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

SUB. 0002.0013.0018

## What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?

"The psychosocial disability model is oft described as the best model for the mental health system. This unfortunately has influenced the focus of the NDIS for mental health services. This is unfortunate as this model continues to mainly address perceived disability, reinforcing stigma and disregards the social reform required. In the community disclosure of a mental illness is still seen as problematic. Once public the person's identity is infected by stigma and it is reinforced over time. Our son in various aspects is high functioning, but as the years have gone from 15 to 38 and he has missed out on various life milestones, his grief regarding what he has missed is growing. He has in fact internalised the stigma and is becoming more aware of his growing social isolation. He says he feels stuck and that nothing can change and the system does not care. The diagnosis of schizophrenia has meant the family has been the main source of support. Yes, your parents love you but that is not enough. The navigation required to address the more complex mental/physical illness are left to the family. At the same time it will be those who suffer from stigma and their families will be the ones to change the minds of the community if given the chance. A Social Recovery model is essential to social inclusion, personal integration and social equality."

# 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?

"Our son has commented that the in his experience between the ages of 15 and 18 the youth orientated system was kinder and it was a shock as to how brutal, uncaring and controlling the adult system was. The trauma experienced in that part of his journey is not recognised. The early treatment and support model for youth mental health is being expanded in Victoria and is long overdue. A similar model is required for the adult cohort. However, singular focus on early treatment disregards the fact the some mental illnesses are life long, which interacts with other life's ups and downs and crises. Therefore the support required must be comprehensive, flexible, personalised, dynamic and socially aware."

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

"Despite the recent increase in the community focus on the problem of suicide, I believe that the nexus between suicide and specific forms of mental illness are not recognised in the community. Further, this nexus is also not addressed fully by the medical profession. Confusion abounds about symptom and cause. Education of the person experiencing mental illness and the family must encompass issues around suicide. This is the starting point for the community at large. Education needs to take many forms, it must be undertaken by a variety of professionals and those with lived experience. More co-ordinated and varied mental/physical/social support structures are needed."

# 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.

"Victorian public hospitals and their related mental health services are well placed to provide comprehensive, specialist and expert multi-disciplined mental health services to assist the wide variety of complex mental and physical illnesses experienced in their catchment area. But for various, structural, funding and other reasons the mental health service is not an integrated, comprehensive system to which our family can attest to over the past 23 years of experience. This leave the family and carers navigating and co-ordinating the arising complex situations. Our son was shunted from a public hospital emergency department to a private hospital, which did not have any mental health expertise because he had private health insurance. This was in total disregard for the physical problems he was experiencing was possibly related to his mental health issues (and medication) and was making his mental state more difficult. Limited training has also meant that how he was treated depended on the compassion or otherwise of individual doctors and nurses. Some did not treat his physical symptoms as real and decided he was drug seeking. At other times when presenting with both phyisical and mental issues his mental condition was ignored and hence aggravated. After having been introduced to in 2006 our son was eventually ""discharged with honour"" to a private psychiatrist. But prior to this discharge our son's white blood cell count was regularly high. We observed this as regular clozapine blood monitoring was undertaken and we asked for the data. Despite our questioning the service did not follow up. Six years later and post discharge to the private sector the ongoing damage to the heart was detected. A private heart specialist has since managed this and convinced the psychiatrist and the second psychiatrist who gave a second opinion to take our son off clozapine. "

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

"Alcohol and drug use complicates an individual's responses to seeking help for mental health issues. As often the process is self medication until the growing addition becomes a individual and family problem. De-criminalisation is a necessary step to changing the mind set and expansion of non punitive treatment. Structural reform is needed to provide personalised, comprehensive and expert care. The money and will to achieve such reforms will be needed. Knowledge and data is already available to identify the communities that are missing out on care. Various institutions such as our GP and specialist doctors are in place, so are our public hospital and mental health services but the co-ordination required by the individual and families is not facilitated. "

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

"Family members and carers need to be seen as integral to the support structures a person will require. For some this will be over a life time. Circumstances are not the same for all families and carers. A NDIS type approach to identify the support needs of families and cares is necessary. On going education is an important component of support for families and carers as the situation for many continues to change as the person they care for grows older. Concern regarding the ongoing support for the family member over time becomes a growing issue. Faster response to drug and alcohol issues will support the family in important ways, including lessing family violence. No one should be discharged into homelessness."

What can be done to attract, retain and better support the mental health workforce,

#### including peer support workers?

"In my observation many working in the mental health system need to take up 2 or 3 different part time positions in various services to make ends meet. I do not know what drives this but it is disruptive for clients and very inefficient for services. Whether, this workforce arrangement is budgetary driven or worker desire for ""flexibility"" I do not know but it seems to be very inefficient.

# 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 question seems to presume that all mental illnesses are the same. Growing realisation around the impact of stress, anxiety and depression on social and economic participation nevertheless leaves those with more enduring complex physical/mental health issues out of the picture altogether. There is also a growing recognition of the skills those on the autism spectrum may bring to a work place but the same thinking is not evident for others. Reverse thinking may be needed to assess what would benefit the person with complex mental health issues while at the same time ensuring that diversity in the workforce does not leave anyone out."

## 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?

"The mental health system must be supported by multi-disciplined teams that recognise the nexus between mental/physical/social aspects of well being. While the private players in the private system are well intentioned and skilled they are not able to provide the co-ordinated care needed by those experiencing long term episodic illnesses. A person centered mental health system would recognise the dynamic nature of mental experiences as they intersect with a persons life stages and their social position. Without such an approach the family has the sole responsibility. While families help navigate the system this still leaves out the social aspects of a persons experience. Recovery is not possible without Social Recovery. A social recovery model is essential to social inclusion, personal integration and social equality."

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

"Change must be based on the recognition that Victoria does have a generally well functioning public health system with a network of mental health services augmented by an extensive range of private GPs and specialist. Change will be achievable if the gaps are recognised and funded to make the system as a whole work more effectively on behalf of the person and what will be best for them and their family. The gap in life-expectancy must also be addressed. Multi-disciplined teams must be in place from the start and not only when failure is experienced. If a service provider with specific expertise is recognised in the private sector this should not automatically mean that the person needing mental health support is discharged from the public system. The private and public health systems must complementary. Our health system has been established over a long time and cannot be untangled quickly. By recognising and funding the gaps people with ability to provide the knowledge for getting the best out of the health system will be crucial to its positive development. What has been missing is the personalisation of the health care and coordination on behalf of the person and the family. The shifting of people in and out of the public system does not assist with long term goals of social integration and adds to confusion and navigation problems. Funding for the public sector must be commensurate with the expectations of

a well funded comprehensive system able to engage with the private sector when needed and not be left to became a residual service, which resorts to practices of seclusion and over medication to cope with the in sufficient staff"

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

"Ongoing research into mental health and treatment is being conducted but from the perspective of a client and their family using the services of the public mental health system they could be excused to think that no research is being undertaken and no change is possible. From a middle class (ability to pay) perspective it seems that you have to manage and pay for a piecemeal system. From the perspective of a working class family (little money), or those outside of the major city centers the public system coverage is too limited and also piecemeal. "