



**AV ASPERGERS
VICTORIA**

**A SUBMISSION FROM
ASPERGERS VICTORIA
FOR THE**

**NATIONAL SELECT
COMMITTEE ON
AUTISM**

JULY 2020



NATIONAL SELECT COMMITTEE ON AUTISM

July 2020

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

ABOUT ASPERGERS VICTORIA (AV)

For almost 30 years, Aspergers Victoria Incorporated (AV) has provided lived experience community support to Aspergers people and their families in Victoria and across Australia. We focus on creating an inclusive and empowering community for all our Asperger 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.

We provide a range of 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.** We currently offer programs proven to help employment outcomes including:

- specialised pre-employment assessments adapted for the specific requirements of each neurodiverse individual that help them identify their strengths and challenges with best potential career pathways
- 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
- job coaching with lived experience coaches to support their transition to work or when they are facing employment issues
- employment training for job support services e.g. Disability Employment Services (DES) and Jobs Victoria Employment Network (JVEN)
- employer training and coaching
- HR advice to businesses to ensure inclusive diversity practices
- programs and workshops with particular emphasis on supporting ASD-1/Aspergers to flourish in social and work situations e.g. our Social Skills Toolkit (evidence based), emotional understanding (Perdekamp Emotional Method) and self-understanding
- advocacy and training of 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 meet-ups to catch up with peers who 'get them' and learn about themselves: including employee networks.



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 ASD-1/Aspergers 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 ASD1-Asperger needs and requirements to a system that really fails to comprehend our intricacies and differences. We have many capable Autistics in our community– and have seen how a strengths' based approach, with a few supportive/preventative health supports for their challenges, can put them on the right life path.

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](#)

WHAT IS ASD-1/ASPERGERS?

Aspergers is now known as Autism Spectrum Disorder Level 1 or ASD-1 or some now come under Social Communication Disorder under the DSM5, 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/ASD1 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 ASD-1 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.

ISSUES

As the school model is changing and becoming less flexible, especially in VCE years, and employers becoming more prescriptive in their recruitment; many ASD-1 are facing barriers to inclusion in normal life of school and work. Those who have not had the right supports in life develop higher anxiety and are often traumatised, and co-morbid mental health issues. The key theme is high anxiety due to **issues with our communication insights, lack of others' understanding and lack of suitable simple supports**. Many of our adults are discovering their own Autism following their child's diagnosis and have managed okay with some basic self-insight and the right supports but with a few unrecognised struggles and often anxiety.

Many Members who have key strengths and capabilities, also have a wide and differing range of individual and often hidden challenges with social communication, executive function and sensory challenges that are often misunderstood by others or seen as non-compliance, which limits our successful study, completion of school and employment. Without suitable supports, system adaptations, acceptance and accommodations, we often experience anxiety, isolation, bullying and trauma at school and in the



employment system, ending up with chronic unemployment, anxiety and other mental health issues and social and economic isolation.

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 peer groups and help team being a key support that understands their lived experience.

AV listened to our Members concerns about our growing unemployment and underemployment and the lack of appropriate resources who truly understand (and not just therapise) their specialist issues, and - **with our community's involvement** – co-designed new programs. We have mentioned some of their specific concerns and comments in this submission.

We have witnessed Autistic unemployment rates grow to be the highest of NDIS disabilities and the fastest growing unemployment group, even though they 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 we have supported have benefited from employing ASD-1/Aspergers people. The impacts we have seen through our supports 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
- Improved work systems and processes quickly analysed by our ASD-1 minds
- Improved business reputation internally and externally
- Increased understanding of co-workers to personal life
- Proven increases in productivity: This was evidenced in 2019 by one new Aspie employee being promoted to another role and being replaced by two new workers.

Australia has **no specialist employment programs that suit ASD-1 needs**. We identified that our vulnerable autistic cohort experience extreme discrimination without structured and ASD-1-informed development



programs that create sustainable job pathways. This resulting economic and social exclusion impacts their entire lives as well as their whole family.

In the last 2.5 years our organisation responded to the expressed needs of our Aspergers Members to create new and innovative employment support programs. AV has been developing key relationships across the employment sector to build greater understanding in the mainstream, as well as build greater opportunities for successful and ongoing employment for ASD-1 individuals. Marginalisation, serious economic hardship and mental health issues result from the lack of knowledge and misunderstanding of Aspergers by employers, co-workers, school staff, and their unsuited environments.

- **Only 6%** of Aspergers employed (Amaze): highest of all disabilities and Autistics are biggest group in NDIS. Unemployment and underemployment is a key issue for our Aspergers individuals.
- Systemic barriers due to social differences mean failure at recruitment/interviewing for employment. Although many have strong job skills, work relationships frequently fail resulting in unemployment and traumatisation. Failure in system to realise and understand different strengths.
- Barriers created by assumption that differences mean ASD-1 are incapable of participating in school or work.
- Work and school environments and approaches focus on **neuro-normal**: employ same type of people, cater to one type of student or employee.
- Parents & families unable to work to capacity due to care-giving supports required or funding adult Aspergers
- Unemployment creates serious and debilitating mental health issues, risks of extreme poverty and even homelessness with significant economic cost to mental health services and social welfare payments and other support required.
- Wasted government funding provided to inexperienced and inadequately educated Jobactive and DES services who lack lived experience and real understanding of the personal and neurological differences and challenges of Aspergers individuals. High agency turnover and lack of specialist training mean they assume inability. Specialised training could change this.
- Misunderstanding by Employment Agencies and Job seeking experiences traumatizes ASD-1 / Aspergers resulting in:
 - withdraw from the job seeking market and/or
 - eventually end up on the Disability Support Pension (DSP) due to mental health problems.

