

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

Terminology is critical. We need to move away from the whole idea of mental problems being an "illness", or at least there should be no assumption of pathology. The current conceptualisation whereby a person with mental health problems is diagnosed with a mental illness is discriminatory and has life-long implications, particularly when the diagnosis occurs in childhood. It contributes to stigma that leads the person and their family to internalise negative beliefs contributing to disengagement, disempowerment and loss of hope.

The general community (and many working within the mental health system) do not understand that the current medicalised system is conceptual; a classification system that says nothing at all about the cause of why the person has ended up in so much distress and in need of professional support and care. This biogenic, illness approach is contributing to prejudice and fear, because it sets people apart as being different, whereas really they are simply people who are no longer coping with the stressors that they are facing in their life.

We should be talking more about "mental distress", and the person's "current coping levels" (emotional, psychological and physical) and trying to understand and ameliorate the psychosocial factors that are currently at play (acute and chronic). We should not be using any terminology that creates a barrier towards us (the Victorian community) seeing the person's behaviour as an understandable and meaningful response (albeit maladaptive) to what has happened and is happening in their daily life. The stories behind how people end up being mentally overwhelmed and unable to cope need to be heard within our communities so that there can be a more wholistic cultural understanding of mental health problems and why they manifest as they do.

We need to understand that people with mental health problems have often isolated themselves from their community and that shame, anxiety and depression are reinforced through ongoing disconnection. Community based interventions are essential and need to focus on reconnection and integration. Interventions within society (not behind the closed walls of a psychiatric facility) will facilitate a cultural shift whereby people in distress are embraced and understood right there within the community in which they live. The community need to start seeing the "mentally ill" as people who are suffering, rather than as people who are different or defective in some biological way. Let us put more money into funding community-based interventions like the one outlined in The Courier: <https://www.thecourier.com.au/story/6107935/how-ricks-cricket-game-changer-is-helping-others-with-mental-illness/>

We need to develop and use alternative frameworks, such as the Power Threat Meaning Framework (<https://www.bps.org.uk/news-and-policy/introducing-power-threat-meaning-framework>) to provide more humanistic ways of viewing mental distress, when that distress is due to social inequality and trauma.

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?

Stigma and discrimination have a huge impact on people seeking treatment and support. If a person has isolated themselves from the community in which they live it is enormously difficult for them to seek help from that same community when they are not coping. When they are not coping their stress response can be extreme and it can be a very dangerous time (even deadly) for family members who are trying to manage difficult and complex emotions and behaviours. The people who are supporting the person with mental health problems must be actively consulted, listened to, supported and respected. They too will often be under extreme stress, but this must not negate them being properly consulted about what they think is happening. They know the factors behind the current deterioration in functioning and this information needs to be given more weight. At the moment, in my experience, the mentally disturbed person is often simply treated as having another episode of whatever condition they have been diagnosed with and treatment is entirely centred on psychotropic medication: their medications are increased in number and in strength and they are then discharged home back to the same situation with no additional psychosocial support, simply tired and subdued by powerful medication.

If a family member reaches out to the mental health team, a doctor, or their relatives' case manager, they must not be turned away because of privacy issues, or because the doctor or case manager "knows better" than the family. There needs to be a genuine partnership between professional workers, the family and the person needing care. In times leading up to a mental health crisis when the family are aware that the person needs treatment and support but the person is still presenting well, the potential for violence and suicide is real, and must not be minimised or ignored simply because of a lack of resources, or because it is a public holiday or the weekend and there is no-one available. Appropriate levels of care and support must be available at all times, especially when urgent intervention can mean the difference between life and death.

Turning up to an emergency department in the middle of a mental health crisis is the worst outcome. It is extremely distressing to the person and to their family and is actually an escalating factor contributing to further trauma.

There needs to be a specific facility in [REDACTED] that will welcome any person at any time who is mentally overwhelmed (not coping) into a safe, friendly, caring supportive, professional non-judgmental (and to me this would mean a non-psychiatric focus). It would need to be staffed by people who are able to manage highly distressed people, by de-escalating the situation, but once a facility was established and working well people would begin to trust that they would be cared for and listened to, with common human decency. For some people that might be enough, but for others who needed more support they could be transitioned into a mid-level facility for overnight care and supervision, and then the next level would be longer admission. Headspace may well be fulfilling part of this role for youth, but older people need this kind of facility too.

Inpatient psychiatric care is much better than it used to be. People are treated much better within the facility: there is more transparency and less abuse, but there seems to be very

little respect given to the needs of families to be involved and included, particularly where there is complex trauma affecting the whole family, such as family violence issues. These issues are very poorly handled in the current system. This lack of expertise is contributing to further trauma with families being left to negotiate their own outcomes.

