When it's not OK not to be OK

Victoria's invisible mental health and education crisis

SCHOOL PHOBIA/ SCHOOL REFUSAL AUSTRALIA SUBMISSION TO VICTORIA'S ROYAL COMMISSION INTO MENTAL HEALTH SERVICES

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INTRODUCTION: CAN'T, NOT WON'T

Hundreds of children and teenagers across Victoria are unable to attend school due to poor mental health and mental illness. Some have patchy school attendance. Others have not been to school for years. These ones are isolated, often live in their bedrooms 24/7 and are unable to leave their home. They barely function. They feel guilty and ashamed. They have given up. They think the world has given up on them too.

Complex, long-term school refusal has distressing immediate, medium-term and long-term impacts on the student and their family. Some of our families describe themselves as 'broken'.

The longer a child is out of school the greater the chance they will require acute health and mental health services and the greater the chance they will grow into adults unable to function independently in the community, some are likely to enter the prison system or become homeless.

The literature calls it 'school refusal'. We call it 'school can't'. Our children are not refusing to go to school. They are unable to go to school.

Parents seek the help of principals, teachers and health professionals. We believe that once we ask for help — help will be forthcoming. We are devastated when it is not.

Instead of receiving evidence-based advice, support and treatment families often receive advice ranging from ineffective to sometimes harmful. Instead of focusing on improving our children's and young people's mental health, the advice simply concentrates on returning to education.

Our children's mental health deteriorates, parents' mental health deteriorates, our families struggle financially and emotionally, and we bounce around the system searching for help.

Our lived experience is revealing that many of these children have diagnosed or undiagnosed neurodevelopmental conditions including autism, ADHD, specific learning disorder (dyslexia, dysgraphia, dyscalculia), communication disorder, sensory processing disorder, auditory processing disorder, and dyspraxia.

Many of these children also have diagnosed or undiagnosed anxiety disorders (typically generalised anxiety disorder, panic disorder, social anxiety disorder) and major depressive disorder.

We believe that the existing evidence-base for school refusal behaviour has not addressed neurodevelopmental conditions, nor has it analysed the school environment.

We believe that the mainstream education system is unable to meet the cognitive, social and emotional needs of many of our children. We believe that most schools do not have an inclusive education environment, that most teachers are not equipped with the skills to teach diverse students with neurodevelopmental conditions or children with mental health conditions. We believe that this is a public health, education, and disability crisis that requires systems levels solutions.

The responses from the education system and the health system indicate they do not understand our children would go to school if they could. Diagnoses are challenged, ignored or dismissed. Advice such as 'tough love', 'consequences' and gradual exposure causes further harm and extends the child or young person's time away from school. It creates an unhelpful battleground between parents and teachers.

If you are lucky to find help it is respectful, compassionate, meets our children where they are at, it's trauma-informed and wraps around them. It catches them before they fall and nudges them when they are ready to take risks. This help is often out of our reach because of finances, where we live or service boundaries. Few of our families are lucky.

All education departments across Australia have a poor understanding of school refusal behaviour. We see this royal commission as an opportunity for Victoria lead the nation. This state's Navigator Program and trauma-informed education approach in its public schools for dis-engaged students are important starting blocks. They are out of reach for most.

This submission will focus on local and systems-level solutions to bridge the gap between the education system, the disability sector and the mental health system to find a way out to get these children and young people out of Victoria's mental health system's 'too hard' basket. In the longer term we want to prevent students experiencing complex and long-term school refusal.

This submission is intended to give a voice to these invisible children, young people and their families. They have sought help and failed, unless they were 'lucky'. We hope our lived experience can help the Royal Commission recommend changes that will support our children and young people to thrive, to recover, to plan a future and perhaps save their lives.

ABOUT US

The closed Facebook Group School Phobia/ School Refusal Australia has almost 900 members across Australia. Approximately 45 per cent of our members are Victorian parents. It's growing fast with almost 100 new parents joining in June 2019.

In 2017 the administrators of our closed Facebook group started peer-to-peer support groups for parents in Melbourne, Sydney, Adelaide and Canberra. We meet monthly in cafes and a community centre that has been kind enough to waive hire fees. These groups are having a significant impact on parents' wellbeing and resilience, so they can support their children and young people. We share ideas and strategies about what's worked and hasn't worked. We are seeing children and young people venture out of their bedrooms after years of isolation and pick up pens and books again.

Our families come from all socio-economic backgrounds. We've given up jobs, been sacked from jobs, moved house, moved state, moved schools, lost friends and divorced as a result of the pressures of school refusal. Many of our families have multiple children experiencing school refusal (but note there are children within the same family who successfully attend school).

Some of our children and young people have been out of school for more than four years. They have tried and tried to attend school. Many want to but can't go due to diagnosed or undiagnosed (but unsupported) neurodevelopmental conditions such as autism and learning difficulties. Others cite bullying and trauma, including family violence. As a result, most develop an anxiety or depressive disorder that is ignored, dismissed or challenged by the education system.

