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**Experiences of University Life for Students with Asperger's Syndrome: a comparative study between Spain and England.**

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## **Abstract**

Research has consistently shown that young people with Asperger's Syndrome (AS) are likely to experience increased anxiety during new social situations yet studies have been regionally and culturally bound with no sense of how experiences or practice differs across countries. The aim of this study was to explore how higher education students with AS experienced attending university in two European countries: the UK and Spain. The objective was to find out if experiences differed between the two countries in relation to contrasting support arrangements and what kinds of interventions might aid students' social well-being at university; an important learning outcome for future practice. This small-scale comparative exploratory study incorporated life-history interviews with nine students with AS. The interviews were transcribed verbatim and subjected to Interpretative Phenomenological Analysis. Four superordinate themes with seven sub-themes emerged from the data which were significant to both groups of students in Spain and the UK attending university. These were 'meeting new people', 'special interests', 'environment' and 'support mechanisms'. Students with AS need and want clear, unambiguous and structured information from academics; support to get to know others in 'small social networks' such as special interest peer groups; more designated 'quiet zones' across campuses; and above all, a move away from ableist notions of AS. To our knowledge, this is the only Spanish-UK comparative study of university students with AS.

**Keywords:** Asperger's Syndrome; Higher Education; Student experiences; Spain; England

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## **Introduction**

Asperger's Syndrome (AS) (Asperger 1944) is regarded from a medical viewpoint as a lifelong neurodevelopmental Autistic Spectrum Condition (ASC), that affects how a person processes information, understands their environment and socially interacts (National Autistic Society UK (NAS) 2015). Predominantly defined as a social impairment (Wing 1981, 1996), the condition is acknowledged to be diverse and on a continuum, with every person individually experiencing associated difficulties including communication deficits, repetitive or restrictive behaviours and/or sensitivity to sounds, smells, tastes, colours and textures (Forrester-Jones and Broadhurst 2007). Those with a high IQ are generally classified as having AS. The participants in this study will have been diagnosed using either the International Classification of Diseases ICD or the Diagnostic and Statistical Manual of Mental Disorders DSM-IV. The most commonly used assessment tools to diagnose AS include the Autistic Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview-Revised (ADI-R), and the Diagnostic Interview for Social and Communication Disorders (DISCO) (Lai et al. 2015). These diagnostic instruments are however, not designed specifically to test for AS, leading to continued controversy around diagnosis of AS (see Howlin 2000, 127 and Leekam et al. 2000). The medical/diagnostic model of AS has also been critiqued for its categorisation of AS as 'abnormal' by medical professionals (Oliver 1990). In contrast, a more social model posits that AS cannot be simply understood in terms of neurological problems (Molloy and Vasil 2002) and is, in part, socially constructed (Goodley 2000, 2001) so that people with AS are dis-abled by society rather than by their impairments. In line with this ontological understanding of AS is a geographical perspective (see Imrie 2000) which considers ableist attitudes towards disabled people. Ableists views reflect beliefs that able-bodied/non-disabled people are the norm in society and that disabled people deviate from that norm due to their inherent difficulties, rather than as a consequence of human diversity (see Davis 1995). It is argued that ableist practices within society are embodied in institutions including universities which are primarily geared towards the 'normal', with adjustments made for the 'abnormal'. For example, mainstream physical and social spaces create disabling barriers to people with AS, who may seek refuge in more 'safe' but isolated environments (Hall 2004). The authors of this study take a more social realist perspective (Rogers and Pilgrim 2014, 19), which both allows coexisting explanations and experiences of AS, whilst also critically scrutinising them. Whilst questioning the ways in which societal values and interests seek to depict reality, we are most interested in the 'emic' or insiders view of their own world, in this case, how students with AS experience life at university.

## **Prevalence of AS in HE**

A lack of consensus in clinical practice concerning symptom repertoires of people with AS has led to the suggestion that diagnosis/categorisation of AS is becoming more frequent (Madriaga and Goodley 2010); picking up behaviour that is simply 'different' to the norm. Other possible reasons for the increased prevalence rate include methodological differences in epidemiological studies, increased general awareness of AS, the development of specialised services, and a real increase in the number of cases (see Wing and Potter 2002).

According to recent online data in the UK (Higher Education Statistical Agency (HESA) (<http://www.hesa.ac.uk>) the number of known disabled students entering higher education has almost doubled in the last decade, increasing from 26,085 in 2004/05 to 50,530 (of whom 1,900 had a declared AS) in 2013/14. Current HESA data for 2013/14 suggests that of the total

numbers of UK HE students at all levels (759,160), 77,795 had a known disability of whom 2,415 had AS.

