Serving the Community since 1930s

Mental Health Foundation Australia
Better Mental Health for All

30th June, 2019

Submission by the Mental Health Foundation Australia
Suite J 450 Chapel Street South Yarra 3141
[redacted]

Commissioners – Royal Commission into Victoria's Mental Health System for Mental Health Services.

Mental Health Foundation Australia
Better Mental Health for All

Introduction :

Mental Health Foundation Australia (MHFA) is an organisation made up of people from all walks of life. It includes professionals, those living with mental illness, families of those living with mental illness, related organisations concerned with mental health and members of the public with an interest in mental health.

We are committed to addressing mental health needs through collaborative effort. We continue to find new ways to add value to our mental health community relationships, to strengthen their foundations to promote better outcomes for all.

The MHFA has been part of the National, and International Mental Health movement for close to 90 years. It has played a significant role in establishing the current network of services and support for Mental Health consumers. Many of the organisations now prominent in the Mental Health sector had their beginnings as a part of the MHFA or developed out of MHFA initiatives.

Our Patron, Our Mission and Our Aim:

Emeritus Professor Bruce Tonge is the patron of the Mental Health Foundation Australia. Professor Tonge is acknowledged as a national and international authority in child and adolescent mental health.

He was foundation Head, School of Psychology and Psychiatry and Head, Discipline of Psychological Medicine, Monash University for many years. Professor Tonge is an outstanding representative for the Mental Health Foundation Australia's mission and aim for what has for 34 years been known as Mental Health Week and most recently the "Mental Health Month"

Mission: Better Mental Health for all

Aim: To activate, educate and engage Victorians about mental health and wellbeing, through a week(now month) of interactive events across the state and removal of stigma associated with mental illness.

What we do:

20 Support Groups

Multicultural Ambassadors Program

12 member Youth Advisory Committee

Scientific Advisory Committee

Monthly Community Education Series

National Mental Health Month

Telephone and Email Information and Referral Services

Future Plans:

The Mental Health Foundation Australia is casting a 'broad net' to provided better services to improve the mental health of all Victorians. We are ambitiously looking to expand nationally, to deliver our services across to all Australians. The foundation is also currently working on opening a fully operational Community Hub in a Melbournian Suburb, which aims to focus on advocacy, education, counselling, training and referral services in the mental health space.

Submission proper:

"[redacted]'s Story" is the story of a consumer who experienced the trials and tribulations of Victoria's (and some other state's) mental health services over a 16-year period.

Tragically [redacted] committed suicide in 2016, accidentally but in the most tragic circumstances, taking others with[redacted]. [redacted] brave [redacted] has submitted, in [redacted] own words and emphases, the family's and [redacted]'s personal experiences with mental health services in the first person. As such, the submission is harrowing but particularly poignant and relevant to the commissioner's considerations.

It should be noted by all commissioners that [redacted] regarded [redacted] struggle in getting help and services to deal with [redacted] illness, as being as difficult as dealing with [redacted] serious illness itself.

While the Mental Health Foundation Australia could have voluminous amounts of information about the mental health system in Victoria, [redacted]'s story encapsulates the most critical concerns in a very personal way.

It is worth noting the Mental Health Foundation Australia has been supporting [redacted]'s family for the past 2 years at great expense to the organisation both personally and financially. We have, sadly, in effect been "the ambulance parked at the bottom of the cliff".

Foreword to [redacted]'s Story: Crisis Assessment & Treatment Teams are in crisis

Current Crisis Assessment Treatment Teams are themselves in crisis. The Mental Health Foundation Australia often deals with serious situations and seeks assistance from regional CATT services. Victorian government websites incorrectly promote such teams as: "A crisis assessment and treatment team (CATT) provides immediate help during a mental health crisis. Experiencing or caring for someone during a mental health crisis can be frightening but help is available 24 hours a day." (https://www.healthdirect.gov.au/crisis-management)

The reality is that most regional mental health services, on their websites or when contacted, refer callers to 000 Emergency in the case of crisis. Most CATT services do not operate after 6pm and certainly not 24 hours. The net result is that Victorian police have become the de facto emergency mental health service in Victoria. This has caused a major strain on the services of Victoria police.

The MHFA is aware of Police services in the Gippsland area where an entire shift involving two officers is involved in the repeated collection of a consumer subject to psychotic delusions who must be collected and delivered to safety. This flow on of the burden of care is economically wasteful and deleterious to the welfare of consumers as police are not specifically trained for such interventions.