Hence, much Aspergers employment talent goes **unidentified and under-utilised** in our economy. This unrealised potential to enhance and contribute to business is ignored and the individual remains unemployed and in the 'too hard basket' frequently being shunted to the DSP or in roles that bypass their IQ or short term roles that fill quotas. This creates serious mental health implications.

WHAT OUR AV MEMBERS TOLD US

We surveyed our AV community to support this submission. Our Members told us:

1. Of those responders who are currently looking for employment, several reasons were cited for why they could not find employment with the following key themes:
 - Not having the right supports to get a job, including managing the interview/screening process
 - Finding jobs that match skills/strengths, and employers that appreciate those skills/strengths
 - Difficulty in managing office or work environments.



2. Although a few responders are leveraging existing supports like NDIS, Jobactive and DES, 45% of responders are not leveraging any supports at all.
3. Many in our community are mostly capable with some communication challenges so do not regard themselves as 'disabled' and refuse to go down the route of those 'disability' supports until they are traumatised and desperate. However, they would use 'neurodiversity supports'.
4. Parents and carers as well as our autistics find our peer meet-ups an essential support for their wellbeing.

Our ASD-1 are the specialist minds in a world of generalist thinkers and provide a currently unappreciated **competitive advantage** to organisations in the future world of work. Our strengths make our Aspies unique employment prospects for companies that engage in specialist industries, often with the need for innovative or highly technical skills including numerical, systems, computing, data, research, design, or the arts. Instead many of our capable Members have suffered extreme and debilitating psychological trauma because of their experiences in the school, job seeking and employment arenas. They come to us feeling broken, misunderstood and unappreciated seeking help.

**We have included the results of our recent survey of our ASD-1/Aspergers Members to support this Submission and some of the comments or experiences from our ASD-1 Members.
This is to help you hear their voices in a united way.**

SOLUTION

- AV does not want to compete with or duplicate existing employment services.
- We can use our ASD expertise to make the existing services more closely adapted and effective for our Neurodiverse jobseekers.
- It is more efficient and cost effective to **educate and train existing service providers and employers** to enable them to assist Aspergers to effectively transition to the world of work and gain and maintain employment.
- AV's key focus is to provide education and support to improve the success in our Aspergers' journey through the education system and transition to and inclusion at work.
- **This impacts them, their families, their employer – as well as government and their local community**

OUR KEY TARGETED OUTCOMES AND IMPACTS

ASPERGERS /ASD-1	GOVERNMENT	EMPLOYERS
<ul style="list-style-type: none"> • Increased employment rate and success • Increased self-confidence/self-esteem • Employment at the level of capability not underemployment • Utilise the creative intellect contributing to business success • Increased level of social skills and social networks • Acceptance and inclusion in the social world • Improved economic independence, mental health, social wellbeing and life satisfaction 	<ul style="list-style-type: none"> • Less Centrelink/Jobactive/DES involvement resulting in huge saving to government • Employment results in decreased welfare dependency and increased tax contribution. • Improved community participation • Reduced demands on mental health/ health systems • Increased employment participation for family instead of being full time carer, • Seen as the Innovation State/Nation 	<ul style="list-style-type: none"> • More productive, innovative and creative staff • Opportunities for greater productivity and efficiency • Improved processes • Dedicated and loyal workers • Improved capacity, effectiveness and efficiency of HR to manage all neurodiverse staff • More inclusive work environment for all workers, which promotes greater understanding and appreciation of difference with flow on effect to wider community

There is one model used previously to show the benefits of employment of Autistics created by & copyright of PwC:

Appendix: PwC's Intergenerational fiscal and economic model

The **economic impact** module is calibrated to the fiscal, macroeconomic and demographic projections and provides detailed economy wide impacts of tax changes.
It allows us to further decompose the impacts on economic outcomes such as GSP/GDP, prices and investment.

The **fiscal impact** module incorporates detailed historic state and commonwealth expenditure and revenue data, including the latest Budget 15-16 information.
Drawing from the demographic and macroeconomic projections, it provides detailed projections of state and Commonwealth expenditure and revenue, including transfers between states and Commonwealth.
This module allows us to develop deep understand and quantification of fiscal impacts of tax changes.



The **macroeconomic** module provides a consistent long run projection of state and national GSP/GDP, developed using a framework consistent with Commonwealth Treasury Intergeneration Report (IGR) framework.
This sets the backbone for fiscal and economic impact analysis.

The **demographic and household** module provides long run population projections consistent with ABS population projections. It provides a projection by age and overlays these with income and consumption profiles which will allow us to incorporate the impacts of ageing on consumption.
This module allows us to capture the impact of demographic trends on spending, generation of income and consumption taxes and expenditure pressures by quintile.

Employment is the most important way that neuro-diverse people can be included in Australian society and so given the opportunity to using our ASD-1 unique strengths to make meaningful contributions, rather than subsisting on welfare.

AV would welcome the opportunity to attend a public hearing and request we are involved in consultations about future employment support initiatives. Our members would like to speak and be heard.

OUR RECOMMENDATIONS (20)

INCREASE ACCEPTANCE OF AUTISM (Recommendations 1 – 4)

RECOMMENDATION 1: BUILD NATIONWIDE VIEW OF ACCEPTANCE OF DIFFERENT MINDS INCLUDING AUTISTICS, MOVING AWAY FROM THE DEFICIT DIAGNOSTIC VIEW

The current deficit view used under the psychological model impacts our community from school through to adulthood. It means many are lead (wrongly) to believe that without intense therapy our Aspergers will never fit in. However, with a strengths based approach promoting acceptance and understanding and where others understand our sensory and communication needs, then it is far easier for our community to feel included and less isolated. This moves away from the fear-promoting model where difference is ostracized automatically, without seeing the value of difference.

