The details below are a very brief summary of some of our family experience in relation to my son [redacted] who was born in 1975
The summary is based on our observations / experiences

Throughout primary school [redacted] was a popular, bright, highly intelligent, sensitive, kind boy with sparkling eyes, but around year 8 at school, he was introduced to marihuana and also commenced abusing alcohol, possibly to mimic his father's alcoholism.

Psychosis, began to appear, but this was outside our family's experience / understanding, so we sought professional family guidance from a number of highly respected professionals, none of whom acknowledged father's alcoholism or the danger signs in [redacted] Statistician helping me with PhD at my home immediately recognized schizophrenia behaviour in [redacted] while psychiatric / psychological (psych) 'professionals' said he 'would grow out of it'. During this adolescent / mid-teen period, [redacted] went from happy school boy to frequently refusing to go to school because he claimed he didn't feel well.

Accordingly I called our trusted, experienced GP, whose 'Diagnosis and Medical Treatment Plan' were:
Diagnosis: 'he's acting out his father's alcoholism'

'Treatment Plan': wait till he gets into trouble with the police and that may spur him into action'. … [redacted] grandfather and father (and now 2 brothers) were/are solicitors. No-one in our family has been in trouble with police and this 'medical management plan' shocked me. The sheer negligence of this medico and the psych professionals and the lost opportunity haunts me daily 30 years later and undoubtedly adds to my stress.

DC, who is currently serving 8 year sentence for paedophilia/rape of boy(s) taught [redacted] self-defence and seemed to form a bond with [redacted] DC also had an association or friendship with RA who paraded as a Family / Cult / Drug Counsellor. [redacted] did not engage with therapists/psychiatrists we took him to, but DC encouraged [redacted] to see RA and specifically to avoid other psych help. In retrospect, this is very disturbing as I strongly suspect that the counsellor was covering up for his friend's paedophilia but at the time, we had no way of knowing this and as RA seemed to have a good reputation we were happy that at last [redacted] was seeing 'someone good'.

Since his initial psychosis, [redacted] has not allowed individuals to stand behind him and has been heard to shout during the night: '*get off me, I'm not your prostitute*'. In retrospect, that RA was unaware of DCs' homosexuality and paedophilia seems extremely unlikely to me.

As [redacted] situation deteriorated my mother asked her GP what to do and was referred to inner Melbourne mental health (mh) services, which sent the Crisis Assessment Team (CAT) to him. They believed he needed to be hospitalized, but he walked away from them, his small terrier in tow and they made no effort to follow up. He took the dog to my home and disappeared. For days neither we nor police could locate him. He drove himself to the mountains and was lucky to be found after some days, with his car deeply bogged in mud in one of the dirt tracks at the base of Mt Baw Baw during the snow season.

After about a month in our local public in-patient unit (IPU), [redacted] re-emerged on risperidone, worked for a while, seemed 'ok' and went overseas, where family and friends he met reported that he was doing very well. His recovery continued until he became homesick and returned home. On arrival, [redacted] was frankly psychotic. Hospitalization, transfer to Clozapine, several disappearances and hospital admissions followed. [redacted] was each time managed at one of Melbourne's reputedly 'top' public psychiatric units.

The revolting revolving door and 'you are not unwell enough': On several occasions over the years, [redacted] has presented at our local public psych unit asking for psych help. On each occasion he has been turned away, only to be returned in ambulance with police escort due to frank psychosis within 48 hours of being turned away. The trauma of this is unimaginable.

Private psychiatrists [redacted] has attended have lacked admission rights to both public and private hospitals. I believe that if a treating doctor takes on a case such as schizophrenia, which is known to be episodic, ethics (and morality) demand that the doctor has some means of helping their patient in crisis. This is not the case. Over the years, several private psychiatrists have told [redacted] in crisis to 'go to the local public hospital' and have made no effort to refer him to someone with admission rights in private care. Their greed in dealing with routine care only – ie the easy way out - with no regard for comprehensive management of the condition that provides their income is reprehensible.

