

1/ This is huge. The stigma and discrimination impedes so many people experiencing mental health as well as their family and friends. It reduces them, it isolates them, it prevents them from going forward and developing into individual/s that could be well-rounded and accepted. Some may never become fully functional and great achievers, but if they can be lifted out of a miserable existence then that alone would be so worth the effort.

It begins with the government recognising this long and ongoing problem. Education is a main factor in reaching younger people who can stimulate change in communities. This could be a school based program for change. Hands-on. Gaining information through showing and telling – introducing a proactive experience through interacting with people with a mental illness. A progressive liaison creating a willingness on both sides to learn more. Shaping better understanding and acceptance by de-mystifying and sorting the myths from reality. This pre-emptive action is a good step in bringing mental illness into the fore instead of being a horror story where unwell people are demonized. Lift the lid on the discrimination and stigma, allow education to bring another side of the story... allow those with a mental illness to stop hiding and isolating themselves. Bring it out and hopefully acceptance will begin the move within our culture and community towards a positive result.

When the family or the person with a mental illness presents to triage or calls for help and is turned away this compounds the stigma and discrimination. This is discrimination! When health professionals working in the mental health field decide over the phone that the person/s asking for help do not need it, this is unprofessional and discriminatory. \*When I phoned triage last year and explained that my son was seriously unwell and needed care, I was told that everyone who phones believes that their situation is serious. I was also told to not call with the same old story, that they wanted some new information before they would respond. Where do you go for help when the people who are supposed to give help turn you away? Other family members had phoned for help as well and they got the same response.

Being homeless, living rough or living in inappropriate accommodation is a problem for those with a mental illness. Living like this exacerbates the problem/stigma/discrimination/abuse/threats.

When my son was in the psychiatric ward they wanted him to exit their service into a caravan in a small town. The caravan was 35 kilometres from a large centre where he

would have to go for food, doctor etc. I asked the question how he would get to the next town when he hasn't got a car or licence. Their reply was, catch the train. I answered that he would then have to wait for hours until the train returned and what would he do with his purchases as he wouldn't be able to carry them all. Their reply was he could buy a trolley. I asked what would he do with his food that needed to be refrigerated and they said, he could buy an esky. This shows the calibre of a worker that was supposed to be caring for a person with a serious mental illness and dual diagnosis.

There needs to be a more educated group of professional people working closely with those experiencing mental health illness. What I experienced was appalling. I believe the sector is underfunded and under-resourced, > this needs to be addressed as well as getting appropriate/dedicated professionals who want to make a difference in mental health.

Many of the workers in mental health are from overseas backgrounds and I found it very difficult to understand them, some I could hardly understand any of what they were saying. If I was from a different speaking background they would make sure that I had an interpreter so I understood. I would ask them to repeat what they said and they did, but it was an effort to understand them. My concentration was shifted from my unwell son to focusing on understanding what the worker was saying rather than the issue at hand.

Government, health officials and doctors/ mental health workers would need to be involved fully... it will take the whole village to bring about change. Trying is a first step but succeeding is a huge joint effort. When people with mental illness "hurt" the whole community hurts, albeit directly or indirectly. Tax payers are not getting their money's worth; unwell people are definitely being short changed. Money needs to be spent, and a lot of it. The old saying, "a stitch in time saves nine", in this case (eg), 9 million dollars saves 19 million in the long run. It's not rocket science.

2/ In my experience not much is working. I found that there were a few helpful people in the psychiatric hospital, and individually they possibly were all good people, but as a working team I would rate them as inefficient. I would give them a fail.

However, that there is a psychiatric ward in my [REDACTED] area is a plus.

What is working? The Carer Consultant person was helpful and informative. I believe the case manager is a good thing and works hard but I think they too are over-burdened in their position.

Funding, resources and dedicated/educated people is what is needed.

Police, paramedics and the like need to be up to speed on detecting a person with a mental illness/dual diagnosis, mental illness/drugs. This is not always the case. However the police I have dealt with more recently I found to be sympathetic. Recently my son has been pepper sprayed and some time ago he was dragged out of his place of living and was left partly naked on his front lawn.

