

# Educational Experiences and Needs of Higher Education Students with Autism Spectrum Disorder

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**Abstract** Little research directly examines the needs of post-secondary students with ASD. The experiences and support needs of 23 students with ASD enrolled in two universities and four colleges, and 15 family members were explored in 15 semi-structured focus groups. Thematic analysis identified five themes: core ASD features, co-morbid conditions, transition, disclosure, and services and support. Most students felt educationally but not socially supported; most families felt support was poor in both areas. Transition from secondary school was often unplanned, and disclosure of diagnosis usually occurred after enrolment, often following a significant problem. Many parents provided substantial student support. Thus disclosure of ASD diagnosis and meeting the individual needs of these students are important considerations as higher education enrolments increase.

**Keywords** Autism spectrum disorder · Transition · Higher education · Students

## Introduction

Autism spectrum disorder (ASD) is a lifelong developmental disorder whose primary features are social-communication deficits, and restricted, repetitive and stereotyped patterns of activities, interests, and sensory sensitivities (American Psychiatric Association [APA]

2013). ASD is also associated with a range of co-morbid conditions and cognitive difficulties, including anxiety and depression (Boyd et al. 2011) and executive dysfunction (Hill 2004). While ASD is associated with intellectual disability (APA 2013), around 50 % or more of individuals have an IQ in the normal range (Centers for Disease Control and Prevention 2014; Mayes and Calhoun 2003).

The prevalence of ASD is currently estimated to be at least 1 % (APA 2013) and in the UK, a recent survey found that 1 % of older adolescents and adults were living in the community with undiagnosed ASD (Brugha et al. 2011). Similarly, White et al. (2011) surveyed 667 USA university students and identified 1.9 % of students with significant symptoms of ASD. Of eight students formally assessed, five met clinical criteria for ASD and none had previously received an ASD diagnosis; only 10 students with an ASD diagnosis were known at the time to the university student disability office. Thus, a significant proportion of adults in the community, including at university or college, may have ASD and may be undiagnosed.

While social-communication deficits and repetitive behaviours tend to improve over time (Howlin and Moss 2012), they nevertheless continue into adulthood (Seltzer et al. 2004), and few adults with ASD, including those with good language and cognitive abilities, have good employment or educational outcomes (Farley et al. 2009; Magiati et al. 2014; Seltzer et al. 2004). Most individuals remain dependent on family support, with at least half remaining in the family home (Farley et al. 2009). Furthermore, even when individuals with ASD do enrol in higher education, they may not reach their academic potential (Van Bergeijk et al. 2008). For example, Wei et al. (2013) reported that in the USA, individuals with ASD had one of lowest rates of college enrolment, with over 50 % of these young adults being in neither education nor employment during the

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initial years following secondary school (Shattuck et al. 2012). Similar findings have been reported in the UK (Howlin et al. 2004). Many students with ASD who are intellectually capable are unable to complete their studies due to problems such as excessive stress, high dependence on families, and social isolation (Glennon 2001; Howlin et al. 2004; Jobe and White 2007; Van Bergeijk et al. 2008).

Lack of education and employment has negative financial consequences for individuals, families and communities (Jarbrink et al. 2007). A UK cost analysis of children and adults with an ASD showed that those with high-functioning ASD (HFASD) suffered significant costs associated with their condition, including lost employment for both families and the individual concerned (Knapp et al. 2009). Such costs can be expected to reduce if there are appropriate community supports and services for people with ASD, including educational services that ensure that children with HFASD complete secondary school and transition to and complete higher education or vocational training. Education and vocational training are the first steps to wider community participation and gainful employment.

Despite difficulties in interpersonal skills, the intellectual potential of many individuals with HFASD is high, provided appropriate educational supports are implemented (Van Bergeijk et al. 2008); pursuing post-secondary school education is possible for these individuals (Taylor and Seltzer 2010). However, without appropriate supports, individuals with HFASD are at risk of exclusion or failure to complete educational qualifications. Recent evidence suggests that help provided for young adults with ASD to transition to, and support them in, post-secondary education or finding and keeping the employment is at best uneven. It does not successfully prepare these individuals to join the adult world (Howlin and Moss 2012). Poor outcomes in transitioning from secondary school to adulthood are illustrated in a recent USA national survey (Shattuck et al. 2012), showing that after young adults with ASD left the public school system, 80 % continued to live at home, only 32 % attended postsecondary education, just 6 % had competitive jobs, while 21 % had no employment or education experiences at all. Further, 40 % reported having no friends.

