Transition to University for Young Adults on the Autism Spectrum

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Abstract

Transition to university can be a challenging time for young people on the autism spectrum. This article examines research pertaining to the transition to university for people on the autism spectrum and uses the findings from this research to formulate evidence-based recommendations for effective transitions. This is achieved through reviewing relevant research on the university experiences of young people on the autism spectrum and conducting a systematic literature review of research on the transition to higher education for people on the autism spectrum. The article ends with recommendations for improving transition experiences, drawing on the findings from the research studies reviewed.

Introduction

For people on the autism spectrum, transitions can present both challenges and opportunities (National Autistic Society, NAS, 2013). The transition to university is one taken by fewer than 25% of young people on the autism spectrum (Department for Education 2014). This may be in part due to difficulties with managing daily practicalities and coping with a new social and sensory environment that does not support differences in social communication and interaction; and repetitive interests and behaviours (DSM-5 2013).

University experiences of young people the autism spectrum

Improving access to education for young people is vital as The National Audit Office (NAO, 2009) identifies this as a key factor in improving the lives of adults on the autism spectrum, identifying that a lack of appropriate support for young adults may result in them not achieving their potential by leaving university without completing their course. The number of students who identify as being on the autism spectrum is increasing rapidly. It has also been suggested that the amount of people at university with an autism spectrum condition might be higher than reported as those people who go to university are among the most 'high-

functioning' on the autism spectrum and are therefore most likely to reach university without having received a correct diagnosis (Hastwell et al 2013).

There are three major UK studies which have furthered our understanding of the university experiences of young people on the autism spectrum by directly involving them in research: Beardon and Edmonds (2007), Madriaga et al (2008), and Hastwell et al (2013).

Beardon and Edmonds (2007) conducted a study between 2006 and 2007 of the local authority provision of services for 238 students on the autism spectrum. A mixed methods questionnaire was developed in order to enable adults on the autism spectrum to express their views on the challenges faced by students on the autism spectrum and identify how services could be improved. The data was categorised into four overarching themes relating to difficulties encountered at university: social interaction; course/curriculum structure; the social environment of the university; and understanding of autism. Difficulties identified with social interaction were concerned with the necessity of communicating with others (in, for example, group work). It was suggested that support to understand non-autistic people's behaviour may benefit people on the autism spectrum, whilst support to understand autism may help non-autistic individuals. In terms of the environment, participants identified difficulties with expectations, activities and sensory experiences. Again, education of the autistic individual about non-autistic behaviours and, vice versa, was identified as a way of minimising the impact of this. Some participants reported that they faced challenges arising from their own and others' understanding of autism. Factors related to the course and curriculum structure, such as rigidity in assessment modes/criteria and bureaucratic requirements, were found to present challenges to some of the participants. Suggested approaches to minimising the stress caused by these challenges were clear communication and mentoring.

Madriaga et al (2008) interviewed eight students with Asperger Syndrome (AS) multiple times during their first year of university. The project aimed to identify barriers and facilitators to positive university experiences through recognising the students themselves as central to the experience. The study found that students initially viewed starting university as a positive experience, viewing attending university as an opportunity to move on from past negative experiences (supporting

the view that transition can present both challenges and opportunities). Some of the participants reported experiencing social isolation, whereas others did not report difficulties in social interaction. Participation in social situations, such as attending fresher's fairs and living in shared accommodation, were not found to remedy social isolation due to the high levels of stress they could produce. Facilitators identified by participants included having effective mentoring and teaching staff being adaptable to different learning styles.

Hastwell et al (2013) carried out a study at the University of Cambridge from 2009-2012 (over three academic years) examining university experiences for 28 students who identified with the autism spectrum. Students shared their views in a range of ways, through focus groups, interviews and questionnaires. They were asked to reflect on their experience of university and identify factors they felt would positively influence their academic success and university experience. The study identified four main factors that influenced student experience: social interaction, the university environment, understanding of autism and academic engagement. With regard to social interaction, 35% of the 28 students reported that they found social situations very stressful, citing large groups of people as *"intimidating"* and unanticipated formal verbal questions being difficult to deal with, resulting in lectures being missed. Students from the study suggested that a social group may have helped with this, to help develop a healthy balance between study and social time. In terms of the university environment, 73% of the participants identified that the university environment can be challenging due to difficulties with sensory overload and a lack of structure/predictability. One particular difficulty identified was living in shared accommodation, which could be very noisy, making studying difficult and very stressful. Many of the participants identified that a lack of understanding and empathy caused difficulties at university, with others making assumptions and underestimating their abilities. Students suggested that people need to have more awareness that communication and empathy require the participation of two parties and are not the sole responsibility of the person on the autism spectrum. With regard to academic engagement, participants highlighted difficulties with changes (between levels of academic study, teaching styles/philosophies and assessment methods). One participant reported that the desire to understand each topic of study so completely impacted their ability to manage their workload. It was suggested that a knowledgeable mentor, who provides information clearly and gives encouragement, could help with this.

