



Vincent, Jonathan ORCID logoORCID: <https://orcid.org/0000-0001-6278-4670> (2019) It's the fear of the unknown: transition from higher education for young autistic adults. *Autism: International Journal of Research and Practice*, 23 (6). pp. 1575-1585.

Downloaded from: <https://ray.yorks.ac.uk/id/eprint/3675/>

The version presented here may differ from the published version or version of record. If you intend to cite from the work you are advised to consult the publisher's version: <https://journals.sagepub.com/doi/10.1177/1362361318822498>

Research at York St John (RaY) is an institutional repository. It supports the principles of open access by making the research outputs of the University available in digital form. Copyright of the items stored in RaY reside with the authors and/or other copyright owners. Users may access full text items free of charge, and may download a copy for private study or non-commercial research. For further reuse terms, see licence terms governing individual outputs. [Institutional Repositories Policy Statement](#)

RaY

Research at the University of York St John

For more information please contact RaY at
ray@yorks.ac.uk

It's the fear of the unknown: transition from higher education for young autistic adults

Journal:	<i>Autism</i>
Manuscript ID	AUT-18-0392.R1
Manuscript Type:	Original Article
Keywords:	transition, higher education, university, college, emerging adulthood, qualitative
Abstract:	More young people with a diagnosis of autism are enrolling and successfully completing higher education courses than ever before and this is set to increase; however, whilst there is a burgeoning body of literature surrounding the transition into this stage of education, there is a paucity of research that investigates the transition as this population exit higher education. This qualitative study is one of the first to identify the specific experiences of young autistic adults making this transition, drawing on semi-structured interviews with 21 students and recent graduates. Findings indicate that transition out of higher education is challenging on both practical and psychological levels, manifested by feelings of anxiety and loss. However, there is also evidence that the same phenomenon can also be understood as a positive departure with important implications for identity development. Findings are discussed in relation to future research and implications for practice in higher education institutions.

SCHOLARONE™
Manuscripts

Introduction

Whilst young adults on the autism spectrum are less likely than their peers to enter higher education (National Autistic Society, 2017b), there is evidence to suggest that this is changing (Jackson, Hart and Volkmar, 2018). Obviously some students on the autism spectrum have always attended university or college; however, it is only relatively recently that data has begun to be collected regarding the participation of specific groups of disabled students in higher education. When reporting was first introduced in the UK in 2003, the recorded institutional figures of those disclosing 'Autistic spectrum disorder/Asperger's syndrome' was just 165 students (Madriaga et al, 2008) but by 2015 this number had increased by 400% (Higher Education Statistical Agency, 2015). Similarly in the US, studies suggest that up to 45% of the approximately 550,000 autistic children who will be transitioning into adulthood over the next decade are expected to enrol in a university, college, or technical/vocational school in the coming years (Jackson, Hart and Volkmar, 2018; Newman et al. 2011).

As larger numbers of autistic students have begun attending university, transitions into and within higher education have received an increasing level of research interest (Elias and White, 2018; Anderson, Carter and Stephenson, 2018; Accardo, Kuder and Woodruff, 2018; Kuder and

Accardo, 2018; Gurbuz, Hanley and Riby, 2018; Hillier et al, 2017; Vincent et al, 2017; Jansen et al., 2017; Cox et al., 2017; Brosnan and Mills, 2016; White et al, 2017; English, 2018; Ward and Webster, 2017; Van Hees, Moyson and Roeyers, 2015; Barnhill, 2014; Pillay and Bhat, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009, Adreon and Durocher, 2007; *inter alia*). Gelbar, Smith and Reichow's (2014) systematic review, which analyses 20 articles describing firsthand accounts of college experiences, identifies practical learning adjustments, the social aspects of higher education, and experiences of induction as the primary foci across this burgeoning body of research literature. Kuder and Accardo's (2018) more recent analysis of the literature reviews eight studies with a focus on effectiveness of interventions or supports at university; only one study (Shmulsky et al., 2015) is specific to transition and this relates to a college induction program and students' progression from first to second year of study. They and others (Jackson, Hart and Volkmar, 2018; Gelbar et al, 2014) signal a need for more comprehensive research into how best to support these young people into and through their studies. Van Hees, Moyson and Roeyers (2015) noted in their qualitative study of 23 autistic students that when starting higher education, their participants were already worried about the next transition.

There is a substantial body of research related to the more general transition to adulthood for autistic populations (Thompson et al. 2018; Roux et al., 2013; Wei et al, 2013; Lee and Carter, 2012; Shogren and Plotner, 2012; Taylor and Seltzer, 2011; Hendricks, 2010; Papay and Bambara, 2011; Hart, Grigal, and Weir, 2010; Hendricks and Wehman, 2009). This literature suggests that transition and future planning can be complicated for individuals with an autism diagnosis (Kirkby, Baranek & Fox, 2016; Lindstrom, et al., 2007) and many frequently struggle to gain competitive employment, live independently, or sustain substantial social relationships. Evidence suggests that where transition goals such as these are not met, this can hinder the establishment of viable adult identities among autistic young people and impact negatively on mental health and overall quality of life (Anderson et al. 2016; Moss, Mandy and Howlin, 2017; Hendricks and Wehman, 2009).

