



## ASPERGERS VICTORIA SUBMISSION IMPROVEMENTS IN DISABILITY STANDARDS IN EDUCATION SEPTEMBER 2020

For almost 30 years, Aspergers Victoria Incorporated (AV) has provided lived experience community support to Aspergers Autistics and their families in Victoria and across Australia. We focus on creating an inclusive and empowering community for all our Aspergers stakeholders whatever the age or gender through a strengths-building approach.

We are the only non-profit / for purpose organisation dedicated to supporting the estimated 30,000 Victorians with neurology that our community still prefer to call 'Aspergers' (currently), as well as their parents/carers/families and professionals who support them. Our primary goal is **empowerment** and building a strengths mindset in our community. Our organisation started in 1991 before Aspergers was a diagnosis with the objective of supporting students who were having difficulty with the school system and finding and keeping friends.

We have surveyed our social media groups and our Members with questions about their experience as well as received many requests for support and help from our families in distress during COVID in 2020. We have attached the outline we provided the DET during the initial Stage 2 impacts with their voices detailed.

We have 19 Recommendation outlined for your consideration below.

### OUR STUDENTS

Aspergers is now known as part of Autism Spectrum Disorder or some now come under Social Communication Disorder under the DSM5, and appears in the ICD-11, with many of our community preferring the 'Aspergers' term and association. Generally, many say they find the broader community have a better understanding of Aspergers as a term and how this implies their capabilities and needs. (However we continue to check our community views on our organisation name and this may evolve with our community views.)

Aspergers autistics have an average or above IQ, specialised knowledge, and often extraordinary creative talent, focus and productivity. We do not have an intellectual disability and are cognitively capable. Our minds create a mainly hidden or quirky difference so people misunderstand and misjudge us and our behaviours. Our niche autistic cohort are intelligent and capable and if given the right supports and the right environment for our individual needs we can manage school and employment and thrive. We are highly productive, loyal, creative, innovative, analytical-driven, specialist thinkers with phenomenal attention to detail

Within the autistic spectrum our Aspergers have unique strengths and challenges in particular we often appear capable but we have hidden needs and often **mask our challenges** including executive function and social communication understanding until we become overwhelmed – and our lives fall apart through anxiety and meltdowns. This is across all Aspergers gender-types.

As the school model is changing towards teams and collaborative learning, with specific academic targets, it is also becoming less flexible especially in tertiary with the peak in VCE assessments. Many ASD-1 are facing barriers to inclusion in normal life of school, and then also work. Those who have not had the right supports in life develop higher anxiety and are often traumatised, and co-morbid mental health issues. If you look at distance education there are a majority who are capable ASD1 students who cannot manage the school environment and teaching approaches.

Many Aspergers autistic students who have key strengths and capabilities, also have a wide and differing range of individual and often hidden challenges with social communication, executive function, **high stress** and sensory challenges that are communicated through behaviour or withdrawal so are often misunderstood by others or seen as non-compliance, which limits our successful study, completion of school and employment. We call this our "spiky talent". Without suitable

inclusive supports, system adaptations, acceptance and accommodations, we often experience anxiety, isolation, bullying and trauma at school which research has proven leads onto chronic unemployment, anxiety and other mental health issues and social and economic isolation. Many teaching staff see the behaviour and not the stress and emotions or sensory overwhelm behind the behaviours.

Schools involve learning in a socially demanding environment with peers. Our intelligent students face their biggest challenges in this social environment without supports that adapt to their learning and inclusion. Our students do not have what the DET system classifies as a “language deficit”, though our ASD-1 students’ literal interpretation and communication deficits impact their ability to learn and be included in the current school approaches.

#### **Our key community themes for Aspergers autistic at school are:**

- the improvements you make to support our Aspergers autistic student help a wider range of students, if not all students to learn and feel better, and are not all costly
- lack of understanding in our wider school community including non-autistic parents and beyond
- high anxiety due to issues with our communication insights, executive function challenges, lack of others’ understanding of our student needs and lack of suitable simple supports.
- School can be a high stress environment which leads to:
  - Reduction in our student’s ability to listen, process and absorb – or engage
  - Reduced ability to process social cues: leading to misunderstanding & bullying
  - Impacts on our executive functioning which leads to a lack of organisation and lack of delivery
  - Stress behaviours

**DO NOT HOMOGENISE AUTISM:** The famous quote from Stephen Shore, a late diagnosed autistic researcher and advocate is: *“If you meet one person with Autism you have met one person with Autism.”* Our education approach needs to recognise we are a diverse and heterogeneous autistic community which requires a variety of supports and organisations. One organisation cannot cover the diverse interests in sufficient detail or speak for the many different voices.

In many schools the curriculum is not suitably engaging for our capable autistics who often think outside the box or process things quicker or slower – so giving *a spikey profile*.

The subjects are often not made relevant to our students and adapted to what they want to learn. They often have a generalised knowledge beyond the average student – or have a spikey profile where they excel in some subjects with no motivation or engagement in others which can mystify a teacher or school. Especially in high school the subjects become more specific, less engaging so with the anxiety impacting their experience schools often lose the engagement of our students.

Many of our adults/parents are discovering their own Autism following their child’s diagnosis. This often means that schools are supporting parents going through a diagnostic revelation while their kids are at school.

**Accommodations that benefit Aspergers autistics learning generally benefit ALL students.**

## **OUR 19 RECOMMENDATIONS ON HOW TO IMPROVE INCLUSIVE EDUCATION IN VICTORIA**

### **RECOMMENDATION 1 : BUILD AN INCLUSIVE EDUCATION SYSTEM THAT ACCEPTS INDIVIDUAL NEEDS, SUPPORTS DIFFERENT LEARNING STYLES & BUILDS EQ**

Going forward we need to accept we need different learning approaches and accommodations for individual learning needs in our education system – whether a student has PSD funding or not. *This would assist not only Aspergers students but all students in the schools.* For some this will be providing some distance learning options and for others it may be a structured school approach or a combination of the two. All Aspergers autistics, need additional supports with or without funding, and should have IEPs.

