

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

SUB.0002.0014.0040

Name

[REDACTED]

What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

"My comments are in relation to people with autism spectrum disorders (ASD) - Promote the understanding, acceptance and valuing of neurodiversity via social and mainstream media eg. TV programs like Employable me. - Provide people diagnosed with autism, and their families, information about the increased incidence of mental health disorders in people with ASD, early warning signs of emotional distress or mental illness and how to get help and manage mental health issues. "

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?

"Mental health practitioners need training in understanding and working with people with autism. People with diagnosed autism can make up around 10% of mental health practice clients/patients (even higher in certain areas of mental health) and between 50-80% of people with autism suffer from a comorbid psychiatric condition, but most psychology and psychiatry training courses do not include any in-depth understanding of autism and how practices may need to be adjusted when working with autistic people. Consequently, most practitioners lack this knowledge, resulting in misdiagnosis and inappropriate or unnecessary treatment (including psychiatric inpatient treatment), over-prescription of medication, and, often, refusal of service to people with autism. This can result in unnecessary traumatising of people and can make people reluctant to seek mental health treatment when it is required. Mental health practitioners need training, as a matter of course, in recognising undiagnosed autism in people who present with apparent mental health difficulties. People with forms of autism that are less obvious (such as Aspergers syndrome) are very often not diagnosed in early childhood but their experience of living with autism in a neurotypical world can lead to them experiencing significant mental health problems. Consequently, they present to mental health practitioners rather than to specialists in autism. However, most mental health practitioners have very limited ability to recognise autism in their older clients, especially girls and women. Not only can this lead to the diagnostic and treatment problems noted above but it is a lost opportunity to identify what may be the primary cause of the person's difficulties. It also precludes the self-understanding and self-acceptance that can lead to an improvement in mental health. If practitioners had training in recognising red flags for autism, how to screen for autism and where to refer people for assessment, this situation might be improved. This training needs to be provided to all mental health practitioners as most would not opt to do this training as they would not see it as relevant to their work as they do not know how prevalent autism is amongst mental health patients nor the prevalence of mental illness in people with autism. To illustrate this from my personal experience: my family member suffered multiple and extreme mental health conditions including anxiety, depression, school refusal, chronic fatigue, body image and eating issues, self-harming and suicidal thoughts for several years and saw 6 mental health practitioners and had 2 psychiatric inpatient admissions before their autism

was recognised (not by a mental health practitioner). After the autism was recognised, diagnosed and understood by everyone, and appropriate adjustments were made to the family members life, the mental health issues greatly subsided and the person returned to (a non-mainstream) school and is now employed and enjoying life and has had none of the extreme mental health issues or need for acute treatment since, albeit with a residue of ongoing anxiety. I have since learnt that this is not an unusual story amongst people diagnosed with autism after early childhood. It is particularly common for women with ASD not to be recognised and diagnosed until adulthood, if at all, and to receive multiple, inappropriate psychiatric diagnoses. I believe that my family members mental health difficulties were primarily caused by the stress, and trauma (eg. bullying), of not fitting into a neurotypical world and once they and others around them understood this, they no longer experienced such a high degree of stress. If this had been recognised when they first began experiencing mental health difficulties I believe they would not have become so acutely unwell and would have been saved from some of the trauma of the experience and treatment."

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

"There is an extremely high rate of depression, self-harming, suicidal ideation and death by suicide in autistic people (see recent research by Dr. Julian Trollor and others). This stems from loneliness, social rejection and disengagement as well as disengagement from employment and other meaningful occupation, along with trauma (eg. bullying, sexual assault and exploitation). As noted above, mental health practitioners and services are ill informed and inadequately skilled to recognise and treat people with autism, resulting in them often not receiving treatment or receiving inappropriate treatment that can exacerbate their problems. Further, many people with autism cannot afford private treatment due to having low or no employment or families who have had to reduce employment in order to care for a family member with autism. Many public services refuse treatment to people with a dual disability, referring them instead (if they're lucky) to a dual disability or specialist service, which have very limited capacity. Suicide in the autistic population could be reduced by: -Better access to autism informed and skilled mental health services/practitioners - Availability of ongoing supportive counselling for autistic people who need more than the 10 sessions a year they can currently get under medicare. -Better information to autistic people and their families about understanding and managing the emotional and mental health needs of autistic people eg. what causes stress and how to reduce it; common mental health issues and how to manage them. -Improved support to families and those living with autistic people so that they can continue caring and providing appropriate support -Greater community understanding, acceptance and valuing of neurodiversity -Greater opportunities and support for social and community engagement and connection for autistic people eg. gaming events/clubs, lego clubs, computer clubs, social events for adults similar to those put on by the Yellow Ladybug group for children. -Greater opportunities and support for engagement in the workforce "

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.

