

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

Attention Deficit Hyperactivity Disorder (ADHD) is the most common mental health disorder in children and adolescents in Australia with a prevalence rate of 7.4%(i). Seventy per cent of children with ADHD will continue to experience symptoms of ADHD into adulthood(ii) leading to a prevalence rate of from 2.5-3.5% in the Australian adult population. (iii,iv)

ADHD is a common, highly inheritable, neuro-developmental disorder that was first described in medical literature in 1775 by the German physician Melchior Adam Weikard, when he described people characterised by a lack of attention.

ADHD is diagnosed on the basis of symptoms and criteria specified in the American Psychiatric Statistical Manual, specifically a pattern of behaviour that is evident in childhood and features inattention, distractibility, hyperactivity and impulsivity. ADHD is subdivided into three types: ADHD combined type of inattention and hyperactivity and/or impulsivity (ADHD-C), which is the most common in clinical diagnosis; ADHD predominantly hyperactive type (ADHD-H); and ADHD predominantly inattentive type (ADHD-I) which accounted for approximately 50% of all identified cases within the large Victorian based cohort research project, Children's Attention Project (CAP)(v) by the Murdoch Children's Research Institute (MCRI).

In Victoria, ADHD is perhaps the most maligned of mental health disorders in children and adolescents.

The stigma of ADHD manifests in stereotypes, discrimination, isolation and social rejection that are so entrenched that even the term 'ADHD' ignites automatic preconceptions about children and adolescents and a strong desire for social distance from them(vi).

ADHD receives frequent media coverage in Victoria and is nearly always portrayed in highly negative and judgemental terms. There is no shortage of children with ADHD being declared as "deliberately naughty", "spoiled brats", "lazy", "indulged".

Parents, particularly mothers, of children with ADHD are vilified as being "bad mothers" who are incompetent and irresponsible and deserving of blame for their child's behaviour.

There are frequently headlines and public outcries that "ADHD does not exist", that "it is not real", that it is "made up by drug companies", and that it is "over-diagnosed", an "epidemic", "fake".

It is attributed to a 'bad' diet and modern lifestyle factors such as too much 'screen time' and violent video games.

Treatment of ADHD has also been reported as 'drugging children', creating 'drug addicts' and turning children into criminals.

The misconceptions, misinformation and negativity of media coverage in Victoria has perpetuated stigma about ADHD and this has not only influenced the wider Victorian community but more significantly has been found to also influence the perceptions and knowledge of professionals who work with children affected by ADHD including teachers(vii). Media coverage and related public stigma has also been found to negatively influence health professionals and doctors responsible for diagnosing and treating children and adults with ADHD(viii).

ADHD is misunderstood and highly controversial in the Victorian community and its validity is publically questioned, challenged and debated. This has created an environment that enables stigma and discrimination to flourish and where people with no knowledge or expertise feel entitled to 'have a say', criticise, reprimand, blame and shame children with ADHD, their parents (particularly their mother's) and also the doctors who are responsible for diagnosing ADHD and creating the so call epidemic.

Stigma that impacts young children can have devastating outcomes throughout life. Children as young as 4 years of age negatively perceive and judge children with ADHD behaviours and feel no sadness about excluding them from play(ix). Up to fifty per cent of adults have been found to actively discourage their children from playing with children with ADHD symptoms(x).

ADHD related stigma and discrimination affects children from a very young age and continues to affect them throughout preschool, primary school, secondary school, and higher education. Parents and families of children with ADHD are also stigmatised. The resulting impact on social functioning is devastating and it is little wonder that ADHD has such high rates of co-morbid mental health disorders.

ADHD related stigma and discrimination is perpetrated by professionals including teachers, family support workers, allied health workers, GP's, paediatricians, psychologists and psychiatrists. The lack of knowledge about ADHD in Victoria by professional who, despite availability of evidence-based research and resources, remain ignorant and misinformed, is of great concern and needs to be urgently addressed. At the 2012 International CHADD Conference in San Francisco, Professor Russell Barkley stated that the failure to acknowledge ADHD as:

"Philosophically, one could make a case given the body of evidence of more than 10,000 articles with 2,000 of those published just in the past five years, anyone within a mental health profession who FAILED to recognise ADHD would be negligent!" (xi)

As the parent of three children diagnosed with ADHD, aged 25, 17 and 16, I have experienced many years of encountering ignorance about ADHD and dealing

with the stigma generated from ignorance. Misconceptions and a lack of knowledge and understanding about the pathology, symptoms and impact of ADHD are so omnipresent that it is often more overwhelming and difficult to cope with than the ADHD itself. The lack of up-to-date evidence-based information about ADHD being presented in popular Victorian media, can account for the negative and challenging attitudes of non-clinical members of the general public, neighbours, friends and family. There is however no such excuse for the lack of knowledge and understanding about ADHD by professionals and clinicians such as doctors, including GP's paediatricians and psychiatrists, psychologists, social workers, youth workers, allied health professionals including occupational therapists and speech therapists, mental health services, mental health support organisations, family support services, teachers including special education teachers, school principals, school counsellors and education psychologists working in schools, police, judiciary, lawyers, clinicians and staff working within the courts, forensic, justice and juvenile services and systems.

I am so tired of trying to access support services for my family only to discover that the service provider has such limited antiquated knowledge of ADHD that their advice is literally useless. Yet when I attempt to provide them with up to date research and information about ADHD or direct them to credible, high quality information I am further judged and stigmatised as being unco-operative or non-compliant, difficult or challenging and my knowledge is dismissed. I am reviled as a 'typical single mother with ADHD children'.

It feels as though I am supposed to feel immense shame for having children with ADHD. I am also supposed to keep their ADHD private and a secret because revealing their diagnosis is damaging and will expose them to social rejection and alienation. Sharing my children's ADHD diagnosis will apparently also expose me as being supposedly an irresponsible and incompetent parent.

In Victoria, the stigma of ADHD has resulted in an environment where those affected by ADHD try to disappear and become invisible else they risk further condemnation and humiliation.