In Spain, it is much more difficult to find comparable published data. Census data estimates that more than 1,300 young people with AS between 15 and 24 years of age enrol in HE though this may be a conservative estimate (Alonso, Belinchon, Blanco et al. 2009, 6). Of the seventy six universities, 24 are private, of which 7 are affiliated with the Catholic Church, and a central data set which discriminates AS from other forms of disability in HE has yet to be published. A study of 59 Spanish universities revealed the total number of students with disabilities to be 17,702, representing 1.3% of the university community although statistics for AS were conflated with the category of ‘mental disability’ (17.3%) or ‘other disabilities’ (15.5%) (see Universia Foundation 2014, 18-19).

### **Policy and previous research**

UK legislation had gradually placed a pre-emptive duty on Universities to make reasonable adjustments so as to prevent a disabled student being placed at a substantial disadvantage (see Disability Discrimination Act (DDA) (1995); Special Educational Needs and Disability Act (SENDA) (2001); Disability Discrimination Act 1995 (Amendment) Regulations 2003; Equality Act 2010). The Children and Families Act (2014) further extended educational support for young people with Special Educational Needs from 18 years to 25 years, requiring that assistance is given to young people during their transition to adulthood including accessing tertiary education. In Spain, the Organic Law on Universities (2001, amended 2004) required universities to guarantee equal opportunities, outlawing discrimination against students with disabilities and to take measures to ensure their ‘full and effective participation in the university’.

Whilst UK policy change led to investigations of the experience of university students with disabilities (see Borland and James 1999; Goode 2007) similar research has been very slow in Spain. In an attempt to redress the imbalance of studies concerning mainly physical disabilities, (see Tharper et al. 2004) subsequent UK studies sought to highlight the experiences of students with specific conditions including AS (see Taylor 2005). Harpur, Lawlor and Fitzgerald (2003) (cited in Madriaga 2010, 41) explored how living in a ‘shrunk social world’ could lead individuals with AS towards mental health problems, and Martin (2006) discussed barriers and support issues for HE students with AS. The emic or insider student voice was largely missing however. Analysing data derived from three focus groups (one with students with AS and two with staff), Knott and Taylor (2014) found conflicting perspectives regarding student’s sensory sensitivities, daily life difficulties and how these impacted on academic progress as well as differences in staff-student perspectives about what would be helpful. Madriaga’s (2010) qualitative study of eight UK HE students with AS who also suffered from hypersensitivities presented experiences of students who reported that they found themselves trying on a daily basis to negotiate inaccessible campus spaces. Using a life-history approach, Madriaga’s study is one of very few studies focussing specifically on the views of participants with AS (Müller, Schuler and Yates 2008). We could find no similar qualitative studies in Spain and no comparative studies of AS student experiences in Spain and the UK.

### **Aim and objective**

The aim of this research was to explore the experiences of university students with AS in both Spain and England, UK. The objective was to find out if any marked differences existed between these experiences.

## **Method**

### **Design**

The study was designed as an exploratory small-scale qualitative comparative project using life-history interviews.

### **Location**

The study was located at two University campuses of comparable age (approximately 50 years old) and size (one had 20,000 students, the other had 29,000). One of the Universities was located in the middle of Spain, the other was in the South of England, UK.

### **Participant recruitment**

Purposive sampling was used with an inclusion criteria of 18 years or over, in full or part-time HE, with a confirmed diagnosis of AS. Several different attempts were made to recruit students to the study including publicising the research within the respective Disability Support Units/Sevicio de Atención Psicológica (from here on called DSU) at both campuses. Posters and general invitations sent to AS student support/therapy groups proved to be the most successful strategy.

### **Materials**

An open-ended interview schedule using a topic guide concerning experiences of university life was developed by the first author using previous literature, and public and patient involvement (PPI). The topic guide included what? why? and how? questions around the following themes:

#### Topic guide

- Thoughts/concerns about entering university;
- Ways of preparing for university;
- Initial encounters and experiences of university life
- Social networks and social support
- Overall well-being
- What might have helped

The topics were deliberately broad, (with prompts used when appropriate) and the nature of the interview kept informal to encourage students to freely add areas of importance to them that were not covered or constrained by the questions. The interview schedule was translated and amended to fit Spanish cultural nuances.

### **Procedure**

Face-to-face interview sessions took approximately one hour each to ensure that enough time was provided for students to consider and answer each question. Responses were digitally audio recorded and transcribed into Spanish and English. The Spanish interviews were then translated into English using digital translators and a native speaker. The transcripts were also read through by the second author, a native Spanish speaker, to make sure subtle nuances were not missed.

## **Analysis**

Interpretative Phenomenological Analysis (IPA) (Smith and Osborn 2003) was utilised since it seeks to delineate the experiences of participants as well as their feelings about those experiences. Each transcript was studied and coded in turn, line by line with sub-themes and themes noted, applying data reduction theory, and micro-analysis (Braun and Clark 2006).