The commercial imperative of many therapy organisations is contrary to this view with many prescribing many sessions of therapy such as Applied Behaviour Analysis (ABA) to try and normalise our intelligent



capable Autistics instead making them feel deficient and with ongoing mental health issues purely due to trauma from mismanagement.

The mental health heritage theory that we all must be “normalised” needs to be re-considered for many who are neurodiverse. Inclusion and a strengths view of self and by others leads overall to greater productivity, improved mental health and community contribution. **Acceptance would help Autistics nationwide and all levels of capability.**

If we moved more towards a social model of disability, in contrast to a medical model, that would help change the incorrect view that difference = inability. Neurotypical society needs to realise that differences in thinking can be a strength and often don't require much change in approach: accommodate the variety of autistic needs, mainly broken into sensory, movement, executive function, language, and social interaction – and move towards realising and accommodating the fact that everyone does not think or work the same way, or require the same environment.

Many Australian societal norms and systems are based on assumptions around these social and communication domains: the expectation that everyone can network in a loud, fluorescent lit-office, or can comfortably make eye contact during interview conversations, or can keep their body completely still during a boring School assembly. This needs to change as society is changing.

"I would love to be in a culture that saw a diagnosis as something to work with and that recognises strengths rather than focusing on the bad (usually how it affects other people such as parents...) I think we could all do well to learn from other cultures when it comes to human differences 👍"

Facebook comment this week from an AV member

"If u don't tell people they won't ever understand. It's good to challenge people's ideas about what Autism is, as there are so many of us hidden in the population. My therapist has ASD and he's done various degrees and runs a company that specialises in supporting and diagnosis. He wears a badge to show people that we can be successful, and to challenge people's perceptions of ASD. I don't generally tell people unless I think they are open minded enough to understand."

Louise

RECOMMENDATION 2: DO NOT HOMOGENISE AUTISM

AV prides ourselves on being interpreters in supporting ASD-1 / Aspergers individuals to negotiate and manage the wider world – we provide a lived experience go-between for them and the system that frequently fails to understand ASD-1/Aspergers strengths and challenges.

We request no move towards homogenising Autism needs so services cannot specifically address the needs of our capable Asperger community. AV is on the Autism Advisory Group for the Victorian State government and will actively and loudly promote the cause of Asperger individuals.

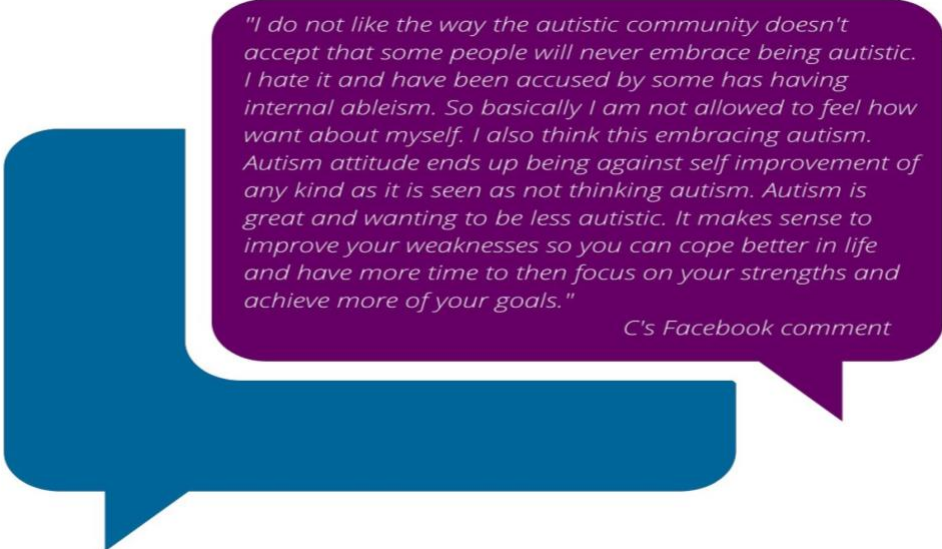
AV's understanding is derived from lived experience which is an imperative prerequisite for learning to speak 'Aspie' and then being able to understand and translate Asperger needs and requirements to a system that really fails to comprehend their intricacies and differences. We have specialised knowledge in how to best support our part of the Autism community.

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."*

Government 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.

This also means accepting that a variety of terms and language can be used by different Autistic people. This includes using whatever terms suit their needs such as neurodivergent, people with Autism or Autistic person, Aspergers or their individual needs. Many still regard their diagnosis as Aspergers Syndrome as valid and we query how some determine this is not valid just due to a change in a USA psychological manual – and one that changes regularly.

Sometimes the loud voices of a few advocates who are capable of gaining voice shout down the voices of others on the spectrum. This needs to be considered – that an influential advocate doesn't speak for everyone. **The Autism community includes our Autistics, parents/families, allies and professional supporters – and they all need a voice. We need a balance of voices to be heard at government levels (see research below).**



"I do not like the way the autistic community doesn't accept that some people will never embrace being autistic. I hate it and have been accused by some of having internal ableism. So basically I am not allowed to feel how I want about myself. I also think this embracing autism. Autism attitude ends up being against self improvement of any kind as it is seen as not thinking autism. Autism is great and wanting to be less autistic. It makes sense to improve your weaknesses so you can cope better in life and have more time to then focus on your strengths and achieve more of your goals."

