

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

SUB. 0002.0028.0642

Name

[REDACTED]

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

"Mental health awareness has massively improved in the wider community in the last 15 years. However the discrimination is huge and continues. This discrimination begins in hospitals, pharmacies and GP clinics where people with mental illness are so often treated as malingerers, 'snowflakes' or attention seekers. No one would dare suggest that about someone with cancer. We need to begin by ensuring that those in caring professions are actually expected to care. The idea of 'tough love' needs to be squashed once and for all. To discover that your mind is not working as it should, and to then get the courage and motivation to take that fearful knowledge to a professional in search of help - at your most vulnerable - and to be turned away, told to get on with life, told to see how you are in six weeks, told you can't have that medical certificate for an essay extension or a few days off work, told you don't look thin yet, or that everyone throws up sometimes - all of which my children have been told - engenders hopelessness: who cares? Health professionals need to greet people with compassion and acknowledge their illness. People with mental illness need to no longer be left til last in A&E (we have waited 7 hours for stitches - it was a private hospital in Melbourne - there were no emergencies; no one was on by pass; we literally waited until there was no one else there at all - and I think the staff had all had a leisurely break as well). Punitive actions toward people with mental health problems by health professionals need to stop. When your daughter is taken by ambulance to hospital for an unrelated event and you find yourself pleading to the admitting doctor not to read her medical record because you believe it will negatively impact her treatment, you know something is very wrong with the response of health professionals to people with mental ill health. Some media success stories of people living with, or recovered from, mental ill-health would be helpful; Celebrating the ways in which many people with poor mental health are living rich, valuable lives. Some positive discrimination around employment and study would help. An advertising campaign that encourages kindness in the community and that models ways to talk to people who have mental ill-health. When I had cancer everyone told me how brave I was; no one tells my kids they are brave. Let's get rid of the idea that if you have mental ill health you are 'failing' at life. "

## **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?**

"Our engagement with Mental Health services began 15 years ago when our daughter, then 13, started self harming. The flow on effect to the family has been: a second daughter with eating disorders and other mental health problems; a son with severe depression and anxiety; and my own fragile mental health which is continually kept in check. What worked well for us? Pretty close to nothing. Initially we sought help through the school counsellor - his advice (that this was attention seeking) -was disastrous. At the time we were living in the Orygen zone. We were not referred to Orygen. As her health clearly declined he handballed her to a local psychologist whose opinions were the same as his, and who offered no 'care'. In fact our daughter was demonstrating

early symptoms of a severe illness which would dominate our lives (borderline Personality Disorder). Early intervention for her and the family would have produced very different results. The only counselling we ever received as parents was some years later when she sought out Orygen. This was a positive. The only other positives out of this complete mess were the actions of a very few individuals - kindness and compassion are rare in the Mental health 'services'. More recently my daughter has had another hospitalisation - this was better (though not great) - and she was, for the first time as an inpatient, treated with respect. More recently still, we attended a day session with Spectrum. It took 15 years of her having Borderline Personality Disorder before we found this group. This was also a positive encounter for us - although the stories being told in that group were disturbingly like our own. Very little has improved since we entered the system. Support people getting early treatment: local care in rural and regional centres (Headspace was literally a life saving initiative) get rid of zoning - it isolates people from their family and friends in order to receive care acknowledge those local issues that impact mental health and work directly with them (drought; institutional child abuse) "

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

"Talking about suicide has helped. I wish I had had the language I needed to have these conversations with my children when they were much younger. As an tertiary educator I see so many students with depression and anxiety. I think the current education system has a lot to answer for. It is competitive rather than collaborative; it judges and measure students; most students are not valued in their classrooms for who they are or what they bring to the class; it places emphasis on getting results rather than on the richness of human life and endeavour; it largely ignores the arts, which provide a way to explore feelings and sense of self. The conversation has to be very up front and in a range of contexts - that suicidal ideation is an indicator of mental illness. When you experience suicide ideation it can seem a reasonable thing to do - you don't necessarily see it as a symptom of illness. These conversations need space and they need to happen all through the community. "

