

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

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Name

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

"Greater visibility in the public eye ? on TV shows, Billboards etc. letting people know that many people are affected by illness which will raise awareness throughout the community who are not directly affected by mental illness (people with mental health issues, their families, friends, carers etc)"

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?

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.

" Lack of funding which affects many areas. It leads to short term focus, with understaffed clinicians being forced to deliver band-aid care, waiting for the people who live with mental health issues (PWMHI) to be well enough to be discharged making repeated relapse common and more likely. Much more funding needs to be given to this important area. The number of people who require assistance has increased in recent years, but the funding has failed to keep up with demand, with treatment / assistance being limited and much needed care delayed for long periods of time due to lack of staff and facilities. Mental health issues, because they are unseen, unlike physical illness, seems to be given less funding and lower priority. When treatment is given, PWMHI and their carers often feel that they are on the clock with either space or clinicians in short supply. This always makes it difficult for clinicians to explain how their element of the system works and how it fits in with the numerous other elements, leaving already stressed out carers, some of which are aged and have little or no grasp of modern technology (smart phones, the internet, emails etc), to navigate an expansive yet compartmentalised system on their own. Opaque system that is not clear or in any way user friendly. The system encompasses many different elements / agencies or points of contact, with PWMHI and carers often using many different points simultaneously ? NDIS, North Western Mental Health (NWMH), local GPs, Service Providers such as Occupational Therapists linked to the NDIS etc ? with just one of these points of contact can involve talking to numerous people (as many as 30 clinicians of the roster team at NWMH in Sunshine). When an individual element is explained it is often done in a quick manner due to being understaffed. 30-page booklets are given (again by NWMH) and this just explains that functions, right and responsibilities of their organisation. oAdded to this, the various elements of the system often don't have a clear idea of how they fit into the larger picture, that is, where

their responsibility ends and where another organisation's responsibility begins. This results in two or sometimes more organisations claiming that they are not responsible, but that another organisation is, leaving the PWMHI and carers stuck in the middle, with care being delayed as a consequence. Clarity is needed here. Additionally, there are times when two or more organisations need to work with each other and more often than not, resist. Mental health issues cannot be broken down into easily divided parts but overlap and interconnect. This is problematic because different organisations resistance (sometimes fiercely, NDIS with NWMH) to work together, arguing that their roles are different, again, resisting the idea that disabilities have parts that overlap and interconnect, forcing already stressed carers to push for coordination and collaboration that should already exist. Carers are often asked to liaise between two organisations, rather than the two contacting each other directly, a process that would be much quicker. This places more stress on the carers and makes their relationship with organisations that are supposed to be assisting them, combative / confrontational, as they come up against a system that is supposed to help and not hinder, treatment for their loved one. Clearly demarcated lines (even when responsibility is unclear to different elements) are counter productive as they go against the nature of mental health. Practitioners must understand this and be more willing to work together, instead of passing the buck' to other elements of the system. Again, underfunding may be part of this problem as more stressed elements seek to unburden their workload. However, this points to another problem, that is putting the needs of the practitioners / organisation before those of the PWMHI and their carers. The lack of team work also persists inside organisations, with some practitioners attempting to override decisions, with little and sometime no information about the case of the PWMHI, made by treatment teams. This happened with my sister. Early that day the treatment team had decided that a rostered would come out to supervise her medicine intake. Unfortunately, that day that rostered team was unable to come but my sister was persuaded to take her medication. When they called later that night to explain why they weren't able to come they asked if my sister had taken her medicine. I responded that she had. The rostered team member then proceeded to say that although she had not read my sister's file, nor had she seen her recent, that the rostered team should not come out in the future since she had taken her medication and was a responsible adult'. This lack of team work and professionalism (she had not read my sister file before coming out and thought that she had a better understanding of my sister than we, the family did) could have been very detrimental to my sister's mental health and the family in general. Furthermore, members of the rostered team have the authority to make decisions without consulting the treatment team, in this case they could have terminated the supervised medication intake visits, which can have an extremely negative impact on the PWMHI. Fortunately, I was able to complain to the team leader which handled the situation, however, practitioners need to realise, and may sometimes forget, that despite their many years of experience their knowledge of decisions made by their colleagues and of the case of the PWMHI is vital to proper treatment. Every person is an individual and every context is unique, providing its own challenges. While practitioners experience allows them to see patterns and gives them many insights, these should be used as part of team work, not to wing it' based on feelings of having acquired enough knowledge to deal with any situation. This attitude can also be seen in a top down approach where practitioner prioritises their knowledge and experience over that of the family's. Insufficient importance is given to the family by many clinicians who seem to believe that their breadth of experience and detailed knowledge of their field should take precedence over families' lived experience with the PWMHI. Carers often have to assert themselves for this to be taken into account, rather than this being the starting point of a relationship between service providers, carers, and PWMHI where the strengths (and weaknesses) of all parties is recognised, utilised and addressed. Direct, quick and efficient access is often avoided, GPs, and mental

