[redacted]

To the Mental Health Inquiry 2019,

[redacted]

This submission has been complied in collaboration with [redacted], a lifelong worker, wife and mother of [redacted] children. [redacted] is the primary companion to her son who suffers chronic complex schizophrenia, her husband who has suffered periodic acute psychotic episodes over his lifetime, and was also to her own mother, whom she cared for during her senior years and into the disability of old age. Throughout all this difficult and demanding support work, [redacted] also worked as a full-time [redacted] and [redacted] until retirement age. [redacted] now offers further support as a grandmother of [redacted] on the autism spectrum, providing respite for their mother and father.

In this submission [redacted] has expressed ideas which have taken form over her extensive experience as a mother, support worker and worker, who has had, and continues to have, regular and intense engagement with the mental health services for over 40 years. She speaks from a position of profound firsthand knowledge, both affective and objective.

[redacted] comments touch on the following areas of the terms of reference and is prefaced by [redacted] who has helped to format this submission and has observed the effect that dealing with the mental health system has had on her mother from her perspective as child, and daughter, who has grown up in a family shaped by mental illness, its corresponding services and our society's response to its manifestation.

Terms of Reference:

- examine the effect of supporting mental health on economic and social participation, productivity and the Australian economy;
- examine how sectors beyond health, including education, employment, social services, housing and justice, can contribute to improving mental health and economic participation and productivity;
- examine the effectiveness of current programs and Initiatives across all jurisdictions to improve mental health, suicide prevention and participation, including by governments, employers and professional groups;
- assess whether the current investment in mental health is delivering value for money and the best outcomes for individuals, their families, society and the economy;

**Preface:**

My mother makes her observations in the detached, informed and thoughtful way that she always approaches people in the working world with. Her thoughtful reflection and politeness of delivery obscures a chasm of emotional pain, as well as deep frustration, endured over a lifetime in response to a system which has often treated her in demeaning, misogynistic and brutal ways.

Stemming from harrowing experiences at the now closed [redacted] Asylum, such as being pressured by psychiatrists to sign permissions for treatments she was not allowed time to fully understand and coerced into decision making without second opinion, all the way through to the contemporary brutality of hospital economic policy coupled with the assisted accommodation system which responds with inadequacy, indeed with stupidity, in evident lack of collaborative cross-sector communication or support for the patient and their carers, being counterproductive to the assessment and handling of people suffering intolerable mental agony.

In light of the deep grief and lengthy emotional processing associated with recognising and coming to understand the manifestation of mental illness in another human being, my mother writes her suggestions from the context of many years of repeatedly experiencing personal shocks, depression and

fatigue, caused in part from an enduring poverty of time, down to the minute and second, where a dysfunctional mental health system coupled with a strident, inflexible culture of work, left time unavailable for her to attend to nurturing a fullness in her family life, nor even to nurture herself in the most basic requirement of adequate rest and being able to maintain habits conducive to good health and wellbeing during crisis times.

The demands of monstrous illness, persistent crisis and a user-unfriendly mental health system over a period of 40 years has contributed to a splintering dysfunction within our family. In turn this has contributed to poor economic and productivity outcomes for other family members, whose experience of growing up with family crisis has not provided an adequately stable platform to launch successfully into a stable, self-supported life. The associated long-term employment and housing stability problems suffered by those with chronic mental illness is shared to a lesser degree by siblings who internalise maladaptive coping habits.

Poorly managed crisis which detrimentally effects the wellbeing of primary care givers contributes to the development of stress and anxiety in children, leading to a lack of capacity for mitigating the development of mental stressors that manifest in adulthood and inhibiting the practice of good decision making. This means maintaining successful interpersonal relationships, which are arguably the basis for maintaining employment, and developing skills of resilience and positive mechanisms for coping with adversity in life, are made difficult from the outset.

The emotional workload I witnessed my mother harness when I was a child is something extraordinary. The best word I can find to describe the atmosphere of the home is *exhaustion.* A proportion of the energy expended by my mother came from the demands of a mental health system which was continually devolving, all reforms hampered by chronic underfunding and relentless restructuring which resulted in less rather than more support services.

