

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

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## Name

Anonymous

### **What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?**

"In my view stigmatisation starts with the DSM and the field of Psychology. Its use of negative labels inevitably contributes to self stigma and stigma in the community. Borderline personality disorder as a label will never make anyone feel ok. Treatment resistant depression infers blame on the resistant patient rather than the psychiatrist's inability to appropriately treat them. Unless the language of mental illness is improved, I fear stigma is here to stay. The inequity in health funding which favours physical illness disproportionately also contributes the perception of mental ill health as less valid, implying the sufferers have less value or should be valued less. When mental health care is not treated as different, the space for reduced stigma is created "

### **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?**

"On most occasions when we needed to access hospital, or a new health professional there were delays in getting appointments, often of many weeks. In the case of hospital, the paucity of beds, particularly in mother baby units led to delays in care which exacerbated my partners condition. It was easier to get in when the delays allowed her condition to deteriorate to the extent that the triage system then prioritised her. Waiting lists for private psychiatrists in Bendigo have been in excess of 12 months for some, with others are not taking new patients. This delay at the earliest point of intervention adds to a sense of hopelessness and lack of relief when things are in a crisis state. Things that have been positive in my experience include: Genuine care and compassion from a number of professionals including 1 psychiatrist in particular as well as some psychologists, and community mental health workers. The local Community mental health team generally were far more insightful and appropriate in their responses to my partner than the majority of professionals. They also were more inclusive of me as a carer. Finding a skilled psychologist capable of working with my partner has been the best but hardest part of my experience of the system. "

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

N/A

### **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.**

"Continuity of care has been problematic in our experience. Each part of the system does its bit and leaves the client to take the next action that is required. This is most problematic with release from hospital. On most of the 6 occasions my partner was hospitalised, she was still unwell on release. There was no proper care plan in place and no assistance provided. Generally, the next step was make an appointment with your treating psychiatrist. Of course, my partner had regular

appointments with her psychiatrist before hospitalisation. It is difficult to understand how post hospital release continuing those appointments would be more effective. At one stage we were encouraged to leave a private mother baby unit because the private insurer only paid the top rate for a set number of days. While we were not told we must leave it was made clear we were less welcome. This clearly undermined my partners confidence in the hospital and we left shortly after. She was still not well however. The mix of private and public system providers often works against clients. Private hospital care is often more accessible in that beds are more available, more targeted in its care with specialist units and provides some continuity. However, episodes in between and subsequent to hospitalisation were referred back to my partners psychiatrist despite their limited availability. The advantage of continuity provided by private psychiatrists compared to the turnover in personnel in the public system, worked against us when the public system, including the community mental health teams, were involved. Their excessive workload and concern for continuity of psychiatry demanded that they referred back to the private practitioner as soon as possible. The private practitioners did not have additional capacity for more crisis type intervention or support. In addition there were obstacles to coordination of care and approach across services. Various attempts by practitioners to better coordinate responses between psychiatrist, psychologists and the public system, including a mother child support program failed. The failure of Medicare to cover psychology for long term treatment is a major issue. This drives a reliance on other services that are not equipped to be clinically effective including Cat Teams, Lifeline and in many cases psychiatrists that only provide short term relief. Families and carers do not seem to be considered as part of treating mental illness. In my experience, my knowledge of my partners illness, patterns, triggers capacity and resilience etc was not valued. Offering an opinion was characterised as interference. This was graphically illustrated in the [REDACTED] Clinic when my partner was in a very distressed state. The moved her to a locked ward and held her there in a sedated state for 2 weeks where her condition deteriorated. Eventually, despite the esteemed h [REDACTED] Clinic stating she would not cope out of the locked ward, my partner's father and I convinced them that she would cope and they agreed to try it. She did cope as we knew she could and was not re-admitted to the locked ward. This resistance to the views of the those who know their loved ones best unnecessarily exacerbated and prolonged her episode. They released her from the clinic within weeks though she was still unwell. "

