Submission to the Royal Commission into Victoria's Mental Health System

A Lived Experience

July 3 2019



The focus of this submission:

1. 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.

- 5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
- 6. What are the needs of family members and carers and what can be done better to support them?
- 9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
- 10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

Submission to the Royal Commission into Victoria's Mental Health System

I am a doctor who has worked in Victoria's public hospital system for the past 30 years. I am sorry to say it, but my overall impression of our mental health system is that it is inept to the point of being dreadful. After watching my daughter's experience of the system over the past decade, I would like the Royal Commission to focus on four key questions:

- 1. What, if anything, is being done to ensure mental health services are evidence-based and actually helping people? Are outcomes being measured?
- 2. Are there rigorous checks and balances to ensure mental health workers and services are behaving ethically? Are complaints to the Australian Health Practitioner Regulation Agency being acted on? Are patterns being analysed to detect rogue operators?
- 3. Are the people delivering mental health services appropriately qualified? Are some working outside of their skill set?
- 4. Are mental health professionals, including psychiatrists and psychologists, excluding families from assessment and diagnostic processes to the detriment of their patients?

My family's experience

There is a saying in medicine that "more is missed by not looking than by not knowing". This certainly applies to my daughter's case. Her journey through Victoria's mental health system has involved no fewer than four mental health providers (one psychiatrist and three clinical psychologists). Even now, after multiple attempts, I consider her to be unassessed because vital information was not sought, not considered, or refused when offered. Here is a short summary of the problems my wife and I have experienced along the way:

- The first and only psychiatrist who saw our daughter made no attempt to find out about her early behaviour or the lead up to her presentation. He prescribed antidepressants, which had very bad side effects, and failed to review her for over nine months. The treatment had no benefit.
- Next, a psychologist saw her for an entire year (10 visits at the taxpayer's expense- Medicare). During this time, we contacted the psychologist to describe our daughter's increasingly worrying behaviour because we thought she may present better than she actually was. To our despair, we were refused the opportunity to pass on any information because our daughter was not in "family therapy". This led us to doubt that the psychologist was properly appreciating the severity of our daughter's condition. At the conclusion of the year, the psychologist deemed our daughter "too hard and out of her field of expertise." She then referred her to "a more expert colleague". We discovered this in a summary letter the psychologist was required to write to the referring GP to reactivate the item numbers. I was exasperated that it took a whole year for the psychologist to reach such a conclusion.

• The second psychologist saw her for more than a year (again at taxpayer's expense). By now her behaviours were bordering on the bizarre and all those around her (immediate and extended family) were frantic with worry. Once again we tried to reach out to the psychologist to provide additional vital information, and once again we were refused. This psychologist provided one diagnosis after another, which was disturbing in itself. She finally settled on a diagnosis of "atypical hoarding disorder" and suggested our daughter buy a book on mindfulness. She then declared that our daughter should see yet another psychologist. (To make matters worse, this psychologist holds a PhD, and is supervising at least one other PhD student. Can we assume that this management represents "academic excellence" in Australian psychology?) As a medical specialist I am speechless.

It was at this stage that we started to see a pattern of behaviour – the exclusion of family, the prolonged series of consultations underwritten by the taxpayer and then the declaration that it was beyond their expertise and that she should see another psychologist. I emphatically suggest that this pattern of behaviour be thoroughly investigated by the commission.

Not surprisingly, important information was not considered in her management. The professionals concerned seemed oblivious to the severity of the situation when she was in crisis. Why would these psychologists refuse to hear from her family? In my medical specialty I would be sued if I did not listen to vital information from a patient's family members. Communication is of utmost importance in medicine, particularly when a patient is compromised and cannot speak for him or herself.

The effect of all of this has been total devastation. Our daughter's current plight is tragic. She has totally lost faith in the mental health system. She is both unemployed and unemployable. She has become totally withdrawn and lives as a recluse. We have been helpless to arrest this decline, and I hold the mental health professionals associated with her – far from being in any way helpful – to be culpable. Not a single day passes when I don't regret having ever sent her for mental health services.

