

SUBMISSION
SCHOOL REFUSAL INQUIRY
JANUARY 2023

Thank you for including Aspergers Victoria in your invitations to submit to this forum.

Key Assertions

1. We have had a lack of School connectedness and with that Schools Can't in our Autistic community since AV was formed in 1991, before Aspergers was a diagnosis in the DSM diagnostic manual. Our Australian COVID-19 lockdowns have created anxiety and social dislocation for many school-age children and the prevalence of school refusal following this continues and is often unrelated to that traumatic period. Rather, lockdown home-schooling opportunities created a generation of young people that realise or regard school attendance in an unsafe environment is simply an alternative way to learn. They choose to stay home where they feel safer and can choose to learn what they want and what they are more interested in online.
2. School exclusion leads to autistic economic and social exclusion and mental health pathways which impacts their entire lives as well as their whole family. Autistic unemployment is the highest of all disabilities and 6 times the rate for the general population.
3. School can't is more due to the school culture and system which fails to build autistic connectedness nor meet the learning and support needs of capable autistics and other neurodivergent with hidden learning differences and different social approaches.
4. Autistics are all too often traumatised by their school experiences and resulting societal exclusion as mentioned above leading to mental health pathways if they don't receive the right supports.
5. School can't has a ripple effect across the entire family especially parents/carers and siblings as outlined below.
6. The reasons why children feel unsafe to attend school are varied and are often a complex mix. One important reason is that students who are categorised as different learners can feel invisible, unsupported, unsafe, unwelcome and lack belonging. Some of this is due to :
 1. the harsh curriculum and lack of adjustments due to the VCAA approaches to learning differences. Current adjustments available once you reach high school are minimal and difficult to access – needing evidence to prove need from deficit-based specialist examinations.
 2. Lack of flexibility and respect in reasonable adjustments and assessment: our students are often not listened to when they attempt to explain their learning and processing needs. This is a lack of respect of the student and their opinion. They are instead forced into the method of that school or teacher. This extends to University and TAFE as well.
 3. Schools cultures lack acceptance of different learning styles: Lack of teacher and Principal training and acceptance is part of this as well as acceptance of differences by parents of other students. The reality is Schools still refuse to accept autistic students due to this perception.
 4. Lack of strengths based educational approaches as well as a lack of funding for non-deficit based supports. Our students want to feel welcomed and appreciated, not singled out as being less in some way.
 5. COVID has added to the anxiety that school creates for our autistics and is one more reason for overwhelm and traumatic wounds caused by their school journey.
 6. Students are unable to voice their needs or be heard in School.

7. Students feel disempowered from the pathway to life and independence towards work of their peers due to deficit based approaches to their needs.
7. Often our niche autistic students are highly capable, camouflage their needs with the concurrent lack of teacher training means they are not diagnosed until later in the system when they are in crisis with anxiety high and some traumatic experiences such as bullying by students, parents or teachers, leaving residual safe and lack of safety.
8. Lack of Autistic Work Readiness during School: Research shows and we see in our teen autistics that many do not understand the importance of school in their future career. AV has discovered directly from our autistic student that the current work experience and career subjects in Schools fail to meet autistic learning needs with the result that autistic students often miss out on the benefits and insight that career understanding and especially work experience builds and with that the motivation to complete school to gain a job. Due to this we developed a codesigned AV Teens Work KnowHow Program which specifically aims to build career readiness and understanding in School students. It also provides support at a stage when School Cant can disempower our students and instead provides customised and understanding support. Increased student engagement in School after completing our Program is so insightful for all.

WHAT IS ASPERGERS AUTISM?

Aspergers is now known as Autism Spectrum Condition Level 1 or 2 or ASD-1 or some individuals now diagnosed more with 'Social Communication Disorder' under the DSM5. Aspergers autistics fall under the umbrella term of neurodiversity of cognitive function and is considered to be in **three percent** of the population in Australia (Amaze 2021).

Aspergers autistics essentially have a hidden differences in how we learn, communicate, socialise and process our world. We mainly have an average or above IQ, specialised knowledge, and often extraordinary creative talent, focus and productivity. Research shows that at least 90 percent of Autistics are highly sensitive to either sound, sight, taste, smell, or touch. We do not have an intellectual disability and have high cognitively capability, often with different processing approaches to information. Our minds create a mainly hidden or unexpected differences so people and especially schools, teachers, assessors and parents often misunderstand and misjudge us and our behaviours. At AV we see our behaviours as part of our communication.

