

Formal Submission to the Royal Commission into Victoria's Mental Health System.

By: Ian Matthews

Subject: Lack of recognition and treatment of Aspergers Syndrome (High functioning autism)

Background:

- 1) 66% of people with Aspergers have suicidal ideation compared to only 17% of the general population. 35% have actually made plans or attempted suicide, yet only 31% report depression.
- 2) Experience of suicidal ideation (66%) compared to those that were depressed (31%) is puzzling, and could suggest a different process for suicidal ideation in Asperger's syndrome than for other clinical groups. Alternatively, this finding might result from under-reporting of depression, perhaps because of alexithymia (difficulties verbally describing subjective emotional experience).
- 3) Asperger's patients with a history of depression are four times more likely to have suicidal thoughts and twice as likely to plan or attempt suicide than those without a history of depression.
- 4) Aspergers was not recognised as a condition until 1994 and was merged back with general Autism in 2014.
- 5) Aspergers tends to affect twice as many men than women.
- 6) Due to the lack of research, the best guess would be that around 100,000 people in Australia suffer with Aspergers.
- 7) Suicidal tendencies of people with Aspergers increase as they get older.
- 8) People with Aspergers tend not to present any differently to the rest of the population. They will generally realise that they think differently to others, but this is not necessarily a bad thing. Although the diagnosis of Asperger's syndrome is not possible without direct testing and observation of an individual, it has been suggested by some authors that many successful historical figures may have had Asperger's syndrome, including Mozart, Albert Einstein, Benjamin Franklin, Thomas Jefferson, and Marie Curie.
- 9) Nearly all the mental health support for people with Aspergers relates to getting them to "fit" into the community. That is, teaching them to hide who they are as they are not socially acceptable. It is the same as the treatment of the LGBT community in the past. That is, they were forced to act like heterosexuals.
- 10) As a person with Aspergers you are told your whole life that you are not acceptable to society and you must hide who you really are. Then society wonders why 66% of us want to kill ourselves.
- 11) The mental health system does not routinely test for Aspergers. From experience, the reason for this is that they would not know what to do with the information if they did know.
- 12) It has been proven that standard mental health treatments do not work on people with Aspergers, yet this is all the system in Victoria will provide.

Except for a very few mental health professionals that have taken an interest in Aspergers, there is a complete lack of understanding in the profession in regard to its affects on depression, suicide, or effective treatments.

- 13) The only significant study of Aspergers, and its affects on depression/suicide, was carried out by Cambridge University up to 2014. The research team was led by Dr. Sarah Cassidy and Prof. Simon Baron-Cohen of the Autism Research Centre at the university. It was published in *The Lancet Psychiatry*, 25 June 2014.

Required Outcome:

- 1) More detailed studies of the prevalence and affects of Aspergers need to be carried out.
- 2) Treatments need to be developed relating to depression and suicide rather than simply teaching suffers how to fake "acceptable" social norms.
- 3) Mental Health professionals must be better educated on the effects of Aspergers and how treatments need to be altered for those suffering with the condition.
- 4) All patients entering the mental health system should be tested for Aspergers.
- 5) There needs to be specialists where people with Aspergers and depression can go rather than the effects being ignored as current.
- 6) People with Aspergers need the same recognition as the LGBT community. That is, recognition that it is all right to be different and you do not have to hide who you are to fit in.

My Story:

I am 61 years old and have gone through my whole life knowing I was different but not knowing exactly how I was different.

I have always demonstrated what I now know are common traits of those with Aspergers. I have an above average IQ, I am often clumsy and are therefore not good at sports. I am particularly poor at any sport that requires eye and hand coordination such as bat/ball games and golf. I have reading and speech issues. I hate background noises and have difficulty with feelings and expressing those feelings.

After continual bullying as a child, you soon learn what is socially acceptable and what you must do to fit in. I have therefore spent my whole life hiding who I am. I had a firm belief that nobody would like me if they saw the real me. Therefore I have gone through without knowing a single person that likes or loves me. Even my wife of 39 years still continually tells me the things I do that are not right and she does not like. If someone that you have been married to for 39 years cannot accept the real you, then you know that nobody else can.

I am not a bad person. I do not have bad or depraved thoughts. I simply see things in a different way. I simply feel things in a different way. Yes, I am different to you, but why does that make me wrong.

The way I see the world has allowed me a reasonably successful business career. My ability to see things that others cant has allowed me to solve issues that nobody else can. However, it always stuck me that I was a person that they dragged out of the cupboard when they had an issue that others could not solve and then put back when the job was completed.

