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

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N/A

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

"Support employers, regulate and legislate so that policies and procedures are in place so that mental health issues do not mean people lose their jobs. My employer is and has been exemplary in providing me with support and actually helping me to access psychiatric assessment and services, because the system could not provide that. Although not all employers will have the capacity to support people in the same ways i have been (such as extra gifted sick leave from a pool, flexibility to work from home, and offering access to an independent psychiatrist for the benefit of both them and myself), there are definitely ways more support can be offered. I've heard people on Anx/depression forums describe how they're an outcast and not supported by their employer at all to recover. Had I lost my job - it was the one part of my life that was not in tatters at the time of my nervous breakdown - I would have killed myself without question. The prospect of not being able to provide for myself and my children would have been the final straw on top of all the other final straws. Me saying my brain broke and I needed treatment and time off to recover shouldn't be any different to me saying I broke my arm and needed treatment and time off to recover.   In addition, when admitted to critical care (███████████████ I was immediately prescribed SSRIs on day 1 despite not having had proper assessment or a confirmed diagnosis. Had I not been stubborn and pushy, saying on day 2 of ████ care that I didn't know what was wrong but I'd had depression before and it wasn't depression but I didn't know what it was yet, could we look at a proper diagnosis etc, and refused to take the SSRIs until a proper and correct diagnosis was confirmed, my treatment would have started on completely the wrong trajectory and the risk of suicide would have actually been made greater by the ████ team attempting (along with my GP) a 'Blanket' approach of saying 'you aren't ok so you obviously have depression, take these anti-depressants you'll be ok'. I actually had PTSD. Not many people apparently have the insight to be able to say 'this isn't normal for my not normal' and the system service providers actually help them to get a proper diagnosis. So the understanding of individual clients' issues still isn't htere, a blanket 'take this tablet' approach is attempted and for many it's the wrong diagnosis, plus some of the medication can actually increase your risk of killing yourself at a time when you're already suicidal. The service providers just aren't resources enough to be able to take the time to perform proper diagnostics with patients and in turn this can lead to a completely wrong path of treatment (wrong therapists, wrong medication, wrong support...). A blanket approach just isn't suitable, but services are too stretched to actually service and assess clients properly. Why assume the alternator is broken on a car when it could be any number of other things, we do diagnostics first, but the mental health system operates the other way - medicate first on an assumption based on a hour's assessment, then realise later it was wrong and has actually made things worse for the patient, they're now on the wrong medications which take months or years to wean off, and have been sent for the wrong therapy treatment with the wrong provider. I'm stubborn and pushy and I know my own mind, many others do not have those luxuries, had I simply accepted the initial 'diagnosis' and incorrect medication and therapy, I'd probably have

actually killed myself for sure. "

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 have to say the ████ team were really good in many ways, but i have no family in Australia and my friends didn't really know what to do. if critical care could have helped them look after me that would have made things easier. Friends have a tendency to run away when they don't know what to do or how they can help or look after you. Support for the carers from day 1 could be much better. I was given a lot of printed information which I couldn't take in at the time, while my friends struggled to support me as they're not healthcare professionals. I wish I had got to a practitioner before I totally broke down, and actually afterwards my boss said he'd noticed things like I'd changed how I dressed (to dark plain clothes and shoes), I'd stopped doing my nails, wearing less make up, stopped colouring my hair...the signs were there and people did notice but they didn't have the knowledge to draw the line of sight from my changed behaviour to the fact I was struggling with severe mental illness. I was still going to work and doing that OK. People either felt they couldn't say anything, or didn't click that the changes were because I wasn't OK. If more bosses, colleagues, friends were aware of the subtle but actually quite obvious changes I was showing (which weren't conscious on my part and I didn't notice them myself), maybe someone would have felt confident enough to ask me about it or just mention it, or actually draw the line of sight to the fact I was really, really struggling and was suicidal. I also felt in myself that because I couldn't describe a specific illness or issue, I didn't see the point in going to the Doctor for help. had I done this earlier I mightn't have had a total breakdown and had to have 7 weeks off work. I now tell friends I wish I'd got help sooner, and I know at least 3 of them have actually gone and got a mental health plan and counselling at an earlier stage because I have flagged my lesson on that one with them. so I'm basically saying if more people were taught what the EARLY signs can look like of someone struggling, they might say something to someone, or the person might realise themselves to get help earlier and prevent such a major incident as I am recovering from. "