Drive inclusion by embedding acceptance and accommodation of differences into the schools curriculum and school performance reporting.

Student Programs that build inclusive learning at schools include:

- Schools need to be providing ASD1 students, and their parents, with more consistent information about what adjustments and supports they can provide – and **even better, encourage student requests for their ideas of their own individual potential accommodations**
- Teachers who are trained and have flexibility so they can adapt their teaching to different and hidden learning styles, and offer suitable accommodations to students
- For inclusive Social time: older Student Playground mentors: who facilitate playground activities and includes others while growing their own leaderships skills; Primary play tree or bench: meet at the bench if you need someone to play/talk with; organised lunchtime activities such as special interest Clubs run by a teacher chess, lego, DnD. Teachers who's role is specifically not just to supervise but support inclusion & play at social times
- Accommodate different learning: we know stories of support such as
  - o Recording lessons so tertiary students can listen later and make notes after, giving them scope to engage in class discussion
  - o agreed student Calming plans: getting a drink, taking deep breaths,
  - o working with noise cancelling headphones a norm in the school
  - o Calming rooms across a school
  - o Specific study planning sessions to support executive function needs
  - o Shared learning aides who float across several classrooms helping anyone who needs it (many of our students hate a specific aid who focuses on them only so then seeming incapable)
  - o The DET could keep a list of some of the innovative accommodation options students have suggested or requested and that have supported learning. (Encourage schools to share this statewide)

The aim should be inclusion for all in the school type **of that student's choice**.

**Annette on AV FB: Smaller classes and more training for teachers.** I keep coming across school staff who think they understand autistic students but are a bit stumped when it comes to my daughter. She's going to a Catholic school and they really have tried many things but it's not working. She simply will not allow anyone to treat her as an object or a cog in a machine. So much so that even her classroom assistant has found her difficult. I've seen school staff demand my children explain themselves and it is exactly the wrong approach. They can't! (My older girl has SPD and a lot of anxiety.) It's exactly the opposite way to handle a kid on the spectrum. S is in year 6 and doing the Social Education Program at the Austin School at The Austin Hospital. Most of last term she refused to do the mainstream school remote learning but was keen to turn up to the SEP lessons both online and on campus. There are only three other kids in the class. I'm not sure exactly what magic they're doing but **I think she feels that people there really get her and care about her as an individual**

## RECOMMENDATION 2: ONE TO ONE SUPPORT - A DEDICATED LEARNING MENTOR

Whether a student with additional learning needs has funding or not they should have access to learning supports to meet their needs. The students told us that **direct and early communication** with them by their teacher or mentor or a allocated **wellbeing co-ordinator at school** would be better. This could include:

1. One to One Support Learning Mentor available: Many have suggested some form of one to one communication to support our Aspergers autistic student, especially in secondary levels. This may not be an aid but someone at school who is appointed to support them with their executive function issues such as planning – such as a wellbeing coach (mentioned below). This would especially help our VCE students.
2. That person could also be in touch with them directly during any remote learning and keep the planning process and keep their learning momentum going
3. Communication about changes to their subject needs and assessments
4. That mentor will help them plan for the changes that COVID brings to their subjects

5. Many of our secondary students especially our VCE students would have preferred direct access to their subject teachers earlier to know what was planned and what is expected of them.

**Leanne** *Uniformity in the way different classes are structured (so they are consistent). A dedicated support person for ASD students; less subjects; regular check ins.*

**FB feedback Lucianne:** A change in the criteria for assistance in public schools is sorely needed. My son received 1 on 1 care in a catholic primary school where he qualifies for funding, but not in his public secondary school which he started this year. Learn from home school 1.0 he was given projects and videos and expected to complete it all in his own time without guidance. He joined in the random class google meets happily, as guided classes meant he could get work done, but only if he could do so without the video, which some teachers were not pleased with. It resulted in very little work being completed because he would get frustrated or upset very quickly and abandon it. Starting 2.0 tomorrow and I'm nervous for him, but after A LOT of discussion with the school he will be attempting only a few core subjects, and teachers have been told not to expect him to complete everything. I cannot be sitting with him all day to guide him and help maintain his focus, as I have 3 other children learning from home as well, but this is what he needs.

One to one support, like he had in his EHCP in the UK. Helping him structure and plan his work (executive function deficits), managing his sensory breaks, and giving positive feedback. Most importantly, allowing the teacher to attend to the other 29 kids as well.

He had just started secondary and this support made a huge difference to both his learning and his attitude to school.  
But here?  
No support at all for autism.

### RECOMMENDATION 3: MORE FLEXIBLE LEARNING OPTIONS & EXTENSION

This awful experience of Covid has demonstrated how our students are all very different and that a flexible approach to their learning needs can support their learning needs at school. The diversity of learning need supports our conjecture that our students need a variety of schools as well as teaching approaches available to find an approach that suits their specific learning needs so they can flourish and feel empowered. This may be taking less subjects, further adaptation to their assessments and more.

Our students though may find some areas of learning challenging, yet can be **exceptional** in others – however due to their challenges they are often missed and pigeon holed by Teachers. This means they often miss the opportunity for extension and discovering true capabilities. This leads to disengagement at school – and often dropping out of the system feeling misunderstood. Some call this spikey profile **Twice Exceptional Learners**. Though classed as disabled in some areas does not mean they cannot be super capable in other areas.

Many of our students feel disempowered in the current education system, trying to fit in and learn in an environment that is often not suited to their **sensory needs and best learning style**. This flexibility needs to be a longer term goal in the current out-of-date knowledge system that needs to deliver students successfully into employment.