"Lack of social and economic engagement/connection, along with trauma and stress caused by living with autism in a neurotypical world are the main causes of mental health difficulties in the autistic community. This would be prevented by strategies noted above ie. improving community understanding and acceptance of neurodiversity, a variety of options for structured social participation (not disability specific services), specialist employment support, improved understanding of the needs of autistic people at school, and prevention of bullying there and in the

community. Once autistic people develop mental health problems they need access to mental health practitioners who understand autism and mental health and how to best treat and support autistic people. As yet undiagnosed people with ASD who experience MH difficulties need practitioners who are able to recognise ASD and know what to do when they suspect it. "

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

"For the autistic community: -Community ignorance, non-acceptance and non-valuing of neurodiversity being seen as other, different, strange, nothing to offer -Social and community disengagement/disconnection and lack of support for engagement -Lack of information to autistic people and their families (and schools) about the social and emotional needs of people with autism, resulting in them not knowing how to reduce and manage stress, have realistic expectations, advocate for their needs, find support, and make social connections -Lack of knowledge and skill in the mental health workforce for understanding and working with autistic people, as noted above, resulting in misdiagnosis, inappropriate treatment and exacerbation of problems or no treatment. "

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

"Carers/family members of people with mental illness and autism need: -Information about MH and ASD -Practitioners with expertise in both ASD and mental health -To be included (and valued) in the planning for and care of the family member with ASD, even when that person is not a young child (with consent of the individual with ASD) -Practical support for managing behaviours and having a break, plus financial support -Carer counselling to manage the stress/grief of caring for a disabled person or a person at risk. When older children and adolescents are diagnosed with autism they are commonly given very little information, often just the name of a website to look at. They should be given the same level of information and support currently provided to families of younger children. This information and support should include information about mental health, as described above. When people with ASD have mental health problems the family needs information about how to best support them eg. by having realistic expectations, understanding the need to reduce stress and how to support the person with ASD to manage stress, differentiating ASD behaviours and coping strategies from mental illness. This requires knowledgeable and skilled mental health workers. Families need support to manage the challenges of living with a person with ASD and mental health issues, eg. skilled therapeutic support and advice, respite, carer counselling, support groups, practitioners who have expertise in MH and ASD. "

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?

"This is the most crucial thing for people with ASD. Social and economic participation makes a huge difference to the mental wellbeing of people with ASD. To do this, autistic people need (see above for more detail): -Greater community understanding and acceptance -A variety of structured activities for social engagement (in the community, not in disability specific services) -Specialist

employment support to secure and maintain appropriate employment -Understanding by mental health practitioners that social and economic participation are very important for mental health but a very difficult thing for autistic people "

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?

"1.Greatly increase awareness raising and training on autism for all mental health practitioners (and make such training compulsory). 2.Provide specialists on ASD in all public mental health services (and private psychiatric hospitals). The specialists primary role should be consultation and liaison to other mental health practitioners rather than providing a specialist direct service (although this should be available too where needed). 3.Produce accessible, multi-media information on ASD and mental health and distribute it to autistic people and their carers/families as a matter of course at the time of ASD diagnosis and when autistic people access mental health services. "

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?

I am a clinical psychologist who had no interest in autism before my family member was diagnosed with it after years of mental health difficulties. I did not think ASD was relevant to the work I did and I thought that if I came across a client with ASD I would know enough to recognise them and work appropriately with them. I now see how ignorant I was and how much I still have to learn. I try to raise awareness and educate my colleagues with varying degrees of success. A more comprehensive and systematic way of doing this is needed as people with ASD make up about 10% of the clients who access mental health services and suffer from very high rates of mental illness and suicide. ASD is not a niche issue it is relevant to all mental health services and practitioners.