I am proud of my children. I see in them so many positives.

It is devastating to me that my clever, creative, witty children feel so ashamed of themselves that they never disclose they have ADHD to anyone other than their treating medical specialist and that the risk of being exposed as having ADHD is quite literally the cause of severe anxiety and depression.

My teenage son is so worried about any of his peers discovering he has ADHD with associated learn difficulties requiring extra support at school, that he refuses to enter the Education Support rooms unless there are absolutely no other students around. He takes convoluted routes around the school making sure that none of his peers know where he is going. He is so incredibly ashamed of having ADHD that he refuses to acknowledge his symptoms despite being diagnosed when he was 5 years old.

He was persecuted at primary school for having ADHD. Other children called him names, excluded him from games, hurt him physically and made his life miserable. On one occasion when he was seven years old, he was tied to a tree by a group of older and bigger boys whilst a gang of children circled around and chanted "hyper-boy" and then took turns poking him with sticks 'dipped' in 'dog poo' and smeared dog faeces all over him including his face and in his hair.

When I collected him from school he was covered in bruises, scratches and grazes in addition to the dog faeces and he was terrified and distraught.

When the perpetrators were questioned about why they did this they responded that my son was a 'druggie' because he took medication at school for ADHD and that ADHD made him a 'maniac'.

There had been a story about children with ADHD on Channel Seven's Today Tonight program a few evenings before this incident where footage of children behaving violently was aired and attributed to ADHD. The story included footage of the journalist approaching the general public 'on the street' and asked them if they believed ADHD was real and if they were worried about ADHD medication making children drug addicts.

The stigma generated by this ignorant, sensationalised, incorrect and irresponsible television reporting had a direct impact on the attitudes of children at my son's school and they reacted by vilifying and physically abusing my son.

Being a mum to ADHD children necessitates constantly advocating against the seemingly inescapable misinformation, the ignorance, the reproaches, the blame and the shame. It means that you are forever in the 'trenches', battle after battle, trying to get support for your kids and trying to educate those who should know but who choose not to access information. It is exhausting and it is time that people with ADHD are recognised as being marginalised and denied services.

The high prevalence of ADHD in Australian children and adolescents means that every classroom in Victoria will have at least two children with ADHD. Because difficulty with paying attention is a defining feature of ADHD, most children with ADHD have difficulty with learning in a classroom environment. Most children with ADHD also have a co-existing learning disability. In addition, hyperactivity makes children restless, fidgety, inclined to blurt out responses and have problems waiting turn. Teachers often struggle to teach children with ADHD and perceive them as disruptive and not trying hard enough.

ADHD children need additional support to learn and to cope with school environments. Getting support in Victorian schools for children with ADHD is literally impossible. The stigma of ADHD as being a behavioural problem caused by bad parenting seems to have infiltrated the Victorian Department of Education (DoE). The DoE has a Children with a Disability program that provides additional funding so as qualifying students can be allocated an integration aide to provide support and assistance at school. The process for applying for funding is overwhelming and involves submitting multiple reports from all of the child's

treating doctors and therapists. ADHD however does not meet the criteria for additional funding and children are subsequently denied support.

The DoE does not collect any information about students with ADHD in Victorian schools. The application forms for the Students with a Disability Program only detail 'Problem Behaviour' as a criteria that could accommodate ADHD however, if ADHD is detailed as a diagnosis on the application, the application is denied as the DoE do not consider ADHD as a problem behaviour.

The stigma within the DoE relating to ADHD must be urgently reviewed. Data relating to students with ADHD must be collected so that accurate prevalence rates within Victorian schools can be identified and so that more support services can be provided to ADHD students and resources developed for teachers and schools.

My son was denied additional funding when he started primary school and due to the difficulties of his ADHD hyperactivity, the school insisted that he was only able to stay at school for 2.5 hours per day and that I had to collect him every day at recess. This continued for three school terms as the DoE refused to provide funding and the school refused to let him stay. I was forced to lodge a case in the Federal Court of Australia on the grounds of discrimination.

My children are now older but I continue to find the stigma about ADHD pervades secondary schools and higher education and that teachers do not understand ADHD and lack knowledge and skills to support the ADHD students in their classes. They continue to see ADHD as something that is embarrassing to have and should not be disclosed but to be kept secret. In doing so they contribute to making children with ADHD feel ashamed, and they deny other students in the school an opportunity to develop understanding, be supportive and be inclusive.

There is a critical need for the narrative about ADHD to be changed. Children with ADHD are curious, creative, energetic and entertaining (xii). 62% of highly successful business entrepreneurs have ADHD(xiii) There is a long list of notable geniuses throughout history who are thought to have had ADHD including Leonardo di Vinci and Albert Einstein.

It was because of the extreme shame my son and daughter felt about themselves due to having ADHD that I decided to attend a community consultation session for the Royal Commission into Victorian Mental Health services.

The stigmatisation of ADHD is so pervasive that even when I attended a community consultation session for this RCMHS, I was stunned by the perceptions of not only other participants relating to ADHD but also the staff of the RCMHS. ADHD seemed like such a novel concept and everyone seemed surprised that I considered it 'worthy' of being a mental health issue. I felt as though I was the only person who had attended any of the consultations who had mentioned ADHD and as soon as I did I noticed the familiar responses of ignorance, judgement and stigma.

Fortunately, I had anticipated some ignorance about ADHD and I had prepared myself by memorising the latest research, information, data and statistics in order to defend ADHD as a mental health disorder. But the mere fact that I had to justify the relevance of ADHD is evidence of how negatively it is perceived and understood even within an environment of mental health consultation that included attendance by mental health professionals and organisations whom I had incorrectly assumed would be knowledgeable about ADHD and mental health.

Not one person was aware of the fact that ADHD was the most common mental health disorder in children and adolescents in Australia. Nor that it has high rates of co-morbidity for depression, anxiety, bipolar disorder, OCD, drug and alcohol abuse issues, eating disorders, personality disorders or that the single biggest determinant of children under 10 years of age who commit suicide is having ADHD and that 25-40% of prisoners have been identified with having undiagnosed ADHD that when effectively treated and managed greatly reduces recidivism. Why is that that these facts were unknown to the people at the mental health community consultation?

