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Autism and the transition to university from the student perspective.

Sinéad Lambe, Ailsa Russell, Sanjeet Fletcher, Chris Ashwin & Mark Brosnan

Abstract

University provides individuals with the opportunity to develop greater independence in living skills and social networks, whilst also gaining valuable qualifications. Despite a high proportion of autistic individuals aspiring to attend university, many either do not seek or gain entry, or drop out prematurely. Although some steps have been taken to develop effective support, a recent review highlighted the scarcity of research into programs designed to support autistic students transitioning to university. In addition, few studies have examined the views of autistic students themselves. This study investigated the perspectives of autistic students transitioning to university. Three focus groups were conducted, each with twenty-five autistic students preparing to start university. Participants were asked about their hopes for starting university, as well as their worries and concerns. Data was analysed using thematic analysis, from which five main themes were identified: The Social World, Academic Demands, Practicalities of University Living, Leaving the Scaffolding of Home, and Transition to Adulthood. The results provide an important account of the challenges autistic students face when transitioning to university, as well as their aspirations. These findings have a number of practical implications.

Introduction

Autism is a developmental condition, characterised by qualitative impairments in social communication and social interaction across contexts, and a repetitive or restricted pattern of interest, behaviour and activity (American Psychiatric Association, 2013). Autism affects 1.1-1.7% of the population (Baird et al., 2006; Centers for Disease Control and Prevention, 2018), with approximately 50% having an associated intellectual disability, ID (Centers for Disease Control and Prevention, 2014). Outcomes in adulthood for autistic individuals without an ID are poor, with low levels of employment (e.g. Taylor & Selzter, 2011) and as few as 15% living independently as adults (Eves & Ho, 2008; Gillespie-Lynch et al., 2011; Howlin, 2000). It is estimated that for each autistic person without an intellectual disability, the lifetime cost to families and society is approximately £1 million in the United Kingdom (UK), due to lost earnings and support services (Buescher et al., 2014). Therefore, enabling autistic individuals to live independent lives needs to be a priority.

Higher-level education, including university, is a predictor of enhanced outcomes in adulthood. Within the general population, university education is associated with higher employment levels, higher lifetime earnings, improved physical and mental health and greater life satisfaction (HM Government, 2016). Despite a high proportion of autistic individuals reporting an aspiration to attend university (Camarena & Sarigiani, 2009), many either do not seek or gain entry into university in the first place, or drop out prematurely (Glennon, 2001; VanBergeijk et al., 2008). It has been suggested that the increased attrition can be attributed to social isolation, difficulty adjusting to changes in routine, and difficulties living independently (Howlin et al., 2004; Jobe & White, 2007).

Legislation introduced in the UK such as The Equality Act, 2010 (Office for Disability Issues, 2011) and the Special Educational Needs and Disability Act, 2001 (HM Government, 2001; 2014) called for higher education (HE) institutions to make reasonable

adjustments to prevent an autistic or disabled person being placed at a substantial disadvantage. Recent changes to the Disabled Students' Allowance (DSA) mean that autistic students will have less access to non-medical support putting more onus on universities to find ways to meet the conditions of the Equality Act (see Layer, 2017). There have been a number of interventions and programmes developed to help autistic students succeed at university (Pugliese & White, 2014; White et al., 2016, 2017; Roberts & Birmingham, 2017; Hillier et al., 2018; Hotez et al., 2018). Although promising, the evidence base for the effectiveness of these interventions remains limited. In addition, a systematic review highlighted a scarcity of research considering the personal experience of autistic students (Gelber et al., 2014). A number of studies have since been published documenting the lived experiences of autistic students attending university (e.g. Gelber et al., 2015; Cai & Richdale, 2016; Van Hees, Moyson, and Roeyers 2015; White et al., 2016), and been used to inform intervention (Hotez et al., 2018; White et al., 2016).

