

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

## Organisation Name

N/A

## Name

Ms Janet Holmes

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

"ADHD is the most common and most treatable ongoing mental condition afflicting Victorians. The single thing that could be done to improve the mental health of Victorians would be to improve the diagnosis of ADHD. Depression rates would go down, anxiety rates would go down, and productivity would go up. The signs and symptoms of ADHD need to be known, and the safety and efficacy of treatment needs to be better understood. The current feeling in the community that ADHD is a rare condition characterised by little boys who can't sit still is wildly short of the mark. The truth is that 5-10% of children have ADHD and that the consequences of this for their behaviour are highly variable. Presentation of ADHD in girls is often very different than in boys and the struggles of more intelligent children are also often missed. Those children whose main presentation is dreamy detachment from the world are rarely picked up either. The stigma of ADHD is largely related to ignorance of its actual effects on behaviour and to the fear and ignorance about the treatment. The fear-mongering regarding all sorts of recreational chemicals has made people anxious about extremely safe medications. The community needs to be educated about the safety and effectiveness of treatment for ADHD. No other mental condition has such safe and effective treatment as ADHD. The groups that crusade against those who treat ADHD need to be treated with the contempt they deserve rather than pandered to endlessly by cowardly politicians and bureaucracy. The upside of ADHD, the creativity, energy and application that, when properly harnessed, can lead to extraordinary achievements, also needs to be better understood. Understanding that a person has ADHD gives them, their teachers and their carers a foundation for understanding their strengths as well as their weaknesses and helps everyone to make better choices for their future. "

### **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?**

"Very little currently works well for sufferers of ADHD. Male children with obvious behavioural problems may be diagnosed, but most cases are missed due to the ignorance of parents, teachers and health professionals. Early treatment for ADHD would mean children being diagnosed in early childhood. One of my children nearly failed three year old kindergarten. I thought his teacher was joking at first, but she wasn't. A properly trained teacher, psychologist or family doctor should have been able to identify probable ADHD at that point and refer us off for the necessary medical attention. Other less pronounced cases might take longer to become obvious, but it should be the goal of every primary school to have identified 90% of children with ADHD by the end of grade six. The average Victorian primary has 260 students of whom between 5 and 10% have ADHD. So the average primary school can expect to have between 13 and 26 students with ADHD. If they don't know who they are, they should. Schools should be expected to work with parents to get these children the help they need. The longer children go without diagnosis and treatment the more demoralised and disengaged they become. In the worst case scenario they are vastly more

likely to end up in prison than the rest of the population. There is little evidence from Australia, but in the USA between 25 and 40% of prison inmates have been found to have ADHD, and a recent study of NSW prisons found 35% of inmates screened positive for ADHD. Getting children the help they need as early as possible would keep the number who end up in prison to a minimum. If this fails, treating inmates with ADHD improves their outcomes after release from prison. The cost of undiagnosed ADHD is far higher than is generally recognised. The most effective way to improve diagnosis and treatment for those suffering with ADHD is to improve the education of teachers, Doctors, psychiatrists, psychologists and all other health professionals who are involved with people having problems. All of them need training in the incidence and variation in presentations of ADHD and empowering to do whatever is necessary to get sufferers help. People with ADHD tend to be found in higher numbers than expected in certain places. They have the same IQ profile as the rest of the population, but their difficulties with the education system tend to leave them with disappointing educational achievement. Their creativity and preference for activity also channels them in certain directions. Understanding that people working in areas such as skilled trades, acting, medical and emergency fields, and teaching are more likely than the rest of the population to have ADHD and its accompanying anxiety and depression would be useful for those whose job it is to help them with their problems. Teachers, as the professional group working most closely with children, especially need to be trained to identify probable cases of ADHD, and empowered to help these children get treatment and support. Currently they are actually forbidden in many cases from even suggesting to families that a child may have ADHD. This causes considerable frustration among teachers, at least those few who can identify ADHD in a child, and leaves many families who would have benefitted from help adrift in a sea of ill-educated professional helpers who end up helping not helping at all. Most importantly, all helping professions need to understand that the most common reason for an apparently intelligent child to be having difficulty in school is ADHD. The situation is far worse in the case of adults. The fallacious idea that people magically grow out of ADHD on their 18th birthday is widespread leaving many with a childhood diagnosis untreated in adulthood and leaving many adults unaware that ADHD could be the reason for their difficulties. As a result of even worse understanding of ADHD in the past, very few people now in adulthood had any chance of getting a diagnosis of ADHD as children. The appalling ignorance of ADHD among doctors and other health professionals means their chances of diagnosis as adults very often depend on their having a child diagnosed. Of course, since not everyone has children and many children aren't diagnosed this is a very haphazard path to help. Many adults looking for help with their struggles with ADHD can expect to be diagnosed with depression, anxiety, bipolar disorder and numerous other conditions before they find any real help, if they ever do. Family doctors, who receive no training about ADHD, are very happy to prescribe medication for numerous mental conditions but most aren't legally able to prescribe the stimulant medications necessary to treat ADHD. This makes them both unable and unwilling to diagnose ADHD and unable to do more than provide a referral to one of the few psychiatrists who treat this condition. Family doctors need to be allowed to diagnose and treat ADHD. The shortage of psychiatrists who treat ADHD means that there is long wait to see one, and they are often very expensive. Adults with ADHD, as with other mental conditions are often not in a position to afford expensive psychiatry, but there is no more affordable option. Giving family doctors permission to diagnose and treat ADHD would make getting treatment much simpler and cheaper and make life far easier for those suffering from this condition. There is no sound reason to deny family doctors the right to treat ADHD. They routinely prescribe other far more dangerous medications than those used for this very common condition. The prevalence of ADHD is approximately the same as for asthma. It should be no harder or more expensive to get