Had an effective and truly operational crisis service operated "[redacted]'s Story" may have been different and not had its doubly tragic consequences.

Case Study: Consumer Lived Experience

PEOPLE SUFFER NOT ONLY A TERRIBLE ILLNESS – BUT THE MENTAL HEALTH SYSTEM AS WELL

[redacted]'s Story

Under the current mental health regime [redacted] was worse off, our family is worse off, and the mental health system is worse of, given what the last 16 years must have cost, especially in hospitalisations – nobody has gained anything at all.

The last sixteen years of [redacted]'s life were filled with suffering – suffering one of the most horrible illnesses, schizophrenia - and at the same time **suffering the current Mental Health System.**

Through these years there were sometimes when [redacted] played a negative part in [redacted] journey, often **because** [redacted] was ill; and there were times when [redacted] desperately tried to manage [redacted] life.
From the beginning there was **very little** opportunity for [redacted] to build up **trust in staff due to constant changes**, or in [redacted] treatment, **no time for staff to get to know [redacted] as an individual**, and not as just one of the many in the 'passing parade' of clients, with the **main focus on medication**. **There is lack of adequate staff, lack of time, in some cases lack of ability, lack of a positive living environment, lack of activities, lack of holistic, positive and more supportive treatments – due to a LACK OF FUNDING, and THE ALLOCATION OF THAT FUNDING**.

Mental illness is said to be hugely on the increase in one form or another. Add to that the problems arising from ICE at the present time. If nothing **significan**t is done to improve mental health services very soon, the crisis can only worsen, and it is already bad enough.

I believe [redacted] suffered all the contributing factors to schizophrenia:

- A number of **really traumatic events** between pre-school age and university, and I do not believe [redacted] received the appropriate help or counselling.
- **Stress** – social, emotional, financial, and study stress while at university.
- Perhaps a **predisposition.**
- **Some use of marijuana**, first socially, then to 'cope' with the stresses.
- Attending festivals where there were **drug**s, of which [redacted] partook.

[redacted]'s journey into hell started in [redacted] at [redacted], a [redacted], where [redacted] was given a [redacted]' which tipped [redacted] over the edge and [redacted] experienced [redacted] first psychotic episode. [redacted]

It is **impossible** to get across the reality and extent of the suffering, anxiety, difficulty and frustration of the last sixteen years, but in brief some of the things [redacted], and [redacted] family, endured include:

- 22 hospitalisations over 16 years, a few of those for periods of 1-3 months, in ACT, NSW, SA and VIC.
- Privacy issues, when we were sometimes given no information as to how [redacted] was, and **no guidance** as to how to deal with the situation.
- [redacted]'s inability to complete studies due to illness and hospitalisations.
- Many unpleasant side effects of the medication, such as feeling 'like of zombie', unable to function. properly, disrupted sleep, lack of motivation, huge weight gain, a loss of self confidence and self-esteem, loss of independence.
- Unexpected discharges from hospital while **clearly still unwell.**
- Really upsetting phone calls between myself and a psychiatrist when I questioned why [redacted] was being discharged when **obviously psychotic** - extremely abrupt, rude and unsympathetic, saying [redacted] can't stay here forever.'
- A discharge when the staff could not tell me where [redacted] had been discharged to; the case manager phoned and asked me if I knew where [redacted] was
- When I (in NE Victoria)received a call from [redacted] (in Melbourne) one night, extremely distressed, saying [redacted] had to gas [redacted] self as [redacted] could not continue and hung up, I phoned the Crisis Team in Melbourne and was told they were **too busy to check on [redacted] – IF** they had time they would **try** to call on [redacted] **some time the next afternoon.**
- Two **positive** things [redacted] got involved in were Outdoors Inc. and the Community Kitchen – till **FUNDING WAS CUT** and they ceased to operate.
- [redacted] also received a grant to set up a community garden at the public housing flats where [redacted] lived, giving [redacted] something positive to think about and do.
- Admissions to hospital very difficult, particularly where police where involved – some police were very good, others dreadful; if a family member initiated the admission it often resulted in very strained relationships with [redacted] who understandably felt let down/betrayed by us, and we often did not hear from [redacted] for ages, leaving us worried and anxious about [redacted].
- Extreme loneliness, sadness, depression, difficulty in making new friends, lack of activities, lack of opportunity for employment, lack of trust , loss of confidence and self esteem
- Handling of [redacted] finances given to State Trustees – while practical and necessary, added to [redacted] feeling inadequate, with a sense of losing [redacted] rights etc
- When [redacted] became unwell while in Tasmania visiting [redacted] father, my daughters and I had to deal with the situation as the current case manager was so **slow, dithering around as how to deal with the situation** – my eldest daughter flew over and brought [redacted] back to Melbourne.
- After discharge from hospital, staff came to [redacted]'s flat each day around midday for 12 months to administer [redacted] meds, which bombed [redacted] out for the rest of the day, [redacted] ended up being awake all night, going back to bed in the morning, only to be woken around midday for the next dose of medication. This was a particularly bad year, with [redacted]'s **frustration and anger at the system building up.**