3/

4/ They are bundled out of the service asap. Into caravans and other very inappropriate accommodation, this is the first step to failure. They don't get proper back up once they have left the service (the case managers etc. are often taking on too much). They often have low esteem and are constantly aware of the stigma/discrimination around themselves so they are very reluctant to reach out or ask for what they need and if they have asked and nothing is done they will not ask again. There is no immediate or close help in rural areas and this usually stops someone from asking for help because it generally isn't accessible unless they drive themselves to the nearest large hospital or in my son's case someone else would have to take him. He is also often without a phone or he has no credit on his phone. I sometimes have to drive fifty kilometres to make contact with him. Some may not ask for help because they are not articulate or think they will be rejected; they might talk about doing things but never do because they feel/believe they are not good enough to warrant help and/or will be the butt of humiliation if they attempt a program. They don't feel included in anything so (in my experience) they go back to what they know, back to the bad, back to the drugs. Their life from there on is a decline back into worsening mental health. And here we go again until another psychotic episode. My son has attempted suicide. I believe he wants to be well but he needs help to be well, he needs a mentor. He is not getting the help that HE needs. I can't do it for him. I am tired, I am exhausted. I want my life; I am [REDACTED] this month and in not the best of health. The more he thinks he is rejected through the health system and community the more he back slides. There are members of his own family that have rejected him too. He feels he has no worth and belongs nowhere. He tries to be polite and interactive, I see him try so hard but it is him trying to be accepted, to be normal. There needs to be something positive in his life and there isn't. He has two sons and two grandsons; he doesn't see any of them. None of them contact him. Outside of his one room accommodation and outside of his isolation, I am the only person he has. It is wearing me down. I don't live in the same town as he does.

There are two other members within our family that have a lifelong mental illness. My son has a dual diagnosis, schizophrenia schizoaffective disorder and Substance use disorder. He has a long history of mental illness and multiple admittances to the psychiatric hospital. He cannot be cured but it is my hope (and I don't know why I still hope) that his illness can be managed and that he can have some quality in his life. At present he has none. He was diagnosed thirteen years ago. Also with a dual diagnosis only the side of schizophrenia is treated and the drug addiction is not looked at unless my son volunteers or seeks rehabilitation. Something must be done with the drug side

of his illness and people like his. They are doomed to failure. It is like going to the doctor with appendicitis and a fractured leg and the doctor only treats the appendicitis. Turning people out of a psychiatric ward who have a drug addiction are almost always going to return. This is not effective and nothing is achieved – it is throwing good money after bad. If it wasn't so serious it would be laughable. In no way is this good for anyone. It is a lose-lose practice.

[REDACTED]

There really needs to be a push for programs to satisfy the person with the mental illness and not the people offering the program. Rural and remote programs have to be moulded for rural people remembering that there is a distance of miles, no public transport or minimal services, some people may not want to get up early to travel to a program so it really has to be appropriate for them. I don't know what to suggest, but it would have to be something that would grab the attention and be an incentive to want to participate in. Once a person has lost motivation it can be almost impossible to get them moving.

5/ Touched on this in the above.

Distance from outlying small communities that have no mental health services or limited services and therefore they have to travel to larger towns/cities.

No or limited public transport, therefore have to rely on family/friends to take them and then collect them.

Financial. My son is on a disability pension. By week two he has no money left. I often have to pay for him and give him a little extra. This is terrible to say but sometimes I avoid him for my own well-being.

No car. No licence.

No phone, no TV, no papers = no contact with the world.

No gainful employment.

No sense of self-worth.

The stigma of a mental illness can be felt more acutely in a small community. The machinations of small communities where everyone knows everyone can be very supportive but there is another side. This other side is not as supportive and reflects a negative view of some individuals or certain families or cohorts. Individuals can be singled out maligned, bullied made to feel shame. If a person with a mental illness comes from a small community and is singled out it can be very difficult for them and their family. Life for them can be a misery.

Isolation, remoteness and no one you trust enough to talk to. It is often easier to unburden to a little known but trustworthy person than someone you know. I personally feel this.