Studies documenting the lived experiences of autistic students at university have provided clarity around the challenges they face and how they can best be supported. Beardon and colleagues (2009) surveyed 135 young British autistic adults about the problems they encountered at university. Students described challenges in social interaction, negotiating the social environment (such as the expectations and presence of others), their own and others understanding of autism, and managing the structure and demands of the course. White and colleagues (2016) used a mixed method approach, including a focus group, with 5 students attending university in the United States of America (U.S.A.). The authors identified challenges in interpersonal competence, instrumental independence (time management, problem solving, organising), academic demands, and separating from the support system. **It is not only the number of challenges that autistic students face at university that is problematic, but also how these challenges inter-relate with each**

other.. Van Hees, Moyson, and Roeyers (2015) conducted semi-structured interviews with 23 autistic students at a Belgian university, and concluded that balancing the three major domains of student life (education, socialization, and independent living), rather than a single skill deficiency or life challenge, posed the greatest difficulty. Similarly, two studies, one carried out in the U.S.A. and another in Australia, found that autistic students deemed the academic support to be adequate, but described a lack of social and emotional support (Gelber et al., 2015; Cai & Richdale, 2016). Some authors have argued for a move to more inclusive practice when thinking about disability. Hastwell and colleagues (2012) carried out interviews and focus groups with 28 autistic students attending a British university. Students reported facing challenges with social inclusion, communication, management of academic demands, anxiety, depression, and low self-esteem. Based on this the authors argued for more flexible and inclusive practice by institutions rather than a 'one size fits all' and disability specific adjustments that mark students out as different.

All these studies to date have been conducted with autistic students already attending, or who had previously attended, university. Less work has been done documenting the views of students preparing to make the transition; much of the work in this area has focused on the views of parents and educators (Elias & White 2017; Elias et al. 2017; Gobbo & Shmulsky, 2014; White et al., 2016). This is important as the perspectives and needs of autistic students preparing for university may be different to those already attending university. Transition periods are difficult for autistic individuals as they struggle with changes in routines and environment, and they have a preference for repetitiveness and restricted behaviour (American Psychiatric Association, 2013). Furthermore, there is a significant negative relationship between the level of stress experienced by autistic students prior to enrolling in a university and their adjustment six months later (Pancer et al., 2000). Understanding the concerns of students preparing to make the transition to university, and whether these differ

from those already attending, will help inform targeted transition programmes, a priority for research identified by Interagency Autism Coordinating Committee (2013). Hence, this study sought to answer two broad research questions:

(1) What are the challenges faced by autistic students preparing to make the transition to university?

(2) What are their hopes for university?

Methods

Participants

Participants were 25 A-level[1] students (20M/5F) with a clinical diagnosis of Autism Spectrum Disorder (ASD; referred to as autism in this study), ranging in age from 16 to 21 years (mean age = 18.04 years, sd=1.43). All participants were attending a university transitional programme at the University of Bath because they had applied to begin a university degree in the next 12 months. Eleven (61%) participants had applied to study a STEM (Science, Technology, Engineering, Mathematics) subject at university, 4 (22.6%) an Art & Design subject and 3 (16.8%) a subject in the Arts & Humanities faculty. A diagnosis of autism had been confirmed via a clinical assessment by health/child development services based on international criteria (DSM 5/ICD-10). Diagnostic information was supplemented by a parent report development checklist (the Social Communication Questionnaire, SCQ; Rutter et al. 2003) and self-report measure of ASD symptoms (Ritvo Autism/Asperger Diagnostic Scale Revised, RAADS-R; Ritvo et al. 2011). Mean scores for the sample on both measures were significantly above the clinical cut-offs (mean SCQ score= 18.95 (SD = 5.76);

[1] A-levels are typically taken around age 18 and for the basis of the entrance requirements for universities in the UK

$t(21) = 3.22$, $p < .01$) and mean RAADS-R score = 116.13 (SD = 26.86); $t(23) = 9.33$, $p < .001$).

Procedure

All participants were attending a three-day transition programme at the university, delivered free of charge. Prior to attending the programme all attendees were sent information about the research study and offered the opportunity to participate. It was made clear that their decision would have no impact on their attendance at the transition programme. All consenting participants were then sent a questionnaire asking them to list their worries, if any, about attending university and the aspects they were looking forward to. This was used to generate a list of prompts for the focus groups that followed.