Many of us have found that implementing the school approach did not work and caused more harm. Instead we removed the pressure and focused on re-establishing our attachment with our child (if it has been damaged trying to enforce compliance to go to school every day).

A New South Wales mother started the closed School Phobia/ School Refusal Australia Facebook group in 2013. This use of social media has connected hundreds of parents who were blissfully unaware that school refusal was 'a thing' until it happened to their family. We believe there are many more hundreds who just haven't found us yet.

Upon joining our closed online group and peer support groups parents cite the most significant benefit of being a member — is that up until that point they believed they were the only family experiencing 'school refusal'.

WHAT IS SCHOOL REFUSAL

Officially school refusal behaviour is defined by Kearney and Silverman (1999) as child motivated refusal, to attend school and / or difficulties remaining in school for the whole day, where students range from ages five through to 17. This definition is inclusive of children and adolescents who want to go to school but stay home due to fear or anxiety, and their parents know that they have stayed at home, commonly referred to as either 'social phobia' or 'school refusal'; as well as children and adolescents who have skipped school without their parents' knowledge because of defiant behaviour or disinterest in school, referred to as 'truancy'.

However, Kearney (2018) acknowledges that the concept of truancy is problematic, as many youth with truancy miss school for other reasons than delinquency, and most parents become aware of their child's school non-attendance problems.

Kearney (2018) has found that there is much overlap between truancy and school refusal and many youths show a combination of externalising and internalising problems. Therefore, the term school refusal behaviour is an overarching umbrella construct that represents a child's or adolescent's inability to maintain age appropriate school attendance or to adaptively cope with school-related stressors (Kearney, 2018).

WALK IN OUR SHOES

Who ever imagined a child or a teenager would not go to school for years.

It is soul-destroying for families to watch the shell of a person, they once knew to be a happy child, merely exist.

In the darkest days, that sometimes lasts for years, the most complex of these children and young people do not leave the house, do not sleep at night, do not shower or brush their teeth, do not engage with other family members and will not engage in health services. They miss important vaccinations. They are violent and abusive. They hate themselves. They are guilt-ridden and ashamed. They are non-responsive. They shut down. They talk about dying. Some do more than talk about it. They spend school camps, graduations, Christmases, birthdays in their bedrooms.

If we are lucky enough to have a child in the patchy refusal stage or the wanting to return stage – parents spend hours, days, weeks sitting in cars outside schools. Each day you dare to hope they will connect, find a teacher who 'gets them', find an interest, and find a friend. Hope is rarely enough. The 'will they or won't they go to school' game played in homes every morning takes an unbearable toll on families.

It can be impossible for parents, particularly single parents, to hold onto their employment while supporting a child or young person experiencing school refusal. Employment importantly provides the financial resources required to access private health professionals, but it's impossible if you have a child under 12 years or a very unwell child requiring constant supervision. Unfortunately, many parents, feel that they must continue to work, and some are leaving children at home by themselves. Most teenagers with single-parent families are in fact leaving their mentally unwell children at home by themselves, because they must work. We must find a better way to support single-parent families where their child is experiencing school attendance difficulties. Dual-parent families have more supports, and commonly one of the parents is leaving their work to support their mentally unwell child.

We look for options. Multiple schools will be trialed and mostly failed. Too often we are told the 'school is full', we're not in the right zone, 'we don't have any autistic children', 'you're too complex'. We battle to get into distance education and then it rarely works. We search for flexible schools and alternative schools with reputations for changing the lives of families like ours. They are the lucky ones and providing a future for our children should not be about luck.

DATA AND RESEARCH

There is no data available to understand the number of Victorian children and young people unable to attend school due to poor mental health and mental illness.

Without an understanding of the size of the problem, research will go unfunded and the current approaches, that are not working, will go unchallenged.

Schools do not provide parents with a consistent approach to appropriately and truthfully record this category of absence without blame or shame. School refusal is not a parent choice.

Some data may exist by looking at the reason students enroll in Virtual School Victoria (formerly Distance Education Centre Victoria) or register for homeschooling.

We hear a lot about the mental health crisis in our young people, but we seem to be making little impact. This phenomena of children and young people experiencing complex school refusal, associated mental illness and suicide ideation is growing across Australia. Victoria has an opportunity to lead the way by understanding the extent of this complex, but hidden crisis and introduce prevention and early intervention at the classroom level.

RECOMMENDATION 1

That the Department of Education and Training start regularly collecting, collating and reporting consistent school refusal absence data to the Education Minister and Mental Health Minister. The data must be from government, Catholic, independent schools, distance education providers, re-engagement programs, special school and autism schools.

