

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

SUB: 0002.0028.0503

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

"I think we need to move away from anti-stigma campaigns that just raise awareness about high-prevalence diagnoses towards looking at how living with mental health conditions impacts on people's everyday lives in a multitude of ways? from not being able to get travel insurance to being too ashamed to disclose childhood trauma histories. I also think that there is a big problem with raising awareness when there are often not adequate support services to refer people to. This is where we need to focus our attention? if there were easily accessible, high-quality mental health services in our communities I think the stigma of accessing them would be implicitly reduced. Many supposedly anti-stigma campaigns (including by large NGOs) are in my opinion, actually quite stigmatising themselves. I am concerned that some mental health conditions are poorly understood by the community more broadly and by workers/clinicians more specifically (such as Dissociative Identity Disorder? which I personally believe is under-diagnosed in Australia, given the high rates of child abuse revealed using the Royal Commission into Institutional Child Abuse, before you even factor in unreported inter-familial abuse) but I worry that a Beyond Blue or MHA-style anti-stigma campaign could potentially do more harm than good and that a focus on better educating medical and health students about these conditions would probably be a less damaging, more helpful way to reduce stigma and discrimination. "

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?

"It is incredibly hard for people to get early treatment and support as the system is so disjointed, fragmented and operates in silos. It is very much a lottery as to whether you get access to a caring clinician who understands what you are going through or whether you get physically and chemically restrained, insulted by security guards and seriously re-traumatised by the whole process. Why would I ever consider referring someone to a system (or using it myself) when I know it is likely to do them more harm than good? Whilst there are some good services out there, it is incredibly hard to find and access them. We need these to be the norm? and readily available to everyone? regardless of where you live, how old you are or what your income is. A no wrong door policy to access, with 24/7 availability, clinicians who are adequately resourced (and not so over-worked they're burnt-out) is required, along with options for those who prefer less medicalised models of care, such as peer support, warm lines, peer-run respite, open dialogue, carer respite and home-based crisis care. Currently CATT teams are simply gate-keepers to determine who is most at risk and therefore most requires a hospital bed (usually on a Treatment order), they are not living up to the ideals of offering personalised, in-home crisis care and support in a familiar environment where someone feels safest and most comfortable, in a person-centred, family-inclusive way. "

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

"Very little is working well in emergency responses to suicidal crises ? particularly for people who experience chronic suicidal ideation. The public health system (including Emergency Departments) is woefully ill-equipped to deal with people who are experiencing such episodes and a noisy, busy, high-stimulus environment like an ED, with long waits to be seen and staff who often treat you like you don't deserve to be there (attitudes such as you're taking a bed from a real patient') is the exact opposite of the timely calm, quiet, compassionate response that people in this state actually require. Ambulance Victoria's referral service, which has the capacity to triage some mental health patients over the phone in their own home is a really good concept, but will only ever be a limited part of the picture as only a small percentage of suicidal patients call 000, or a more immediate emergency response (i.e. an ambulance) may be required. There has been some good work around encouraging people to be more open about talking about suicide and this is probably a good thing ? (although as a side note, we need to be careful that Mindframe Media Guidelines are not arbitrarily applied to all lived experience speakers as if they are gospel) ? but the options of where to refer someone if they do disclose suicidal ideation or intent are very limited. This is compounded when someone has recently been released from hospital ? yet still reports being suicidal ? and you just know that calling a CATT team or ambulance to take them back is just going to perpetuate the cycle of admission-retraumatisation-discharge-readmission. (It is heartbreaking to have to sit with someone you care about, on a Friday evening, when they have just been discharged straight from an HDU to home (alone) ? with no safety plan ? and they report that they are still feeling suicidal and worried they may try to act on these impulses. Do you suggest they present to ED again for another 15+ hour wait? Do you try to get through to a triage number where your phone battery goes flat before they take the 2-3 hours+ to answer? Do you call 000 and hope they don't end up handcuffed in the back of a police van? Or do you just leave and pray they will still be alive in the morning?!!) I think also the potentially negative impact of interacting with bureaucracy cannot be over-stated. So many people who attempt, or want to attempt, suicide have had, or are in the process of having, difficult dealings with government or other departments such as Centrelink, DVA, NDIA, Workcover, TAC etc When Governments make the decision to, for example send out a Robo-debt letter for a \$500 debt to a Centrelink customer ? they don't comprehend that the powerlessness and fear that this can provoke can tip someone over the edge. I am certainly not condoning intentional welfare fraud, nor saying that Governments/authorities shouldn't be accountable for the payments they administer ? but they do need to be extremely mindful of the mental state of the clients they are interacting with. And no-one should be pushed to breaking point over an honest mistake (that may have occurred years ago). We could also do with 24/7 suicide support lines that offered better continuity of care, and multi-disciplinary care, for people who struggle with ongoing suicide risk. Current help lines are very much focused on identifying and referring people but are less equipped to offer meaningful, ongoing engagement ? and yet this could be a convenient, cost-effective model of care. Opportunities for consumer-led organisations to offer peer support groups for people who live with ongoing thoughts of suicide (such as the Alternatives to Suicide approach) could provide another valuable option. "

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.

