

ROYAL COMMISSION INTO VICTORIAN MENTAL HEALTH 2019

FORMAL SUBMISSION LETTER d3 chk

From: [REDACTED]

Email: [REDACTED]

Phone: [REDACTED]

30 June 2019

Preamble

I have replied to your response to my online formal submission so you can connect this letter with that information. At the time, I did not have this letter ready for submission and was not aware I could have uploaded it then. I have also sent it to your Royal Commission (RC) email to make sure that you receive it.

I believe it is important for the RC to know people's personal experiences and my son cannot speak for himself at present as he is currently in the [REDACTED] and therefore having to go through another traumatic experience at the hands of the [REDACTED]

I know that you are unable to respond to personal experiences directly and that the results of the Royal Commission are quite a way off. I am intending to make contact with the Health Commissioner and the Australian Health Practitioner Regulation Agency – contact details I obtained from your website – concerning our personal issues with the Community Psychiatrist who has treated and will continue for the present, to treat my son at [REDACTED].

This letter focuses on explaining our experiences with [REDACTED] Mental Health System over 17 years.

Anything that is unclear I will be happy to discuss with you over the telephone or in person. While my son lives in [REDACTED] and I used to live with him, I moved to Melbourne [REDACTED] 9 years ago. Over the years, since my son was 14/15 years old, I have connected with various consumer bodies. They told me they have heard many complaints about the [REDACTED] Mental Health System. Therefore, I knew we were not alone in our concerns.

My son and I have wanted to make a formal complaint about our experiences with [REDACTED] Mental Health for years but I was concerned that such a complaint would put his interactions with doctors and staff further at risk. All this time of course we were hoping some stability would come to my son's situation. Unfortunately, this has not happened.

As mentioned, my son is in the [REDACTED] after suffering a recent relapse. When we first heard about the Royal Commission, he was OK with me putting a submission in and I would have involved him or encouraged him to do his own submission. However, he is not likely to be well enough prior to the submission closing date.

Later, he may be well enough to decide how public he wants this submission to be.

While I am happy to discuss any clarification questions over the phone or in person I am waiting on surgery at the [REDACTED] in the next month. I should be well enough a week to ten days after

surgery to discuss in person with your officers should you wish to do so, otherwise on the phone. There are many issues with the Victorian system, as practised by [REDACTED], that are a problem – best explained by our story.

My son (S) 32 became ill with depression/anxiety when he was 14/15. Due to bullying at school, he was unable to perform at his optimum level.

Over the years, he has had further diagnoses: bipolar, schizoaffective disorder, and schizophrenia none of which was conclusive. Numerous medications/treatments have been used, and while some symptoms may have abated a little, he has not been able to tolerate the anti-psychotics; he has suffered numerous physical and emotional and psychological side effects which have just made him worse and in no way able to manage his life or gain back an ability to create a productive life.

The side effects he has suffered include severe anhedonia; rolling eyes; rashes and other skin outbreaks and maybe some I have not remembered. He has felt like 'zombie', with no motivation and no ability to enjoy anything he might try and with his general depression and lack of self-esteem becoming worse, his mental health has frequently moved him to suicidal emotions. As well as the psychological and psychiatric issues, he has been suffering for many years with severe 'IBS' which at present is almost impossible to treat. He is in frequent severe pain and very miserable. I discovered through a current 'Catalyst' program that there is new research happening into the difficulty of treating IBS. Severe pain is very debilitating and emotionally draining and depressing all of which S has experienced on an ongoing basis. All of this together with the unsuccessful dealing with the psychiatric issues had made his life intolerable.

Due to his condition, he has not been able to work; his school friends abandoned him; he is absolutely isolated and unsupported except by me. Being his mother, while we have had some very useful (to him) interactions there have also been times that he has been quite angry with me and not wanted me to be a support – probably not uncommon with parents and adult children.

I am always here for him however.

Due to his condition and the unsuccessful management of it, he has actually missed the searching, growing-up and creative learning that usually occurs during one's adolescence and young adult years.

S is very intelligent, clever and has multiple gifts – musical, singing, and academic which he is unable to use and therefore his self-esteem has reached rock-bottom and he feels he is worth nothing and has nothing worthwhile to contribute to the world. This has depressed him further and pushed him into delusional thinking about his own power and importance.