RECOMMENDATION 2

If not already happening the Department of Education and Training needs to ask at the time of registration if a family is choosing homeschooling or distance education due to school refusal. This data must be collated and part of the reporting to the Education Minister and Mental Health Minister.

RECOMMENDATION 3

The absence reporting system used by parents on school websites collecting reasons must include a consistent mental health/ school attendance difficulties option that removes blame from the child and the parent.

RECOMMENDATION 4

That the Victorian Government advocate for a consistent school refusal data collection approach across all education departments and schools across Australia for the purposes of understanding the issues and sharing and allocating effective resources for a therapeutic outcome.

RECOMMENDATION 5

That the Victorian Government invest significant funding into school refusal behaviour research for students with neurodevelopmental conditions, children from trauma backgrounds, and school bullying. This research needs to be undertaken in ongoing consultation with parents and carers of children experiencing school attendance difficulties (across Australia). We recommend a participatory action research methodology partnering with School Phobia/ School Refusal Australia.

TREAT MENTAL HEALTH AS SERIOUSLY AS PHYSICAL HEALTH

The mental health awareness campaigns tell us ‘it’s okay not to be okay’.

This message has helped adults to have important conversations. However, it is hollow to parents whose children and young people are not okay. They are still told they must get them to school with little or no regard for diagnosed or undiagnosed mental illnesses.

When a child or adolescent has a serious physical illness requiring long absences from school the focus is on their recovery, not the learning they are missing.

When a child or adolescent has poor mental health or mental illness requiring long absences from school the education and mental health system focuses on their return to school, not their recovery.

Parents feel abandoned and blamed. Their children and young people remain unwell and unable to go to school. The future looks very bleak. They feel like they have let their children down.

School refusal is often the trigger for families to seek assessments of their children leading to diagnoses previously mentioned in our introduction.

Children and young people on the autism spectrum make up a disproportionate number of school refusers. Autism is not a mental illness, it is a neurodevelopmental condition, but an unsupported autistic child can develop mental illness. A significant proportion of autistic children and adolescents have co-occurring anxiety disorders, major depressive disorder, obsessive compulsive disorder and eating disorders, in addition to co-occurring neurodevelopmental conditions including ADHD, specific learning disorder, auditory processing disorder, sensory processing disorder, communication disorder, dyspraxia, and intellectual disability (30 to 50 per cent).

We are parents, not researchers, but we conclude there is not an increase or ‘explosion’ in the number of children with autism, ADHD or learning difficulties. What has changed is the school environment. Dramatically. Since today’s parents went to school changes include: increased group-based learning, increased inquiry based-learning, less explicit instruction, classrooms are no longer separated by walls, a busier and sometimes more unpredictable curriculum, rows of single desks have been replaced by group tables, and of course there is a far more complicated online social life. This all creates an unimaginably complex environment for these children to learn in.

Many of our children and young people also have formal diagnoses including suicidal ideation, anxiety disorders, clinical depression, obsessive compulsive disorder, post traumatic stress

disorder, complex trauma, eating disorder, panic disorder, agoraphobia, oppositional defiant disorder, developmental delays and selective mutism.

If a successful businessman, a sportsperson or a politician publicly announces they are taking time out to recover from a mental illness they are praised for their 'courage'. If adults with a mental illness are not forced to go to work, then children and adolescents should not be forced to go to school.

Many of our families have learned the hard way. When children are well, they can and will learn.

RECOMMENDATION 6
Acknowledge that school refusal behaviour is a mental health condition requiring immediate mental health services and supports. This means full wrap-around services and supports to children, their parents and carers, their school including all teachers who have contact with the student. Recovery from mental illness must take priority over learning.

RECOMMENDATION 7
Develop and provide all school wellbeing teams, including school nurses, school counsellors and school psychologists, with regular professional development to identify and refer school refusal children and intervene before strategies are implemented that can exacerbate poor mental health. Provide school refusal behaviour resources to all families that include School Phobia/School Refusal Australia peer support contact details.

RECOMMENDATION 8
Introduce trauma-informed care and an attachment approach to mental health services supporting children and young people experiencing school refusal.

RECOMMENDATION 9
All school staff should receive yearly trauma-informed and attachment approach mental health training.

RECOMMENDATION 10
That the Victorian Government advocate for the mandatory inclusion of trauma-informed and attachment mental health training in undergraduate and Master of Education programs.

RECOMMENDATION 11
Provide comprehensive professional development to mental health nurses, psychologists, and CYHMS counsellors so they understand autism, how autism presents differently in girls and young women, autism, mental illness and school refusal issues. Without this knowledge emergency

departments, mental health inpatient units and child and adolescent mental health services can exacerbate distress, a entrench school refusal and break these children's and young people's trust in health professionals.

RECOMMENDATION 12
All medical and health professionals and allied health professionals must complete a minimum mandatory level of training in disabilities. This must be embedded in their university studies as mandatory, and to further develop these skills through ongoing professional development.

