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TRANSITION TO TERTIARY: BUILDING BRIDGES IN SECONDARY SCHOOL, MAKING IT WORK FOR YOUNG PEOPLE WITH ASPERGER'S SYNDROME

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ABSTRACT

Transitioning from high school to university is a major step for most young people but for those with Autism Spectrum Disorder (ASD) the difficulties are exacerbated by facets of the disability. This paper reviews some of the specific difficulties for highly intelligent young people with Asperger's syndrome (AS) who would like to undertake tertiary study. It also considers solutions suggested in the literature and the experience of one small private tertiary provider in meeting the needs of a student (whom we shall name Joshua) undertaking a BSc who had been diagnosed with quite severe Asperger's syndrome and Attention Deficit Hyperactivity Disorder (ADHD). A case study method involving interviews with 'Joshua', his mother, several peers including a student tutor, current and past lecturers as well as in-class observations was used. This approach enabled the identification of particular issues for Joshua, which together with the effective, practical solutions that were developed and implemented, assisted in achieving a successful outcome for both the student and provider.

INTRODUCTION

"Autism spectrum disorders (ASDs) are lifelong developmental disabilities characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours and sensory sensitivities" (Autism Spectrum Australia, 2013). The prevalence of ASDs is increasing

and Autism Spectrum Australia gives statistics of one in 110 children with an ASD (2013), while the Centers for Disease Control and Prevention in the United States of America cite one in 88 children identified as having an ASD (2008). The term autism 'spectrum' indicates a range and at the higher functioning, mildest end some children have been diagnosed with Asperger's syndrome (AS) or High Functioning Autism (HFA). Sansosti, Powell-Smith and Cowan (2010) noted that while "at present there are no diagnostic guidelines for HFA; the term most commonly is used as a clinical descriptor to differentiate individuals with classic autism". Attwood (2013) added in relation to AS and HFA, that despite minor differences related to language ability, cognitive delay and neuropsychological profiles, "their similarities are greater than their differences".

Transitioning from high school to university can be challenging and somewhat disorienting for many students, with changes in routines, independence requirements, living arrangements, social patterns and different learning and study modes. For those diagnosed with an autism spectrum disorder (ASD), even if it is high functioning autism (HFA) or Asperger's Syndrome (AS), these general transition difficulties are exacerbated by features of their disorder which often result in a reluctance to attempt university or even a premature withdrawal from the course of study before completion (Madriaga & Goodley, 2010; VanBergeijk, Klin, & Volkmar, 2008).

Increasing numbers of intelligent young people with ASDs in high school (White, Ollendick, & Bray, 2011), who have been educated in an inclusive setting look to tertiary education as the next step in their lives. Camarena and Sarigiani (2009) cited Grigal and Neubert (2004) supported this perspective in suggesting that inclusive education for students with disabilities may predispose them to view college as a natural post-school progression. Increasingly, parents want their children with ASDs, educated with their peers (Zager & Alpern, 2010).

A number of specific difficulties that are characteristics of the spectrum are especially relevant within tertiary education. Addressing these and determining solutions in relation to coping with the demands of tertiary education is extremely valuable in achieving tertiary success for young people with ASDs, these include:

- Accommodation and living away from home (Anderson, Shattuck, Cooper, Roux & Wagner, 2013).
- Serious anxiety resulting in physical symptoms such as nausea, sweating, obsessions, fearful anticipation and low frustration tolerance (Trenbath, Germano, Johnason & Dissanayake, 2012), and inability to devise solutions in these conditions (Reaven & Hepburn, 2006).
- Hyper-sensitivity to sensory stimulation – light, sound, smell and touch (Sofronoff, Attwood, & Hinton, 2005; Lawrence, Alleckson, & Bjorklund, 2010).
- Deficits in executive functioning such as lack of organisational skills (White, Ollendick & Bray, 2011) and time management (Roberts, 2010).
- Difficulties understanding non-verbal communication, body language, social cues and social conventions (Adreon & Durocher, 2007; Zager & Alpern, 2010).
- Social interaction and conversational difficulties that are often barriers to group work (Madriaga & Goodley, 2010).
- Stress caused by orientation issues and having to negotiate unfamiliar areas and classrooms at university (Luckett & Powell, 2003).
- Managing change, especially unexpected changes in routines and programs (Roberts, 2010), transitioning between activities and classes.
- Lack of interest in (or motivation towards) areas not related to their personal interests (Schlabach, 2008).