treated for ADHD than it is for asthma. "

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

"One of the most common symptoms of ADHD is depression. The condition is basically one of low dopamine levels in the brain, which amongst its many roles, helps regulate mood. So it would not be unexpected for low levels of this neurotransmitter to cause depression in many. Unfortunately it is very common for people with ADHD to be diagnosed with depression and treated for that with depression specific drugs, instead of ADHD. This can provide some relief from symptoms but is usually not very successful, certainly less successful than treatment with ADHD medications. While there is very little research in this area, what little there is supports the logical expectation that if people with ADHD are feeling depressed, but not getting treated or getting treated for the wrong condition, they are more likely to commit suicide than people who don't have ADHD. The risk of suicide among those with ADHD is about 30% higher than the non-ADHD population. Accurate diagnosis and proper treatment of people with ADHD could be expected to help prevent suicide in people with ADHD. "

### **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.**

"The modern civilised world bears little resemblance to the world we were designed to inhabit. A tribal existence on the plains of Africa, while it would have many deleterious outcomes would probably improve the mental health of most of us. This is not an option many can access. For the rest of us the lack of training and general ignorance of teachers and health professional regarding ADHD makes getting treatment and support extremely difficult. The prohibition of family doctors diagnosing and treating it make getting treated more difficult and more expensive than it should be. It makes no sense that a condition as common and as debilitating but easily treated as ADHD should be so ignored and maligned in our community."

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

"Rural populations have poor access to psychiatrists and struggle to find one who is qualified to diagnose and treat ADHD, which is a rare specialism even in Melbourne. It's hard in the cities but in rural areas there are long drives and long waits for help, if it can be found at all. Giving family doctors the training and legal ability to treat ADHD is even more important to rural communities than the cities. Prison inmates have ADHD at far higher rates than the rest of the community and would benefit enormously from effective treatment but rarely if ever get it. It needs to be a high priority of government to identify and provide treatment for those who would benefit from it. The unfortunate obsession with the possible recreational uses of some of the medication used to to treat ADHD, at the expense of rational calculation of the benefits to the sufferers and the community of treating the condition, has meant that many of those who would benefit the most have been denied treatment. This is greatly to the detriment of our whole society and it should be a priority of government to remedy it."

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

"In the case of ADHD, which is my primary concern, the most overlooked support families need is to recognise that ADHD is extremely heritable. If one member of the family is afflicted it is highly

likely that many others are as well. In my own family, everyone has it. Me, my brother, my three children, and I'm fairly confident, both my parents all have/had ADHD. If community understanding of ADHD were more accurate and less influenced by anti-ADHD zealots who make it their business to spread misinformation about the condition it would all be much easier to manage. It is very common to hear otherwise sensible people casually discuss the "over-diagnosis of ADHD" as though it is a settled issue, which is the exact opposite of the truth. Indeed if people understood the condition and the treatment better they'd realise that giving a child (or anyone else) who is misbehaving, stimulant medication, isn't going to improve anyone's life unless they really do have ADHD. Most people I know who have ADHD keep it very quiet. Few people understand what it means and there is no benefit from making it known, only costs. Better education and understanding of what ADHD really means for adults as well as children is greatly needed."

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

"Getting treatment for ADHD is unnecessarily difficult and expensive. The few psychiatrists who take the risky step of specialising in ADHD need far more support and far fewer regulations and punitive investigations into their treatment practices. They frequently face audits and enquiries into their practice which threaten their own mental health and generally add a degree of difficulty to their lives that make treating ADHD not worth the effort. This leaves sufferers with very few and expensive options. It is essential that family doctors be able to diagnose and treat ADHD and that all doctors not be penalised for helping a community so badly in need of help. The punitive regimen of regulation and oversight that treaters of ADHD face should be dismantled, and family doctors be educated and empowered to treat this common and debilitating condition. At least 5% of the population has ADHD. The few psychiatrists who treat this condition cannot begin to manage such a workload. Those few GPs who are qualified to diagnose and treat ADHD are impossible for patients to locate as they do not make their ability known publicly from fear of persecution by anti-ADHD zealots. This is unacceptable. If all GPs were given the training necessary to treat this condition, bearing in mind that it by no means rare, on the contrary, then those zealots determined to persecute doctors treating ADHD would be unable to isolate a few for special treatment. "

### **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?**

People with ADHD can live normal successful lives. Most of them already do. Diagnosis and treatment with the extremely safe and effective medications which we have for this condition can help enormously. Just because people appear to be coping with their lives doesn't mean they don't need help. People with ADHD also have many valuable strengths to offer. These need to be appreciated and capitalised on while deficits are ameliorated. The public ignorance and fear of the stimulant drugs used to treat ADHD needs to be corrected.