There is, however, a much smaller range of studies that focus on transition for autistic people with higher level qualifications (Bolourian, Zeedyk, and Blacher, 2018; Cashin, 2018; Dipeolu, Storlie, and Johnson, 2015; Walker, 2012; VanBergeijk, Klin and Volkmar, 2008) and there are currently no studies that uncover the firsthand transitional experiences for the increasing population of autistic people exiting university or college. According to Cashin (2018) such a lack of research on educational trajectories among autistic populations is concerning and must be addressed. Therefore, at an exploratory level, a qualitative research design was deemed appropriate for this study. As such it serves as one of the first to identify the firsthand

experiences of young autistic adults making the transition from higher education and as such offers a unique contribution to the field.

The current study aimed to address the following broad research questions:

1. How do young autistic adults perceive their transition from higher education?
2. What are the perceived barriers to a successful transition from higher education?
3. What enables a successful transition from higher education for young autistic adults?

Methods

Participants

A total of 21 young autistic adults from across England participated in the study.

Inclusion criteria for the study included (1) participants had received a formal diagnosis of (autistic spectrum disorder or Asperger's syndrome) from an educational or health professional; (2) she or he was within 12 months of completing university study or had graduated within the last five years at point of data collection; and (3) able to participate in data collection. Given that all participants were enrolled on or had completed a university Bachelor's degree at a minimum, it was not considered relevant to include exclusion criteria with respect to cognitive ability. The sample included both autistic students exiting higher education and recent graduates in order to reflect the experiences of those in the midst of it as well as some that already made the transition although it is recognised that these two groups are likely to reflect differently on their transitions given their respective distance from the events and so may limit, to some extent, the specificity of the findings. A further limitation of this sample is that it does not directly compare the experiences of autistic higher education students and graduates with those of their neurotypical peers (Gurbuz, Hanley, and Riby, 2018).

Participants ranged in age from 21 to 26 years ($M = 22.19$; $SD = 2.04$). Of the twenty-one participants, 15 identified themselves as male and 6 identified as female. Twenty out of the 21 participants identified as White (95%) and one as Afro-Caribbean (5%). In total 10 of the participants were students within 12 months of completing university (8 Bachelor degrees; 2 Masters degrees) and 11 were recent graduates (8 Bachelors degree, 2 postgraduate certificate, 1 PhD). Participants reported on their firsthand experiences of transitions from eight universities across England and one in Canada.

The majority (n= 17) self-reported a diagnosis of Asperger's syndrome and four self-reported a diagnosis of autism; all but two had received their diagnosis in childhood. Co-occurring diagnoses were self-reported by 8 participants (38%), with 5 identifying depression, 1 identifying an anxiety disorder, 3 identifying dyspraxia, and one identifying a gastrointestinal condition. Two participants disclosed more than one co-occurring diagnoses (See Table 1).

Recruitment

Participants were recruited purposively using snowballing techniques. A website was created to disseminate information regarding the study, including the ethical commitments and consent forms, as well as the researcher's contact details for participation. This was shared by national and regional supported employment providers, including United Response and Specialist Autism Services; published via online platforms including Twitter and Facebook; and disseminated on a UK-wide JISC mailing list, 'Autism Practitioners in HE' (Austismpractioners@jiscmail.ac.uk) which serves researchers, disability practitioners, and careers advisors working with autistic students in higher education across the United Kingdom. Participant contact details were gathered over an eight month period and stored in a secure database on a password protected computer. Participants did not receive any reimbursement for taking part in this study.

Procedure

Institutional ethics approval was granted by the researcher's ethical review board [RS201554] and written informed consent was obtained from each participant prior to data collection. Where data collection did not take place in person, consent was confirmed with a digital signature and emailed to the researcher.

The interview protocol was part of a larger study. Two overlapping but separate sets of questions were developed for current students and recent graduates respectively (appendix 1). These were piloted prior to use and then administered identically for each of the participant groups. The first series of questions asked the participant about the period prior to completing their university course and how this is / was experienced; the second set aimed to identify the participant's short-term aspirations and what might impact on their capacity to achieve these; and the final set of questions asked the participant about their longer term plans and what might affect their capacity to achieve these. Rather than a specific two-probe rule (Anderson et al., 2016), follow-up questions were tailored to the individual and the answers they provided.

In total twenty-one detailed semi-structured interviews were conducted, fourteen of which were face to face. Where it was not possible, due to geographical restrictions, for interviews to

take place in person, five interviews were conducted using Skype®. Interviews ranged in length from 37 to 122 minutes ($M = 81.40$; $SD = 20.23$). One interview was conducted asynchronously over email with a participant for whom social communication caused high levels of anxiety. Where spoken, interviews were audio-recorded using a digital voice recorder and transcribed verbatim. A possible limitation of this study is that it only captured data at a single time point; future studies might take a longitudinal approach in order to assess the extent to which this population's transition needs and outcomes change over time.