Some of his strong characteristics are honesty, sensitivity, wisdom and insight, and belief in people. When he is unwell the doctor would see him as a person with no insight into his condition. Since he has been on medication he has not been able to love others or shown care and concern or confidence to relate with others. When he was younger, he was the life of the party, happy joyful and very communicative with nearly everyone he met. Whatever has happened to create the condition, and then the medications have made this situation infinitely worse.

This has affected his ability to relate with the treating team at [REDACTED]. Instead of them understanding, they have been judgmental, told him he was lying about his symptoms, and totally failed at building any trusting ongoing rapport with S. I would think it should be the responsibility of the treating team to build such rapport and to try to help S deal with the difficulties he has on the medications and help uplift him and work with him.

Instead, they have ridiculed him, told him he was lying, and displayed complete 'tunnel vision' in the treatment approach. While such medications can and do help some people to stabilise without many impossible side effects; S seems to be one of the small percentage who has drastic reactions that he cannot live with long term. His doctor has not believed him and accused him of only feigning the symptoms to get off the meds. This is a disgusting non-professional approach and inexcusable for the doctor. This doctor's attitude and directions have also influenced the workers who have been case managing S.

One of the case workers proudly stated at one meeting which I attended a few years ago, that he had successfully worked with some difficult cases and that he would have S sorted in a couple of weeks. He totally failed and just got himself removed from the case (prideful and professional neglect) and left my son with a further deflated sense of himself, in considerably more emotional pain and feeling a total failure as S blamed himself for not being able satisfactorily to relate with the treating team. He was further alienated and depressed.

My son is an intelligent human being, with many gifts and talents with which he could make a valuable contribution to society. The breakdown with the [REDACTED] Mental Health treating team has left both my son and me with nowhere to turn. Since leaving school, S has had two unsuccessful attempts at University: Law and Management; and Engineering with granted scholarships to help but unfortunately the unsuccessful treatment approach to his condition has left him in despair and unable to complete his courses.

Rather than try to understand S and build a good working rapport with him the Community treating doctor has gone down the path of seeking to place S on a CTO which has further destroyed the trust between S and [REDACTED] Mental Health Treatment Team and made communication almost impossible.

I have experience with other Mental Health Systems in Victoria. I have a 64-year-old brother (B) who was diagnosed with schizophrenia when he was 16 and at medical school and who lives in Bendigo. He has had a long journey of treatment with a number of hospitalisations.

He has had only two doctors in that time, both who have been able to build a good, trusting relationship with B. They have treated him without 'tunnel vision'; creatively sought the best approach based on good overseas research, and within Australian law, and with lateral thinking, and positive involvement of the client, have been able to plan and execute a successful treatment plan, adaptable when required, and proved extremely versatile and educative over four and a half decades. He is on minimum anti-psychotics and been able to hold down two long-term jobs, the most recent working as a consumer advocate for the Bendigo Mental Health system.

Therefore, I am aware that there are pockets of Mental Health treatment in Victoria and Australia that differ significantly from the inappropriateness of that in [REDACTED]. Some consumer groups have indicated that flexibility within the law is possible and that the approaches are dependent on the thinking of the doctor at the top of the chain. My brother and other friends treated in Bendigo have nothing but praise for their treating doctors and teams. I am so sorry and despairing that this is not our experience.

My son is not currently in a position, either physically or financially, to move to Melbourne or Bendigo so here we are again about to be subjected to the trauma and torture of [REDACTED] relationships.

The treating team holds the responsibility for the successful building of rapport with a MH client who is already hurting and struggling. Seemingly incapable, last time, they discharged S with no doctor support to discuss his issues and problems with the medications. They left him without a caseworker, to support him in his struggles. So, alienated, he had no-one to relate with and walk with him through such a traumatic time in life, and help build a trust to enable the sharing of thoughts and emotions, that would encourage the building of a workable psychological plan.

Such a plan would help with management of depression and anxiety and the lack of motivation and anhedonia – all of which so negatively affect recovery. It is inappropriate to compare him with other clients, as each person is an individual, with different needs and capabilities.