### RECOMMENDATION 4: PRIORITISE MENTAL HEALTH & WELLBEING SUPPORTS FOR **ALL** STUDENTS (MINDFULNESS IS NOT ENOUGH)

Anxiety is one of the key issues for our students and families. During COVID when community anxiety is at a peak and change is a constant this really impacted many who have a tendency to worry with their usual routines and supports falling away and massive fearful change. Anxiety is often within their family as well. Mindfulness has been

proven to only support a portion of our autistic students – and can actually make some of their mental health issues worse.

We would recommend:

- A move away from reliance on mindfulness only and include other programs such as the Self Reg stress program mentioned so the individual student can choose what help them
- Provide wellbeing co-ordinator in each school with counselling/coaching training and autistic understanding. These wellbeing reps would also be specifically part of VCE Aspergers student support team
- Many of our students especially our VCE students would have preferred direct access to their teachers earlier to know what was planned and what is expected of them.
- The students told us that **direct and early communication** with them by their teacher or mentor or a **wellbeing co-ordinator at school** would have been better. This does not have to outline exactly what will happen and DET statements– but just to know their needs will try and be accommodated and supported by the school.
- Having a dedicated trained and funded **wellbeing coach** (who is trained in supporting Autism) at schools would support many of our students manage their stress and anxiety and provide one to one support mentioned above.

Mindfulness has not been proven to be a key support for our ASD1 often forcing them to confront their busy internal world, and then feeling incapable. Access to coaching and counselling options if more important. However some did not wish to use the tele-health providers being someone they did not know or not being able to engage with the technology. Something to be considered.

**Belinda:** *Just gonna say it: why does it take a global pandemic for them to provide mental health and wellbeing support to VCE students? There's been large increases in depression, anxiety and suicide related to VCE for years! I'm glad they've finally done it, but wish they had done it years ago.*

Further work is needed on reviewing the stress supports required created by the hidden challenges of our capable ASD1/Aspergers students. Many of our students try and hide their worries which comes out in behaviours such a refusal to engage and more – which is mis-interpreted or mismanaged by their teacher and schools.

COVID times and the switch to Remote and flexible learning has highlighted the fact that there is no one-size-fits-all approach when it comes to supporting autistic girls at school. It has confirmed the need for a more flexible and individual needs-based approach, where autistic girls are given the opportunity to learn in the environment and style that works best for them.

## RECOMMENDATION 5: SPECIFIC AUTISTIC VCE SUPPORTS & BROADEN SCOPE OF VCE ASSESSMENTS

**Sue on AV FB:** *I think VCE English is a problem for many. Analysing relationships and emotions??? My son was lost when asked to annotate smilies and metaphors. English teacher said he won't get and study score to get him in a uni even though he excels in math. Discrimination pure and simple.*

**AVFB:** *My daughter has lost all confidence in English and is determined to continue. The book they are studying is all about relationships and her brain does not manage the analysis of this. However language is one of her key strengths in her testing. She did not want to study English language as it is too basic.*

**AV Member:** *my son has a handwriting problems as well as slow processing and anxiety. In VCE he is only allowed either a laptop or breaks in exams, not both. This puts him at a real disadvantage – the assessors are very inflexible despite being given his assessment details.*

The feedback from our community included:

- o Ensure English novels are not all about **social communication and relationships** are available for our cohort. This is their key challenge in understanding relationships and puts them at a great disadvantage in VCE English.

- Need more of a **wellbeing focus** with no specific communication from school wellbeing team or mentors or teachers. Wellbeing means our student and all students learn better. We recommend a wellbeing co-ordinator at every school to support and ensure our autistic wellbeing
- Early communication from the school and often, even if they did not know the DET decisions they could touch base and check on our Autistic student wellbeing
- Knowing anxiety in our VCE is higher in autistics which also challenges their executive function and ability to manage exams at the best of time. Schools needed to step in to support this asap to keep their momentum and encourage them – and DET/VCAA needs to allow for more exam support.
- Their inability to access physical course needs during Pandemic situations. For example one student could not access the photography dark room or his arts equipment. This was also an issue in TAFEs.
- In Pandemic provide direct access to their teachers earlier to know what was planned and what is expected of them – or learning mentor
- Higher anxiety about any changes to be made to the plans they have made for the SAC and other assessment requirements
- provision for access to suitable equipment possibly via loan if they can't access school due to COVID
- clear communication from VCAA about how they plan to manage changes to dates and assessments
- due to COVID, VCE feel they have an added disadvantage – concerns still about if VCAA will assess this when difficult enough to get recognition of support

VCE needs to be reviewed as a whole anyway and how it impacts our Aspergers VCE students. It expects them to respond in a standardised way in their writing, communication and executive function, which is not possible without considerable effort. **Mostly our student's different minds don't fit the current VCE education model.**

**CARRIE Member:** We are all just hanging in there. We fluctuate between spending hours trying to complete simple tasks to abandoning VCE. If I thought that my son's depression wouldn't get worse with this outcome, **I would tell him to quit school.**