Validity

Transcripts were emailed to participants as a form of member-checking (Denzin and Lincoln, 2013). This allowed the participants to ensure accuracy and provided each with the opportunity to comment, amend or challenge how the encounter had been represented before analysis took place. Obtaining participant approval before using the data in this way facilitates reciprocity between researchers and participants, which is an increasingly important priority in autism research (Fletcher-Watson et al., 2018; Chown et al., 2017).

Following the procedure outlined by Miles, Huberman and Saldaña (2013), data were analysed through an inductive and iterative process with the aim of gaining a deep and full meaning of the participants' experience of transition from university. This was achieved through the close reading of transcripts, identification of 'codes' assigned to representative statements based on their internal homogeneity (Patton, 1990), and visual memoing. The software package NVivo-11® was used to aid higher-level abstraction where codes were assessed in relation to other coded extracts as well as the complete data set. These were finally refined into four themes with extracts selected to exemplify these. Whilst it was useful to identify the frequency of particular codes (see Table 2) producing descriptive validity through content analysis was not the goal of this study.

Findings

Analysis led to the generation of four overarching themes with sixteen subthemes. These include transition as (1) a source of anxiety and avoidance; (2) a positive departure; (3) loss; and (4) identity development. Data extracts are identified using participants' pseudonyms and any identifying information has been changed or removed.

Themes and a sample of subthemes are presented in Table 2.

[Insert Table 2 here]

Transition as a source of anxiety and avoidance

A significant theme across all twenty-one of the participants' accounts was transition as a source of anxiety. Participants used words and phrases such as 'distracted', 'dread', 'stressed', 'terrified', 'nervous', 'anxious', 'strange', 'odd', 'worry', 'panic', 'fear', 'crisis', 'apprehensive', 'not in control', and 'scared' to describe their experiences of preparing to leave university (n=61 coded items). As Izzy explains, alongside what any 'neurotypical' final year student may be experiencing, being autistic means 'you have all the extra worries that no one else has', largely related to social and communication demands, organisational requirements, or managing highly stimulating sensory environments. This excerpt from John, a history graduate, shows how anxiety has been a consistent emotion throughout many of his transitions made across the life course,

(John) I've always been... it's just that kind of anxiety that I've always had moving onto something different. I had anxiety before I went to school, I had anxiety before I went to secondary school, I had anxiety before coming to university, I have this anxiety now that I need to go out and get a job.

(Interviewer) And how did that manifest itself for you?

(John) Worry in the pit of my stomach, focusing on other things, trying not to think about it too much because I know it will just worry me, stress me more.

John's experience identifies two important issues related to anxiety: firstly, it is frequently exacerbated by transition to new contexts; and secondly, it can lead to avoidance activities. Both of these were also identified by other participants; for example, Lily discussed why 'fear of the unknown' is so problematic for her,

I think it's the unknown. Like not knowing what's going to happen and then thinking the worst sometimes I guess; it's more not anything that is actually there, it's the not knowing... (Lily)

I'd say it's the fear of the unknown because you don't know what is going to happen, you don't know if you're going to succeed or fail. I think that plays a big part of it. (Izzy)

For both Lily and Izzy it was the inability to be able to predict what might happen next that was challenging, especially where this may lead to uncertain or undesired outcomes. Education frequently provided a known 'structure', which when removed generated anxiety: 'you've got

that security in learning...and then once that security goes you don't know what you'll be doing' (Theo). Hence, the unknown nature of transition from university to whatever might be next appears to make this more difficult than previous life course transitions.

For some of the participants, where levels of anxiety were significantly heightened in the final months of university, their mechanism for coping was to avoid engaging in the transition process at all. Like John's comment above suggests, cognitive space was simply given over to focusing on 'other things', which might include final year exams, dissertations, or assignments. These types of displacement activities appear to be strategies used to manage the experience, especially where there is difficulty accepting that significant change must take place.

It's one of those things where I don't acknowledge that it's a big transition... So it's kind of one of those things where I don't accept it until it's right there. (Alice)

I have been constantly worried about the future, mainly death but also life and what it might hold...I think it is much easier to worry about the future than to be in the present. I think it's easier to get focused on, for me, to be pessimistic and go into a place where you are thinking 'what am I going to do with my life?' rather than just being there and being in it...I am always working against myself, I am always trying to reach a place where I am self-destructing because when I am self-destructing I do not need to take on responsibility, it's everyone else's responsibility to look after me and I constantly have to fight that urge because I know that deep down I don't want to be that and I would rather be functioning and doing well. (Lewis)

I don't recognise stuff in my future until there is something that I can do, there's no point trying to worry because if I start to worry it will spiral out of control, so yeah I do tend to... if there is something in the immediate and something that I can do then I'll try to focus my attention on that and anything after will have to wait. (John)

From the extracts above, and final year Creative Writing student Lewis' in particular, it is clear that thinking about the future can be deeply troubling at psychological and even existential levels. He described it as an inner struggle between doing what he knows will help and 'self-destructing' in order to have a valid reason for not having to engage in the process.