### **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.**

"My first daughter fought and fought for her mental health, and continues to fight. Too often she has been turned away from public services because she's not 'sick enough', but is refused treatment in the private system because she's 'too high risk.' I have pleaded with psychiatrists to put her on their books only to be told by receptionists that 'Dr X will not treat your daughter because she is too high risk.' We have been turned away from public hospitals because she's 'better cared for privately' - whatever that means. Zoning is crazy. The family home is in [REDACTED] my daughter now lives in Melbourne. She came home to me a few years ago because she knew she was unwell and declining in mental health. We sought assistance locally - nothing; she sought assistance in Melbourne - nothing. Couldn't get a psychiatrist or psychologist appointment, despite being on the books of both. I was in daily contact with the [REDACTED] mental health services who said - if you come to crisis point, come in. Crisis point and a high risk of suicide came at 10 pm one night. We went to A&E as previously advised and the CAT came. They said, 'take her home, she's out of zone and we're not giving her a bed.' I had to leave my 13 year old son home alone as I then drove her, at midnight, from [REDACTED] to the [REDACTED] to get her in zone. The only light in this Kafka-esque story was the kindness and care with which she was treated at [REDACTED] and the responsible and person-centred way the consultant psychiatrist there

managed her case. "

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

"Not my area, so a brief comment: mental health in [REDACTED] is pretty awful. It's like it's infectious. The seeds are planted in generations of institutional child abuse and the silencing of pain; and they are nurtured by poor psychiatric services for the population and long, grey winters. "

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

"My family is a mess - strong because we've stuck together and we are all still alive - but a mess nonetheless. It is not our oldest daughter's illness that created the pressure that has irrevocably altered the lives of the rest of us - but the lack of care for the family in that context. Let me give you a comparison. In 2014 I was diagnosed with cancer. I underwent surgery, chemo and radiotherapy. I never felt uncared for or unvalued. I had access to a social worker, dietician, physio, personal nurse, art therapist, yoga therapist, oncology masseuse - you get the picture. My family had access to counselling and support groups. We were cared for. Five years later that invasive and traumatic experience is a blimp behind us. We have grown and moved on. In contrast, in 2003 my daughter demonstrated the first signs of mental illness. None of us were cared for in any way - not physically or psychologically. In total, since then, she has spent about a year of her life in hospital. All of these admissions, except the most recent, were traumatic. She has rarely been treated with respect or as a person with agency but in crisis. She has either had decision making taken from her in the most cruel and undermining way, or she has been expected to act like a rational person, when in the depths of illness-induced irrationality. She has received close to no support services (she did have, and responded positively to, art therapy in Orygen and the Melbourne Clinic). For 10 years we were always on crisis call, day and night. Even now, I do not turn my phone ringtone down at night. Because of stigma and a desire to protect her privacy (again because of stigma), I could not tell even my family what we were going through - there was no one to call on. Consequently, the other two children, despite our best efforts, suffered. The second child desperately sought our attention and developed eating disorders which she still struggles with. Our youngest child, who we thought was protected, has ongoing struggles with depression, self worth and social anxiety. I cry as I write this. What would our lives have been like if we had been cared for? Perhaps we would be able to have family events; perhaps we would be living healthy lives; perhaps we could achieve our potential. What would my husband and I be like as parents if we had not had to endure the 'shame' imposed on us by health professionals for not 'managing' our daughter? (I want to briefly add a story here. Our second daughter hemorrhaged after having her tonsils out and I took her into A&E - it was serious and she ended up in intensive care. While we were in A&E my older daughter - not coping with crisis - slashed her arm and needed stitches. Her father brought her into the same A&E (note - regional area, only one A&E). The doctor who saw her stitched her up and then brought her into me, sitting with the second daughter, to make her 'show us what she's done', despite her father being in the waiting room and me being there for a completely different purpose. His appalling lack of compassion, empathy or even understanding remains one of the worst experiences of my life. It still brings up feelings of anger and worthlessness). The loss of productivity has been huge as I spent years diving in and out of work, just keeping afloat. Even now, my very talented and highly intellectually gifted children fight to complete their studies and to hold down jobs. The loss to the community when this is replicated across thousands of families is enormous. Spend the money on family counselling,

early intervention, appropriate PD for health workers, breaking down stigma so families can go to support groups or ask relatives or friends for help - and in the end the government will save billions. It's too late for my family - but don't let this continue for another generation. "

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

"Not my area - but there is a massive problem with the nature of the workforce, and the culture of interaction with patients and their families. "

