2019 Submission - Royal Commission into Victoria's Mental Health System

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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Give proper consideration and resources to mental health prevention, early intervention, treatment and recovery as is done to other physical health issues so it becomes an accepted and normalised health issue."

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
It is exceptionally difficult to access treatment and support especially in the early stages when mental health issues are emerging - this is especially true for young people where there are no speialist youth mental health services in the community

What is already working well and what can be done better to prevent suicide?
N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.
N/A

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
N/A

What are the needs of family members and carers and what can be done better to support them?
"Treat as equal partners in treatment and care, with a focus on supporting the person in their families and providing support for families. take responsibility for treating the person rather than using the family as the care provider to fill in all the shortfalls and failures of the system."

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
N/A

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
Specialist youth services in the community

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
N/A

Is there anything else you would like to share with the Royal Commission?
"Is there anything else you would like to share with the Royal Commission? Yes I want to tell my daughter's story of the pain and isolation she experienced as she battled 3 years of major depression and anxiety from age 15-18. As a carer and parent, it was a living nightmare of having a child with a life threatening condition and not being able to find an effective treatment, of having to try and navigate a non-existent system and act as case manager, primary carer, advocate and supporter. There is no specialist adolescent mental health care available in the community. GPs refer to private psychologists and psychiatrists. There is a shortage of adolescent psychiatrists. To find appropriate providers in private health system requires good networks and word of mouth. It is a long painful, exhausting and extremely expensive process. In our case we went from Developmental /Educational Psychologist to Clinical Psychologist to GP to Paediatrician, to Adolescent Psychiatrist to another adolescent psychiatrist and so on. In the end there were 2 psychologists, 2 dieticians, 2 OTs, 1 GP, 1 Paediatrician, 3 Psychiatrists over 3 years until we finally found an effective treatment which involved participating in a clinical research trial of Transcranial Magnetic Stimulation in young people with Major Depression at Monash Health. After years of absolutely ineffective treatment of CBT and SSRIs (4 different types) within 5 days of daily 30 minute TMS treatment there were small signs of improvement, after 10 days we became hopeful something real was happening and by 15 treatments the depression was gone. It took another year to recover and rebuild a shattered life. My daughter has a profound sense of grief for those lost years where she missed so many of the positive and life affirming experiences of early youth her academic progress and aspirations lost as she went from gifted student to scraping through her VCE. Even so she was the only one of all her psychologist and psychiatrists clients to have not dropped out of school and to have actually got her VCE (ATAR 51). She was unable to keep up with her friends, participate in school life. She survived through her own grit and determination but was close to losing all hope by the time we found the TMS. Three years is too long a time for a young person to experience profound unrelenting and severe panic, anxiety and depression. It is a crucial time in a young person's development and identity formation which disrupts the essential tasks of social and emotional development. It also took all of my resources and all the resources I didn't have to get through it. I am tertiary educated with a background in psychology, public health and government. It took months to get through assessments (usually up to 4 sessions with a psychiatrist) and initial getting to know you' sessions, finding an acceptable provider that a young person can connect with, going through trying a new SSRI at least 3-6 weeks to determine the effect another 2-3 weeks to change over to a new SSRI and to get up to a therapeutic dose etc and all the while the young person is hanging by a thread, only to find it has little to no effect. I went on the websites such as Beyond Blue, Black Dog, tracked down the only specialist youth service Orygen Youth Health (we were out of catchment), found out that SSRIs are not recommend for under 18s (but everyone does it as there is nothing else). I read the