Transition as a positive departure

The second theme, transition as a positive departure, relates how some of the participants' perceived leaving higher education in optimistic terms. Many participants used words like

‘incredibly excited’, ‘happy’, ‘fun’ and ‘mostly optimistic’ to describe the experience. Lewis described feeling ‘ready to go into the world...I feel much more prepared to talk to employers, meet people, try to organise myself’ and Eliza makes a comparison between getting to this point in university and finishing a marathon: ‘I’m looking forward to it...you know when it’s just you can see the finish line and you really want to get it’. Such comments indicate a positive desire for transition and signal the temporal nature of the phenomenon in perceiving it as a juncture point between the completion of one life stage and the beginning of another. However, whilst some participants related excitement about the future this was generally balanced against other emotions. Theo, Arthur, Matthew, Winston, and others described a ‘mix of feeling quite sad to leave but excited’ (Max).

Very often, perceiving transition as a positive departure was catalysed by having a clear sense of what might be next. Where participants making the transition from higher education had identified postgraduate courses or possible employment trajectories and had gained some experience in these (52%; n=11 see Table 2) this tended to be viewed as enabling and led to a more positive framing. As Poppy suggests, ‘I’m feeling alright about it now ‘cause I’ve kind of got the gist of what’s going on.’ In this sense then, transition appears to shift from being a primarily emotional issue to a practical one as the two statements below attest,

Well I always had my heart set on working in schools. So I wasn’t really concerned about that. I just put all of my efforts into getting ready for my final year and getting the degree and then trying to figure out things from there. (Izzy)

I guess quite early in final year, I was definitely planning on doing a masters, it was just where; so I started looking through the options (Winston)

For others, where there was a clear alignment between what they had been studying and what was next, this also made the transition more manageable, as Tom, who was finishing an MA in creative writing, reports,

It hasn’t been that bad since it’s basically doing what I was doing when I was at University except I’m not at university since what I’m doing is watching anime, reading manga, reading books, I’m

writing, I'm making videos. So I'm just doing my every day routine really, it's just removed the university from it.

These experiences portray the mixed, but potentially positive, emotions that transition from university may generate and indicate a level of contingency between practical readiness and psychological responses to the phenomenon.

Transition as loss

The third theme identifies transition in terms of loss. In particular participants perceived it as loss of independence, loss of friendships, and loss of momentum. Whilst on first reading such a list could be interpreted in negative terms – as loss often is – it is also indicative of the fulfilling experiences, meaningful relationships, and positive trajectories that those on the cusp of transition had worked hard to achieve and were thus scared to lose. For many of the participants the greatest loss experienced as part of the transition was of independence, particularly where this was precipitated by having to move back into the family home.

Yeah so I didn't want to go back home because I liked how independent uni made me and the feeling that you could go out when you wanted and cook what you wanted and then to go back to where I used to live...It felt restricting. (Poppy)

Anxiety comes from the prospect of not getting a job because I don't want to go home... I'm doing a tonne of stuff in uni right now – a job, internship, trying to get my grades, alongside hobbies...it's nice to have the independence and I don't want my mum and dad breathing down my neck. (Arthur)

I have enjoyed my experience of term-time independent living as a student and feel competent in that context... I have noticed this even during weekends at home that made me feel "homesick" for my university accommodation. (Ezra)

Loss in this context again relates to control. Whilst at university the participants were able to make simple but significant decisions about their own lives. To some, being able to decide what or when to eat, what to wear, or how to fill a day may seem trivial but for these young adults these skills can represent years of hard work developing practical and organisational processes and strategies. Feeling 'competent' in the university context was important to them and they felt

positive about how they had developed and matured; in this respect they no longer felt like the 'child' they had been when they began their university course. However, this is just what appears to concern them most about returning to the family home; participants saw this shift as a loss of independence and control and so 'restrictive'.

Transition as identity development

Participants made a clear connection between finishing university and its implications for their personal identities. Like the previous theme, this also relates to returning to the family home and reflects anxiety about how they perceived themselves or were perceived by others. For many of the participants, leaving university signalled the socially-acknowledged transition to adulthood, validated by having 'a place to live and a job', which was realised for 24% (n=5) of the whole sample and 45% (n=5) of the recent graduates. For Grace the primary reason that she went to university was to gain the necessary skills to establish herself as an independent and self-sufficient adult and so to fail in this endeavour was contrary to everything that she and others had worked for.

The last worst scenario is me living at home for a year 'cause I've moved away from home to gain independence, to get a job, to show my parents I can cope on my own and there's me going for the three years, then paying my accommodation to me going I can't handle it, to not getting a job, I don't have the skills, I need to come home to get more - it's kind of contradicting the whole reason I've gone to uni, I've got my own life and can do what I want... although I'll have a first degree and I might have a job, I might be becoming a little closer to being independent but I wouldn't be independent if I was living at home. (Grace)

For Grace, her identity is linked to her parents' perception of her and making a successful transition to adulthood is about proving to them that she can independently cope with life; in doing so she puts immense pressure on herself to be successful from the point of graduation. Other participants also related the importance of the positive identity as a member of the workforce. For example, John states,

I know that I would feel the next level of fulfilment if I have a job, if I'm getting paid and I'm enjoying it... Knowing that I've been able to get a job would be sort of be another level, almost, on the checklist of life for me.