Why is it that despite it being the most common mental health disorder in children and adolescents in Australia, there are no ADHD services provided?

Why is it that despite it being the most common mental health disorder of children and adolescents in Australia, there is no information about ADHD on websites dedicated to mental health such as Beyond Blue, Mind Australia, SANE and Headspace?

The general public perceives ADHD as illegitimate and therefore they are entitled to criticise and judge children and their parents in the most negative and damaging ways. Despite a wealth of evidence showing the need for support and services and the devastating impact undiagnosed or poorly managed ADHD can have, there is a little if any public support in Victoria by mental health professionals to counter the misinformation with facts. There are no public figures or celebrities in Victoria who are willing to speak out about having ADHD and be ADHD champions. There are no positive role-models in Victoria for kids with ADHD to counter the shame and the stigma and to let them see that there is hope.

There is a long list of highly successful international celebrities, sports stars, notable academics and public figures who have been diagnosed with ADHD and who openly discuss their diagnosis and present a positive image of ADHD and share strategies that have helped them manage symptoms. The impact of positive role models in reducing stigma of ADHD cannot be underestimated. Unfortunately, there are virtually no Victorian or even Australian public identities who are willing to proclaim they have ADHD due to concerns that ADHD is so negatively stigmatised in Victoria that they may jeopardise their careers.

Celebrities who have publically discussed having ADHD include Jim Carey, Ryan Gosling, Justin Timberlake, Adam Levine, Michael Phelps, Will I Am, Simone Biles, Jamie Oliver, Solange Knowles, Richard Branson. Publically discussing ADHD in a positive manner has helped begin to change the stigma about ADHD internationally and has been inspirational for many people with ADHD who feel alone, useless and hopeless.

It is important for the RCVMS to recognise that ADHD is currently associated with a long list of mental health co-morbidities most of which are exacerbated by the stigma and discrimination children with ADHD experience, particularly within the school environment, which can impact their capacity to not only learn and achieve academic potential but also develop appropriate social skills, and form friendships. The social rejection of children with ADHD leads to social isolation, loneliness and a range of subsequent resulting mental health disorders in addition to ADHD.

The prevention of the negative outcomes of ADHD such as the development of co-morbid mental health diagnoses, is dependant upon changing the perceptions of neurodiversity and ADHD within the Victorian education system.

Many of the poor outcomes associated with ADHD could be prevented or minimised if children with ADHD are identified, diagnosed and appropriately managed with early intervention strategies. People with ADHD can lead highly successful lives given access to ongoing support in childhood and throughout life for themselves and their family.

It is the stigma of ADHD that is often more difficult to cope with, particularly for children, than it is to cope with the symptoms of ADHD.

How to improve the Victorian community's understanding of ADHD and reduce the stigma and discrimination.

Before any plans are developed relating to strategies to improve understanding of ADHD by the wider Victorian community, ADHD must first be understood and recognised by Victorian mental health clinicians.

Mental health specialists need to recognise that they contribute to the stigmatisation of ADHD by failing to recognise, identify and diagnose ADHD particularly in girls and women due to gendered based perceptions of how ADHD presents. There is also overwhelming international evidence that ADHD has a high prevalence amongst forensic populations(xiv) and yet there is little understanding of ADHD amongst Victorian mental health practitioners treating children, adolescents and young adults who are at risk of or who have committed a criminal offence. There also needs to be ADHD training for police, court officials, lawyers and the judiciary.

Psychiatrists need to be provided with appropriate training to identify, diagnose and manage ADHD, including looking for ADHD as a co-morbidity of many mental health diagnoses.

Likewise, psychologists need to be trained appropriately in identifying ADHD and referring when suspected for appropriate diagnostic assessment.

Mental health clinicians particularly leading psychiatrists and psychologists need to advocate for ADHD to other mental health clinicians, medical disciplines and the general public to ensure that misinformation and ignorance is countered with facts, knowledge and understanding.

Leading psychiatrists and psychologists need to ensure that they change the public discourse about ADHD and that negative media coverage about ADHD is challenged.

Mental Health professional organisations such as The Royal Australian and New Zealand College of Psychiatrists and the Australian Clinical Psychology Association and the Australian Psychological Society need to ensure that ADHD related stigma amongst their membership is identified and addressed with mandatory professional development programs and that ADHD is thoroughly covered in the curriculum for students training to become psychiatrists and clinical psychologists and psychologists and that graduates actually have the skills and competency to identify and manage ADHD.

Leading mental health clinicians with expertise in ADHD need to ensure that professionals from other disciplines and fields that deal with ADHD children and adolescents are also provided with professional development about the aetiology of ADHD and appropriate management. In particular, professionals involved with education, including teachers, school principals and staff employed within the Department of Education, including senior staff responsible for developing policy.

Teachers must have a thorough knowledge about ADHD, they must understand how ADHD impacts children and learning and they must have the skills to support children with ADHD within a school environment. Stigma about ADHD that is perpetuated by teachers is particularly damaging to children as it impacts on their own self stigma, their relationships with peers and the stigma of other parents. Teachers are pivotal in changing the future for children with ADHD.

Victorian teachers current level of knowledge and understanding of ADHD must be ascertained using a validated assessment instrument such as the ADHD – specific knowledge and attitudes of teachers (ASKAT) instrument to identify ADHD-specific teachers knowledge and attitudes(xv) . Once a base level has been researched, profession development programs must be developed in accordance with the research findings. Training programs about ADHD must be mandatory for all teachers to ensure teachers are equipped with accurate information and skills to manage ADHD children in their classrooms. Evaluation of the training

must be designed into the program to ensure that teacher's knowledge and understanding of ADHD has improved.

ADHD must also be thoroughly taught to undergraduate students studying education who will be teaching in Victorian schools.