This has been a never-ending cycle of uselessness.

My son is a good, moral, intelligent, caring, clever, and creative person. He like me needs to know about his treatment and have a say in it. Active listening with him and showing respect and a serious interest in his struggling heart will have him respond positively to the doctor and worker. The treating team seem not to be able to get past the judgments they make about S's personality and attitudes, and rather than work constructively with him they alienate and belittle him and strip him of all confidence. In desperation, S will then become angry with them, fight their suggestions and finally cannot bear any interaction with the Treating Team. I am not saying that my son is perfect and would not be a challenge to work with – he would be I imagine. S is not to be blamed, ridiculed, and abandoned and would respond well to positive engagement and involvement in the process without rude, uncalled for judgments.

When we first went to [REDACTED], when S turned 26, the doctor told us (I was present) that he would treat S as an adult, not as an adolescent. This did not seem to include 'equal rights' of the client to be totally involved in decisions about his treatment. This definitely was not 'client-friendly' communication, treating S with respect and including S, the client, in the decisions about his situation. They would feign 'listening' then ignore all that S said about himself and indicate they did not believe him.

Early in this 'condition cycle' when S was still at school, we did go to see a Psychiatrist at the [REDACTED] Clinic and a specialist in adolescent Psychiatry but as a sole parent since my son was 15 months and on a pension I could not afford to continue. We ended up with the public system after S's first psychotic attack, which saw him admitted to the Swanston Centre.

One would think after all these years there would be some significant progress. Sadly, the situation has deteriorated significantly.

There are two other issues.

Support for family members and carers: seems to be non-existent through the Victorian Mental System. I have engaged with caseworkers and doctors. Mostly they are happy to get rid of bothersome me. There needs to be the option for a good support team, as well as the official workers and doctors and family – a team working together to promote good manageable recovery of the client. VMIAC has been a good consumer group to talk with but their funding does not allow them to offer support that is more personal.

Financial Assistance: On discharge from hospital into the Community Health System at [REDACTED] the staff told us there was some financial assistance available to help with certain of S's immediate needs. All these emergency needs, at that stage were directly a result of his illness.

When we applied, we discovered that the rules (set by who?) i.e money to get the garden cleaned up or a one-off cleaner in the house, or petrol for car) were such that they would not approve financial help that had been given before or in their opinion, was not directly related to his condition. Each person's need when they are ill is quite probably the same each time, as each personality will have a pattern of behaviour that is similar to previously for example, may not be able to care for the house or the garden TEMPORARILY. A client needs the urgent issues to be attended to immediately so they can work specifically on recovery. We believe we were deceived about the financial assistance available. With recovery being such a heavy burden, some little encouragement in the form of small financial support can help avoid depression setting in when released from hospital.

Our family are on the low end of income earning scale yet we have still tried to support S by paying to have his dogs looked after when in hospital, having his yard attended to, and have personally cleaned his house ready for discharge. He has no dogs now. After one episode, when his severely damaged car was unusable, his father (now passed away) paid to restore it to working order. My daughter has two young children, and I have my own health issues and we cannot offer the same degree of financial support. Some financial help at discharge is often vital.

Last year, on his own initiative, S went to a support group in [REDACTED], which was around \$8-10 per session. The coordinator said that NDIS would cover it as S was waiting for the approval of his NDIS application. Of course, it was not approved, was it? He could not afford the costs at the time, neither could I, so he never went back. NDIS – useless!

I have discovered that on discharge my son is never clear of delusions, and is looking with trepidation at having to engage with people he feels not only do not understand him, but don't want to. Therefore, we are starting from behind scratch each time. Frequently being discharged on a CTO, because the doctor thinks S will not stay on meds, together with above mentioned issues, S is significantly disadvantaged in his recovery.

The alternative: take notice of what S says; help him learn to manage the situation or **FIND THE CORRECT MEDICATIONS AND OR OTHER TREATMENT approaches.**

Get his diagnoses correct! Get rid of the tunnel vision!

Take notice of overseas research and practices! If things are not working, be creative – do not just follow practices THAT ARE OBVIOUSLY NOT WORKING.

