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

SUB. 0002.0017.0004

[redacted]

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Stricter policies,guidelines and better training for service providers and treating professionals (including hospitals) on how to respond to sufferers better. Public education via media and other forums to promote better understanding. "

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 believe that our mental health system has been neglected for so long that only a complete overhaul will suffice. We need to ensure that there are the specialized services out there to begin with which means we need to start with our Universities to make sure we are providing the right training and incentives to our future generations of treating professionals. We need to increase the amount of sessions under a mental health plan in our public system from 10 to at least 50 per year. Funding needs to be allocated based on need not category. Get rid of waiting lists by ensuring services are better resourced to provide treatment when needed. Dont continue to neglect those who have already been neglected by only focusing on early treatment. Headspace is not the go to for all early interventions. Mental illness can occur at any age so it is wrong to think that they are the only ones.

What is already working well and what can be done better to prevent suicide?
Exactly what I said above.

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.
What makes it extremely hard is the lack of communication between state and federal systems. Federal systems like Centrelink and the NDIS rely on State services to provide the evidence and treatment needed. If this is lacking then the sufferer is declined services like the Disability Support Pension and/or access the NDIS. A lack of services and specialised services in the public health system makes it extremely difficult for people to be treated.

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"As an Aboriginal woman who provides disability advocacy and NDIS appeals support to my local Aboriginal Community I feel that the services available do not properly acknowledge the higher prevalence of disability and, in particular, generational trauma within our community. We do not have culturally specific trauma specialists or service providers. We have a great building by a serious lack of specialists. "

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

As a carer I believe that we need to stop being treated like slave labor. We need to be properly compensated for our caring roles. We need to be included in our loved ones treatment plans in the knowledge that we know our loved ones the best and are a resource not a hindrance. We deserve to be treated with a lot more respect that we currently receive.

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

Much more money needs to be allocated to better resource and create new service providers. We need to provide better incentives to the future workforce to ensure that they are properly compensated for their work everywhere and services are retained.

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?

All of the above.

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?

Training for Specialised treating specialists in our Universities. No more unreasonable waiting lists. Ensuring that sufferers have access to treatment when needed just like someone with a physical illness.

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

"Money, money and more money. Funding needs to be allocated on need not category. "

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

No.

Submission

My name is [redacted] I am a Palawa woman and part of the Wathaurong Aboriginal Community in [redacted]. I work as a disability advocate and NDIS appeals support officer. I am also the carer for a 22 year old daughter who has Borderline Personality Disorder.

In my submission I will be speaking on two levels. Firstly from my perspective as a disability advocate where I will argue that Federal systems like Centrelink and the NDIA are intrinsically linked/interdependent on State services. Secondly from my perspective as the carer for my daughter with Borderline Personality Disorder who cannot access services because they do not exist or are woefully inadequate.

I started working as a disability advocate for the [redacted] association in [redacted] in 2010. Prior to this I worked for a Disability Employment Service Provider from which I was retrenched. It was this role that led to me being inundated with referrals for people needing advocacy to apply for the Disability Support Pension (DSP). Ex work colleagues who still worked in the industry were referring their clients to me for assistance as they did not know what to do with them. They reported that they needed to keep referrals quiet from their managers or they would be reprimanded. The organisations did not want any clients being exited from their programs of support because they would lose money from the Government.

The overwhelming majority of referrals were for people suffering from a plethora of mental health conditions. It appeared that eligibility for DSP for those with mental health conditions was becoming extremely hard to prove. It also became apparent that strategies were being put in place to increase difficulties for the sole purpose of reducing the number of successful claims. For example, in 2012, the Treating Doctors Report was removed from the DSP claim form. This was the only guide a treating professional had for reporting. It was replaced by a very simple check list that did not ask for what was actually needed by the applicant thus setting applicants up to fail. The evidence required was either too costly or simply not available.

Staff at Centrelink are being told that they cannot answer any questions from applicants on eligibility criteria. They cannot even give them a claim form. They insist that one will be posted out. The issue is that along with the claim form comes a letter giving them 14 days to provide medical evidence. This can't be done due to a lack of services, extremely long waiting lists and/or because it cost too much. A letter is then received telling them their claim had been rejected. There is statistical data published and readily available showing that the percentage of DSP Claim rejections is now greater than 72% and rising. People are falling through the cracks of our broken mental health system.