Most of the available information about how best to support students with ASD in higher education is based on professionals' expert knowledge and experience working with these individuals (e.g., Dillon 2007). Little research has directly examined the experiences and needs of people with ASD, or effective educational supports that address their needs. Research is essential to support the development of programs that target the needs of young adults with ASD. The aim of the current study was to directly examine the experiences and support needs of students with ASD

currently enrolled in either Technical and Further Education (TAFE) colleges or Universities in Victoria, Australia. As families remain a significant source of support in the lives of adults with ASD and many still live at home, family members of these students were also included.

## Methods

### Participants

Twenty-three Victorian (Australia) students with ASD were recruited from the metropolitan and regional campuses of four TAFE colleges and two universities. These students must provide evidence of a formal diagnosis of ASD to receive services from their institutional disability support unit. Fifteen family members (14 parents, 1 sister) were recruited through the students.

### Materials

#### *Students*

The Autism Spectrum Quotient (AQ; Baron-Cohen et al. 2001) is a 50-item, self-report screening questionnaire relating to behaviours associated with ASD. Questions are answered on a 4-point Likert scale, which are coded 0 or 1 for scoring. Scores  $\geq 26$  are consistent with the presence of ASD (Woodbury-Smith et al. 2005).

Students also completed questions including demographic information, and information about preparation for higher education, academic performance, motivation, disclosure, disability support, academic support, social support, student rights, transition support provided by their family, social and educational support provided by their higher education institution, and awareness of the Australian Federal Disability Discrimination Act (DDA) 1992. Answers were open-ended, yes/no, or rated on a 4-point or 6-point Likert scale.

#### *Family Members*

Family members completed a question about their awareness of the DDA and rated the support provided by the higher education provider for their student's education and social support needs.

The Social Communication Questionnaire—Lifetime form (SCQ; Rutter et al. 2003) consists of 40 yes/no questions primarily related to the social-communicative difficulties found in ASD. Scores  $\geq 15$  are indicative of ASD (Rutter et al. 2003), however in the standardisation sample those with a diagnosis of Asperger's disorder scored from 10 upwards. Furthermore in children a cut-off

score of 11 has been reported to be more sensitive (Allen et al. 2007). Thus, we used a score  $\geq 11$  as indicative of ASD.

### Focus Group Themes

After reviewing current literature on the needs of higher education students with ASD, an initial list of themes was identified that may be applicable to students and their parents. For the student focus groups themes included course selection, transition to higher education, orientation, disclosure, disability support, assessments, academic support, organisation, stress and anxiety, social life, and daily living. These were used to develop 22 questions for the student semi-structured focus groups. The questions were open-ended and researchers explored the students' higher education experiences. For family member focus groups themes around transition to higher education, concerns about their child with ASD, actual support provided to their child, views on the support provided by the higher education institution, the support needs of parents, and their child's need for self-advocacy skills were used to develop 17 focus group questions (see Table 1 for examples of Focus group questions).

### Procedure

Ethics approval was obtained from the University Human Ethics Committee, following which permissions were obtained from the students' institutions as required. Students with ASD registered with their Disability Support Unit were informed about the study by unit staff. Where student permission was granted students were then contacted directly by the researchers. Following student

permission, student-nominated family members were also invited to participate in the family focus groups. Participation was voluntary and informed consent was obtained.

All focus groups were conducted at the students' respective higher education institutions. Each focus group consisted of a single session lasting from 1- to 3-h. Nine focus groups were conducted by two researchers with one as a lead facilitator (RC), and the other as a co-facilitator and note taker, and the remaining six focus groups were conducted by the first author. Focus groups varied from one to four participants; nine were student focus groups and six were with family members. An Olympus WS-450s digital voice recorder was used to record all focus group sessions.