When we requested that the meds be given in late afternoon or evening we were told they could not do that as there was **not enough time and they could not pay overtime**.

- During this time the staff apparently had a form to fill in relating to their visit, one of the questions being "**Do you feel suicidal today**?" This not only infuriated [redacted], but was also extremely depressing, especially when it happened almost every day, very often from another 'stranger' (case workers constantly changed).
- After one of [redacted]'s visits to me, the case manager told me I was 'untrustworthy' as **I** had not administered [redacted]'s meds.
- The public housing flats where [redacted] lived for the last 8 years was the most **depressing and negative place one could find, especially for vulnerable people.** The place was riddled with rats and mice, almost everyone living there probably had problems with either alcohol, drugs or mental illness; the police often called at night when there was some disturbance or violence going on.
- During one of my visits [redacted]'s neighbour came to [redacted] front door, aggressive and abusive and I was quite frightened. When I wanted to phone the police [redacted] said not to, as it would be worse when I left – **what a way for vulnerable people to live**.
- During **the last eight years** the clinic [redacted] was under had **case managers constantly changing**, so **little continuity of care**, or chance for them to get to know much about [redacted], or for [redacted] to build up trust in staff
- I was **never once able to make an appointment with the psychiatrist** – who only saw [redacted] **twice a year**.
- The doctors changed every three months so there was also **no continuity of care** there either, with [redacted] having to constantly be dealing with yet another stranger.
- On more than one occasion, **because the psychiatrist was away,** action could not be taken eg having [redacted] care transferred to where [redacted] was staying with my daughter and where [redacted] was having [redacted] injections and where **they were very concerned about** [redacted] and felt they should be monitoring [redacted] – so [redacted] **was not monitored**
- Similarly, when the family finally arranged accommodation outside of Melbourne to a better living environment and requested the transfer of [redacted] care to that area, **nothing could be done for some weeks until the psychiatrist returned from wherever [redacted] was**. I took it upon myself to contact the local mental health services in the [redacted] and informed them that [redacted] would be coming, that I was not confident they would receive the relevant paperwork in time, and gave them what information I could
- [redacted] was switched from one heavy medication to another a number of times, with long periods in between when we do not believe the effects, or lack thereof, were adequately monitored
- I question the amount of information passed from one service to another; I was sometimes asked what medication [redacted] was on, or what dosage [redacted] was on
- [redacted] was given a copy of an assessment to have [redacted] put back on a CTO, at a time when [redacted] was very low. In it was a statement saying that they did not expect to see any improvement in [redacted] condition within the next twelve months – not exactly something positive for [redacted] to read at that time

[redacted] finally moved into [redacted] new home in mid March [redacted] so very happy to be there. We felt this was the beginning of a much better chapter with 100% improved living conditions and environment; and, while still having the same problems, the mental health team is much smaller and more personal, with the promise of more continuity of care.

We knew that [redacted] was quite depressed, and really unwell despite the injections which were doing **absolutely nothing** to help [redacted].

- After phoning 000 around midnight one Thursday and telling ambulance staff that [redacted] thought [redacted] was going to hurt himself, [redacted] was taken to the Emergency Dept. and then discharged from Emergency Dept. at **2.30am and walked home alone.** Next morning [redacted] phoned and asked if [redacted] could come to me for the week-end. **We struggled through the week-end, and [redacted] was admitted to hospital** (via a local GP) **on the Monday** because [redacted] was so suicidal

I now believe that by that time [redacted] got to [redacted] new home in Wangaratta [redacted] was actually much more unwell, and suffering far worse depression than [redacted] let on. I believe [redacted] tried to hide things as [redacted] was always afraid of being given more medication with horrible side effects.