It is imperative that teachers understand that their own attitudes about children with ADHD can powerfully influence the outcomes of children both negatively and positively. Children with ADHD who are supported by understanding teachers who create inclusive classrooms are more likely to lead successful lives and less likely to feel alienated, socially rejected, academic failures, anxious, depressed or suicidal.

The stigma about ADHD must firstly be addressed amongst clinicians and professionals working within mental health, other health disciplines (such as General Practice) and teachers and professionals working within schools. This must urgently be pursued.

Once strategies have been developed to overcome the stigma, ignorance and misinformation about ADHD within the most key professions as detailed above, strategies can then be developed to tackle to stigma of ADHD within the wider Victorian community including changing the narrative of negative media coverage to media stories that are scientifically accurate and informative and that are compassionate and foster the creation of a Victoria that is inclusive and supportive of families dealing with ADHD.

REFERENCES;

(i) <https://www.youngmindsmatter.telethonkids.org.au> Young minds matter. The mental health of Australian children and adolescents. Overview. 2017

(ii) <https://www.ranzcp.org/practice-education/guidelines-and-resources-for-practice/adult-adhd-practice-guidelines> Kneebone, M. Adult attention deficit hyperactivity disorder (ADHD) practice guidelines: Expert Panel Discussion [Video file

(iii) <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/1471-244X-13-18> Sciberras E, Effron D, Shilpzand EJ, Anderson V, Jongeling B, Hazel P, Ukoumunne OC and Nicholson JM, (2013) The Children's Attention Project, BMC Psychiatry, 13:18

(iv) <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-017-1463-3> Katzman MA, Bilkey TS, Chokka PR, et al. Adult ADHD and comorbid disorders: clinical implications of a dimensional approach. BMC Psychiatry. 2017;17(1):302.

(v) Sciberras et al (2013) op.cit.

(vi) <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0051755> Fuermaier ABM, Tucha L, Koerts J, Mueller AK, Lange KW, Tucha O (2012) Measurement of Stigmatization towards Adults with Attention Deficit Hyperactivity Disorder. PLoS ONE 7(12): e51755.

(vii) https://www.researchgate.net/publication/258013943_Does_Knowledge_About_Attention-DeficitHyperactivity_Disorder_Impact_Teachers'_Reported_Behaviors_and_Perceptions Ohan, L. J. , Cormier, N. , Hepp, L. S. , Visser, A. T. & Strain, C. M. (2008). Does Knowledge About Attention-

Deficit/Hyperactivity Disorder Impact Teachers' Reported Behaviours and Perceptions?. *School Psychology Quarterly*, 23 (3), 436-449

(viii) <https://link.springer.com/article/10.1007/s00787-018-1256-3> French, B., Sayal, K. & Daley, D. Barriers and facilitators to understanding of ADHD in primary care: a mixed-method systemic review. *European Child and Adolescent Psychiatry* (2018). 018-1256-3

(ix) https://www.researchgate.net/publication/317405591_Only_you_can_play_with_me_Children's_inclusive_decision_making_reasoning_and_emotions_based_on_peers_gender_and_behavior_problems Peplak J, Song J, Colasante T, Malti T. "Only you can play with me!" Children's inclusive decision making, reasoning and emotions based on peers gender and behaviour problems. *Journal of Experimental Child Psychology* 162 (2017) 134-148.

(x) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3430836/> Mueller AK, Fuermaier AB, Koerts J, Tucha L. Stigma in attention deficit hyperactivity disorder. *Atten Defic Hyperact Disord*. 2012;4(3):101-114.

(xi) <https://www.lawyersweekly.com.au/wig-chamber/23594-judiciary-need-to-recognise-importance-of-adhd-on-crime> Nolte D. Judiciary need to recognise importance of ADHD on Crime. *Lawyers Weekly* 10/07/2018

(xii) <https://www.mcri.edu.au/cap> The Children's Attention Project (CAP) Tips for managing ADHD in the classroom (ongoing project)

(xiii) <https://www.youtube.com/watch?v=XdT4DliX7Nk> Torrens J. ADHD as an entrepreneur's superpower TEDxSyracuse University. YouTube 27/18/2018 [video file]

(xiv) <https://bmcpyschiatry.biomedcentral.com/articles/10.1186/s12888-018-1858-9> Young S, Gudjonsson G, Chitsabesan P, et al. Identification and treatment of offenders with attention-deficit/hyperactivity disorder in the prison population: a practical approach based upon expert consensus. *BMC Psychiatry* 2018; 18: 281.

(xv) https://education.biu.ac.il/sites/education/files/shared/adhd-specific_knowledge_and_attitudes_of_teachers.pdf Mulholland S. ADHD-specific knowledge and attitudes of teachers (ASKAT): Development and validation of a new research instrument. *International Journal of Educational Research* 77 (2016) 109-116.

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

SUB. 0002.0030.0164

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

"When I tried to progress to the next screen for this Submission a 'message' in red text stated that ""Please limit the response to 20000 characters. I have deleted my response to this question and I shall endeavour to upload it to the attachments - however I am rather tech challenged and I am very worried that I will not be able to send my answer. "

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?