Some rural people live alone or in a farming community, could have left school early/be less educated, have a learning difficulty and not able to articulate well. Feel a bit like a "bushy" and keep to themselves not wanting to get caught in conversation, feel way out of their comfort zone. Due to how they view themselves and how they believe others view them, the isolation and the stigma can turn them to alcohol or drugs to take the 'pain' away.

6/ I will be specific in part and at other times I will try and “show” through experience what my/our needs are. Support is essential requirement for those who care for people with a mental illness. This support must fit the needs of the carer –in one way bespoke support– but that may be too much to ask for. The support in my experience is limited and if there is more available then I am unaware of it. The support that was referred to me was prohibitive due to the 100 kilometre trip to attend. Support must come from a genuine/trustworthy/confidential foundation. I am skeptical around support, if it doesn’t meet my requirements I discount its use to me. I cannot afford to drive such distances simply to evaluate the viability of it. Speaking on the phone gives a small snapshot of the support available but in my experience it really doesn’t tell enough. I want help, not road trips and phone conversations. Yes, one has to start somewhere but none of what was on offer made me want to attend. I am a private person and that could be due to upbringing in rural/small communities. I grew up in the bush. There is the matter of small communities where I live (less than [REDACTED] population) to believe that my details will be strictly confidential. For me the most frustrating instances was dealing with the people working in the psychiatric ward who would not return your calls/give straight answers and failed to notify/include me of issues arising or had already occurred. If contact was made they were frequently difficult to understand, also they often didn’t call back when they said they would. It was usual to be not included in decisions/not bother to tell me about my son’s health/well-being. I would ask, how is my son? The frequent answer would be, e.g./ “He slept well, he has been up and had his breakfast.” This is not the answer I am looking for. I want to know how his mental situation is, is he getting better, has he been agitated, has his meds changed, have you locked him in ICU again. It was frustrating.

At a point in my son’s stay in hospital I made a formal complaint. After weeks of waiting for a reply the time had lapsed beyond the specified time that they were to respond. I phoned to query what was going on. I was told that the complaint had been dealt with, a family meeting had taken place and the complaint had been signed off. I was gob smacked and angered. None of what they said had taken place. This seemed to be typical of them. I was not the only family member who had made a complaint and they were treated the same. With the help of RIAC, (Rights, Information and Advocacy Centre), my complaint was referred to MHCC (Mental Health Complaints Commission). The result of this was mild. Perhaps my complaint was not worth complaining about. One or two changes were made as a result of my complaint. One was that a person with a mental illness will not be assessed by any mental health worker who personally knows

them, unless there is no other option. My son was assessed by a person he went to school with. Last year before my son was finally admitted to the psychiatric hospital... I have included below a section of my complaint though slightly altered to de-identify persons.

I phoned triage. I was told that the assessment of my son was completed and closed off and could not be reopened. The person went on to say that they required "new" evidence for them to act again. The person said they didn't want to hear the same things already being said, it had to be new. Not that my son was unkempt, disheveled, not caring for himself, saying strange things, getting agitated and behaving in a disorganized manner: unresponsive, yelling... didn't want to hear that because it had been heard before. I said I was afraid for his safety and he has threatened and attempted suicide before, but the person on the phone didn't respond positively. I never called them again. I felt that I had been turned away and what I was saying was trivial to them and not worthy of a response. I felt that it would be useless to try and engage with them again to plead the case for my son. So I waited for some further deterioration in my son's already serious condition to get worse so they might intervene, so he could get appropriate care for his illness. One didn't have to be a specialist clinician to see that my son was severely unwell. Our position; my position was/is unsustainable, but I had no one to go to for help.

At a point of recovery my son was moved from hospital to a step down unit and placed on a CTO, (Community Treatment Order). He was there for a day and he got on drugs and was taken back to the psychiatric ward. **No one told me.** His food etc. was thrown out or taken. No one knew where it was.

While my son was in the psychiatric ward he was able to procure illicit drugs, probably ICE. He did this on a few occasions.

My son told me last year he wanted to take his life. He was very emotional and eventually he said, he was tired of this prejudiced world, tired of being abused and mistreated as an unworthy sub-human. His words "*... I cannot be who I am, I am judged and discriminated. I cannot even be human...*" His words were haunting. It was, and continues to be terrible for him. He is on a Community Treatment Order and his life is a misery. He is getting his medication but he is not getting the right kind of care that he needs to get well.