literature, asked everyone I knew, friends of friends. I was told by everybody to avoid hospitalisation at all costs as the effects would only be detrimental. We went through numerous mental health plans, and secondary plans we had weeks that involved seeing up to 5 different health service providers as well as school meetings with counsellors, educators, year coordinators, we had suicide plans, safety plans, code words, safe places to bolt to when panic set in. There were also gym and yoga subscriptions, complementary health care by naturopaths, meditation apps such as smiling mind. We did everything that was recommended and everything we were asked to do. We lived in the greylands of misery and isolation where surviving was a day by day, step by step process. Living with mental illness and caring for a young person with mental illness is very lonely. There are low levels of awareness and understanding in the community and you are questioned and judged on a regular basis. Despite having a life threatening illness, there is not the same level of support that is made available to young person and their family with an equivalent life threatening physical illness such as cancer. As a single parent and sole provider for our family, I had to maintain full time work. Sadly my workplace was not supportive and it was extremely stressful trying to balance the demands and expectations of work against those of an extremely and acutely ill young person. In addition, I was left with considerable debt as most of the cost involved out of pocket expenses. There were no state based services provided and limited access to Medicare and private health insurance coverage. Ten sessions per year of psychological services through Medicare is not commensurate with the severity of the problem and levels of care required. Our GP endeavoured to get us access through other plans but that only provided another 5 sessions per year. Despite having the highest level of private health insurance that quickly ran out. Seeing private medical specialists can cost up to $450 for an initial visit (paediatricians & psychiatrists) while both psychological assessments and psychiatric assessments can cost up $2,000 to $3,000 dollars (occurring over 4 sessions and includes the provision of a report). There were always gaps between service fees and rebates, with out of pocket expenses at 30 to 50% of the total cost. I am still working to repay the debts I incurred paying for mental health care over those 3 years. In the end, I saw an article in the Age about the TMS trial for young people with depression run by Dr Michael Gordon at Monash Health and knew from my research it was a promising treatment. I made contact with the researchers, my daughter was assessed as suitable and over the next month had daily treatments of approximately 30 minutes duration (20 treatments in total). My daughter has gone back for 1 month, 3 month and 6 month follow ups and been assessed as depression free. She has a level of residual anxiety and continues on a low level SSRI to manage that. She has successfully completed a bridging course to university which was supportive and cohort focussed. She is now in her third year of her degree and continues to rebuild her life. As part of the research process we were asked to reflect on the experience of TMS and its benefits. I would like to share these with the Royal Commission : ?It is a non-invasive, low impact treatment with little to no side effects part of the research protocol was to deliver the lowest dose possible required to have a clinical effect ?It was easily tolerated and did not involve pain or discomfort my daughter even slept through some sessions ?It can be given as an outpatient and does not require hospitalisation ?It did not interfere with her ability to go about normal daily activities ?It was effective with notable improvements after 10 treatments ?There were no negative effects during or after treatment on cognitive function and memory ?It came at no cost as it was provided as part of the research protocol we agreed to complete questionnaires before and after each session and attend follow up (if we could not access the TMS trial, it could have cost upwards of $20,000 in the private system). Potential issues with TMS which, while not a factor for my daughter, may arise for other young people with less support ?It requires the young person to have adequate sleep, eat properly and not consume alcohol and or other drugs ?It requires daily attendance where at least 3 treatments are received in a weekly period until 20

