it doesn't have to be excellent, just good!) and consistent care

and accommodation and workers who genuinely care, are consistent and know their job well. I firmly believe that it would be very unusual to live in the ""system"", have great mental health and NOT have these things. How we improve these things is by giving those who live in the system a voice about their care and their needs. And to do this at various stages, when they are well and unwell. For my mother, when she is well, she would love to get in the kitchen and help cook meals and to help out with decisions and the daily running of the facility. This would assist her to feel connected to the facility, however I don't believe she is generally able to. It also comes down to making sure that these professions- SRS staff, case workers, housing workers are treated as genuine professionals. They are well trained, they are paid well and respected for the work that they do. This ensures that the system attracts better quality staff and that they both approach their job with a higher quality of care and are treated the same. Their case loads and houses are less stretched. They leave less often, they are happier in their jobs, and so they want to interact with their clients and create better outcomes for them. They respond to clients needs more effectively and quickly and our systems are less about responding to crisis and more about doing quality preventative work. There is less paperwork and quality client interaction is more highly valued. workers stay in one job longer, and clients feel that they can build a relationship with their workers/housing staff and have their needs met. In addition to this, I sometime wonder how it is that my mother has had so much assistance and mental health support over the last 20 years and she still struggles to be well. In many societies, what we call ""mental health issues"" are seen as a cause for the community to gather around the person and to support them to rise into their next level of self evolution. They are seen as a sign of growth and life transition and the person ultimately moves into their next phase of life. In the West, we tend to blame the individual, cast them off and treat them like there is something wrong with them. I feel that there is a lot that we can learn outside the medical system about how we can provide more community based approaches which normalise mental health as being a continuum of wellbeing that every single one of us are continually moving along, rather than it being the focal point of pathology. Obviously, there are times where this is needed as well, however I feel that every one of us should grow up with a really good understanding of mental health, wellbeing, emotional intelligence and the like. It also cannot be presumed that families teach these things, and therefore this needs to be a much stronger focus for schools."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"I feel that there're a lot of things in this, including intergenerational trauma that is often unresolved and impacts on parenting capacity and societal norms around what it means to focus on health/wellbeing, express emotions and prioritise our self care. There of course are many people living in long standing situations of extreme stress as a result of the above, along with domestic violence, housing and financial stress, drug and alcohol issues etc. As mentioned above, there need to be an array of services available, as many people do not respond well to sitting and talking. We need to have programs which are incredibly diverse and allow people to explore and create through all realms of their wellbeing. Those that allow them to move, use their bodies, make things. And those that encourage that person to develop an interest or skill at the same time. Things that help people to feel proud of themselves and their achievements. Things that shift the way that they perceive themselves, and by default they start shifting some of the underlying trauma/mental health stuff. I do not believe that the response always needs to be directly related to the mental health issue at hand, it just needs to get them thinking, feeling and doing things differently. I would love to see the Government prioritise funding for these things. I also feel that for people to experience life differently, they need to be exposed to different ways of life, from people

who also get here they are at. Whether this is through lived experience programs, or having role models who have had a similar experience and also moved on and done other things with their lives."

