

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

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

"On the Autism spectrum as a person living with high functioning Asperger's, I attended a university based internship with the Australian Public Service. Accessing this work opportunity was important because it dispelled long held myths about work capacity. This was from my perspective and those of the staff in the workplace. Organisations like <https://www.and.org.au/> need to be commonplace for both university and non university potential workers. A second issue is that participating in the program caused an administrative burden. Centrelink had trouble dealing with the program and was a barrier to future participation. I have found attending primary health care workers to be problematic as they do not understand the behaviours of Asperger's. A recent interaction at a private hospital ended in marginalisation as staff and administrators could not understand the reactions their processes caused. Attendance in a recent parenting program at Anglicare provided an opportunity for other parents and workers to see how Aspergers think. Interestingly those parents who had parenting problems with Aspergers children for the first time saw how an Aspergers adult developed from a child by hearing my story. This provided hope. Anglicare workers were keen for an Aspergers person like myself to consider running programs to assist parents. Apparently my story was more effective than the trained workers however the trained workers were necessary to facilitate the interactions. Beyond parents with Aspergers children, other parents were engaged to understand and see the place Asperger's persons have in society."

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?

"As a person with Aspergers, I have been trying to find a social group. I found nothing except a few far away opportunities. There needs to be exciting social groups that facilitate Asperger's people self organising. Isolation and feeling like the 'other' in mainstream society creates a feeling of anomy. These meets provide informal treatment by sharing stories and obtaining loose referrals for help. I discovered my Aspergers at age 48. It was discovered by the University Union Health Care. this is because Universities are a place Asperger's fit in. Diagnosis of Aspergers needs to be free and placed in ways that Aspergers congregate in. Because the diagnosis of Asperger's is expensive, it can disrupt a persons life for decades until found out by observant persons like I experienced. Diagnosis should not be by chance. A number of times I have engaged in organisations like BeyondBlue on chat lines. The support is not good. Aspergers often live in alternate online lifestyles. The chat lines are essential. The current provisions are underfunded, limited, poorly understand mental health specifics like Aspergers. I conducted a study into Internet Gaming Addiction. This is because Asperger's like the online communities and gaming. However Asperger's are prone to Internet Gaming Addiction. A lack of understanding and support is crippling to Asperger's and those on the Autism Spectrum. Internet Gaming Addiction is now up for study in the DSM Health manuals. More needs to be done in understanding this

condition as it is a problem in society as a whole."

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.

"The cost of good mental health is prohibitive. I find that I need to join Private Health Funds to get some private coverage. However fortnightly visits are important for my Asperger's and I need to fall back to Medicare provisions with large gaps. Psychologists are not bulk billing. Depression is a side effect of being 'othered' in society when on the Autism spectrum. The causes need to be better understood because common thinking is that antidepressants are the prime way of dealing with this. I also find the reliance on drug therapies to be problematic. I am Antidepressant unresponsive. When this revelation occurs to health providers, they become stuck in how to help."

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

"As an Asperger's my drivers to poorer mental health are: Depression: by being 'othered', lacking job opportunities, comfort eating leading to obesity linking to poor health in general. Isolation: there is no social outlet to mix with people. For those Asperger's they need service adjustments. For example think about dating. How does an Aspie meet a future partner when they do not interpret feeling the same way as mainstream society. They need a solution that provides for basic human sexuality. Consider going to the supermarket. The Aspie may want to buy multiple sim cards for their internet devices. They buy in bulk because it is logical. The staff get upset at the Aspie approach and claim they are engaged in fraud. The Aspie has trouble interacting with the claims and chooses to avoid. Having a social group to interpret these problems and get workarounds is important. Family Violence: the Aspie has meltdowns when social interactions wear them down. Society condemns behaviour like a meltdown. This isolates the Aspie. The Aspie may need to engage in Parenting classes to understand how to parent a neurotypical in light of their social and emotional limitations."

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

"Aspie husbands need parenting and spouse support programs. Aspie partners need spouse support programs. Aspie's need social groups to give family and spouses alone time as they can be emotionally draining. Aspie parents need parenting programs because they may have trouble understanding how to parent neurotypical children. Aspies have trouble interacting with institutions. When parenting school aged children, the Aspie parent has trouble working through issues with the schools. The Aspie parent is in as much need for an orientation to the school as the new child is. The Aspie may send in lots of emails to understand things choosing not to attend in person. The school and education department may become upset."

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

"A simple component is to put high functioning Aspies into the mental health workforce as with reasonable adjustment, they can interpret Aspie behaviour. Aspies learn from scripted behaviour."

A fifty yerr old Aspie is an asset to supporting other younger Aspies because they have learned the scripts and adapted over time. Specific entry points for Aspies should be encouraged just like jobs for ATSIC to support their own indigenous community."

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?

N/A

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?

"THE NDIS application procedure is a mystery to me as a high functioning Aspie. Because I am not connected with prior supports, I have no support to enter the NDIS system. Using my GP has been difficult as their 10 minute consultations and lack of understanding of the system yields rejection noticed which is ludicrous. Therefore the Victorian Government should continue non NDIS supports until this NDIS system is mature. Otherwise a gap is created that I am now falling through."