There is a saying that goes something like this:

Insanity is repeating the same thing over and over, even when it is not working!

This is what they do with S. No wisdom at all!

The Royal Commission: please deal with these type of issues. There needs to be more flexibility and a total overhaul OF THE SYSTEM and even some doctors.

THANK YOU FOR LISTENING AND READING.

I DO PRAY FOR CHANGE, NOT JUST FOR OUR SAKE, BUT FOR THE MANY WHO ARE SUFFERING UNDER WHAT I THINK CAN BE CONSIDERED GROSS INCOMPETENCE BY SOME PROFESSIONALS, AND IN SOME CASES THE SYSTEM.

[REDACTED]

[REDACTED]

[REDACTED]

improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

Sorry! My answers are mixed up a bit but I think you will get the gist. I HAVE A LOT I CAN SHARE BUT HARD IN A SMALL SPACE - however I am very grateful for this opportunity. What makes it hard: ALIENATION which badly affects self esteem; NO SUPPORT SERVICES TO HELP FAMILIES AND PATIENTS & support people to WORK TOGETHER TO CREATE THE BEST PREVENTIVE WORKABLE LIVING SITUATION FOR PATIENT; MY SON'S TREATMENT AT THE HANDS OF ██████████ HAS BEEN ABOMINABLE; I HAVE WANTED TO OFFICIALLY COMPLAIN BUT DUE TO CONCERNS REGARDING REPERCUSSIONS ON MY SON AND HIS TREATMENT I HAVE WAITED FOR THIS OPPORTUNITY; Because of the limitations of Victoria's Public Mental Health procedures which is a serious systemic problem WE HAVE NO WHERE TO TURN; no options other than the pathetic situation in ██████████ relating to people/men over 26; I can't go into all the fine details here but I have reams to say; MY SON HAS JUST BEEN TAKEN TO HOSPITAL YESTERDAY AGAIN: that we have to deal with this system yet again is horrific for us; AND NEVER PROVIDES US WITH ANY LONG TERM RESOLUTIONS.

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

"The Drivers: I HAVE BEEN TOLD THAT THE ATTITUDE OF TREATING DOCTORS DEPENDS ON WHO IS AT THE Top and WHO EMPLOYS THEM; THAT THE TOP/SUPERVISING DOCTOR's APPROACH TO M H TREATMENT IS SIGNIFICANT AND HE/SHE WILL APPOINT TREATING DOCTORS WHO SUPPORT THEIR APPROACH; this is terrible. THERE ARE SOME FANTASTIC TREATMENT ALTERNATIVES IN THE USA THAT CANNOT BE USED HERE DUE TO NARROW MINDED TUNNEL VISION OF AUSTRALIAN/VICTORIAN PSYCHIATRISTS; SUITABLE ALTERNATIVE TREATMENT PLANS ARE NEEDED FOR PATIENTS WHO HAVE EXTREME REACTIONS TO ANTI-PSYCHOTIC DRUGS; and who need help , support; empathy; warmth respect and understanding.... and a doctor who believes a patient knows something about themselves and does not ridicule all a brave patient says about themselves. "

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

FAMILY MEMBERS AND FAMILY CARERS ARE THE MOST ALIENATED BUNCH. Family members CAN BECOME depressed and extremely anxious due to their interactions with Victorian MENTAL HEALTH DOCTORS AND WORKERS IN OME CASES. I have even been deceived and lied to both deliberately and by omission at times. FAMILIES KNOW MORE ABOUT THEIR PATIENT THAN DOCTORS GIVE THEM CREDIT FOR; their knowledge might not be professional in the same way but nonetheless it is AWARE; TRUE; EMPATHETIC AND LOVING AND OFTEN WISE. Most doctors we have dealt with have never a skerrick of human love or wisdom in their analyses; communication or treatment options. WE NEED A NEW CREATIVE APPROACH TO MENTAL HEALTH TREATMENTS AND SYSTEMS IN VICTORIA/AUSTRALIA.