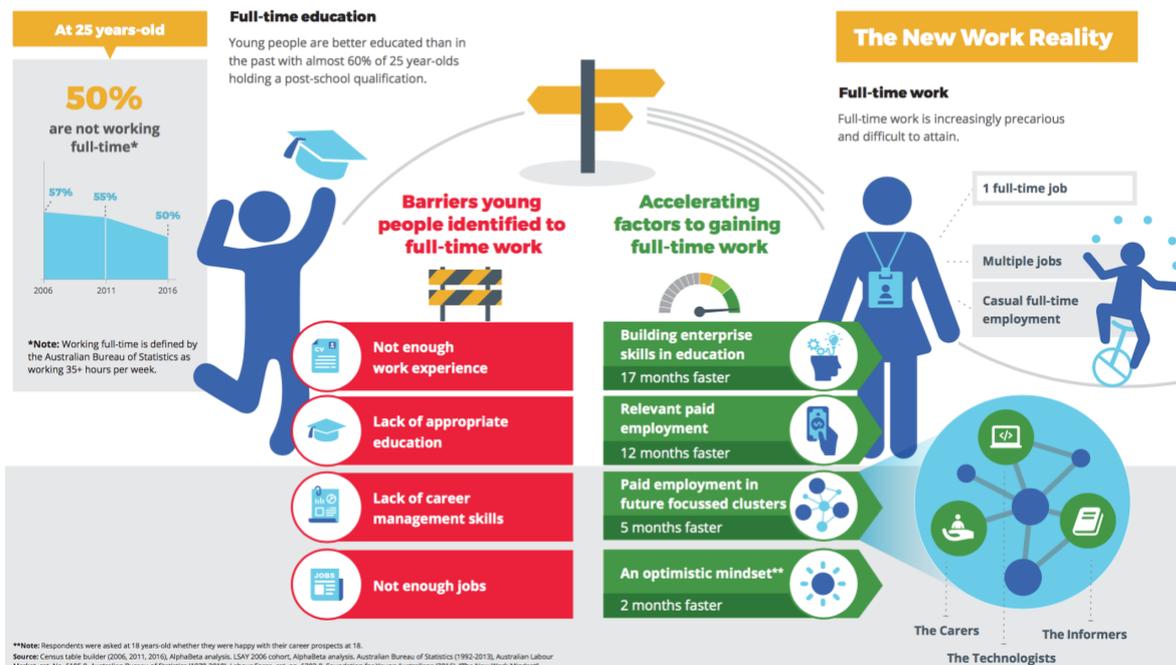
## **RECOMMENDATION 6: WORK READINESS RELEVANT SUBJECTS & SUPPORTED WORK EXPERIENCE**

According to the research by the **Foundation of Young Australians** our students all need improved access to Work Experience opportunities as well as education approaches that get them ready for the world of work.

This requires support for our autistics to develop suitable enterprise and work ready skills.

AV has developed a customised **Teen student work readiness program with supported work experience** opportunities so they do not miss out on such opportunities. We developed this program following community feedback that they missed out on work experience as their school could not provide them the right experience opportunities to meet their needs or they did work experience which went very wrong and they were almost traumatised by the lack of appropriate supports. Our Work Experience Program is funded by the NDIS and is already proving to improve outcomes for our students.

**This report followed 14,000 young people's journey over a decade (15 to 25 years old) and found...**



## RECOMMENDATION 7: TEACHER TRAINING IN STRESS & ANXIETY MANAGEMENT- AS WELL AS AUTISM

Following the Inquiry into Autism Services (Vic) the State government already accepted the need for more specific teacher training, and this is especially needed to manage the hidden differences of our Autistics/Aspergers students who can try and camouflage their issues.

### We would recommend an approach that helps all student but especially our ASD1 students:

- Schools create stress cycles as stress is contagious: it is proven that schools can build stress in the community and a whole school approach to stress management so this stress cycle is managed s critical. The Self Reg program is just one that tackles how each individual as well as schools approach this.
- On an ongoing basis schools and teachers need more training about how to realise signs of stress vs misbehaviour. Each student will need slightly different ways to manage their own stress and the teacher and schools need to be able to accommodate these. Often in ASD1 students just recognition of their own stress and a basic self developed plan will assist
- Programs such as the Self Reg Program by Prof Stuart Shankar are being rolled out across schools in Canada. These programs also help all children – including those with other learning styles and those with undiagnosed conditions. If we reduce stress all students learn far more effectively and can manage their behaviour better.
- Teachers should have student stress management as part of their role description so they don't trigger students and can teach at their best

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## RECOMMENDATION 8: INCLUDE SOCIAL AND EMOTIONAL LEARNING FOR ALL STUDENTS

One of the key difficulties for Aspergers is reading social cues and responding to social situations. However, research has shown how emotional intelligence and stress management are key for the future success of ALL students. This is not something that just those with differences should have to learn as if they have something 'wrong' with them.

Across the world the importance of emotional intelligence for the future of work is being researched and highlighted. We need this learning embedded in our education system for everyone. Canadian schools use the Self Reg program which improves self understanding and stress levels as well as learning outcomes for ALL students. (<https://self-reg.ca>).

We know many current Victorian "Personal and Social Capability" programs don't support our Aspergers/ASD students. In future these need to involve :

- 1) **whole school approach : lead from the Principal**
- 2) specific **evidence-based** programs that support ALL students build EQ and manage stress; and
- 3) **be measured and reported to create accountability and transparency**: so parents can assess school suitability

The social curriculum programs would need:

- To be a key part of teacher training programs with annual coaching updates;
- Specialist trained supervisors within each school that support the teachers to achieve this each day/week as issues arise. You must **not** let such issues build up or significant problems develop.

## RECOMMENDATION 9: FUNDING OR CHANGE THE SYSTEM

Even without funding our Aspergers student must have supports, especially during COVID. If it is not provided individually it needs to be provided through a system of new supports or approaches to learning. Without this, the expense of the mental health supports, and resulting unemployment after school make this earlier change in approach worthwhile in longer term economic costs.

Without reasonable accommodations and supports a large cohort of our student are traumatised by their schooling experience, become school refusers or means many leave school early, failing to reach their potential and the statistics show they start a pathway of mental health challenges. and end up in the mental health system with too many cases of suicide. **Often the supports required are adjustments and do not require large expense, more an adaptation of approach.**

In Victoria our Aspergers students miss out on funding supports, (except in the Catholic System) they lack the system classifies as a "language deficit" or "behaviours of concern" though their literal interpretation and social communication deficits and executive function issues impact their ability to learn and be include in the current school approaches. Some have funding through the Catholic System instead and some have NDIS but many don't.