## **Reliability**

Initial coding of all of the raw data was completed by two of the authors. The transcripts were then analysed independently by the third author, with codes compared to check reliability (Lincoln and Guba 1985), in this case yielding a good level of agreement (65% of the codes were the same). Using Atlas-ti (6.0) to help organise the data, codes were then collectively analysed and organised until saturation point had been reached (Fiese and Bickham 1998). Credibility checking occurred towards the end of analysis with participants, who mostly reported that the themes were representative of their experiences.

## **Ethical Considerations**

The study gained ethical approval from a UK University Ethics Committee, and ethical procedures of the Spanish University were adhered to. Voluntariness of participation was made clear at the start and half way through each interview, with withdrawal an option up to the point at which the data had been analysed anonymously. Participants were given the opportunity of choosing the venue for their interview and measures were taken to ensure a quiet and distraction free environment (for example a ticking clock was removed prior to one interview). Permission was sought from each student to record the interview and data was anonymously coded. Participants were invited to contact the respective UK and Spanish researchers and/or DSU if they had any concerns/queries post-interview. Excerpts from participants' transcribed interviews are presented as exemplars to the findings (participants' names and other identifying data including gender has been anonymised).

## **Findings**

### **Participant characteristics**

Nine participants (5 Spanish and 4 UK students with AS) were recruited and interviewed. This small sample size is consistent with IPA (Smith and Osborn 2003) which seeks to gain in-depth personal experiences of individuals about a phenomena rather than quantifying responses to pre-conceived questions. All of the participants had received a clinical diagnosis of AS during childhood. Six of the nine participants suffered from sensory sensitivities, mainly to noise and smells; one had epilepsy, and two suffered from depression and/or obsessive compulsive disorders. The average age was 22 yrs and one was female. The group had been at their respective universities between one and four years. Whilst all of the students in the UK lived in university residences, the five Spanish students lived with their families (in Spain, support for students with AS does not include support in student residences). The study group was representative of the Humanities, Science, and Social Sciences.

Four superordinate themes and seven sub-themes emerged from an inductive analysis of participants' perceptions of their experiences of university life. The use of substantive quotes by participants from both Spain and the UK demonstrate the largely universal nature of the experiences of students with AS.

### **Theme One. Social relationships**

### **Sub-theme: Meeting new people**

Whilst a social network is arguably central to quality of life for gaining and clarifying information, (Forrester-Jones and Hatzidimitriadou 2006) leisure and friendship/love (Forrester-Jones 2001; Forrester-Jones and Barnes 2008) navigating social relationships proved to be one of the most difficult aspects of every day life for all of the study participants across both countries and the most significant theme derived from the qualitative data. Integral to this theme was the sub-theme '**meeting new people**' the prospect of which caused anxiety for individuals before their arrival at university, as explained by P1, P5 and P8:

'My main concern was to meet new people because in high school you know your classmates since elementary.' (P1, Spain)

'Upon entering, you are afraid of having no friends, and that it is pure fear ... The first day, I had no idea what was going to be there, I was wondering ... what do I do? I personally, have the reaction of touching my hair and tugging of the hair, anxiety, anxiety ...when you meet people ...

Interviewer: what would help reduce it?

Knowing someone. The first few days ... to know someone who is already in college ... at least someone you trust. To have a friend before going to college, to not be alone..' (P5, Spain)

*'Would I make new friends, considering I'd be among people who have a lot more in common with me, than any other person in school?'* (P8, UK)

The difficulties encountered by P5 and P8 relate to what Rodríguez Muñoz (2013) calls 'non verbal blankness', often accompanied by feelings of inadequacy. Initial 'failures' could lead to feelings of isolation as stated by P8:

'I feel like I don't really umm, have much in common with them, I [tried] to like mix with them at the beginning of term, but originally I just realised that well pretty much all of them [weren't] interested and [didn't] want to get to know me that well, so I just [felt] a little bit isolated you know' (P8, UK)

Such anxiety corroborates the literature (Attwood 1998; Forrester-Jones 2014) which suggests that social communication and interaction difficulties (symptomatic of AS) can be particularly difficult during transition periods from child to adulthood when a degree of independence is suddenly thrust upon the individual (Janus 2009). Whilst anyone can find transition difficult, for people with AS there can be additional obstacles due to their characteristics and behaviours, for example, their reliance on unchanging routines and difficulties in organising and planning in an environment which allows for more freedom (Hendricks and Wehman, 2009 cited in Fertig 2015, 12). For some participants, transition from home to University with all its new academic and social challenges triggered bouts of obsessive compulsive disorder, depression and paranoia, as well as physical exhaustion as explained by P2 (UK):

'...the social stress and the workload – it makes me feel physically exhausted in the middle of the day, and so I will return to my room after a seminar and just slump on my bed and just go to sleep for hours.'