C's Facebook comment

RESEARCH: *‘An important question for any theory of political representation involves balancing a representative’s justified partiality in advocating for policies that would help its constituents with its general obligations not to impose certain harms on others. Though moderating representative claims can address the particular problem of partial representation it does not eliminate this latter question. In practice, representatives need not choose categorically between these two approaches to dealing with partial representation. Instead, **they might pursue a federated model of representation where representatives of particular subgroups speak on behalf of their smaller constituency when addressing certain issues but come together with other representatives, either under the auspices of an umbrella organization or as part of an ad hoc coalition, to speak as one about issues affecting a broader group of people.** There are examples of this type of federated model in health advocacy.*

*A similar approach to representation may ultimately be well suited to **the autism community**. As we began this article by noting, people with ASD have widely varied characteristics, skills, and abilities. That they share a **common diagnostic label** is largely a product of the way that ASD has been defined by psychiatrists. Indeed, the creation of ASD as a formal diagnostic category is a relatively recent development, which followed several decades of attempts to “categorize the heterogeneity in autism spectrum disorders” (Grzadzinski et al. 2013). It was not until 2013 when the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) removed Rett syndrome and combined autistic disorder, Aspergers disorder, pervasive developmental disorder not otherwise specified, and childhood disintegrative disorder into the single category.’*

RECOMMENDATION 3: ADULT DIAGNOSIS SHOULD NOT BE NECESSARY FOR GAINING FUNDED SUPPORTS OR SHOULD BE EASIER TO GAIN

This is where needs-based support similar to NDIS should be available. For many adults, diagnosis is expensive and the diagnostic tools available/used do not suit adults. Many adults can often assess if they are capable Autistics but there is limited ability to use this to gain supports. Assessment for ASD-1/Asperger adults can be a simpler process. The other option is for there to be an avenue through Medicare for reimbursements for adult diagnosis. **The current Mental Health Plan offered through GPs is critical to supporting our undiagnosed Autistics.**

"It totally pulled my world apart. So many questions, so much doubt. But it gave me explanations more than answers and tools, strategies and method. I am who I've always been but now I accept and understand why I am. I've got so many quirks that sometimes embarrass me. I have an awkwardness and put too much pressure on myself.

However, I'm grateful for my diagnosis because it tells me I'm normal for me. I'm not alone in my difference, and I have as many strengths as I do weaknesses. Autism to me isn't an illness, a condition or a handicap. It's a type of person. I'm neither proud nor ashamed of my autism, I'm just me being me."

Geoff - diagnosed at 39

"Yup, late diagnosis. 20 years of psychologists and psychiatrists and not one pegged it till a suicide attempt and CATT said i was."

Tim

"Right here. It explained a lot. But it took a sharp eyed clinician who questioned all of my past diagnosis to make the right call. And yes I went through the whole gammut of blaming/wondering what might have been - etc etc etc. Now im just glad to have some understanding of what exactly is going on."

Ed

"Diagnosed at 49 high functioning. Explained a lot. didn't notice till my son was diagnosed in his teens. I asked where too from here doc said at my age I have probably found my own way of dealing with things and would be too hard to change and I like the way I am but...Early diagnosis is the key. '

Dale

RECOMMENDATION 4: EDUCATE GOVERNMENT DEPT.S AND SYSTEMS ABOUT AUTISTICS: NOT INCAPABLE, ASSUME COMPETENCE

The needs of neurodiverse people including Aspergers people should be specifically considered in the redesign of government programs including Jobactive. Our ASD-1 and 2/Aspergers needs are unique and need either a specialist sub program within Jobactive or ideally a dedicated ongoing national program established and funded to support our unique and valuable people and allow us the opportunity of self-fulfilment and to contribute.

EXAMPLE: Chrissy's story is typical for many Aspies. Ten months ago Chrissy came to Aspergers Victoria's Jobseeker Coaching Centre and asked if we can provide an employment advocate to accompany her to one of her Jobactive employment meetings as she was unable to convince her employment consultant that she was cognitively able to do work greater than shop assistant or processing work. Chrissy had noticed on her intake form that intellectual disability had been written in her notes. Chrissy presented with slower processing, had auditory issues and sensitivities and had left school after year 10 because of severe bullying by fellow students. She did not have an intellectual disability. Her IQ was 120. The employment consultant had dismissed Chrissy's extraordinary creative talent and desire to follow a career in web design. During the meeting, the employment consultant stated that because Chrissy was Autistic she would not cope with tertiary study or with a career in that field. Needless to say, because of AV's advocacy, Chrissy is now studying a Cert 3 in media and through AV's work experience program is looking to do work experience in a Media firm to evaluate her skill set and requirements of her work environment.

"I would be interested in learning more about a National Autism Plan. I would hope it would bring more awareness about what autism is and how it affects people. I would also hope it would lead to more work places to be inclusive and to see that capable autistic employees can bring unique talents and abilities into a workplace."