"In Victoria, there are no ADHD-specific services. Mental Health Clinicians often say that they know about ADHD' but my experience has been that these service providers have extremely limited knowledge about ADHD that is invariably out-dated and tainted by stigma relating to a mother's capacity to discipline her ADHD children - particularly when a mother is a sole parent. ADHD has had a significant impact on my three children (25, 17, 16) who have all been diagnosed with ADHD. My 16 year old son was diagnosed first when he was 5 years old and attending pre-school. The preschool teacher was concerned about his behaviour and recommended a paediatrician assessment. I was unable to get an appointment with a paediatrician at a public service due to there being a more than twelve-month wait time for an appointment. I therefore made an appointment with a private paediatrician who advised a series of assessments. After a very long and exhaustive assessment process, that involved not only assessment by the paediatrician but also multiple appointments with a private psychologist and also a private child psychiatrist and a battery of pathology tests to rule out any organic medical cause for my son's behaviour, my son was diagnosed with ADHD. I was provided with a one-page leaflet about ADHD and advised to seek early intervention support through the local Community Health Centre Nillumbik Community Health. Because my son had not yet started school he was able to access special subsidised programs for pre-schoolers that included weekly sessions with an Occupational Therapist, a Speech Therapist, a full cognitive assessment by a neuropsychologist and for him to attend group sessions with other pre-school children to prepare for starting school. These services were all free, however being able to attend daily sessions with the various therapists, in addition to attending pre-school, severely restricted my capacity to work and I was forced to reduce my hours at work. The impact of having to reduce my hours working in combination with massive medical bills from my son's diagnosis assessments, was financially devastating for my family. The early intervention services were fantastic and really helped my son with fine motor difficulties such as holding pencils, using scissors, social problems like taking turns in games and in conversations and how to manage symptoms of fidgeting and restlessness by having fiddle toys and weighted vests. The therapists understood ADHD and the impact it had already had on my little boy's ability to make friends. He was rejected by all the other children from kinder who avoided him, wouldn't let him join their games, and called him names. He was only 5 years old yet he was friendless, sad and sometimes talked about how he wanted to die. The allied health therapists were understanding of

his loneliness and they helped him to learn skills so he could better connect with his peers and to make a friend when he started school. My son developed a trusting relationship with the therapists and I appreciated that the services were close to home, and were free of charge. Unfortunately, my son became ineligible to continue accessing these services as soon as he started school. This was an early intervention scheme for pre-school children to help with transitioning to primary school. Once children started primary school, it was apparently the Department of Education's (DoE) responsibility to provide support and therapy services. This never happened. Consequently, The only thing that I consider to have worked well' in relation to accessing services for mental health, was the early intervention service for pre-schoolers.

WHAT CAN BE DONE BETTER TO PREVENT MENTAL ILLNESS? ADHD is the most common mental health disorder amongst children and adolescents in Australia with a prevalence rate of 7.4%. Over recent years there has been an explosion in international research about ADHD that has identified numerous organic and structural differences in ADHD brains including the identification of specific groups of genes that account for 76% of ADHD and make ADHD highly inheritable(i,ii) , There are also several structural areas of the brain that have been identified as being different in ADHD brains compared with neuro-typical brains including differences in brain size, the frontal lobe, left temporal lobe, left central sulcus and bilateral cuneus(iii) Research relating to brain differences in ADHD is rapidly progressing. Given that ADHD is now widely recognised and accepted as a genetic neurodevelopmental disorder that affects on average 5% of the general population it is important to remember that it is diagnosed by behavioural paediatricians, child psychiatrists and adult psychiatrists according to the DSM criteria and that medication to manage symptoms can only be prescribed by these mental health specialists. It is therefor recognised as a mental health disorder. It is equally important to recognise that despite ADHD being recognised as a mental health disorder, it is an accepted fact that many if not most mental health clinicians in Victoria have a very poor knowledge of ADHD and that there are very few ADHD specialist mental health clinicians. Prevention of a highly inheritable neurodevelopmental mental health disorder is debatable, however prevention of co-morbid mental health disorders that are common with ADHD may be possible and should be the aim of developing a comprehensive ADHD specific program to better manage and support people diagnosed with ADHD from childhood through to adulthood.

ADHD and Coexisting Conditions: Children (iv)

Children with ADHD	Children without ADHD
Learning Disability 45%	5% Speech Problems
Depression 12%	18-50%(v)
2% Conduct Disorder	2% Oppositional Defiance Disorder
3% Anxiety	41%
15-22%	2% Additional coexisting conditions
27%	

and problems include the following: ?44.8% of children who have ADHD also have severe sleep problems(vi). ?83% of ADHD children are victims of bullying (vii) ?31% report frequent bullying ?35% of adolescents with ADHD drop out of school ?Girls with ADHD have 5.6 times higher rates of bulimia, and 2.7 times higher chances of developing other eating disorders. ?25-40% of children in juvenile justice setting have undiagnosed or poorly managed ADHD. Early intervention and support by ADHD-specific services is essential to prevent development and severity of co-existing conditions in children with ADHD. A program designed to provide expert ADHD-specific care is urgently required. This would include access to mental health clinicians to assess for early symptoms of co-morbid mental health disorders and to implement early intervention treatments. Access to a range of allied health practitioners from when children are diagnosed in early childhood and to continue through to adulthood, would be particularly beneficial and would help to protect against developing mental health co-morbidities. For example, on-going support from psychologists to help with the emotional struggles of having ADHD and being the different' child who is often socially excluded by peers. Access to Occupational Therapists to assist with

developing strategies and skills to cope with hyperactivity, fidgeting, and executive functioning problems such as organisation skills, memory skills, planning skills, and life skills that are often problematic for people with ADHD such as financial skills, driving safety skills. Also, Speech pathologists to assist with communication skills to help facilitate better peer skills and prevent peer rejection, social isolation, loneliness. Adolescents and young adults may find ADHD life coaches helpful with organising, planning and prioritising life events. Services that provide support within schools need to be developed to ensure that children with ADHD achieve their academic potential and to reduce the burden associated with low academic achievement and school drop out. Prevention of developing co-morbid mental health disorders is also dependant upon school environments. Schools that facilitate inclusive environments, that adopt strategies to help ADHD children to learn and that support teachers to develop skills and knowledge about ADHD are essential for the wellbeing of children with ADHD. Due to the high rate of co-morbid learning disabilities, easy access to learning support staff and programs funded by the DoE is also critical to supporting students with ADHD. It is only in recent years that ADHD has been recognised as progressing into adulthood in about 70% of diagnosed children(viii). As children become too old to continue being managed by paediatricians they need to transition into adult care services. Currently there are few options available for these young adults and most of these are provided by private psychiatrists with fees beyond the budget of school leavers. It is also only over recent years that ADHD has been recognised as occurring in girls and women. Previously ADHD was considered by the medical profession to be a male only disorder. Girls with ADHD present with different symptoms to the male counterparts and are less likely to present with hyperactivity and more likely to have ADHD inattentive type (ADHD-I). With greater recognition of ADHD in girls, there is a growing number of adult women seeking assessment for long term mental health problems within the context of a missed ADHD diagnosis. Women who are now parents of children with ADHD frequently recognise the children's symptoms as being the same as they themselves experience. There is a growing body of evidence that many women have been incorrectly diagnosed with a range of mental health disorders that did not adequately respond to treatment, because their underlying mental health disorder was in-fact ADHD. Clinicians need to ensure that they have the knowledge and skills to identify ADHD in girls and women to prevent incorrect diagnoses of other mental health conditions but also to ensure correct management when there is co-morbidity. Early identification, diagnosis and management of ADHD in girls may facilitate greater support, understanding and acceptance of their ADHD and provide skills to better manage symptoms and thereby help prevent the development of co-morbid mental health conditions.