The layers of rejection from Federal systems are exposing people to repeated trauma. The cost associated with this affects all of us in a devastating way. This devastation and neglect is so entrenched that I believe the only road to recovery is a complete and utter overhaul of the system, services and the way we treat people with a mental health condition. Yes it is the federal systems that are rejecting these people but it is the lack of state services that is enabling such rejections and subsequent trauma.

As an advocate I had a client who had his DSP eligibility revoked due to a 'dob in'. This 'dob in' was challenged and subsequently disproven with my assistance but the resulting review of his DSP, which he had been on for the past 28 years, was revoked. This was because the acceptable evidence had changed which meant he was no longer eligible. The goal post had been shifted dramatically. What eventuated from that point on is what could only be described as Government sanctioned bullying for the next 3 years.

My task was to assist him to reclaim the DSP. This meant gathering the necessary evidence to tick the right boxes. What I had not counted on is the fact that Centrelink refused to liaise with me as his representative. He couldn't liaise with them because he did not have the capacity to do so. I also couldn't get anybody to fund a much needed assessment to prove his mental conditions. The Transport Accident Commission (TAC) refused as it was too long ago that he had his accident. He couldn't afford a Neuropsych Assessment to prove a suspected Acquired Brain Injury. This assessment is not funded under the public mental health system. He was becoming increasingly suicidal and a real risk of harm not only to himself but to others.

I managed to engage the services of a Victorian Legal Aid lawyer who successfully supported my client to have his DSP reinstated. This was after 3 years of battling the system and obvious prejudice against my client.

I understand that Centrelink is a federal organisation but eligibility for people with a mental health condition relies on State services being readily available. This includes advocacy and legal representation.

I currently have a 3 month waiting list as I am the sole disability advocate servicing [redacted] along with National Disability Insurance Scheme (NDIS) Appeals support of 6 hours per week. My advocacy work is State funded.

Federal and State services need to interact with each other. They cannot and should not be separated as this is detrimental to the person with a mental illness needing assistance. Yes we do get the offer of grants from the State Government every now and then but these have to be applied for every time. My organisation has only 5 staff to service all of [redacted] and that includes the Executive Officer. We are not adequately resourced to apply for grants. We already provide regular statistics on our work. Why is this not used to substantiate the need for additional funding?

I have only once been successful in getting legal representation for a client needing assistance with appealing the rejection of their claim for DSP. Every other case they declined on the basis that they did not believe the matter would settle. In all of these cases it is probably worth noting that the cases did successfully settle regardless but not without significant trauma being inflicted on the person in the process. This is despite advocacy assistance. Advocates are not a substitute for a lawyer. We are not trained as lawyers and are most definitely not paid as lawyers. We are also not a substitute for case management. We are grossly underfunded and underpaid for the work that we do and this must be addressed.

Mental health doesn't just affect the sufferer. It affects the whole community. If supports are not made readily available then the sufferer becomes re-traumatized. This in turn affects the carers, service providers (assuming they exist) and the community because you then have untrained and/or under resourced people trying to respond to a crisis. The whole system is therefore crisis driven.

Another case study will I think highlight the lack of resources for people with a mental health condition and the need for case management to be reinstated.

I had a client with a severe mental health condition seeking housing assistance. I attempted to assist her as much as my role as an advocate could but it became apparent that there was nothing further I could assist with.

Lack of treatment/ support caused her to become abusive and violent to me. The matter climaxed with her attempting to bash down my office door. Emergency services were unable to assist me because they were too busy and understaffed. We took out intervention orders which she ended up breaching. The police failed to take action on this.

The courts referred her to 6 months of intensive case management. It seemed that such case management is available in extreme circumstances via the courts system. Interestingly the appointed case manager ended up contacting me for referral to advocacy. I had to tell her no due to the intervention order in place. The NDIS contacted me as well for assistance with the NDIS access request. I again had to say no.

Being held prisoner in my office and lack of action by the Victorian police was extremely traumatizing for me and other people. It could have been avoided with adequate case management and support services.

Advocacy should not be the default for everyone else's too hard basket. We are being asked to provide services that we are not funded or trained to provide. Everyone is grossly underfunded and under-resourced. This needs to be addressed as a matter of urgency before something more serious occurs. People who fall through the cracks, now gaping chasms, become vulnerable to exploitation, be it drug abuse or terrorism. This is the price of underfunding resources and services for people with a mental health condition.