Three focus groups, with 8-9 students each, were convened on the first day, before the programme began. Focus groups were chosen as they are considered to be particularly useful when there is little prior research in an area as it encourages conversation between participants creating shared meaning and encouraging elucidation of non-shared perspectives (Kitzinger, 1994; Braum & Clark, 2006). It was acknowledged that for autistic participants, this may not be have been their preferred context for sharing their perspectives, particularly for those with higher social anxiety. This method has been used successfully with autistic students in previously (Cai & Richdale, 2016; Hastwell et al., 2012; White et al., 2015) and steps outlined below were taken to minimise anxiety.

Focus groups were facilitated by an academic staff member from the Psychology Department at the University of Bath experienced in working with autistic students (University Lecturer/Reader in Psychology including a clinical psychologist) and supported by a clinical psychologist in training. Facilitators were skilled at encouraging participation and engagement as well as being sensitive to difficulties that might arise for this group, such

as anxiety. Focus groups began with facilitators reiterating the purpose of the research and reminding participants that participation was voluntary that they could withdraw at any time. In each group show of hand questions were used initially to help participants relax, such as *show of hands, who has been to this city before*. Then warm up questions were used, such as *what subjects are you hoping to study?* When participants seemed more at ease, facilitators progressed on to the topic guide, which was developed based on the available research in this field. It included open-ended questions such as *What worries you most about starting university? What about university life are you looking forward to?* It was acknowledged that some participants may struggle to talk in a group. If this was the case more specific prompts, based on students' earlier responses to the written survey, were used to generate discussion. The focus group lasted approximately 90 minutes. At the end participants were thanked for their involvement. The study was approved by the Psychology Research Ethics Committee at the University of Bath (ref 13-119) and all participants gave written informed consent.

Qualitative Analysis

The focus groups were audio-recorded and transcribed verbatim. Transcriptions were then checked for accuracy by two members of the research team. A data-driven thematic analysis was conducted according to the procedures outlined by Braun and Clarke (2006). This inductive semantic approach was adopted so that resulting themes were analysed from the explict meanings of the data itself, and not from the researchers' preconcieved theorticial perspectives or interpretations beyond the data to suggest its underlying meaning.

The transcripts were read several times in addition to listening to the audio recordings, in order to become familiar with the depth and **breadth** of the content. Following this codes were identified based on features of the data that the researcher (SL) considered pertinent to the research questions. Codes were checked against the whole data set and

similar codes were combined to form themes. Thematic maps were developed to aid the generation of themes and consider the links and relationships between themes as recommended by Braun and Clarke (2006). At this point, any themes that did not have enough data to support them or were too diverse, were discarded. This refinement of the themes took place on two levels, primarily with the coded data ensuring they formed a coherent pattern, secondly once a coherent pattern was formed the themes were considered in relation to the data set as a whole. This ensured the themes accurately reflected what was evident in the data set as a whole; and coherence in the themes reflected Elliot, Fischer and Rennie's (1999) criteria for quality in qualitative research. Codes and themes were examined by a member of the research team (AR) to conduct a 'credibility check', as recommended by Elliot, Fischer & Rennie (1999). They provided suggestions and corrections. Any disagreements were taken to another member of the research team (CA) who made the final decision.

Once a clear idea of the various themes and how they fitted together emerged, themes were defined and named. Considerations were made not only of the story told within individual themes but how these related to the overall story that was evident within the data. The final stage of the report production involved choosing examples of transcript to illustrate elements of the themes. These extracts clearly identified issues within the theme and presented a lucid example of the point being made, thus laying a 'confirmability trail' (Erlandson, Harris, Skipper & Allen, 1993), another suggested criteria for quality control in qualitative research.

Results

The two research questions were (a) what are the challenges faced by autistic students transitioning to university and (b) what are their hopes for attending university. In organising the data it was not feasible to divide themes based on these two questions because it emerged that the challenges and hopes were interlinked within each theme thus considering them together provided a more authentic narrative. Five main themes emerged from the data: The Social World, Academic Demands, Practicalities of University Living, Leaving the Scaffolding of Home, and Transition to Adulthood. These are defined and expanded on below.

The Social World was defined as that which related to the social environment and the participants relationship with it. Within this theme, three subthemes were identified: (a) understanding of the social world, which refers to how they make sense of the social aspect of their environment, (b) my place within the social world, referring to how they see themselves in relation to the social environment, and (c) surviving the social world, which refers to the strategies or approaches used by participants to manage the social context they find themselves in.

