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

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

"*Have a word with the Prime Minister about his use of the phrase ""lifters and leaners."" *Run an education campaign that helps people understand the difference between short-term blues (even those that fit the diagnostic category of 'depression' versus chronic, long-term highly debilitating depression. Ditto anxiety. *Run an education campaign that educations people about PTSD

*Mental illness is not contagious. Statistics re sufferers of mental illness to bust a few myths *Education dept education programs *LGA led programs *TV and social media campaigns "

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?

"*The Better Access program probably saved my life. * Early detection .... which requires a high level of awareness with GPs, and community education (to enable family and friends to encourage people to seek help) * Easy to find information re support for people with CALD * Enable easy access to / require second opinions for ""treatment-resistant conditions My story: I started seeing GPs in the late 1980s/early 1990s because I was feeling unwell, sleeping badly, lethargic, anxious. Most GPs didn't seem to know what the problem was. One GP told me I had depression and if I still felt that way in 6 weeks I should come back for medication. He didn't seem to empathise with my situation and didn't explain anything or educate me as to why this should happen. I knew nothing about mental illness, felt the discussion was very clinical (I didn't feel he saw me as a person) and was afraid of psychotropic medication. I didn't go back. In 1994 I had a complete breakdown and struggled enormously to function at all and to hold down 8 hours of work per week. I saw an empathetic and informative GP who helped me manage symptoms, obtain income support, deal with bureaucracy, and who in 1995 referred me to a psychiatrist. The psychiatrist diagnosed depression, said it would probably be life-long, prescribed medication and offered ""supportive counselling"". This psychiatrist also assisted with obtaining income-support and navigating bureaucracy. In 2007, after the introduction of the Better Access program I started seeing a clinical psychologist who, at the very first consultation, heard my story and diagnosed PTSD, which she put down to an emotionally difficult and unsupported childhood and a life-threatening incident in 1984.   She started treating me for PTSD and although it took a number of years of hard therapeutic work, I began to improve. In other words - well informed, empathetic & informative ""first responders"", along with CORRECT diagnoses and thus treatments   "

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

"Not sure what is working well. I have had periods of feeling suicidal and suicidal ideation but have generally been driven by a desire to survive and recover. I have a cousin who suicided in 2017. After a previous suicide attempt she had been admitted to hospital. I don't know many details except that according to her brother she was discharged from the ▮▮▮ Hospital too early. He knew she wasn't ready to be released, that it was too soon. Within a short period, perhaps a week,

she attempted suicide again and this time was successful."

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.
"Things that make it hard to experience good mental health: difficult childhoods (it's a wild frontier if children don't luck out with good parents & happy homes) discrimination based on sexuality, ethnicity, introversion (it's a world that favours extroverts and the majority mainstream) bullying income insecurity social isolation (especially for migrants, elderly, some CALD people) What helps improve: community programs whether LGA funded or through community health centres informations & resources for CALD communities government initiatives/support for people with income insecurity more info for GP and other referral services"

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
Outside my realm of experience and knowledge.

What are the needs of family members and carers and what can be done better to support them?
"Needs: Education about mental illness, clear information about support services"

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

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 am a disability pensioner. I do not work and for about a decade was very debilitated. I knew that it was important to avoid complete isolation so dragged myself out of bed once or twice a week to see friends or family or to attend life-drawing classes. I chose life-drawing because: a) it appealed b) it wasn't compulsory to attend every week c) I could pay only for classes I attended d) I didn't let anybody down if I didn't attend e) I got to meet interesting people f) classes were held in the evenings rather than the mornings (this fitted with my sleep patterns) Since my level of function has improved I have joined a group advocating for action on climate change and increased equity in socio-economic outcomes, joined a local community group advocating for improved facilities and services in my local neighbourhood and volunteer for a couple of hours a week at a local organisation which supplies info and services to extremely disenfranchised members of our community. I also occasionally attend free lectures or community events. I can't speak about improved economic participation because I haven't been able to work since 2004. I can say that as someone unable to work in an age cohort where most people do, I have felt disenfranchised, discriminated against (most places that offer a concession price only knock about $1 off, so paying for eg a movie is much more proportionately expensive for me than a working person). Having a tiny income in our consumerist society is like becoming a second- or possibly third-class citizen. "

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?