RECOMMENDATION 13
All medical and health professionals and allied health professionals must complete a minimum mandatory level of training in school refusal behaviour.

RECOMMENDATION 14
Acknowledge childhood mental health conditions and increase teacher knowledge and skills in identification of mental health conditions so they can refer children to within school mental health clinical services and supports by trained clinicians.

RECOMMENDATION 15
Provide parents and carers with ongoing mental health literacy skills within each school community to increase parent and carer knowledge and skills to aid in the early identification of mental health conditions and to link in with trained clinical supports.

RECOMMENDATION 16
Provide funding for ongoing outreach services to parents and carers and their children (if the children will engage with schools).

RECOMMENDATION 17
Provide provision of ongoing learning via email/ internet whilst student is mentally unwell and unable to return to school if they are able to engage.

RECOMMENDATION 18
Provide ongoing transitional support for students to gradually (extended period may be needed in more complex cases, for example one to three years) and successfully re-engage and return to their mainstream school.

RECOMMENDATION 19
Provide the Virtual School Victoria (formerly Distance Education Centre Victoria) with the same funding that all mainstream schools receive for mental health and wellbeing of their students.

SCHOOL RESPONSES DO NOT WORK FOR COMPLEX SCHOOL REFUSAL

The current evidence-based school refusal interventions have not been validated for diverse student populations, for example students with neurodevelopmental conditions, students with multiple health difficulties, students with post traumatic stress syndrome and/or complex trauma.

The interventions to re-engage students experiencing school attendance difficulties, are effective in at most one third of cases.

Parents are shocked our children's and teenagers' diagnoses are ignored, dismissed or challenged. Schools just telling parents they need to increase attendance without plans to address the underlying health and environmental issues is futile.

Consequences, contracts, incentives, removal of all screens and devices, reduced or gradual exposure generally do not work with complex school refusal kids. Some teachers and principals threaten or indeed do visit the family home. Parents are threatened with protective children's services, fines or court. Thankfully not too often in Victoria.

Our children's and young people's behaviours escalate at home when parents attempt to implement the school's recommended approach — 'to insist that their child go to school', 'to communicate that school is a non-negotiable' and 'to remove all technology'.

These approaches may sound appropriate. However, these approaches on our children with neurodevelopmental conditions, children who have been subjected to school-based trauma (caused by exclusion, rejection and bullying), as well as children with post traumatic stress disorder or complex trauma, result in escalation of a child's distress, and escalation of the parent's distress.

Many parents are also experiencing physical violence due to these approaches. Fear and shame mean they usually do not call the police. Instead they try to de-escalate the behaviours of themselves. It's frightening. If they do call, the police take their distressed child to an emergency department. They are subsequently sent home with no support from either CAMHS /CYMHS or the hospital. It is important to note acute in-patient mental health units are not appropriate places for autistic children.

If these behaviours happen at school the students are told not to attend. They are expelled or suspended. When these behaviours happen at home and parents are not believed and these children who are 'dead inside' are told they 'need to be at school'.

In our personal experiences, after attempting these approaches recommended by schools our children become even more mentally unwell and respond by shutting down. Shutdown occurs after repeated fight/flight responses. In shutdown state both the sympathetic nervous system and the parasympathetic nervous system are caught in a deadlock, (pervasive arousal withdrawal syndrome – PAWS). Others describe shutdown as a freeze response where the child dissociates (Shanker, S). This shutdown response requires further investigation.

Implementing the school-recommended approach also damages the bond between the parent/carer and child. This response damages attachment. This dysregulates the parent/carer, who experiences ongoing chronic high levels of stress, distress and trauma, caused by the physical violence of their child or teenager.

We don't think the school approach to complex school refusal is malicious and it should be noted some schools are listening to parents and doing better than others. However, most schools don't know that they don't know how to help these students. This Royal Commission provides the opportunity for us to speak out about our experiences and we urge a major change in school responses to an early intervention approach and a mental health approach.

New school resources and responses for this set of children and young people must be developed urgently in ongoing consultation with parents and carers of children experiencing school attendance difficulties.

RECOMMENDATION 20

Discontinue support of professional development workshops to schools and wellbeing staff where the following takes place:

a) a clinical risk factors approach focused on within child and within parent and family system
b) neglects critical analysis of the school environment, for example school climate, school culture, school administration, and school organisation
c) neglects critical analysis of educational funding arrangements at both the state and the national level
d) neglects critical analysis of what it means to be 'inclusive'. Accountability is poorly overseen regarding inclusive education policy translation into inclusive education practice
e) neglects a serious discussion about the high prevalence rate of bullying taking place in all schools across Australia
f) promote that school personnel threaten and coerce parents into making sure that they 'get their children to the school gate'

g) communicate that it is a parent's job to get their kids to the school gate, and if they don't, then they are a dysfunctional parent
a) communicate to school personnel that schools are to communicate to parents that they must comply with the school's demands, for example a 'return to school contract'. If parents do not comply, the school are to threaten parents and carers with child protection services, police intervention and court proceedings in response to alleged 'neglect'.