It is clear here how, for most, making the transition to an adult identity is conceptualised in linear terms with a range of criteria which can be checked off one by one.

The final way transition from university impacted on identity development was with respect to participants' improved self-concept. A shift in how participants viewed themselves as they moved into and through this stage was reported; their comments often referred to confidence, control, and emotional stability.

Simply put, I'm a lot less lonely. I have managed to meet a lot of new people and that has provided a kind of fresh perspective on things...I feel better equipped than I was when I came into university...both the skills that I have learned here, the ability to socialise, jump on opportunities, managing myself... (Lewis)

I'm a lot more confident...I couldn't get a bus without panicking, even if it was one that I got all the time, it would still be a huge deal. Where now I'm a lot better, particularly with having been abroad and having to get on with it, that's made a massive difference, it's made me a lot more confident and less anxious – well I wouldn't say I'm less anxious but just better dealing with it maybe. And I think just having a better ability to know that if things do go wrong that I can deal with it, whereas before I thought the world would end pretty much. Yeah, so that's helped...I don't know that it would ever necessarily happen – but if I got to stage where I didn't get anxious doing things, I would feel like, yes I've achieved it kind of thing. (Lily)

The psychological dimension of transition is clearly as important as the practical one and in many respects interacts contingently. As Lily's comments suggest, her capacity to complete practical tasks such as get a bus or have a conversation with a stranger (which are frequently necessary conditions for successful transition to employment or independent living) are dependent on the psychological resources she has for managing emotions like anxiety. She does not suggest that she has fully made her transition to an 'adult-in-control' identity and signals scepticism that this will ever happen.

Other participants also recognised a similar positive shift in their personal identities, including being 'more self-aware, more mature, a lot more mature' (Robert) or more 'able to push myself and go further than I have before, to test my boundaries and do things I'm not comfortable with' (John). One participant, Martin, reflected on his identity since completing his education, 'I just feel like I'm a completely different person. If you met me two years ago my confidence wasn't there like it is now and that has developed'. Whilst some participants clearly experienced

frustration and anxiety as a response to their imminent or actual circumstances as part of the transition, almost all related a feeling of improved self-concept and identity development.

Discussion

These data extend our knowledge of the way transition is experienced, especially for young autistic adults completing higher education. The participants' accounts suggest some overlap with the burgeoning literature related to the transition *into* higher education; for example firsthand accounts at both of these time points report challenges around a lack of routine and reduced structure (Anderson, Carter and Stephenson, 2018; Simmeborn-Fleischer 2012) as well as high levels of loneliness, depression and anxiety (Cai and Richdale 2016; Pinder-Amaker 2014), especially with respect to encountering new physical environments and meeting new people (Van Hees et al, 2014). Difficulties around executive functioning, broadly understood as one's capacity to engage in goal-directed behaviours (Barkley, 2012), are also relevant for those engaging in any kind of transition activity and often contribute to poorer outcomes (Fleming and McMahon 2012; Gobbo and Shmulsky 2014). However, transition *from* higher education is also qualitatively different to transition *into* higher education insofar as it is a transition into the unknown. In beginning school, moving between primary and secondary education, and even coming to university, whilst there is a level of unpredictability, these destinations can be known: one can visit the school or campus, sit in the lecture theatre, meet the teachers or professors, talk to current students (Barnhill, 2014), and thus conceptualise one's identity and place in that context. Whereas, when autistic students and graduates are faced with as-yet-undefined next steps, fewer provisions can be made to support them in this transition, which can increase the challenge involved in this experience.

Participants' accounts tended to suggest a preference for following a clearly mapped and predictable life course pattern. This typically included checking off 'objective' demographic markers and linear passages of youth into adult life, such as getting a job, living independently,

forming romantic relationships, and exercising greater mobility without parental involvement (Heinz and Marshall 2003; Cohen and Ainley 2000; Mayer & Müller, 1986). That notwithstanding, participants often reported experiencing life course flux, characterised by discontinuities and reversals. This is concurrent with Arnett's (2000, 2004a, 2004b) theory of emerging adulthood, which proposes five distinct dimensions within emerging adulthood: 'identity exploration,' 'experimentation,' 'feeling in-between,' 'negativity,' and 'self-focus.' There is some evidence of identity exploration and experimentation but the over-riding experience is that of liminality where, like other emerging adults, autistic students and recent graduates find themselves as 'neither adolescents nor adults but somewhere inbetween, on the way to adulthood but not there yet' (Arnett, Žukauskienė, and Sugimura, 2014:572). These authors theorise that markers including accepting responsibility for one's self and making independent decisions are achieved gradually over time rather than in a single event and that it is this lack of identity achievement that can cause anxiety, which is certainly represented in these data and elsewhere (Anderson et al, 2016; Baldwin and Costley, 2016).