If my brother was discharged early from his periodic stints in hospital - which he inevitably was, and still is, again and again for year after year after year, which always results in his supported accommodation refusing to accept him back because they recognise him as being acutely unwell, it is my mother who the hospital bullies to solve this situation.

The locked wards once reserved for mentally ill patients now overflow with acutely ill, often violent drug addicts owing to the underfunding of Government supported drug and alcohol rehabilitation facilities. Some mental health wards units have developed policy against accepting intoxicated or detoxing addicts now refuse patients who present with complex interrelated problems, who, due to a lack of alternate facilities now have nowhere to go at all and pose significant risk to themselves and others in community settings.

My own experience of this dysfunction between the mental health silo, the medical emergency silo, the greater hospital policy and the general lack of facilities funded to deal with people who present with complex afflictions, happened when my brother was overdosed on sleeping medications administered by an unskilled night staffer who were quite justifiably afraid and unable to deal with a scary psychotic man. When faced with unrelenting refusal from the psychiatric ward registrar to admit him at the onset of a psychotic episode, despite repeated requests from the accommodation day staff who had recognised the signs of that developing acute psychosis, the night staff were forced to manage a situation they were not equipped for. My brother suffered a massive seizure as a result of the sedative overdose and was finally admitted to the emergency ward where he was kept for 12 hours because neither the main hospital nor the psychiatric ward had the capacity to assist him, both counter claiming that his condition "is a medical issue not a psychiatric issue" and " is a psychiatric issue not a medical issue". Finally, he was given a hospital bed in the general ward only because myself and my younger brother refused to let the hospital discharge him into the street.

I attended this situation as my brother's support, travelling from my regional home to the outer [redacted] suburbs. As I was underemployed at the time, I could not afford accommodation near by and subsequently spent 3 nights sleeping on the hospital floor while my brother paced a hospital room, floridly psychotic, overseen by a security guard who was assigned by the hospital in the absence of a bed in the psychiatric ward. This was extremely inappropriate, given my brother has paranoid schizophrenia and the proximity of a uniformed guard who was outwardly hostile toward him, even accusing him of being a drug addict at one point, elevated the tension of the situation considerably.

It took me over a month to recover from the stress of the event. I lost time from work, failed an exam I could not attend which was catalyst to dropping out of a vocational training course I was a quarter way through, and I needed to use the Medicare system for treatment of anxiety for some time afterwards.

A costly experience from a productivity and an economic point of view. Yet this situation was commonplace and like so many others which my mother has endured on regular basis since my brother was 17 years old. He is now [redacted].

**Statement:**

**“** Psychological distress is associated with:

- unemployment (Reavley et al. 2011),
- low income (Enticott et al. 2018; Reavley et al. 2011),
- low social capital (Phongsavan et al. 2006),
- low social connectedness and social support (Atkins et al. 2013; Levula, Harré and Wilson 2018);
- workplace characteristics (Considine et al. 2017);
- poor quality diet (Hodge et al. 2013; Nguyen, Ding and Mihrshahi 2017),
- limitations on physical functioning (Atkins et al. 2013; Byles et al. 2014) and physical diseases (Byles et al. 2014).

*There may be limits on how much change [mental health] treatment can produce where such risk factors are present and persisting. Dealing with these risk factors may require a* ***greater emphasis on prevention*** *(Jorm 2014) and on* ***social factors that lie outside the domain of mental health services*** *(Mulder, Rucklidge and Wilkinson 2017). (Jorm 2018, p. 1061)…**”*** (page 4)

This statement already points the Commission in the right direction i.e that government is ultimately responsible for addressing the risk factors.

1. people who are unemployed or underemployed have low incomes in a time of rising costs of living particularly in the cost of rental accommodation and food;
2. this exacerbates low social capital (no ongoing work colleagues, less opportunity to participate in social activities through discretionary spending);
3. limited protection for low income workers through government-initiated policies (e.g. removal of penalty rates in service industries; the harsh economic treatment of single mothers; the disgusting reduction in social housing which ensures continuing homelessness) and poor governance (enforcement of regulations which were instituted to protect low income and temporary workers);
4. poor quality diets are ensured when wages are low and pensions inadequate to meet the rising cost of food like meat, fresh vegetables and fruit. If you check the supermarket shelves you will easily see the cheapest food items are the least healthy.