School's Trauma Impact : Living in schools and a world that isn't designed to support or respect these sensitivities can be traumatic, especially if you are more sensitive, feeling unsafe, and lack support and understanding at school for 6 hours each day. [Research](#) also has shown that Autistics also have a higher sensitivity that causes trauma and distress more readily such that specific stress experiences can give them similar symptoms to PTSD without that level of serious trauma more from repetitive incidences where they feel unsafe. This article in Psychology Today postulates that School is giving our Student PTSD: [Are We Giving Autistic Children PTSD From School?](#)(2021). This traumatic start to their lives set in motion a life of isolation and barriers without the right understanding and supports.

Our community's **parents and carers** have been found in [research](#) to have a level of fatigue and overwhelm similar to that in military campaign soldiers. Many of our parents have some of autistic characteristics themselves, or find they are caring for an isolated autistic student with mental health trauma. This then impacts their employment ability as they step more into a carer role – and their own mental health challenges. Our peer groups and help team being a key support that understands and validates their lived experience, where they can share their story and feel understood and welcome.

Also when a family have a student who is refusing to attend school it has a ripple effect across the siblings and other family members as well with a judgemental stigma of exclusion and inability.

Our autistic cohort are intelligent and capable students and if given the right supports including sensory supports, the right environment and an appreciative teaching and school approach that suits our individual needs we can manage school and employment and thrive. We are highly productive, loyal, creative, innovative, analytical-driven, and specialist thinkers with phenomenal attention to detail.

School Can't (Refusal) in our community

AV has direct experience of School challenges for our community through:

- our Teen Work KnowHow Program which provides a full support work experience for eligible autistic teens and we include Teens who have had school refusal or at risk.
- our Teen peer group which meets monthly for over 15 years
- our parent peer groups which meet online and in person for over 32 years

All of our activities are codesigned to support our autistics managing school refusal challenges and their families. We provide trauma-informed supports to assist and guide our members with this challenge.

We assisted with establishing a 'School Can't' parent peer group 6 years ago which then became independent. We did not have enough resources to support the running of this group and continue to have limited resource support with no ongoing government funding. This peer group was established due to the already existing need across our community prior to COVID. We find that more than 50% of the teens who attend our monthly teen peer group are dealing with or have had School Can't challenges. The challenge with such a parent peer groups is ensuring a positive and empowering approach is taken to ensure the peer group does not become about everything that is wrong with that child or that situation. It must be empowering. Often the parents are in as much of a traumatised state as their child once the child is out of school.

The School Can't is noticeable higher as our students reach the higher levels of secondary school where assessment and the curriculum narrows with less options to suit their needs.

We call it 'school can't' as it not that our autistic neurodivergent children are refusing to go to school. They are unable to go to school for a variety of reasons. These signs include

- Knowing they are not safe and don't feel welcome
- Nausea and vomiting at the thought of school
- High anxiety to the point they can't leave their home if school is their destination
- Trauma related symptoms due to past school experiences including bullying by teachers, parents and other students
- Lack of sleep and resulting ill health

A recent Autism CRC report [The Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?](#) **Reports:**

“Over the past decade, educational and public health researchers have recognised the importance of social and psychological connectedness to school as a protective and promotive factor for all youth (Centers for Disease Control and Prevention (CDC), 2009; Griffiths, Sharkey, & Furlong, 2009; McNeely, Nonnemaker, & Blum, 2002; Resnick et al., 1997). In addition, school connectedness is influenced by educators' and parents'

perceptions of school connectedness to the school environment. **School connectedness** has been defined by Goodenow (1993) as “the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment” (p. 80). Overall, educators and specialists felt some connection to the organisations they worked with, with specialists rating their connection lower than that of educators. In comparison, **parents of students on the spectrum rated their child’s connection with the school as low**. Overall, ratings from the students themselves were the lowest, indicating low levels of school connectedness amongst students on the spectrum. “ **This report has extensive details about how Schools need to accommodate autistic students.**

As the school model is changing and becoming less flexible and more streamlined especially from year 9 and in VCE years, with mainstream approaches to social and team activities a key requirement, many autistics are facing barriers to inclusion and traumatic experiences in their school and work lives. Due to misunderstanding of our communication and social differences, many people assume disability and total incompetence.

Work Readiness from School: Many autistics do not understand the importance of school in their future life and career. This is partly due to our difficulty with generalising new experiences and their impact on our future without additional and autistic-suited explanation.

AV has discovered that autistic students often miss out on the benefits and insight that autistic co-designed career development in School provides and with that the motivation to complete school towards gaining a job.

Due to this we developed a codesigned AV Teens Work KnowHow Program to build career readiness and understanding in School students. One of the interesting program outcomes is students’ increased engagement in School after completing our Program. As awareness of our program grows we find more and more neurodivergent but also non-neurodivergent students want that career insight and to understand more about how school is relevant to that future pathway into work.

