

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?

"I think a lot of stigma has already been reduced, however it still exists and there is still not an understanding of how mental illness manifests which contributes to the stigma and a lot of misunderstanding around people living with mental illness. An understanding that being mentally ill doesn't necessarily manifest in ways that people can see, and that there are many people trying to hold down jobs and function day to day that are not obviously to the outside world, mentally ill. Just because someone appears to be what is considered to be "highly functioning", even by those in the mental health profession, and they are trying to work, it doesn't mean that they don't need help and they won't benefit from help, and it doesn't mean that they are not struggling. I was suicidal and drinking 2 bottles of wine a night at my worst point, and still getting up at 6.30am to go to work, feeling like I would rather jump in front of the train than get on it, and having the shakes by midday. But to everyone around me I was ok because I was still going to work and pretending I was ok. It wasn't until I was admitted to hospital that people around me realised I wasn't ok, and then I had the stigma of a hospital admission and being told my family that "you're not a nutter, you don't need to go to hospital". It should be ok to be open about suffering from a mental illness rather than being worried that your boss will fire you because he/she thinks you can't handle the stress, or you need to take time off when going through an acute phase. Someone can be ok most of the time but then need time and support during an acute phase, then once they have recovered go back to work. "

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?

"There are some good supports that are available but knowing how to access them is key. PARC and community support services such as ERMHA have been supportive of me in the past, but before someone was able to put me in touch I had never heard of them. PARC was suggested to me by the staff at the hospital, and ERMHA was found for me by a friend who just kept ringing mental health support services until he found someone that would work in our area and would come out to see me and assess if I was an appropriate candidate for support. As I appear to be "highly functioning" by mental health standards they nearly didn't decide to take me on, but they did and it was incredibly beneficial to me, so I think these kind of resources need to be careful in making judgement for care on appearances and whether or not someone appears functional. I was actually really struggling and was no longer working, but I doubt if I had still been working I would have been able to get that support. Care should be given to those who are working as well to help them stay in their job, rather than getting to a point where they have to quit or take time off because they are hospitalised, because in the long term, it will be beneficial for them to return to work. I think there is less of a focus on prevention and ongoing management, and that this needs to be addressed as well as acute crisis treatment, as an acute crisis could be avoided for some if they are getting the right management and treatment. The Mental Health plan is a good first step

in realising that treatment is not easy and does require time and counseling. However it is extremely short sighted in only offering 10 sessions that can get a medicare rebate a year. This is not even once a month, and for those recovering from, or trying to prevent another acute crisis this is not enough. Once a month would be beneficial, but even better would be more frequently. Many people require seeing someone weekly for treatments like Dialectical Behavioural Therapy but this is just not realistic for people in a compromised financial position (as many who suffer from mental illness are). I realise that budget constraints mean that this is not necessarily realistic, but I think there would be those for whom 10 sessions is ok, and those for whom it's not, and a good GP should be able to help and discern if someone needs more and put this on a plan. On that note, proper GP training is key. I know there are many that do not write the plans properly and many that don't have a good understanding of how to help and refer someone with mental illness. It should be part of their initial and ongoing GP training. I am lucky to have been seeing my GP for the last 30 years (although I am only 34!), and though she is really hard to get in to see, and she doesn't bulk bill, she is worth it because she knows my history and what I need, and she knows her stuff and what to recommend. I dread to think what will happen when she retires, because from what I have been told, this is not the norm. PARC was suggested to me as a "step up-step down" model - a step up for those that perhaps are reaching crisis but before they require full hospitalisation, and a step down for those coming out of hospital. I'm not sure how much they are used in the "step up" part but more access to this for people who are pre-hospital could be useful in freeing up beds for acute cases while giving these people the support they require without them getting to the point where they need to be admitted."

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

"I know that there is hospital admission and helplines for those who are suicidal. They can, however can be hard to access. My experience of hospital was great, I had a CAT team come to assess me and strongly suggest that if I voluntarily admitted myself it would be better for me (so that I could prevent an involuntary admission). I have also used phone lines but had varying degrees of how useful they were and how quickly I could access help. I'm also aware that there are cases where people are turned away because hospitals are full, or leave while waiting admission. There need to be enough public hospital beds and it would be better to have them in all hospitals rather than just the biggest, because the private hospital and private mental health system is prohibitively expensive for the majority of people."