Discharge: was generally not followed up adequately. On one occasion, [redacted] was discharged without any medication or instructions. Case management/psych 'care' may merely consist of a short monthly visit, principally to check on blood cell levels. Psychology, someone to talk to, is not part of the norm. During [redacted] first hospitalization, the mature consultant asked what I expected of treatment. When I said I hoped [redacted] would be happy, the consultant looked shocked. I got the impression that if a patient is breathing, neither harming himself nor putting community at risk, hospital 'care' has been fulfilled…. But:

Schizophrenia is widely recognized to be a bio-psycho-social issue.:

- Bio – little is actually known about the 'bio'
  - unlike other illnesses/disease states – no reliable biological markers have been found,
  - there is no way to determine whether changes shown in brain scans are due to stress/ trauma / medication or to 'mental illness',
  - genetic vulnerability is likely but it is polygenetic. No single gene has been found to be responsible.

  In other words, very little is known about the aetiology and biology of schizophrenia, yet 'treatment' is pharmaceutical / polypharmacy, often ad hoc and often with more and more meds added to counteract side-effects of each in progression. We wouldn't treat our dogs by making them take psychotropic drugs ad hoc – and especially not when vast research has indicated that psycho-social interventions do work (and at less cost than a lifetime of medication and its side-effects).

- psycho- social –a considerable body of evidence exists linking schizophrenia to psychological trauma but in the 25 years of 'care' within the public health system, no talking therapy has been offered or been available to us.

[redacted] was extremely intelligent and though his cognitive skills are poor, he retains amazing manipulative / problem solving skills. A high level of clinical skill would be required to engage him, but as with many other friends' loved ones, current mh services do not provide time / facilities / opportunity for talking therapies.

Psychosis is a family issue, rarely a single person issue. At our local mental health unit, 'case manager' is now referred to as 'mh clinician'. These 'clinicians' have a range of backgrounds and may have very limited, if any, training in psychological methods such as family therapy, trauma informed care, cognitive behavioural therapy, so how can they be expected to take on some of the most difficult family and alcohol and other drug (AOD) issues that society presents?

Lack of availability of psychological therapy is one of the biggest downfalls of our system. Psychology must be given an equal status as medical care in the management of psychosocial challenges / mental illness. It is cheaper, has good success in many cases, also saves the cost of medication and avoids the side-effects of medication.

Q1: Reflecting on mental health services, what you think is currently working well?

Public -In our family's experience, as described above - **absolutely not 'fit for purpose':**

- Inadequate – talking therapy has not been available. 'Mental Health clinicians' are not trained in family therapy and tended to avoid the family and in any event, inadequate resources for spending time with the person in crisis and/ or their family[1] ,
- Community care is lacking and hospitals are merely crisis centres with overworked staff, insufficient beds to meet demand, so individuals have nowhere to turn for good care,
- Almost total reliance on ad hoc pharmacy/ polypharmacy – 'if one drug doesn't work, let's add a few more'. This is criminal – each drug has numerous untoward side-effects. Drugs are metabolized differently by some individuals and DNA testing for cytochrome enzymes can alert clinicians to risk but DNA testing is not done even when individuals' response is not as expected.

Private…. Perhaps a very small proportions of psychiatrists do take comprehensive care of their patients, but our family has dealt with about 5 highly regarded private psychiatrists and none have done so – ie in the main, private 'care' is hampered by lack of sufficient numbers of psychiatrists taking up the difficult cases and managing them appropriately. (See above).

I worked in health care for >40 years and currently volunteer in the mh milieu, so should have good contacts. Nevertheless, in 2018, when the public system sought to discharge [redacted] I attempted to find a private psychiatrist who would manage schizophrenia. In response to a variety of recommendations, I rang **16** psychiatrists located in our area. Only three were prepared to take on a 41 yo male, living semi-independently, who had held down the same part-time job for over 10 years, had not touched marihuana (or any drug other than alcohol) for two decades but who suffered from schizophrenia and had an alcohol problem. We never got to discussing fees – I would happily have paid any reasonable fee – but few were willing to treat schizophrenia. My friends have experienced similar indifference by psychiatrists to treating difficult problems. Most prefer to treat the worried well.