All these issues can only be adequately addressed by governments. While governments of any persuasion put short term economic growth as their top priority to the neglect of other policies that create a healthy and functioning society there will be little hope for the mentally ill among us to fulfil whatever potential they have. In the end economic prosperity can only suffer from this **lack of long term vision.**

**Education**

While most children receive an adequate education at primary level it is increasingly apparent that this applies only to those children who are capable of receiving it. Those children who are handicapped in some way (autism, dyslexia, and other neurological divergencies) are woefully poorly catered for, and thus open to negative experiences like bullying and loss of self-esteem which exposes them to possible mental ill health outcomes like anxiety, depression and self - harming. There is developing evidence of children becoming suicidal as a result of school experiences. Teacher training courses and lack of classroom support in the form of support staff **must** be addressed. No child should leave primary school without being able to read with understanding and having a basic grasp of mathematics**.** Australia is already heading down the PISA list in its educational results – we are ranked 21 on the scale, equal to Vietnam and eclipsed by the 20 countries ahead of us, including New Zealand. Teacher training courses need investigation and revision as to content quality and adherence to the best of international models. For example, anecdotal evidence is that some teachers consider that autism is a behavioural problem rather than a neurological condition requiring adaptive teaching techniques. The Victorian Education Department's website is full of motherhood statements about how diversity is catered for in its schools, yet at the individual school level there is often a lack of funding for teacher aides in classrooms where there are ASD and other neurologically diverse students in the state system. One hopes that the NDIS may alter this situation, but effective and comprehensive teacher training in the area, and ongoing professional development for existing teachers and principals is also **a vital necessity**. More children are being diagnosed as having neurological differences such that nearly every school will have a cohort of children who require assistance to avoid on-going damage to self-confidence, and developing anxiety and depression. **The connection of educational experience and mental health seems to be not on the radar of most governments, state and federal.**

**Lack of basic governance in relation to Supported Residential homes**

As with the banking industry, the building industry, the restaurant industry, the energy industry, the aged care industry among others, the policing of the Supported Residential Service aspect of the Mental Health system leaves a lot to be desired. The idea of shutting institutions and creating community care for the mentally ill was a wonderful idea in theory. It lost something in the setting up as private operators became providers. As with aged care, many operators saw the prospect of a profitable business *without being competent in the provision of specialised care*. It is difficult for the layman parent/carer to find out how often/when/if these institutions are inspected until the media lets us know or to ascertain the qualifications of the operator.

The quality of care varies a lot:

- meals e.g: my son is given soup and a roll for dinner most evenings, breakfast is a choice of cereal or toast, but not both, and one hot drink. Lunch is sandwiches. He has better and more varied meals when he is in hospital. He is in an SRS that charges more than the usual rent so I wonder what those residents in standard rental SRSs are eating.
- staff levels e.g. my son is in accommodation that has minimum staff – one person works from 9 – 5 doing all the cooking, laundry, and dealing with residents, visitors and phone calls. There is one person on overnight duty, who prepares and serves breakfast. The medication is given out by the overnight staff member, who may/may not be a nurse.
- qualifications & experience of staff. In my son's SRS the previous owner was an ex-psychiatric nurse who hired at least 4 other staff to do the cooking, and interact with the residents. He sold the "business" to a new proprietor, who, though well-intentioned, approachable and sympathetic, has reduced face-to-face staff in an obvious effort to cut costs and increase profits, and has no previous experience with psychiatric patients.

**Government regulations are useless unless rigorously enforced.**

**Revolving door hospitalizations**

The practice of discharging patients who have been hospitalized for a psychotic episode within a certain number of required (by the hospital) days is a **pernicious** practice for the following reasons:

1. the treating doctor is forced to compromise his/her medical standards for an economic bottom line decided by accountants, regardless of the health of the patient;
2. the patient is returned to his/her accommodation where support may not be available before he/she is well enough so the patient relapses and is re-admitted, or self-harms, or harms someone else. The cost to the government of such a system must be very high.