On an occasion some years earlier my son's father phoned triage for help for our son. They did not come. The next day our son drove his car at force into a power pole. The car was a write off. He had to pay for that power pole. It took him years.

2018. Just ten days before my son drove his car into a lake at speed he had been assessed as well. And it was said by the assessor that my son, "*...looked the best he had seen him.*"

In the following months my son was admitted to the psychiatric ward and consequently made an involuntary patient. The police were involved and they called the mental health team to come for my son.

An irreversible traumatic episode occurred, including: one seriously unwell person (my son) and loss and damage to property and individuals including financial loss. Not only was the car written off, but far more worrying events ensued with possible far reaching consequences. Through inaction of the mental health team to come when we called for help a series of dreadful events unfolded. I firmly believe, without a doubt that the mental health team did not do their job. It remains in my mind and I believe some workers are not fit for the job.

7/ This sector is underfunded and overworked. Working with vulnerable people needs dedicated health professionals, better than what we have. They must be in the job for the patients, not for the paycheck. They need incentive to **want** to work in the mental health sector, to be dedicated to make a difference to those suffering mental illness. How do you retain anyone who wants to stay in a job, who is absolutely dedicated to bettering the lives of others? Incentive, advancement, great work place, ongoing training, financial reward... These people also need to be evaluated on a regular/yearly basis to see that they are still effective and satisfied, or are they not really suited? They **must** be able to liaise efficiently /effectively and make themselves easily understood in relation to patients/carers/family. It is a priority that these vulnerable people are treated as needed. They are human beings not packaged goods.

8/ In small communities it is difficult to see what opportunities there are for people with a mental illness. There is a greater need for rural and remote people because of where they live. I only have suggestions and no real solutions because of the nature of the whole picture: proximity to larger centres, transport, keeping their interest etc. If they lose interest then you've got it wrong. Employment would be good for them if that was possible, or an experience like employment where they engaged in an activity every day or so and develop a routine. A buddy system might work for some where a volunteer or person shows them the ropes and help them learn and participate. Their self-esteem needs to be built upon and programs would be more beneficial if they were in the mainstream community, rather than only people with a mental illness. People with a mental illness are part of the main stream population and they need to mix in to engender cohesion and acceptance and be part of the community. This would be a win-win. IF ONLY it could come to pass.

9/ A calm, welcoming feel, yet workable environment where the unwell are treated with respect and are the main priority. Where the clinical medical model is not what smacks you in the face. An idea – there could be screened/police checked/competent volunteers who could greet visitors and talk to patients, complete/help with small tasks that would free up the health care workers and allow them to focus on the well-being of the patient. Perhaps the volunteers could make courtesy calls to patient's carers/family but not give professional advice re the patient. Make sure > the patient/carer/family have all the required paperwork in order, and give out information such as >the onus is on the establishment to advise the carer/family of confidentiality and nominees/next of kin etc. Carers/family do not always know what is available to them/expected of them and to absorb shocks at a critical time the volunteer could have already briefed them. Activities for wellbeing, nutritious meals. Most importantly the health-care workers/clinicians/doctors etc. must be –see question 7. If we fail to take this opportunity to put in place essential and great plans, then we are planning to fail and stay the same as we currently are.

10/ Collate the material that the Royal Commission has received in response to the call for submissions relating to the mental health system. Gather information, common themes, look for ideas and advice from those that work in the business and those that are consumers and their carers and families – they are the ones most affected.

I would not like to see “experts” have all the say and the “last” say about how to move forward for they may have a conflict of interest. This must be transparent to garner trust and extend the open hand of good will.

Those that work in the mental health sector must be subject to scrutiny and be more accountable for outcomes.

11/ At present the mental health system is shameful. Yes, there are good people who work there but maybe they're in the wrong job, and as a whole it is hard to have respect for any part of it. It certainly needs a make-over. Even with this Royal Commission, I will only believe it has got better when I see it for myself. I've been bitten... and it was painful and that is what I remember!