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

SUB: 0002.0032.0078

Name
Anonymous

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Often mental illness occurs if person has experienced trauma, neglect or abuse during formative years. Neuroscience shows mental and emotional barriers are more substantial than being able to snap out of it. There is a spectrum of levels of incapacity and also ability."

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?
"When people do present for help, in clinics or ED, only discharge with definite follow up treatment organised. "

What is already working well and what can be done better to prevent suicide?
"Being able to discuss suicidal thoughts and feelings in a way that reduces the intensity, fear or shame behind them. A psychologist suggested I find a mental health team, as they felt isolated dealing with me, so I had regular 3 week appointments with a gp, and a psychiatrist and saw her on a mental health plan."

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.
N/A

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

What are the needs of family members and carers and what can be done better to support them?
"To be included in treatment decisions and ongoing communication when needed. Token family sessions are not sufficient, even counterproductive as the issues are unpacked and family members left to manage tension without enough time to work through issues."

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

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?
Much more integration of services. More home visits.

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?
N/A

SUBMISSION to ROYAL COMMISSION into MENTAL HEALTH

Mental illness has surrounded me my whole life. It has been my normal. My father, mother, brother, sister, husband, and son, have all been given a complex mental illness diagnosis. I was born in 1960, am the oldest of 5 children, have lived the carer role as a child, teen, young and older mother. I also have my own lived experience of mental illness (Major Depression from 1988, possibly Bi-Polar Mixed State mentioned 2017).

My story is one of inter-generational trauma. Both my parents had functional sides and good qualities. Their trauma was largely unresolved from World War II and their early childhoods. My mother was 13 when the war ended. She spent it in a small village called OverSchie on the edge of Rotterdam, The Netherlands. My father was placed "in care" at 6 weeks, from around 6 years he was in St Vincent's Orphanage South Melbourne. He joined the Navy at 18 and worked the minefields in The Coral Sea. Both my parents worked hard to overcome their difficult experiences, held various jobs and did various studies, and expressed many aspects of good care, but during the period of my childhood, they were seriously unwell. I have been frequently involved with DHS and/or mental health system to get myself and/or my family members access to meaningful support. I have been very torn about whether knowing/stating the limits of their care for me, and my siblings, is a disservice or betrayal of them or an acknowledgement of the struggles my generation suffered. I feel survival guilt, often wanted to join “my dead people”. It was not gratuitous, I do not know how I could managed things better.

Both my parents were given a diagnosis of schizophrenia which resulted in myself and 3 of my siblings being made state wards in 1966. These experiences were traumatic for all of us, each in our own way. Later 3 of us were returned home. My parents had another baby, but my father died that year of complications to pneumonia in 1971. I remember him treated as a malingerer by the examining doctor at the Royal Melbourne Hospital and told to go home, but he died that night. I was 11. Mother struggled on as a widow. One brother and one sister were diagnosed with mental illnesses, in their late teens (They had been 4 and 2 when they went into foster homes etc.)

I left home and worked for public service depts from 1977 - 1986 began BA at Melb Uni in 1983. I also taught piano part time. My sister was 21 years old when she suicided in 1986 whilst living in the half way house attached to [redacted] She also worked for the tax office and studied youth work. My brother was discharged into my care, once when I was 22, but there was insufficient follow up. If he was discharged to my mother, me or just let go into the streets, I still experienced great stress dealing with his pain and anger. Ten years after my sister's death he did finally suicide. My daughter and son were exposed to violent scenes. Just before my brother's death he was discharged from [redacted] into the care of his wife and 6 week old baby, because there were no beds, as they were closing [redacted] The timing and decision to change my brother's diagnosis in order to clear their decks has made him a martyr to de-institutionalisation.

I had "bonded" with my husband over mental health issues, although our marriage did not survive and I left after 16 years after advice from a nurse from my first CAT team incident. I had cared for my husband who was diagnosed with schizophrenia in USA (born USA) and tried my best to love him into health (everything I could think of). At that time I had no diagnosis. I left my job at ATO to look after his baby from another partner (they had met as inpatients at Royal Park Hospital). DHS Adoptive services assessed and approved me, but dropped the case when the 2 biological parents disputed paternity in the Supreme Court. I was left with the full-time care of the baby. Throughout all of this I raised the three children (2 biological) with a culture that included arts, sport and sciences in our lives and/ hobbies etc.My husband worked in IT but was very paranoid about his ex, her family, and then me (even though my 24 hour support lead to him gaining early custody of his first born). My husband was 10 years older, but too mentally unwell to offer support to me or did not want to(?). I was torn by the demands of both families. Within a few years I was in a state of physical (serious neck issues) and mental torture, my every feeling and action and caring was compared between the 2 girls. Despite tensions and break ups and problems there are also good qualities in my children. Eg., My middle daughter worked at Melb Uni for 7 years after graduating with her MA and works for the governor and my son is a fine musician.

I have watched the MH system change over time, first visiting my father at Macleod Repat when I was 10. My mother had electric shock treatment in 60s. My sister was picked up by police in distressed suicidal states. Perhaps my brother would have benefited from services at Spectrum. Perhaps it is all about access to funding, progress and timing. Family members came to the funerals. I lost seven close family members and friends to suicide. My sister's death may have triggered 3 to 5 copycat suicides within 18 months (including 2 uncles related by marriage). There was no real or co-ordinated support for our families to deal with this and my extended family became fragmented. When I reflect, it looks as if I lived through a war too. I had to tuck my feelings away, in order to care for small children, which I did with varying success but was often overwhelmed.