### Focus Group Analysis

Focus group recordings were transcribed from the audiotapes by RYC (4 groups) and the remainder (11 groups) by an external transcription service. Filler words such as "um", "you know", and "like" were eliminated to aid readability and data analysis. Before analysis, the audio files and transcripts were compared for accuracy, and any errors corrected. NVivo 9 software (QSR International 2010), was used for organizing and coding data. The initial list of themes developed for the interviews was used to code all the transcribed data and at the end of the first coding iteration, some themes were added while others were removed. Both the first and second authors reviewed the themes and conferred, and a second iteration of coding was conducted by organizing the information into sub-themes in order to refine and specify the coding information. This final set was used to organise and report the findings, which are presented anonymously.

**Table 1** Examples of focus group questions

#### Students<sup>a</sup>

Do you feel you needed more support during the transition from high school to university/TAFE?

What things did you do to prepare yourself for university/TAFE?

Some examples are taking a summer course at the end of high school; attending camp prior to first day of class; reading through information on the university/TAFE website; studying the campus maps, taking a tour of the campus; locating the classrooms for the first day of class; registering for classes prior to first day; visiting the cafeteria; visiting the bookstore; meeting the lecturers; reviewing the weekly schedule; attending orientation week

If you have a chance to give advice to your university or TAFE to improve your experiences, what advice would you give?

#### Parents<sup>a</sup>

Did you help your child plan the transition from high school to university/TAFE? Transition planning includes uncovering, developing, and documenting the skills, challenges, goals, and tasks that will be important as a student in tertiary education (yes, no)

If yes, how long ago did you start planning for this transition?

If yes, what are some of the things you and your child did to plan for the transition?

If yes, was this transition planning a formal process or informal?

What are some of the things that you worry about your child being at university or TAFE?

<sup>a</sup> Prompts used related to student and parent response to the initial questions and ensuing discussion

## Results

### Demographics

All students were registered with their institution's disability support unit. Twenty-two students had an AQ score, SCQ score or both scores consistent with their ASD diagnosis; one student had an AQ score <26 and no SCQ score. Majority of students were completing an undergraduate degree or a TAFE qualification and most lived at home (see Table 2 for student demographics).

### Higher Education Experiences

One student did not answer these questions, thus responses are from 22 students unless indicated. Most students (63.6 %) felt their educational needs were met, but few felt their social needs were met (27.3 %), while 27.3 % of students rated social needs as not applicable. Under half of family members thought that their student's educational (42.9 %) or social needs (35.7 %) were met. Overall, students (63.6 %) felt 'somewhat prepared' for higher education, but only two (9.1 %) felt well prepared; nine students (40.9 %) undertook readings of lecture or tutorial material prior to classes. Seventeen students reported their academic performance for the previous semester; only one student had failed and 10 (58.8 %) received a B average or second-class honours.

Fifteen students (68.2 %) had lost interest in university or TAFE activities or coursework, with 10 (45.5 %) of these students wishing they had someone to motivate them. Causes of poor motivation included disinterest in the subject area ( $N = 4$ ), workload ( $N = 4$ ), content difficulty ( $N = 2$ ), lack of energy and depression ( $N = 2$ ), and feeling overwhelmed ( $N = 1$ ). Two-thirds (68.2 %) of the students had discussed their learning needs at the beginning of their program; the remainder either did not wish to disclose for fear of discrimination or were not diagnosed when they began their program.

**Table 2** Student characteristics

$N$	23
Mean age (range)	$M = 26$ years, $SD = 11$ (17–59 years)
University	15 (11 undergraduate, 4 post-graduate)
TAFE (college)	8 diploma or certificate
1st year students	4
Program	Science or Technology: 30.4 % Arts or Social Science: 47.8 % Other non-Science: 21.8 %
Female:male	7:16
AQ score ( $n = 22$ )	$M = 29.8$ , $SD = 8.3$
SCQ score ( $n = 14$ )	$M = 23.8$ , $SD = 7.2$
Living with parents	61 %

Most students (72.7 %) reported interacting and networking with other students, and those who did not (18.2 %) reported this was due to communication and social barriers. Almost two-thirds of the students (63.6 %) had someone to speak with at their institution when they felt anxious or troubled, primarily disability support staff. Although less than half (40.9 %) the students knew they had rights under the DDA (1992), almost all students (90.9 %) felt that if their needs were not being met, they could discuss this with institutional staff. Two thirds of the family members (67 %) knew about the DDA.