Quote from AV Survey

EMPLOYMENT (Recommendations 5 – 13)

In our survey to support this submission the following supports were stated by our responders to be the most beneficial in helping to find a job:

1. Majority of respondents stated a job coach with Aspergers experience
2. 70% stated work readiness training programs
3. 60% stated having a mentor at work and/or ongoing training

For those responders who were successfully able to get a job, majority responded that they found the job through their own personal networks (family, friends, etc). Very few have found success with either broad online platforms (SEEK, LinkedIn, Ethical Jobs, etc.) or specialist services (a disability recruitment service, supported government services). Additional ways mentioned that helped in finding employment included:

- Volunteering activities
- Training courses
- TAFE study

For those in work the key requests were:

- More training of employers/staff to understand Aspergers and inclusion
- More work readiness training programs to support my Aspergers needs, i.e. from a Aspergers trained employment organisation

RECOMMENDATION 5: AN EMPLOYMENT GRANTS PROGRAM FOR SPECIALIST ORGANISATIONS



Representing neurodiverse people in employment such as AV, to provide funding that will allow us to provide a range of employment based support services directly including:

Our World of Work experience program for Aspergers students which we have developed and require funding to progress further. Our research shows this will deliver work readiness skills in the most effective approach: preparing both the Asperger as well as the employer and requiring less job matching services by independent parties:

Our World of Work program provides:

- Specialist career advice to gain the most suited & sustainable employment, including required support.
- Communication building program “Social Skills Toolkit” for pre-work students and applicants: On the Jobactive website front page it highlights that “Employers want good communication skills” so ASD-1/Aspergers need to be given supports to build these skills earlier. Our program includes this by building it prior and on the job.
- Preparation and train more employers to understand ASD-1/Aspergers
- Coaching and mentoring by lived experience to support ASD-1/Aspergers into and on the job

This will all result in improved employment skills, improved life skills, growing self-advocacy and awareness of neurodiverse contribution through actual delivery of outcomes, abilities and contribution

RECOMMENDATION 6: PROVIDE SPECIALIST RECRUITMENT SUPPORTS FOR AUTISTICS CAPABLE OF WORKING IN EXISTING ORGANISATIONS BUT DISADVANTAGED BY THE CURRENT RECRUITMENT SYSTEMS (OR ENCOURAGE CHANGE RECRUITMENT PRACTICES)

It is well documented that Aspergers jobseekers encounter significant barriers to entering the mainstream workforce. The specific systemic barriers to employment such as:

- misunderstanding of job requirements as well as a tendency to interpret job requirements strictly and literally
- current assessments used in the system direct them to apply for the wrong type of roles and miss their key strengths
- lack of self-awareness and understanding of their abilities and challenges: often told they are incapable
- the application process which eliminates differences, not assessing strengths and capabilities
- video applications and interview processes which play to social skills, not knowledge or ability – and increase autistic anxiety and overload
- networking challenges which create disadvantage
- disclosure leading to discrimination due to misunderstanding of Autism and assumptions that they are incapable/disabled.

The reality is the majority of our community refuse the inadequate system supports and try and do it themselves or bow out of the system all together.

Jobs Victoria recently recognised and attempted to address this issue when they were recruiting for one of their head office cadetship positions at Department of Education and Training (DET) Victoria. With AV, the Jobs Victoria representatives created a specialised application and interview process to suit the Asperger/ASD-1 applicants and they recruited very successfully.

Our World of Work supports include:

- specialist assessments and interpretation to support individuals sourcing the more suited employment roles: Autistics then have realistic expectations and self-understanding
- coaching support to assess roles, prepare their CV and for interviews
- communication skills building program “Social Skills Toolkit” to help them prepare for interviews and the recruitment process.

EXAMPLE: Cathy was recorded by her support agency as having an intellectual disability even though her IQ was 120 – only because she was extremely anxious in the interview situation due to past bad experiences and her processing speed being slower particularly when she was very stressed. The only jobs she was offered or supported to apply for were processing jobs and the final straw was the employment service suggested that she apply for Waverley Industries a supported employment service for people who physically and cognitively challenged.

EXAMPLE: Anna had experienced anxiety disorder for which she was recently hospitalised had disclosed to the employment service that she experienced severe noise, crowd and light sensitivities. They then only offered her unsuitable positions at the busy local swimming pool, and in shop assistant work in large crowded shopping centres.

EXAMPLE: Mark who has had multiple unsuccessful jobs in retail and who is very literal and has difficulty recognising non-verbal social cues and a very slow processing speed was constantly pressured by services into applying for front of house work or bar work in very busy hotels and restaurants.

“I struggle to socially interact with people but have been given no support by my employment consultant to learn these skills in order to improve my chances of gaining employment.”

Thomas

These are only a few of the stories that have been shared with AV regarding their experiences of accessing employment services. AV Members would be very happy to provide additional personal experiences at any Senate meetings.

RECOMMENDATION 7: SPECIALIST WORK PREPARATION AND TRANSITION SUPPORTS

Many of our Members who had undertaken pre-employment job application and interview training through their disability or other employment service commented that this training and support was ineffectual and inappropriate as it was not tailored to suit the particular challenges and requirements of Asperger jobseekers. It was broader disability training often assuming intellectual challenges and without the **insight of lived experience**.

Our capable ASD-1 Autistics need specialist career supports that related to their strengths and support their specific challenges which are often a myriad to decipher- needing specialist insights. Our capable and knowledgeable jobseekers specific challenges include the inability to read between the lines with regard to interview questions, inability to understand verbal and non-verbal cues, difficulty with eye contact, mind blindness and failure to read contextual cues.



This job readiness training resulted from the many Aspies who have presented to our various AV meet-up groups and Drop-in-Centre who have never been employed and have lived very isolated lives. They have no understanding of the expectations of a work environment. This deficit was also evidenced through our interactions with employees who were in precarious employment situations and who approached AV for support.