The researchers developed an acronym to encompass principles of good practice for positive university transitions for people on the autism spectrum – REAL (reliable, empathic, anticipatory, logical). It is suggested that these factors are central to good practice as *reliability* reduces stress caused by unpredictable change, *empathising* enables staff to understand student concerns, *anticipating* (what may cause stress) enables changes to be made in advance, and being *logical* enables students to understand expectations.

In common throughout these studies (Beardon and Edmonds 2007; Madriaga et al 2008; Hastwell et al 2013) is the finding that difficulties encountered at university are concerned with the social environment, the institutional environment, academic expectations and people's understanding of autism. The move to university can, therefore, be a challenging transition. However, it may also be viewed as a 'fresh start': an opportunity to leave negative past experiences behind (Madriaga et al 2008).

Systematic literature review of university transitions for people on the autism spectrum

To further explore transition planning for young people on the autism spectrum, a review of recent literature was undertaken. A range of databases was included in the search (specifically AMED, the British Education Index, Child Development and Adolescent Studies, CINAHL, Education Abstracts, Education Research Complete, PsychArticles, PsychInfo, and SocINDEX) using the EBSCO search site. The following criteria were applied to the search:

- Research studies from the UK only (due to differences in educational systems in different countries);
- Articles published within the last 10 years (2005-2015) to ensure currency of evidence;
- English language documents only to avoid mistakes being made in the translation of documents.

The search terms used were autism (and alternatives), transition (and alternatives) and university (and alternatives). A Boolean search was performed using 'wildcards' to ensure alternative spellings and plurals were not unnecessarily excluded.

The search yielded six results which, after scrutiny of the abstracts of these articles, provided two relevant research studies. See appendix for a table of information about these articles. Figure 1 provides an explanation of how the results were narrowed down to the relevant articles.
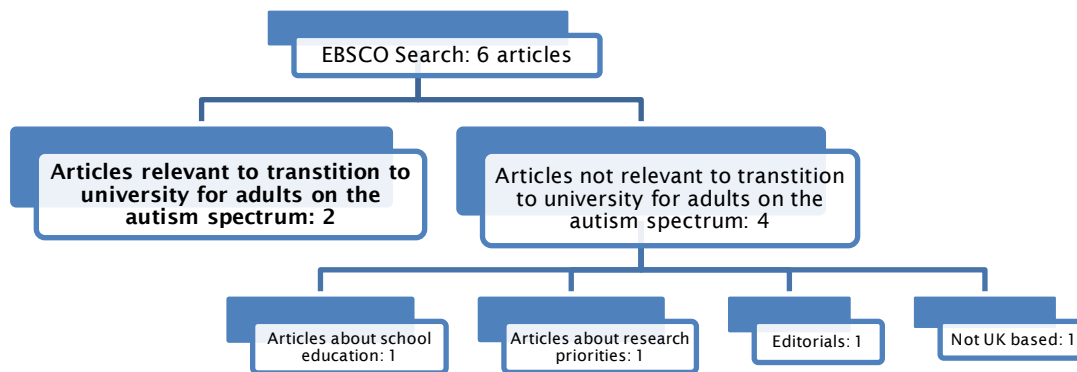

Figure 1: Selecting relevant articles from the EBSCO search.

The two relevant articles identified both originated from the Madriaga et al (2008) study discussed in the previous section. Madriaga and Goodley (2010) examined longitudinal data from the life histories of eight students on the autism spectrum at UK universities to identify barriers to participation in academic work. They found that barriers were encountered in lectures (such as not providing hand-outs prior to the lecture and not encouraging participation of students), group work (due to social anxieties, for example), and assessment (due to access to additional support requiring forced disclosure and segregation). Madriaga and Goodley (2010) concluded that the barriers identified result from unsuitable social, physical and institutional environments and not 'deficits' or 'impairments'.