ADHD and Coexisting Conditions: Adults(ix)	Coexisting Condition	Adults with ADHD
Adults without ADHD	Any mood disorder	38.3%
depressive disorder	18.6%	7.8%
12.3%	1.9% Bipolar disorder	19.4%
Any anxiety disorder	47.1%	19.5%
8.0%	2.6% PTSD	11.9%
3.3% Panic disorder	8.9%	3.1%
4.0%	0.7% Specific phobia	22.7%
9.5% Social phobia	29.3%	7.8%
compulsive disorder (OCD)	2.7%	1.3%
15.2%	5.6% Alcohol abuse	5.9%
2.4% Alcohol dependence	5.8%	2.0%
2.4%	1.4% Drug dependence	4.4%
0.6% Intermittent explosive disorder	19.6%	6.1%

WHAT CAN BE DONE BETTER TO SUPPORT PEOPLE TO GET EARLY TREATMENT. The burden of

undiagnosed, poorly supported and appropriately managed ADHD is significant. This is particularly evident in prison populations where 25% of prisoners have undiagnosed or mismanaged ADHD. Diagnosis and treatment of ADHD within this population has been shown to reduce recidivism (x) It has also been found that should this population of incarcerated people with ADHD been diagnosed and effectively treated as children, they may well have had a different life trajectory. Prevention of crime, involvement with the justice system and incarceration must be considered feasible and achievable if ADHD is treated properly in childhood. This would have significant outcomes on the lives of the individuals, their families and in particular -their potential victims. There would also be significant financial benefits associated with the reduction in costs of policing, court appearances and prison. It is a curious fact that 25% of prisoners have ADHD but also 62% of highly successful business entrepreneurs have ADHD (xi). ADHD does not have to be a negative condition. With support to help children with ADHD and their families to learn to better manage their symptoms and by creating inclusive environments that eradicate shame and stigma about ADHD and instead build pride and confidence, children with ADHD can grow into adults who can lead highly successful lives. The stigma of ADHD has been researched as a factor that prevents parents from taking their children to see a paediatrician and be diagnosed with ADHD and receive appropriate treatment. The stigma of ADHD and medication has also been shown to influence parents not to give their children medication, and for children to refuse to take medication. Not getting diagnosed also prevents any possibility of accessing support services with in schools. In order to support people to get an early treatment for ADHD it is important the treating clinicians understand the impact ADHD stigma can have. It is important that teachers, who often first notice the symptoms of ADHD, are sensitive when they approach parents to suggest referral for assessment of ADHD. If diagnosis is perceived as being highly negative then early treatment will not be accessed, however a kind and thoughtful explanation of the benefits of early treatment and the positive outcomes that are possible with ADHD can allay parental fears and enable children to access the treatment that is available. The cost of accessing specialist doctors is a substantial barrier to getting early diagnosis and treatment for ADHD. There needs to be great availability of low cost or public services to enable parents of children with ADHD to afford services. Likewise there needs to be affordable services for adults with ADHD.

REFERENCES

(i) <https://www.genome.gov/news/news-release/Linking-genes-to-ADHD-by-mapping-connections-in-brain> Carey T, Linking genes to ADHD by mapping connections in the brain. National Human Genome research Institute. News 08/03/2019. (ii) <https://www.medscape.org/viewarticle/557612> Surman C, Faraone S, Neurobiology and Genetics of ADHD: An interview with Stephen V. Faraone, PhD. Medscape Psychiatry. 4/07/2019 (iii) <https://pubs.rsna.org/doi/10.1148/radiol.2017170226> Sun H, Chen Y, et al Psychoradiology utility of MRI imaging for diagnosis of attention deficit hyperactivity disorder: A radiomics analysis. Radiology 9Vol. 287, No.2) 22/11/2017 (iv) <https://chadd.org/about-adhd/co-occurring-conditions/> ADHD and Co-occurring Conditions Fact Sheet (v) <https://pediatrics.aappublications.org/content/pediatrics/133/5/801.full.pdf> Sciberras E, Lycett K, Efron D, Mensah F, Gerner B, Hiscock H. Anxiety in Children With Attention-Deficit/Hyperactivity Disorder Pediatrics 2014;133;801 (vi) <https://jamanetwork.com/journals/jamapediatrics/article-abstract/379359> Sung V, hiscock H, Sciberras E, et al. Sleep problems in children with attention-deficit/hyperactivity disorder: Prevalence and the effect on the child and family. Arch Pediatr Adolesc Med. 2008;162(4):336-342. doi:10.1001/archpedi.162.4.336 (vii) <https://parentsforadhdadvocacy.com.au/parents-and-carers/> Hopkins D, Kuchel L, Freedman R Parent & carer experiences of ADHD in Australian schools: Critical gaps. Parents for ADHD Advocacy Australia 2019 <https://www.ranzcp.org/practice-education/guidelines-and-resources-for-practice/adult-adhd-practice-guidelines> Kneebone, M. Adult attention deficit hyperactivity

disorder (ADHD) practice guidelines: Expert Panel Discussion [Video file] (viii) <https://chadd.org/about-adhd/co-occurring-conditions/> ADHD and Co-occurring Conditions Fact Sheet (ix) <https://bmcpopsychiatry.biomedcentral.com/articles/10.1186/s12888-018-1858-9> Young S, Gudjonsson G, Chitsabesan P, et al. Identification and treatment of offenders with attention-deficit/hyperactivity disorder in the prison population: a practical approach based upon expert consensus. BMC Psychiatry 2018; 18: 281. (x) <https://www.youtube.com/watch?v=XdT4DliX7Nk> Torrens J. ADHD as an entrepreneur's superpower TEDxSyracuse University. YouTube 27/18/2018 [video file] "