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.

"I think there are varying degrees of competence of doctors, specialists and support workers which makes people's experiences different, and if someone is churning through multiple people, rather than just one person, this can lead to conflicting information and diagnoses. As first port of call, if someone comes in to see a GP, their GP needs to be able to discern if they need mental health services. I know that this is not always the case for many, and most people I know do not have a good relationship with their GP, especially if they are having to see someone who bulk bills, they will often end up seeing many, or someone they don't like or doesn't listen to them because they don't get that choice. A GP may not suggest a mental health plan, so the patient may not be aware that they can see a psychologist and get some money back for it. Bulk billing psychologists and psychiatrists are extremely hard to come by, Many people with mental illness are going to be more financially strained than others, so the ability to be able to afford support services is key."

Access to a free mental health support worker if they can't get access to a psychologist, but many don't know they have this option, and when I tried to get one for a friend I was told that she now has to be on the NDIS, which is ridiculous, as she may not even get on it for a start (even with anxiety that means she can't work) and the amount of work involved to apply for it and work around the red tape is anxiety producing in itself. A one stop phone line that can refer someone to a trained GP, a support service, or a bulk billing psychologist or psychiatrist would be great, as someone could ring, even a GP if they weren't sure and have their options fully laid out and made clear. My experience with psychiatrists hasn't been great- when mine suddenly retired, I managed to get in to see someone at a bulk billing clinic. He didn't seem to want to take prior history into account and went down his own path of re-diagnosing me with something different and adding a new medication. My psychologist who I had been seeing for some years suggested a consultant psychiatrist she knew of and trusted so I went to him (and he was really expensive). But he gave me a lifetime diagnosis of Borderline Personality disorder in looking at my entire history, as even though I don't meet the full diagnosis criteria now, he could see that I had in the past. A diagnosis that made sense to me as after 17 years of living with mental illness, saying that I just had ""depression"" or ""anxiety"" fit. This is what my retired psychiatrist had thought, but the new one didn't. The new one moved on, so I had to find a new one again, and despite the fact that he had been suggested by the consultant psychiatrist, he proceeded to go down a new path in looking to diagnose me with Binge Eating Disorder (which I also probably have admittedly) and medicating me for this, but I had concerns as the medication for this is expensive, and can actually produce anxiety, which in someone who already gets overwhelmed and anxious is maybe not the best idea? Medication - can be extremely expensive, and for some people, a love-hate relationship. It's hard to stay on the medication to keep you well if you can't afford it. It's also hard to stay on a medication if it makes you tired so that you can't actually function to get to work. and my consultant psychiatrist told me that if the bad side effects outweigh the good, then another medication is recommended, but I see people that are crippled by their mental illness, and then crippled more by their medication. So they end up in a catch 22 situation. Medication management is so important to a lot of people in staying well, but I think many doctors, including GPs, prescribe and don't actually follow up to manage it. And if you can't afford to see a psychiatrist to prescribe and manage your medication, you are stuck with your GP who may not have the specialist knowledge required."

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

"Having to be on the NDIS to access a mental health service is a ridiculous idea (as I was told when trying to find a support worker for a friend in a rural area). Someone suffering from a mental illness does not want to be seen as disabled, and they may be fine for the rest of their life if they can get the right treatment when they need it. Lack of access to affordable services and GPs, psychologists and psychiatrists who have the correct knowledge to help people means that rural communities miss out. Those in low socioeconomic situations who don't have the means to pay for treatment miss out. We need funding to help people. Even if someone suffering from chronic illness (not just a mental illness) is given a health care card for a period of time (or permanently if it's a permanent illness?) to help access services this would help. I apparently earn too much money to get a health care card now even though I still earn less than \$40K a year (and my pay is variable on how much I work, which is based on how well I am). I would estimate I spend around \$100-150 a month on medication (for multiple illnesses) and another \$200-300 on doctors appointments, depending on how many I have in a month. The safety net is there, but it is a lot out of pocket and doesn't include medications. I live in the suburbs, so I can't imagine how much

worse this is for someone in a rural area that may not be able to work."