If you adopt the inclusive culture mentioned below, improve teacher training – with some social & emotional learning for all then the accommodations required likely would reduce for many students – not just our ASD1.

## RECOMMENDATION 10: CHANGE OF TERMINOLOGY

Move from "disability" language so instead of "Program for Students with Disabilities it becomes the "Program for students with **Learning Differences**": This will immediately build support in our whole ASD/Neurodiverse community who are seeking a more inclusive understanding.

Many refer to our Aspergers as Twice Exceptional or 2E in the USA: can be very capable or even gifted – yet with learning differences that can hold them back. More about Twice Exceptional students and how their 'disabilities' mask their giftedness: <http://australiangiftedsupport.com/articles/twice-exceptional-or-gld/>

## RECOMMENDATION 11: SUPPORT FOR UNDIAGNOSED LEARNING DIFFERENCES

Many of our students do not get diagnosed until late in school or as adults yet we hear of stories where trained teachers can see they require accommodations and support – and they aren't provided until diagnosis. This is where needs-based

support should be available. For many of our capable Autistic students they will mask and try and manage when simple supports can help them.

## RECOMMENDATION 12: PARENT COMMUNICATION & SUPPORTS

During COVID the mental health strain on some parents and carers was significant so Schools or DET need to provide more supports during times of crisis to the parents of autistic students. The requirement for constant supervision not possible for working parents, who also needed to provide technical support for online. Some parents had multiple children at home so could not manage at all, especially if autistic themselves. This created strain in the family home and on relationships between parents and with siblings. Many of our parents were dealing with students who locked themselves away, stopped eating, were not sleeping and some had students who started to self harm due to their anxiety and helplessness.

With this 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 have some of autistic characteristics themselves, or find they are caring for an isolated autistic adult with mental health trauma. Our AV parent & carer peer groups and help team being a key support that understands their lived experience.

A key support in crisis times would include:

- specific communication to parents about their student's options for support. A School Wellbeing co-ordinator could be tasked with this. This was especially for those parents supporting ASD VCE students and their mental health needs
- Additional Mental Health funding for parents

## RECOMMENDATION 13: DISCOVER INDIVIDUAL STRENGTHS - FLEXIBLE CURRICULUM & EXTENSION

Aspergers have an amazing memory as well as expert focused interests. You can inspire motivation and achievement in ALL students by being flexible in your curriculum approach to encompass their expertise, strengths and interests. However this is beyond the ability of many teachers trying to complete existing curriculum tasks.

The curriculum must extend **twice exceptional, Aspergers and ALL** students by encouraging teachers and schools to capitalise on their areas of strength and then support these students with their learning challenges and accommodations. Not categorise them as incapable because they have one aspect of learning challenge.

## RECOMMENDATION 14: DISCOVER INDIVIDUAL STRENGTHS – POSITIVE PSYCHOLOGY APPROACHES

As shown by the Geelong Grammar Wellbeing studies by Martin Seligman, and the Positive Education Schools trialling this that all students benefit from a Positive Psychology approach to their lives. This approach to wellbeing means that student learn better – as well as learn to work better. We hope government also includes this both in:

- Teacher training
- School curriculums
- Leadership Training and KPIs for Principals

This is not positive behaviour systems which set our students up for feeling like they are failures within the current system:

***Tanya:*** *Our school still uses a "positive behaviour" system which is pretty much **not** achievable for kids with Aspergers. My son is despondent as he does the best he can, but will never be neurotypical and this is setting him up for failure.*

## RECOMMENDATION 15: DIVERSITY OF SCHOOLS

A diversity of schools is essential to cater for broader learning needs rather than the approach of trying to include everyone in the one school model. For example, we know of Asperger student who do not want the one large high school at [REDACTED] which does not cater to their needs of a smaller class and no uniform. The smaller schools they attended are being merged into one large local school.

For our students having access to Distance learning, or specialist behavioural schools such as [REDACTED], AYCE programs and government funded specialist schools such as [REDACTED] offering programs for our highly capable students

who need specialist learning approaches. The “Special” Schools can rarely accommodate our Aspergers/ASD1 students need for extension and capable learning.

### RECOMMENDATION 16: SCHOOLS DISCIPLINE APPROACHES AND SCHOOL REFUSAL

**Individualised Consequences:** Research also shows that suspension or exclusion from school as a punishment for behaviours related to our student’s ASD has a long term detrimental impact including a predictable mental health deterioration. We request the DET ensures schools shift away from reliance on knee-jerk exclusion to address problem behaviours in a more constructive way (Self Reg as well). Consequences must be agreed with each student and focus on instruction and inclusion. Primarily look behind the behaviour and determine the purpose of the behaviour. Knowing the purpose has direct relevance for determining how to respond. Often the consequence can be something that means they are still on campus in some way.

One possible replacement technique that also teaches social consequences and builds lifelong understanding for all students is the restorative justice consequence system. ([www.centerforrestorativeprocess.com/restorative-justice-and-restorative-practices.html](http://www.centerforrestorativeprocess.com/restorative-justice-and-restorative-practices.html))

### RECOMMENDATION 17: INCLUSIVE ADVOCACY

We are informed by many of our community parents that they are told by their school they cannot bring advocates with them to meetings with the school about their child. This has been said to be a DET mandate. However with many of our parents being autistic, as it is mainly genetic, this places them at a disadvantage to support their child in school. If there is a regulation around this we request this changes asap so parents in our community can have support to advocate for their student’s needs.

### RECOMMENDATION 18: PARENT BEHAVIOUR CONTRACTS

Parents of non-ASD kids at school also need clear expectations about their behaviour as a parent and towards inclusion. Workshops and clear guidelines about how to be inclusive as well as clear Parent behaviour expectations are essential– or you will not see a change towards true inclusive culture in schools.

