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

SUB.0002.0029.0177

Name

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination? N/A

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?

Where services are supported adequately in terms of human resources and funding there is a lot of good being done. Access to hospital beds during acute episodes is limited and effects a revolving door solution which exacerbates many conditions.

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.

"Where hospitalisation becomes necessary for treatment, inadequate care is too frequent. While there are many very competent, caring staff who see their duty compassionately and professionally, there are others who are, to put it bluntly, incompetent or bullies. This may be because the system under which they work lacks in training, guidance or simply in good management principles."

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?

"In the case of incurable, cyclical conditions like Bipolar Disorder, family members need to be able to trust that the medical profession and other providers are sufficiently resourced to treat and care for the patient. Whilst the disorder is not the person, acknowledgement within the system that being at baseline is not necessarily 'well', and that sufferers of BD will need ongoing management, which they individually cannot monitor, seems an appropriate response. Ignoring a person when they are not manic nor under an Order is not appropriate. Guidance for the patient in formulating an Advance Care Statement seems necessary: but who will take some responsibility for this?"

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

"In hospitals, clear policies and guidelines that model caring and health oriented outcomes are

needed on a day to day basis. Work conditions, particularly in inpatient wards, need to be carefully monitored and managed. This implies best practice ongoing training of management and staff: particularly psychiatrists."

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?

"In the case of BD, maintaining healthy community connections and expectations is paramount. If, in manic episodes, ties and trust are eroded, every aspect of rehabilitation into the community becomes fraught. Thus, early and effective treatment during manic episodes is essential: the status quo of not sectioning a patient unless 'they are a threat to themselves or other's safety' stands in total opposition to their right to be treated."

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?

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?

I attach a document describing my most recent experience as a family member of the critical and ongoing medical response to my niece in her manic episode 2019. It highlights a lack of best practice in one regional hospital.

Respectfully submitted to the

ROYAL COMMISSION INTO MENTAL HEALTH

VICTORIAN GOVERNMENT 2019

I have concerns about the:

Inability of services to provide appropriate ongoing care for long term cyclical admissions

Inability of services to act in the interest of the patient due to restrictions legislated by the definition and usage of "voluntary" versus "involuntary" admission status, and the flow on effect of this to family and supporters

Lack of duty of care for patients with uncurable, lifelong, manageable but unmanaged conditions

Lack of consultation from medical/ mental health team with family or concerned supporters of the patient

I start shaking when I try to express any of this. I do not apologise for giving **my** perspective of one person's mental illness journey and its effects on those around her. I have encouraged others in her support network to do the same.

For the past twelve years I have been closely involved with other family members in the support of my niece who was diagnosed with Bipolar Disorder at age twenty in 1990 but with almost annual manic episodes since 2007.

The isolation of her chosen residence, provided and lessens the daily stress that she deals with. Thus, it is an ambient environment, but also means she is separate from family help in times of need.

Twelve years of almost annual admissions for acute manic episodes, followed by longer periods of relative calm, mean that the should have a clear record of my niece's medical history, but in a recent request it was clear that these records were not accurate: while she was admitted for a total of six weeks over a ten week period last year, the record stated only two weeks.

When my niece is in a manic state it is unclear but unlikely that she is taking medication. In fact, her state would preclude her ability to do so. She is, however, no doubt through strong fight or flight responses, capable of controlling her state for short periods when, for example in an interview to assess her psychiatric state, particularly after being sectioned and admitted to hospital, or at a potential discharge interview. She succeeds, thereby, in not being an involuntary patient, or in leaving hospital before well. Unfortunately, such exertions both deplete her energy and feed her mania and belief in her supremacy.

Instead of being treated in hospital until she reaches a stable baseline, she will/has been frequently be allowed to leave far before she should: because she can, because she is 'voluntary'. Even when she is an involuntary patient, she has been discharged many times after a simple interview with a psychiatrist with NO input as too how she is communicating/relating to family and other community members, clear indicators of her state of mind. This represents a LACK OF DUTY OF CARE, to allow a very sick person to be dropped onto the streets while incapable of rational judgment.

That these early discharges are a result of a need for beds to be vacated for other patients is evident, but also leads to a question of the competency of the people involved in the decisions and the policies and protocols that are there to guide them. These early discharges also lay claim to an inordinate number of occasions when emergency services, both Police and Ambulance, are involved: a ridiculous waste of resources.