Further, while these characteristics tend to be found frequently in people with autism spectrum disorders, it must be noted that the spectrum is wide ranging and within it there are also wide variations from person to person (Barrett, Prior, & Manjiviona, 2004). Luckett and Powell (2003) observed that the strengths and deficits of young people with ASDs are much particularised. Dr Stephen Shore who consults and presents on ASD is quoted as saying: “If you’ve met one person with autism, you’ve met one person with autism” (2014).

Compounding difficulties for young people transitioning from high school to tertiary education are a number of other important issues at this time in their lives. These include changes in social and living arrangements that tend to occur in late adolescence and early adulthood. Social isolation and difficulties encountered while living away from home can lead to depression. Jantz (2011) commented on the apparent lack of support groups for young people with AS and found in her recent study of 35 young adults with AS that they would welcome the opportunities to counteract loneliness and depression through social interactions. However it must be remembered that the very characteristic difficulty experienced in making friends for those with AS impedes the potential attraction of social groups in this context.

Further, concern has been expressed by both parents and their children with AS/HFA about the readiness of tertiary institutions to provide programs and settings that address the particular needs of young people with ASDs (Camarena & Sarigiani, 2009). Camarena and Sarigiani (2009) found that both adolescents with HFA and their parents had clear tertiary educational goals but serious apprehensions about the preparedness of tertiary institutions to cater for their needs. Parents in this study were concerned that having had to educate secondary schools about the needs and abilities of their children, they would have to do it again for tertiary institutions (2009). This perception is supported by a comment from Pillay and Bhat (2012, p. 142) “college personnel typically have neither the resources nor the guidelines for best practices when working with a student who has the diagnosis of Asperger’s Syndrome”.

Jennes-Coussens, Magill-Evans and Koning (2006) noted that as young people with AS move into adulthood they still rely heavily on their families for support (Barnhill, 2007). Hendricks and Wehman (2009) in researching transition for young adults with ASDs found that most continued to live at home. Adreon and Durocher (2007) add that several researchers have suggested that many students with ASD may find it helpful to live at home for at least the first year of tertiary study adjusting to the academic and organisational demands of tertiary study before adding the living away from home challenges.

The goal of the present study was to outline the issues that young people with AS/HFA face in attempting to undertake university studies and how these were successfully addressed at Joshua's tertiary provider. In addition this paper also discusses how the strategies used to assist Joshua could be generalised to other tertiary settings.

METHOD

This investigation used a case study approach to examine the pathway of a young man (Joshua), diagnosed with severe Asperger Syndrome and ADHD, who had successfully completed his third year of tertiary studies (at reduced load) towards a BSc with a major in Information Technology and minors in Physics and Mathematics in a small, Christian, College of Advanced Education in NSW, Australia.

Following a behaviourally difficult childhood, Joshua's diagnosis of Asperger's, ascertainment at level 6, was first made at the age of 11. Displaying an aloof, self-centred manner, he was also diagnosed with ADHD manifesting in an inability to relax and concentrate. During the semester time of his tertiary study he typically took two kinds of medication: slow release Ritalin in the morning to assist his concentration during the day, and Catapres in the evening, in order to relax and sleep better.

Data were obtained from a number of sources including Joshua's lecturers (current and previous), his peers in the School of Science and Mathematics, his family and of course, Joshua himself. Using observation and interviews, both the impediments to a successful study program and the strategies used by lecturers and Joshua himself to overcome these difficulties were explored. Multiple in-class observations were conducted in Joshua's Mathematics

classes and in a required subject concerning the nature and philosophy of science. Semi-structured interviews were conducted with three of Joshua's peers, from both Physics and Maths classes for approximately 30 minutes each; with his mother alone and finally Joshua with his mother present for support. Three of Joshua's lecturers (two current and one from the previous year) were also interviewed at length. All interviews took place towards the end of the first three years of Joshua's tertiary study, by which stage it was clear he had completed his minors in Mathematics and Physics.

