



Selected summary of key themes and comments from autistic people and their families on their experience within the education and employment systems

### Background

The following paper presents a collated summary of long-form responses to a national research project into the experiences of autistic people in Australia conducted by Professor Sandra Jones of the Australian Catholic University, on behalf of the Australian Autism Alliance.

These responses are unedited and offer an unfiltered insight into how autistic people and their families and carers have interacted with the education systems at the primary, secondary, vocational and tertiary levels, and their experiences in the workforce and broader employment system.

The summarised responses are intended to give insight into the experience of autistic people through their open responses to questions. As such this paper should not be considered to be a representation of Professor Jones' full research report.

### Education: Experiences in primary and secondary schools

<b>Section 4: Education – Primary and Secondary</b>
---

<u>Asked of ALL</u>
---------------------

4.12 Is there anything else you would like to say about autism and education?
---

<i>(eg., about your own experience or what could be done to improve autistic people's access to and inclusion in education)</i>
---

### Responses:

- 1322 from parents/carers

### Key Themes

- Ongoing education and training on ASD for all teachers and aides

- Educating students on ASD
- Little support from DET
- All ASD children should receive funding no matter what level and their IQ
- More funding for 1:1 supports
- Sensory/quiet spaces at school
- Better/more education for staff regarding girls with ASD
- Better education in pre/post grad courses
- Bullying
- Difficulty finding the right fit (school)
- Not enough places in special schools
- No inclusion in mainstream schools
- Being refused enrolment to school due to disability

## Comments

- *A definite increase and ongoing education on ASD for all teachers. Proper support teams for schools to access. Greater support with human resources in classrooms to support management of children and their education. One is two support for anyone with a level 2 diagnosis mandatory. Level 1 with 1 is to 5 support or daily check ins with a case manager. Access to expert supports via inclusion and guidance officers throughout schooling.*
- *A lot more could & should be done to educate everyone, other parents, teachers & kids about autism, what it means, what they can do for & with the child with autism etc. A lot of issues would be avoided if this was done. My son tackles other kids, & hurts them without meaning to, parents are emailing the school complaining, & my son is punished.*
- *All public education should be supported better, to improve student wellbeing, and counterbalance the limiting values of competition and survival of the fittest. If the general atmosphere and culture in a school encourages broadmindedness, a love of learning and is actively inclusive, autistic people benefit alongside all students.*
- *As a teacher, I do not think that enough training is provided to mainstream teachers and support staff to understand autism well enough. I taught in mainstream schools, but now in a special school, and I know that mainstream schools are nowhere near well enough equipped with the knowledge, strategies or resources to successfully integrate children with more complex autism.*
- *Childcare facilities didn't receive enough funding for my child to cover the FULL cost of an additional worker. Enrolling my child meant that they required an additional worker, and would therefore be out of pocket. As such, they said they wouldn't hire additional support and my child would be at significant physical risk if they attended. This meant my child had no access to childcare, and this effected my employment opportunities.*
- *Doing mainstream with autism is extremely challenging and exhausting but with the right supportive school there is hope*
- *I feel although very bright they get left behind and are not able to navigate the emotional side of school. I spend a lot of time having to go in and advocate for my child*
- *It's about finding the right fit & not trying to make them fit. I don't think there is enough support in the private education space, it's funded differently. I believe my daughter is just as worthy of a private catholic education but feel as though she is disadvantaged by not getting the right amount of support in the classroom. Public school she has 15 hours per week but the school was not the right fit. Too big. Found the right school but minimal individual support. It is up to the teacher who has 30 students.*

- *Mainstream school funding is inadequate to meet the needs of some children whose intelligence negates their ability to attend specialist school but whose behaviours are too challenging for mainstream programs*
- *My child has been suspended repeatedly. She has been suspended for up to 14 weeks at a time. The school is not equipped to manage her challenging behaviours*
- *Schools and education departments should be made to be more transparent when it comes to funding for disability access. Not once in some 12 years of schooling have we been given a straight answer as to how much funding is provided or how it is spent. We are suspicious that the funding is diverted for other purposes but obviously have no proof of this as there is no transparency at all and no accountability.*
- *This is our 2nd school as my daughter had 4 years of school refusal and our first school didn't have the capacity to cater for her, we now live separately as a family for the school term. 8 hours apart for 10 week terms with no financial support from any government group*
- *I'm very upset about the line between disability and education. My son can't get the care he needs with his education at the special school because you have to under a "certain line". Now my son is back in mainstream school after only attending the special school for 1 year. Now he's back to being bullied again and having no friends, which is playing a big impact on his mental health, self esteem, education etc.*
- *My son doesn't fit into either special education or mainstream, I am not able to home school. There needs to be an alternative*
- *Our son's school has completely left him out of every school camp, mainstream excursion and Aboriginal education experience. During the excursions with his support class we are required to attend so that our son receives the support that he needs. He no longer wants to attend school.*