A definition I found states: Person-centred means treating a person receiving healthcare with dignity, respecting their preferences, needs and values and involving them in all decisions about their health treatment. The term recognises that a person's needs may be broader than their mental health treatment and care.

'Involving her in decisions about her health treatment' while she is obviously incapable of reason is ludicrous. It also seems to me that, often, my niece's treatment has been driven by fear of litigation (something she often threatens) and expedience rather than her long-term broader needs for recuperation.

I attach my "feedback" sent to clarify the above. If I were to change the present situation, it would be by a rational and caring response to the 'hopes' I posed to the hospital.

But further it would be a change in balance between patients' rights and the system's responsibilities towards them: neglecting the patient's need to be treated is unacceptable, and if the 'voluntary' paradigm exacerbates the situation it needs to be rejigged. Somewhere in this the Advance Care Statement (?) becomes paramount, but where is the guidance in formulating this into something that works for both patient and medical providers?

Each year, I imagine we can do it better. This year, we believed we picked up my niece's escalation much earlier than before, but it made no difference. if anything, her recovery was longer and more destructive than before. I hope that with the learnings from this year, it will improve next year. If the system improves...

To the Consumer Liaison Coordinator
Feedback with regard to the treatment in
from
Preamble
As I look at the 16-page document on my computer that describes the past nine-week experience of the mental health services on my family and me, I hesitate to believe that it is not worth writing this.
It has to be worth it. It has to be, in some way, recognised as a plea for your institution to improve in its service to mental health patients. It has to be, in some way, and hopefully not insignificantly, responded to in a way that will provide a better experience for all stakeholders in the reach. It is, in part, my response to twelve years of your care for my niece, years ago, treated by your teams for most of those years, and who is worthy of respect by the medical profession teams in your system by more than a revolving door.
I would like to write my thanks to your mental health team, as I do each time I call to give information regarding when she is admitted. I make sure I thank the staff who answer my calls. But this is a missive of complaint, not thanks.
Background
Bipolar disorder is a very difficult disorder to treat. Yes. I have lived with bipolar disorder through mother for some forty-five years. I have known since she was two years old. And I have been involved in bipolar disorder since 2007. Unless your staff have been there for twelve years, I probably know her disorder better than they: in fact, better than she does, because I do not have the amnesia that she does of her manic stages.
mania was brought to the attention of your staff on February 22 nd of this year. It was noticed by members of her family independently, who, on communicating concerns, realised crisis was near. was informed. had no insight into her state, and the next day was 200 kilometres away. was taken by police to after a psychotic incident. Her daughter was taken into protection by DHHS and put into kinship care. After a few days in where the staff, with no or little knowledge of condition, deemed her capable of accepting treatment, was voluntarily admitted to the was taken into protection by DHHS and put into kinship care. After a few days in the staff, with no or little knowledge of condition, deemed her capable of accepting treatment, was voluntarily admitted to the was one of many admissions in nine years out of the past twelve. It was one of many admissions in nine years out of the past twelve. It was one of many admissions in nine years out of the past twelve.

Your records should show that has been admitted many times for being highly manic, for being a threat to her own health, as well as others' at times. They should also show that she was discharged while still manic on more than a few occasions. This was referred to by one consulting doctor last year as a "necessary risk".

When is in hospital, there is a mental health team to support her: I am sure there is a psychiatrist, a medical doctor, multiple nursing staff, canteen staff, admin, cleaning staff and so on who support her, hopefully towards recovery and return to a stable community life. When she leaves, usually but not always, she is assigned a case worker for some time.

There is also another team that supports — it includes her father and step-mother, her aunt (in place of her infirm mother), her ex-father-in-law and ex-mother-in-law who care for her three older children, her brother and sister-in-law, her cousin (and family) who is full-time kinship carer for her daughter while is hospitalised, her three older children, the father of her daughter, and perhaps a few true friends. These are all important stakeholders in health and welfare, who are in frequent communication and who share information about in the hope that her recovery is as smooth and efficient as possible. This team knows outside the hospital, and has knowledge of her past and her aspirations: mostly pretends this team does not exist.

is known by this second team in all of her stable, down and up times: in the last of these, she is known as frequently imperious, overbearing, promiscuous, paranoid, invulnerable, and despite being highly manic, can be lucid and rational for a very brief time if she feels it will lead to her heightened liberty. can be recognised by this team as needing help well before, and after, medical teams accept the fact.