RESULTS / DISCUSSION

During the student's Individual Education Planning sessions in high school it is essential that consideration be given to life after school. In addition, for students with AS/HFA their active participation in the planning is important; however, Hendricks and Wehman (2009) reported that this happened in less than half of the meetings they investigated. Hendricks and Wehman (2009, p. 83) commented: "Placing the individual at the center of the transition process is a pivotal component of planning that has been greatly overlooked." These authors also strongly recommended that the sessions should be led by the students themselves and that planning should begin when the students are aged between 10 and 13, intensifying in upper secondary. For some of these students and their parents, as noted previously, tertiary education at university is the next logical step, and so the transition planning process needs to be very practical, addressing both the student's own needs as well as the likely deficits in the receiving institution's programs.

An important part of transition planning is working through the issues with the student, in an interactive dynamic process so that the decision-making is carefully considered which is critical in achieving self-determination (Wehman, Schall, Carr, Targett, West, & Cifu, 2014). It is important for the student and his/her parents to understand the requirements of a particular career, by including work experience or even observation, to investigate the student's interests and abilities and to find the closest match as should be done for any student. However for students with AS/HFA it is vital to also to ensure that the particular deficits and characteristics related to AS/HFA do not clash with the chosen career, such requirements to

interact with people they do not know.

In addition, the subjects chosen at university need to be investigated carefully. For example, many students with ASDs find group work difficult and it may be more appropriate to undertake some subjects online (Adreon & Durocher, 2007). However, even some on-line subjects have group work. Regarding group work, Joshua commented: "Online group subjects. That did not work at all. One of the subjects that I failed." Joshua goes on to explain the difficulty with the sequential process that was required to complete the assignment as a group. His mother added:

we've called XX Uni now and contacted the equal opportunities officer there and organised for him to do alternate work instead of group work. So if any of the subjects come up with group work, we've already crossed that bridge; his lecturer has to, by law, offer him something instead of doing group work. It was an expensive and painful lesson to learn.

Additionally, Joshua undertook a reduced load of three rather than four subjects per semester which reduced his stress level and which he was then able to complete successfully.

While some tertiary institutions are trying to address the students' general needs through training in communication, socialisation, appropriate behaviour and self-advocacy skills (Camarena & Sarigiani, 2009) some are also charging for this additional program. Farrell (2004) noted a fee of \$4,500 a semester in the Pittsburgh, USA, area that was in addition to a government grant to the institution to assist in supporting students with AS. Smith (2007) pointed out that if this is considered a reasonable accommodation for the student then there is a conflict. However, intentional training in these skills, especially for university, may be more appropriately conducted by high schools over a number of years, including on campus sessions at the local university.

The critical role for a tertiary provider would seem to involve understanding, accepting and supporting the young person with AS/HFA. However, rather than a default reaction by universities to problems arising after the student has commenced studies, secondary schools are well-placed to develop supportive, effective transition plans that could build a bridge to the tertiary sector and smooth the pathway for young people with ASDs. The following

paragraphs consider some of the specific issues mentioned previously, drawing on research literature and using Joshua's experience to suggest solutions for young people with AS/HFA attempting university study.

Accommodation

For many young people aged 18 - 25, leaving home for independent accommodation has been considered to be the desirable norm (Anderson, Shattuck, Cooper, Roux, & Wagner, 2013). These authors noted that in recent years increasing numbers of young adults are remaining longer in the family home, frequently for tertiary educational reasons (2013). Therefore young adults with ASDs who continue to live with parents as they undertake tertiary studies (as recommended by Adreon and Durocher, 2007) are not failing to achieve independence but are actually following an emerging social trend with practical benefits. Joshua, the student in this study, remained in the family home while undertaking tertiary studies which enabled him to have support in regulating his medication for his ADHD; provided meals and general necessities as well as assistance in organisation.