Whilst the ability to problem-solve is generally important within social contexts, in their study of FE/HE students with AS with a neuro-typical (NT) control group, Goddard et al. (2007)



found that the sample of students with AS suffered autobiographical memory (AM) impairments such as slower memory (including visual memory) retrieval. AM is required to reconstruct past memories of experiences, including feelings. If a student with AS is unable to recall and share their previous experiences of events, (e.g. what occurred at a student party the previous night), there is no term of reference to facilitate social intimacy (Nelson 1993) and no experiential data-base to guide future social problem-solving behaviour (see Goddard et al. (2007, 291). The difficulties students had in this area are exemplified by P4 UK who had joined a sporting society but had difficulties fitting in socially:

“...we have socials every Wednesday night after match day. I didn't go to any [socials] last year and this year I've been to one. I didn't play any games last year and I thought I'd just watch and take it in, even *though I had the kit...The captain... bumped into me one night...and he was very drunk and he was very harsh on me and then I didn't want to join*”

In the absence of providing explanations/shared experiences as to his non-engagement in the game or socials it is not unreasonable to presume that the captain may have perceived P4's behaviour as reflecting little interest in the society.

### **Sub-theme: Fear of disclosure of AS**

Worries about meeting new people were often replaced by concerns about how to maintain new contacts. Tied in with these feelings were decisions around '**disclosure of AS**', another subtheme of social relationships which was significant to all of the participants regardless of which country they were from. In general, for these students, diagnosis of AS (which from a social constructivist view point is a pejorative construct) felt like a positive act as exemplified by P2:

'...all through my life it has been almost crucial to have that diagnosis because it gives me a reason why I have the problems I do and why *I'm different. I mean, if I didn't have it, I would assume that I was mad ...it would just be too - why can't I fit in, why not?...but ... a diagnosis of Asperger's gives you access to the support services and to things like disability living allowance. It makes life easier. Also, for myself because I have something to attribute my idiosyncratic behaviours and eccentricities.'* (P2, UK)

P2 demonstrates how self-awareness and understanding of AS can be useful in terms of identity and tangible support. 'Having to disclose' to staff, to pre-warn of any possible difficulties, was similarly found in Knott and Taylor's (2014) study which highlighted how students were more likely to disclose their AS to staff than students. In this study, disclosure to staff also appeared to be one route to gaining social network members and was appreciated by participants:

'Meeting some teachers has been a very good experience. Really the goodness of some of them is very large and ...they are very special people and very friendly. Also the kitchen staff have always been very kind to me and very affectionate' (P9, Spain)

Most participants in this study also generally feared telling contemporaries about their condition. Negative responses relating to stereotypical and incorrect notions of AS seemed to be the most pressing concern, explaining their fear of disclosure:

'It is not a thing one should go out there carrying a banner saying 'Hello I am Bob and I have Asperger syndrome!''(P9, Spain)

T've not got a problem admitting it, I just have a problem with how some people might

see it. '(P6, UK)

'If I said to someone...*I've got Asperger Syndrome*, they might start reading up on it and find some terrible stuff about it; they might get onto autism and on to low functioning.' (P2, UK)

'My fear ... is that they will reject me before they know the truth. I prefer it if they know me first and then I can tell him I'm Asperger. Otherwise, people are rejecting something they do not know ...they need to release their prejudices' (P5, Spain)

Such fears of disclosure corroborated the theme of 'disclosure of diagnosis' in Knott and Taylor's (2014) study. Although Butler and Gillis (2011) concluded that stigmatisation is a result of the association of behaviours linked to AS and not the label itself, the quotes above suggest that participants in this study were concerned that their contemporaries would not fully understand the label of AS and in turn, reject them. Butler and Gillis (ibid) go on to advocate that a better informed community about the positives as well as the negatives of AS would lead to more acceptance of any differences individuals with AS display, in the knowledge that no two cases are alike. However, their suggestion that interventions to help individuals minimise behaviours which attract attention is arguably counterintuitive to the ideology of 'accepting difference', and is more akin to the medical model and ableism as discussed by Madriaga (2010).

Participants especially feared that others would incorrectly associate their condition with intellectual disabilities. To avoid this, time for others to 'get to know' them as individuals was important before disclosure occurred:

'Above all and foremost I would like people who know that I have Asperger's syndrome to not think it means mental retardation. People have actually confused the colloquial jargon Asperger with lack of intelligence or a delay. They use [the term] Autism or Asperger Syndrome, as an insult and that is one thing I do not like at all and that's when I get more angry...using 'autistic' to describe a stupid person or an annoying person, is something I do not like no, no, no, no' (P9, Spain)

'...If you disclose too early, people are going to automatically make judgments...*because unfortunately*,... as soon as you mention Autism, Autistic - the things that are going to *flash into most peoples' minds is the typical classic autistic* – disabled, low functioning, because that is probably the view of autism which is spread most widely. For example, if you look at programmes on the television about autism it always seems to start off...`little so and so is autistic and needs constant care and it is very low functioning...' So the technique I use is...get to know people first, so that they can get to know me before I *disclose the Aspergers*. *And don't disclose if it is not necessary. There's no point...* The only time that I think I would break that would be if there was some reason why it was of real importance. Some emergency or something where they would need to know.' (P2, UK)