The participants in this study articulate clearly the practical and psychological dimensions of transition from higher education. Practical elements are evidenced by their apprehensions regarding where they would live next, what job they might do, how they might sustain a meaningful lifestyle, or how they would maintain relationships that they had worked hard to establish during their time at university. The extant literature tends to emphasise the practical dimensions of transition (White et al., 2017; Kuder & Accardo, 2018; Cai and Richdale 2016; Dipeolu, Storlie, and Johnson, 2015), particularly where data is derived from parents and practitioners attempting to identify successful interventions. It is also important, however, to recognise the psychological dimension to transition, as in many respects these two interact contingently. These data suggest, when autistic students and recent graduates are prepared practically this can alleviate some of the emotional strain of moving onto the next stage of life; conversely, when they are psychologically overwhelmed this can make practical planning challenging and lead to avoidance strategies as a means of coping.

Finally, there was a strong representation of negative emotions, including anxiety and fear about an unknown future; such findings concur with other research in this area (Bolourian, Zeedyk, and Blacher, 2018, Rydzewska, 2012; Giarelli et al., 2013; Nolan and Gleeson, 2016) and speak to the challenges involved in making the transition from higher education. However, it is significant that often these were balanced against other more positive emotions including a sense of pride at achievements and excitement about what might be next. Recognising this is important to avoid characterising autistic people's transitions across the life course as necessarily problematic; this study thus offers a more holistic and potentially affirming perspective through which to view this phenomenon.

Limitations and future directions

Given the paucity of studies that investigate transitions from higher education for autistic young adults, there is a need for further research, particularly across a wider range of institutions, academic disciplines, and individual trajectories. Whilst this study does provide some indication of how this transition might be experienced it has a number of limitations. Firstly, as with some other qualitative studies among adult populations (Baldwin and Costley 2016; Tint and Weiss 2018) this study did not administer diagnostic assessments for eligibility purposes and relied on participants' self-reports. Future studies might seek to employ more rigorous evaluations of autism symptoms using, for example, The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001). Secondly, whilst there is evidence of rigorous sole author qualitative research in this field (Alqahtani, 2012; Simmeborn-Fleischer, 2012; Gray, 2006) the qualitative analysis here may have been enhanced and inter-rater reliability established with the inclusion of additional collaborators.

There are also limitations in relation to the sample. Fundamentally, it was not representative of all autistic university students or recent graduates; in fact the majority (86%) of the sample studied subjects in the arts, humanities and social sciences and there is thus a possible

ascertainment bias that must be accounted for. This is notable as many studies show that autistic university students are more often drawn to STEM subjects including science, engineering and mathematics (Wei et al., 2014; Lee, 2014; Chen, 2009). Furthermore, this sample included 15 males and only 6 females. Whilst this approximately reflects the traditional male:female gender distribution of 4:1 in the autism community (Elsabbagh et al., 2012), some studies suggest that female autistic students' university enrolments could be as high as 47% (Dillenburger et al., 2016). This being so, the sample here may over-represent male experiences of transition from higher education and future studies ought to consider to recruit one which is more representative. Finally, given the relatively small sample size it was not possible to use parametric statistics or examine the extent to which findings were influenced by individual characteristics (e.g., gender, institution type).

Conclusions

This qualitative study is one of the first to identify the firsthand experiences of young autistic adults making the transition from higher education. As such it makes an original contribution to the field and offers a starting point from which to develop.

The four themes derived from the twenty-one participant interviews indicate that transition can be understood as a source of anxiety and avoidance; a positive departure; loss; and identity development. Based on these it concludes that whilst transition is a practical matter it is also a psychological phenomenon, deeply related to identity development and what it means to be an emerging adult in the twenty-first century. It suggests that autistic students and recent graduates leaving higher education experience many of the same challenges that other young adults do but posits that these are frequently amplified given the specific differences related to their autism and, at times, other co-occurring diagnoses. There is evidence that such experiences are not necessarily negative and that the transition from higher education can, for some, be a positive departure.

On the basis of this study, it might be recommended that transition planning for autistic students leaving university ought to be integrated into provision before the final year of their programme and particularly before they are in the midst of final exams or submissions, when psychological strain is typically at its greatest (Van Hees, Moyson and Roeyers, 2015; Bolourian, Zeedyk, and Blacher, 2018). Moreover, there would be value in autism-specific training and guidance for careers staff and other practitioners to ensure that they are informed about the specific needs that this group may have; access to a careers/transition mentor who could facilitate the wider transition to employment and other aspects of adulthood; and better liaison between universities, local service providers and employers at this transitional stage (c.f. Pinder-Amaker, 2014). This would increase the possibility of students being able to identify their next transition step, organise the support required for this and, therefore, increase the likelihood of a successful transition from higher education.

Funding Acknowledgements

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Declaration of Conflicting Interests

'The Author declares that there is no conflict of interest'.

References

- Accardo, A. L., Kuder, S. J., & Woodruff, J. (2018). Accommodations and support services preferred by college students with autism spectrum disorder. *Autism*. 1362361318760490.
- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic*, 42(5), 271-279.
- Alqahtani, M. M. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10(1), 15-22.