Anxiety

Anxiety is also a common problem for people with AS and the impact of anxiety on young adults with ASD was investigated by Trenbath, Germano, Johanson, & Dissanayake (2012). Three major themes emerged: triggers for anxiety (such as interactions with others and fearful anticipation); experiences of anxiety (such as emotional reactions, physiological reactions or obsessive thoughts); coping strategies (such as computer games and withdrawal). For these young people undertaking tertiary studies, the effects of anxiety can severely impede if not prevent, successful academic outcomes unless addressed. It is clear from this study that much of the anxiety is linked to new, unknown experiences, environments and change, as well as interaction with people with whom they are not familiar. Another aspect of anxiety management within the IEP goals relates to the student's own ability to understand and manage their anxiety. A number of studies have explored Cognitive Behavioural Therapy (CBT) to address anxiety issues for people with ASDs with some success (Reaven et al, 2009; Sofronoff, Attwood, & Hinton,

2005). Gaus (2007) described dysfunctions and distortions in the cognitive processing of people with AS leading them to misperceive information about themselves, others and the world around them. CBT offers an approach to realign these inaccurate perceptions with reality and therefore reduce some of the anxiety. The necessity for stress-related coping strategies (including CBT) needs to be acknowledged and accommodated by both secondary schools and tertiary providers.

To address anxiety experienced by young people with AS/HFA, Individual Education Plan (IEP) planning in the final years of secondary school needs to consider the various aspects of university life that may cause stress. Gillott and Standen (2007, p. 359) found that “change, anticipation, sensory stimuli and unpleasant events” were critical issues for young adults with AS. Many visits need to be made to the university, to classrooms, facilities and routes between buildings. Krell and Perusse (2012, p. 35) suggested being “a college student for a day” is very helpful. Visits and interviews are also essential to particular personnel including Disability Services and lecturers. Disability Services provide support for students with special needs including authorisation for additional support from lecturers and are an essential contact for potential students. It is important for the student and his/her parent(s) to have initial face-to-face contact with lecturers. Pillay and Bhat (2012) cited an example of a professor who was reluctant to provide a quiet place for the student with AS to undertake a quiz, free from distractions. However, upon realising that Disability Services would find a suitable site and provide monitoring, thus also supporting him, he was quite amenable. Nevertheless, as Smith (2007) also notes, Disability Services provide support for students with many different disabilities which may not always meet the particular needs of student with AS, therefore parent contact and discussion are essential.

Hypersensitivity to sensory stimulation

University cafeterias and student meeting places are frequently noisy and crowded consequently it may be more expedient for the student to bring lunch from home initially rather than face the confusing hubbub of a cafeteria unless they can go with a support person such as a friend. However sensory overload may be an issue even

then (Lawrence, Alleckson, & Bjorklund, 2010). Similarly registration is another difficult area that often includes waiting time in an unfamiliar environment. Joshua’s mother commented: ‘Registration is a hard time, a lot of people, sitting around, waiting, noise, confusion... since then we’ve done it on-line.’

Initially visiting the library, negotiating an unknown environment and interacting with library staff could also be problematic so that using the online facilities of the library can be a practical alternative. Fortunately for Joshua, the college at which he studied is small, with lecture rooms in the School of Science clustered around a courtyard, which limited the need for transition over lengthy distances. His parents met the lecturers with him and were able to negotiate solutions to some of the issues including a small private office in which to study quietly. Joshua commented:

...pretty important because I can’t focus in crowded areas. If I can’t hear myself think, I can’t get anything done, I can’t figure out what I need to do and what I’m having problems with. I think having a place that was isolated for most of the time certainly helped ...

Joshua also found bringing lunch from home (which also then accommodated his particular food preferences) and using the online library helped to reduce anxiety-raising experiences. In addition, a cell phone and the ability to text his mother as needed, decreased his stress levels and gradually reduced in usage as he settled into his study program (as recommended by Adreon & Durocher, 2007).