She lives in our home – barely speaking to anyone. If it were not for our capacity to assist in this way, she would be homeless walking the streets. She spends her days walking the streets talking to her-self. (People look on with quizzical looks on their faces.) She is so impaired that she can't even negotiate and manage her unemployment status – the only reason she keeps receiving Newstart support is that she repeatedly visits GP's to get medical exemptions from looking for work. She repeatedly misses job support appointments and medical appointments, which usually result in her Newstart being repeatedly suspended, and her missed medical appointments simply being billed to Medicare and re-scheduled (when this is clearly a sign of the severity of her situation). Her current GP and employment support service provider are oblivious to her mental status. None of

these providers have offered advice or support for her to transition onto the Disability Support Pension to remove the stress and anxiety associated with reporting to Centre Link job agency on a regular basis, or to seek mental health support. No one seems to care, either way they get paid by the federal government for services rendered.

Anyone who spent even an hour with her would see that she has overt, severe mental health problems. Yet, she has been seen by not one, not two, not three, but four ... FOUR mental health professionals. There has been no meaningful intervention. I am shattered at the inability of so many "experts" to properly assess and diagnose. I am even more shattered at the total inability to understand the severity of the situation, and their seeming total indifference to all this.

I feel like I want to clearly articulate to them, "Do you even understand what you are dealing with here!?" I am not able to because of "confidentiality" yet, as a family we are made to live with the consequences. My daughter's plight is one of crisis. She is effectively totally disabled and totally disconnected due to profound mental illness. Yet none of the professionals who have seen her seem to even be aware of this. I re-state: she has never been properly assessed, and none of the professionals took into account the available information we, as a family, have to offer.

The flow-on effects are similarly devastating. The mental health of all remaining family members has deteriorated – everyone in the house has either left, or lapsed into deep sadness (the grief is overwhelming) - and we are left with the prospect of a severely disabled person being with us forever – the mental health services having completely failed our daughter and our family.

We, as a family, have asked for support. The only offering we have received (Beyond Blue and Head Space) is to maintain the supports we as a family have already in place (a clean warm house with a room she can escape to, access to nourishment, additional money when required and surrounded by people who love her) and to weather the storm on our own.

Possibly the worst part of all is the realization that we will be left with this horrible outcome and that this represents a major investment of hardworking taxpayers' money???!!!

I would still like to get her properly assessed, but as God is my judge I wouldn't know who to send her to, and I, too, have completely lost faith. As a senior medical consultant in the public health system, I know poor practice when I see it. I also know how scarce funding for evidence based treatment is, so it's galling to see this utter twaddle going on at the taxpayer's expense.

Having watched my daughter's "treatment" for several years, I can't help but suspect a flagrant lack of academic rigour in mental health services, along with an absence of quality assurance and a lack of evidence based clinical guidelines.

Furthermore, this whole sordid episode has the distinct feel of a "racket" about it. Patients seem to get referred around in circles with no actual diagnosis or meaningful management. Twice we got, "I don't know what the problem is, but I have a friend who's really good at this type of thing." I have to wonder if the "friend" is saying the exact same thing and returning the favour by sending a patient back in the other direction. I implore you to investigate this type of practice.

The mental health practitioners will be giving impassioned pleas for more resources and money for mental health. I strongly urge you to exercise restraint. Before allocating more resources for current mental health services, the standard of practice and quality of outcomes must be evaluated.

You may wish to consider the following:

Quality Assurance

The underling premise appears to be that if we ramp up the availability of mental health services, all will be well. This carries the presumption that we have evidence-based treatments with good quality assurance.

I am sorry to be so blunt, but the evidence, such as it is, raises serious questions as to whether or not the psychology profession even knows what it is doing or what it is trying to do.

Currently, the majority of psychology research publications fail the reproducibility test. Scientific fraud is a worldwide problem in a range of areas and Clinical Psychology seems to be particularly badly affected. This means that even if there were recommended guidelines, it is uncertain as to whether they are grounded in good science. I refer you to the following website for elaboration:

https://nobaproject.com/modules/the-replication-crisis-in-psychology

I urge you to consider the option of establishing an Australian Office of Research Integrity to act as watchdog for dubious research findings and to guard against the implementation of strategies that have not been properly validated with reproducible results. This is discussed in this article:

http://theconversation.com/weakened-code-risks-australias-reputation-for-research-integrity-98622

It is completely inappropriate to demand more money and/or more resources without having evidence based clinical guidelines and outcome measurement tools in place. Otherwise, it may well be that the problem is NOT lack of funds, but rather ineffectual treatment, in which case more funding is simply "throwing good money after bad." Without outcome measurement tools and clinical guidelines, there is really no way of knowing if what you are doing is working.