Understanding of the social world: Throughout the discussions patterns emerged relating to the types of social interactions participants were more concerned about at university and those which they found easier. One distinction that emerged was between structured and unstructured socialising. Participants described finding it easier to know what was expected in structured social situations such as class time and group work, however once outside of a structured framework, participants reported experiencing high levels of anxiety and discomfort.

> ‘If I’m with a group and it’s a structured sort of work task I find I can do it sort of contribute but if it becomes unstructured I get more anxious so it’s sort of like instead of sort going out

of school during lunch…I tend not to go … whereas I would talk to them in school if it's about work or a club task' (Group 1)

There was a sense that unstructured social time can be unsafe based on past experiences of bullying.

'if it's unstructured I would generally, I'd sit by myself somewhere where I know, I'm sort of reasonably safe' (Group 1)

Participants were more concerned about group activities which they reported finding more difficult than one to one friendships. Participants were astute at recognising how one type of social interaction could lead to another, which may be less desirable.

'one of my fears about groups is if I'm with someone I know and then we went out to town or something and then they saw their other friends and start talking to them then I'd sort of be on the outside whilst they were talking cause I don't know them and don't do well with meeting new people, then I would then feel uncomfortable and not sort of join in so then sort of just be on my own' (Group 1)

Some participants spoke about social media as a preferable method of socialising. It was described as minimising the complexity usually associated with social interactions, in particular non-verbal communication, which many participants reported struggling with.

'I would I'll use my phone or stuff rather than talk to other people I would communicate through Facebook rather than talking to them face to face and I feel almost like of course I'm socialising' (Group 2)

Participants recognised that university holds a number of social experiences that are unique to that context. One group spoke about Fresher's week (the very first week at university, typically before classes start)**,** a prominent social event unique to university. They spoke about fresher's week as combining many of the different challenges and fears they have related to socialising.

> 'I think cause fresher's week is quite busy isn't it and there's lots of people round and like again I struggle with groups or being in a crowd and that sort of thing so I'm sort of going to be very anxious that week I think and sort of going to be quite on edge' (Group 1)

> 'I'm worried about really social flatmates, like people who have people over all the time…It can get just awkward if they're constantly around but you don't know them cause you have no reason to connect' (Group 3)

Thus students had concerns about the types of social situations they may face at university reporting concerns about unstructured activities, group social situations and Fresher's week and a preference for interaction that are one to one, structured or conducted through social media.

My place within the social world: Socialising was highlighted as one of the biggest concerns that participants had about starting university. Participants spoke about experiencing bullying in the past and how that has led them to view socializing as dangerous and exposing.

> 'I don't think I'm necessarily worried about getting bullied or anything at university I think it's more, I'm, it's made me more cautious so and changed my attitude towards, you know my

> confidence, in social situations because I know it can happen I'm more wary and slightly paranoid about being in those situations' (Group 1)
>
> 'I've become a lot less inclined to put my, to risk putting myself in those situations I now don't do it because I worry about it happening even though I know it's unlikely to, I don't want to risk it happening again' (Group 1)

Participants discussed the barriers to integrating successfully into the social world at university. Many reported worrying about doing or saying the wrong thing and the social consequences of that as well as the effort required to avoid this.

> 'If you do take things literally, which is what I do, that you'll sort of get teased … and like if you don't get the jokes or you know if you're not very good and sarcasm or anything like that so I'm a bit worried' (Group 1)
>
> 'It's really its hard work it's just that it'd be easier not to have friends because then you wouldn't have to put the effort in. If I'm writing a text I have to think about why I'm writing the text because, I have a tendency to write spiels of everything… you have to fight not to because things go wrong' (Group 2)

This extended to understanding social norms at university generally. Participants demonstrated a conscious effort to pre-empt how they should behave in relation to different aspects of university life that others might not consider.

> 'There's several stairways in between the shower and I'm not sure what I should do. Should I get changed after, immediately after I get a shower in the bathroom or go up in a towel?' (Group 3)

Across all groups, participants spoke about their perception of themselves within the social world. They spoke about 'looking foolish' or 'stupid', 'being a terrible person', 'a nightmare housemate' or being a 'loner'.