Outside things that required eye/hand coordination, I have not found anything I cannot do if I put my mind to it. Whether it be technical work like computer programming, dealing with legal contracts or writing Government Legislation. I can build or repair most things, including building houses, electrical, plumbing, carpentry, plastering, etc. On motor vehicles I can rebuild motors, gearboxes, etc, along with panel beating, spray-painting and upholstery.

Around 15 years ago I started to suffer from anxiety due to the continual pressure not to be myself. I was diagnosed with depression at the time and have been on various medication ever since.

The depression medication tended to reduce my limited emotions even further. The death of my son-in-law a couple of years back was the thing that highlighted how poor my life had become. I felt basically nothing on being notified of his death in a car accident. As I was notified around 12.30 am, my only thought was that it was time I was going to bed.

Even though I knew I was not emotionally right, I did not know what to do about it. Over the previous 15 years I had been on just about every anti-depressant known to man. None had really helped.

For a long time I tried to think of what I could do to make me happy. I could not think of a single thing. My depression is not linked to an event that can be analysed and dealt with, I am simply depressed all the time and I do not know why. I do not have any "good" days. I simply describe my days as bad and worse. The "bad" days are where I feel I can still hang in there, the "worse" days are when I do not want to go suffer through life any longer.

Even though my doctor knew I had suffered with depression for over 15 years, and the pills were not really working, he offered no real alternative. He had never ever raised Aspergers. It was up to me to search for treatments other than pills. I came across Transcranial Magnetic Stimulation (TMS). At my request, my GP referred me through to a Psychiatrist who eventually approved TMS. I had two full treatments of TMS without any change in my depression.

After TMS I actually felt worse. I was assured by everyone that this could not happen. Again it was up to me to do my own research. I found that research was being carried out my Monash University in regard to the effect TMS could have on the treatment of Aspergers. Even though only a couple of treatments of TMS had been shown to have dramatic effects of the emotions of people with Aspergers,

nobody had bothered to look into what effects TMS treatment for depression could have on people suffering from Aspergers. The people carrying out the TMS treatment for depression were completely unaware that TMS was being used for Aspergers. To this day I am still not sure whether the TMS treatment I had actually made me worse or not. As they are in the very early stages of researching the effect of TMS on Aspergers, nobody can state with confidence that it did not have a negative effect on me. Yet the Mental Health Profession will continue to prescribe TMS and ECT to asperger people without knowing its affects. This is extremely dangerous.

It was only hearing a news item on adults with autism that I decided to test myself for autism/aspergers. Nobody ever suggested it to me. I did every test I could find and they all showed that I had a very high chance of having aspergers. I told this to at least half a dozen psychiatrists and a similar number of psychologists. None of them were interested. None of them saw a link to my depression. None of them suggested I be formally tested.

I contacted the various asperger societies, etc. None had any interest in the link with depression even though it has been shown that 66% of asperger sufferers will look at committing suicide. Their sole focus appear to be with getting children to fit in with society and helping sufferers fake their way into employment.

I contacted the various professional bodies for mental health professionals to find people that may have an expertise in Aspergers. I could only find professionals dealing with getting children to fit into society. They could not tell me of anyone that specialised in depression for people with aspergers.

Even though I do not like the idea of having my brain fried with electricity, it appeared that the only thing left was to have Electroconvulsive therapy (ECT). So again I had to organise this treatment myself.

I had a bad reaction to ECT and ended up in the intensive care unit of the hospital. After having a similar reaction now on two different occasions, it appears that ECT is too risky for me and off the table as a further treatment.

Due to the lack of research we will never know whether the reaction to ECT is related to Aspergers. I am certainly not prepared to go through it again for them to find out.

However, my reaction to the ECT has spiked the interest of a Professor in psychiatry. I have now been formally diagnosed with aspergers. For the first time I am comfortable that I have someone looking after me that is prepared to look at me as an individual rather than just applying the standard treatments. Even with this new interest and focus, I fear that there is no cure for my emotional state. There appears to be nothing that anyone can do that will make my life bearable. I must now decide on how long I give them to find an answer before I decide that enough is enough.

Formal Submission to the Royal Commission into Victoria's Mental Health System.