To be able to make the most of recruitment services, such as Jobactive, students need a better self-awareness and readiness for the employment world. Improvement in career guidance/readiness of students is a key priority in line with the recommendations in the report from the Inquiry into Career Advice Activities in Victorian Schools (22/8/2018) (with the added requirement that the training of Career Guidance teachers). Our World of Work program is designed to provide this through our Workshops and trained coaches.

This work readiness needs to start earlier for Aspergers. Early intervention for employability skills should get priority funding if you wish to reduce reliance on government supports later in their career process. Without such intervention Jobactive supports will not succeed.

In 2019 AV developed and used:

1. **Social Skills Toolkit** - this program which uses an evidence based model to provide communication skills and personal insights for Teens and Adults so that they can understand and learn communication and social requirements for their life and work worlds. This work readiness workshop prepares Aspie individuals to understand the world of work.
2. **Pathways to Work** - this AV work experience program is for 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.

RECOMMENDATION 8: PROVIDE SPECIALIST ON-THE-JOB SUPPORT COACHING TO MAINTAIN EMPLOYMENT FOR AT-RISK ASD-1/ASPIE WORKERS

Through our work providing employment coaching to Aspie employees, it became very evident that assisting Aspie employees to **maintain their job** was equally vital as assisting the jobseeker to find employment. Few agencies do this well as they are often more focused on getting the ASD-1 person into a quota-role and lack experience and specialist training in working with ASD-1/Aspergers.

In particular, most employment agencies or job coaches don't comprehend the critical impact that sensory sensitivities and mis-communication can have on an ASD-1/Aspergers ability to maintain their employment.

More recently AV's World of Work Program has been delivering on-the-job specialist employment coaching for Aspergers in a range of employment settings including Medibank, the Rise program at Department of Health and Human Services (DHHS) HHS, Department of Environment, Land, Water and Planning (DELWP), DET, Linfox, Infosys and Our Watch. Critical to this was coaches with specialist training and lived experience of ASD-1/Aspergers.

The main focus of this specialist coaching support is also to educate the employer, HR, managers and co-workers about ASD-1/Aspergers in the workplace and also to ensure that the Aspie employee has appropriate understanding of the job requirements and the social and work expectations of a business



environment. AV WOW program is currently developing a **Coach Training program** to teach employment coaches how to successfully coach Aspies in finding and keeping employment.

Again AV is very happy to share more of their member's stories about the lack of and the critical need for Aspie savvy employment coaches.

EXAMPLE: Letty has been employed by an information and technology company for 8 months. She contacted AV's WOW Job Coaching service because she was struggling to get to work before noon each day. Letty experiences very severe noise sensitivity and was exhausted by the loud noise of the air-conditioner, the constant chatter of the open plan work environment. Her desk was situated near the kitchen area where everyone congregated. She had asked her manager to shift her desk but was told that there was not other space. She used noise cancelling headphones to try to block out the noise but these only muffled the cacophony of sound around her. Her anxiety had reached extreme levels and her doctor had prescribed a higher dose of medication which made her feel really drowsy during the day. Letty was becoming very depressed about her work situation and was thinking that she would have to resign. After just two coaching sessions with her manager, her manager was then willing to accommodate her needs and move Letty, as well as discuss ways that she could work from home for some of her work week. This assisted Letty to be able to cope with the office noise on the days she would be at the office, and the employer then kept a valuable and productive employee.

From the multitude of stories just like the two above what AV has learned is that for our employment coaches to successfully place Aspies into appropriate ongoing successful employment, the coach as well as the employer's team need to **truly understand ASD-1/Aspergers** in order to understand the Aspie's needs, and to be able to teach the employer to effectively understand and communicate with their Aspie employee.

Again AV is very happy to share more of many member's stories about the paucity of and the critical need for Aspie savvy employment coaches.

RECOMMENDATION 9: EDUCATE AND SUPPORT EMPLOYERS ABOUT NEUROLOGICAL DIVERSITY IN THE WORKPLACE TO ENSURE THEY UNDERSTAND THE DIVERSE CAPABILITIES AND INDIVIDUAL NEEDS OF THEIR AUTISTIC EMPLOYEES

The second most important aspect of employment that is not adequately addressed by both the general and specialist employment service providers was the type and amount of on-the-job support and training provided to the employer, their staff and HR.

This is achieved through a two pronged approach for the first few months of transition or when we are called in once issues arise:

- Training of staff and managers working with that team member
- On-the-job employment coaching and support for the ASD-1/Aspergers employee.

AV's **World of Work team** has been delivering coaching in a range of employment settings including Medibank, the Rise program at DHHS, DELWP, DET, and Linfox.

From the multitude of stories AV has learned is that to successfully place Aspies into appropriate ongoing successful employment, the employer, including staff, must effectively better understand and communicate with their Aspie employee - they need to learn to 'speak Aspie' in order to understand the Aspie's needs. They also need to allocate an internal mentor.



One employer stated to AV that since she 'had learned to speak Aspie from our lived experience team and understand the needs of her Aspie employee she had become a much better manager, not just for the Aspie but for **all her staff**. They can also then see which of their available team positions suit ASD-1 strengths and knowing they have specialist support they become more open to taking on more neurodiverse staff – we saw this in recent coaching at Medibank.

The main focus of our AV coaching support is really to educate the employer and co-workers about Aspergers in the workplace while also ensuring that the ASD-1/Aspergers employee has appropriate understanding of the job requirements and the expectations of this business environment. Most agencies don't particularly do this well unless they are specifically trained/experienced in working with Aspies. In particular, most employment agencies or non-specialist job coaches don't comprehend the critical impact that sensory sensitivities can have on our ability to maintain employment, as well as difficulties interpreting instructions due to challenges understanding some **language approaches**.