### Focus Groups

Five key themes encompassing 10 areas were identified within the focus groups and are explored here under each theme subheading.<sup>1</sup> These themes encompassed the core features of ASD (Social-Communication difficulties and Structure, routine and sensory sensitivities), common co-morbid conditions (Psychopathology, Executive function, and Fine-motor skills) in individuals with ASD, Transition, Disclosure, and Services and Support (Disability, Academic and Family). Both the core features and co-morbid conditions impacted on students' transition experiences whilst the other themes identified are related to factors that are directly associated with the transition and higher education experience of individuals with ASD.

### Core ASD Symptoms

#### *Social-Communication Difficulties*

People with ASD have a tendency to interpret others literally (Attwood 2007). This can affect students' interpretation of teachers' instructions, leading to misunderstandings, which often have a negative impact on the student-staff relationships, peer relationships and student learning outcomes. Students may also become stressed as a result.

The sister of one student worried about the misunderstandings between her sister and lecturers. A student commented on misunderstandings with a staff member.

Student: I got an email from a lecturer once. I asked him, I've done this, is that okay or do I need to do this? He said, no what you did is fine. But what he meant was, no what you did isn't fine and you need to

<sup>1</sup> Extracts from the focus groups use the following conventions:

Short pause: ...;

Words omitted to shorten quote: (...);

Explanatory information added by authors: [text];

Multiple speakers: Student 1 etc.

do this. (...) Sometimes people say something but mean something else and [people with autism] don't understand the connection between an innuendo and a follow on statement.

Students with ASD often experience communication difficulties but do not want to draw attention to themselves, or appear different from other students; two students described their reasons for not seeking help.

Student: (...), I had absolutely no help [for] my situation at the beginning of the year. I didn't want to be treated differently, I didn't want to be treated like I had some kind of disease, which I think sometimes we are treated like, like we're lesser people or something.

Social-communication difficulties meant that students may prefer not to participate in group-discussions, or group assignments due to the inter-personal communication challenges presented, and the stress this may cause.

Student: I've had difficulties in tutorials, especially philosophy tutorials. Because you're expected to exchange ideas across the room and people discuss ideas. One person speaks and one answers. You don't know when to speak, start speaking. And when you actually get the chance to speak another person jumps in. I'm not sure if I should keep talking or stop talking. So that's a difficult situation for me.

Parent: x often came to me recently and said that in particular with group activities or work requirements that have to be done, she gets extremely angry and upset and stressed when other students don't contact her with work that has to be done, promptly.

Student preferences for assessment types differed greatly and some students described their ability to articulate their thoughts in written or spoken form.

Student 1: (...) I can't articulate my thoughts very well. I mean I can't write them down, I can speak it and talk about it in very, very knowledgeable. I just can't write about it.

Student 2: (...) I speak in gibberish and have to...you know it takes me 10 min to...pre-thinking to kind of you know...prebake a sentence. By the time I think of how to say something the conversation has moved on. But in writing I can say exactly what I want.

### *Structure, Routine and Sensory Sensitivities*

There was a consistent theme of students' preference for daily structure and routine. The lack of structure at

university compared with secondary school was unexpected and problematic. Students expressed a need for structure in academic settings, and difficulties were experienced when this structure was missing.

Student: I always assumed that uni would be just the same as school. When I got to uni - lack of structure. It was okay for the first six months but on the second I was wasting my time away on computer games, not doing the work. I wasn't getting the help I could have had. I think I just treated uni like school but less intense.

When structure was in place, students were able to cope better with the demands of their courses. Nevertheless, students with ASD had difficulty dealing with changes in class routines, as one parent noted: "Even just a new room or building is something really bad for [my son]."

Many students recognised their own preference for structure and routine. As one student noted: "For me, when uni forces me to use a structure and doing it in 10 smaller assignments each week, then that's okay. If I try to set a structure myself I never follow it. I plan but I don't follow it through."