Q2: Reflecting on mental health services, what do you think is currently not working well	**Q3: What needs to change to improve Victoria's mental health services?**
Prevention – clearly not working currently as demonstrated by increasing numbers, esp. drug, alcohol and gambling victims.	Need • Education of community from primary school to adulthood, School programmes must include o healthy diet as a way of life – tuck shops to eliminate sugary / fat foods, o physical exercise as a way of life, o positive rather than negative education, but lead to an awareness of the dangers in AOD abuse and gambling o minimizing screen time, o outdoor education, o healthy after school programmes, o contribution to community programmes to help the underprivileged, o mentoring, o programmes to increase self esteem, self efficacy, o early intervention for vulnerable students

[1] Throughout, 'family' refers to 'friends and family of choice'/ carers - ie *the meaningful individuals in the clients'* lives.

	• Education of school staff, community leaders, sporting associations, primary care providers so they provide examples healthy lifestyles and they learn to recognize those at risk and can take appropriate steps to prevent further damage, • Reduced access to illegal substances – including during school years, • Improved social conditions - reduced unemployment, poverty, family violence, improved access to safe affordable housing, • Early intervention and access to appropriate care before addictions take hold.
Drug and Alcohol Services / Dual Diagnosis services	AOD services must be increased, with many more residential programmes. Individuals completing the programmes need to retain their relationships with a mentor / clinician to help them to remain drug free. Follow up is essential. AOD services and mental health services need to be integrated because many individuals suffer from both drug, alcohol and mh challenges. Often gambling is also part of this picture and services need to be integrated and work together.
Early intervention	**Need to reduce our focus only on hospital / medical model and to introduce community based care because currently an individual in distress has nowehere to turn for help**….. My son has several times presented at one of Melbourne's major public hospitals which has a large psych facility and been told: 'you are not sick enough for treatment' …. Is this healthcare? Would it be tolerated in cancer or cardiac,? …'I can see your blood pressure is up, but we need to wait till you have a stroke till we can do something' or 'sorry we can't treat your cancer till it's metastasized' **Community based, talking therapy focussed early intervention has been shown to reduce the need for hospitals and to provide a better path to recovery and long-term success than our current system..** Successful early intervention models have been shown to have far better long-term results than 'Treatment as Usual' – eg • Open Dialogue,[2],[3],[4],[5],[6] • Early Intervention Services[7] which include a range of : o family psycho-education, o family counselling, o cognitive behaviour therapy, o family therapy, o vocational / educational counselling, o social skills training / management, o crisis response team / crisis management, o the option of properly administerd and monitored medication

[2] Seikkula J., Aaltonen J., Alakare B., et al (2006) Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. *Psychotherapy Research*. 16(2):214-218

[3] Aaltonen J., Seikkula J., Lehtinen K., (2011) The Comprehensive Open-Dialogue-An approach in Western Lapland: 1. The incidence of non-affective psychosis and prodromal states *Psychosis* (3)3: 179-191

[4] https://www.theguardian.com/society/2015/oct/20/parachute-therapy-psychosis-new-york-uk

[5] http://power2u.org/alternatives-to-hospitalization/#PracticeGuidelines

[6] https://www.health.org.uk/improvement-projects/peer-supported-open-dialogue-pod-in-nhs-mental-health-services

[7] Correll, C.U, Galling R., Compariosn of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis: A Systematic Review, Meta-analysis, and Meta-regression. et al (2018) *JAMA Psychiatry 75(6) 555-565.*