““For school leavers on the autism spectrum, regardless of academic ability, the rates of successful participation in post-secondary education or further training are only half that of students without disability, and only one-quarter that of all other students “ source

A Research study by the University of Western Sydney: “[THROWN OUT INTO THE WORLD: TRANSITION TO POST SCHOOLING FOR AUTISTIC YOUNG PEOPLE](#)” prioritises for our autistic students a **Recommendation 6: More Resources and Access to Work Experience is Needed in Schools to Support Autistic Young People to Prepare for Transition** .

The Evidence of a lack of student engagement in career understanding is glaring and needs improvement. AV already has extensive learning about this from our AV Teen Work KnowHow program which needs more funding from government and commitment to building work experience as a student school engagement strategy.

Anxiety support: The key theme is autistics develop high anxiety due to differences in our communication, lack of others’ understanding, trauma in our lives and lack of suitable simple adjustments and supports. Many of our adults are discovering their own Autism following their child’s diagnosis and struggles with their own anxiety. Autism is genetic and often at least one parents share characteristics of their autistic child.

Many Members who have key strengths and capabilities, also have a wide and differing range of individual hidden differences and challenges with social communication, executive function and sensory challenges that are misunderstood - or seen as non-compliance - and that misunderstanding

limits our successful study, completion of school and employment. **Without understanding** with system adaptations, acceptance and accommodations, we often experience anxiety, isolation, bullying and trauma at school and then in the employment system, ending up with chronic unemployment, anxiety and other mental health issues and social and economic isolation.

This resulting economic and social exclusion impacts their entire lives as well as their whole family.

Victorian Department of Education

We believe that this is a public health, education, and disability crisis that requires system levels change and quickly to change this trajectory. The education engagement level of our community is dropping and fast.

We are part of the Autism Advisory Group supporting the hard work of the Inclusive Education team at the DET Victoria who have various plans to improve a limited number of schools approach to be more autistic-led. However, they face the difficult reality that the current mainstream education system and its culture is unable to meet the cognitive, social and emotional needs of many of our neurodivergent learners. They also lack the funding to deliver real change. Their lack of funding means their new inclusive programs only reach a small number of state schools, not independent or Catholic.

The key failure here starts with government and then leadership in DET and VCAA who fail to regard school change, changes in curriculum plus assessment approaches and School Can't as a priority to invest in major changes. This flows onto a lack of accountability in Schools around this with what seems to be a lack of transparent external reporting and measuring of this by independent processes.

We believe that most schools do not have an inclusive education culture, environment, that most teachers are not trained or equipped with the skills or flexibility in curriculum to teach diverse students with neurodevelopmental conditions or children with mental health conditions.

Our school system needs major consistent overhaul across Australia to:

- Ensure Education leaders make this a priority before it becomes a tsunami
- Make schools more inclusive of different learners needs with positive psychology and trauma informed based approaches with wellbeing a key KPI
- Ensure school cultural change for those with hidden differences
- Measure and track the rates of school can't in each school and the causes using independent measures and transparent reporting for families/community

Some independent and Catholic schools are doing this better in some cases. The Knowhow is there but the DET universally fail to track this or adopt approaches and knowhow from local success stories.

UNEMPLOYMENT RESULTING FROM SCHOOL CAN'T

Following on from the lack of suitability of the current School system, we find that the systemic attitudes and barriers continue for our autistics into employment. Autistic unemployment rates grow to be the **highest** of NDIS disabilities

Australian Schools have **no specialist work readiness employment programs in Schools that suit Aspergers autistics specialist needs**. The current work experience program is unsuited without adequate supports leaving our autistics

- Unaware of what work is about
- Lacking understanding about why school is a pathway to employment: and therefore lacking
- We identified that our vulnerable autistic cohort experience extreme discrimination without structured and autistic informed development programs that create sustainable job pathways.

Even though our autistics are capable, loyal, intelligent, productive and creative employees once employed (Curtin Research 2018). In 2015, unemployment for ASD was 31.6% over three-times rates for people with disability (10.0%) and almost six-times non-disabled (5.3%) (ABS) and this is growing with structural job market evolution.

UNEMPLOYMENT RATE (ABS 2017)	
ASD	40.8%
People with a disability	10%
People without a disability	5.3%
Costs of Autism (est.)	\$8.1 - \$11.2bn

This lack of employment inclusion is a missed opportunity for our economy as recent research by Curtin University WA has proven that with minor work adjustments and appropriate education and support, Aspergers and Autistics make contributions beyond average employees including:

- higher productivity
- high attention to detail
- strong work ethic
- high quality work

Workplaces AV has supported have benefited from employing Aspergers autistics individual. The impacts our AV supports deliver include:

- Trained/coached staff become better managers for all workers
- Better work atmosphere, engagement and improved team thinking
- Increased innovation from different perspectives allowing the team to think outside the box?