health clinicians do not give their email addresses even to carers (and seemingly not always to each other), instead carers are asked to leave messages on answering machines or make appointments. While this may be valid in some circumstances such as prescribing medication etc where doctors need to see the PWMHI, but in instances where carers are attempting to coordinate between different branches of the system, this can lead to delays in access to other parts of the systems, unnecessary stress for the carers and PWMHI. Organisations (NWMH) have stated that their policy is not to give emails to PWMHI because it could create a possibility where a PWMHI may write an email with suicidal ideations that could be seen to late. While this may be valid, it doesn't explain why carers are not given email addresses of clinicians, but are instead made to use more lengthy processes, again delaying care for the PWMHI and increasing the stress and fatigue of carers. It also creates a feeling of mistrust, as these organisations are seen as resisting accountability. Phone calls and messages can be said not to have been received, but emails stay in the system and must be responded to. Insufficient understanding of influence that people outside of the family / carer dynamic can have on the person with a mental illness. The advice of experts may be taken more readily, than those of the family member / carers, even if those words are exactly the same. However, clinicians have taken a more legalistic view, with their authority only being seen in terms of what they can or cannot legally compel a PWMHI to do, not in terms of the importance that their position holds in the eyes of the PWMHI. While a clinician may not be able to demand that a PWMHI take anti-psych medication if they are voluntary, their request, and the reasons behind it, is much more likely to be accepted at certain times, than those of their families', because of the authority of their position and the fact that they are outside of the family dynamic. The timely intervention of clinicians can save weeks or months of distress. Medicalisation of mental illness. By this I mean the notion that mental illness stems predominantly from biological factors (e.g. a chemical imbalance in the brain). However, by giving overwhelming priority to biological factors, other factors such as social or familial context (social / environmental) are often placed as a distant secondary priority. The main focus is more often than not, getting the right mix and dosage of drugs right. This approach ignores the role that the patient's social life or lack thereof, plays. It also ignores issues with confidence and independence, perceptions of being inferior, lack of self-management (being able to manage stress and change etc), not being able to obtain goals that other people can, all of which (and more) are part of the overlapping and interconnected web that makes up mental illness. By failing to give equal priority to these and other similar elements of mental illness is never holistically addressed, increasing the chances of relapse, and perhaps making relapse inevitable, since PWMHIs that take anti-psychotic drugs often grow tired of the negative side effects which are ever present. By focusing on other factors of the PWMHI's illness and building up their coping mechanisms / confidence / ability to achieve life goals, their symptoms may and often do reduce, decreasing the need for drugs and their negative side effects and thus avoiding relapse. While this already exists in the system, as stated above, it is often seen as far less important than biological factors. As such this view, and approach to mental illness must change. GPs, with limited knowledge and training in mental illness are permitted to prescribe and therefore change medication which has had severe negative results. This also results in PWMHI shopping around for GPs that will accede to their wishes. While PWMHI's voices should be heard, they are not always the best judge of what constitutes the best treatment in their condition. PWMHI should be prescribed medication only by their (single government funded) psychiatrist who has expertise in their field and a good knowledge of the person. More support is needed for carers and carers need to be made aware of the support that does exist. NWMH does offer support for carers but it seems to be very limited. Education for carers is extremely important but is offered in a very limited way throughout the year (biannually), with carers left to figure out what works best through a system of trial and error instead of building

on the experience of others. Needless to say, this has a negative effect on the mental health of both carers and PWMHI alike. Additionally, it was only 13 years after my sister diagnosed with a mental health issue that myself and the family became aware that there were support mechanisms for carers! Better monitoring needs to take place when admission does take place. The mental health review boards should make more frequent visits (at least weekly) to check on patients' care and to make sure no abuse occurs. Delays in this can and have left lasting mental scars on those that have been abused by staff. "

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 understanding / education about mental illness in society in general Lack of awareness of mental health facilities in their area Lack of access to mental health treatment due to under funding. The system works effectively once a crisis has developed but due to being understaffed is more often than not, unable to give treatment / care in the early stages Lack of staff and facilities Better paid positions in the private sector resulting in mental health practitioners leaving the public sector for the private sector"

