ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM SUBMISSION

Introduction:

I am making this submission to the 2019 Royal Commission into Victoria's Mental Health System in the following capacities:

- Carer/family member of someone living with a severe episodic mental illness
- Victim survivor of family violence and sexual assault
- Consumer of mental health services due to my own lived experience of mental health issues resulting from the family violence and sexual assault I have survived.
- As a mental health professional

Carer/family member:

My mother suffers from bipolar disorder. I am 40, and although she has suffered from this illness since before I was born, she only received the official diagnosis when I was 22. Since her diagnosis, my mother's health has deteriorated rapidly. She has had numerous involuntary admissions to [redacted] Adult Acute Unit and Aged Mental Health Unit (Steele Haughton) since 2002.

Since my mother's diagnosis, I have been her main carer and support person. My mother has also received support and care from other members of our family and also her friends within the Ballarat community. The responsibility of this care has been shared in particular with my mother's older sister, my older brother and my father- who is my mother's ex-husband. Supporting and caring for my mother has been a long, traumatic and often very lonely journey where as a family we have received almost virtually no assistance from [redacted]

In the 18 years in which we have had to regularly engage with the CATT team, Adult Acute Unit, Aged Mental Health Unit, [redacted] and my mother's various case managers/treating clinicians during her numerous periods of being subject to a Community Treatment Order (CTO), [redacted] has never once offered my family or I any referrals to support services for carer/family members of a person with a mental illness. Everyone in my family who has been involved in my mother's care has suffered from vicarious trauma and carer fatigue. Being in a carer/support role for my mother has taken an incredible toll on my own physical and mental health. It has also impacted my ability to achieve my career and study goals due to the amount of leave I have had to take to focus on my mother's care needs.

[redacted]

My family members and I have been actively excluded from attending [redacted] We have often travelled for over 2 hours to be present for the hearings and taken time off work to ensure that we could participate. [redacted] has advised us in advance we could attend, however when we arrive at the hospital to attend the hearing we are told we cannot be present as it is against my mother's wishes. This has been incredibly distressing and inconvenient for us. It has made us feel disempowered and that the [redacted] has not shown any regard or understanding of the critical role we have played in supporting my mother throughout the years she has become acutely unwell.

A consumer's right to access their own medical records through FOI:

Whilst a consumer of mental health services should be able to continue to access their own medical records through FOI when they wish to do, they need to receive a lot more support from the health service they are linked with when they do. My mother requests her records through FOI after every admission and this has had a disastrous impact on her relationships with her family members in particular. My mother currently views her medical records as a document which proves how she has been persecuted for the last 18 years. She does not see it for what it actually is, that being a document which records all the individuals who have cared enough to want to see her get professional support and care so she can return to a point of wellness. Even though [redacted] would have been informed every single time that my mother has requested her medical records through FOI, her case workers have never thought to inform the family members involved in my mother's care that she has done so. If [redacted] had been proactive rather than silent in this regard, it would have made a huge difference to my family in being able to respond to the resulting change in my mother's attitudes and behaviour towards us.

Advance Statements:

[redacted] has allowed my mother to update her Advance Statement during periods when she has been experiencing a manic episode. My mother has subsequently used this document as a tool of manipulation to play psychological mind games with her key family support people. She deliberately names contact people on the document who have no interest in playing an active role in her care and who she can coerce and manipulate. When my mother is unwell, she updates this document to ensure that no one who will challenge her behaviours is contacted by [redacted] It is really disappointing to see a document which could ultimately play such an important role in giving a consumer of mental health services more agency and choice in their own healthcare and treatment decisions, being allowed to be abused in such a way. The way this document has been allowed to be used at [redacted] has caused much distress to my family. Members of her immediate care team which include my aunty, brother and I have been excluded from being given information about the welfare of our loved one, however at the same time [redacted] have allowed known perpetrators of family violence and sexual assault who have been abusing my mother to have access to her whilst she is an involuntary patient.

Prevention and Recovery Care (PARC) facilities:

The PARC step up/step down treatment model is an extremely effective and therapeutic treatment model. My mother would have benefited greatly if she had been able to access a form of treatment like this during the last 18 years. This would have been particularly beneficial during periods of time when my mother was experiencing homelessness as a result of family violence and needed time post-discharge from the Adult Acute Unit to be in a supportive environment whilst she sought transitional/permanent housing options. I suggest that the Commission looks to North Fitzroy PARC as a model of best practice in this type of residential mental health treatment. It should not be a postcode lottery of which consumers of mental health services get to access quality care options such as these. The Commission needs to ensure funding for this type of residential treatment is expanded across of all of Victoria, which a key focus on improving access in regional areas.

