

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?

"I have a lived experience with D.I.D. and a somewhat self-educated understanding of it. I am concerned that D.I.D. might not get a great deal of consideration in the Royal Commission as it's not as talked about or as understood by the mental health sector, let alone the public. It has been sensationalised in movies such as Sybil which are extreme and do more harm than good in creating an environment for people to come forward for help. I only just learned that I could make a submission to the royal commission so my submission here will be limited and a bit rushed so may not be fully structured. I would appreciate the opportunity to talk more openly and completely with the royal commission, (although anonymously to protect my family and my employment). A lot of people don't understand D.I.D. and there are few psychiatrists who are highly experienced with it as D.I.D. can't be treated by medication. It's a trauma-based condition. It's often disregarded. In many cases it is not even recognised. Even in the mental health sector there aren't a lot of organisations that deal with it. As a result, there is a gross lack of understanding and support from the mental health system. Patients who are D.I.D. rarely seek therapy because they are D.I.D. as most patients don't know that they are when first seeking therapy. In fact, I dare say Australian stats are similar to those in USA where the average patient is in the mental health system for an average of 6.8 years before being correctly diagnosed. On average D.I.D. patients are receiving 2 to 3 previous psych diagnoses before being diagnosed as D.I.D. Many of whom were previously incorrectly and harmfully medicated for a condition that can't be medicated. Women are more likely to be diagnosed with depression and prescribed benzos. In my instance, I had a great decade with an employer and then the company got sold and new management were brought in who were intimidating and bullying which triggered a major dissociative event. It was as a result of this what I was off work on work cover for 2 years after a diagnosis of D.I.D. The review said that but for the intimidation in the work place, I would have been reasonably expected to have continued my successful career I had had to date. Unfortunately, the employer did not want me to return to work after the two years because they did not understand the condition. This had a great economic affect on my life. It also greatly changed my social structure. The government needs to educate employers about D.I.D. and the value they can bring to the work place. The discrimination shouldn't be allowed, but they got away with it, because by law they only needed to hold me job open for a year at that time. Had the employers not been abusive, I may have still be employed there. Instead I eventually went on unemployment for the first time in my life, something I had never wanted to do. It was only for a short period of time, but it could have been avoided in the first place. It also placed an undue expense on the welfare system. "

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 far as preventing D.I.D., that is of a larger scope than this royal commission as it means helping to heal all the broken parents who inflict trauma on their children and cause the D.I.D. It's

also greatly linked to the issue of domestic violence and sexual abuse. Even when there is one loving parent, they cannot always protect the children from the trauma as they themselves are victims of it. In terms of early treatment and support, the average age for women to be diagnosed with D.I.D. is in their 20's and 30's. In my case, I saw my first psychiatrist at aged 13 after a failed suicide attempt and after 2 sessions he told my mother I was fine and I promptly tried to take my life 2 weeks later. I saw a number of counsellors, ministers and psychologists before I was finally diagnosed in my early 30's. Twenty years wasted and traumatised by treatments that were ineffective and brought more grief and despair. I would like to see this be changed for so many people who are suffering now. The course of so many D.I.D. sufferers' lives could be greatly improved with early diagnosis and therapy. Not only do psychologists and psychiatrists need to have more training in identifying it (psychologists so they can refer the patient to a psychiatrist), but also GPs. When I was finally diagnosed and told my GP who had been treating me for approx. 7 years, he said it made sense in hindsight as I was always so different when he saw me in the clinic. I had no idea as to how I had presented and he had no idea to explore that as an option. Had he had more training in the signs, he may have referred me to someone, but he didn't. In addition, a large number of D.I.D. patients have a long history with welfare, social or legal systems and undiagnosed and untreated patients have been or are incarcerated. Little is known about D.I.D. by most of the community and as a result it has a great stigma attached to it and even more fear around D.I.D. than there is around bi-polar or schizophrenia. Even people who have some training and understanding of it can miss it. For example, in my case a friend who is a community development worker and had in fact counselled D.I.D. patients, was initially disbelieving when I told her I had been diagnosed as D.I.D. I had to remind her that she had only ever been with me in stress free social events at her house or mine. She was later convinced when she met a child alter. "