"First point of contact -- highly educated GPs & other referral sites (educated re mental illness recognition, services etc) Second or even third opinions for 'treatment-resistant' people in order to eliminate the possibility of undiagnosed mental health conditions. much more money invested in beds for acute and chronic conditions. investment in community support services Awareness and de-stigmatising programs for patients, practitioners, community education "

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
Cannot respond to this question.

Is there anything else you would like to share with the Royal Commission?
"I believe my experience of a lifetime with episodic and later chronic mental illness highlights some typical themes relating to mental illness, the need for early detection, the need to identify vulnerable people & the costs personal and societal if this doesn't happen in a timely fashion. I have complex PTSD. My childhood was difficult. My parents were self-involved and struggled to cope with their four children, each other, life's vicissitudes and their own selves. There was some illness, some financial insecurity and a lot of fighting. It was like growing up in a war zone. My parents provided a decent roof over our heads, food on the table and education but I felt I was on my own and that I brought myself up. I looked to other families to learn how things could be. At about age 8 I tried to commit suicide. At about age 14-15 I developed anorexia. At age 17 (in my final year of school) I suffered a bout of major depression for about 3 months. After I left school I deferred higher education because I wanted to learn more about the world and I wanted financial independence. I couldn't see how I could study and leave home. In the end I left home at age 22 and immediately felt a sense of liberation and much of the darkness lifted.   At age 24 I was held-up at gunpoint while working as a bank teller. About 6 months later I left this job as I was afraid I might be held up again (this happened - stories circulated about people held up 2 or even 3 times). I retrained and started working in other employment. A few years later, after some other major stressors, I developed a feeling of malaise, the blues, sleeping issues, anxiety and started seeking help. Most GPs didn't recognise that I had mental health issues. One did but his manner was very clinical and I felt unheard/unseen. I was afraid of psychotropic medication (how would I still be me?) and had internalised stigma about mental illness and medication.   My symptoms worsened. I found myself trying to leave a job AND a relationship at the height of the early 1990s recession. Life was unbearable and I didn't know which way to turn. I was in my early 30s. In the end I found a way to leave both, but almost immediately, after so much stress, collapsed into an almost catatonic state. I could barely feed myself and indeed asked friends to feed me one or two meals a week. I dragged myself to my part-time job (8 hours per week) in order to keep afloat financially. It took the rest of the week to recover enough to go back for the next 2 lots of 4 hour shifts. I had enrolled to study full-time but had to drop out.   Fortunately at the university I encountered an empathetic, supportive GP who saw me weekly for long sessions. During this time I improved to the point where by year's end I was prepared to take psychotropic medication and had a much greater understanding of what I was experiencing. I started studying full-time the following year but by year's end was struggling and from then on studied part-time and worked part-time. In 1995, at age 35, I was referred to a psychiatrist who diagnosed major depression and said I would be debilitated for the rest of my life and require medication for the rest of my life. She provided supportive therapy only. I trusted her and didn't think to ask for a second opinion. In the year 2001 I suffered a second devastating collapse and breakdown. I had been studying part-time, and working part-time. I felt like I was in a thousand pieces, the size of peanut deep within my body,