5.11	<p><u>Asked of those who answered YES to "Are you /they currently enrolled in some type of further study?"</u></p> <p>Is there anything else you would like to say about your / their post-secondary education experience? What could be done to improve your / their experience accessing a post-secondary education?</p>
------	--

#### Responses:

- 90 from autistic adults
- 47 from parents/carers

#### Key Themes

- More understanding from the teachers.
- Better training for the educators to understand the student's needs.
- Lack of disability supports eg. Mentor, buddy, guidance with enrolments, one on one tutoring
- Course deadline flexibility
- Late diagnosis

#### Illustrative Comments

- *His life at university has been impacted by his refusal to tell the university that he is autistic, he feels that it would single him out and expose him to the same bullying he experienced at high school.*

- *Never felt supported at high school and career advisor suggested he should find a trade. It was made clear to the school he hoped to achieve an athletic scholarship to a US college which has subject requirements for eligibility, however the school would not allow him to do some of the required subjects as they did not have the ability to support him, making the process a lot more challenging. All students should have access to support needed at school to help them achieve the outcomes they hope to achieve*
- *Consideration of access needs for Autistic students is almost non-existent - there needs to be education for administrators etc of universities and VET/TAFE*
- *Had to be home-schooled for high school due to bullying. No educational support provided as my mother had to do this all on her own.*
- *Hmm. MAYBE JUST MAYBE neurodiversity modules and units could be introduced into training, and as required qualifications to be able to teach or be in charge of the structure of a school, in the same way OHS learning is required*
- *I have suggested on many occasions to my university that it would have been extremely helpful to have a dedicated autism/ADHD department/area on campus (and on all the campuses), where students could freely access face-to-face specific help, workshops, groups, peer mentoring and private support for their autism/ADHD, which I feel would also help to lower the stigma of autism and ADHD on campus, but to no avail as the executives of the university feel that there is more than enough help and support on campus and throughout the university on all the campuses, which is just not true. Nor do the executives seem willing to listen at all that way more help and support are needed.*
- *I think what could be improved is an Autism-focused service from deciding what course to take (e.g access to career counsellors as my Uni doesn't allow you to see them unless your a student which I think is stupid and disrupts the settling in the process). Also, it would be great if this service that Uni could have would help you from O-week to post-graduation e.g. from dealing with lectures, admin staff, challenging and complex situations such as complaints and advocacy etc. (Also particular support on how to engage at other supportive services such as counselling and perhaps training staff in Autism awareness, an University Autism plan under the Disability plan would be a great start!*
- *It's been horrible, I don't feel like I am listened to at all in the support services, and the teaching has been so inconsistent. Half the lecturers straight up refuse to record lectures, disability service did not advocate for my need despite having an auditory processing disorder, they just said that was it and they can't change it. It has taken me 8 years to get to doing my last semester of my degree. The whole experience has been depressing*
- *Improve transitional skills from high school to university through self management skill education*

## Employment: Personal challenges in finding a job

Section 6: Employment	
6.20	Asked of all autistic adults AND all parents/carers responding on behalf of someone aged 18+ What is the most difficult thing about finding employment for you / them personally?

### Responses:

- 665 from autistic adults
- 323 from parents/carers of autistic adults

### Key Themes

- Anxiety at interviews
- Interview process
- Being a carer and their responsibilities
- Disclosing autism
- Finding a job that is supportive & accepting of ASD
- A job with suitable and/or flexible hours
- Maintaining employment