> 'it took them actually saying to me why don't you talk to anyone to actually realise that I was being that terrible person who was just sitting there making everything awkward so it's just hard' (Group 3)
>
> 'a lot of pupils want to hang out with others and I sometimes feel left out which is where the loner part comes in' (Group 2)

Despite these challenges participants spoke about a desire and hope to be part of the social world at university coupled with a fear of being isolated if they cannot achieve this.

> 'I'm looking forward to it (university) if I can make friends and do the social side of it but I know that if I can't its just gunna be an absolute nightmare' (Group 1)
>
> 'My fear is it will be like secondary school. No friends, no, didn't talk to anyone because it was so much easier not to and it wasn't pleasant so I felt the need to change and when I say it wasn't pleasant, I don't mind being on my own but being on your own with people around you is more feeling left out then if you're on your own (Group 2)

Surviving the social world: Participants described a number of strategies that they planned to use to negotiate the aforementioned challenges at university. Two main perspectives emerged. The first involved strategies to minimise or avoid social interactions altogether. Although many participants endorsed this as a strategy there was also recognition of the consequences it has socially.

> ‘I feel uncomfortable doing in a social situation so I’ll say you know I need to go and talk to my tutor or something when I don’t just because I don’t want to you know be hang around too long and I struggle with it and I then, people start feeling like well he’s a bit you know, they don’t believe you after a while cause it’s, you do it, if you do it too often which is several times is considered too often they then start disbelieving you and thinking that you’re just trying to get out of it which you are but then they’re not as necessarily as friendly as they would have been’ (Group 1)

The second perspective reflected the hope that university would provide a fresh start and held the potential for social experiences different to those previously experienced. Participants described plans to become involved in clubs and societies and take more ‘risks’ when socialising.

> ‘over the coming year I’m going to try and go into social situations more and I think the more that they’re positive the more confident I’ll get…I’m worried but I’m also sort of interested to see whether my fears will you know grip or if you know they don’t have any basis‘ (Group 1)

Academic Demands was defined as that which related to the course itself and their academic performance at university. Participants described feeling excited about the academic component of university. Participants spoke about being taught by experts in the field and focusing on a subject that they enjoy.

> ‘for the first time you know I sort of get the sense that the people who are going to be teaching me are actually sort of proper scientists who are actually writing a paper right now’ (Group 1)

However there was also recognition that university would be more demanding academically and participant's worried about not succeeding

> 'uni is much harder than A-level and you have to come in after how many months of doing nothing at the top end already and it just a few steps below absolute master of that field and you have got to perform at that level …and if you can't do that level then you've paid 9000 pounds to say oh I've failed a course' (Group 3)
>
> 'even if I work really well and study hard it still might not be enough (.) my best isn't good enough that sort of worry' (Group 2)

The main areas participants anticipated struggling with included time management, meeting deadlines and managing different demands.

> 'I can obsess over something and just fret about it to the point that you know everything else pales into insignificance' (Group 1)
>
> 'I might end up getting distracted and not necessarily be able to do everything in the time that I have available' (Group 3)

In contrast some participants felt that university may be less challenging in relation to these things because courses are more focused

> You're not doing multiple subjects it only really going to be one subject and its gunna be something that you're much more likely to enjoy (Group 3)

Some participants described strategies they hoped to use at university to manage these difficulties.

> 'I'm going to have to try and get a get a timetable (inaudible) saying you know these are the days where I've got an assignment I will try and at least start them and write may be half of it sort of thing you know and urm dedicate cert to sort of you know certain times sort of thing to start them' (Group 1)
>
> 'Time management has always been a problem for me so I've got a book with some really good strategies for it' (Group 2)

Practicalities of university living: This was defined in terms of the day to day practicalities of moving to, and living at, university. Practical concerns could broadly be divided into two categories, those relating to the transition to university and those relating to ongoing life at university. Participants described the anxiety caused by having to move to an unfamiliar place and difficulties with finding their way around.

> 'If I go into a place I don't know I get quite anxious' (Group 1)
>
> 'the trouble with a big city or anywhere you're unfamiliar with, it's a lot more like dangerous' (Group 3)

Some participants discussed plans to get in touch with disability services within the university. Many of the participants spoke about having co-occurring difficulties such as dyslexia and dyspraxia that interfere with their learning. Although participants were aware of some support that is available (e.g. DSA) provided by the UK Government, they were concerned about falling behind in the interim time between starting university and these supports being put in place.

