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

SUB: 0002.0013.0008

Name
Anonymous

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Better media campaigns on mental illness, improved school programs, workplace programs."

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?
N/A

What is already working well and what can be done better to prevent suicide?
The system is not able to respond to mental illness flexibly since the introduction of the NDIS - the need to have a plan to access psychosocial supports is a barrier to social and community supports that are not your GP or a pyschologist.

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.
"For eating disorders, If you are under 16 - there is no inpatient programs other than if you are acute ie medically compromised then it is usually when you are at deaths door (in our experience even then it took going from [redacted] as [redacted] would not inpatient our 13 year old to Royal Childrens who immediately put her in stating she was dying). For over 16 - inpatient programs are voluntary which is contrary to how the eating disorder operates Outpatient services are one dimensional, voluntary, enabling for the eating disorder, lack evidence base and despite lack of success over years (in our experience 5) remain the only option in the state. In [redacted] the Maudsley Program is a set of scales and a dietician with a Psychiatrist seeing our child a couple of times a year."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"Lack of evidence based practice, poor legislation in Victoria versus other states such as NSW regarding guardianship leading to poorer outcomes for the most deadly mental disorders such as eating disorders. Our experience in accessing treatment in NSW is that our daughter received inpatient treatment that was step down - she arrived dying so went to hospital, then clinic for four months, then outpatient group. The psychiatrist had full oversight, regular meetings with family/ daughter and was prepared to enact guardianship to save our daughters life. After 5 years of a high risk eating disorder, constant suicide risk, her experiencing homelessness (sleeping rough) to enable her to not eat she has been out of hospital for over a year and we live in NSW to enable an effective safety net of mental health services."

What are the needs of family members and carers and what can be done better to support

them?
"They need to be heard. I called ambulances multiple times and we arrived at [redacted] hospital only to be told they would not inpatient our child, they did not think that she was suicidal despite her having told us she had a plan, when she was going to do it etc because she lied to them - they did not listen to us in fact often implied it ""is just the eating disorder"". We had one mental health worker say ""I hate working with eating disorders"" - that was in reference to our child. Sensitivity would be great!"

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
"In regional areas there is a total lack of expertise in Psychiatry. Leading Psychiatrists move to regional towns due to ego, titles and in our experience lack the commitment to map outcomes/ sustain evidence based competence/ maintain commitment to good clinical governance. When we asked [redacted] about outcomes from the eating disorder program they could not even tell us - evaluation is critical! Therefore, incentives for researchers, leading international and national Psychiatrists that have the expertise is critical. Young People with eating disorders in [redacted] are put on the [redacted] Children's Ward with no activities - left in a room with the eating disorder and no distraction just waiting for their next meal. The nursing staff are trained through a short course and really have no idea or desire to work with the cohort. The model of care needs an overhaul, the staffing needs an overhaul and peer support would advantageous if the person is fully recovered/ can handle triggers ie references to weight, food as they are likely to be targetted by consumers who are unwell."

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?
"Education and training should be linked to psychosocial support programs, be flexible (online, face to face, practical, formal) in order to facilitate pathways to skill development in a structured but safe way. "

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?
For eating disorders: Specialist Inpatient responses to young people under 16 years - flexible individual treatment planned pathway which informs length of stay Better capacity for sectioning young people to mandate treatment for an eating disorder Specialist Inpatient responses to young people over 16 years - as above Research investment (longitudinal studies) into treatment for eating disorders broader than Maudsley Workforce development - recruit leading Psychiatrists and Treatment Teams to lead best practice responses to eating disorders in order to address the morbidity rate and poor health outcomes for people with eating disorders in Victoria

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
Propose legislative changes to the mental health act in relation to the treatment of eating disorders to reflect NSW and immediately review [redacted] Eating Disorder Program as it offers a substandard model of care for Victorian young people with an eating disorder.

Is there anything else you would like to share with the Royal Commission?

"My daughter was a highly intelligent and happy child. Her attachment and love was strong. She had friends, attended school and generally enjoyed life. She had however experienced trauma through the loss of her home and resultant death of her previous home based family day carers in the Kinglake Fires. ███ was first diagnosed with Anorexia Nervosa when she was 13 years old. She was hospitalised in the Royal Children's Hospital (RCH) after numerous calls for help were made to the ███ Access Team and after presentations at ███ Hospital Emergency Department. At this time, ███ was not at school, not eating, under her bed crying saying over and over that she wanted to die and as parents we provided 24 hour supervision due to calls to ███ and requests for hospitalisation being refused. At this stage we were concerned she would die either due to the eating disorder or suicide. On a particular occasion during this time, ███ refused to admit ███ despite an ED presentation/ mental health assessment but after assessment the very next day at the Royal Children's Hospital we were told that she would have died if she had not presented and she was immediately admitted. On the drive there, she cried saying she wanted to die, that nobody cared. Her hairs by this stage where all standing on end and she was a frail skeleton. ███ was hospitalised for 3 days and referred to the ███ Eating Disorder Clinic in ███ where she undertook the Maudsley family based treatment. A s parents we were told that was the only option or CAMHS which we had tried but the clinician actually told ███ and I that she hated working with people with eating disorders so only wanted to work with the parents and that Maudsley was the most successful model to treat her condition. Approximately 12 months of family based treatment caused extreme stress on the family due to the supervision of all meals and watching her every move. The motto of the program is never leave them alone with Anorexia'. The need for supervision lessened for a short period and she was exited from the Eating Disorder Clinic as we were told that she had recovered sufficiently. During the program she was initially seen by a psychiatrist sporadically but eventually it was just a set of scales and a dietician every time she undertook this program. At no stage was any of the underlying issues such as trauma, grief, loss addressed as food was the only medicine'. The subsequent 18 months continued with periods of full supervision in an attempt to prevent relapse but she never stopped struggling on a daily basis with the eating disorder. Again we were told to do Maudsley as it was the only and best option. Two and a half years into this type of treatment, ███ ran away and spent a night on the streets and we were beside themselves. ███ had never used drugs, smoked, drunk a sip of alcohol and was a naive/ vulnerable young woman on the streets because Maudsley breaks family units when it is the only treatment option. ███ returned home after calling me to say that she missed me and she was scared. ███ had not eaten and stated that she had run to avoid the supervised meals. ███ stated that she could not live with the constant supervision and so to keep her safe the family gave her some autonomy. The ███ Access Team also advised to give her space despite the only option for the Eating Disorder Service being Maudsley or a very poor hybrid so we were asked to allow the eating disorder to win.. ███ was exercising in the shower, at 2 am, at school during lunch/ morning tea and avoiding food wherever possible. Within three weeks ███ was hospitalised at ███ hospital for 20 days and released to family based treatment even though we stated that the eating disorder would sabotage this treatment and probably cause ███ to run away. We feared that ███ would become a street kid but the professionals again chose family based Maudsley treatment. We asked about interstate and overseas options at this stage and we were told they are not successful by Dr ███ and that he believed ███ would recover via Maudsley. On discharge we managed to get her to comply with the program by giving the eating disorder no space until we received a text from her and knew she was planning to run away again. We called the ███ Access Team daily, the Eating Disorder Clinic and anyone who would listen but there were no alternatives offered to family based treatment so ███ was given space in order to keep her in the home. The