### Comments

- *Being accepted as an autistic person. Journalists are accepting of 'difference' but at my age I cannot cope with a lot of stress so that work is no longer suitable for me. Also the discrimination and harassment by management I experienced at my last two jobs means I do not have job references and this makes it very hard for me to get another job because potential employers insist on these.*
- *Communication skills, social anxiety, executive functioning difficulties, auditory processing disorder*
- *Employers not having an understanding about autism which leads autistic people like myself being misunderstood and then "let go" for atypical behaviour/reactions*
- *Employment has always been difficult or impossible for me as for all my adult life I have lived with autistic burnout, which was made much worse as I was not diagnosed with autism till last year age 47. Now I know I am autistic I am learning how to manage myself and my life much better. With further learning and therapy, I will be able to manage my condition better, and maybe one day find some part-time employment. I do not think it likely I will ever be able to work full-time due to the exhaustion and fatigue caused by sensory and social situations. I will always need to manage and regulate my life carefully, and I need a lot of quiet time alone to regulate and recover after sensory and social inputs. I currently do volunteer work in the local school library for 2 hours on 3 mornings a week, and each day it takes me at least 1-2 hours to recover afterwards.*
- *Filling out forms, making phone calls and communicating with people I don't know is draining on my executive function and means that I am unable to do other things with my time*
- *Finding a job that is suitable - hours, location and flexibility. I am the primary carer of two school aged autistic children who need my care on an ad hoc basis and require various appointments. The children's father (my ex) refuses to take the kids to any appointments so it falls upon me.*
- *Finding something that will suit my sensory needs, and that will accept me as I am.*

- *I cannot even imagine a job which would suit my needs and disability, let alone one where the employer would be able to accommodate my needs. I prefer to volunteer as then I am able to say when I am too unwell to help/ work.*
- *I have social anxiety so I am rejected from many jobs for being socially awkward or not having enough confidence. Too many jobs most highly value social skills and it takes me a while to adjust to new people. As such, job interviews and trials are usually embarrassing. I am not good at networking and being told to apply for jobs in person gives me lots of anxiety. It can also take me longer to learn some manual skills (e.g. setting up equipment) and so being put under pressure to perform these tasks in interviews also highlights my weaknesses and results in rejection.*
- *In my experience I had had no difficulty with finding employment, my challenge has been with maintaining it. I have the ability to demonstrate my skills and to engage in an interview, however the gaps in my ability emerge after a matter of weeks or months in employment. In some circumstances I have struggled to maintain employment beyond 6 months, whilst in other situations I have maintained the employment at significant emotional turmoil to myself and conflict with others.*
- *The interview process. It can be difficult for me to process the questions and respond with coherent answers in a timely fashion.*
- *The traditional recruitment process is extremely ableist, from the way that job ads are written (e.g. only wanting people with a licence even if no driving is involved in the job, or wanting people with years of experience for an entry-level job, or expecting applicants to be already perfect at every skill), to the unspoken rules and expectations (e.g. being expected to write a thank you email after an interview), to the way that interviews are conducted altogether. Also, the relatively recent emphasis on networking is disheartening for people with social challenges.*
- *Writing my CV, answering the selection criteria and the interview. My brain especially doesn't function well in interview situations - my mind goes blank, I can't remember how to say some things, I stumble over my words and sometimes stutter, I don't know where to look, I feel like I'm being interrogated by the Gestapo, I have difficulty interpreting their questions and figuring out what they're looking for in an answer etc etc etc. I have difficulty not stimming during interviews and have to have great control over my face to not indicate all the turmoil and confusion going on inside my head.*

## Employment: General challenges in finding a job

6.21	<p>Asked of all autistic adults AND all parents/carers responding on behalf of someone aged 18+</p> <p>What do you think is the most difficult thing about finding employment for autistic people in general?</p>
------	---

### Responses:

- 643 from autistic adults
- 301 from parents/carers of autistic adults

### Key Themes

- Anxiety
- Lack of understanding/empathy of ASD
- Discrimination
- The right employer

- Flexibility
- Interviews
- ASD Stigma

## Comments

- *Better support and knowledge is required by the potential employee and employer*
- *Anxiety, social skills, prejudging, low self esteem, lack of support*
- *Community attitude is KEY barrier.*
- *Employers don't have the time for extra need workers*
- *Having the self-confidence to apply and the interview process is very overwhelming. Group interviews are hard.*
- *People do not want to hire a person with a disability. Stigma Anxiety about being judged*
- *The fact that people need to change the way they speak to them or adjust the environment or adjust the training to suit the learning style or provide support, and many don't have the time, resources or willingness to put in the extra effort. The initial application and/or interview - this is where communication disorders and impaired social skills become obvious to the employer, and they are often disregarded on this basis before they have the chance to prove themselves capable of the tasks involved in the job. Some people expect autistic people to fit a certain mould - good at computers, coding, maths or some other innate talent. But that doesn't fit most.*
- *With severe Autism, the difficulties of emotional regulation are not easily managed in a workplace. Employers can't be watching for and managing emotional outbursts.*
- *Not seen as being 'value for money'*
- *Finding a supportive workplace*

## Employment: Other general comments on experiences in the workforce and employment system

<b>Section 6: Employment</b>	
6.22	<u>Asked of all autistic adults AND all parents/carers responding on behalf of someone aged 18+</u> Is there anything else you would like to say about your / their employment experience? What could have been done to improve your / their employment experience?