By this time [redacted] had no trust in any mental health staff, hated having injections which were doing nothing for [redacted] anyway, and had an overwhelming sense of fear about everything – staff, treatment, how [redacted] could continue, even mistrusting of family at times. [redacted] desperately wanted a job but could see no way of getting one, [redacted] was afraid of the future, [redacted] told me [redacted] felt [redacted] was a burden to everyone, that no-one understood what [redacted] life was like.

[redacted] spent two nights with me in [redacted] and when I returned from a walk on the [redacted] [redacted] , I found the police waiting for me at home with the news that [redacted] had died in a head on collision just out of town, , along with the driver of the other car, and my car a write off .....

Tragically in [redacted] [redacted] died in a head on collision, along with the driver of the other car. Though there was no finding of suicide, the family has to live with the fact that it may have been suicide - and that another family also suffers a devastating loss.

We are all struggling to come to terms with the culmination of the last 16 years of struggle - our devastating loss, the terrible journey [redacted] had to endure, and the overwhelming sadness that [redacted] did not get to enjoy what I think could have been a somewhat better chapter for [redacted].

Why, and how, did this happen?
With no witnesses to the actual collision, we are just left with questions. The eventual conclusion of the investigation was that

*[redacted]'s mental state could not be ruled out;
*neither could the possibility of a blackout or seizure be ruled out due to a medical condition [redacted] had, and which were also *side effects of the heavy medication* [redacted] *was prescribed*.

We, [redacted] family, have to live, not only with the loss of our loved one, and a person of worth;
- we have to live with the questions around what happened on that day;
- we wonder whether [redacted] had a blackout or seizure (which [redacted] had had in the past)
- we wonder whether there was something going on physically for [redacted], as [redacted] had told me on more than one occasion that [redacted] felt [redacted] was going to collapse, felt [redacted] could not do much as [redacted] had no energy
- we also have to acknowledge that it *may* have been suicide on [redacted]'s part because of [redacted] **low quality of life**
- AND we have to live with the fact that another person died along with [redacted], and [redacted] family is also grieving their loss.

I can understand that [redacted] may have had a plan, perhaps to drive into a tree?
But I find it very hard to believe that [redacted] would have deliberately driven into an oncoming car with someone in it. I also believe that [redacted] would be devastated to know that that person also died in the collision.

But we have to live with it all.....

[redacted] was not only a loved [redacted], [redacted] was very intelligent and a thinking person, [redacted] had a great sense of humour, a beautiful singing voice, could turn [redacted] hand to things practical, was patient and kind to the elderly and kids, and had a great concern for the environment – what a loss of an essentially good human being .....

I think of the many hundreds who endure what [redacted] did, many with no family support, they are completely alone. **It has to change.**

I would suggest that a more **positive path** would be that **psychiatrists and medication**, while necessary, form a much **smaller <u>focus</u>**, with the **<u>main focus</u> and time** being taken up with more **positive** and holistic treatments including things like behavioural/cognitive therapy, counselling, psychology, psychotherapy, meditation, yoga or tai chi, activities of all sorts (such as Outdoors Inc), involvement in community kitchens, and appropriate exercise, or small group walks. **This, instead of sitting around with nothing to do, smoking cigarettes, often very lonely, and becoming depressed.**

I feel this would have greatly improved [redacted]'s attitude towards [redacted] treatment teams and [redacted] treatment, [redacted] co-operation, as well as [redacted] quality of life.

Balance the **cost and outcome** of such treatment with the current one which usually includes numerous very costly admissions to hospital .....
I know and accept that this is an extremely difficult field, with much to be learned still.
In our world today things that are working quite well are often changed, just for the sake of changing.

I suffer the grief of the loss on a [redacted], a loved family member and a person of worth – and even worse is the grief of what [redacted] had to endure through [redacted] illness and the Mental Health System.

It is too late for [redacted], it is too late for us, but .....

Here is something that is NOT working - WHY NOT CHANGE THE SYSTEM?

This detailed account was courageously written by [redacted] and approved for submission to the Royal Commission on the understanding of anonymity. All dates and details are correct but confidential.