Issues

On March 11, 2019, was discharged by some unknown process from your hospital. She had been sending erratic, inappropriate messages to various people on that very day and the night before and was defined as rapid cycling at a rate of ten minutes by two members of her family team during the twenty-four hours after her discharge, which was effected after just 14 days since admission.

So why, and this is my first question, was discharged when it was clearly inappropriate: she had extremely limited control over her mood and little rational thought, much less insight and social awareness? Time out of hospital, away from medication and defined expectations, simply exacerbates her mania. Many of the text messages she was sending were aimed at the kinship carer of her daughter: such inappropriate contact can only be disadvantageous to her communal recovery.

was sectioned and returned to from where it was deemed that she would accept treatment voluntarily, on March 16. Within the next two weeks, absented herself from the ward overnight twice. This was not reported to her registered nominated person, and requests to know whether was safely in your hospital or not were refused by a member of the nursing staff – saying "call the police if you are worried", not accepting that it was inappropriate to call the police if were in fact in the hospital. It was

clear that was not accepting of treatment, but apparently in their wish to vacate a bed, your staff decided was discharged at her own wish: rather than defining that she needed to have treatment and admit her involuntarily.

For the next ten days, was left to her manic devices. She was promiscuous, she drove a car when she had no rational judgment, she threatened one person with death by shooting and another with kidnapping. It is ludicrous for the hospital to say that a person with such limited rational judgment "decided to leave" the hospital. It was clearly her condition that decided to escape treatment. Eventually the police caught up with her and she was returned to the hospital.

The irony of this is that within the first days of hospitalisation, in fact on Friday March 1st, when called me as a family member, I informed her of presenting manic behaviours, requested she should read records carefully, and warned her to make no attempt to discharge without input from the family.

So, my next question is, why was there no attempt to ask family about state prior to her release on March 11, nor on March 27, nor prior to weekend leave that was granted under the most spurious of conditions on April 24th? Medical staff would have learnt, if they had asked, that was too busy to sleep, using her phone to disturb people with inappropriate communications at all hours of the night, posting multiple fantasies on social media, indicating her manic state.

Consequently, the next question is, why was phone not removed from her during night time when she obviously needed sleep for her recovery, as is indicated by prescribed sleeping pills? I requested removal of her phone on March 19th and this was acted on. After 3am calls the Sunday morning, I called Monday April 22nd, only to be told the phone had been removed the night before. How comforted I was to know that was receiving some care she needed! However, when more midnight calls were made on Thursday April 25, and I called the next day, I was confronted, when I had asked to speak to doctor or psychiatrist, by a member of the nursing staff saying they could not remove the phone unless the patient was taking photos etc of other patients. I had asked to speak to a medical practitioner so that treatment appropriate to needs could be implemented.

The next question is, when I left a message on this day for either the doctor or psychiatrist to call me back, why I was not contacted? This was only another in a line of requests that were neglected, including one to the Director of the Unit, left as a message on an unattended phone on March 20th requesting a call back to talk about issues with Duty of Care for Again, when I called on Saturday April 27, asking for the request to be transmitted to either doctor or psychiatrist, and to be left in writing, the request was apparently ignored.

It is now nearly ten weeks since we pointed out to your organisation that all was not well with I If anything, she is more elated and less rational than when she was admitted in March.

One would hope that your staff would be using **evidence-based learning** to find effective medications during such a frame of time.

One would hope that the **process of discharge** from your facility is one that is informed, careful and caring.

One would hope that your team would **allow** time to stabilise enough before she negotiates the challenges of the outside world.

One would hope that your team members would **use effective communication skills** to both give and receive information appropriate to improving health and well-being.

One would hope that your team can read the words of the Act to understand that communication via mobile phones is not needed nor mandated twenty-four hours a day.

One would hope that your **policies are designed and used** to benefit staff and patients work towards health and well-being.

One would hope that your team **cared enough about a patient** admitted to your facility **to inform the police** if a patient in your care was missing, or at least the nominated person.

One would hope that **responsibility will be accepted** and improvements planned and executed.

It is clear that consistent duty of care is gravely missing in your organisation, and needs to be addressed as a matter of systemic urgency. One saving grace is that over the past ten weeks a few individuals in your team I have spoken to have stepped up and shown that they are worthy of the professions they belong to. I am sure there could be more.

Faithfully,

The above was responded to on May 1 by a standardised email that apologised for my "experience" of their communication.

It talked of the "wherein families/nominated person are included in discharge planning, to which I had not been given consent to be involved – my point was that no-one was consulted in most instances.

Since May 25, has been discharged, is stable and cooperating with