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

"It is my experience that the sector puts a lot of pressure on families to ""fix"" or solve the situation and often without appreciation that there is a lot of unresolved currents and difficulty for families where one member has mental illness. An example of this is where I had a phone call from a support worker of my mother's one day. She told me that she was my mother's new housing worker and my mother's housing was due to fall through and she asked for my email so that she could send me a list of SRS's so that I could find somewhere new for my mother. I refused to do this and informed the worker that it was her job to do this. I offered to help her, advising that I could tell her where my mother had lived previously and where we had already deemed inappropriate. This worker insisted that I find the accommodation, however I again refuse. Given that it was a few days before Christmas and the worker was going on leave, she decided to leave the matter until the new year. I then had a call on Christmas Eve from the SRS saying that they were evacuating my mother that day. I told them that they could not do this and that my mother either needed to stay at the SRS or the SRS could have my mother admitted to hospital, if she were that unwell. The SRS again insisted that I take my mother. I live in a share house myself, and our family are not in the position to care for my mother. I again insisted that the SRS had two options, and that we would take my mother out for Christmas Day. In the end, the SRS decided that my mother could stay, however she was told that she had to stay in her room through the 37 degree days over Christmas. Examples such as this one create an enormous amount of stress on our family. When our mother is well, we generally all function reasonably well. When our mother is unwell, it is really hard to navigate emotionally and practically. Often, the system does not assist with this. It is not our fault that our mother is unwell and we can only do what we can to support. Over the years, I have learned that I need to have very strong boundaries to be able to grow up as a healthy young woman in my own accord and to live accordingly, while also navigating my mother's life and health and our family dynamics as best as i can. When my mother is unwell, and I have contact with the system, I feel like there is an undercurrent of blame that the family should do more. While my Aunt tends to respond to a lot of mum's practical needs, I tend to navigate the contact with the system. When our mother is unwell, she lashes out both verbally and physically towards my Aunt, and this is awfully distressing for her. She is now in her 70's and is not well. I honestly am fearful about her aging, as I cannot provide the level of care that is needed when my mother is unwell on my own. I have visited my mother in hospital and unless we take her things, she has the clothes that she arrived at the hospital on only. I feel that there is a lot more that the SRS's can do to make sure that my mum is sent to hospital at least with the basics for her to take care of herself.   In addition to this, as a family, we often feel confused when our mother is in hospital as we tend to get pieces of information without the full picture. We often do not fully understand what the lead up was of her arriving in hospital, or what has been done to resolve the situation before she leaves hospital. At times my mother is sent home when we are told that she will be kept in hospital. At times my mother's treatment has gone against what is recommended for her.   One example this was when my mother had a heart attack after receiving two rounds of ECT at one hospital. It was recommended that my mother is never given ECT again. She was then transferred to another hospital,seemingly without her records, where she was again given another round of ECT. On another occasion, my Aunt called the hospital late Saturday afternoon, who informed that my mother would be kept in hospital over the weekend. I visited my mother late on

the Sunday afternoon, and she informed that she had been sent home Saturday night, the SRS called the hospital in the middle of the night and had her again admitted. My mother had spent the entire of the Sunday lying on a bed in Emergency Department, waiting for another bed to become available at another hospital. My mother reported that she had not been given her insulin which she takes twice a day. Essentially, communication, consistent housing and workers, and an appreciation of the level of stress placed on families, with this being minimised as much as possible."

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
"As per previous page. A huge part of it is in the perception of workers both inside and outside the sector, work loads, and allowing workers the space to do really great quality work, which is what drew them to the profession initially."

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?
"My mother has no real qualifications and very limited work experience. As a result of her treatment (high levels of Chlomazapane over an extended period of time), and later possibility of misdiagnosis, we have also been told that she may have an Intellectual Disability. Given this, I am not sure what my mother's work capacity is. To see my mother working somewhere, no mater what role would be amazing! I know that she loves helping at a soup kitchen, which would suit her as she likes being around people and cooking. Social enterprises are phenomenal in my mind, and to see more of these that support people with mental illnesses to work would be incredible. Funding grants for these and similar innovative initiatives would be amazing. If the Victorian Government funded me, I would open one on your behalf! I also feel that programs which support people living with mental illness to develop life skills are really important. Those that help them to live more independently. I know that my mother does not know how to use a mobile phone properly, to use a computer, to understand how to best utilise her finances etc. "

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. A full review of the SRS system. I personally feel that there are too many people in one home for the staff to keep an adequate eye on the needs of each. An example of this is when I once visited my mother and her hand was a scrunched up. I asked her what had happened and she said she did not know. She thought that she had had a stroke five days beforehand. I asked the staff about this and they did not know, nor seem fussed about the matter. 2. Funding for creative and flexible approaches to mental wellbeing promotion, social enterprises and life skills programs 3. Consistency of housing, staff and workers. Well trained, respected and caring 4. Support for extended families 5. Promotion of mental health, emotional intelligence and wellbeing in schools 6. Anything that promotes and encourages understanding, awareness and community"

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
Listen to as many people's stories as possible Recognise the dire importance and need and fund the mental health sector to do the incredibly vital work that they do very well Think outside the box as much as possible. We need to be innovative in order to have different outcomes. Increase the

focus on prevention

Is there anything else you would like to share with the Royal Commission?
Thank you for doing this Royal Commission- your job really matters and I'm glad that you are doing this. I'm looking forward to hearing what comes of it!