### **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?**

"A condition suffered by 5% of the population cannot be managed by such a restricted group of highly priced people as the few psychiatrists who treat ADHD currently are. The excessive regulation and punitive oversight of those who treat ADHD needs urgent reform. GPs need to be

trained and empowered to treat ADHD. I believe there are some GPs allowed to treat ADHD, but the stigma against ADHD makes it impossible to discover who they are because they don't make this information public for fear of persecution by crusading groups of anti-ADHD zealots. This is hardly an acceptable situation. I understand this is a federal issue but the Victorian Government needs to advocate on our behalf for the rationalisation of the PBS and the TGA. Currently Vyvanse, one of the most effective treatments for ADHD is only available on the PBS for children, or those who were diagnosed as children. This is the most bizarre and inexplicable restriction of a medication ever. It is the only drug ever to be so restricted and there is no rational explanation for it. Those of us unlucky enough not to be diagnosed until adulthood have the added disadvantage of having to pay through the nose for a private prescription for the most effective medication available for this condition. Furthermore, other medications for ADHD are not available in Australia at all. Adderall, Dyanavel, Evekeo and many others aren't available in Australia at all because the cost of getting approval is too high to be economically viable. It is not in the interests of the Australian public that access to highly effective medications be denied to us as a result of the high cost and uncertainty inherent in applying for government permits. The burdensome and punitive regimen of regulations that doctors who treat ADHD must suffer under needs to be lifted. "

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

"Public education about the prevalence, symptoms and treatability of ADHD would support improvements in the treatment of sufferers of ADHD and the treatment of the doctors who treat it. This is bizarrely, just as important. The stigma attached to ADHD is so extreme that even the doctors who treat it suffer from it. It's worse than being a specialist in syphilis in the 19th Century. Unless public misconceptions about ADHD and the treatment for it are ameliorated the situation of sufferers cannot materially improve. We need government support for self-help groups as well. Both financial and organisational support. The nature of ADHD makes it difficult for sufferers to organise effectively. "

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

"ADHD is an unusual condition. It's not clearly a mental illness as such, though it is often associated with mental illness and if left untreated can lead to mental illness. It doesn't develop in adolescence or early adulthood the way so many mental illness do, but is clearly present from birth, and contrary to previous opinion it does not evaporate on one's 18th birthday, but persists into adulthood and often worsens in later years. ADHD is an atypical neurological condition which has widely divergent presentation and outcomes for different people. Many people with ADHD live highly successful lives, but many others struggle diligently with their problems until they finally have too many balls in the air to manage. However all people with ADHD have certain issues in common and would benefit from diagnosis of their condition, if only to warn them of the pitfalls of their impulsivity and unlikeliness of them succeeding in a desk job. The fact that the medication for ADHD is the most effective treatment in psychiatry deserves to be better known. If you do have to have a mental condition, this is the one to have! People with ADHD may not need or benefit from medication, but that should be a decision for them. Now that I know what to look for I see undiagnosed cases of ADHD everywhere. I know that they suffer from a permanent knot of anxiety in their chest. I know their lives are an ongoing duel with chaos. I know that help is available, but so hard to access that even knowing you need help is so difficult many of them will never even get that far. And if they do look for help they will probably be told, erroneously, that they have anxiety and will be prescribed medication that, at best, papers over a few cracks, and at worst, makes

them feel even less able to cope. Usually however I say nothing. Because the stigma and ignorance surrounding ADHD is so intense that most people simply cannot believe they might have it. The vision in their heads of the small boy running hysterically round the school yard, which is all they "know" about ADHD, has no relevance for them. Younger people are more receptive to the possibility since most of them had friends in school who had ADHD, but for most people over 35 it's simply inconceivable that they could have such a thing. Yet they do, and they aren't getting the help they need. This must change. My [REDACTED] has just completed a master's degree in agriculture with an average mark of 85% and is planning to do a PhD next year. Before she was diagnosed with ADHD she was obviously very intelligent, and she was managing her university degree, but with enormous difficulty. Once she was properly treated for her condition her average mark went up approximately 15%. She was able to access the university's disability assistance program, which meant she had a quiet room to do her exams and more time to complete assignments. Not only did she get better marks but her self confidence increased and she started to become more ambitious for herself. There is no chance she would be planning to do a PhD without the help resulting from her diagnosis. There are many thousands of other Victorians who struggle every day with things they know others can do easily, not realising that there is effective help available. They deserve help. "