Executive Functioning

Gobbo and Shmulsky, (2013, p. 14) define executive functions as: “higher order mental abilities governing the capacity to start, stop, and persist at cognitive, emotional, and behavioral goals”. Within the context of tertiary study executive functions are essential as students undertake assignments designed to increase their knowledge and academic abilities. Time management and organisation are two vital areas that frequently present difficulties. Adreon and Durocher (2007) mentioned a number of simple strategies including the use of tutors. Within this context Joshua found having peer-tutor support extremely valuable. His lecturer

prearranged a student who had successfully completed the subject previously and who was well-organised, to assist him two or three times a week for one or two hours. Joshua was able to pay the student for their time from his disability allowance. The tutor commented:

I set up specific questions/ tasks for him to work on; this is written down and I leave it with him. Some days when I'm explaining it, it just clicks and he's eager to start writing even before I've finished explaining it, and he shuts down what I'm continuing to say. So I let him get out what he's got on his mind, so to speak.

Joshua's Mother added:

The first time I walked into Michael's room after she'd been tutoring him I said "Oh my goodness XX's been here, hasn't she?!" and he laughed at me because everything on the desk was in neat piles with lists on the top telling him what he had to do, and he takes it all very seriously.

Additional support also came through several peers. The lecturer explained the situation and asked them to help keep Joshua on track, look out for him, go and talk to him in his room from time to time about the subject, assignments etc. This proved quite effective and had the added benefit of increasing Joshua's social interaction. Another lecturer commented:

He has interaction with the other students; he might even crack a joke in class. Sometimes he'll come out with some really funny things in class related to that lesson. Also, the other students aren't fazed if he gets up to pace at the back of the room if he's a bit stressed.

Communication and Lecturers' Interest

Despite people with AS frequently being described as having "serious impairments in communication, social interaction and language" (Montgomery, Stoesz, & McCrimmon, 2012, 4.), difficulties with reciprocal conversation (Barnhill, 2007), or one-sided interaction (Madriaga & Goodley, 2010), there is evidence that many young people with AS do value people showing a supportive interest in them. Madriaga and Goodley's (2010) study of young

adults with AS at university noted that "students desire their lecturers to enjoy being with them and being interested in them"; they appreciated the lecturers who worked to "break down the communication barrier" (p.121). In fact one of the respondents in the study perceived that a "lack of interest became a barrier to his achieving a sense of inclusion" (p.121).

Joshua's mother noted:

He works very well on a personal basis. It was absolutely critical that he had somebody that he could connect with who was interested in what he was doing. That personal relationship will develop, it doesn't happen overnight, obviously. The adult/lecturer will need to keep coming back to develop the connectivity.

The personal interest by his lecturers, tutor and peers contributed greatly to Joshua's success.

Lecturers' Understanding of ASD

In addition, it is vital that lecturers have a basic understanding of the characteristics of students with ASD, as well as their learning needs; such as: direct language, clear, specific instructions, peer note taking, preferential seating and communication with support persons e.g. tutors or parents (Smith, 2007). This understanding of and interest in, students with AS was illustrated by a comment from another of Joshua's lecturers:

A lot of times he's (Joshua) staring out the window and you think that he's not taking any notice and then you ask him a question and he'll be the first one to answer. And he's got it right. He might not be watching the board or what you're doing but he knows what's going on.

The lecturer was asked: "For other students with Asperger's what would be your advice to their lecturers to help the students get through?" He replied,

They need a tutor to give them that individual help and the lecturers need to have some time for the student as well. Personal time. I kept encouraging him and having good communication with him and now he'll come and ask me questions if he needs to know something.

CONCLUSION AND RECOMMENDATIONS

Students with Asperger's Syndrome who wish to continue their studies past secondary education into the tertiary field and are intellectually capable deserve the opportunity to do so. However, without communication, collaboration and cooperation between all parties, success is at risk. Secondary schools, where identification of potential and individualised planning begins, can be the start of the bridge to further education. In secondary school the student, parent, learning support teacher and counsellor can address the necessary development in anxiety reduction, management of change, problem solving, communication and social interaction. Secondary learning support staff and school counsellors can pave the way for and expedite parent and student contact with lecturers and disability officers at the selected tertiary institution. In addition, they can supply a report suggesting specific strategies that will support the student in the new educational setting. Secondary schools can be the critical factor in the lives of young people with Asperger's Syndrome in bridging the gap between school and tertiary education.

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