By: Ian Matthews

Subject: The difficulty in obtaining Mental Health help in Victoria

Summary:

After 15 years of medication not working, I am the one that had to research other treatments. I am the one that had to request non-medication type treatments such as TMS and ECT. I am the one that had to find a psychiatrist and hospital to do this. I am the one that had to approach my health fund to have the treatment as an outpatient rather than being trapped in hospital for months. I am the one that had to organise transfers between the private and public hospital systems. I am the one that had to explain why I was being transferred between the two hospital systems. I had to diagnose myself as having Aspergers and then have it confirmed by the professionals.

I am the one with the mental health issues. I want to get better. What I have found is that the only person that cares about my health issues is me. It really wears you out and you just feel like giving up so many times. Instead of helping I find that the system only makes things worse.

I looked to the Mental Health system to give me a reason to keep on living, all its done is make everything feel more hopeless. I now wish that I had stayed a zombie on medication and not gone anywhere near the Mental Health system.

Details:

- 1) It is extremely difficult to find mental health help in Victoria. It seems that the only time you will receive attention or help is if you threaten suicide. But you will only do this once as you soon find out that you will have control over your life taken away from you if you do. You will basically be locked up in a mental health ward somewhere and kept there until you can convince them that you are no longer a threat to yourself, whether this be true or not.
- 2) I like and trust my GP. However, for 15 years he prescribed various anti-depressants that never really worked. I am the one that had to request to be referred to a psychiatrist for non-medication treatment, such as TMS.
- 3) I quickly found that psychiatrists are highly over paid. Therefore they tend to only work a few days per week or go on holidays on a very regular basis. You can forget about getting into see one with a descent reputation and are therefore left to see the ones that nobody wants to see. Even then it will generally take around 1 month to get an appointment.
- 4) My current psychiatrist changed my medication. The new medication appears to be having an adverse affect on my mental health and I have not had a proper nights sleep in 2 weeks. Even though such things are relatively common with changing medication, I cannot get in contact with my psychiatrist. He is at his clinic, I leave a message for him each day,

which his staff swear they are passing onto him. So he won't return my calls, he only works at his clinic 2 days per week and I can't get an appointment, what am I suppose to do. It just reinforces to me that there is no hope and nobody cares.

- 5) Psychiatrists do not trust other psychiatrists. When being transferred between them, they will not pass on your medical records to the new one. The new one will not trust what the old one has done and will insist on repeating all the work again at between \$700 and \$1,000 per hour of course.
- 6) Very few psychiatrist appear to have admitting rights at more than one hospital. Of course the psychiatrist at the new hospital will not trust the recommendation of the previous one. So I had a psychiatrist recommend TMS for me at a private hospital. We had a bit of a falling out and I asked him to refer me to another psychiatrist at the same clinic for the same hospital. Of course I had to have a full evaluation again because the new psychiatrist did not trust his colleague. Several months later I went back for ECT, as the TMS did not work. Saw a 3rd psychiatrist at the same clinic for treatment in the same hospital. Even though both previous psychiatrists at that clinic had recommended ECT, I had to go through the process again as he obviously did not trust the findings of 2 of his colleagues. Due to issues, I was referred to the public hospital system for ECT. Even though the referral was specifically to have ECT and the reasons why, the public hospital staff obviously did not trust the private professionals and I had to go through the full evaluation process again. The public hospital referred me through to another private hospital for treatment as they were too full. Again, a new psychiatrist and another full evaluation before they would do treatment. As the public hospital forgot to tell the private hospital some vital information, the private hospital did not have the facilities required and referred me back to the public hospital. Because I had been officially "discharged" from the public hospital, I had to go through the full evaluation process again. Had a couple of treatments at the public hospital and then they transferred me to another private hospital as they wanted the bed. Of course I had to go through the full evaluation with another psychiatrist again. All this took 6 months of evaluations and waiting for appointments with psychiatrists. You do not realise the negative impact on your mental health when to have to continually convince people that you are nuts and deserve treatment.
- 7) The lack of cooperation extends to between psychiatrists and psychologists. Psychiatrists have told me that their main role is the medical side of your mental health issues. That is, prescribing pills, organising ECT, TMS, etc. If you want to get to the bottom of what might be causing your mental health problems, you are told to see a psychologist. Yet they will not recommend a psychologist or pass on any of their findings to the psychologist. It is the same as a surgeon carrying out a back operation and then sending to a physiotherapist without telling the physio anything about what he did. To this day I am unclear as to the line dividing the work carried out by a psychiatrist and psychologist.