Access Team stated that the relationship was more important than her eating so to stop the eating supervision. Within one week ███ had restricted food to lettuce once a day and was medically compromised. We took her to the emergency department at ███ and after 3.5 hours ███ was making it clear that she was going to run. We spoke individually to the Triage Nurse to say that ███ needed a bed or to be moved to a private space or there would be a scene in the emergency department. The Nurse said she could not assist and shut her window on us in the end with absolute disdane. ███ then attempted to run and we had to restrain her in front of a full waiting area. we had to ask the Triage Nurse to call security and then assisted with restraining as by that stage she was bashing her head on the ground. We were distraught and humiliated. ███ was then admitted and had to be shackled to the bed which we are convinced could have been avoided. ███ talks about these events as deeply traumatic with lasting impact on her psychologically/ causes her ongoing nightmares and anxiety. After ███ had been in hospital for 3 nights, we attempted to call the relevant parties to arrange a care team meeting but received a call after 5 pm saying that a plan was already being developed. When asked why we weren't consulted given we were looking at interstate and overseas options, there was finally a recognition that perhaps we should be part of the process of recovery planning for our very sick child. The advising Pyschiatrist recommended that we continue with a hybrid Maudsely model at this stage which we did until ███ began physically assaulting us, locking herself in the bathroom at the service during appointments and eventually running away again. This time she was on the streets for far longer, sleeping in disability toilets and it was only the Paediatrician ███ who offered effective ongoing support to us as parents during this period re planned hospitalisation. A meeting held during this time with the Pyschiatrist ███ where we asked ███ if he had contacted anyone including child protection in relation to ███ running away he asked if I (her mother) had. As her mother I had contacted the Police but it was the services duty of care to act when a minor was at risk. At this stage the Pyschiatrist was questioning hospitalising her on return and it took for me to threaten to go to the media for him to agree to a period of hospitalisation. On the last serious presentation at the Emergency Department via ambulance (called by us concerned that ███ was dying but would run if we took her) ███ was assessed by the ███ ███ Mental Health Access Team and deemed her to not be at risk of harm to herself or others despite her acute anorexic state. The treating doctor provided her with vitamins etc and told her she was I quote healthy. When we asked for the Access worker to refer her to the ███ Clinic he stated that he doesn't do that and that we would have to. When asked what we could do given her BMI versus the BMI required by the Clinic (her BMI was way to low) - we were told they could not assist. After much arguing the dr agreed to refer ███ to the ███ Clinic but we later found out he did not provide adequate information. We referred ███ to Brisbane then Sydney ███ Clinic and begged for admission. After extensive explanation of her history, lack of assistance, lack of options, they were appalled and were extremely responsive so she was placed on the waiting list. During this time we had to call an ambulance again due to her dizziness and fatigue which attended but they told us that ███ would not admit her so no point in taking her again to the ED. We drove ███ to Sydney as she was unfit to fly and she was admitted to ███ Clinic where she was soon ambulanced to the ███ Clinic and gastro fed. The Pyschiatrist told us that she was approximately 4 - 6 days from death and that if they had known how sick she was the Clinic may not have accepted her but they are glad they did. ███ remained in the Clinic for 4 months post hospital. The first thing the Pyschiatrist said to me (her mother) was we've got this. Whatever it takes. They validated our pain, lack of service response and how sick she was. ███ said: No one should go to the hospital where they do not have the skills to treat eating disorders because they don't have the correct methods because they are not briefed enough and use methods which are ineffective. She still says; there should never be another ███

We almost lost our daughter, our marriage and our future which is just plain unacceptable in a first world country. We decided to move our employment, sell our house and relocate to NSW to ensure ongoing first world care for our child. I would never entrust my child to the care of [redacted] [redacted] again and I am deeply concerned for other young people with eating disorders in the region. I have not included every example of poor medical and mental health treatment as there were so many, or lack of comprehensive evidence based models available but I hope that the above provides an overview of the dangerous treatment practices in relation to eating disorders in [redacted] for your consideration. "