Sensory sensitivities, for example to noise, may impact students' ability to cope within educational settings, and their coping behaviours may be misinterpreted by staff or peers.

Parent: My son is very sensitive to noise. If he's trying to study and there's a bumble-bee, he will get distracted. Quiet rooms are very, very much preferable, but not always possible. Walls without too many things, too many distractions is preferable because he gets distracted, which leads to anxiety.

Student: Those block out strategies [for reducing external stimuli] can appear as though you're vacant and not taking it in. (...) as a lecturer or tutor you can be looking at someone and you can think 'oh that student's spaced out' when in actual fact they're reducing the stimuli and that's what I talk about in my learning journey.

Core symptoms could affect students either individually or in combination. For example this student appears to have misinterpreted information about course and exam content, and refers to the need for structure to his/her learning.

Student: I once [failed] an exam with question on it, I thought well we didn't learn that. Do you know what I mean? And it was thrown in. Because it was out of the pattern and out of the structure of where I had to learn, it's thrown me.

## Co-morbid Conditions

### *Psychopathology*

Anxiety, OCD, and depression were a common theme commented on by both students and parents.

Student: Because the anxiety level is always there and just to survive each day and stick to your routine and not get off line, not get off topic or focus and to leave those obsessive compulsive disorder traits like cleaning and whatever else it may be, right down away.

One parent commented that students with ASD operate “on a level of anxiety that is equivalent to year 12 students [final year of secondary school], all the time”. Parents also had to manage their child’s anxiety and stress levels.

Parent 1: [My daughter] rebels or sometimes she would go into a deep dark depression and it’s quite common for Asperger’s to have depression with what they have as well. She’s on medication for that.

Parent 2: So is mine.

When stress and anxiety levels get extremely high, students may display anxious and unacceptable behaviour on campus. One student related her distress when her lecturer refused to help her.

Student: I’ve had a screaming fit in the middle of the corridor at the admin building. My particular lecturer walked away from me when I asked for help and I said, don’t you walk away. And I really lost it.

Most students developed coping mechanisms to reduce their anxiety, including reading, playing computer games, going to the library, seeing a counsellor or avoiding anxiety-provoking places and situations.

Student: I think what we’re talking about too is reducing the anxiety and I think if you get to [X’s] age and stage or mine or whatever, all people learn strategies to reduce their anxiety down. The problem is the anxiety level for young students is triple. Everything becomes magnified.

### *Executive Function*

Most students described themselves as being quite disorganized; parents also commented on their child’s poor organisation skills. Poor organisation had a negative impact on academics.

Student: I can get to class on time because I catch the bus and I have to be down at the bus stop before 7:15. I’ll be trying to wake myself up about 5:00 to have

breakfast and grab all my stuff but handing assignments in, I’m not that good because while everyone else has finished, I’m still struggling to even start sometimes.

Parent: [He] can learn, but it’s just his organisation skills that he can’t keep up with. (...) and that’s what lets him down. If he could organise himself he’d be okay.

A few students added that they can be organised and plan in areas that interest them but they are unable to plan for other areas of their lives.

Student: [I am] really disorganized. I try to be organized but it’s this uphill impossible struggle. It’s a wharf of chaos. Everything is just so random, chaotic, and I’ll try to be organized but it’s not going to end up being organized. I’ll just try to make it not as disorganized. Trying to minimize the damage.

Several students felt that one reason they were poorly organised was due to their being easily distracted and/or having difficulties with focussing on multi-component tasks.

Student 1: I find from past experience in high school was that it was very difficult for me to concentrate. I tend to notice things like [the] ceiling, or the examiner walking about, and that gets me distracted. And I can’t concentrate on the actual questions.

Student 2: That’s why I decided to get note takers. Problem is when I note take, I’m writing down what I heard last but not listening to what the teacher is saying now.

Students also commented that it took some time to process new information, impacting on their ability to absorb new information and complete assessment and classroom tasks on time.

### *Fine-Motor Skills*

Slow or poor hand-writing were reported by several of our students. This resulted in difficulties with note taking in class, on time exam completion, and staff having difficulties reading student work.