> ‘my biggest worry is the first month or so before you know the disability allowance gets me this all this equipment, because I know that I’m going struggle because my working memory is so appalling I cannot take notes in lectures’ (Group 1)

Participants spoke about the need to develop practical skills such as getting groceries, cooking, budgeting effectively and being responsible for buying toiletries and cleaning products and maintaining a clean house. There were varying levels of confidence amongst participants around being able to manage these things and they differed on what elements worried them most. However a theme running through this was anxiety about organising all these different elements.

> ‘you are totally learning to live independently by yourself and you’ve got to do things like manage your money get your work in on time and all that kind of stuff’ (Group 2)

A number of participants spoke about feeling less worried about practical issues related to university because they have been practicing some of the necessary skills at home.

> ‘I use to be really homesick but I go away for weekends quite regularly by myself now so I'm a lot more use to it’ (Group 2)
>
> ‘I’m less concerned about the management of my money things because I got forced into managing myself when I started sixth form so I’ve already done it (Group 3)

Leaving the Scaffolding of Home: This was defined in terms of issues related to leaving home and school. Participants described family as providing support, predictability, reassurance and prompting, and they shared worries about the loss of these aspects of home life when

moving to university. Participants spoke about how families provide a safe stable place that is separate to the outside world. However at university these boundaries are not as clear and there is less separation between home, academic and social lives.

> 'friendship bonds they're less stable than family bonds, there's not a link in the background that's always there its more dependent on what you do its more if something goes wrong it might seriously cause problems whereas at home you've got family and school are separate entities' (Group 2)

Participants described how family support provides scaffolding, which compensates for some of the difficulties they experience due to their autism. Family members provide support and encouragement to face and overcome difficulties engaging socially.

> 'for me at least that's [socializing] no longer as much of an issue…I have two older sisters and they have the tendency to like throw me in at the deep end with a load of people I didn't know' (Group 1)
>
> 'My main problem is I go in to a shell and if I'm not forced to socialise I just go to my room and don't talk and don't say anything and if I don't go to school then urm I don't go out I just do my own things. I might end up going to university and never talk to anyone. They [my family] force me to do things' (Group 2)

Participants described parental use of prompting around time-management and schoolwork and noted the difference in support and structure around managing the academic demands at university compared to at home and at school.

> 'through like my A levels my dad really helped and helped me to get coursework in on time'

> ‘not having or people that you have at home to kind of encourage you to do your work and having to motivate yourself’ (Group 1)
>
> ‘the big thing is going to be that you don’t have… teachers or whatever to look over your work to make sure it’s done right’ (Group 2)

Leaving home also brings changes in routine and predictability. This extended from small changes in how the day is organised to the loss of valued activities that make up home life.

> ‘for me it’s like getting out of bed and sorting the animals out at home and if I go to university I won’t be able to that and yeah that sort of that will be a massive change I think’ (Group 1)
>
> ‘you might be used to having you’re dinner at like five or something but you might have to have it later at university and like small things can affect your routine’ (Group 3)

Furthermore changes in predictability did not just relate to routines but also the predictability of family members and their reactions.

> ‘I can predict my parents pretty well after eighteen years so I can sort of judge how they’re going to react to different situations and I like that it means I don’t have to fret about what’s going to happen if I say something or if I do something [wrong]’ (Group 1)

Transition to Adulthood: This was defined in terms of issues that related to becoming an adult and being more independent. Despite the concerns about leaving the safety of home life (described above) there was also a sense that starting university represents a transition towards adulthood and holds the potential for developing independence and having new experiences.

> ‘I think it [university] will be positive as it will help you to live independently and prepare you for adult life in the future’ (Group 2)
>
> ‘at school you’d have your parents and teachers and that but then you’d just have the teachers here [University] and like you kind of like build up like it’s taking the crutch away as it were’ (Group 3)

University was also described as helping people pursue their interests and move towards their desired career.

> ‘moving on with your life actually starting to think about careers and what you actually want to do … it’s sort of scary stuff to do but soon as I decided what I wanted to do then that’s fine I want to go do that ‘ (Group 1)

Consistency of themes across groups*:* These themes came up across all three groups, though there was variation in degree to which they were discussed; Group 1 spent more time discussing social situations, whereas Group 2 and Group 3 focused more time on the academic demands and practicalities of university.