- Anderson, A. H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48(3), 651-665.
- Anderson, K. A., McDonald, T. A., Edsall, D., Smith, L. E., & Taylor, J. L. (2016). Postsecondary expectations of high-school students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 31(1), 16-26.
- Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *The American Psychologist*, 55, 469-480.
- Arnett, J. J. (2004a). *Adolescence and emerging adulthood: a cultural approach*. Pearson Prentice Hall.
- Arnett, J. J. (2004b). *Emerging adulthood: the winding road from the late teens through the twenties*. New York; Oxford: Oxford University Press.
- Arnett, J. J., Žukauskienė, R., & Sugimura, K. (2014). The new life stage of emerging adulthood at ages 18–29 years: implications for mental health. *The Lancet Psychiatry*, 1(7), 569-576.
- Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 20(4), 483-495.
- Barkley, R. A. (2012). *Executive functions: What they are, how they work, and why they evolved*. New York: Guilford Press.
- Barnhill, G. P. (2014). Supporting students with Asperger syndrome on college campuses current practices. *Focus on Autism and Other Developmental Disabilities*, 1 (7) 73-89
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5–17
- Bauman, Z. (2000) *Liquid Modernity*, Cambridge: Polity
- Bolourian, Y., Zeedyk, S. M., & Blacher, J. (2018). Autism and the University Experience: Narratives from Students with Neurodevelopmental Disorders. *Journal of Autism and Developmental Disorders*, 1-14.
- Brosnan, M., & Mills, E. (2016). The effect of diagnostic labels on the affective responses of college students towards peers with 'Asperger's Syndrome' and 'Autism Spectrum Disorder'. *Autism*, 20(4), 388-394.
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher educational students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31–41.
- Camarena, P. M., & Sarigiani, P. A. (2009). Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus on Autism and Other Developmental Disabilities*, 24 (2), 115-128.
- Cashin, A. (2018). The Transition from University Completion to Employment for Students with Autism Spectrum Disorder. *Issues in Mental Health Nursing*, 1-4.
- Chen, X. (2009). *Students who study science, technology, engineering, and mathematics (STEM) in postsecondary education*. NCES 2009-161. Washington: National Center for Education Statistics.

- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., ... & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability & society*, 32(5), 720-734.
- Cohen, P., & Ainley, P. (2000). In the country of the blind?: Youth studies and cultural studies in Britain. *Journal of Youth Studies*, 3(1), 79-95.
- Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., ... & Wolz, A. (2017). College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, 58(1), 71-87.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2013). *The landscape of qualitative research: Theories and issues*. Sage.
- Dipeolu, A. O., Storlie, C., & Johnson, C. (2015). College Students With High-Functioning Autism Spectrum Disorder: Best Practices for Successful Transition to the World of Work. *Journal of College Counselling*, 18(2), 175-190.
- Dillenburg, K., Jordan, J. & McKerr, L. (2016). School's out Forever: Postsecondary Educational Trajectories of Students with Autism. *Australian Psychologist*, 51(4), 304-315.
- Du Bois-Reymond, M. (1998). 'I don't want to commit myself yet': Young people's life concepts. *Journal of Youth Studies*, 1(1), 63-79.
- Elias, R., & White, S. W. (2018). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, 48(3), 732-746.
- Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcín, C., et al. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5(3), 160-179.
- English, L. (2018). Supporting the transition of autistic students into university life: reflections on a specialist peer mentoring scheme. *Good Autism Practice (GAP)*, 19(1), 63-67.
- Fleming, A. P., & McMahon, R. J. (2012). Developmental context and treatment principles for ADHD among college students. *Clinical Child and Family Psychology Review*, 15(4), 303-329.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., ... & Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism*. 1362361318786721.
- Gallacher, J., Ingram, R & Field, J. (2009). Learning transitions: Research, Policy, Practice. In Field, J. Gallacher, J. and Robert Ingram (editors), *Researching Transitions in Lifelong Learning* London: Routledge
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44(10), 2593-2601.
- Giarelli, E., Ruttenberg, J., & Segal, A. (2013). Bridges and barriers to successful transitioning as perceived by adolescents and young adults with Asperger syndrome. *Journal of Paediatric Nursing*, 28(6), 563-574.
- Gobbo, K., & Shmulsky, S. (2014). Faculty experience with college students with autism spectrum disorders: A qualitative study of challenges and solutions. *Focus on Autism and Other Developmental Disabilities*, 29, 13-22.

- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- Gurbuz, E., Hanley, M., & Riby, D. M. (2018). University Students with Autism: The Social and Academic Experiences of University in the UK. *Journal of Autism and Developmental Disorders*, 1-15.
- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150.
- Heinz, W. R., & Marshall, V. W. (2003). *Social dynamics of the life course: Transitions, institutions, and interrelations*. Transaction Publishers.
- Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*, 32(2), 125-134.
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.
- Higher Education Statistical Agency (2015) [online] <https://www.hesa.ac.uk/data-and-analysis/students> <Accessed 14.04.17>
- Hillier, A., Goldstein, J., Murphy, D., Trietsch, R., Keeves, J., Mendes, E., & Queenan, A. (2018). Supporting university students with autism spectrum disorder. *Autism*, 22(1), 20-28.
- Jackson, S. L., Hart, L., & Volkmar, F. R. (2018). Preface: Special Issue—College Experiences for Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48(3) 639-642
- Jansen, D., Petry, K., Ceulemans, E., Noens, I., & Baeyens, D. (2017). Functioning and participation problems of students with ASD in higher education: which reasonable accommodations are effective? *European Journal of Special Needs Education*, 32(1), 71-88.
- Kirby, A. V., Baranek, G. T., & Fox, L. (2016). Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *OTJR: occupation, participation and health*, 36(2), 55-64.
- Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 722-731.
- Lee, A. (2014). Students with disabilities choosing science technology engineering and math (STEM) majors in postsecondary institutions. *Journal of Postsecondary Education and Disability*, 27(3), 261-272.
- Lee, G. K., & Carter, E. W. (2012). Preparing transition-age students with high-functioning autism spectrum disorders for meaningful work. *Psychology in the Schools*, 49(10), 988-1000.
- Lindstrom, L., Doren, B., Metheny, J., Johnson, P., & Zane, C. (2007). Transition to employment: Role of the family in career development. *Exceptional Children*, 73(3), 348-366.
- Madriaga, M., Goodley, D., Hodge, N., & Martin, N. (2008). *Enabling transition into higher education for students with Asperger syndrome*. Sheffield: Sheffield Hallam Press
- Mayer, K. U., & Müller, W. (1986). The state and the structure of the life course. Human Development and the Life Course: *Multidisciplinary Perspectives*, 6 (3) 217-245.

- Miles, M. B., Huberman, A. M., & Saldana, J. (2013). *Qualitative data analysis*. Thousand Oaks: Sage.
- Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders*, 47(6), 1830-1837.
- Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)*. NCSER 2011-3005. National Center for Special Education Research.
- Nolan, C., & Gleeson, C. I. (2016). The transition to employment: the perspectives of students and graduates with disabilities. *Scandinavian Journal of Disability Research*, 2 (3) 1-15.
- Papay, C. K., & Bambara, L. M. (2011). Postsecondary education for transition-age students with intellectual and other developmental disabilities: A national survey. *Education and Training in Autism and Developmental Disabilities*, 78-93.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks: SAGE Publications.
- Pillay, Y., & Bhat, C. S. (2012). Facilitating support for students with asperger's syndrome. *Journal of College Student Psychotherapy*, 26(2), 140-154.
- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22, 125-137.
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(9), 931-939.
- Rydzewska, E. (2012). Destination unknown? transition to adulthood for people with autism spectrum disorders. *British Journal of Special Education*, 39(2), 87-93.
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and developmental disabilities*, 50(1), 16-30.
- Shmulsky, S., Gobbo, K., & Donahue, A. (2015). Groundwork for Success: A College Transition Program for Students with ASD. *Journal of Postsecondary Education and Disability*, 28(2), 235-241.
- Simmeborn-Fleischer, A. (2012). Alienation and struggle: Everyday student-life of three male students with asperger syndrome. *Scandinavian Journal of Disability Research*, 14(2), 177-194.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566-574.
- Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PloS one*, 13(3), e0194758.
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45(6), 1673-1688.

- VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38(7), 1359.
- Van Hees, V., Roeyers, H., & De Mol, J. (2018). Students with Autism Spectrum Disorder and Their Parents in the Transition into Higher Education: Impact on Dynamics in the Parent–Child Relationship. *Journal of Autism and Developmental Disorders*, 1-15.
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B. & Ledger, T. (2017). 'I think autism is like running on Windows while everyone else is a Mac': using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research*, 25(2), 300-315.
- Walker, D. M. (2012). Asperger's/Autistic Spectrum Disorder project: transition from higher education to the workplace. *Journal of the National Institute for Career Education and Counselling*, 28(1), 51-58.
- Ward, D., & Webster, A. (2017). Understanding the Lived Experiences of University Students with Autism Spectrum Disorder (ASD): A Phenomenological Study. *International Journal of Disability, Development and Education*, 1-20.
- Wei, X., Wagner, M., Hudson, L., Yu, J. W., & Shattuck, P. (2015). Transition to adulthood: Employment, education, and disengagement in individuals with autism spectrum disorders. *Emerging Adulthood*, 3(1), 37-45.
- Wei, X., Christiano, E. R., Jennifer, W. Y., Blackorby, J., Shattuck, P., & Newman, L. A. (2014). Postsecondary pathways and persistence for STEM versus non-STEM majors: Among college students with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(5), 1159-1167.
- White, S. W., Elias, R., Capriola-Hall, N. N., Smith, I. C., Conner, C. M., Asselin, S. B., ... & Mazefsky, C. A. (2017). Development of a college transition and support program for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(10), 3072-3078.
- Zager, D., & Alpern, C. S. (2010). College-based inclusion programming for transition-age students with autism. *Focus on Autism and Other Developmental Disabilities*, 32(2), 768-773.