RECOMMENDATION 21
Create an evidence-based first aid response kit that all schools must use when a student starts displaying school refusal behaviour. This should include a thorough assessment for learning difficulties, autism and ADHD, provide information about the Navigator Program and School Phobia/ School Refusal Australia's peer support details. This kit must be developed in ongoing consultation with parents and carers of children experiencing school attendance difficulties.

RECOMMENDATION 22
Provide all principals, wellbeing staff and teachers with three-level training that includes:

a) prevention strategies (whole of school approach to reduce risk factors for school refusal behaviour
b) early intervention strategies (immediate services and supports for students at risk ie within 2 weeks of school refusal behaviour
c) treatment strategies (ongoing wrap-around support for students) within four weeks of school refusal behaviour starting.

This training must be developed in consultation with parents and carers of children experiencing school attendance difficulties.

RECOMMENDATION 23
Review the current primary and secondary school environment to understand its impact on students with autism, ADHD, learning difficulties and mental illness. Based on this knowledge recommend consistent adjustments that will benefit all students and create calmer classrooms and healthier students who are able to learn.

RECOMMENDATION 24
That the Victorian Government advocate for mandatory inclusive education practice training in all undergraduate and Master of Education programs. This would give all teachers the skills to write individual education plans (IEPs) and implement evidence-based interventions that support diverse students with all neurodevelopmental conditions based on recommendations provided by clinicians (psychologists' comprehensive assessments, speech pathology assessments, occupational therapy assessments, audiologist assessments).

RECOMMENDATION 25

Make all Victorian schools inclusive. Inclusion does not mean 'special education' schools/units/ classrooms. Inclusion means supporting all students' individual needs supported (accommodations, not modifications) within a class of their same aged peers.

Introduce a universally validated measure of inclusive education practice that all education systems (government, Catholic, independent) must adhere. Parents should have access to this data on the NAPLAN portal. For example, see the Centre for Studies on Inclusive Education (CSIE) Index for inclusion: developing and participating index for schools. Booth, T and Ainscow, M (2002) Link: https://www.jugendfuereuropa.de/downloads/4-20-3946/Index%20English.pdf

RECOMMENDATION 26

If a student with a disability enrolls in the Virtual School Victoria their disability funding should transfer with them.

HEALTH PROFESSIONALS RESPONSES

Long waiting times in the public system mean families are in holding patterns and school refusal becomes more complex and entrenched.

Families who access private paediatricians, child and adolescent psychiatrists and psychologists also face long waiting times (if they are taking new patients) and high fees (a paediatrician or child and adolescent psychiatrist can be approximately $500 for the first visit). This is out of reach for many families.

Long waiting times in both the public and private sector means waiting times of sometimes six months to see a specialist. Early intervention is impossible.

Then there's the logistics. Children and young people unable to go to school are also extremely difficult, usually impossible, to get to appointments. They are difficult to get out of the house full stop. Very few health professionals make home visits.

High cancellation fees, sometimes 50 per cent of the appointment costs, exacerbates the stress on an already financially and emotionally strained family. We are told we have to bring our unwell children or we will be unable to claim the Medicare rebate.

Our families desperately need outreach clinicians coming to their homes several times a week, for however long it takes to get their children mentally well and then work on re-engagement with an appropriate learning environment. It may not be the current mainstream education system, if the mainstream education system is inadequately prepared to support our diverse children.

RECOMMENDATION 27
Introduce a model of clinicians in public health services who can provide consistent and effective treatment in schools and in the home. These children will rarely visit them.

RECOMMENDATION 28
Review the gaps between Medicare rebates and the cost of accessing private clinicians for treatment and assessments and investigate the possibility of bulk billing or early intervention through NDIS.

RECOMMENDATION 29
There needs to be support for parents, particularly sole parents, supporting children unable to attend school due to poor mental health to hold onto their employment (in some form).WHAT'S

WHAT WORKS: THE LIVED EXPERIENCE

After failed consequences, contracts, incentives, gradual exposure and shut down—parents and carers pick up the pieces.

For many of us, when we realised the school-recommended approach did not work we stopped. We removed the pressure and focused on re-establishing our attachment with our child if it has been damaged whilst trying to enforce compliance to go to school every day. Instinctively we have turned to a trauma-informed approach to help our children feel safe.

We seek assessments that ultimately help us understand our children's behaviour. Then we work on addressing their mental health. We have had the most success when a return to school is child-initiated and driven and we are lucky enough to find the appropriate supports and learning environment.