Discussion

This study aimed to identify, for the first time, the concerns and hopes of autistic students preparing for the transition to university, with a view to informing how to better shape and improve support for autistic students transitioning to, and during, university (see Hotez et al., 2018; White et al., 2017).. The themes identified were based upon the ‘autistic voice’ of

students approaching this transition, whereas previous research had focussed upon the views of parents and teachers (e.g. Elias and White 2017; Elias et al. 2017). The concerns and hopes of potential autistic students were interwoven within five themes.

Socialising at university was the most frequently voiced concern across the three focus groups and this was reflected in the first theme of 'The Social World' which was expected given the centrality of social communication and interaction to a diagnosis of autism (Hastwell et al., 2012, Madriaga et al., 2008; White et al., 2016). However these results go beyond simply identifying the social world be challenging, and provide a rich insight into the experiences of autistic individuals and their understanding of the social environment. Participants were actively making sense of the social aspect of their environment, their place within this social environment, and how to survive it. It was clear that participants were motivated to develop and sustain social relationships at university, albeit expressing a preference for one-to-one, structured socialising. There is an increasing awareness of the emotional impact that social isolation can have on autistic individuals (Whitehouse et al., 2009). In line with this, participants in the present study articulated an acute sensitivity to social 'norms', an awareness of social difference and the negative impact of social avoidance and self-imposed social exclusion. Participants described social evaluative concerns consistent with cognitive behavioural models of social anxiety (Clark & Wells, 1995; Connor, 2007) with some of these concerns derived from how others might perceive their attempts to 'manage' social situations. The use of social media, such a Facebook to manage social communication was identified as a strategy. This has previously been found to be effective medium for social communication by members of the autistic community, but does then not extend to offline social communication (Brosnan & Gavin, 2015). Students arrive at university, often having negative bullying experiences from peers (Cappadocia et al., 2012; Humphrey & Symes, 2010), with some participants reflecting that

social interaction was consequently seen as a potentially risky situation and avoided. In contrast those that chose engagement as a strategy for socialising reported previous positive experiences of persevering with initially anxiety provoking social situations. It is incumbent upon universities to highlight (and enforce) their anti-bullying policies and procedures.

In addition to the social aspects of university, students described concerns, about time management, prioritising different demands, and retaining an appropriate level of focus (i.e. obsessing versus becoming distracted) under the theme Academic Demands. This is consistent with previous studies (Beardon et al, 2009; Hastwell at al., 2012; Madriaga et al., 2008; White et al., 2016) and difficulties following multistep directions, keeping materials organized, and being a "self-starter" in educational settings have been reported (Rosenthal et al., 2013). It is plausible that executive function deficits associated with autism are relevant here (e.g. Joseph & Tager-Flusberg, 2004). Beyond academic demands, participants also had concerns about their ability to adapt to a new place and routine, and managing the associated anxiety as well as manage independent living tasks such as cooking and budgeting, under the theme Practicalities of University Living. Again, given the diagnostic criteria for autism, it would be expected that transitioning to university would challenge a preference for sameness or routine. Crucially, however, despite these potential challenges, there were also hopes that excited participants expressed around both Academic Demands, such as learning from experts and focussing on a subject of interest, and Practicalities of University Living, such as developing independence.

These social, academic and practical challenges will be faced without the students' familiar support network. Under the theme Leaving the Scaffolding of Home, participants described the important role parents and families play in helping them manage challenges, as well as providing a predictable and stable platform separate from the wider social world. The participant's concerns about the loss of family support is consistent with other research,

reporting that autistic individuals find it difficult to use and maintain independent living skills without prompting and support, most often provided by family (Taylor & Seltzer, 2011; Tobias, 2009). Despite these challenges, the theme Transition to Adulthood revealed that participants see university as an opportunity for achieving future aspirations, such as a career, making a fresh start and as a gateway into adulthood. Participants also seemed to be taking an active role in preparing themselves, with many reporting practising living skills and considering new strategies to help adapt to a new environment. Supportive parents and families working towards the student supporting themselves (without additional support) prior to transitioning to university is clearly a desirable strategy.