Student: My handwriting is of really poor quality, so uni gave me a computer to type. I used to get marked down on that in high school because they weren’t able to read it.

### **Transition**

We asked students about planning transition to higher education and their choice of study area. Most students

were studying in an area of interest but they arrived there via a variety of paths. Many students made the decision regarding area of study themselves while others obtained assistance from parents, careers advisors, disability support officers, and teachers. A student described his course selection process.

Student: Careers people at [my high school] was very helpful. I told them my interest and what I'm thinking of going into, she gave us the subject guides from different unis, and also if I didn't make it to [my preferred university], she gave me flow chart with different options for TAFE.

Transition from secondary school to higher education was often not formally planned and several students felt they needed more support over this period. Two students enrolled in a TAFE transition program for students with special needs, but this course was a negative experience for one student. Many parents provided support to their children for the transition from high school to higher education, while some students felt they did not prepare enough for the transition.

Parent: (Son's experience of a TAFE transition course): That was a disaster. It didn't work at all. They weren't able to communicate with me. (...) it'd just a horrible, horrible year. (...) He ended up suicidal and they really didn't tell me anything until I took him out of the course.

Student 1: I discussed [about transition] with Dad and some of his concerns were I'd be dealing with big lectures or lack of structure and what have you. A lot of my preparation was the day in the life of a uni student and folio workshops, speaking to the careers coordinator. (...) I visited [the university during orientation the year before]. On enrolment day, my Dad and I met the disability liaison officer the first time.

Student 2: I kind of didn't prepare for it. I didn't quite expect it to be the same as high school. But I wasn't expecting it to be as far removed from high school as it was. I didn't really lay the groundwork necessarily to prepare yourself for it.

## Disclosure

At most Victorian higher education institutions the first opportunity for students to disclose their disability is at enrolment. However, only one student did so because her parents encouraged her. Disclosure usually occurred because parents informed the institution's disability unit, either with, or without (student <18 years) the student present: "Well [my son] didn't want me to but I went and spoke to student services at [TAFE]"; or students were prompted to disclose by their parents, high school teachers,

or teaching staff at their higher education institute: "I don't think my mother would have given me any choice in the matter anyway."

A few students linked in with the disability support staff themselves, explaining the benefits of disclosure.

Student: In 2004 I actually had a nervous breakdown and that then led me to have having the diagnosis and once I was diagnosed I linked into [my university] and that provided me with resources. That dramatically altered my studies. I went from failing to succeeding.

## Services and Support

### *Disability Support*

Disability support staff reportedly assisted students in a range of areas, including time tables, subject selection, time management skills, special arrangements for exams and assignments, lecture or classroom aids for behavioural issues, peer mentoring, note-taking for classes and exams, raising class awareness of ASD, advocacy and referral to other services. For example:

Student: My special exam arrangements were mainly time extensions and rest breaks. And having the exam done in a separate room than the other people. And also when I have to do an essay type exam, I can do it on a computer.

Although comments about disability staff and support provision were mostly positive, students also had negative experiences including staff attitude, support being slow coming, unsuitable support, support staff being unable to provide help until proof of ASD diagnosis was provided, limited knowledge of ASD, long wait time for appointments due to limited resources, and insufficient support. There was a need for support that was targeted at the requirements of individual students. Due to stress and associated anxiety and depression, provision of timely support was critical for students with ASD.

Student: It's really hard to get a meeting with the [disability unit]. If you go into get an appointment for the first person, you're looking at 2 months. But even [if you are registered with them] you still need to wait for like a few weeks.

Parent: [My son] was put in full-time because it was cheaper to do full-time than part-time. I thought this is going to be too many hours. He won't cope. (...), within a couple of weeks he was stressing out majorly, going suicidal. .... The fact of writing things down and listening is too much. So we organised a note-taker but (...) he didn't actually start until the

second term. So all the first term, every day he's stressing out, "I want to do this but I can't do it, I can't cope". It was really bad.

### *Academic Support*

Helpful alternative arrangements, reasonable adjustments in teaching style and the importance of flexibility and support that addressed the specific needs of individual students were the main themes that arose regarding academic support.