treatments have been completed taking approximately 4-6 continuous weeks ?It is not stand alone treatment but requires concomitant therapeutic support While clearly not all cases of depression will respond to TMS, my overall impression was of an effective treatment that could be given at the earliest opportunity following a diagnosis of Major Depression. If my daughter could have accessed this when first diagnosed she could have avoided 3 years of misery and all the complications associated with severe mental illness. Her developmental and academic trajectory would not have been disrupted and she could have continued to engage in her day to day life. While she remains depression free there is still a need to focus on preventing reoccurrence this has been on managing anxiety and associated life skills such as regular meditation and exercise, adequate sleep, social interaction and the achievement of small successes such as academic progress, part time work, and a growing network of friends. She remains worried that the depression may return and is especially concerned that as an adult the most effective treatment for her may remain out of reach. Unbelievably, TMS is only available to her as an inpatient in a psychiatric hospital. This appears to be due to the requirements of private health insurers. It is not in her interest and nor is it cost effective and productive for an otherwise well person to undergo unnecessary hospitalisation and all the associated disruption to work and study for a treatment that can be given as an outpatient. It also requires maintaining the highest levels of Private Health Insurance in order to be able to access private inpatient psychiatric care should it be required. I know our experience is not isolated. There is a significant and increasing number of young people experiencing mental health issues particularly anxiety and depression, self-harm and eating disorders. Left untreated or without effective treatment it quickly escalates to major depression, suicide, alcohol and drug abuse and addiction, chaotic and unstable lifestyle with increased risk for unemployment, homelessness and victimisation and exploitation. The prevalence is hidden but astonishing as there is not a family in our network of friends and family and friends of friends who does not have at least one child (adolescent) experiencing one or more of these issues. This is occurring in stable families without associated parental issues of breakdown, family violence, alcohol and drugs or financial instability. As a society we are doing something very destructive to our children they are under extreme pressure to succeed within a very narrowly defined set of parameters. Social media has increased this pressure and they no longer have the obscurity of childhood to dream, develop their selves in a way that supports difference and just be average at school, in sport or in life. The ones who succumb to these pressures seem to be the slightly more sensitive, less robust, more quirky who are slightly more anxious than their peers. In less pressured times they may have meandered their way through to be the late flowers blooming. Now they are crashing in droves with many surveys of young people reporting compromised mental health with up to 40% experiencing anxiety. The prevalence of eating disorders is rife and increasing. In 2014 Lucy Clark wrote a very poignant article in the Guardian about her daughter's experience. It lead to an out pouring of similar stories from across the country and further research to understand what was happening on a more systematic level complied by her in a book Beautiful Failures which identifies society's quest for success as harming our children. Prevention entails a societal response which is focussed on the wellbeing of our children and puts them at the centre of holistic service provision and design. Once a mental health issue has developed there is a complete absence of specialist youth services in the community, there is no one to help navigate the system and finding the right help appears to be a matter of luck. There is a shortage of specialist youth mental health providers, and this with lack of access to treatment services means opportunities for early intervention and treatment are lost, increasing the likelihood of entrenching a lifelong disorder. There are few effective treatments, little to no evaluation of what is being provided, nor monitoring of progress. More support needs to be given to research institutes to develop effective treatments such as TMS for young people and to

these treatments into clinical and community settings as quickly as possible. The window between onset of mental health problems and access to treatment needs to be shortened dramatically. Recommendations The Royal Commission may wish to consider the following actions: A dedicated prevention strategy for children and young people with a focus on reducing the loss of mental wellbeing experienced in adolescence and the teenage years it needs to be holistic, centred on the needs of young people, reform of the current secondary school system to reduce its corrosive effects on wellbeing. A focus on early intervention to stop the development of more serious mental health problems Improve detection and treatment of early childhood cognitive impairment and disabilities such as ASD, ADHD, learning difficulties, hearing and speech issues which undiagnosed feed anxiety, poor self-image and educational disengagement Reducing the delay between the onset of mental health problems and accessing treatment and support Making the first episode the last episode through rapid access to assessment and specialised treatment in the community (not in the private system) Introduce system navigators and specialised supports to guide young people and their families to appropriate care Provision of specialised youth mental health services in the community and establishing these throughout Victoria Use person centred models of care which involve and empower young people in their own care plans, where possible Ensuring youth mental health services in the community are committed to supporting the young person stay engaged with their education, identify and address related issues such as cognitive impairment and learning difficulties, provide other social supports Recognise the role of families as primary carers and involve them as active partners in the assessment and treatment process Developing effective treatments for young people through properly funded research in centres of excellence, well-resourced clinical trials and reducing the time for effective treatments to be widely available Continued monitoring and regular reassessment of progress of individuals in treatment as well as RCT evaluations of treatment regimens so much of what is done and is standard practice is not working At a workplace level, more support should be provided to individuals with mental health issues and their carers, including accessing leave at short notice, reduced hours and workloads during periods of crisis, protection from bullying and harassment and job insecurity, reduction in stigma and isolation. "