On a more personal level I am the carer for my daughter who has Borderline Personality Disorder (BPD). My daughter was first misdiagnosed with Bipolar at the age of 14 by a GP who put her on medication for it. I sought a second opinion from a psychiatrist who said she had BPD. He advised that she could not be formerly diagnosed until she was 18. She began getting treatment from a mental health nurse who specialised in this disorder under the governance of this psychiatrist. As a concerned parent I proceeded to educate myself by reading as much material as I could on the disorder. I soon discovered that there was a lot of misinformation and myth surrounding the disorder. One of these was the belief that diagnosis couldn't occur until the age of 18.

Nothing seemed to be working and I started counselling to better understand and deal with the physical and verbal abuse I was receiving.

My daughter was self-harming by cutting herself. Eventually I got her into student accommodation in [redacted] The self-harming progressed to include drug and alcohol abuse along with numerous suicide attempts.

She started to receive treatment from [redacted]. I had various phone conversations with her psychologist. I remember her asking me to tell her how I feel which led me to writing up a letter where I poured my heart out. She never saw it. Eventually they closed their books on her. The reason given was because she wasn't attending enough appointments. She couldn't because she was too unwell. Her attempts to overdose on her medication resulted in her medication being restricted to weekly prescriptions. This meant that she had to get out of bed, which she could not always do, and go to the chemist. The chemist manager treated her like a drug addict. She also refused to acknowledge the closing the gap status on her prescription. I had begged the psychologist to lift this weekly restriction as it was not benefiting her. She refused saying they didn't want to be responsible for her overdosing. I said it would never be their responsibility but hers. My overwhelming feeling was that they wanted to close her file because they considered her too hard to deal with.

The next few years are a blur of ambulance trips and various crises. It continues today. I was, and am still, in extreme debt trying to rescue her from the various disasters. Housing, impulse issues, Myki fines, and complaints are a constant. This included one against a police officer who treated her appallingly when she tried to report a crime.

I am constantly rescuing her from Centrelink payment suspensions because she cannot comply with the mutual obligations. She would if she had access to adequate supports.

Throughout it all I am faced with a general ignorance of BPD. My daughter is in pain and no one is helping her. Indeed no one knows how to help her.

I can't afford a private psychiatrist and what is on offer via the mental health system is either non-existent or woefully inadequate. My daughter, and I, began to lose faith and trust so she went untreated for many years.

I tried to engage the services of [redacted] by putting myself on their Family Advisory Council. They tried to fob her off by saying she wasn't suitable because she wouldn't turn up. This was incorrect and turned out to be a 'misunderstanding'. Eventually someone came to see her. They referred her to [redacted] which supposedly had an 8 week waiting list. She never got contacted by them and it's been 3 years now. Instead they referred her to a wellbeing male counsellor at the local Aboriginal Coop, [redacted]. Apart from the inappropriate gender of the counsellor it was a totally unqualified counsellor.

I convinced her to engage with [redacted]. On her 3rd session with the psychologist she was told that she didn't know how to help her. You are only given 10 sessions per year under a mental health plan so this was something she couldn't afford to have wasted.

Eventually she helped herself in regard to the drug & alcohol abuse by home detoxing and getting into a drug rehabilitation facility run by the [redacted]. The reason why she was forced to home detox with my assistance was because there was no bed available in a detox unit in time for her to go to the rehabilitation place. Again lack of funding meant that there was very limited space. Once there they kept trying to toss her out saying that she was too unstable mentally.

She was subjected to racist remarks and homophobia by the other residents. Eventually she retaliated verbally and ended up being the one who was punished. She tried to commit suicide there and was told this was against the rules. They knew that I was in hospital at the time so they drove her to a backpackers in [redacted] and left her to rot. I complained to the [redacted] hierarchy and they apologized but that was it. My daughter then spent the next 12 months homeless, staying at a backpackers surrounded by drug dealers and trying to remain sober. She couldn't return home to me because I couldn't afford to support her and because of our volatile relationship.