### Responses:

- 405 from autistic adults
- 184 from parents/carers

### Key Themes

- More support
- More volunteer opportunities
- Employers to have a better understanding of autism as a disability
- Inclusive employment practices by companies as a priority
- Training and empathy from employers and co-workers
- A mentor, support person or advocate within the workplace
- Difficulty with expectation in work social events
- Better understanding of sensory issues and sensory accommodation
- Bullying within the workplace
- Part time and flexible jobs
- Feeling “lucky” to have a job
- Training for employers and potential employees in interviewing
- More support from employment agencies writing CV
- Proper enforcement of anti-discrimination laws
- Late diagnosis

### Illustrative Comments

- *Better community education about Autism and potential communication & anxiety issues. Possibly, an Autism centred employment website?*
- *Courses available to prospective employers and co-workers to provide an overview of how to support individuals with Autism would be a start. It is a Spectrum so this would not encompass all relevant information to support all individuals with Autism, however, it would provide an insight.*
- *Disappointed in understanding and inconsistency of disability support agencies. High turnover of staff, not enough time support given. Not enough choice in agencies. Some won't even get back to you after several attempts to contact them. Feel like they're in it for the funding not the promises they advertise.*
- *I think to educate employment agencies to better understand people with autism.*
- *Working in a disability enterprise has been ok. He has the supports and some understanding of his autism. However it is repetitive work with little stimulation and I know he is capable of so much more if we could find the right environment. Also, the system of a disability*

*enterprise is very unfair monetarily. They receive a large amount from his NDIS plan to support him. They also receive the payments from the companies that pay for the work provided. Yet they only pay the employees \$3-4 per hour. They are raking in the money from two sources while our kids have to stay on disability support pension to survive. It is more like "somewhere for them to go each day so they are not staying home" than employment.*

- *All kinds of 'normal' stuff is MUCH harder when you have sensory processing issues, for me an open plan office with fluro lights is like trying to work in a disco. A desk that is also near the lunchroom has actually brought me to panicky tears just from the noise. "Team building" activities often directly make you feel more isolated and different and are often even more anxiety producing - 'Getting to know you' games should be abolished! But if you don't participate you are seen as not a team player. I have literally needed to take 2-3 days off to recover from 'social' events planned by work as a 'fun' activity.*
- *Empathy and an effort to understand that different people can do things in different ways and that is ok. I was accused of being rude, cold, angry, scary and emotionless in the workplace. It made me very uncomfortable. But also confused, as I could not understand why they felt this way. I did a good job, and this was acknowledged, also.*
- *I am an intelligent, articulate, pedantic, passionate person. Yet, not a single employer would give me a chance. Not in my teens, not my 20s and not my 30s. I gave up. Taking a chance on any person who appears to have the drive and ability to do a job should be enough, despite their obstacles (and if anything the fact they are striving to overcome and deal with their obstacles and have been for decades, should demonstrate the gusto of the person, which is always overlooked).*
- *I am one of the top performing employees in my company's location. However, I wouldn't be if I didn't have extra supports from them. I have learnt from my most recent successful experience, that if open conversations are able to occur with direct management in relation to my preferred learning style, the support I would like for my role, how I would like feedback, and so forth. This allows me to feel in control of the situation, and allows me to reflect on how I want to be supported versus my 'difficulties or support needs'. It normalises the situation - a situation that actually is very normal. As a very high functioning Autistic, being in control and respected is paramount to my success.*
- *I just live and work, because I cannot kill myself. It's making me so depressed after I start to work for surviving. I can feel it's killing me. Mentally and physically for sure.*
- *I wish the mantra 'bring your whole self to work' applied to us. We're welcome as long as we act like everyone else. And if we want to succeed we have to pretend to be something else. I'm so tired and I can't even talk about why.*
- *Not working has been the best twelve months of my life. The POVERTY i am experiencing right now is worth it when I am not forced to function, pretend i am neurotypical to fit in. I am very rarely having shut downs now. Customers would often complain about me and it was always simple misunderstandings about something I'd said or the way I'd used tone/body language. Managers didn't care about my side, only the customers opinion mattered.*