Student: Flexibility. I think flexibility in terms of support services. Flexibility in terms of learning. Flexibility in terms of assessments. And then to be able to tailor the support to the students, so it works with them.

When ASD students received appropriate and timely academic support from their college or university, their anxieties were greatly reduced.

Student: I got a form that lets me get extensions because sometimes I freak out a bit. People can't really see it. I just keep it inside.

### *Family Support*

The majority of the parents, usually mothers, of younger students played an important and active role in their child's life. Many parents supported their child at home providing organisational, financial and emotional support.

Parent: Planning, reminding him, having his timetable on the fridge, so that I know which days are uni and which days aren't. But as far as meals [are concerned], I'd be looking after him as though he was a school kid.

Many parents felt they did not have the opportunity to provide as much support as they could within the academic setting. There was a lack of communication, or communication breakdown between parents and staff, sometimes associated with privacy laws, which could lead to negative consequences for students with ASD.

Parent: I explained that [my son] would not speak to her because he was ashamed but how could I help him. Well, we can't help you then.

## **Discussion**

The aim of this study was to understand the experiences and needs of higher education students with ASD and we obtained information from 23 current students and 15

family members. The students generally felt their educational needs were met, but did not believe that they received adequate social support, while parents generally reported that their child did not receive either adequate educational or social support. With one exception, students who had undertaken assessments the previous semester had passed their courses. Five themes affecting students' progress in higher education were identified: (1) core features of ASD, (2) co-morbid conditions, (3) transition preparation, (4) disclosure of diagnosis, and (5) services and support. Core ASD traits and co-morbid conditions, particularly anxiety and depression, and executive function difficulties (e.g., organisation, time management, attention) contributed significantly to students' difficulties at university or TAFE, which support previous research (Bellini 2004; Billstedt et al. 2005; Zager and Alpern 2010).

The transition period from secondary to post-secondary education is a critical time for students with ASD (Van Bergeijk et al. 2008) as it prepares them for higher education and provides the structure needed to reduce stress and anxiety. Many of our students had no formal transition planning and they did not feel adequately prepared. Where preparations were made, parents were often significantly involved, as well as teachers and careers advisors. Pancer et al. (2000) study of neuro-typical students found an indirect relationship between their stress level prior to enrolling in university and their adjustment six months later. As students with ASD typically experience stress levels exceeding those of their neuro-typical students (Glennon 2001), transition is even more likely to affect adjustment, indicating the importance of appropriate transition planning. Effective transition planning should identify the services to be provided and those responsible for implementing them, timelines, intended outcomes, and monitoring and follow-up procedures (Roberts 2010). One of the key considerations for transition planning is the disclosure of a student's ASD diagnosis to their higher education institution (Adreon and Durocher 2007).

In Victoria, students with disabilities are provided with additional assistance if they formally disclose (including proof of diagnosis), and register with their institution's disability support unit. Most of our students disclosed after enrolment, once classes had started, not at enrolment. Students can indicate if they have a disability or special needs at enrolment, but they are not required to disclose their specific disability, or to register with their disability support unit. Additionally, the potential benefits of disclosure of diagnosis and registration are not provided. Several students only disclosed and registered with their disability support unit following crises, which may have been averted if they were already known to services. If higher education institutions are to provide adequate services and supports for students with ASD before crises



occur, it is essential that they are aware of these students. This cannot occur without disclosure of ASD diagnosis and registration with support services.

Students with ASD may choose not to disclose due to past negative experiences, fear of discrimination or labelling, or a belief that they no longer have a disability. Bullying in secondary school is a common experience for adolescents with ASD (Van Roekel et al. 2010) and in the course of the focus groups most parents and some students reported bullying at secondary school. Thus, students may fear that disclosure will again expose them to bullying or other negative experiences. Students who successfully complete secondary school may also believe they no longer have a disability. A national, longitudinal, transition study (Wagner et al. 2005) found more than half of students with a disability receiving special education services during secondary school believed they no longer had a disability when they transitioned to higher education. Education about the confidentiality and benefits of disclosure will help students with ASD make informed choices on whether or not to disclose.