"I think one of the biggest barriers to good mental health is social and community isolation. When people are struggling with mental illness or ongoing psychosocial disability it is often very hard to engage with the very things that promote mental health - like community participation, appropriate exercise, healthy eating, employment, education, meaningful activity etc The extent to which

loneliness exacerbates mental health difficulties cannot be overstated ? thus accessible, affordable, appropriate programs that encourage people to engage with their community are essential. I personally found St Vincent de Paul's Compeer Program invaluable, as well as private hospital out-patient programs (such as DBT), community peer support groups, community mental health groups (such as walking, art therapy, gentle exercise etc), which have helped me to stay connected with my community. However, I have needed mental health specific supports and services, and not just mainstream (one-size-fits all) programs. I think access to affordable, accessible trauma counselling (e.g. psychology) in the community is vital and the current 10 sessions a year funded under Medicare is woefully inadequate for people with ongoing or complex needs to be able to get the support and treatment they need. This means that they often end up having to see a psychiatrist (if they can find and afford one) simply because there is a Medicare rebate or they jump from one short term service to another without having the opportunity to establish a good therapeutic relationship. In in-patient environments, the lack of continuity of care and the need to constantly have to re-tell your story to each new staff member, or worse, rely on one clinician's subjective interpretation of your presentation as hurriedly written in case notes with no-one bothering to check it has been documented correctly, is both frustrating and counter-therapeutic. There is extensive research suggesting that it is often not so much the type or modality of therapy that is used, but rather the quality of the therapeutic relationship that determines the success or failure of therapy ? yet our mental health system (in the public sector at least) there is not only no time to establish such a relationship, often there is no psychotherapy offered at all. The whole focus is on stabilising patients on medications, or administering ECT, so that they can be discharged as soon as possible as there is usually someone else who needs the bed more. Whilst step-up, step-down services are a great concept, in practice they are often hard to get into, not available when required and not always flexible enough to cater for individual requirements (for example may not live in the right catchment.) I also think that there needs to be an MBS item number specifically to encourage doctors and Medicare providers to be able to meet and have multi-disciplinary care conferences about their patients who are accessing multiple services/supports. Currently the only communication that typically occurs is basic referral letters to meet Medicare funding requirements or brief phone calls to meet duty of care' requirements in a crisis. Also, the interplay between physical and mental health needs greater emphasis to help address the significant life expectancy gaps for people living with serious mental ill health. There are probably already good examples of health promotion programs, but these need to be applied to, adapted for and adopted by mental health settings, and prioritised in funding arrangements. Whilst recognising that PBS funding of prescription drugs is a federal issue, I'd just like to mention that the vast majority of the psychiatric medications I am on are not covered by the PBS. However, having tried over 20 different psychiatric medications, with some proving to be ineffective, some causing intolerable side-effects, and having experienced many different adverse reactions (from allergic reactions to medication discontinuation syndrome bad enough to require hospitalisation) I simply cannot take many less expensive first-line treatments. I am not advocating that all available medications be listed as first-line PBS options, but it would be good if there was some capacity for specialists to be able to prescribe PBS-funded/discounted second or third line treatment options (typically costing from \$30 to \$80 a month per drug) when other drugs have proven to be ineffective, unsafe or intolerable, and professional second opinions have been obtained. Whilst there would be a cost to this, it would be significantly less than the cost of hospitalisation, or other treatments that may be required from ceasing effective medication treatment due to the cost (especially when on a pension). "

What are the drivers behind some communities in Victoria experiencing poorer mental

health outcomes and what needs to be done to address this?

"We need to look at all of the social determinates of health ? including poverty, homelessness, drug and alcohol abuse, family violence, geographic isolation (and the tyranny of distance), unemployment and under-employment, the casualisation of the workforce, stigma towards people from certain backgrounds (e.g. CALD communities, people who identify as LGBTI etc), comorbidity and importantly how we respond to traumas (both individual traumas like child abuse and community traumas like natural disasters). Until we address all these sorts of issues (with a whole-of-society and whole-of-Government approach), mental health treatment is only ever going to be a band-aid solution to a massive hemorrhage. "

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

"The first thing that can be done to better support families, friends and carers is to provide good quality mental and physical health care for the person they are caring for. However, this needs to occur in a holistic context that recognises that there is no such thing as a 'typical' family, that carers come in many guises, that family can be 'logical' not just 'biological' family (i.e. family of choice) and that there is very high prevalence of interpersonal trauma that occurs within families that is never identified, named or called out. I think re-imagining the way services deliver support ? so that an individual's entire network is factored into their care planning would be incredibly useful, such as is done in Open Dialogue approaches. Many carers also have mental health difficulties themselves and I think this is often not acknowledged. Nor is the fact that in some instances, family carers can actually be past or even present abusers in the context of family violence or childhood trauma. I think just as each mental health consumer is unique, so too is each mental health carer' or support person and so will want and need different things ? offering a variety of different supports and options is essential. My carer has found a carers walking group (that has guest walkers speak about topics such as Centrelink and Estate Planning, and then stops at a caf afterwards), along with occasional wellbeing retreats, to have been the most helpful things for her; but other carers may prefer carer peer workers, helplines, more traditional support groups, support around the house etc "