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

"Many undiagnosed D.I.D. people are self-destructive and are in and out of hospital for self-harming and / or suicide attempts. Not only is this traumatic for the person and their family and friends, but it is also creating a huge financial cost to the medical system. Money that would be better invested in early accurate diagnosis and treatment. Clinically there appears to be a reduction in suicide attempts once a person is diagnosed with D.I.D. and this was certainly true in my case as a diagnosis can bring great understanding. Usually there is one part' that is suicidal and when that is understood by the patient, they can use internal dialogue to work through the issues rather than one part' just acting out on an impulse that isn't really desired by the whole person. Emergency nurses and doctors are on the forefront of this and need to be trained to look at not just the suicide attempt but clues that a patient could be D.I.D. After at least two hospitalisations for suicide attempts, I had to see the psych before discharge, however on neither of those occasions was the psych even remotely aware that I was D.I.D. I think that is partly due to the fact that as an undiagnosed D.I.D., my main fear was that of being locked up in a psych hospital and never being released so I would tell them what I thought they needed to hear in order to make sure I would be released. That's a protective part' of the D.I.D. internal system. The other factor is that psychs usually only have one session with a patient and rarely if ever would an undiagnosed D.I.D. person reveal alters/parts in just one session. Either trust would need to be built, which takes time, or the stress trigger would need to be that great that the patient can't help but dissociate. The problem with that is that usually with the suicide or self-harming event, the stress event that triggered that, has released the short term fear or other trigger and much like a pressure cooker, that psych is now talking to a less scared, less triggered part and the patient presents as calmer and more in control, so the root cause gets overlooked. Nurses and doctors

would also need to learn how to be more sensitive to the patients in the way they talk to them and the way they treat them, even when they are well meaning. For example, once after slashing myself multiple times (almost 20 years ago), a nurse was sponging my wounds in a bath. She chose that moment, when I was physically exposed and vulnerable, to ask me why I did this to myself. She wasn't being judgemental, but her timing was way off. Any chance she had of connecting was destroyed. After an overdose one time I was hooked up to an IV for 3 days to flush my system. I only spoke to a psych once. The rest of the time I was left alone in my room and whilst a hospital is not a baby-sitting place, it wasn't good to be left alone with my thoughts for so long. The one time I had a cry in bed the nurse snapped at me and told me to get up and go for a walk, totally dismissing there may have been a legitimate need for me to express pain at that time. There are other examples to share, not for myself, but to help the emergency and medical system to understand how crucial their role is in helping patients who don't fit the traditional medical illness role.' "

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.

"GPs need to be taught to be more aware of the possible repercussions of their actions, particularly as they relate to mental health. A few years ago, I had a work cover issue where my ear drum was damaged by some internal jack hammering by contractors that should never have taken place. Unfortunately, my usual GP wasn't available and when I saw a substitute at the clinic, he wrote a report for my employers. Thankfully I read it first because he listed my D.I.D. in the report to my employer. It had nothing to do with the physical injury and even worse, the doctor didn't even know what D.I.D. was, he just listed it without even talking to me about it or asking me about it. Had I not opened his letter and read it first, he would have exposed me in the workplace and put my job at risk. I don't care how much discrimination is not allowed in the work place, large employers know how to be shifty in getting rid of staff. I had to re visit my usual GP to get him to edit the report as he agreed it had influence on my ear condition. Another issue is the quality of referrals. GPs make referrals without really understanding in a psychologist or psychiatrist is fully conversant in the treatment required. It would be good to see a dedicated association for referrals for people with D.I.D. and for some easy signs for doctors to look for to give them an idea of referring someone to a psych for possible D.I.D. and other conditions. GPs generally see patients more regularly than other people and so are in prime position to pick it up early if they know what to look for. Dentists are another field that need training in understanding D.I.D. as by the mere nature of what they are doing, they inflict pain on patients. An undiagnosed, and even a diagnosed D.I.D. patient can have an alter misinterpret the pain if a child part is present. This can be distressing for both patient and dentist. I'm not sure if asking for mental health conditions are on a standard dental patient record or not. It would be worth considering; however, it is also tempered with the reality that D.I.D. patients don't want to be followed by a label that creates fear in so many others. To this end it would be good to see the government create a wide media campaign to debunk the myths of D.I.D. just as they have with de stigmatising anxiety and depression. One of the things that makes it hard is that once a diagnosis is put in your medical file it stays there forever and follows you wherever you go. Before I knew the government had put our records online for any medical clinic to access, I went to the clinic across from my work as I was not well whilst at work. It was not a clinic I had ever been to. I had started to fill in the form but stopped when I saw I had to list any mental health issues so decided to leave but the receptionist said she'd already brought up my records from my GP. This was distressing as these staff were also my customers and I didn't want them knowing about that aspect of my life. I have removed myself