### RECOMMENDATION 19: TACKLE GROWING SCHOOL REFUSAL ISSUE

COVID has added more of a spotlight on this already growing issue. Aspergers students have high intelligence and yet often fail to reach their academic potential in the current Victorian school and tertiary system. With their capable Aspergers mind, they also have challenges with social and communications with sensory sensitivity which lead to anxiety, isolation and often drop-outs. This is one of the highest growing diagnostic categories in the education system and these intelligent, creative students are ending up with mental health issues and the DSP

A key issue in our community is school anxiety which if not managed can lead to inappropriate behaviours and School Refusal. This leads on to home schooling or total drop-out. The effects of this include mental health issues for the child, parents and long term effects. There is little support available to families going through this.

[WA schools initiative: [www.education.wa.edu.au/documents/1212285/0/QA+factsheet+-+specialised+learning+programs+August+2016+CCM+JME.pdf/Ofd3a8d1-Of24-47c8-87aa-28f0337a971b](http://www.education.wa.edu.au/documents/1212285/0/QA+factsheet+-+specialised+learning+programs+August+2016+CCM+JME.pdf/Ofd3a8d1-Of24-47c8-87aa-28f0337a971b).  
[www.perthnow.com.au/news/western-australia/wa-government-to-invest-in-autism-programs-for-kids-in-public-schools/news-story/0eac09ccc78baf7d1325b2492afa7b6a](http://www.perthnow.com.au/news/western-australia/wa-government-to-invest-in-autism-programs-for-kids-in-public-schools/news-story/0eac09ccc78baf7d1325b2492afa7b6a)]

Other Reading:

- **Tony Attwood** [www.tonyattwood.com.au/books-by-tony-m/archived-papers/77-appropriate-educational-placements-for-children-with-aspergers-syndrome](http://www.tonyattwood.com.au/books-by-tony-m/archived-papers/77-appropriate-educational-placements-for-children-with-aspergers-syndrome)]

## OUR COMMUNITY'S COVID SPECIFIC FEEDBACK

Our remote and flexible learning experience during COVID highlighted how we need different types of schools and teaching approaches as we have such a variety of individual and educational needs.

During COVID some of our students have flourished in their online-remote learning without the anxiety provoking social environment of school. However, others have totally dropped their bundle and refuse to learn online or accept any change. We will cover anxiety specifically below. We have gathered direct feedback using social media channels and included some example to provide voice.

As with YLB, some of our students thrived : (from YLB submission)

- Reduced anxiety in dealing with social issues within the classroom
- Freedom to address sensory needs and movement breaks as required
- Less noise, less sensory overwhelm resulting in more learning time
- Less pressure around daily executive functioning tasks, such as getting dressed, getting to school on time.
- lack of bullying, no playground or friendship issues to deal with.
- for some students (but sadly not enough) remote learning provided more 1-to-1 support
- Some parents say they realised and understood better from first-hand experience of their child's issues with learning at school
- Some primary schools organised online social playtime with supervision

However many of our students also experienced learning challenges:

- Much higher anxiety through the change and uncertainty of not knowing next steps and if things would return to their 'normal'. Changes to their school routine: not knowing when school may change format again (happened overnight initially). Schools must minimise change or communicate it well where possible for our students.
- Inability to learn using online platforms: executive function and learning challenges means they were unable to process this medium : with no other options available (see below). Some were simply distracted by other online options. Some also found online far more tiring and overwhelming so learnt far less.
- Online distractions when not used to that: schools not implementing security in how online is accessed so kids can access wesbites etc that are unsafe and parents can't supervise that if working from home
- Executive function overwhelm: without teacher direction or parent involvement meaning they withdrew from doing activities. Many struggled to stay on task without this.
- Lack of communication from government schools about their approach
- Lack of 1:1 support from their school (tertiary offered it less). Loss of existing supports such as aides and therapy. No school check-ins on their wellbeing (see VCE).
- Lack of social connections: many Asperger students are not on social media due to bullying issues, and online communication with their friends was difficult to organise, given executive function issues. This social disengagement lead to some retreating and staying in their rooms, loss of existing friendships and strategies, loss of social confidence and worth.
- Some did not receive the adjustments to the learning required despite requests to their school
- No school support for how students could change their learning approach to online and the organisation planning this change requires
- No specialist support from the school losing all previously gained accomodations
- Refusal to accommodate students's needs if they needed to be on campus
- Overall exhaustion leading to stress behaviours and overwhelm
- Real loss of progress and momentum leading to fear of return and for some a new total disengagement with a return to school. For many girls the fear of losing friends and social impacts were more noticeable. School refusal is already an issue across our Asperger students as you will see outlined below. It seems without suitable transition support COVID will be adding more to the numbers who remain outside the mainstream school system.
- This message from an AV Member was from a School Principal for the July term stage 3 start, discouraging attendance even if they can't learn remotely: this was a very common message from the schools:

community can take to support our students is reduce the risk of transmission of Coronavirus (COVID-19), is to ensure that **anyone feeling unwell (both staff and students) to remain at home to ensure our VCE students remain safe and can continue to learn onsite.**

The school will continue to support the children of our essential workers and we are aware at time both parents shift work requires them to send their children to school. If we can minimise this as much as possible, this will ensure the safety of our VCE students who are undertaking VCAA exams for tertiary entry. Learning at school will be no different to home. All students will be expected to complete online learning and a teacher will be assigned to supervise the students. Students will need to use identified spaces and toilet facilities (if onsite learning is required). There will be no Education Support classroom support and students will be accessing the online learning delivered by their teacher that their peers are accessing from home. The difference being, they would be in an unfamiliar classroom environment, will have distancing requirements in place, will not have close teacher interaction and no 1 to 1 support and will not be allowed to touch others or engage in contact sports and may not have outside play. All these issues make for a very different classroom environment to what students are used to. This may be a particular issue for students with unfamiliar teachers and an unfamiliar classroom structure, changing daily in some circumstances. Our COVID-19 Resource Hub has been established again and you can find relevant updates and resources for both onsite learning (11 and 12) and online learning (7 - 10) on the school's website.