Discharge planning and appropriate referrals to community sector organisations/government services/housing providers:

Throughout the last 18 years of my mother regularly engaging with [redacted] due to her mental health issues, she has been consistently failed when it comes to discharge planning and referrals to external support services. My mother has faced homelessness, financial hardship, loss of employment, family violence, financial abuse and sexual assault as a result of how vulnerable she has become due to becoming acutely unwell. The responsibility of assisting my mother to navigate through the often complex world of accessing support to live independently in the community has fallen predominantly on her family members. Given that Mental Health Services are staffed by a multi-disciplinary team of professionals who are the gatekeepers to a wide range of information about supports and services for consumers/carers/family members, I really feel like my mother, my family and I have been failed repeatedly by the lack of a basic duty of care shown towards any of us.

My recommendations for the Commission:

- Access to referrals for support services for carer/family members should not be a postcode lottery. Wellways has an excellent program called Snapshot. This is an education program designed to assist family members, carers and friends of people with mental illness to maintain their own wellness and gain awareness of the range of support options available to them. This model of carer/family support needs to be rolled out statewide.

- When a mental health consumer who is subject to a CTO and is actively being case managed by a health service requests their medical records through FOI, the consumer should be offered the opportunity to be supported by their case manager to understand the content of their records. The case manager needs to be aware of the increased vulnerability of their client through reading records and how this could trigger a decline in their mental health and also cause the client to disengage with their normal support networks and become aggressive to individuals who have been involved in notifying CATT teams which have resulted in involuntary admissions.

- The Commission needs to make a formal recommendation about the appropriate use of consumer's Advance Statements. These documents should only be able to be updated when the person suffering a mental illness is in a period of wellness and can make informed consent to the contents of the document. If these documents are updated when a consumer is having an episode of their mental illness, then they are subject to manipulation by both the consumer and individuals who seek to take advantage of the consumer- for example: perpetrators of family violence. Where there has been a documented history of family members/carers providing consistent care and support for a consumer of mental health services, their right to access information about their loved one should be taken into consideration, even if the consumer is actively trying to exclude them from accessing information. Mental Health Professionals need to ensure they read a consumer's case history thoroughly before choosing to exclude a carer/family member from being informed about a consumer's treatment and discharge planning.

- Currently consumers of mental health services can request that carers/family members be excluded from Mental Health Tribunal Hearings. The Commission needs to consider how inappropriate and completely traumatic this is for carers/family members. Whilst a Health Service is responsible for the treatment of the consumer whilst that person is in their care, when that person is discharged back into the community or taken of a CTO, it is then their carer/family members/friends/community members/colleagues who are left to provide support and care to the consumer. The decisions which are made within Mental Health Tribunal Hearings impact as much on a consumer's carers/family members as they do on the consumer. Given the in-depth case history and knowledge of current context of the consumer becoming unwell, carers/family members should not be excluded from

Mental Health Tribunal Hearings should they wish to attend, and the Tribunal members should always invite them to have the opportunity to speak.

- I recommend that the Commission investigate improving discharge planning processes, particularly in regards to implementing a more integrated service delivery approach and improving referral processes to community sector organisations, government departments and housing services which can provide appropriate supports to consumers upon discharge.

Family Violence and Mental Health:

I am a victim survivor of family violence and sexual assault. Since 2007 I have been a Survivor Advocate with Safe Steps Family Violence Response Centre. This advocacy role has led to me being involved in the creation of primary prevention resources, delivering speaking engagements and training to a range of organisations, doing media interviews, participating in the co-design of improved systemic and structural responses to family violence, as well as challenging victim blaming myths and changing community attitudes towards family violence and gender equality.

My lived experience of family violence and sexual assault has led to me developing depression, anxiety and PTSD. I have survived two long-term relationships where I was abused physically, psychologically, verbally, financially and sexually. I never suffered from any mental health issues prior to the abuse, however the devastating impact these relationships have had on my life has been extremely debilitating. Both during and subsequently to being in these relationships I have experienced periods where my emotional distress was so severe that I would actively contemplate suicide as an option to end my suffering.