EXAMPLE: Paul is a newly employed worker in a large company who are beginning to feel that Paul's productivity in the office is not worth the high levels of time and resources that his manager and buddy are investing in him. Paul's on-the-job support had been completed by his employment agency but Paul was still not performing to the company's expectations. Aspergers Victoria were called in to identify what the problem could be and provide solutions. It was clearly evident after talks with Paul that he had auditory processing issues, was very literal and did not understand verbal or non-verbal social cues. Paul's employer felt that he had provided clear work instructions to Paul but on examination he was not clear or precise enough. When I commented on this the employer said that he felt he was being rude to Paul, but Paul stated to the employer that I he would much prefer for the employer to be straight and blunt than Paul feeling confused and wrong all the time. It is really important for the employer to really understand the perspective of the Aspie and learn to speak Aspie while the Aspie is assisted to learn to speak Non Aspie.

RECOMMENDATION 10: NEW REQUIREMENT FOR AUTISM TRAINING OF EMPLOYMENT SUPPORT AGENCIES MANAGEMENT AND STAFF NATIONWIDE TO RETAIN LICENCE

The loudest story which is told over and over from our Members is that the government funded agencies including those managing Transition To Work program to provide employment supports **FAIL to understand the abilities and nuanced challenges** of our capable ASD-1 / Asperger population. Whatever the Aspie's age the story is the same. The repeating themes include:

- not understanding or misunderstanding the characteristics of ASD1 Aspergers: **predicated on expectations of what is 'normal' & implications of disability**
- undervaluing the skills sets of the Aspie jobseeker or employee: assuming they are incapable and intellectually challenged
- employment Agencies don't understand that Aspergers is a different mind with challenges that can be accommodated often quite easily
- not realising the simple support needs that help our Aspergers flourish and
- lack of appreciation for their 'intellectual capacity and high cognitive functioning': not seeing past their differences or co-morbid anxiety the job seeking process exaggerates.

The lack of suitable training and high turnover of employment staff in government funded employment agencies is the other problem most frequently cited by our Members and survey respondents. Generalised disability training is inadequate and actually damaging and disempowering for the Asperger jobseeker who has report that the services are frequently useless in providing realistic employment opportunities for them. This mismanagement and putting ASD-1 into the wrong roles to meet quotas creates additional trauma and mental health issues with likelihood of lifelong unemployment.



With such turnover, training in managing capable Autistics is a priority and regular and updated training of these agencies and their staff must be mandatory. AV has created training with our lived experience team which improves real understanding of our community. The other option is fund specialist agencies instead.

On-going funding support needs to be based on outcomes as well as user feedback surveys – as it is for other funded organisations.

EXAMPLE: George is 39 years of age and has two engineering degrees but who has limited social and interpersonal skills has now been to 5 DES providers because of the constantly changing personnel has now applied for over 200 jobs in conjunction with his various DSP service providers has been only able to secure car cleaning employment and was recently unsuccessful in his application for chemist delivery person. George has lost hope in finding a job that can match his skill set.

RECOMMENDATION 11: MONITORING OF EMPLOYMENT PRACTICES - AV ENDORSES JOBWATCH'S SUBMISSION TO JOBSEEKER INQUIRY VICTORIA

Specifically, these [Jobwatch Submission Recommendations](#) nationally:

- Expand the definition of Employment Activity discrimination in the *Equal Opportunity Act 2010* to expressly make it unlawful for employers to:
 - a) dismiss an employee for the purpose of preventing the employee from becoming protected against unfair dismissal: and
 - b) dismiss an employee because their employment subsidy expires.
- Reverse the onus of proof in relation to Employment Activity discrimination so that the onus of proof rests with the employer to prove that it didn't unlawfully discriminate against its employee.
- Require annual reporting by certain employers regarding relevant employee statistics, e.g., length of service, employment subsidies, employees with disabilities and other disadvantages etc.
- Make employers who systematically abuse Government subsidies ineligible to benefit from further subsidies.

RECOMMENDATION 12: GOVERNMENT TERMINOLOGY OF "DIVERSITY" TO INCLUDE NEURODIVERSITY SO INCLUDE AUTISTICS IN TENDER PRE-REQUISITES

We are aware of government terminology that diversity includes gender, indigenous/race, disability. This means that in government tenders, corporate contractors are required as part of contract to employ people from a range of diversity backgrounds. If this was changed so this tender terminology specifically included "neurodiversity" you will more effectively capture our capable Autistics in this employment opportunity.

RECOMMENDATION 13: SUPPORT PARENTS SO THEY UNDERSTAND BEST WAY TO SUPPORT THEIR ASD1 JOBSEEKERS

Our model is based on research from Canada and internationally about how a 'Circle of Support' is critical. Our programs include educating and empowering parents. Our educational events also cover these topics.

Recommendations 14 – 21:

RECOMMENDATION 14: SUPPORT OF SPECIALIST PEER SUPPORT ORGANISATIONS WITH CONTINUED FUNDING TO ENABLE NON-COMMERCIAL SOCIAL ISOLATION SUPPORT.

Recognition of the preventative health support and mental health benefits that peer supports can provide and the insight of lived experience must be taken into account. Homogenised peer groups for 'carers' or for 'autistic teens' are not specific enough for the needs of our community. We started off with just a few peer groups in the 1990s with the demand continuing to grow for this preventative health support. Our community do not find enough support, acceptance or understanding elsewhere.