We have found that when parents take a trauma-informed and an attachment approach to school refusal behaviour, that over time, the child's mental health improves, and they are then able to re-engage with learning. We have discovered flexible learning environments use a trauma-informed and attachment approach to working with children from diverse backgrounds that include complex trauma, as well as kids with neurodevelopmental conditions and kids who have experienced school-based trauma due to peer exclusion, rejection and bullying.

There is growing body of research on school bullying and the association between school bullying and the development of child and adolescent mental health problems. There is also evidence that school bullying places adults at significantly greater risk of the development of adult mental health conditions. Bessel van der kolk has extensively researched child and adolescent developmental trauma and argues that school bullying is associated with developmental trauma. Whilst Ken Rigy, an Australian psychologist who specialises in bullying research and the development of evidence-based whole of school prevention interventions, in his most recent work, stated that schools are currently poorly equipped to implement evidence-based whole of school prevention interventions to address the significant (25 per cent of students experience school bullying as the victim) bullying that is taking place in all schools across Australia.

Many of our families have found the introduction of animals (if we didn't have any) or the ongoing relationship with our child and a pet, for example, dog, cat, bird, equine therapy, has been beneficial. There is a growing evidence-base for animal assisted therapies for trauma and other mental health conditions, as well as for autistic people.

Other trauma-informed therapies, including art therapy, music therapy and drama therapy, are also helpful for our children with their mental health recovery. Whilst we all know the benefits of physical activity, and we all encourage our children to start walking with us, often, they are too mentally unwell to engage in physical activity for a long time.

Once they start to feel better, we are also implementing physical activity into their lives daily. Many of our children do not find cognitive behaviour therapy or any 'talk therapy' helpful when they are really mentally unwell. However, we have found that using a trauma-informed approach and finding ways to connect with our children based on their interests is the most successful way to reconnect with our children.

Our 'lucky' families have found that the most appropriate approach to supporting children and families, where the child is experiencing school attendance difficulties, requires skilled clinicians and teachers who are capable to providing full wrap-around long-term support to the child, whilst also providing ongoing support to the parents/carers.

We have also found that supporting parents in our online and face-to-face peer support community, by providing them with a safe, supportive, empathetic community, they are able to reduce their feelings of isolation, loneliness, helplessness, hopelessness, shame and humiliation. They increase their self-efficacy that they are a competent parent, that they can cope with the stress that comes with being a parent to a child or young person experiencing school attendance difficulties. Their stress and distress reduce. In a domino effect they learn to find strategies to continue to address their stress and distress by forming friendships online with other parents, they arrange to meet up locally for coffee and a chat, they connect to their general practitioner to seek mental health support for themselves with a clinician (psychiatrist, psychologist, mental health social worker), a counsellor. They find ways to increase their support network locally and they reintroduce activities into their lives that give them joy and which protect their own mental health.

Some parents have also met up with their children who are a similar age, at a similar stage of school refusal and have similar interests. Regular face-to-face catch ups for these children is way too difficult but we have seen a few who've had ongoing online contact – usually communicating while playing an online game – that has been a positive part of their recovery.

We remove the pressure, we nurture, nourish and respect. We wait patiently and remove all small and large demands. We provide opportunity when they are ready. We calm down ourselves and become the home counsellor. We let them know it's not their fault, that we will fight for them and never give up on them.

Our success with these responses is anecdotal. It is slow, but it is the only success we have. These children return to learning usually in an alternative or unconventional environment and they thrive. They remember very little of the dark days.

Our conclusion for schools, health professionals and researchers is that when children have good mental health, they self-regulate and they want to learn.

RECCOMENDATION 30

Review current approaches to school refusal to assess what's working and include the parents, children and young people with lived experience.

VICTORIA ALREADY KNOWS HOW TO RE-ENGAGE STUDENTS

Currently a successful return to school is a matter of luck, rather than good planning. It is rare.

Trauma-informed education practices are working to restore good mental health and re-engage our children.

Anecdotally we understand secondary schools such as Oakwood School, Pavilion and Swinburne Secondary School are having great results connecting with disengaged young people. These schools have simplified timetables, fewer subjects in a day, shorter break times, smaller class sizes, sometimes one on one programs, activities that keep them interested and engaged and strong and effective wellbeing programs.

These schools have teachers who are skilled at connecting with children and young people. Students, who may be filled with shame and guilt, feel no judgement. These schools develop intentional plans to meet them where they are at, help them feel success early, catch them before they fall and nudge them to take risks when they are ready. This is important for a child out of school for multiple years.

A few lucky families fortunate to access these schools have seen success they never dared dream possible. Luck's role in a young person's recovery is untenable.

RECOMMENDATION 31
Build more Oakwood Schools and extend the Oakwood program to primary school. Trauma-informed education is working with these kids, including autistic kids.

RECOMMENDATION 32
Create a think-group comprising researchers, teachers who are expert at re-engaging students, experts from flexible learning environments an parents with lived experience.