There needs to be a primary role for clinical psychologists within the mental health system, from the very first contact right through to community-based care. Specialised units need to be developed so that clinical teams including clinical psychologists can provide evidence-based treatment for specific problems, such as eating disorders, or "borderline personality disorder" and complex post-traumatic stress. ***There needs to be trauma-informed care and practice throughout the mental health system.*** Adverse childhood experiences need to be systematically documented and integrated into treatment plans. The buffering influences of treatments that improve sleep, exercise, nutrition, mindfulness, mental health and healthy relationships can be prioritised (Dr. Nadine Burke Harris, *The Deepest Well: Healing the Long-Term Effects of Childhood Adversity*, Pan Macmillan, 2018), so that healing can occur.

There are very good clinical psychologists working in the private system and some of them bulk bill, but within the public system clinical psychological services are virtually non-existent (at least in the experience of my family of origin), which is completely unacceptable, and is one large contributing factor to the medicalisation of distress. I understand that there is a critical shortage of health professionals in regional Victoria, but this issue must be addressed as a top priority if the quality of treatment is to improve beyond drug-based treatment. Psychologists could be attracted to work in rural settings by waiving their HECS debt for Clinical Psychology Masters Degrees, or through scholarship programs like that offered by the NSW State government aimed at increasing school counsellor numbers: (https://www.nsw.gov.au/news-and-events/news/free-degrees-to-increase-number-of-school-counsellors/?fbclid=IwAR3P-T6J11smhh2sb9YniZlt0iOayJThoRtCdLXuUhR4Q_d177b1QXZZsSw).

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

It is all very well to have phone help numbers, but what is needed are people on the ground to be available to offer real care and support in times of crisis, when the person is overwhelmed by a sense of hopelessness and despair. The system needs to be able to accept them time and time again with non-judgment and to impart a sense of hope. The stigma of our system that classifies you as being ill crushes that hope, and our system turns people away at their times of greatest need, particularly if you have certain behaviours that are classifiable as "borderline personality disorder", the very people at highest risk of suicide and who need constant non-judgmental care and support. Within the past 10 years [REDACTED] acute mental health services actively turned away a relative of mine who presented in a state of extreme distress (with child in tow) wanting mental health care and support. They were turned away on the grounds of their BPD diagnosis. Another time, more than 10 years ago another relative was turned away because they did not fit the criteria for being acutely "mentally ill", despite presenting following an incident of family violence and having a long-standing psychiatric diagnosis with multiple, extended hospital admissions from childhood. They were turned away without being offered any care or support. These types of

experiences have the potential to seriously affect the person's likelihood of seeking help in the future. Addressing this issue is critical in terms of reducing the rate of suicides.

Having a case worker is a step in the right direction, someone who visits at home and who is assigned to the person in need, however it is counterproductive when they are only available for a very limited number of hours per week, and their workload precludes anything but superficial support; a case worker needs to be available in times of crisis. Too often they have a very poor understanding of complex family issues particularly family violence.

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.

Good mental health is impacted by adverse psychosocial events, particularly childhood abuse and trauma, poverty, intergenerational trauma, lack of housing stability. These factors cause mental health problems and must be addressed directly so that trauma can be resolved. Adopting the Adverse Childhood Experiences (ACE) Questionnaire (Felitti, Anda et al 1998) would help to educate all health workers (and others), including GPs to understand the impact of adverse experiences on patient wellbeing, without the patient having to tell their story time and time again. The person themselves can also be helped to understand their story in terms of these factors without the need to introduce psychiatric diagnoses that can harm and cloud real understanding of underlying factors, that may well be mediated by biological factors, but which are rarely caused by them (except in cases where there is a medical condition underlying the mental distress). As expressed in the The Blue Knot Foundation Newsletter, Jan-Feb 2016, to relate to people in a trauma informed way is to consider the question of "what happened to you?" rather than "What's wrong with you?".

https://www.blueknot.org.au/Portals/2/Newsletter/ASCA%20Newsletter_Jan-Feb%202016_WEB.pdf

As I have outlined above, widespread and easy access to fully qualified clinical psychologists would be of enormous benefit towards improving people's mental health. This needs to be a top priority, and the number of sessions available to people through Medicare must not be arbitrarily capped; the decision as to what is needed must come from the clinician.

Some older GPs in [REDACTED] actively disparage psychological services and recently (2016) refused to provide a referral to a relative with a longer standing psychiatric diagnosis who asked to see a psychologist for the first time after more than 30 years in the mental health system. They had never accessed psychological help in the public system. This beggars belief and highlights the level of systematic ignorance of the importance of psychological treatments and support.