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

"I am so isolated here with no family and friends find it hard when you're really sick to help you, they don't know how and are so busy with their own lives and families. Spending Christmas alone etc is really difficult. But I didn't know where to go (I still don't). I often volunteer at community lunch or homeless support services over Christmas but was too ill to sort it out in time because I'd had a complete breakdown myself. It seemed like the whole world shut down over Christmas and I was shut out of everything. I didn't know what options I had to just spend time with others whether that was as a volunteer or a receiver of support or both. I still don't. I didn't realise there were regularly held anxiety support groups etc until AFTER I'd had a breakdown. More promotion of support services he help people feel connected in society would have really helped me. I literally had no one at times and for long periods. Relying on friends puts strain on friendships as well at a time you totally don't wan't to ruin them, but you do. It makes you further isolated. Even when I got my mental health plan, my GP and psychologist never told me about any support groups, facebook pages/groups etc that were available. had I known I would have used them. But this would in turn put more strain on their limited resources. In short, support isn't promoted well enough, and resources are not enough for those groups to support everyone who would access them if they were better promoted. I also found it impossible to actually articulate how I was feeling in words so calling lifeline etc wasn't an option for me. Others have told me they are really good, but again under-resourced. Once I was released from critical ████ team care after a

couple of weeks, I had a minimum 3 week wait for a psychologist appointment, which was torturous. I know another person who experienced the same thing at the same time, they weren't ███ team'd but were suicidal, and had to wait 3-4 weeks from GP referral to appointment. My psychiatric referral was made on October 31, my first appointment with a psychiatrist is going to be May 31. If we are not the right fit for me I'll probably have another few months until I can find another. This is also not helpful. The chasm between critical care and my initial psychologist appointment (3-4 weeks) almost pushed me over the edge and then to wait 6 months for psychiatric has also not been helpful. I have had to chase up and chase up and chase up the psychiatric appointment. This means I am still not on the correct medication and there are other conditions I am suspected to have but can't yet be confirmed. I was close to suicide many many times and friends were more helpful in those moments than the system could ever be because the resourcing has been eroded to the point that it no longer actually works properly. People kill themselves in moments of desperation, if you don't know where to get help or they're too busy to answer the phone (not their fault), you might just go over the edge and end it all. Even though you might not have if you'd have had support at the right moment. When I am suicidal I honestly don't want anyone to see me like that, but I need a voice of compassion and reason to help me through those moments. I still don't know the answer. "

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 links between gut health and brain health are poorly understood by both practitioners and the general population. It's an evolving field of research but warrants much more attention. The lack of social connectedness is a real problem for many. Building communities that are supportive is key. I have had issues finding practitioners that will support my want to use natural substitutes like medicinal cannabis and 5-htp. I still don't have that in my care team. My GP refuses to prescribe medicinal cannabis, I assume because she is caught up in the big-pharma commission for prescribing traditional medications and also hasn't and won't do the training course. All the GP's I've consulted have been the same. Funding for the use of psychedelics in therapy in Australia is way behind other developed nations and is still an issue. Trials are underway but are impossible to join and very over-subscribed and under funded. The reasons for this are not clear but it can be argued that big-pharma is blocking this because pharma companies don't actually want people to stop buying and consuming their medication, even though it can make things worse through side effects and also be the wrong thing for some patients. I can't access medicinal cannabis in victoria without risking losing my own money and getting into trouble with the law. I'm not a fried stoner wanting a free high, I have a biology and nutrition background and have done many years of meditation as well. Just because I don't want to take traditional SSRIs with all their known issues, I am disenfranchised from having a care team that will help me select and use alternative treatments. At no time has any practitioner discussed the gut-brain health aspect, that's all bee through my own investigation and research and implementation. There just isn't a holistic approach to mental health at all. it's all about medicating the symptoms without treating the causes, and only using outdated traditional pharmaceuticals. Doctors need education, and the researchers doing this alternative work need funding and promotion. I've had repeated experiences of my referrals not being received, getting lost, not being done or not being acted upon. All contributed to delaying my recovery and gaining access to services. On many occasions I have had to chase up my own referrals, look for my own psychiatrist, worry about whether I can pay for things, and who knows what happens to referrals that are just not received? I've also had to remain in charge of providing information across my providers as they seem