Madriaga (2010) re-analysed the data from the above study to focus on the spaces at university that may be difficult for students on the autism spectrum to access. It was identified that fresher's fair (and week), the student pub, the library and student accommodation can all be environments that are difficult to access. Access to university facilities was found to be made difficult by the social and sensory environment of these places. These two studies provide additional relevant information about the environmental barriers that may be encountered by students on the autism spectrum. Furthermore, the 'voice' of students on the autism spectrum is central to the findings.

Recommendations for successful transition:

Reviewing the evidence collated has led to the following recommendations for services that should be made available (but not assumed necessary) for a young person on the autism spectrum attending university away from the family home:

- **Clear and timely information**

It is important that links with support services are developed as early as possible prior to the start of the university course (Hastwell et al 2013). Having an identified support person at the university enables the student to ask questions/raise concerns and ensures that they are made aware of the services available to them (Hastwell et al 2013). Support available should be flexible so that a range of needs and preferences can be met (MacLeod 2010). Following the principles of REAL (Hastwell et al 2013), institutions should provide clear information in prospectuses/on websites about how to disclose disabilities and access support services (prior to enrolling at the university).

- **Staff who have knowledge and understanding of autism**

Specialist training on supporting students on the autism spectrum should be mandatory for all teaching and support staff at the university (Hastwell et al 2013). Different levels of training can be provided depending on staff role but ALL staff should receive some level of training. This fosters an environment of inclusivity, rather than segregation and difference (Madriaga 2010).

- **Pre-entry orientation events**

University taster days can provide prospective students with information about courses and services and provide tours of key places, such as the library, accommodation, teaching facilities and the student's union prior to the other students arriving (Hastwell et al 2013). This may enable students to become familiar with the environment when sensory input is at a more manageable level, and reduce the stress that may be caused by unanticipated change. Gardner et al (2012) suggest gathering information about attendees (such as their interests, plans for the future and any questions they have) prior to organising the event so that it can be tailored to the requirements of those attending. At a taster day developed by Gardner et al (2012) the following topics were included: meeting people, getting involved in groups and societies, accessing support and managing coursework. Gardner et al (2012) also provided prospective students with tours of university

accommodation and the university cafeteria. Gardner et al (2012) found that the pre-entry orientation event helped prospective students to feel *"safer and more prepared"* (p.264) for starting at university.

- **A social group for students on the autism spectrum**

Young people on the autism spectrum may encounter social challenges at university, compounded by the expectations placed on them to manage a varied workload, develop independent living skills and take initiative for their own learning (Beresford et al 2013). Students on the autism spectrum may also have experienced social exclusion and bullying, increasing their anxiety about entering new social groups (Beardon and Edmonds 2007). Within higher education, contact with peers is not only important for pastoral and support reasons, but provides an educational function through clarifying expectations of assessments and catching up on missed lessons (MacLeod 2010). A social group for students on the autism spectrum was put in place at Cambridge University following student feedback that this would facilitate receiving a more holistic university experience that is not purely focused on academic study (Hastwell et al 2013). MacLeod (2010) suggests that some individuals on the autism spectrum may prefer online communication to direct social contact. It would, therefore, be beneficial to also have a virtual social group available to students on the autism spectrum. Indeed, participants in MacLeod's (2010) pilot study of an online peer support network reported that online peers were a highly valued source of support from whom participants would proactively seek help and guidance.

- **Specialist mentoring**

Mentoring refers to a time-limited goal-orientated relationship that supports both personal and vocational learning and development, in which an experienced person provides guidance and support to another less experienced person as directed by the mentee's goals (Mentoring and Befriending Foundation 2014). A mentor at university could help a student on the autism spectrum with the transition to (and throughout) university life. It is important that a mentor approaches issues from the viewpoint of the individual experiencing them, helping the person to navigate a sometimes challenging social/physical/cultural environment, rather than trying to change that person to fit in to a non-inclusive environment. This is exemplified in this quote from Beardon and Edmonds' (2007) study:

"People need to get over the idea that the 'neuro typical way is the right way and any other way is wrong [...] People with AS don't need to be cured, or trained how to be 'normal'. It's the 'normal' people who [...] need to be taught not to be prejudiced and discriminatory, and to accept and accommodate us for who we are" (p.6).