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

"ADHD IS ASSOCIATED WITH HIGH RATES OF SUICIDALITY IN ALL AGE GROUPS AND IN BOTH BOYS AND GIRLS Suicide risk is high among primary school aged children with ADHD. Impulsivity, rather than depression has been found to be the most important and significant risk factor for suicide in children(i) . 20% of children with ADHD have been found to be suicidal with 19.8% experiencing suicide ideation; 21.82% having a plan for suicide and 22.86 a history of previous suicide attempts. Children with ADHD are 4 times the risk of non-ADHD children for suicide ideation (ii). Sixty per cent of children aged 5-11 years who died by suicide had ADHD making it the biggest risk fact for suicide in primary school aged children(iii). 25% of suicidal children under the age of 12 years of age had ADHD(iv) More than half of adolescents with ADHD have suicidal thoughts and 10% have attempted suicide with girls at higher risk of attempting suicide and boys at higher rate of completed suicide(v). One third of adults with ADHD have had suicide ideation and 16% of adults with ADHD have attempted suicide. Patients with a co-morbid diagnosis of other mental health diagnoses including mood disorders, schizophrenia, alcohol/drug abuse, are at greater risk of suicidality than patients without an ADHD co-morbid diagnosis. This highlights the importance of raising clinicians' awareness of the need to screen and treat comorbidity in ADHD, which may reduce suicidality. The high risk of suicidality in patients with ADHD across all age groups is of great concern. It is essential that routine screening programs are introduced asking questions relating to suicidal thoughts for all people with ADHD. My daughter attempted suicide when she was 15 years old by taking an overdose [REDACTED]. She was taken by ambulance to the [REDACTED] Hospital and admitted for cardiac monitoring. She was assessed by a member of the CAMHS team in relation to her suicide attempt and was diagnosed with depression and was advised to see a psychologist urgently. I was advised that because she had ADHD she did not meet the criteria to be admitted to the CAMHS at the [REDACTED] Hospital and therefor I need to find a private psychologist. I found the cost of seeing a psychologist beyond my financial capacity at the time as each consultation cost \$100.00 despite the Medicare Mental Health Plan. Once my daughter had used her 6 consultations provided by the Mental Health Plan I had to stop her from seeing her psychologist as I could not afford the fees. I contacted [REDACTED] in Greensborough but I was informed that due to my daughter's ADHD diagnosis she did not qualify for mental health services through [REDACTED]. Between the ages of 8 and 12 my son was a patient of the [REDACTED] CAMHS due to some on-going difficulties with peer interactions at school. When he was 12 and about to start high school I was advised that he no longer met the criteria to receive care through CAMHS due to his ADHD diagnosis. I found this very distressing as I knew my son was highly likely to experience difficulties transitioning to secondary school and that the withdrawal of support from CAMHS would make him particularly vulnerable to deteriorating mental health. Despite requesting and explaining the importance of continued care by CAMHS at least until he had settled into high school, I was advised that he did not qualify and had to be discharged from the service. Transition to secondary school was very difficult for my son and at the end of first term he became particularly agitated and stated that he

wanted to die on several occasions. One morning he told me he was going to jump in front of a train. I was extremely worried about him and gravely concerned that he would indeed jump in front of a train. When I was contacted by his school because he had not arrived, I became frantic. I contacted Melbourne Trains who issued an alert to all stations to try to find my son. I drove to each station along the train line he took to school and ran up and down platforms trying to find him. The police were also trying to find him. He was a child who was totally socially isolated and without a single friend, who was lonely, very sad, ashamed of having ADHD and had a distressingly low opinion of himself and who was highly impulsive. His risk for suicide was high. After spending all day searching for him, I had to go home and just wait. Fortunately, he didn't attempt suicide that day and came home later in the evening saying that he just couldn't do it'. I contacted ██████████ CAMHS and informed them of what had happened, however I was advised again that because he had ADHD, he could not be admitted to the service for mental health care. I contacted ██████████ in Greensborough but I was informed that due to my son's ADHD diagnosis he did not qualify for mental health services through ██████████. Both of these examples highlight how suicidal thoughts and attempts occur in adolescents with ADHD yet they are denied access to mental health programs. Multiple studies relating to ADHD and suicidality have identified the high risk of suicide if there have been previous attempts and the greater risk of death by suicide due to the impulsivity of ADHD. There is an evidenced-based and urgent need for mental services to regularly screen children and adolescents with ADHD for suicide risk and to identify and treat developing co-morbid mental health issues. It is essential therefore that an ADHD diagnosis is NOT exclude from mental health services, particularly CAMHS and ██████████ and that immediate strategies are developed to insure children and adolescents with ADHD have access to ADHD trained and competent mental health clinicians in youth targeted mental health services.

REFERNCES

- (i)https://pediatrics.aappublications.org/content/138/4/e20160436?utm_source=Weekly+Spark+10%2F7%2F16&utm_campaign=Weekly+Spark+October+7%2C+2016&utm_medium=email A.H. Sheftall, L. Asti, L.M. Horowitz, A.Felts, C.A. Fontanella, J.V. Campo, J.A. Bridge Suicide in elementary school-aged children and early adolescents Pediatrics, 138 (2016), Article e20160436
- (ii)Sheftall et al (iii) Sheftall et al (iv) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5371172/> Balazs J, Keresztesy A, Attention-deficit/hyperactivity disorder and suicide: A systematic review. World Journal Psychiatry 2017 March 22;7 (1) : 44-59. (v) Balazs et al (ii) Sheftall et al "

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.