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

"I think we need to make mental health an attractive career option for people ? which includes having job security (not just casual, split-shifts), equivalent pay to comparable other professions, adequate staffing (and in public clinical environments in particular, enough time to actually spend with patients ? not just doing paperwork), high quality, affordable professional development opportunities and a workplace culture that is inviting, supportive, respectful and hopeful. I think that peer workers need much clearer role clarification, appropriate peer-supervision, quality training, good networking opportunities with other peers, and recognition that using your own, authentic lived experience day in and day out can be particularly taxing and draining. Peer work needs to be respected for the magic it can bring to recovery and not just be used to try and fill all of the gaps in the system that can't be filled by other workers. "

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?

"I think more equitable, easier and timely access to the NDIS for people with psycho-social

disability would significantly help with improving social and economic participation. I also think that a program - not unlike PHaMs or PIR - that people can get easy access to when first diagnosed, or attempting to engage with services, is essential ? that can offer community-based support (and possibly some peer groups) for a couple of months up to a year or 2 whilst people work on their recovery. Clients who are still struggling after this time, or whose conditions appear to be likely to be permanent could then have a familiar worker assist them to apply for and transition to the NDIS. We probably also need more programs in workplaces to support employers to employ people with mental illness ? when this can potentially carry the risk of absenteeism and impaired job performance at times, whilst also potentially providing loyal and committed employees if they are supported appropriately. Reasonable adjustments in the workplace are essential (as required under anti-discrimination law, but not always put into effect.) "

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?

"I think the Royal Commission needs to prioritize the following 5 areas: -Reducing compulsory treatment, improving safety and quality on inpatient units (including ensuring sexual safety for patients), reducing (or at least documenting and recording) chemical restraint use, and working towards eliminating seclusion and restraint. -Filling the gap between 000/Ambulance/Emergency Departments and waiting to see a clinician or doctor in the community. There needs to be much better options for people in crisis, and also people who are at risk of crisis, without having to rely on emergency departments, (or becoming stuck in a revolving pattern of ED-inpatient admission-discharge-ED-readmission). -Access to affordable trauma counselling in the community ? especially for people with a history of childhood trauma or complex post traumatic conditions and/or dissociative disorders. This could be through expanding access to psychologists (and other allied health professionals) but the importance of continuity of care in the therapeutic relationship cannot be over emphasised here. When a service is taken over by a new provider ? on paper the client may still have access to the same level of supports, but if an established relationship is lost, this can be extremely retraumatizing and can significantly damage the therapeutic and recovery process. -Greater emphasis on valuing the importance of peer work ? both as a recognised profession, and as a form of community connection. -Improving access to NDIS for people with psycho-social disability and providing better alternatives for people who are not eligible or do not wish to apply. "

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

"A commitment from Government for adequate ongoing funding, but also an appetite for innovation and change. We don't just need more of the same (e.g. acute hospital beds), we need new and innovative approaches like Open Dialogue, Intentional Peer Support, Peer-run respite centres, warm lines, 24/7 crisis lines for people with chronic mental health challenges, improved carer respite options, high quality adjunctive digital mental health services, affordable/accessible community education, wilderness/outdoor programs (e.g. Out Door Inc), programs that incorporate both physical and mental health promotion, peer health coaching, Hearing Voices groups, Alternative to Suicide groups, animal/pet therapy programs (such as peer support dogs or Equine Facilitated Learning), creative art therapies, music therapy and so on. When carefully run, and valued and appreciated by consumers, these programs are not necessarily any more expensive than funding visits to consultant psychiatrists, and can be proactive, rather than reactive ? like hospitalisation, ambulances, ED presentations etc whilst also offering individuals significantly more

choice and empowerment."

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

"I am only alive today because I have access to an amazing private psychiatrist who has gone above and beyond to support me over more years than I care to admit. I also have a carer who has stuck by me for decades despite many, at times very painful, challenges. However, I find myself feeling guilty for the fact that I have (most of the time) had access to good mental health care (largely through luck and private health insurance). Access to quality care should NOT be a lottery. It should be a fundamental human right. I shouldn't have to be ashamed to tell people that I have a good, affordable therapist, because this is impossible for so many people to access. I think the role of women's hormones in mental health needs to be researched a lot more ? I know for me there is a definite link there, that is at times quite literally life-threatening ? yet it has been incredibly hard to access doctors trained or skilled in this specialised area. I am disappointed that the opportunities contained in the 2014 Mental Health Act around promoting patients' rights (such as the use of Advance Statements) have not been taken up (to any great extent). I think this is not so much a fault with the Act itself, as a lack of willingness or resources in services to effect the cultural changes required. But when you have the President of the Victorian Mental Health Tribunal stating at a community forum (RACV Club, 15th May 2019) that Victoria relies far too heavily on compulsory treatment orders, and that there are unrealised expectations of the (new) Act, it is clear we still have a long way to go. "