She was put on a 6 month waiting list for a one off assessment by [redacted]. I had been contacting [redacted] since she was 16 trying to get her accepted by them for treatment. Each time they said their role was to help treating clinicians but not to provide direct treatment as they were too small and underfunded. She tried to return to [redacted] but they have a 2 year rule that says she cannot re engage with them after 2 years. She is now with [redacted] but they do not specialise in BPD and she has a limited time with them due to age restrictions. When you turn 22 you are no longer considered youth in many organisations. She had a drug and alcohol counsellor from [redacted] but only until she turned 22. She now has visions of living on the streets because she will no longer have any supports in place.

After 7 months of waiting she had her one off review with [redacted]. She was advised that they would take her on for treatment but they had a 9 month waiting list.

My daughter has been subjected to horrific treatment by the public and services. An ambulance officer told her that he can't be coming out to her in the middle of the night because she had an argument with her parents. She was 16 and not living at home. She had cut herself quite badly so called the ambulance. In hospital a Dr said that she had to find better ways of dealing with things. A psychologist said that being raped did not mean she had post-traumatic stress disorder or depression. A police officer told her to grow up and act her age when she tried to report a crime in extreme distress. The cycle of ignorance and neglect continues seemingly with no end in sight.

I am so tired of being judged by so called professionals. A nurse who was supposed to be assessing my daughter for [redacted] ask her questions like "how can you afford weed and alcohol?" I put my hand up and said here I am …the enabler. She put her glasses down her nose, looked me in the eyes and said "why on earth would you do a thing like that?" My response was that I have been left with no alternatives adding that I found it extremely annoying to be judged by someone who clearly hasn't got a clue on what it is like to care for someone that has no access to proper treatment.

I consider myself a fairly switched on and educated individual. I have tried for the last 8 years to get help for my daughter. She can't access DSP or the NDIS because she can't get the evidence she needs. Specialists and treating professionals simply aren't available to treat her and those that are do not have the specialization needed. We are fighting a losing battle because the services are not there and those that are there are inadequate or unaffordable. I just want to scream every time I hear that millions of dollars are being given to [redacted]. This seems to be the box tick for all Governments so that they can say they are providing early intervention. You simply cannot provide early intervention to those who have already been neglected in the mental health system. It's too late. Funding needs to be allocated on the basis of need not age or category. Above all it needs to ensure that there are appropriate services and specialists.

A lot of money was spent on the new extension for the [redacted] but where are the specialists that are needed to treat the generational trauma that is predominate in our community? Where are the specialists that will be considered appropriate for treatment and evidence for DSP and /or NDIS? Where are the Occupational Therapists? What good is a building without adequate services? Indeed what good is a mental health system without services and specialists? What good are 10 sessions per annum under a mental health plan for chronic mental health conditions that clearly require at least one session per week?

Our mental health system is broken. It needs a complete overhaul. This needs to begin with ensuring we have appropriately trained specialists to provide treatment in the public health sector. To do this we need to look at our universities to ensure we are providing the necessary training, resources and incentives needed to have the specialists so badly needed everywhere.

We then need to ensure that there are no gaps or waiting lists in services. Sufferers need to be assured that they can receive appropriate treatment when they become ill the same as anyone with a physical illness.

Services and the community need to be educated to understand that there is no difference between a mental illness and a physical illness. People with a mental illness deserve the same respect as everyone else. The only way to achieve this is through education and stricter guidelines and policies for services.

Our hospitals need to acknowledge that the needs of someone with a mental illness are as individual as those of someone with a physical illness. Emergency responses need to reflect this more appropriately. My daughter cannot handle the Emergency Room (ER) in a hospital as it is full of triggers for her. It is set up for physical emergencies only. She is forced to wait several hours before she is seen and when she is it’s by an untrained triage nurse who has no idea of what her needs are.

Finally we need to stop treating Carers like slave labour. We need to be properly compensated for our role. Most of us are extremely poor as a direct result of our caring roles. I am lucky because I now have an extremely supportive work place. This was not the case before. We, like anyone else, suffer burn out. We then become sick ourselves which is yet another layer of cost on our community. We need to be treated with a hell of a lot more genuine respect than we currently get. We are the ones that know our loved ones the best. We need to be included in their treatment much more than is currently the case.

Everyone needs to be funded better to provide the service and care required. All funding needs to be long term. A massive overhaul of mental health education, training and service provision is what is needed to fix a system that has been left to rot for far too long. Yes it will be costly but it will be far more costly not to do so.