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

N/A

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

"As a carer(partner) of someone with a chronic mental illness in rural Victoria, my experience of the mental health system has been marked by a succession of failures, missed opportunities and exclusion. This has contributed to my own burnout and challenges to my own mental health and wellbeing. I have recently decided to separate from my partner to protect my well being and that of my young child. The health system's failure to adequately support us as a family contributed significantly to my burnout. This in turn contributed to our family breakdown after 13 years. In that time my partner would have been assessed and treated by 3 successive psychiatrists regularly, had 6 hospitalisations in 3 different private clinics and public wards involving more than half a dozen other psychiatrists. The CAT (community mental health) teams have been involved on at least a dozen occasions. I have lost cost count of the number of psychologists that have tried to

work with my partner. We were involved with a program to support new parents with mental health issues and relationship counselling. My partner has been told she has a generalised anxiety disorder, treatment resistant depression, major depression, mood disorder and more recently, and accurately as having a borderline personality disorder (BPD). The impact of these different diagnoses included inappropriate treatment with an overreliance on medications, which are relatively ineffective with BPD and delays in finding the right kind of help. As a carer and partner, it prevented me from accessing the information that may have been useful in better understanding and responding to my partners behaviours. To this day, no one has referred me to the resources available to families supporting people with BPD. I found them too late to be of real value as our relationship was already too damaged. This is symptomatic of a broader failure in referral to supports both for my partner and myself. Despite all the interactions referred to above, which include two stints in mother baby units, I found out only by chance about the Special Childcare Benefit (as it was previously called). This provided in home care for my infant at no cost for a number of years. It enabled me to continue to work (vital for my own mental health), my child to have positive female carers in her life and some sense of normality. In our experience there was no comprehensive case management approach to referral to supports outside of the medical system for my partner or myself. Most professionals were not even aware of many of them. This is an essential requirement in my view. At the first contact with the mental health system, families and carers should have a case manager to look at the range of needs they may have individually and as a family and link them to the available supports. The experience of caring for my partner with a serious mental illness has been traumatising. At very few points on the journey have I felt at all supported as a carer. The impact on me has been profound and adverse. As a rural Victorian, access to carer support groups is limited. Having a young child that needs to be cared for when my partner is unable to do so further limits access to support. Support also needs to be specialised. While there may be some commonalities, the most empowering thing I experienced was a diagnosis for my partner that finally explained her behaviours. The information and support I need is different than for carers of people with other mental illnesses. Support groups or professionals need to understand and be resourced to respond appropriately. Support also needs to be practical. The most important support I had was the Special Childcare Benefit mentioned above. Respite has been a challenge and has not worked at all for us. The mental health service has an option to house my partner temporarily in a supported short term facility but always advised against it believing the exposure to other people there would make her condition worse. Conversely, I could not take a break as I was unable to keep up with tasks at home and work obligations. Support with home maintenance, upkeep would have been a great assistance. Support should also recognise the financial cost of caring; transport, medications, lost income from reduced work capacity and psychologist fees that are not covered by Medicare and cost thousands of dollars each year. I find myself in a situation where the cumulative impact of caring, relationship breakdown and costs past and into the future will ensure that we are all reliant on the state in old age. "

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

"One of the key challenges I encountered was that lack of expertise of many psychologists including clinical psychologists. The unregulated, highly emotive state of distress my partner exhibits was clearly beyond the scope what most could deal with appropriately. To this day, only 1 out of more than a dozen psychologists has competently responded to and made substantial progress with my partner. At the other end of the spectrum, a clinical psychologist we were seeing for the first or second time expressed deep concern at my partners mental state and told us

that in her professional view my partner had been released too early from a private hospital following the administration of ECT. I was in attendance due to my partners state. We were told to wait while she contacted the hospital to resolve what she thought was a serious situation. After some period of time passed she returned told us that she could not contact the psychiatrist and we should go home while she followed up. We never heard from her again. Another professional' in a management position terminated my partners support from a mother baby support service over the phone having never met my partner at a very vulnerable time. This caused her to become more unwell. In other cases professionals bought into the distress, amplifying it, and in one case leading directly to hospitalisation. While undoubtedly most psychologists are capable of treating most patients, more complex and entrenched illness seem to be beyond the training or skill level of most. My experience suggests many practitioners are unaware of the limitations of their training and unable to identify when to refer to specialist or more experienced practitioners. It took us four years to find a competent psychologist. The hopelessness and suffering incurred during that four-year period would have been avoided potentially if better standards of training and practice were in place. Greater specialisation, improved selection processes and deeper skill development for psychologists should be a priority. Properly funding the system to reduce case loads and the related staff turnover, better integration and referral should assist with workforce retention"

**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?**

N/A

**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?**

Properly fund the first point of contact to reduce wait times for initial clinical responses. Improve integration between the system elements both private and public. Case management for whole of family support Properly fund mental health care proportionate to its prevalence I the community Ensure psychology and not just psychiatry are embedded in the funded mental health system

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

N/A

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

"Recognise the vested interests that have created and benefit from the lack of integration within the system. When the most affordable/subsidised access is to the least helpful segment of the system for many experiencing mental ill health, the system is fundamentally flawed. Access to quality psychologists must be addressed. "