## WHY ASPERGERS VICTORIA

We strive to be interpreters in supporting Asperger autistic individuals to negotiate and manage their world- a go-between and empowering support for them in a system that frequently fails to understand Aspergers.

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 Asperger Autistic needs and requirements to a system that really fails to comprehend our intricacies and differences. We have many independently capable Autistics in our community– and have seen how a strengths' based wellbeing approach, with a few individualised supportive/preventative health supports for their challenges, can put them on the right lifepath.

We provide a range of community inclusion supports services to support Aspergers - from kids to adults, parents/carers, professionals and employers – to discover their strengths and empower them to flourish. Our Board all have lived experience as do all of our staff and volunteers. At AV we have more recently prioritised developing the best employment supports for Aspergers. Our programs derive from the real stories and feedback that we hear every day from our Aspie jobseekers as well as our lived experience team.

Australia has no other specialist,Aspergers/autistic lived experience specifically designed with our community to support Aspergers to flourish.

1. Peer groups: peer meet-ups to catch up with peers who 'get them', learn about themselves. Duing COVID especially our parent groups have expanded and are now nationwide.
2. Workshops to build capabilities
3. Advocacy support for parents
4. our help and information portal provide dedicated Aspergers/ASD1 information
5. Workshops to train teachers about specific ASD1 student needs
6. **Pathways to Work** - this AV Work Experience program is for tertiary school students. Preparation for work for Aspergers needs to begin as early as late primary school. If education was made more relevant for the current job market and includes communication and social skills supports, enterprise building focus with a work readiness focus for Aspergers earlier in the current education and the DET support systems. Here we would like to work more with school career counsellors to ensure our Aspergers stay engaged at school by realising their career plans. Also by ensuring their career assessments are suitable for their neurology and communicated to them in the right approach.

## 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](#)



## Key Community feedback for Department of Education & Training

Issue: COVID-19 school and education impacts

27<sup>th</sup> April 2020

- Year 11 and 12 are disengaging from school: can they go back first?
- Minimal guidance for year 12s about assessment changes and SACs, end of year, University options adding to issues and anxiety
- VCE added disadvantage – how will VCAA assess this when difficult enough to get recognition of support?
- Need clear directions on who can attend campus if need support: hard to advocate when don't know requirements. Directive very broad 'disabilities' and diagnosis and issues learning is not sufficient for many schools.
- Huge issues managing such a fearful change: created added anxiety in many kids
- Zoom and online does not suit many Asperger kids. This can be confronting social interaction and exhausting.
- Online distractions when not used to that: schools not implementing security in how online is accessed so kids can access websites etc that are unsafe and parents can't supervise that if working from home
- Need more breaks in how teach material & give social time online somehow
- Getting support from aides or home help in some way: taking kids for a walk or other exercise/break.
- many have other kids also learning at different levels/behaviours
- social anxiety for many of our kids: missing routine & support of friends
- **more DET training, outlines & advice for parents on how to manage at home arrangement**
- **how will DET support those who have fallen behind the rest of level once school returns?**

**Carrie** - I think it's important to mention to the Dept that students with **executive functioning issues** are really struggling. There is a greater emphasis of "Do it yourself!" A problem for my son is he is in **Year 12** and is supposed to be learning independently. I support that view but in reality he would not finish school simply because his tasks are embedded within a school website. Searching for tasks and info is a problem for him. Unless I find the info his head is in his hands overwhelmed! Depending upon mood, I can help him locate info. Generally though, I'm told to stop interfering! The stewing over tasks for hours is not only unproductive but has skyrocketed his depression. This week we have had to increase meds. Meanwhile minimal guidance is given from teachers and SACs are approaching. When I emailed his teachers for support a few were compassionate. One teacher basically said deal with the co-ordinator. We are all just hanging in there. We fluctuate between spending hours trying to complete simple tasks to abandoning VCE. If I thought that my son's depression wouldn't get worse with this outcome, **I would tell him to quit school.**

**Lisa** My son is in yr 11 and already had a week of home schooling. I was busy with work so left him to it and it was a disaster. Vice Principal called to say he attend 5 out of 16 classes. He will not sit at a desk and only comes out of his room for food and the toilet. I am thinking of asking the school for him to attend as a 'vulnerable' student. Vulnerable to failing year 11. Already failing maths methods so has to drop out which impacts his uni choices.

**Antoinette** - The same for my 18 year old who now wants to quit school

**Carrie** - My Year 12 mentioned that last week 🤔. This is such a struggle

**Samantha** Online distractions.

Without constant supervision will they switch to surfing the net or playing games.

My son has already used my credit card to purchase add ons for an app the school is using over \$400 worth.

I worry this will happen again

**Eileen** Aspergers Victoria there is too much interpretation by schools as to who is able to attend campus. My grade 6 son who is ASD, ODD, ADHD, dyslexia for which he has an aide and I have been told that he can still learn from home. Of the department made a list that specified what disabilities could attend campus it would help

**Ana** - We are having a really tough time with online learning. 12 yr old son HATES the video sessions, is really struggling due to his executive functioning, needs us to be with him for every single session - exhausting for all of us! Also, the full day is just too much. Too hard to sit at the computer for most of the day. At least at school there's breaks between classes and other people to talk to.