incapable of actually communicating themselves. Extra strain on someone recovering from a full nervous breakdown and suicidal mindset. A single point of contact to work with the patent across all providers would be really helpful.A flow chart of services and how to access them would have been really helpful for me, I found the system impossible to actually navigate whilst I was suicidal, I didn't understand what was available and how to access services, and even though I keep trying I have yet to find a care team that has the knowledge and ability and willingness to help me use natural alternatives. I pay for them all myself so I give up other things to do this, and risk legal action as well. Why should I have to do this?? Where is the support in the system, and the knowledge? I still don't know if the psychiatrist I've waited 6 months to see will support me in this approach. Also, I hear of many many people who can get Valium at the drop of a hat, yet I always take less than my prescribed amount and only when I need it (I'm going through PTSD therapy which does require some relief now and then). I don't take it every day like may but my GP is really unwilling to provide it so I have it there when I need it. I don't understand this and it isn't helpful. No wonder people end up Doctor shopping. As I discussed above the chasm between critical care and psychology/psychiatric is terrible as well. "

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"I'm not sure, isolation, poor diet and access to decent food, plus poor education about what you can do to look after yourself physically and mentally would all help. Why aren't kids taught about mental health and the links between this and physical health more at school??"

What are the needs of family members and carers and what can be done better to support them?
I'm not sure as I'm the person with mental health issues and I don't have anyone looking after me. That's a better question for those who have tried to help me. some formal information and education would probably be helpful.

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
"Decent pay and conditions, proper resourcing, better training, and better promotion of holistic health approaches. Probably a better question for those in the mental health workforce."

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 often can't attend support groups etc because I'm trying to single parent and work and get better. If I could access these via audio/video conferencing I could still attend when my kids are in bed, which would really help and also limit the isolation I experience having no family around.flexibility in workplaces is also key and support and regulation and legislation to help them achieve this would help"

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?
"Stop discriminating against those who want to source natural/alternative healthcare and medication options, increase the availability of those options, fund more research into those alternative options (after all, it can't really be robustly argued that the traditional approaches have

worked, or we wouldn't be having this Royal Commission would we?!), don't stigmatise or fine or prosecute or exclude from the system those who want to take alternative treatments, supplement the cost of them like traditional pharmas, stop sitting in the pockets of big-pharma, educate healthcare professionals about the alternatives available, make sure people have access to affordable decent food and are educated about how important this is in supporting good mental health. the whole system is overloaded and underfunded.Make the system clearer to navigate and ensure patients have easy options (maybe a website where you can click on your pathway and find practitioners and support options available), give patients a say in what medications theyre happy with taking, and support those who want to try natural alternative."

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
"Not a question for me, probably one for healthcare professionals"

Is there anything else you would like to share with the Royal Commission?
"Only that if my employer had abandoned me I'd have just ended it all, so getting employers on board and resourced with policies and funding and support would be helpful for many.Also I've seen friends who genuinely want to work have to resort to NDIS due to genuine health issues, they can't even pay their rent on the money they get, it adds to their distress and pushes them towards suicide even more."