3. It is, as a result, a system which undermines public trust in it and as a result, in the doctors who are employed in it.
4. It puts a huge load onto the case workers of the patients, who are overworked and underpaid already.
5. It creates intense anxiety in the carers of the patients.
6. It can cause a ripple-on effect in SRS accommodation, where an unwell person can cause other residents anxiety re his/her behaviour, thus raising tension levels for all and possibly aggressive confrontations.

**Inadequate numbers of case-workers**

Social workers are the front-line of the government's mental health system. Social workers are overloaded with clients, underpaid, experience vicarious trauma and suffer from burn-out. It would be interesting to find out how many are lost to the profession as a result. This means that clients experience a recurring lack of continuity of care over the long term as their case workers regularly disappear to be replaced with a newcomer.

**Mental Health Wards in public hospitals**

The built environment has improved enormously over the last decade including attention to creating attractive surroundings, separate bedrooms with en-suite facilities, comfortable social spaces and organized activities. However on the basis of observation at visiting hours there seem to be flaws in the following areas :

1. nursing staff are recruited from agencies and the ratio of permanent nurses (if any) to temporaries is hugely weighted to the latter;
2. the majority of nursing staff are sequestered in the nursing station/office doing administrative tasks with a minimum of nurses actually available to patients;
3. the 'on duty' nurses are responsible for up to 6 patients each, all of whom have different levels of need, yet are also required to open security doors when visitors arrive and leave (surely a job for a non-nursing person), talk with parents/carers/other visitors and deal with patients having issues seemingly all at the same time;
4. discharge procedures in some hospitals are chaotic to say the least in my experience, in contrast to the excellent methods used in non- mental health wards. The following has happened to my son : discharge on a weekend with no medication but a script to be filled when there are fewer

available pharmacies open, some of which do not carry the medication required; discharge without notifying the SRS that the patient will be arriving; discharge without notifying the relevant case-worker; discharge without notifying parents/carers. To a large extent such procedures seem to be the result of lack of knowledge by nursing staff of any written discharge procedures set by whoever is in charge of the mental health units (assuming that such a person/body exists). Since a majority of these nurses are agency nurses in temporary situations, this is not surprising.

**Public Mental Health Outpatient Services**

While these are very valuable resources, they have one outstanding flaw: the lack of continuity in doctors, who seem to be regularly rotated around the system so that long term care of chronic patients is disjointed.

**Further thoughts:**

- The main causes of angst over the last 10 years have been accommodation issues and the revolving door hospital experience.
- There needs to be more flexibility in the workplace generally to allow for late starts or paid mental health days for workers with family members who suffer from mental illness and those who have mental illness themselves.
- Implementing greater public education regarding the secondary impact of mental illness on families and workplace relationships is important to reduce ongoing stigma around mental health issues.
- The provision of in-school lunches for students whose parents might be struggling organize their weekly family tasks due to managing crisis would be a great help.
- Respite holiday programs for youth and for families who need a break for and from their kids during crisis times would have been helpful to me over the years
- Over the years I found it <u>really difficult to negotiate the system to get information/action which was useful and relevant</u>- when your child/partner is in the middle of a psychotic episode the immediate options are limited almost exclusively to calling the police and once they are involved you lose any control over what happens next. Crisis Assessment and Treatment Teams are located in each metropolitan region, connected to the Community Mental Health outpatient

centres, but to find their phone numbers is difficult at the best of times. In times of escalating crisis it is very difficult to access those contact details within the sprawling websites and when phones are busy or unmanned, which is frequent in my experience. Newcomers to the experience must find it horrendously stressful.

- The Mental Health system is also only geared to be a crisis-response organisation. Apart from privately organised bodies like Beyond Blue or church-run groups like Re-Gen there seems to be no government organisation which offers guidance and support for those who feel in danger of declining mental health. Re-Gen offers training in supporting such people. (http://www.regen.org.au/education-training/mental-health-first-aid), Surely an Australia-wide government program of a similar nature could be offered.

This concludes the submission. Thankyou for reading.