Individuals were therefore concerned that others would behave differently towards them following disclosure. The difficulties of explaining their condition was also evident:

'...*I do not know how to explain to them ...Previously, I had an experience of explaining AS to other students...and it was a fatal disaster!*'(P7, Spain)

'...some of them have seen that I sit with the notetaker and ask me 'why don't you write your lectures? I could tell them that I'm super intelligent and taking it all in, but I do tell them the truth. *I tell them that I have an LLP [individual learning plan] ...I think the worst thing that comes to everyone's mind is that you're going to be stereotyped.*' (P4, UK)

At the same time, misunderstandings due to AS students' difficulties with unwritten communication rules (Tantam 2012) could cause negative social experiences to occur, with one student stating that another student had been 'harsh' with them because they did not 'fit in'. Some participants recounted experiences of bullying and teasing since childhood which they felt were being replicated at university. Shtayermman's (2007) exploratory study of bullying suggests a possible causal link between victimisation and high levels of depressive and anxiety disorders. It is possible however that some of the perceived bullying were examples of miscommunication which led to assumptions of teasing or discrimination (Tantam 2012, 454). Whilst this does not negate the feelings of anguish caused, it does support the need for greater understanding of AS and highlights 'the potential benefits of knowledgeable advocates and mentors to help mediate misunderstandings' (Fertig 2015, 38).

Another participant stated:

'...my AS and my difficulty in socialising, has caused problems as well, because I have been able to annoy people. Such as [staff]. *They found me a terrible pest. I'd talk to them for ages, and I'd end up getting half banned from there.* (P2, UK)

Here, P2 demonstrated non-adherence to conversational norms (including turn-taking), and was at risk of losing social acceptance (Tantam 2012, 455). At the same time, they were able to understand and articulate their inability to read social cues (Madriaga 2010), and could see the world from the other perspective. Such intuitive understanding of other people's feelings, otherwise known as empathy, is what people with AS have been said to lack (Baron-Cohen 2008; Attwood 1998)! The quotes also show how participants experienced others' social treatment of them based on attributes, behaviours, or reputation that are socially discrediting (Brown et al. 2003; Craig et al. 2002). Stigmatisation can include overtly negative behaviour including labelling, verbal abuse and rejection as well as more subtle socially exclusive behaviour such as restrictions in opportunities (Jahoda et al. 2010; Szivos and Griffiths, 1990). Such treatment can lead to secondary outcomes including poor self-image, low confidence, self and/or societally-imposed constraints (Jahoda and Markova, 2004), limited relationships and a lack of social belonging (Forrester-Jones et al, 2006, 2012). At times, corroborating Müller, Schuler and Yates (2008, 177-178), such experiences left students from both countries feeling lonely:

'Difficulty in having relationships with most of my peers. Yes, when I do not know *what to do*...loneliness sometimes a little, I do not know who to go to. I know nobody' (P7, Spain)

'I had stress in the beginning, and I was more nervous. I was a little lonely' (P1, Spain)

Serendipity sometimes played a part in gaining companionship, if not friendship:

‘Two or three of us would walk down to [dining room] to have dinner in the evenings and just talk about things and stuff like that.’ (P6, UK)

For others, maintenance of previous friendships remained important. For example, P6 continued to play on-line games with their ‘homefriends’. They also visited other fellow gaming enthusiasts on campus to play video games, since they had left their own games console at home. Whilst the motivation to interact with others appeared to be primarily functional, and the activity required few social skills, it provided a focus for peer discussions, and provided a means of social networking.

For some, such as P8 the well-being benefits of increased social interaction was tangible as they explain below:

*‘... I don’t want to let this good feeling go away you know, so I wanna yes, try and build it up.’* (P8, UK)

The need for social interaction and the development of a network of social relationships was therefore significant to the study participants. Yet, each interviewee reported difficulties negotiating the basis upon which these relationships might start and be maintained. For the majority, the interlinking theme of ‘special interests’ was an important basis for social interaction.