RECOMMENDATION 33
Prioritise research funding to examine the flexible learning environments across Australia, to inform mainstream education systems across Australia. Work in partnership with flexible learning environments, mainstream education, parents and carers, and children. Find out what these flexible learning environments doing differently that has enabled them to support diverse students with trauma backgrounds; neurodevelopmental conditions; and/or mental health problems. Consider providing this model within the mainstream setting.

LEADING THE WAY WITH THE NAVIGATOR PROGRAM

We welcome the Andrew Government's recognition of this growing issue with the planned expansion of Victoria's Navigator Program at a cost of $44 million. We are concerned about the children unable to access this service due to its slow and staged roll out. It is urgently needed across metropolitan and regional and rural Victoria immediately.

The Navigator Program has changed the lives of a few of our young people. It has demonstrated it understands the complex issues and that just telling these kids to go to school will not work. The experience is not uniform, and we would urge the Victorian Government to implement a consistent approach.

Unfortunately, not all schools are informing parents about the program. They often find out about the program once they find the School Phobia/ School Refusal Facebook Group. This can cause huge delays in accessing the program if they are in an eligible area. Schools do not seem to be very aware of the program or its success.

Parents with children or adolescents out of school for a significant period face many hurdles. An unplanned re-introduction left to chance will rarely be successful. The Navigator Program is key to re-engaging our children.

Recommendation 34
Accelerate implementation of the program's stage roll out across Victoria. Families, trying to avoid long-term complex school refusal, cannot wait years for this support to come to in their area. They need this program now.

Recommendation 35
Extend the Navigator Program to primary school students.

Recommendation 36
Improve access times to the Navigator Program. Families have experienced waits up to six months. Early intervention requires contact and access within four weeks of displaying school refusal.

RECOMMENDATION 37
Expand the eligibility for access to the Navigator Program. Early intervention is better than years in a bedroom. Kids and their families shouldn't have to hit rock bottom before they get access to help that works.

RECOMMENDATION 38
All kids experiencing school attendance difficulties within four weeks need to be provided with the Navigator Program outreach.

RECOMMENDATION 39
Make it mandatory for schools to ensure parents of children and young people experiencing are made aware of the Navigator Program.

RECOMMENDATION 40
Establish an ongoing advisory committee for the Navigator Program. This committee should include trauma informed care and trauma informed education experts who have successfully re-engaged children and young people back into learning, teachers and importantly parents and carers with lived experience and young adults with lived experience.

RECOMMENDAITON 41
Establish a parent and carer advisory committee to work with the Navigator Program research team.

RECOMMENDATION 42
Ensure the data and outcomes associated with the Navigator Program are robust and what's working is replicated across the state without delay.

RECOMMENDATION 43
Share the Navigator Program data with research teams across Australia and internationally so we can improve the research and improve the outcomes without everyone re-inventing the wheel.

RECOMMENDATION 44
That the Victorian Education Minister, Health Minister and Mental Health Minister advocate that their counterparts at COAG implement the Navigator Program model in their states and territories.

OLIVIA'S STORY: JUST GET HER TO SCHOOL

When Olivia was little she was labelled 'spirited'. Indeed, had a mind of her own that set her apart from her peers. At that age it made her interesting. It also meant she was challenging. She was aggressive, violent and she could not sleep. Over the years general practitioners, paediatricians, psychologists and teachers dismissed her parents' inquiries about the possibility of autism. If she was, they said, she was she would 'be autistic in all settings' and pointed to positive parenting. (Thankfully the understanding of autistic girls masking and imitating their peers at school has come a long way.)

Following an interstate move, [redacted]-year-old Olivia who had always attended school and received good reports, refused to leave the family's temporary accommodation. The dramatic response didn't make sense.

When she started at her new school, attendance was patchy at approximately 40 per cent. There was hope things would improve with a move to a grammar school for the start of high school. At the start she managed four days a week. As attendance worsened her parents removed all technology. It was her only 'currency'. 'Just get her to school' and 'she'll be fine when she's at school' was the advice. By the end of the first term Olivia completely shut down. She started headbanging on doors — deadlocked so she could not run away. She stopped speaking. She stopped eating. When she did speak, it was about dying.

The initial psychiatrist assessment was autism and an anxiety disorder. One of the visits took place in the carpark, through a barely open window, on the way there she threatened to jump out of the care and had tried to put her foot through the windscreen and remove the dashboard. A younger sibling sat in the backseat traumatised. The psychiatrist said she may never return to school.

The school, which had hundreds of girls, said they had never had an autistic student before. They offered kind words and some work to do at home. She was [redacted] years by the time she had an official diagnosis – seven months after her 'shut down'. She was diagnosed with Autism Spectrum Disorder level 3 in both categories indicating the very significant support she required and an anxiety disorder. Subsequently she was diagnosed with untreated depression.