donning a papier mache outer self in order to negotiate the world. I was in enormous pain, mentally and physically. I worked 3 days per week constructively, positively and productively and then collapsed into bed for most of the rest of my week. Eventually even that was clearly unsustainable and I resigned in early 2004. At this point I lost a lot of faith in psychiatry - I was under the care of a psychiatrist, taking medication, seeing her regularly. This enormous collapse shouldn't have been possible. The next 5 years were an absolute nightmare of pain, debilitation, shame, isolation. I was in bed for some, most or all of each day for the next decade. For the first 5 years of this decade I would lie awake until about 3 or 4 am, unable to fall asleep, experiencing terror and telling myself that if people like Nelson Mandela could get through decades of life imprisonment and come out to live a meaningful life, i could survive this. The following 5 years felt like a constant bad dream. Life was still surreal. I was in bed some of each day or most of each day or all of each day. From 2004-2014 there were many days (perhaps 10%) where I got up feeling ok, but by the time I finished eating breakfast I felt compelled to go back to bed, drawn there as if by a heavy pulling at me. For much of the time if I could manage the dishes and to sweep the floor of our one bedroom flat I felt I had pulled my weight that day. I also, of course, felt like a burden and a failure. In 2006 my partner also suffered some mental health issues and for a period of about 9 months couldn't work. We lived on our savings for a lot of this time but finally sought government assistance. I applied for a disability pension and he applied for a sickness benefit. Around this time it became clear that our living environment was far from ideal for someone suffering with my mental health issues. We lived in a one bedroom flat that was less than 40sqm in a densely populated suburb known for partying. Because of my debilitation it took 10 years before I was well enough to move house. I tried acupuncture (which helped a bit), made sure I did some exercise each week, started doing yoga, attended weekly life drawing classes when well enough to keep a feeling of being connected to the world and dragged myself out of bed once or twice a week to meet people so I didn't feel completely isolated. Much of this social interaction felt quite fraudulent. I couldn't meet people ""from where I was at"" so I had to tap into a former self and interact from that place within me. It was the best I could do, and genuine so far as it was all that was possible and bits of the former me still survived. But it was in many ways a show and that too caused pain. In 2007 the Better Access program enabled me to see a psychologist who diagnosed PTSD and started treating me with EMDR as well as other therapeutic techniques. I developed a much more sophisticated understanding of my life's experience and did a lot of work on issues arising from childhood and the inadequacies in the way I had been parented. Under supervision I tried reducing and then stopping my medication in late 2010 (at age 50) but this went awfully and I changed psychiatrists and resumed medication. I have worked with my psychologist since 2007. The frequency of consultations has tapered as I have become relatively well. Unusually, my psychologist has been available to me by email as well as in person and this has been extremely useful at times of high stress due to life circumstances.   Apart from the suffering itself - the agonies of mental pain & the terror and feelings of inadequacy that comes from high-level anxiety - I chose not to have children. It seemed to me, and still does, that I couldn't adequately parent a child if I had trouble coping with myself. Children deserve far better. A significant, if not major portion of my own issues and suffering comes from having inadequate parenting in the first place. As well as not experiencing the joys and challenges of parenting, and all the ways in which being a parent binds a person to their local community and ""normal"" life, I have missed out on having a career. I forewent higher education after leaving school because I wanted to learn more about the world and be free to leave home at any moment should that seem necessary. In my early 30s I chose to go to uni because it had become clear my employment prospects were limited without it. It took 8 1/2 years to get my first class honours degree. After that I started a post-grad diploma but was forced to quit studying when I had my second major

breakdown. I have been on a disability pension since I was 46. So - no children or grandchildren. No career - so no decent income, no superannuation, no status in the community, and limited choices in the the very many aspects of life that are affected by income levels. And much shame - despite all the knowledge I know have about mental illness and why I suffer from it, I still have internalised social stigma. I still feel shame, I still feel judged, I still feel mental illness is seen as a personal failing, an inadequacy. Pretty much the first question most people having on meeting someone new is What do you do? And what do you answer when you struggle to do the dishes and sweep the floor? Or when you seem ""normal"" but your life is far from ""normal""? Or when you really don't feel that you want to go into why it is that you don't work or have children? I am deeply grateful for the income support I do receive, for the fact my psychiatrist bulk bills, for the acuity, empathy, generosity and enormous toolkit of my psychologist. I am grateful for the deep empathy and emotional and financial support offered my partner. I am grateful for the intelligence I have been able to bring to my own situation and the resourcefulness and grit. I am grateful for my life, for the good fortune I have had in being born of Anglo-Celtic descent in this country at the time I was. I am grateful for physical mobility, for the cultural and intellectual nourishment Melbourne provides, and the peaceful environment of the suburb in which I now live. I am grateful for the beauty of flowers and sunny blue skies, for the sight of birds splashing in the birdbath and the sounds of magpies singing. For having a space in which to do yoga, for a garden to play in. But my life has been very painful much of the time, at times excruciatingly so. And if the Commission can can learn from my experience to reduce the likelihood of such suffering in future, then I will be glad.   "