The themes identified therefore have the potential to greatly inform how universities prepare for the transition of autistic students. In respect of social situations, considering the facets that students find less challenging i.e. individual interactions and/or structured group situations can help with social integration. A preference for one to one and structured social situations also has implications for teaching practices. Many of the academic components of university are inherently social, for example tutorials and groupwork (e.g. problem based learning groups). These methods have been shown to be effective with the general student population and are becoming increasingly popular with students and viewed as effective teaching methods (Walker et al., 2015). Such practices may alienate autistic students who find these more 'social' teaching activities anxiety provoking, impacting on their learning. Universities will need to be more flexible and inclusive in their methods of teaching. This is particularly relevant following changes to DSA in the UK, which means autistic students have less access to non-medical equipment to aid note taking etc. (Layer, 2017), thus placing greater responsibility on universities for meeting requirements of the Equality Act 2001. University staff structuring the group formation process and explicitly detailing the roles of group members and the precise nature of the group work, would be beneficial for autistic students.

Online academic forums will also be more accessible, allowing autistic students to engage in discussions and ask questions, more easily than face to face in lectures and discussion groups (after Brosnan & Gavin, 2015).

Encouraging students to access university societies that share an interest may also provide a structure to support social interaction. As such, preparing university societies to be autism aware is also important, and potential autistic students can be made aware of the available university societies in advance of the transition. Typically, however, the time to join university societies in Freshers' week, which was highlighted as a particular concern by participants. The first week of university, usually referred to as Freshers' week, was highlighted by some participants as a daunting time because it is busy and crowded. Hastwell et al. (2013) make recommendations including a quiet hour at the start of each day with reduced numbers and low/no music as well as a buddy system to help autistic students navigate Freshers' week. A Freshers' 'buddy' (or mentor) may also help to combat the sense of being excluded or a 'loner' spoken about by participants in the current study. There is a growing evidence base for the effectiveness of mentorship programmes at university (Ames et al., 2016; Roberts & Birmingham, 2017) and mentoring may be particularly relevant for autistic students who acknowledge concerns about losing familiar sources of support. Previous studies in this area report the academic support provided by university to be adequate but lacking in social and emotional support (Gelber et al., 2015; Cai & Richdale, 2016). The lack of social emotional support provided by the family was identified as a key theme for autistic students transitioning to university, indicating that mentoring schemes need to adapt to support this aspect of the transition. Preparing for a shift from family/teacher support may be aided by practical skills development such as cooking meals, budgeting, and time-management. Combined with a gradual reduction of the scaffolding provided by others

to support such activities. This may increase student confidence about some of the demands of university transition.

Changes, which make university more accessible to autistic students, will make the university environment more flexible and increase the degree of customisation to the benefit all students regardless of their individual abilities or learning preferences (Layer et al., 2017). In applying these recommendations, it is important to note that there is no one size fits all and that any supports should be tailored to the individual student's needs, which may change depending on their stage in the student life cycle.

There are a number of limitations to the study, which should be noted. The degree to which this sample is representative of autistic students is unclear. Participants plan to attend university and volunteered to attend a transitional programme, which suggests good academic attainment and confidence to seek out development activities, which may not be representative of wider autistic population. The use of focus groups might have meant that students with higher levels of social anxiety were less likely to share their perspective as much as they may have in other environments. Also because this study was looking at student perspectives on making the transition it required them to project into the future. Autistic individuals can struggle to imagine possible futures (Crane et al., 2013) and thus there may be other aspects of the transition that would be problematic but that were not identified. The views of students without autism were not sought, and it is not clear if these are universal student concerns or specific to autistic individuals. This could form the basis of interesting future studies. With the right support, university provides an opportunity for autistic students to develop independent living skills and follow their career aspirations, while also furnishing them with positive social experiences and a more positive social identity. This study highlights specific practices which educational institutions and support services could implement to ease university transition. The study also illustrates students' views about the

positive aspects of university education which may inspire others. More broadly, the findings of this study provide a rich insight into the views and perspectives of autistic young people as they prepare for a significant life change. These young people showed levels of insight into their behaviour, the challenges they face, self-guided management strategies and the perceptions of others, to a degree that is not always perceived to be commensurate with an autism diagnosis.

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