**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?**

"There is a desperate need for more day programs and support groups. There also needs to be a range of these - some aimed at people on the edge, just coping, who need a particular type of support; others for people in a maintenance/holding sort of pattern getting back on their feet; and others aimed at flourishing - so these might include drama and music, social activities, book clubs - where people have common needs but don't have to always talk about them. There is a need for people to learn to be well. It is frequent for people to leave hospital and have no support. If you're lucky someone might give you a contact number. Departure plans are next to useless. They usually say, go to A&E where the same cycle starts again; or they say contact your psychologist, who gives you an appointment for a week's time. Exit care from hospitals is woefully poor. The community needs to understand that people are not defined by this illness - though the illness impacts them as people. It's a fine line. But you can be mentally unwell and creative and clever. Being mentally unwell shouldn't make you a pariah, though it often does. Incentives for employers to take on people with a history of mental illness need to be put in place. Again - people need the chance to experience what it is to be well - and they need the supports that assist them to become well. People with mental illness need to be trusted and valued in the community as being able to do worthwhile things; if things do go pear-shaped, employers needs supports and strategies for assisting workers."

**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?**

Remove zoning prioritise appropriate out patient care prioritise family care and support engender a culture of respect and compassion

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

invest money - money spent on this will will come back ten fold invest time - health professionals need further education; there must be a culture and expectation of their responsiveness to patients and families. try using cancer care as a model - what would happen if the same supports and whole person care were invested into mental health services?

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

"This is an opportunity. For fifteen years I have filled in forms, answered online surveys and fought for my family. I have seen very little improvement. I'm pretty sure we'll look back on this in 50 years time and be horrified at the barbaric ways that people were treated; we will mourn those we lost, and the lost potential of others; there will be some sort of parliamentary apology. Make

this the point of change; keep the government accountable. I am grateful for this chance to get my feelings and experiences on record. Thank you."

## Royal commission into Mental Health – notes

### Tsunami effect on family:

- isolating (privacy of person with illness);
- impact on mental health of others in the family (three children);
- loss of productivity; reduced capacity to work; need to take sick leave and carer's leave
- constant rearranging of appointment and events; never able to plan; cannot take a holiday
- reduced capacity to enjoy life; no opportunity for family or individual events that foster well-being (what do you do with the suicidal member of the family; the member who can't bear to be in public; the one who can't eat in public; the one who is intensely anxious?)
- we didn't ask to have children with mental illness – it is very clear to us that there is a sense right throughout mental health services that this is in some way our fault; that we are responsible for our children developing mental illness. It is equally apparent that governments and health services do not care about our children
- our children are incredibly intelligent, highly gifted and very creative individuals. Recent research into giftedness has drawn the clear correlation between giftedness and mental ill health. Australia is missing out on everything our children can contribute by inadequately caring for them. You wouldn't dare do this if they had cancer.

### Poor quality of in-patient care:

- lack of empathy amongst nursing staff (the myth of tough love)
- cruelty of some nursing staff
- nursing staff who don't read information – or don't apply it (e.g. about triggers)
- nursing staff who disregard family comments/insight
- nursing staff who refuse to follow doctor's drug regimes
- nursing staff who provoke patients
- nursing staff who take inadequate care of patients' belongings
- nursing staff who leave patients in places of risk (e.g. in high dependency units with other patients who pose a risk to them)
- nurses who refuse to listen to family and insist they know what happened, even when they are making assumptions
- nursing staff who arrange to have patients sectioned AFTER the family have left, and without conversation with the family
- nursing staff who say the patient is 'attention seeking' and therefore refuse to meet any of their needs – including serving meat to vegetarians, withholding drugs, not doing prescribed blood tests; treating property such as teddy bears, art work and art supplies with disregard
- doctors who do not read notes prior to discharge
- doctors who blatantly lie to families and patients
- doctors (private) who refuse to take on patients because they are too sick – too great a risk; public system for whom these patients are not sick enough

- doctors who do not listen to nursing staff and therapists, and override their advice re discharge
- lack of respect for individual patient; judgement of family
- the constant push to discharge patients - leads to insecurity and a feeling of needs not being met; also a sense of not being worthy/valuable – even the family do not get any respite because everyday discharge is talked about even when the patient is patently unable to cope in the world
- discharge without a plan
- discharge without an adequate plan
- discharge followed by an attempt at suicide within 6 hours – either in-patient service is not catering to the patient's needs or discharge is too early

#### Zones:

- can't receive treatment if out of zone
- denied treatment on presenting to a hospital when out of zone
- family and patient living in different zones (can't come home when ill and still have access to services)

#### Medications:

- costs are high because many are only on PBS if the patient is diagnosed with schizophrenia
- we pay our daughter's medications; if we didn't she would be largely unmedicated because she cannot afford them