**Emma** Can we get access to extra learning support even when the learning is online? I had to push for some extra one on one calls with teachers but it's a check in rather than helping with tasks 🙄

**KB** As ESO requires a 3rd party to interact with students can that 3rd party be another ESO.? DET has said no to individual zoom sessions to support learning due to this 3rd party thing. What are the ESO going to do to support their funded students? Each student should have fair access to the learning content at home as well as in the room. Will students be penalised for skipping classes as they get overwhelmed? Many will not adjust to learning at home because that is done at school.

**Jayne** My daughter (recently diagnosed Autism 2) was about to change schools as getting to school every/most days has been too anxiety provoking for her. Now we don't know what to do...we were going to look for an alternative school, but with all schools online for next term at least, what do we do? Try and convince her to push on with her current school as she at least doesn't have to leave the house now? Sign up for Virtual School Victoria instead? Or start at a new school online?

**Tina** My daughter is ASD and is regressing. She's 5 and in junior infants. Her anxiety is building again and they had only just got her using school toilets before the finished up. She's waking at night crying to go to school and see her friends. She did have social issues which had improved immensely but I think we will have to start again. We live in a house of 4 adults and she is the only child.

**Stacey** Children not used to remote learning being left behind school curriculum especially in VCE years. How make up this learning?

**Paula** Not sure how energetic 7 year old will learn independently on line while his mum works on line

**Belinda** I really doubt that my son will cope with learning online. I'm very limited in what I can help him with, plus our internet is really crap and drops out a lot of the time. And even getting him to do homework at his previous school was a massive battle.

He's not coping that well with all of this, and for now the only thing keeping him from totally losing it is being able to continue with his VCAL program.

**Jess** Damage to parent child relationship due to no time apart to allow parents to regulate. We have no intention to worry about schooling but I'm sure it will create anxiety because she WANTS to do it, but will be too anxious to do so. I welcome to opportunity to homeschool. But not in isolation.

**Eileen Aspergers Victoria** there is too much interpretation by schools as to who is able to attend campus. My grade 6 son who is ASD, ODD, ADHD, dyslexia for which he has an aide and I have been told that he can still learn from home. Of the department made a list that specified what disabilities could attend campus it would help

**Donna** I actually think my daughter (11) may do better because the social pressure is reduced. No need to work in groups, not needing to wait for their turn etc. And they love anything online.... only time will tell if the actual process of participating and staying on track and motivated each day will be a success. Our holidays are extremely chilled with minimal stress.

**Kathryn** My son had a week of online learning before the holidays and managed really well, I had to leave him home on his own and he did all his work but left anything (maths) for me to help with. He has just started year 7 so only worries about his social progress. My daughter is already telling me she won't do any home learning so that will be a battle! I'm a teacher so I'm lucky I can help my kids, but also am suffering extreme anxiety about how I am going to teach remotely because it's such a huge change!

**Sheree** I'm really worried how home education is going to effect my sons' social skills and executive functioning. I think they will both regress and have more issues when returning to normal school times

**Tammy** - Agree...all the Zoom meetings, with too much talking, and daily changes in schedule is causing us to have one very unhappy and anxious girl. As she said her tummy is having that yuk feeling all the time 😞

**Maria** - We're just focussing on doing 2 hours in the morning (anything else is a bonus). I have found that checking in, getting instructions then doing work offline and reporting back has worked better for us..although this may not be possible for all formats. Our teachers have been really good emphasising that health and wellbeing of families come first, then school...but then again it's grade 1, so not like year 12. Hope this week is easier for you all.

**Caren** – My son started on Lovan 3 weeks ago as his anxiety sky rocketed and he started having panic attacks. He's 14 and in Year 8 this year. The school have been exceptionally supportive and have agreed to a modified distance learning program. I have asked for all his teachers to provide only work that is integral to his learning and to exempt him from everything else. Would love it if the department could set up a program where we could have an extra pair of hands in the home to help where needed. This would be invaluable. We don't have NDIS yet as too much on my plate. Even happy to pay a contribution, if they offered reduced rates

**Tammy** - "Autism home help" would be soooo amazing! Even just for someone to sit with the child to help explain tasks, We have also started doing an hour walk everyday to get those jittery feeling out. It's also so important for the other family members to have a break from the autistic person to clear their head and get space....as I sit here typing my 9 year old is meowing like a cat at her 6 year old sister....at least it's happy meowing!  
I know everyone has their challenges during this time but I honestly don't think people understand how difficult it actually is for people living in a house with neurodiverse kids or adults.

**Catherine** - It is a disaster for us. The lack of routine and structure, lack of social connection and role modelling from peers, is causing so much behavioural disturbance that all we can focus on is getting through our day, let alone do the school work. ASD kids - or at least my ASD kid - needs more than anything to learn social skills, self regulation around others, pragmatic communication, interaction with peers etc. None of which I can deliver at home. The only time it is possible to get any work done is when my ASD child is asleep. He needs our full attention otherwise. Zoom sessions are my sons worst nightmare. He struggles with social interaction at the best of time and video calls just increase the pressure on him to communicate and he shuts down.  
In summary it is a shambles and the sooner schools reopen the better!

### **Positives of online**

**Bek** My son is loving home schooling and it's great for him not to have the pressures (social especially) of school. It's a great relief for us, as it's something I've been considering for him.  
My other son is also enjoying it. He's more motivated and more social, so it's great to see it suits him too. I'll be interested to see how the school manages the music side of his learning, as this is his passion and specialisation at a specialised music school and I'm not sure how it will translate to online.

**O:** Home is my child's safe space. Homework has always brought extreme distress. How can we make this intrusion of school into home, ok for our new remote learners. **Jo** this is my son also. I am lucky I have an area of the house we have turned into the school room so hopefully that helps but getting him engaged at home may be difficult.

**Vicki** We already home educated our 2 autistic sons as school wasn't meeting their needs. Since we started they've not only caught up with their peers they actually over taken them. It suits their learning style so much better as you can give them 1 to 1