It took me many years of disclosing my abuse to services such as my local GP clinic, hospital employees, police and magistrate court staff before I was finally referred to a counsellor for psychological support. My mental health has improved dramatically as a result of having access to the ongoing therapeutic support of a trauma specialist psychologist. However despite having regular treatment through my psychologist, there can be periods where life events can trigger my PTSD, depression and anxiety and I have to rely on services such as Lifeline, Beyondblue and my employer's EAP program until I can secure a new appointment with my psychologist. I also find that being limited to 10 sessions per year under my Medicare Mental Health Plan means that I cannot always access treatment with the specialist who knows my case history as often as I need it when I am going through periods of increased mental anguish. It can be really exhausting to have re-tell my story to crisis line phone counsellors to give them the context of why my past traumatic experiences have led to my current distress. This has frequently caused me to remain frozen in a state of emotional pain and receive no support at all during periods of crisis.

The mental health issues which I now suffer from as a result of the family violence and sexual assault I experienced has had a devastating impact on my ability to complete my university degree and achieve the career goals I had aimed for. My mental health issues have also impacted me on a physical level, as when life events trigger my depression, anxiety and PTSD, it causes the muscular injuries I sustained as a result of the violent assaults I endured to flare-up. This causes me to be in excruciating pain, which then in turn affects my ability to work, and requires me to seek out expensive osteopath treatments for relief from my symptoms. This vicious cycle of emotional and physical pain has absolutely crippled me financially and made it extremely difficult to support myself. I have not been able to afford to take a holiday to get some time for the respite, healing and recovery I so desperately need since 2012. All my financial resources go to meeting my immediate living costs and paying for specialist healthcare treatment which isn't covered under Medicare and only partially covered under my private health insurance. This only contributes to the state of stress and anxiety which I feel like I am almost constantly in. However in the places I work as a professional, I have to continually put on the mask that I am coping and that everything is ok, whilst at the same time living with the daily reminders of how the trauma I have experienced has forever altered my mind and body.

In 2015 I made a submission and was called to give evidence at Victoria's Royal Commission into Family Violence (see attached Witness Statement document). Recommendations 104 and 106 were as a result of my testimony. I call upon the Commission to refer to Recommendation 104 in particular, which suggested that:

> "*The Victorian Government increase investment in programs to ensure that people who have been affected by family violence have timely access to group-based or individual counselling for as long as they need. The counselling should be delivered by practitioners with appropriate training.*"
> (https://w.www.vic.gov.au/familyviolence/recommendations/recommendation-details.html?recommendation_id=153)

Although there have already been some commitments made by the Victorian Government in regards to implementing Recommendation 104, I would suggest that the current response is still far from adequate. The Commission need to build on Victoria's Royal Commission into Family Violence's existing response by investigating how the following factors need to be improved:

- Having family violence and sexual assault counselling sessions given their own Medicare Item number.
- Training more mental health professionals to become trauma specialists
- Ensuring that all mental health professionals who receive referrals for clients/patients who are victim survivors of family violence and sexual assault are trained in trauma sensitive practice.
- Making access to trauma specialists more affordable and accessible through enabling clinicians to bulk bill their treatment so that consumers do not have to pay a gap fee.

Privacy of Family Violence Information Sharing Scheme requests and minimising inadvertent risk to victim survivors:

- Family Violence Information Sharing Scheme's impact on victim survivors' privacy when they are involved with the Mental Health Tribunal.
    - This issue/ question has been raised with mental health workers, with concerns that a family violence perpetrator might have access or knowledge that an information sharing request was done in their name, which might put the victim survivor at risk.
    - It would be ideal for the Commission to provide clarity on this issue so that all health services have the same procedures, policies and clinical guidelines.

- Family Violence Information Sharing Scheme and patients' right to access information under freedom of information (FOI)
    - This issue/ question has been raised with mental health workers, with concerns that a family violence perpetrator might have access to information that an information sharing request was done in their name. If a perpetrator is

    - to request his case notes/ information under freedom of information this may inadvertently place a victim survivor at risk.
    - It would be ideal for the Commission to clarify on this issue so that all health services have the same procedures and policies on this issue.

- My Health Records.
    - There is a potential risk of information obtained from the Family Violence Information Sharing Scheme from patients' medical records being accessible via their My Health Records.
    - It would be ideal for the Commission to clarify on this issue so that all health services have the same procedures and policies on this issue.

In order to deliver the best mental health outcomes for mental health consumers presenting with family violence, it would be ideal for the Commission to provide clarity on this issue so that all health services have uniform procedures and policies on implementing the Family Violence Information Sharing Scheme while also acknowledging consumer's rights and privacy/ freedom of information.