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

"I don't know if I can say much about this, as to be honest I keep my family and friends in the dark about my mental illness as it has destroyed relationships in the past where people just don't know how to respond. A good idea might be more education about mental illness, or even a few rebated sessions with a psychologist to explain the illness of the individual, or also to help the family member/carer to cope with the demands of supporting someone."

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

"I guess with anything, money speaks volumes. I'm not really qualified to answer much about this. I know that mental health workers are subjected to physical and verbal abuse and this can cause them to leave the area prematurely. I don't know if peer support is particularly well paid. And if it is part time it is potentially less attractive to someone who is trying to make enough money to get by."

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 experience of living with mental illness and other illnesses has meant that I have gone from being a university educated graduate working in a full time research job to someone working in a field that doesn't require my skills, using little intelligence, working a part time job and a casual job and barely getting enough money to live on (actually I would say not enough to live on since I am unable to rent on my own or save to buy a house, which means I have to live with my parents, which is rather degrading for a 34 year old who has been very independent in the past and is quite capable of it if not for the money situation). Constant doctors appointments mean that I can't work full time, and I am too exhausted or ill to do that anyway. Working full time would exhaust me and lead to more mental health issues. I had to leave my field due to an acute crisis and was unable to work for over a year. I was supported during the crisis in one job, but then that ended and I wasn't offered another one in the new lab (whether because of my extended hospital stay due to mental illness I don't know) and the second job I landed was far too stressful and I had little transition support into a different role let alone mental health support and had to quit before I hit an acute crisis again. I had very little support from Centrelink even though I had documentation from my doctors that I couldn't work. There was access to a payment for a health crisis but only for those that had a job or study to return to, which excluded me. I was not interested (although probably eligible) in applying for a disability support pension as I was not disabled and wanted to return to work eventually. Based on my experience: More opportunities for part time work for those that can't work full time would be beneficial, and flexible work that allows people to work around when they are ill and when they are well would also help, however I am aware that in terms of a business looking to do this it is not good for business. Also more help for those that are unable to work due to illness. Mental illness is not necessarily a disability and someone shouldn't need to go onto a disability support pension, and if they do, it should be reviewed every few years, as people can and do get better. I know people on disability who if given the right treatment, would be able to work, but they don't have any incentive to as they can be on the pension (and it will be a long time as they are only in their 20s). Or I know people who can't get the pension and get put on

newstart with the wavered requirements. If they can't work and have to be on newstart, they should have new requirements of seeing a centrelink provided support worker and help from centrelink to find bulk billing services where they can get the right treatment so that they are not on welfare forever. Because having a job and contributing can be healing in itself, and I get extremely frustrated working my butt off and hardly getting by when I know that there are people doing nothing to make themselves better and just relying on centrelink payments without getting the help they need and deserve. Conversely, if someone has doctors saying that they do need centrelink temporarily while they get back on their feet, they should be able to get the help, get the medical support, and then get support in getting back to work. My experience with centrelink was very poor, and the job provider that they sent me to wasn't really much help, as I actually already had a part time job of a few hours a week, I just wasn't capable at the time of working any more than that, but needed money to support myself. Centrelink still seemed to think I needed to look for a job when I had one and ignored the letters from doctors. Not having money is stressful in itself and can actually contribute to increased anxiety so if we can help people get well when they are ill, and transition to something where they can earn money when they are well - even if this doesn't look like a regular 9-5 40 hours a week job- we can both reduce the burden on society in caring for those with mental health, as well as supporting those with mental health to have better work and social opportunities. This requires working with support services and health practitioners for each person and assessing them as an individual, not just a one size fits all approach."

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?

"More sessions that are able to be claimed under medicare on a Mental health plan. More support for those who are unable to work in getting access to money and support. For those in low socioeconomic circumstances, better access mental health support workers and bulk billing psychologists and psychiatrists who can diagnose and give ongoing management and treatment. Better training for GPs in identifying who needs support and giving them the information and access to services that they require. More beds for those who need immediate hospitalisation and treatment, and more access to hospitals with these beds. Better recognition that prevention and management are just as important as immediate treatment, and for some this will not require much, but for others this may be lifetime management to be able to avoid going back into a crisis. Remove the difference in medicare rebate between counseling psychologists and clinical psychologists to make both accessible."