- **Accessible services (such as fresher's fair and library)**

Madriaga's (2010) study highlighted that there are particular spaces within universities that may be difficult to access for students on the autism spectrum. Barriers to access may be reduced by providing tours of these spaces prior to the start of the university term (see "Pre-entry orientation events" above). For particular events, such as fresher's fair, instating a 'quiet hour' at some point during the fair and/or providing a buddy with whom students can attend the fair may help (Beardon et al 2009; Hastwell 2013). Additionally, creating an online fresher's fair may enable more students to 'attend' virtually and join the societies in which they have an interest.

Conclusion

First person accounts of university experiences of adults on the autism spectrum suggest that difficulties encountered at university are largely concerned with the inflexibility and non-inclusive nature of the environment (Beardon and Edmonds 2007; Madriaga et al 2008; Madriaga 2010; Madriaga and Goodley 2010; Hastwell et al 2013). Services should be put in place to facilitate a smooth transition to university, taking account of the challenges posed by the social environment (meeting new people on a social and academic level), the institutional environment (understanding structures and expectations), the academic environment (managing workloads) and the physical environment (the sensory challenges posed by places such as libraries, fresher's fairs and shared accommodation). Whilst support should be made available to manage these challenges, it should be recognised that some students may choose not to access any or all of the support services. Additionally, a flexible approach should be taken (such as offering services both face-face and online) to cater for a range of preferences.

References

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Appendix: Articles obtained through EBSCO search

Article reference	Participants	Methodology	Findings	Included/ Excluded
Madriaga M & Goodley D (2010) Moving beyond the minimum: socially just pedagogies and Asperger's syndrome in UK higher education. International *Journal of Inclusive Education, 14(2):* 115-131.	Eight students from UK universities	• Longitudinal (over one academic year); • Life history interviews.	• Barriers: lectures, group work, assessment. • Difficulties are caused by social and physical environment (not 'deficits' or 'impairments').	Included

Madriaga M (2010) 'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies, 8(1):* 23-34.	Eight students from UK universities	• Longitudinal (over one academic year);
		• Life history interviews.
			• Difficult spaces to access at university:
			  ○ Fresher's fair and week
			  ○ Student pub
			  ○ Library
			  ○ Student accommodation
			• Access to university facilities made difficult due to the social and sensory environment of these places.
				Included

Parsons S, Lewis A & Ellins J. The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey. *European Journal of Special Needs Education,* 24(1): 37-58.	113 parents of disabled children	• Online survey about educational concerns and priorities for disabled children.	• Parents of children on the autism spectrum not given enough information when choosing a school
			• Difficulties accessing the educational environment due to:
			  ○ Assumption/attitudes of others about autism
			  ○ Lack of knowledge/understanding of autism from school staff
				Excluded (about school)

King G, Zwaigenbaum, L, Bates A, Baxter D & Rosenbaum P (2012). Parent views of the positive contributions of elementary and high school-aged children with **autism** spectrum disorders and Down syndrome. *Child: Care, Health & Development. 38(6):* 817-828.	Sixteen families of children with autism or Down syndrome	• Interviews
		• Grounded theory
			• Benefits of parenting a disabled child:
			   ○ To parents;
			   ○ To families;
			   ○ To society.
				Excluded (non-UK and about school)

Pellicano E, Dinsmore A & Charman T (2014) What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18(7):* 756-770.	4 autistic adults, 27 parents of autistic children, 20 practitioners and 11 autism researchers	Focus groups and interviews.	• Future research should focus on improving people's day-to-day lives. • Greater involvement of the autism community in priority setting and research.	Excluded (about research priorities)
Blunt C, Blyth C, Chapman R, Frost L, Hayward D, Hughes R, Perry B & Townson L (2012). Editorial. *British Journal of Learning Disabilities,40:* 83–84.	Editorial	Reviewed articles published by the journal.	• Articles not accessible to read (due to jargon); • Articles speak about people with learning disabilities as a homogenous group; • 'Inclusive' and 'partnership research' used with varying definitions.	Excluded (editorial and not about transition to university for people on the autism spectrum)