    - Furthermore, it would be beneficial for the Commission to seek clarification with the Mental Health Tribunal Board on perpetrators access to victim's survivors' information under the family violence information sharing scheme. To ensure that the risk to victim survivors is minimised, the information sharing requests made about the perpetrator should never be shared with the perpetrator. These requests could either be made FOI exempt or redacted to ensure that perpetrators are never aware of a request being made.

    - It is imperative that the Commission investigates whether requests made under the Family Violence Information Sharing Scheme could result in the request being documented in any way on a patient's My Health Record and that steps are taken to mitigate the risks which this would pose to victim survivors.

    - Failure for the Commission to provide clarification on these issues might lead to detrimental outcomes for family violence victim survivors hence making the good intentions of the Family Violence Information Sharing Scheme pointless. It would be beneficial for the Commission to look at the benefits of the Family Violence Information Sharing Scheme and mental health, and at the same time consider the above mentioned complex issues that might impact the safety and wellbeing of victim survivors and children of family violence.

Perpetrator response:

- Perpetrator services need an overhaul. We are letting them and the entire community down. This should be an absolute priority if we are aiming for cultural and big picture societal change.
- Mental Health services need to ensure that they are mindful of the implications of misidentifying the predominant aggressor in circumstances of family violence.
    - When a patient and their partner/family member/carer each claim of violence has occurred against them, mental health staff must look beyond the visual evidence and consider the context of the act of violence by identifying controlling behaviour in the predominant aggressor and fear in the victim.

- Mental Health employees must be able to recognize the tactics of power and control. They must consider such issues as: the severity of injuries inflicted by each party, the difference in size and weight of the parties, the demeanour of the parties, any prior complaints of violence, claims of self-defence and the likelihood of further injury to a party.
- The determination of the predominant aggressor, and the reasons for that determination, should be included in a patient's notes. Otherwise, perpetrators will be able to successfully manipulate the system and victim survivors will not be protected. As a result, victim survivor may not seek support the next time violence occurs.
- If the predominant aggressor is misidentified, there could be important legal consequences for the victim, such as the denial of custody of children, of housing rights and of immigration rights. Additionally, without being identified as a victim, a person would not be eligible for housing support or other forms of assistance they may be eligible for.
- Mental Health employees need to be trained appropriately to recognise the implications of allowing perpetrators to have access to visit their victims, when their victims are patients within a therapeutic setting.
- Mental Health employees need to be aware of the incredible vulnerability that victim survivors of family violence, who are at the same time consumers of mental health services. Employees need to be vigilant and manage the risks of perpetrators coercing victim survivors into signing documents such as Power of Attorney documents whilst they cannot give informed consent.

Family Violence Consumer/Lived Experience Consultant:

Using Monash Health as a model of best practice, all health services should seek to employ a Family Violence Consumer/Lived Experience Consultant to provide specialist consumer input into their mental health programs. These types of roles would provide consumer input into work relating to family violence, trauma and family sensitive practice. Victim survivors selected for roles such as these would:

- Participate in the co-production of the family violence, trauma and family sensitive practice mental health training
- Attend and contribute to working group and projects related to family violence, trauma and family sensitive practice
- Contribute to quality improvement, policy and program development in the Mental Health Program around family violence and family sensitive practice
- Represent the Mental Health Program and co-present at family violence forums
- Support and mentor Consumers who contribute to this project
- Contribute to staff education, training, and professional development opportunities as required.
- Share their experience as part of providing a lived experience perspective to encourage mental health staff to be proactive in their response in relation to family violence issues.

It is really important that the Commission makes recommendations which formalise the importance of consumer representatives/peer workers within the mental health/AOD/family violence sectors. Individuals who have lived experience of these issues can play a critical role in improving the Mental Health System's treatment of its consumers, through ensuring that co-design principles are applied at all times. When Mental Health Services collaborate with consumer representatives they achieve a client-centred approach which achieves a greater range of therapeutic outcomes.

<u>Other recommendations for the Commission to consider:</u>

- Improving access to and funding for alternative therapies such as equine therapy, art therapy, massage and trauma sensitive yoga.
- Improving access to and funding for companion animals such as dogs to support individuals living with mental health issues.
- Providing funding to animal welfare organisations to be able to make pet respite care available for individuals who need to spend extended periods in the care of health services and who have no friends or family members who can look after their pets whilst they are receiving treatment. The Commission could consider looking at the Safe Steps Family Violence Response Centre "Pets in Crisis" Program as a model to replicate in circumstances such as these.