This means that, if the problem doesn't improve, there's no way of knowing if it's a resource problem or just bad practice.

If this issue is not addressed first, then I have grave concerns as to whether this commission inquiry will achieve anything useful.

Regarding quality assurance:

- Is there any objective evidence that what is being done is working? (I note
 that the incidence of mental illness and suicide has not reduced in spite of
 our dramatic increase in expenditure and increased access to mental
 health support via the "Better Access" Medicare scheme.)
- Do we have outcome measures in place, and are we recording good data?
- Are we benchmarking ourselves against world's best practice? In fact, is it
 unclear what world's best practice actually is? (I refer to my previous
 comment regard research rigor in the psychology field.)

AHPRA and the following up of complaints

I suggest that complaints against mental health practitioners for the last period of time (10 years) be reviewed to see if AHPRA is performing due diligence, independent of the registering boards. Does AHPRA have appropriate disciplinary capabilities and, in the cases of substandard practice, has AHPRA exercised appropriate independent disciplinary procedure? Does AHPRA have the mandate to undertake independent investigations of complaints and take appropriate disciplinary actions? It should.

Reciprocal referral patterns

I may be mistaken, but I get the distinct impression that reciprocal referrals are occurring in a "quid pro quo" manner, i.e.: "you send me one and I'll send you one." I just wonder whether "referrals for mates" has become something of an endemic problem. Whilst it is necessary for GPs to be involved in the referral process, this could easily be happening without their being cognisant of the issue. I suggest the inquiry investigates whether this occurs frequently. If so it represents a serious breach of ethical standards and should be dealt with severely.

This link gives a breakdown of item numbers across medical and allied health:

https://www.mja.com.au/journal/2015/202/4/better-access-mental-health-care-and-failure-medicare-principle-universalit

Inappropriate allied health professionals practicing outside their skill set

It has come to my attention that other disciplines are becoming increasingly involved in mental health practices. Given the money involved and available (Better Access Medicare scheme), this is hardly surprising.

Occupational therapists and social workers seem to have appeared in mental health care system via the Better Access Medicare scheme. I am not making any comment about their place in the overall allied health system, but I suggest that this is examined to review whether or not they are practicing within their skill set. These disciplines have generalist training and approaches. Consumers of these services require clear defined skill expertise (specialization) to inform consumer choice about therapeutic expertise, focus and expected outcome for people with mental health support needs.

Exclusion of family from the assessment and diagnostic and therapeutic process

Is it not the case – for those presenting with mental health issues – that their premorbid personality and childhood behaviour are extremely relevant in the assessment process? If so (and I know this to be true) then all who saw my daughter are guilty of professional negligence. Three times we tried to pass on information about her childhood behaviour and of her dramatic deterioration. None of them would accept information from us. Each time we were told, "Sorry, there are privacy issues." Let me be clear. It was us seeking to pass on information – not the other way around. After 30 years in public health, I am very familiar with patient confidentiality. I suggest this issue is investigated. If it is common, it represents a serious breach of professional standards, in which case the standard of education and quality assurance need to be examined.

I am sorry to be so negative, but my experience of the mental health system is one of total bewilderment. No wonder people are taking their own lives. As a public health consultant, I would describe what we received from this system as absolutely pitiful. And as a taxpayer, I resent the fact that so much money that could be allocated elsewhere appears to be wasted. As a father I am shattered that my daughter and family has had such a devastating experience with the Victorian mental health system.

I will follow the Royal Commission with interest. If (as I suspect) we are coming up well short of world's best practice, then the upshot of this inquiry must be to get the house in order before any new funding is allocated.

I am remaining anonymous at this stage for two reasons – I wish to protect my daughter's identity and I still work in the public hospital system, and will continue to do so for the foreseeable future. I re-state that I am a public hospital senior medical clinician of 30 years standing. I am very familiar with evidence based medicine and quality assurance. I know substandard practice when I see it.

For my family, the Victorian mental health care system has been a total failure.

That said, I would be happy to follow up on any issues I have raised if it was felt to be potentially helpful.

Thank you for the opportunity to allow me to share our experience of the Victorian mental health care system.