I have seen psychologists and psychiatrists intermittently since 1984. Then after motherhood, family therapy alerted me to family dynamics. It was important to de-pathologise life for me, and get back to basic aspects of life and parenting. Bed times nutrition activities etc.

I've witnessed changes from large hospitals to community care. The intention in dismantling the old system may have been good, but has left us with a fragmented mental health system. Moving the locus of care into the community also can move it onto the backs of young mothers. Anyway that is what happened for us. I have never been an inpatient, personally, but have attended Emergency in 1977, 2015-6 and had a number of home visits by a CAT team from 2002 - 2015. For me the treatment in the community has been fairly successful, but I have been highly motivated to make things work.

It is exhausting to research and navigate current services. People who are very unwell, easily give up at the complexity of chasing a trail of contacts and phone numbers, many mh workers/doctors have moved on. There is a need for more INTEGRATED and family inclusive services. Better than offering one "family session" or randomly running groups on random topics. I understand the benefits of offering choice, but people really do fall through the cracks in the system.

Despite advances, the suicide rate increases. I used to question everything I did to understand how I could help or improve our situation. I no longer take it all personally. Its so much bigger than me. I looked after my sister in one orphanage, changing nappies and dressing her, but then we were split and she was in other homes and foster care for 7 years. A lawyer has suggested I sue the state for returning us to our parents, because of how things turned out. I cannot do that. Today (5 July) I received notice of a decision to award me a Recognition Payment by Victim Services NSW for $1000 for indecent assault in 1966 when I was in [redacted] (I applied in 2016). I may look for Redress in the future but need time away from the paperwork. I do hope the premature deaths in my family are not in vain. They highlight problems in the emergency departments, and problems in the general treatment. All 3 deaths were investigated by the coroner.(Dad 1971, [redacted] 1986, and [redacted] 1995) but I was either too young or not well and did not attend at the time. I have since applied and received paper copies of the Coroner Reports. EDs need better protocols and training and funding. Success should be measured not in getting patients out the doors, but in not having episodes or deaths soon after a discharge.

Now, I am supporting my son who has been diagnosed with Bi-polar I, to navigate the mental health system and the justice system, after a second episode which was very badly handled and ended up with him in detention for 4 months. He has stabilised since, was given a diversion which has been discharged, but 2 weeks would have been reasonable, not 4 months, with abuse, a lot of isolation or lockdown. Maybe it was just bad timing as I had my date to meet the Royal Commissioner at the Mantra on the same day of his first hearing in the Magistrate's Court.

There is a need for strong social and family minded services. Many services offer only one family therapy session. That is not enough. It opens up pain and vulnerability. There is not enough time to disarm defensiveness or give due attention to historical traumas and their consequences. We are left gaping and to work through it on our own again. My son and I are accessing joint sessions through Reclaim program at Relationships Australia, as I had made a submission to the Royal Commission into Institutional Sexual Abuse as a secondary victim. My father, my sister and I had all experienced abuse. I found a record of it in my father's psych file and her file. It has been revealing and a long journey for me. During my 20s a large issue was coming to terms with my parents' diagnoses of schizophrenia and whether or not I had it. It was frightening. My father was dead and my mother was burdened highly defensive, entangled in The [redacted] Church, and in denial.

My son experienced difficulties at school from a young age, kinder. Was it my fault? In part. I could not hide my pain from him all the time. I do not know how witnessing violence, the divorce, and my personal struggles effected him. I certainly did not want to harm him and tried to compensate taking him on camping holidays, to Sydney to visit my other brother, to sports and to drama and music activities. I tried to get guidance from [redacted] the but was sent away and told I catastrophised. There have been a few times I have been blamed for the situation by counsellors. It did not help. I thought my personality tended towards responsibility and I tried to please. I probably understated my circumstances rather than exaggerate them. I managed with the help of sporadic private psychology sessions. With all the extremes of social backgrounds, (my ex husband's family were well to do Americans). It was important for me learn about and focus on healthy human development regardless of class or culture. I pleaded with services, saying I needed help, but they ignored my son and I ended up often home-schooling him. Now a young man, my son has struggled to find stable, ongoing work.

In 2015, my son had a major episode where he was transferred by police to a hospital emergency department. I was out for the afternoon. I found out they discharged him without his wallet. The next day, my son was arrested after a pseudo-bomb scare, which saw him and detained for four months. This traumatic experience for both my son and I could have been avoided if the hospital did not discharge him. My son wouldn’t have lost four months of his life in the justice system if he was given proper treatment.

Simply discharging people is negligent in my view, and although I received an apology from [redacted]. It has had a negative impact on my son. I have presented twice to Emergency for myself. One time ([redacted] I was given phone numbers which were 2 years old as doctor had moved to Alice Springs. The other time ([redacted] I was triggered socially by a bully into a panicked highly suicidal state (with def plans) given a bed and allowed to calm down without medication through the night and released in the morning.

Families and carers need to be treated as critical parts of the team, and for medical practitioners to both share information and to ensure that everyone is on the same page when it comes to treatment. Treatment is possible, but treatment should not be mere medication compliance. There is a need for workforce training, especially GP's and more trauma informed practice understanding across the whole workforce. Many service providers seem overworked and under resourced, making it difficult for them to provide effective and meaningful care and support. Lack of continuity of care is hugely wasteful.

I have only survived as a carer and consumer by building my own system of services/professionals which support my mental and physical well-being, including psychological support, my GP and osteopath. I had to make this happen on my own. It took a very long time to find a good GP. With many, I felt stigmatised as they ignored my physical issues.

[redacted]