Students generally found disability support staff helpful; staff advocated on behalf of students, provided support during times of crisis, and ensured that a range of academic supports were provided. They were also able to educate teaching and non-academic staff about ASD; together with individualised student support, this can enhance student academic outcomes. Disability support staff also provided critical referrals to other student services, including counselling; counsellors can assist in addressing co-morbid anxiety and depression.

However, a lack of timely support may have unforeseen mental health consequences for the student, or the student may drop out. Several students and parents referred to the need for timely support. Lack of timely support seemed to relate to the number of support staff employed and suggests a need for more staff, and thus increased disability support funding. Researchers have noted that traditional disability support services in higher education are currently insufficient in meeting the needs of students with ASD (Ellison 2013; Knott and Taylor 2014; Van Bergeijk et al. 2008). Students with ASD may also need support options beyond the formal accommodations offered on campus including skill development such as self-determination and self-management (Getzel 2008). One strategy proposed to help students with ASD in improving their social and academic outcomes is peer mentoring (Adreon and Durocher 2007; Hart et al. 2010), which can be organised by the disability support unit. One of our students discussed mentoring as a form of support.

A range of research has assessed student mentoring in higher education (Crisp 2010). For example, students who participated in face-to-face mentoring programs

had a higher grade point average and retention rate (Campbell and Campbell 1997; Sorrentino 2006), and peer mentoring using self-regulated learning can be effective in supporting students with ASD and may contribute to improved academic success (Ness 2013). Online mentoring with four higher education students with ASD was perceived as positive and students reported learning new skills including studying, time management and social communication strategies (Richdale et al. 2012). Thus, mentoring may provide support for higher education students with ASD, but potential mentors will require training about ASD (Richdale et al. 2012).

Students registered with their disability support unit can also receive academic support via alternative arrangements, and reasonable adjustments to teaching style and assessments for their courses. Disability support units provide support and advice on time-tabling, subject selection, time management skills, examination conditions (e.g., separate room, extra time), restructuring of assignments, lecture theatre or classroom aids for behavioural issues, and note-taking, and raise awareness of ASD. Tailored supports can increase the chance of academic success (Glennon 2001) and our students reported that flexible academic support targeted at their specific needs was extremely helpful.

Poor communication, planning and organisational skills, which many individuals with ASD experience, including many of our participants, may be reflected in difficulties understanding instructions, and organising, planning and completing assignments. Furthermore, while none of our students reported having a specific learning disability, students with ASD may be affected (Shattuck et al. 2012). The disability support unit can provide referrals to the academic support unit.

Similar to Shattuck et al. (2012), majority of our students still lived at home with continued family support. When the student had not disclosed, or given explicit, written permission for their parent to advocate for them, privacy laws affected communication between parents and higher education staff when the student was 18 years or older. In some cases, this led to negative consequences for the student; a collaborative approach between staff and parents was often crucial in supporting the student and increasing the likelihood of their success. Thus, where a student still relies substantially on a parent or significant other for support, it is important that the student gives written permission for this person to advocate and communicate directly with disability support staff. Awareness of the potential benefits of a collaborative approach that includes families and higher education staff is important and formal processes that will facilitate such cooperation are desirable.

## Conclusions

Student and parent report indicated that many of our students were not receiving adequate educational or social support in higher education. Higher education institutions may expect to enrol more students with ASD in the coming years; meeting the needs of this growing population will be extremely challenging if these students' support needs are not understood and provided. Our findings provide evidence about impediments and facilitators of educational success for clinicians and teachers working with young adults with ASD. As well as the expected core features of ASD and co-morbid conditions affecting educational outcomes, transition planning, disclosure, disability and academic support and families contribute to the success of students with ASD. Disclosure and registration with disability support services appear critical to adequate support. Research on the best way to provide educational support and research on social support is needed.

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## Compliance with Ethical Standards

**Conflict of interest** The authors have no conflict of interest to disclose.

**Ethical Standard** As stated in the Procedure, ethics approval was obtained from the authors' university Human Ethics committee, permissions as required were obtained from other institutions, participation was voluntary and all participants provided informed consent.

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