from public medical records, but this company already raised my records and I am sure they were not removed. The government needs to understand that even with the best intentions, some of their programs threaten people who need help the most. There needed to be 12 months warning of the government's plan to make online records, rather than launching it and then telling us to unsubscribe. The damage was already done. "

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

I can't talk to this.

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

"When a patient is or has been suicidal, I think a lot more needs to be done to help the family know how to best support the person. These strategies would need to differ depending on if the patient was under age or an adult; single or in a marriage. It is a difficult time for the whole family who are only afraid their loved one might succeed next time, so they suffocate the person with scrutiny which only serves to further isolate the patient. Self-harming is just as stressful on family members who often falsely believe that suicide is the inevitable next step. Any support to help families navigate these challenges times with effective communication rather than from a place of fear, would be a great service to our communities."

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

I can't talk to this.

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?

"There is still a lot of fear around employers knowing about mental health issues and fear of losing employment. Even in large organisations that espouse acceptance and understanding, there is the fear from individual managers who only want to focus on targets and budgets and people who aren't mentally well are just an obstacle to reaching business objectives. For example, on last year's R. U. OK? Day, our workplace was plastered in posters for managers to take time out to talk to staff that day. I was going through a traumatic personal crisis and was holding it together until I got to work and saw the posters asking R U Ok and I said, No I'm not.' I asked to speak to my boss and she spoke to be for 30 seconds before saying she was too busy because she had queues of customers (I work in retail). Had the signs not been there I would have made it through the day, but the signs triggered a response and then one manager failed meet the company's expectations of her support. That made a farce of the whole thing. The government needs to help educate companies in how to make tangible differences in the workplace rather than just driving the bottom line and only paying lip service which does more harm than if employers don't promote R U OK day. There are some days when a person with mental health issues, isn't sick in the physical sense, but isn't in the right mental state to be at work. Every employee has the same allocated number of sick leave days and should be able to take them for a mental health day which is just as crucial as a physical illness. The problem with this is that employers demand to know why you are absent and although it is reasonable, there are some days when a person with D.I.D. may be dissociating due to a stress trigger and as such, until the person can work through

the issue, a child part might be the one who has to call the employer. Text messages aren't allowed to prevent those people who are just calling in for a sickie to go out somewhere or because they are hungover. I'm not sure how this can be resolved, but I know I have been distressed on the phone with an employer when having to call in sick for a mental health day. Then there's the awkwardness of returning the work the next day. When you try to do the right thing and go to work, but then need to leave early because you really weren't in the headspace to be there, most employers get annoyed (in retail) and say you should have stayed home. It's a complex issue, because 80% of the time when you go to work you make it through even if you thought you wouldn't. I believe most people with D.I.D. want to work and be functioning members of society but when triggered the stress can be overwhelming. Maybe the government could work with employers to develop a process for mental health days to be taken in a way that is less intimidating. Before leaving work if staff want to go home, it is not enough to speak to your department manager, you are made to speak to the store manager for approval first which just appears to be a form of intimidation to stop people from even asking. It creates unnecessary stress on legitimate people. "