- 8) Unless you threaten suicide, it is extremely difficult to obtain help for mental health issues through the public hospital system.
- a) I was obtaining ETC treatment through the private hospital system. However, I suffered extreme delirium as a result of the treatment. I needed to be restrained to prevent injury to myself or staff. The public hospital system is the only area that has facilities to restrain patients. Therefore, my psychiatrist referred me to our local public hospital and explained why.
 - b) The public hospital would not admit me based on the recommendation/explanation of my psychiatrist. I had to go through the standard process involving their CATT team.
 - c) I suffer from anxiety and I am in a constant state of “fight or flight”. I therefore do not like being confined to a hospital, but have found that I can tolerate it and push through my fears for up to a week. However, the normal ETC treatment is 3 treatments per week for 4 weeks.
 - d) My depression gets considerably worse when left alone with my thoughts. My times alone in a hospital ward are particularly bad.
 - e) The other public hospitals in the group offered ECT as an outpatient service, but this particular hospital did not due to having no suitable facilities due to renovations taking place. They were unwilling to refer me to another hospital in their group that was a lot closer to my home and would carry out ECT as an outpatient. Due to some lines drawn on a map, I was not allowed to approach this other hospital directly. This other hospital said they would take me, they just required the CATT team to book me a bed. After agreeing a few times to do so, when it actually came to booking the bed, the CATT team refused and insisted I be treated as an inpatient at the hospital considerably further from my home.
 - f) Even though the Mental Health Ward at the hospital I was eventually admitted to stated that they preferred the CATT team to book a bed for patients, the staff in the ward stated that they always refused. It was only my insurances and complaints to the hospital that got me directly admitted to the ward.
 - g) What the CATT team insisted on for the admission of patients is for the patients to present themselves to the Emergency Department at the hospital and request treatment. The CATT team acknowledged that you could be forced to wait up to 2 days in Emergency before being admitted to the ward. So the CATT team insists on a person with mental health issues to sit in a chair in Emergency for up to 2 days in order to get the help they needed and had already been determined by the CATT team to be required. I was told that if you are not prepared to wait for 2 days in Emergency then you must not be sick enough to require their resources. The public hospital is wasting Emergency resources having patients waiting and being further assessed there rather than simply giving the patient a phone call when a bed was available.
 - h) Even though the public hospital admitted having a shortage of beds, they wanted me to tie up a bed for a week just to get blood tests that could be carried as an outpatient at their pathology department. I was

actually sent from the ward to the pathology department to have the tests done. During this week in hospital I was to have no other treatment other than the blood tests. It was just their way of reserving the bed for me in order to have the ECT treatment starting in a week's time.

- i) Then there are the stupid rules within the mental health ward that are enforced mindlessly. You are not allowed to have any phone or computer charging cords in case you try to kill yourself or others with them. Yet I was allowed to have my CPAP machine that had miles of cords with it. Then there are the no-smoking rules anywhere on the hospital property. Anyone that has given up smoking will know how hard it is and the anxiety it causes. Yet patients that are going through significant mental health issues are forced by the hospital to give up smoking at the same time. There are usually courtyards that use to be used for smokers that are now locked and not allowed to be used. The patients are confined to the ward and are certainly not allowed to leave the hospital grounds. And of course their cigarettes and lighters are confiscated on arrival. I know that smoking is not healthy and should not be encouraged, but is this the right time to force people to give up. Other patients in the hospital are not subject to such treatment, only the mental health patients.

Required Outcome:

- 1) Professional opinions should be respected across the sector. If a psychiatrist's opinion is not to be trusted, then they should be deregistered and not paint all psychiatrists with the same brush.
- 2) Patients should not have to go repeated evaluations just because they are transferred to a different hospital.
- 3) Patients should not have to deal with a system stacked against them. There needs to be an advocacy service that can look after the interests of the patient rather than the patient having to battle the system.
- 4) It should be possible to be admitted directly to the ward rather than having to wait in Emergency for a bed to become available.
- 5) To free up beds, treatment should be carried out as an outpatient when reasonable to do so.
- 6) Patients should be treated with a little respect and should not have the non-mental health views of the hospital forced upon them.

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

Organisation Name

N/A

Name

Mr Ian Matthews

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

N/A

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

N/A

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

N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

"This is the first of my submissions. It deals with the special needs of people suffering with Aspergers. There are around 100,000 people in Australia with Aspergers. 66% will think about committing suicide and 35% will make plans or attempt suicide. Normal treatments have been proven not to work. Nobody appears interested in dealing with this VERY high risk part of the community. My full submission and details are included in the attached Word document."

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

N/A

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

N/A

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

N/A

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?

N/A

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?

N/A

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

N/A

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

N/A