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

"EVERYONE INVOLVED SHOULD HAVE A SAY ABOUT THE SYSTEMS AND HOW THEY WORK AND WHATS IMPORTANT; BY A LONG SHOT PSYCHIATRISTS ARE NOT THE ONLY

PEOPLE WHO KNOW STUFF AND WHO HAVE WISDOM AND INSIGHT INTO THE BEST STRUCTURES, TREATMENTS AND SUPPORT SYSTEMS ; People living with the situations are totally overlooked in Australia/Victoria. This is bridging on denial of human rights. "

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?

"AS I SAID MY SON HAS BEEN ILL ON AND OFF SINCE HE WAS 15. He HAS NO FRIENDS; NO HELP TO PREPARE HIMSELF FOR INVOLVEMENT IN A SUPPORT GROUP; HE HAS NOT BEEN ABLE TO WORK; he has not been financially able to keep his dogs which were his life; we could never get support to care for his dogs while he has been in hospital and doctors and workers have had no understanding of how vital it was for him to have them - the only form of normality in his life. Financial support for a patient's needs when I'll and hospitalised is abominable; Help with animals; help with the yard and cleaning the house; there is so many things. I have my own health issues and am due for an operation any day; financially my travelling from Melbourne to [REDACTED] is costly and difficult: I am a 68 year old pensioner I don't just have money lying around! My daughter and I have paid to have yard done; dogs looked after, personally cleaned the house at great cost to us physically, emotionally and financially with not support from the system at all. We have not minded supporting my son but my daughter has her own young family now and I am unable to do the physical stuff. Normally he can look after himself but it takes about 4-6 months for his situation to escalate and this is a long time for things to get out of order. [REDACTED] staff have told us money has been available for their clients but when we have applied there were so many ridiculous restrictions that never took into consideration the clients personal circumstances. Involvement in the [REDACTED] MENTAL HEALTH SYSTEM HAS CREATED SO MUCH STRESS AND ANXIETY FOR US."

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?

"INCLUSION OF INTERNATIONAL RESEARCH, AND NEW PRACTICES AND LATERAL THINKING IN ESTABLISHING THE BEST SYSTEMS AND PRACTICES AND TREATMENTS IN VICTORIA AND AUSTRALIA THE APPOINTMENT OF CREATIVE FORWARD THINKING DOCTORS AT THE TOP WHO ARE AWARE OF THE LATEST BEST OPTIONS/ALTERNATIVES FOR MH TREATMENTS. MORE COMPREHENSIVE SUPPORT SYSTEMS FOR ALL THOSE INVOLVED WITH A CLIENT PLANS & TREATMENTS INDIVIDUALLY ADAPTED TO A CLIENTS CIRCUMSTANCES AND NEEDS IN CONJUNCTION WITH FAMILY AND OTHER SUPPORT PEOPLE NOT JUST DECIDED BY TOTALLY OUT OF TOUCH SO-CALLED PROFESSIONALS"

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

THE ROYAL COMMISSION SHOULD MAKE SURE THAT NOT ONLY DOCTORS AND POLITICIANS ARE INVOLVED IN THE STEPS FROM HERE. There needs to be a good cross section of the community. Many doctors are arrogant and think they because they are trained they have more rights to a say and know more - THIS IS A FALLACY. We should receive a full report on RC DELIBERATIONS...and current treating doctors and systems should be made aware they are under the microscope FINALLY!

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

AS I SAID WE HAVE BEEN DEALING WITH THIS FOR nearly 18 years. I HAVE GROWN UP WITH A BROTHER WITH SCHIZOPHRENIA and his experience with his doctors has been significantly better. Even though the system was lacking the sensitivity and wisdom of a doctor can make a difference. I KNOW WE ARE NOT THE ONLY PEOPLE WITH EXTREME FRUSTRATIONS - there will be lots of people who won't be able to submit to the RC - those of us who can represent many many more people. Thank you for the opportunity. I DO HOPE THIS PROCESS CREATES SIGNIFICANT CHANGE. I AM ACTUALLY SURPRISED WE ARE STILL COPING... although I can't say my son is . ***** I DON'T NECESSARILY NEED TO BE ANONYMOUS but my SON DOES FOR PUBLICITY REASONS- references to [REDACTED] together with my name would identify him. He may not mind being involved when he is well again down the track. Now that he is back in hospital I would worry about it affecting his treating doctor's relationship with him.