"Children with ADHD are denied funding for additional support by the Department of Education (DoE). ? This leads to greater difficulty in a classroom due to impulsive and hyperactive behaviour which increases the likelihood of classmates excluding the ADHD child from play. ? Teachers with limited out-dated knowledge about ADHD stigmatise children with ADHD and fail to create inclusive environments and to support class peers to understand the difficulties and the strengths of ADHD children. ? Children with ADHD are socially isolated and alienated by their peers. They feel ashamed of having ADHD and of their impulsive and energetic behaviour which they struggle to control at school. They are bullied by other students and become increasingly worried about saying or doing something impulsive which could exacerbate the bullying and the social exclusion. ? Due to the constant fear of behaving hyperactively and impulsively and appearing foolish and due to inattention making it difficult to follow conversations with peers leading to further social alienation, it is understand that children with ADHD are a great risk of developing anxiety and depression. ? 50% of students with ADHD achieved less than the

national minimum standard during NAPLAN testing. Poor academic achievement is associated with poor mental health in later life. ? ADHD diagnoses excludes accessing mental health services for children and adolescents. School psychologists employed by the DoE have a very poor understanding of ADHD (from personal experience) and are not available to support children at school on an on-going basis ? Challenging behaviour at home when medications have worn off and due to the frustrations of miserable days at school with no friends, can lead to home life being difficult and parents struggling to manage the behaviour and the conflicts. The impact can be severe upon siblings. ? No help or support is available. Unless privately accessed however unaffordable. ? Referral to parenting programs can take months and when finally appointment arrives counsellor advises strategies that have been proven to be ineffective for children with ADHD (such as rewards charts). Parenting program is ineffective and unhelpful as program provided by staff with little if any knowledge and understanding about ADHD. Parents (mother) feel like failures. No other help or support is available. ? ADHD children develop co-morbid mental health disorders. ? Difficulties continue throughout life .. This trajectory can easily be avoided by: ?The DoE recognising that children with ADHD need additional support and therefor providing funding for integration aids to support children with ADHD in class rooms and in the playground. ?The DoE providing appropriate professional development to teachers to ensure that understand ADHD and have the skills and the resources to better manage ADHD children at school. ?Enable children and adolescents with ADHD to access mental health services for young people including CAMHS and ██████████. ?Establish an ADHD-specific program of multidisciplinary professionals to support people with ADHD from diagnosis in childhood and though out adolescence and into adulthood. This service needs to be linked to schools similar to the programs available to people diagnosed with autism spectrum. "

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

"People with ADHD experience poorer mental health outcomes due to the poor recognition, understanding and knowledge of ADHD amongst specialist mental health clinicians and the lack of ADHD-specific services. The stigma of ADHD results in shame that exacerbates likelihood of developing co-morbid mental health problems. ADHD is widely debated in the media and within the Victorian community in regards to it's validity and treatment and there are few if any mental health clinicians who regularly champion ADHD in public and counter the negative misinformation. There are also no local popular public figure or celebrities who have ADHD who are will to advocate for ADHD due to the assumed negative impact this will have their career due to the stigma! ADHD must be recognised by mental health clinicians as a disorder that they have inadequate information and knowledge about and there mental health professional bodies and organisations must instigate professional development programs to ensure clinicians have the skills to manage ADHD. As discussed previously, it is imperative the DoE increase funding to provide better support for ADHD children and that data relating to ADHD is collected by the DoE. "

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

"Children with ADHD can be extremely challenging and difficult and can create absolute chaos at home. Many children with ADHD also experience frequent disciplinary problems at school and parents are frequently called to come to school to assist. This can have a devastating impact on a parents' career. I was called at least twice per week to come to the school to deal' with a situation'.

I lost my job as a result. The impact of ADHD and the parents' employment naturally has a significant effect on the financial wellbeing of the family. In addition, the costs associated with accessing therapy, further burdens the family's finances. ADHD is inheritable and it is not uncommon for families to have more than one child with ADHD. I have three children with ADHD and our home is frequently comparable to a three-ring circus! My children are explosive and will impulsively react to situations, comments or conversations in unanticipated and inappropriate ways. I am a sole parent and I find it is absolutely, totally exhausting at times to parent my ADHD children. I have accessed: ? [REDACTED] CAMHS ?Private clinicians (but I can no longer afford) ? [REDACTED] Family Services Family Violence early intervention program ? [REDACTED] parenting program ? [REDACTED] problem behaviour program ? [REDACTED] None of these programs had experience in ADHD and I found that the strategies they suggested were ineffective. When I informed the program clinicians about the lack of improvement I was made to feel as though I was doing it wrong and that it was my fault and that I was a failure. I have since discovered that it is well documented that the strategies I was advised to implement are known to be ineffective with children with ADHD. The impact of ADHD upon siblings can also be significant even if the siblings also have ADHD. Some of my children have more severe ADHD than the others and the impact of their behaviour towards their sibling can be terrifying at times. There needs to be an ADHD-specific program developed that utilises a multidisciplinary approach to not only treat and support children with ADHD but also their families to better manage and cope with the craziness of ADHD homes! "

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 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?

N/A

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

"1) Identify the gaps in knowledge and skills of mental health clinicians relating to ADHD 2) Develop professional development training programs for mental health clinicians about ADHD to ensure they are competent in diagnoses, identifying co-morbidities, treatment and management regimes. 3) Develop curriculum about ADHD for undergraduate medical, nursing, allied health, psychology and teaching students. 4) Research level of knowledge and understanding of ADHD using a validated instrument to establish base level data amongst educators including teachers, school principals, support workers, and staff working for the DoE. 5) Develop a strategy and implementation plan to provide quality professional development to teachers about ADHD and assess for improvements. 6) Revise the formatting of forms and data collection processes for the DoE and ensure that ADHD is specifically noted to ensure accurate data is collected and thereby enable suitable allocation of funding for ADHD students. 7) Allocate more funding for the DoE to

utilise in direct support of students with ADHD. 8) Ensure that integration aids employed to assist students with ADHD are receive thorough ADHD-specific training and regular professional development. "

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

N/A