Being an autistic girl, she had to hit rock bottom before she was recognised. In the seven months between shut down and diagnosis she did not leave the house (except under duress for assessment appointments with a psychologist).

The school gave incorrect advice about distance education. Based on the advice the family unenrolled from the school. Distance education said she was ineligible to enroll. Leaving the school removed the pressure on their daughter. They were relieved they were no longer paying more than $30,000 per annum in unused school fees. They were lost because they

no longer had an anchor in the education system. Later when they sought some paperwork, the school response was clinical and uninterested. Devastating.

For the next two years, she was awake all night and asleep all day. She lost all her friends. The family could not use the television, fans, heating, hairdryers or the vacuum cleaner because the noise and vibrations would send her into a rage. They had to creep around the house. Young siblings could not have friends over. If it rained, the sound on the roof or dripping drains meant there was hell to pay. Her responses were out of proportion, but an indication of how unwell she was. She was violent and aggressive. She barely functioned.

They returned to [redacted] to rebuild their lives. They borrowed money and gave up high paying jobs. They estimate school refusal has cost them $250,000. Doctors and health professionals seemed unable to help. Olivia refused medication suggested to help her sleep or ease the anxiety and depression. Mental health services for adolescents advised her parents to 'park the autism' and focus on getting her back to school. They advised she take up an outside activity or sport. Playing netball or going to the gym was unrealistic when she couldn't walk on the footpath in case someone looked at her. She was unable to engage with her distance education studies – she was enrolled for a year and did nothing. An alternative school was trialed unsuccessfully.

A psychologist with expertise in autistic girls and autism helped using a program specifically designed for autistic teens with depression. When she left the practice there was no connection with her replacement and she stopped the therapy.

The family stopped trying to 'fix her'. She stayed in her room for two years and started venturing out in the third year. She was provided with love, respect, compassion and nutritious food and opportunities to connect with the world. Almost three years since her 'shut down' she asked to return to school.

They called schools known for their flexible reputation and alternative approach. On one income private schools were no longer an option. They got nowhere – 'not in the zone, try your local school'. They had tried to avoid the local as years earlier the receptionist told them they did not take autistic students. The local school was unprepared for such as student. Olivia, wearing her new school uniform, made it for her agreed lessons over three days. A substitute teacher, either unaware of Olivia's circumstances or a believer in a bit of 'tough love', singled the new girl out for not having the right equipment for class. Olivia did not return. The newly bought uniform and school bag stayed in the wardrobe. The family mentioned they were near the top of the Navigator Program waiting list. The school said they had seen no success with the program.

Concerned Olivia may not bounce back from the failed school attempt they welcomed two social workers from the Navigator Program into their home. They spoke to Olivia and her parents with respect, understanding and compassion. They suggested education options no one before had mentioned and that had evaded their desperate Google searches.

Olivia slowly embraced the second chance. It took a term for her to interact with other students. It took six months before Olivia travelled to school on her own. After a year Olivia asked if she could move to a more 'regular school'. Today she attends a school with a flexible learning approach in the same year she would have, had she not missed any school. She loves school. She is excited about what she is learning. She sometimes tops her class. Her family will be eternally grateful that they were very, very lucky to find passionate teachers who were skilled at removing the shame, saw her potential and not just her challenges, helped her feel success and helped her to see was worthwhile and could learn again. She is excited by her future and is enthusiastically researching career options.

This wrap-around support should not only be available for a few based on where you live or whether you are lucky enough to find the people who know how to navigate the system.

**names and identifying details have been changed. The experience is real, unfortunately the ending is rare.*

Your contribution

Should you wish to make a formal submission, please consider the questions below, noting that you do not have to respond to all of the questions, instead you may choose to respond to only some of them.

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

- That children and young people's mental illness is taken as seriously as adult's with mental illness.
- That children and young people should not be forced to go to school
- That children and young people on the autism spectrum make up a disproportionate number of school refusers

2. 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?

We have experienced success using the Navigator Program returning complex 'school refusing' student back into education. This program roll out must be immediate, not staged.

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

4. 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.

- When children and teens are not provided an inclusive and supportive school environment -
- children with autism, ADHD, learning difficulties are developing mental illness as a result of the school environment
- There has not been an explosion in diagnoses, but there have been dramatic changes in the classroom over the last 20 years.
- There needs to be more professional development of autism for health, education and mental health professions

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

The current evidence-based school refusal interventions have not been validated for diverse student populations, for example students with neurodevelopmental conditions, students with multiple health difficulties, students with post-traumatic stress syndrome and/or complex trauma. The professional development currently informing schools how to respond to families with children and young people experiencing complex school refusal must be withdrawn. New resources & responses must be developed in conjunction with parents and carers.

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

Respond with respect and compassion. Schools should stop dismissing, ignoring or challenging diagnoses that explain why a child is unable to attend school.

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?
8. 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?
9. 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?

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

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

[redacted]