Our Groups have been designed by our Aspergers peers and provide unique opportunities for connection with those dealing with similar challenges and growing similar strengths. During COVID our online groups have expanded nationwide and many of the attendees are appreciating this support and peer community gathering. We had a teen from Alice Springs join our Teen Discord Group this week and his parents joined our Teen Parent Group with such relief to find others who share their experience.

Many Aspergers/ASD-1 Members continue to tell us our groups and events are their **only community activity** each month and how they look forward to it. With our Teens Groups, our isolated teens have requested twice monthly, as there are many who cannot manage the social demands of school yet want to have friends and feel included. For some teens and also young adults, this provided their first true friendships and first birthday party/dinner invitations.

Our lived experience organisation's peer groups continue to expand to provide essential peer support including for:

- Parent and Carers (Carers Victoria cannot provide the specific understanding and support our parents are seeking)
- Partners
- Teens: Dungeons and Dragons, Minecraft servers, social activities such as bowling
- Young adults
- Adults
- LGBTQIA
- all of whom have different issues to share and grow together

In the world of more commercially based services, having a lived experience not for profit provides our community with an organisation **they feel they can trust** and an organisation that understands them at its core – and most importantly, speaks their language. Lived experience organisations needs to be supported as well as Autistic-led organisations.

RECOMMENDATION 15: IMPLEMENTING A NATIONALLY CONSISTENT SCHOOLS APPROACH FRAMEWORK/OR BEST PRACTICES AND EQUALITY IN FUNDING SUPPORT FOR AUTISTIC STUDENTS. WITH FORMALISED NATIONAL KNOWLEDGE SHARING AROUND EDUCATION INCLUSION AND SUPPORTS

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 system classifies as a “language deficit”, though our ASD-1 students’ literal interpretation and communication deficits impact their ability to learn and be include in the current school approaches.

There needs to be a change in all education systems to move towards the Queensland funding model to support the needs and challenges of our ASD-1 Autistics.

In Victoria our students miss out on funding supports, (except in the Catholic System) as our students do not have what the system classifies as a “language deficit” though our ASD-1 students’ literal interpretation and social communication deficits impact their ability to learn and be include in the current school approaches. The trauma and stress of not being able to manage school and the education system means many leave school early, fail to reach their potential and the statistics show they start a pathway of mental health challenges. Victoria is trying to change its model but the set-up of the Education Department means that those with special needs are often not accounted for.

Without funded supports our community is traumatised from their schooling experience and ends up in the mental health system with too many cases of suicide.

RECOMMENDATION 16: ENABLE A NATIONAL EDUCATION SYSTEM THAT ACCEPTS AND SUPPORTS DIFFERENT LEARNING STYLES

The aim should be inclusion for all in the school type of their choice. The approach of trying to include everyone in the one school model is not feasible – we need different types of schools and teaching approaches as we have such a variety of individual and educational needs. For some this will be distance learning and for others it may be a structured approach or a combination of the two. A diversity of schools is essential to cater for broader learning needs. The States need to have accountability in how they deliver this for Autistics which impacts their future funding.

If education was made more relevant for the current job market and included communication and social learning supports, enterprise building focus with a work readiness focus earlier in the current education and the DET support systems we would be having less issues once our Members leave school.

RECOMMENDATION 17: IMPROVE CO-ORDINATION BETWEEN GOVERNMENT AGENCIES SUPPORTING AUTISTICS INCLUDING NDIS, CENTRELINK AND JOB SUPPORT

Improve the interaction between services provided by the Commonwealth, state and local governments, including:

- health and mental health,
- education,
- **employment,**
- justice, and
- housing;

These services all also need specific requirements about building understanding of autistic strengths and challenges. This has been done for gender and indigenous – and now autism requires this inclusion.



GOVERNMENT departments should also continue to **role model** for employers by increasing their targets to include autistics in their roles and design roles to suit autistic strengths and capabilities while meeting challenges.

RECOMMENDATION 18: MORE AUTISTIC-COMMUNITY-LED RESEARCH

More research is needed:

- about ASD-1 in employment and specialist supports that work
- into specific challenges so research learnings build knowledge and suitable approaches for specific challenges across Autism

Build understanding of the heterogeneity of Autism and the variety of approaches that support common challenges. The autistic community can tell us what they need more information about. The Autism CRC has made a start on this approach and should be supported and broadened. Funding needs to also be provided to the issues of our more capable Autistics – as well as the more severely challenged.

RECOMMENDATION 19: NDIS SUPPORT

We agree with the submission by Autism Advisory Support Service on the improvements required for NDIS supports and request the Inquiry consider these thoroughly.

RECOMMENDATION 20: CRISIS SUPPORTS for SAFETY NET FOR FAMILIES IN CRISIS

Currently there are no safety nets for families who cannot cope with children presenting with escalating violent and aggressive behaviours. For those who call an ambulance, they are given a sedative and by the time they reach the hospital, they are calmer and are told to go home. For those with no informal supports they are faced with nowhere to turn and an on-going cycle in and out of hospitals and mental health wards.

RECOMMENDATION 21: NATIONWIDE MEASURE OF THE PREVALENCE OF AUTISM IN AUSTRALIA

We need a consistent measure to track this including capability levels under the diagnostic system. This should also include Social and Communication Disorder which many in our community are diagnosed under instead.

It is imperative that AV be consulted with regard to understanding ASD-1/Aspergers and developing programs and training as we are the only organisation that is specifically dedicated to understanding and representing Asperger individuals. We are an organisation that is for Aspergers and by Aspergers WITH ASPERGERS.

**Thank you very much for inviting our submission.
We welcome feedback and insights that are helpful for our community.**