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

■■■■■■ history of psychiatric care is appalling, as documented in the Burdekin Report ("Human rights and mental illness: Report of the National inquiry concerning the human rights of people with mental illness" Volume 1 and 2, 30 OCT 1993, <https://apo.org.au/node/29708>) and the legacy of this system remains; there is a great deal of mistrust of the system because of its failure to deliver adequate outcomes (i.e. improvements in peoples social and psychological functioning) but also continuing abuses that are accepted as par for the course within the current system, and lack of respect for people with mental health problems and their families. The system is still contributing to the traumatisation of patients and their families (see below). Where ever you find systematised abuse you will find high levels of mental health problems (distress and trauma). Although Lakeside Hospital was bulldozed, remnants of this system survive today, in deeply ingrained attitudes and human rights abuses that are not called out often enough because of the overwhelming vulnerability of those experiencing them.

It would be enormously beneficial to have truly independent mental health advocates for patients and their families to help them access (and demand) better mental health outcomes. Independent advocates (not employed by the area health service) could help patients and their families navigate the mental health system (and the justice system), and demand better treatment outcomes. Independent advocates would also enable the systematic documentation of breaches of patient and family rights as well as gaps in the system that needed to be addressed.

In a recent experience (three years ago) I was forced to appeal directly to the supervisor of ■■■■■■ Health Services in order for my concerns about the safety of my 80-year-old relative to be taken seriously. Prior to his son's voluntary admission to the ■■■■■■ Inpatient Psychiatric Unit his son had engaged in a serious incident of family violence against him. As a result of the incident the police took out an AVO on behalf of the father and began criminal proceedings against the son. Despite police involvement, the incident seemed to have no impact on clinical decision making. There was no independent forensic assessment – when I asked about this the doctor on duty had no idea what I was talking about. Discharge planning was done without any meaningful consultation with family or the police. When I tried to explain to the nurse in charge and to the consultant psychiatrist my concerns about the acute danger the father faced with imminent discharge of the son, they were not receptive; the nurse in charge said that they did not wish for patients to become "institutionalised" by having more than a two week stay. Discharge was delayed by a couple more days, but only after directly appealing to hospital administration, and appealing to their duty of care to the family. No support was given to our family to manage discharge, and no support was given to help the family deal with the legal ramifications of the family violence, which included the patient having to attend court (his case worker was not available to attend), and the family having to advocate for the son to have criminal charges dropped.

It is very wrong for families to have to simultaneously advocate and care for a family member immediately after they have had violence directed towards them. The family might be desperately trying to keep their relative out of the criminal justice system because they know that the system will not solve any of the problems that led to the creation of the situation; in fact it will inevitably escalate psychosocial problems, and have irrevocable

implications for the long-term family care of that person. This is an impossible situation for a family to navigate alone. To have been supported by a family violence unit, or an experienced forensic mental health consultant who could have advocated for the best outcome for both the patient and the family as a unit, would have been invaluable.

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

Family members need to be included in and informed about the mental health care of their relative. The issue of privacy and consent is not simple; family must not be excluded on the basis of the relative's opinion alone. There needs to be a balanced discussion about what is needed, rather than leaving these issues to be decided when the person is unwell, and might be paranoid, violent etc, and when the family are struggling with issues such as guilt, shame and fear that cannot be openly and safely expressed. This is particularly crucial when there are or might be issues of family violence affecting the carer and other family members. This situation must be acknowledged. The family / carer's situation must not be minimized or dismissed because of a narrow focus on the mentally disturbed person without reference to the wider context. There is an **absolute duty of care** to the family to ensure their safety and wellbeing too, but as explained above, in my experience this duty of care is rarely acknowledged let alone addressed, even in the most serious cases, where there is police involvement and AVOs in place. Issues of discharge are based solely on diagnostic criteria, for example whether the person is acutely "mentally ill", rather than based on the psychosocial issues that underlie an admission and will obviously affect discharge.

Additionally, family should be offered support, care and psychological therapy too because family are impacted by the mental health of their relative. A family systems approach would be ideal.

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?

We need basic care, basic dignity, basic human rights for people with mental health problems. But mostly we need to change the system so that they don't end up feeling like they are hopeless failures, with mental illnesses that are part of who they are because of their DNA. As the system improves and treatment outcomes improve the barriers that are now in play (cultural, psychological, social, medical) will also lessen so that young people do not have to face them. For those who have been excluded for many years (decades) from accessing work, and from community acceptance and connection the issue of trauma has first to be addressed before there is any hope of improving social and economic participation.

Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

Widespread easy access to clinical psychological services must be offered from the outset, and must be integral in prevention, treatment and rehabilitation services. Psychiatric treatments and psychotropic medication must never be the only treatment offered, and neither should they be the focus of treatment. I think that the whole power structure of mental health facilities needs to be challenged. The directors of mental health facilities should not automatically be psychiatrists who have a particular orientation to treatment and who affect the overall ethos of a mental health facility (i.e. more authoritarian rather than collaborative). There needs to be a major shift towards the treatment of psychosocial factors underpinning mental health, and this can be managed by privileging psychological and social treatments.

Access must be easy and non-prejudicial – if a person is in psychological distress they should never be turned away from treatment. It goes to the heart of the issue that treatment needs to be primarily about care and support and respect of the person and their family, rather than treatment approaches based on diagnosis first and treatment second.

I would like to see **independent patient advocates** within the system, not paid for or beholden to anyone but the patient and their family. This could be something that is incorporated into the NDIS scheme, so that full time (24/7) properly trained independent advocates are available specifically to help people with mental health problems access appropriate and adequate treatment. Currently, it is up to families to advocate for their relatives, but it is a difficult job that requires a great deal of skill, dedication and persistence, and not everybody has someone to be advocate for them. Having independent patient advocates would go a long way towards improving accountability and transparency, as well as improving outcomes for patients and their families, and for the communities in which they live. As an aside to this point, the voices of many people who do not have strong family advocates will not have been heard by this Royal Commission, at least not in the same way as those with families with the skills to advocate.

A priority would be to move away from the conceptualisation of mental distress being pathology based to one where psychosocial factors are privileged (see again <https://www.bps.org.uk/news-and-policy/introducing-power-threat-meaning-framework>). This would represent incredible progress towards humanising the mental health system.

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

I would like to see a campaign that involved sharing real, meaningful stories of all sorts of people dealing with mental health issues, in their own words (played by actors) and clearly outlining the psychosocial factors that are involved and the psychosocial interventions that can dramatically improve someone's situation. *No psychiatric terminology*, just human stories that make sense and destigmatise.

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

Overwhelming mental distress, combined with inadequate support is a fundamental driver of family violence, and this needs to be recognised and addressed rather than denied. It needs to be recognised that people with mental health problems can be extremely dangerous to themselves and also to the family members who they are closest to and who they rely upon for their care. I am tired of hearing statistics quoted on the low association between violence and so called "mental illness", because for those of us who have to deal with family violence issues those statistics are irrelevant. I also think that a lot of the violence is hidden; there is a great deal of shame within families with this issue, especially in older family members.

Violence and deaths that are labelled as being due to "toxic masculinity" reflect the confusion in our culture around the issue of mental illness versus mental distress. The system is not equipped to deal with complex issues around violence and mental distress but would rather focus on "mental illness" classifications. The prospect of being diagnosed with a mental illness would very much discourage and shame people who might otherwise seek support when they find themselves resorting to family violence when they are not coping with life.

We need the mental health system to accept their duty of care to people with mental health problems (and their families) who come in contact with the justice system to provide expert support, such as for example forensic clinical psychologists. This support must be provided no matter that they live in rural or remote areas. All family that are affected must be consulted, regardless of whether they live close by. This approach would dramatically improve the long term incidence of violence and suicides within the Victorian community. It would bring hope to my family who have been dealing with family violence issues for decades without support and with no hope, until now, for a better future. Every time we have experienced an incident of family violence over the past four decades, we have steeled ourselves for the death of a family member, yet nothing within the mental health system has given us hope to expect anything different.

Another major issue to address is that of the medical side effects of psychotropic medications. The message from psychiatry is that harmful, life-limiting side effects (such as diabetes, renal failure, suicidal ideation, heart attack, stroke and sudden death etc) are simply the price to pay for mental health. But why should we accept this, when it would not be acceptable in any other area of medicine? We can do better, and it is our almost exclusive reliance on psychotropic medication, particularly in regional and rural areas, that has led to such poor medical health outcomes. This situation really needs to be challenged. What are the drivers behind it? To my mind it reflects the devaluing of the lives of people with chronic mental health problems, and over reliance on psychiatric treatments at the expense of psychological and social treatments, as outlined above. Putting the onus on the individual to make lifestyle changes is a cop-out too. These drugs are powerful and immediately compromise the health of the people who take them.

The lived experience of being raised within a family with chronic complex mental health issues is extremely difficult. I have a background in Clinical Neuropsychology, but even so it has taken me many years to come to terms with my upbringing and to have a nuanced perspective of the complexity of mental health issues. Having an independent body such as The Royal Commission into Mental Health to hear our stories is incredibly empowering, and also very overwhelming. The courtesy, care and respect that is being shown to our community is powerful and healing and underscores what has been missing from the mental health system for far too long.