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

" Assistance needs to be given to help families and carers navigate the whole system which is vast. A case worker that has detailed knowledge of all areas of the system would be of benefit here. If such a thing exists now, many families and carers are not aware of it. The case manager would have to also be able to deliver the information in an easy to understand manner, taking as much time as necessary to explain which organisation does what, how, when etc. This requires flexibility and understanding the needs of the carers and PWMHI which is often missing, with organisations employing a one size fits all method of communication, making carers and PWMHI feel that they are wrong for not understanding (NDIS). Greater coordination between different organisations taking the stress off the carers that are often left to do this Assisting family member / carers that are working. Often the stress of caring, navigating the system, and working all at the same time, leads to neglect in one or more of these areas. Temps could be brought to cover their positions while they deal with acute problems of loved ones. Having more carer support staff. Harvester only has one that works three half days a week. Nowhere near enough to effectively support carers and family members. Groups where families can meet and support each other. Carers need to be made aware of the groups that exist in their area and how to contact them. Carers are often under stress, so the easier things are made for them the better. Practitioner saying that there are groups in carers area, leaving them to find the group adds yet more stress to their lives. Being made aware of what support does exist. As stated above my family was only made aware that carer support existed 13 years after the diagnose of my sister's mental health issue. Better financial support. Navigating the mental health system takes time and is often detrimental to the amount of time carers can work. Furthermore, improving the PWMHI's wellness through normal social activities such as going the movies, trips to the country and within the city etc. can be costly and need to occur regularly due to many people with mental health issues either working few or no hours, therefore greater financial support is necessary. "

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

"Better funding for the system overall as many practitioners are over worked. Better salaries /

conditions ? less incentive to leave the public sector for the private sector Having a clearer and easier to navigate system "

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?

"Groups where people with similar mental illness can meet. Socialisation is often difficult because those with mental illness have had very different experiences than those of other people, and at the same time different experiences from others with mental illness, as all mental health issues are different and so are the degrees that they are lived. Two people with the same mental health issue but different degrees may not be able to form effective relationships. These groups would offer support, ending a sense of isolation, and feelings of being excluded from society. They would also boost confidence as they could lead to the forming of friendships or romantic relationships, both of which are often lacking with people that suffer mental health issues but make up an important part of the human experience. When they work in sheltered workshops the government should subsidise their pay directly. At present the government appears to subsidize the employer with people with a mental illness getting different levels of a normal wage depending on their ability. Some may only earn \$5 an hour resulting in the feeling of being exploited. By directly subsidising their pay they are given a sense of normality and financial independence which translates into confidence. This provides an opportunity for people with mental health issues to fully internalise the idea of been differently abled instead of this notion been seen to be used solely as a slogan. When employed outside of sheltered work shop payment though still not on par with normal pay standards, is often significant higher. Better work conditions for PWMHI. These need to be regulated by regular inspection by the government. Employees with mental health issues are often not told about their break, leaving times or other rights. These rights need to be enforced as some PWMHI many not have the confidence to assert themselves and ask for these rights themselves which often results in employees being overworked. Advice and guidance about budgeting should also be given to enable PWMHI to live independently. Better support for finding work. My sister was registered with an employment agency that specialised in helping people with (mental) disabilities, yet she remained unemployed for many years. In the end, it was the family that found her a job. The employment agencies either lack the sufficient motivation or competency to do their job properly. Education on how to use technology (smart phones, the internet etc) as this is now a basic feature of daily life. PWMHI inability to use technology further excludes and isolates them from society, while having a good understanding would do the opposite. This should be given in courses with people of the same intellectual capacity so that PWMHI can feel comfortable and confident in their surroundings and actions. Not all PWMHI should not been seen to be independent as is often the case with the current NDIS system. This places a burden on PWMHI and their carers that they may not be able to carry, which could harm their sense of self-worth and confidence and lead to stress and anxiety not mention their progress in achieving their goals. Instead, their independence should be seen as a goal, something to be worked towards. "

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?

"Increased funding Increased coordination between organisations Formation of a case manager to help carers and patients effectively navigate the system and the provision of the case to all that need it. Moving away from the medicalisation of mental illness to an approach that deals with other elements / issues ? social, familial, employment, self-management, independence Education

and support for carers "

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

"decision / policy makers must understand the importance of mental health and allocate the necessary resources for it. At present, mental health does not appear to be of significance to policy makers. Once their attitudes change lasting change will be possible."

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

N/A