Community services	**<u>Community care is essential. Troubled individuals should have access to community centres 24/7. These should have non-medicalized overnight facilities staffed by experienced mh clinicians, with psychiatrists on call for hospital transfer if needed.</u>** Co-ordinated community facilities offering comprehensive continuity of care made sufficiently pleasant for staff to be retained long-term area a must. No-one can unburden their serious problems to a psychologist only to find them routinely replaced by new faces. A successful Mental Health System needs continuity and co-operation between medical, hospital, community, psychological, social (including educational and vocational) care. Can a Victorian Royal Commission achieve this, or will the system fall short due to fragmentation because the commission is not a national one?
Continuity of Care	Mental health issues are personal. Treatment is personal and relies on forming a healing relationship with the therapist. For success, this needs to be long-term and therapists must have extensive family therapy and related training such as Trauma Informed Care. Mental health services must offer job satisfaction – not only adequate remuneration, but also pleasant conditions, suitable advancement opportunities, mentoring, safety and the opportunity for attractive hours, especially for parents.
Talking therapy / psychological services	Psychological services must have an equal place to medication in mh care. There must be availability of comprehensively trained mh clinicians with Family therapy, Trauma Informed Care and related training. Open Dialogue is a method that has been shown to reduce long-term disability. It has been introduced in many places across the globe with success.
Hospital 'care'	Beds are short, staff are overworked and the opportunity for true therapy missing from the hospital environment we experienced. One hand had no idea of what the other was doing. However, the solution is definitely not just more beds. The solution is to avoid the need for beds by better community care, better prevention and to use the beds only for the most challenged individuals. Safety of all – patients and staff alike must be assured. Some female only areas are needed. [redacted] was forced to listen to hours of yelling and continual screaming at a time when he needed a quiet environment in which to reflect, relax and talk to someone caring. But no-one had the time to listen and family were generally treated shoddily.
Discharge	Post discharge follow-up was exceedingly poor. [redacted] was discharged without instructions, without follow-up appointment, without introduction to the person who was to continue his 'care' and without any medication. Upon realizing this, I was forced to contact the ward and to ask for appropriate information and to return to pick up his medication. Drug free step up and step down residential units providing assistance with daily living and emotional support must be available if mh 'care' is to succeed.

Follow up	Without follow-up care, individuals relapse and end up on the 'revolving door'. Programmes to guide and assist individuals to take up their rightful place in the community are essential components of a properly functioning mh system. Hospital is only one step towards recovery and continuity of care in the community should be an essential component .
Lack of comprehensive health care	Individuals being managed in mh systems die 10-25 years earlier than the community. Every person within every mh service must be checked at least annually for systemic / physical health and it must be followed up. To reduce the side effects of medications, exercise and dietician must be integrated into the treatment plans of all in mh care. Hospitals are health care facilities and to honour their role as health care providors they must attend to general health issues .

4. Is there anything else important that you came here to talk about today, that you did not get a chance to say and want to share?

Housing and Homelessness

Housing First' models have been shown to help homeless individuals regain dignity, self esteem and to reintegrate into the community. Much work needs to be done to address homelessness and to provide assisted, semi-independent accommodation. This needs to be accompanied by life skills education and of sufficiently long duration that the residents are able to look after themselves and have established a meaningful life prior to discharge.
[redacted] who had not used drugs other than alcohol for over two decades and who had dried out of alcohol in his most recent 8/52 stay in hospital, was discharged to a drug den. It is a great credit to him that despite his surroundings, he has not indulged in drugs other than alcohol, but discharging to such a location is a recipe for failure that cannot continue.

In conclusion,

The rising toll of homelessness, drug use, psychiatric morbidity affects not only the individuals who are directly involved, but also those around them. If these issues are not addressed, the toll on society will be immense. Hopefully the Victorian Royal Commission will be able to integrate and vastly improve community and hospital services into one co-ordinated system providing comprehensive mental, systemic and physical health care.

Thank you for the opportunity to describe our experiences. I write as a carer about the poor 'care' that my son has received.

If you fix the mh system, the life of all carers will improve immeasurably.