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

"Every time there is a news story that involves anything about mental health, Beyond Blue Helpline, Lifeline and/or Suicide Prevention line numbers are quoted after the story. This is great, but these services are already stretched. So more funding for these so more people can have their call taken would be great. Also a phonenumber or website that people can call or access that gives them full access to what is available for people that need help with their mental health, whether they are accessing for someone so they can get all the information they need in one place, learn what a mental health plan is, the different kinds of support available, and what may be best for them. It could also give them information to take to their GP, or suggest GPs with experience in mental health that are in the location of that person (and also other types of support workers). Also information for carers. Something where people don't have to hunt the information that they need down, and that gives them clear information on what they are entitled to. I'm not aware of

anything like this that exists and many people don't know about mental health plans, or chronic disease management plans, and their GPs don't tell them, so there needs to be somewhere someone could find this information if they can't get it from their GP. "

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

"Based on my experience living with a mental illness and other illnesses, I don't think that people realise the level of effort that is required for some people to remain "well" and participate in society. I am intelligent (according to everyone else, I don't feel that anymore) and because I work and socialise with friends I do appear highly functioning. But that doesn't mean that I don't need support- I rely greatly on my psychologist, both as someone to talk to, but also in helping me to problem solve and give me the support that I need. I can only see her every 2-3 weeks due to finances and work however, and because she is not a clinical psychologist I don't get as much medicate rebate, though I have found her more useful than clinical psychologists I have seen in the past. I have suffered from mental illness since 16, first hospitalised at 17, and not diagnosed properly until 33. Only a specialist in borderline personality disorder managed this, and made the link between my polycystic ovarian syndrome and BPD. I relied a lot on alcohol to self medicate when I was younger and overtime this also turned to binge eating (which certainly doesn't help the PCOS though I try hard to maintain or lose weight). Between this and the medication I have to take for both mental illness and PCOS, I don't know if this has caused me to develop ulcerative proctitis, which is causing havoc for me now and a great deal of stress, as the medication for that lowers my immune system, so work is being severely effected either by me getting sick, or suffering from something I have eaten. The stress is in turn severely effecting my mental health, but I don't feel like I have a lot of support- financially I have to keep working, and maintain the hours that I am working in order to be both keep on top of work and not let my work colleagues down, but also so that I can afford to go to all the appointments I need to - regular appointments with GP if I'm sick or need a mental health plan renewal, gastroenterologist, dietitian, psychologist and psychiatrist (who I am currently not seeing as I don't have time/money). As well as all the medication I need to get. SNRI, the pill for PCOS (which is not on the PBS), metformin for PCOS, mezavant for colitis and probiotics/vitamins to try to maintain general health. There is not a lot of support for someone like me. I have times that I question if it's even worth going forward and I struggle to see a future for myself, and I am not considered a priority because I can work and earn money. But I am struggling to maintain this at the moment, work is suffering, but there is no option for me to take time off to recover as financially it's not viable. I basically feel like a complete failure at life as I can't even afford to live alone now my housemate has moved I'm back with my parents. It is degrading and I feel a shell of the person that I could have become. There has been a medication change suggested that could help me, but the only way to change would be over months and very slowly as I am unable to afford to be admitted to a private hospital for a quick transition. And I don't even know if they would work and if a slow transition would be worth it, for all the withdrawal symptoms and medication rebound that I would have to deal with in doing it that way. I explain all this, not because I have the answers, or expect you to have the answers or need your pity (I actually hate complaining, not that you can tell from this!) but because I need people to see the different perspective in my story- I am not someone who can't function and has to rely on complete support, and because of that, the support available to me is restricted. Certainly being able to get more rebates for my psychologist visits would be a start. I am sure that there are so many more people out there that are trying to scrape by and survive but are looked upon as not "needing" help, and I want to bring them to the attention of the commission as well. If we can get the help we need we can keep on going and contribute and work, therefore we pay tax and help fund these services. If we can't get help we risk falling into acute mental health crisis again and

end up costing more because then we need more intervention and further ongoing management. Thank you for reading and taking submissions. I am not going to upload any further supporting documents, as this is just a reflection of my lived experience, and I don't think it requires them."