ABOUT ASPERGERS VICTORIA (AV)

For 33 years, Aspergers Victoria Incorporated (AV) is a members-driven grassroots NFP and has provided lived experience, peer community support to autistic individuals and their families and professionals in Victoria and across Australia. Our team of 80% autistic staff and 60 volunteers all have autistic lived experience and focus on creating an inclusive and empowering community for all our Asperger stakeholders whatever the age or gender through a strengths-building approach. We prioritise employing autistics in our team to ensure we build autistic employment and our lived experience knowhow in autistic employment.

We are the only non-profit/ for purpose organisation dedicated to supporting neurodivergent autistics who are independently capable across their whole life, as well as their parents/carers/families and professionals who support them. Our primary goal is empowerment through listening to lived experience, co-design and building a strengths mindset in our community.

We provide a range of autistic co-designed and delivered services to support autistics - from kids to adults, parents/carers, professionals and employers – to discover their strengths and empower them to flourish through:

1. Employment supports
2. Community inclusion and belonging initiatives

We have no ongoing government funding which limits our potential expansion in our peer-led services. We rely on Membership fees, donations and resources for writing grants.

Our lived experience community contribute to our way of working and program design which is essential to our success in supporting our autistics.

Evidence in our Programs and Autistic research shows how a strengths' based approach, with a few supportive/preventative health supports for their challenges, can put them on the right life path at minimal cost. Without this autistic School exclusion leads to economic and social exclusion which impacts their entire lives as well as their whole family.

With support of our Members we co-created innovative employment support programs. Our programs derive from the real stories and feedback that we hear every day from our autistic jobseekers, members families as well as our lived experience team. Our programs are proven to help employment outcomes including:

- WORK KNOWHOW PROGRAM providing work experience for Teens at secondary school and young adults which includes work readiness workshops and job coaching through to a supported work experience placement where the employer and staff are briefed and educated in autism understanding. This builds school/tertiary success and engagement as well as foundational career pathways and understanding.
- WORK READY
 - Specialised pre-employment assessments adapted for the specific requirements of each autistic individual that help them identify their strengths and challenges and best potential career pathways
 - Evidence-based workshops to build our Aspergers understanding of the requirements of preparing and applying for the world of work, while creating self-awareness and specific skill development. These have particular emphasis on supporting Aspergers to flourish in social and work situations e.g. our Social Skills Toolkit (evidence based), emotional understanding (Perdekamp Emotional Method) and self-understanding
- JOB COACHING: lived experience coaches support autistic transition to work or when they are facing employment issues with an employer
- EMPLOYER TRAINING:
 - employer training and coaching so they are more autistic-ready including communication approaches/resources, employee training, workplace assessment and appropriate accommodations
 - HR advice to businesses to ensure inclusive diversity practices and assist with issues that may arise managing autistic staff to achieve their best. This also includes attraction, screening, assessment, recruitment, on-boarding and ongoing support and development.

- DIVERSITY ADVOCACY teaching business, managers/co-workers, government organisations, schools and teachers - we are part of the Victorian Government Autism Advisory Group (AAG), and collaborate regularly with a wide network of Autism organisations locally, nationally and sometimes internationally
- PEER NETWORK MEET-UPS for autistic to catch up with peers and peer mentors who 'get them' and learn about themselves: including employee networks. This includes our Job Network Group where autistics gather to share, compare employment issues.

We also provide ongoing community inclusion supports such as our help and information portal, peer meetings and education events and workshops on key community issues and topics for our 700 member families. Australia has no other specialist, lived experience employment programs available specifically designed with our community to support Aspergers/ASD-1 to flourish.

We strive to be interpreters in supporting our niche autistic individuals to negotiate and manage their world- a go-between and empowering support for them in a system that frequently fails to understand their hidden differences. AV's understanding is derived from our basis of lived experience which is an imperative prerequisite for learning to 'speak Aspie' and then being able to translate autistic needs and requirements to a system that really fails to comprehend our intricacies and differences.

LINKS TO OUR RECENT GOVERNMENT SUBMISSIONS

- [Inquiry into Services for People with Autism \(Vic\)](#)
- [Inquiry into Sustainable Employment for Disadvantaged Jobseekers 2019 \(Vic\)](#)
- [Jobactive Inquiry](#)
- [Senate Select Committee on Autism](#)