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 number of free counselling sessions available for people with D.I.D. and other mental health issues. Treatment is long term therapy. DSM-V says 5 years with 1 to 2 sessions a week. With the current system of 6 free sessions a year and up to 10, that falls far short and few people could afford to pay out of pocket for the remaining 40 plus sessions per annum. Given that D.I.D. is created through childhood trauma, my understanding is that it's not covered my health insurance as it's a pre-existing condition, even if the person didn't know that they had it when they took out insurance. As a result, many people just have to keep functioning the best they can. Train more psychiatrists in D.I.D. Train more GPs, nurses, dentists, school counsellors and police to see the possible signs of D.I.D. I believe sometimes police think someone is being deliberately obtuse rather than dissociating. Create a database of psychiatrists experienced in D.I.D. so GPs can have greater success in making referrals. Spectrum Personality Disorder Service deals with borderline personality disorders only. This is not the same as D.I.D. I also think it's important that there be some guidelines developed around how and when to tell a patient that he/she has D.I.D. I have been told from someone who worked in the industry that they didn't always tell D.I.D. patients that they were D.I.D. as it could do more harm than good. I think that does a great disservice to D.I.D. patients who are generally highly creative and highly intelligent and who deserve to be told the truth of their condition with supports in place. The truth of a diagnosis may bring initial distress, but it can also bring a lot of clarification and understanding of why someone's life's been the way it was. It can also bring some relief when they understand that it's something that can be treated with the right kind of therapy and that there is hope for the patient to become fully integrated. People should be given the dignity to know what is wrong with them. I heard of a community development program a number of years ago that sent someone into various church denominations to teach ministers about how to look for the signs of domestic violence in their members. Many ministers said they knew their flock and that wouldn't be happening there. But at the end of the program, most if not all of them admitted to finding it once they knew what to look for. It would be great if this could rolled out for D.I.D. also as many ministers do lay counselling with people. Any psychiatric assessments made in the prison system should be done within a specified time-frame (suggested 24 48 hours). This should be automatically organised even if the legal aide lawyer isn't understanding of mental health issues. All prison/remand assessments should be done face to face, not through a glass pane. This means there need to be enough

meeting rooms at prisons to meet the demands. "

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

"A financial investment in more training for psychiatrists to diagnose and treat D.I.D. Develop more collaborative therapy and training developed with the help of D.I.D. people who live this, rather than just a clinical approach. I hear it works in A. A.'s 12 step program which has a great deal of success. A team of D.I.D. people who are closer to being fully integrated could work with psychiatrists and GPs and other medical professionals. "

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

"I believe that one of the ramifications of D.I.D. is how the justice system deals with it. DSM-V says the only person who can diagnose someone with D.I.D is a psychiatrist but given the nature of the condition how can they diagnose in one assessment when someone is in the legal system. That is all that is funded by Legal Aide. There are deficits in the system where legal aide lawyers, who know little about mental health, can wait up to 12 months to get a psych assessment done for a person on remand. If the person was dissociating at the time of the alleged crime, then the alter that committed the crime is most likely not present during the assessment anyway. Even though there is only ONE PERSON and as such the person is responsible for any crime being committed, there is no allowance for mitigating circumstances if there is not a timely assessment done. The flip side is that as it's true that most D.I.D doesn't want the public to know they are D.I.D. then even more so for people caught up in the prison system. Most prisoners with D.I.D. don't know they have it, but even if they did, they don't want other inmates or even guards to know in case they get abused and taunted for it and thus make prison life even harder. D.I.D are groups of traits and suppression of certain parts that isn't necessarily apparent. When in the justice system, you're getting someone who's not completely integrated so arguably not able to be judged in the same way as someone who isn't D.I.D. and yet that is what happens. The impact of dissociation can make it look like you're not being empathic when most people are distancing from the painful emotion and when someone's being sentenced it can makes them look callous even when they're not, an increase their sentence as a result when in reality, they might just be terrified to feel. Need to system to build its capacity in this area, both from a funded treatment and from a justice perspective and a public awareness to reduce stigma. The complexity of the issue and why it needs a specialised response and there isn't adequate understanding and support and funding. If there aren't already other lived D.I.D. people talking to the royal commission, I would count it a privilege to do so in an anonymous manner so as not to impact my family or my employment. Many thanks for taking the time to undertake this royal commission and for the desire to improve the services for all people who suffer various forms of mental health issues. "