## **Theme Two: Special Interests.**

### **Sub-theme: feelings of strength**

Around two thirds of the participants talked about their ‘special interests’ (a term coined by one of the participants, P2 and so used here) which included their chosen academic areas of study as well as their hobbies) and how important they were to them. This was therefore a significant theme for students with AS in both the UK and Spain. For example, P4 enjoyed interacting with those on his course, because of the ‘shared enthusiasm’ for the subject. He liked to talk endlessly about the topic:

*‘..I think the plus side is because all of us have the same passion for [the subject] and so that’s been good.’* (P4, UK)

Participants tended to spend a great deal of time reading around their interest subjects which often led to a realisation that they were far more knowledgeable of the subject compared to their non-AS peers, reflected in their good assessment grades. Special interests therefore embodied **feelings of strength** (an important sub-theme) leading to self-confidence:

*‘Studying gives me confidence. If I don’t study for a while I get a real withdrawal effect, and I feel far worse, far more paranoid, far more inadequate. I think that the Aspergers does play a part in it, because of the...rigid structure that is needed.’* (P2, UK)

*‘It is not easy to become a university student, and... a person with Asperger syndrome has to do much more than what many other people do...people who have no psychological problems who are also here.’* (P5, Spain)

Getting that first [the highest grade available and equivalent to over 70%] was absolutely fantastic for me and umm considering I'd never watched [literature] films

before....getting that first was probably the best moment for me (P4, UK)

Some participants were motivated to study further in relation to their special interest:

‘It’s one thing to pass, and another to learn many things that I like such as statistical software....I have fallen in love with it.’ (P5, Spain)

‘I would say that going to University objectively is fantastic for somebody with AS because if they can study their special interest certainly, they would thrive. In an academic environment there is going to be more leniency, you are going to be allowed to be more eccentric than you would be elsewhere, which is brilliant. (P2, UK)

When asked what advice P5 would give to prospective students with AS P5 insisted:

‘know your strengths and promote them in order to strengthen them and overcome difficulties.’ (P5, Spain)

Similarly, P9 (Spain) said:

‘You are smart, if you are able to get into college. *That’s* important. Never doubt your intelligence, if you have been able to come in to *university...*’

A couple of participants advocated referring to their strengths before declaring their AS on the basis that this would achieve acceptance faster with prejudice avoided. People with AS have been found to describe their strengths more positively than their NT counterparts (see Lorenz and Heinitz 2014). Self-validation possibly boosts their sense of self-worth, compensating for any deficits in self-esteem and confidence lost due to previous negative social encounters (Fertig 2015).

Sometimes, however, talking about ‘special interests’ could cause problems, as recounted by P2 who enjoyed chatting about his academic subject to administrative staff who did not always appreciate the dialogue:

*‘It was awful because I’d go and chat to them and they didn’t get very interested in my essays.’* (P2, UK)

Most of the students combined their academic special interest with their hobbies:

‘Most of the people I meet are actually doing [the history] course or doing things to do [with it]... *I’m in a re-enactment group that meets on a Sunday (Normans, Vikings, Saxons that sort of thing) and a new group that we set up this year, a military history society...for people who like war*’ (P6, UK)

Winter-Messiers et al. (2007) observed that the strengths of people with AS rarely receive the same amount of attention as the so called ‘social deficits’ of the condition. They further state that little research has been carried out on the effect of ‘special interests’ in relation to social interaction despite the fact that sensory processing difficulties and fine motor strength can be improved when AS individuals become completely absorbed in their special interest. In turn, emotional strength may improve through mutual special interest and related social interaction.

### **Theme Three: Environment.**

#### **Sub-theme: Physical environment**

Whereas NT people are, generally regarded as multi-tracked (see Williams 2006, 84) many individuals with AS are thought to be mono tracked (Forrester-Jones and Broadhurst 2007) finding it difficult to process more than one set of sensory information at a time. For some, there may be a time delay in processing information and for others, perhaps a sensory sensitivity to noise. As stated earlier, the majority of participants in this study reported that they had some kind of sensory difficulty. For the UK participants in particular, a quiet living environment was important. Wanting to live on campus, in close proximity to resources could prove counter-productive since campuses are generally noisy environments. P2 found unusual or loud noises difficult to the extent that he preferred to live with other 'very quiet' students, stating:

I preferred my room right at the top rather than on the third level [as] the people, were all very, very quiet. They were *all doing boring quiet subjects*...like accounting, and stayed away in their rooms and were very quiet, but I liked that.' (P2, UK)

Similarly, P4 found noise as well as change in living environment to be problematic. This latter issue contributed to the student's decision to return to the same study-bedroom in their subsequent academic years to avoid the stress of 'change'. This need had to be balanced with the prospect of living with first year students, who were enjoying newfound freedom and de facto often behaving in a noisy way:

*'Well, I'd have to say living in the same room has been a huge benefit. The only difficult aspect of it is you know, the new neighbour... I knew that it would get noisy. ...but I didn't expect it to be continuously loud...That has been the most difficult...'* And I'm still in the same room, same room, same kitchen - only difference is new neighbours and I must say these are more messier than last years....*if I do well here I will be living there next year in the same room'* (P4, UK)

The quotes above demonstrate the participants' ability to weigh up the positive and negative aspects of living in communal residences. Such socio-spatial flexibility once again challenges the so-called conceived wisdom of AS deficits (see Gillberg 2000). Whilst the Spanish participants lived with their families at home and did not report issues with campus residences, moving from familiar to unfamiliar environments either to enter university for the first time, or to move from one lecture theatre to another was mentioned:

'Adaptation of being in a city, instead of a town. Noises, smells, to be in a hurry....'  
(P1, Spain)

'One of the issues that concerned me most, was the fact that I had to go [to some lectures] by bus, which caused me to be late for the lectures. It required a lot of effort for me because I do not live next to the University precisely. Another of my concerns was to go to meetings, deliver papers, etc. Another problem has been to attend laboratories. I had no experience of them, and although no one seems to be concerned by it, it was a fairly big problem to me. (P5, Spain)

P5's experience reflects how the journey to lectures could cause difficulties for people with sensory sensitivities, corroborating the findings of Hendricks (2010) and Krieger et al. (2012) concerning the workplace. For P4 being a returning student meant that he felt familiar with his environment including where to find his lecturers, which he found reassuring:

'...This year I feel confident. I know where everything is. I know if I need resources, where to go...if you have the same lecturers as last year you know what they are going to be like...You know that every lecturer will have office hours where you can see them...it's good that I know where everything is. I can go for, like my walks. I know where the buses are, what times they run....and I know where the nursing centre is, the doctors and yeah, the best thing about returning and living on campus is you know where everything is'. (P4, UK)

But like P5, P7 also found attending 'different places' for lectures difficult:

Classes are in different places, one in one corner and another in another corner, and you have to find them and you have to know where each class is. It would be great if you could have some advisers, like people who have already entered the university. (P7, Spain)

Physical barriers were therefore encountered in unique ways, highlighting the heterogeneity of the condition, as well as the physical environments of campus universities which in the case of the two studied here, appear to be configured in a way which does not take into consideration the variety of needs of students and which might be described as ableist (geared more towards people without AS).

#### **Sub-theme: Learning environment**

Linked to the physical context, the learning environment referred to the academic structures and processes in place, including lectures, seminars, teaching styles and assessments. Given that learning tends to be facilitated within large and medium sized groups in most European universities, it is unsurprising that the participants had some difficulties navigating these systems. P9 sometimes found noise in lectures to be intolerable and had to remove himself from the situation:

'... I go out of the lecture theatre. I stand still in a cool place. I feel a horrible heat as if I were baking in my own juice. And the struggle may last an hour. I may call someone about it or send a voice message to [name] and they tell me what to do about it.' (P9, Spain)

Evidence of coping strategies including self-removal from difficult environments to 'safe places' has been found elsewhere (Madriaga 2010). Other students felt that variations in how modules/courses were presented, as well as different assessment patterns between modules were difficult to deal with:

'...then there are exams and assignments. Some modules are easier for me, I learn them much better, and other ones are worse. But the real difficulties are the [differences in] organization and other aspects of the lectures which have not been too good....and it costs me a little emotional weariness, going from one place to another, but I can still do it...I have trouble with organizing myself, considering that, and in addition, the university has trouble organizing itself. For example, say I want to know certain timetables, certain classes. They may have been put on the official website schedules, but in the end, these classes don't happen! Or they [lecturers] inform us that classes will take place, and then they change them at the last minute, without warning. Oh it is so worrisome!' (P9, Spain)

P9 also illustrates how a world which dictates self-organisation can be hard for someone with AS, who may experience slow cognitive processing, making it difficult to follow a string of instructions (Hendricks 2010). P7 similarly found self-organisation problematic:

‘I am lost when it comes to organizing things. I have chores to do every day. I cannot do things to arrange myself. Everything is very chaotic.’ (P7, Spain)

Healey et al. (2006) and Goodley (2007) call for a critical, more social pedagogy which allows for and includes creativity within teaching and assessment models which embraces the needs of ‘quirky’ marginalised learners (see Giroux 2003; Nind 2005; Goodley 2007, 317) who, according to this study, may not be extraordinary to any one particular country.

#### **Theme four: Support mechanisms**

Support mechanisms which included the sub-themes of **formal** and **informal** social support appeared to be integral to buffering difficult issues faced by Spanish and English students with AS as well as maintaining their social well-being.

##### **Formal support**

All of those interviewed had received formal support from their respective DSUs including information and help with decision making with for example module choices as well as living environments (e.g. as already mentioned, P4 preferred to stay in his study bedroom year on year and gained support from DSU members to do so). Good working relationships between the DSUs and other university ‘agencies’ were evident on both campuses. Such support was highly valued, and appeared to be a lifeline for some:

‘Especially interventions of trusted people, my tutor, psychologist, confidential persons...I resorted to a tutor who helped me with maths stuff but even so, things turned out to be too great to bear. In late February, I consulted [DSU staff] and she advised me to do another subject, as it would be more healthier for me.’ (P9, Spain)

At the same time autonomy to reject as well as accept formal support was important. For example, P5 and P6 preferred to be largely independent of their DSU, P5 preferring to ask for help only when needed or wanted:

‘[For some modules], I’ve never been to ask for help ... then ... the issue is that there are subjects for which I have to demand help ... lecturers are not going to ask you ... if you need help or not ...you must go and ask.’ (P5, Spain)

This was to avoid any risk of social stigma that being accompanied by a ‘note taker’ might attract. Instead, P5 would have preferred to have had more subtle support:

‘In general, I would like to have obtained more support from my lecturer to explain how the labs work, how the exams are done and especially from my classmates. This might have help reduce the social gap between me and my colleagues.’ (P5, Spain)

##### **Informal support**

Informal support was reported as very important by of the participants. Two students, P8 (UK) and P6 (UK) mentioned that their family provided emotional support and decision making in terms of choosing which university to attend:



‘Yeah, I go home every two or three weeks. Either because something is going on at home or just miss them, miss the family’

‘It was just me *and one of my parents coming round....*’

Similarly, students acknowledged financial support from family and encouragement from friends although family support was not always what was needed or wanted:

‘*Parents... they are not always the best help, they may have good intentions but really their opinion will not always be the best option.*’ (P9, Spain)

In general however, informal support appeared to be something students felt they lacked and this subtheme related primarily to the type of informal support they wished for, including a guide or someone who could cushion the effects of new situations and problems:

‘Knowing someone. The first few days ... to know someone who is already in college ... at least someone you trust. To have a friend before going to college, to not be alone... to not be alone’. (P5, Spain)

‘It would be advisable having a small guide at university, not necessarily a close friend, but rather a person like a teacher, a specialized professional support, a tutor that would help to know where things are.’ (P9, Spain)

Given that social support has been found to be associated with positive outcomes such as happiness (Chadsey and Beyer 2001), self-esteem and confidence (Srivastava 2001), mental health (Wall 1998) and leisure activities (Forrester-Jones 2001) it is unsurprising that both formal and informal support mechanisms were so important to participants.

Finally, despite the struggles and stresses of university life, the next two quotes exemplify the positive aspects of university life, which appeared to be typical of the sample:

‘*I actually got the best grade. I actually got, out of 100 I got 90 and so that was a shock. That was my first, first. And that gave me more confidence.*’ (P4, UK)

‘I think the best thing, apart from getting a degree of course, is that I've actually finally found myself. (P8, UK)

‘It has changed me in that I am more mature for the experience. (P1, Spain)

Similar to the results of Chiang et al. (2012) and Chiang et al. (2013), and Knott and Taylor (2014), personal expectations of academic achievement as well as social participation is equally as important to students with AS as it is for NT students. In Knott and Taylor’s study, (ibid, 416) both staff and students reported a need for ‘support for academic development’. Further exploration of this concept and possible academic supports for students with AS would be useful

### **Limitations.**

The study was small-scale. A larger, quantitative random controlled trial would increase the reliability of the findings. Women with AS were also under represented compared to general

population studies and so a mainly male perspective is provided. Research indicates that females with AS are more likely than men to report mental health problems linked to feelings of 'not fitting in' socially (Baldwin and Costley 2015). Nevertheless, the study sample reflects higher male to female ratios within diagnostic rates (see Baron-Cohen et al. 2001). Whilst the ethnic mix within both samples was limited, the cultural mix between the groups meant that some level of AS population representation was achieved. This study therefore does not report on any experiences the participants had with other people with AS. A subsequent larger study (in progress) charting the differences in experiences of university life between students with and without AS will include an exploration of this aspect.

### **Concluding remarks**

Since this study concentrated on the HE experiences of a particular sub-group of students, the authors were mindful that reported experiences of university life might not necessarily be extraordinary to students with AS. Nevertheless, the in-depth nature of this exploration meant that certain realities were evident. The argument made by Wenzel and Brown (2014), that more students with AS are entering HE appeared to be played out in this study. On the one hand this represents a move towards a more inclusive and socially just HE. On the other hand, this study indicated that students with AS continue to encounter difficulties in relation to social and functional adaptations whilst at university. Diagnosed with the same condition, those with AS are not a homogeneous group. Nevertheless, the types of experiences of HE reported in this study appeared to transcend EU borders. There was evidence of specific institutional/systemic difficulties in both the Spanish and UK campuses which could be changed in order for students with AS to fully engage in what has commonly been termed the 'student experience', levied as an important goal for universal university rankings. Shared practice across the two EU states must surely be mutually beneficial.

Whilst the majority of the participants praised their respective universities for providing academic support, their experiences suggest that there is still work to be done and the similar findings from two European countries strengthens this plea. In particular, clear unambiguous and structured information and communication (including alternative communication styles and use of WhatsApp, email or social networks (Carpio and Callejas 2014) is to be encouraged as well as a greater understanding of AS (Carpio 2012, Carpio and Galván 2012; Galván and Carpio 2013). Though not specific to students with AS, help to learn the social mores of the role of 'student' might avoid communication difficulties encountered.

Winter-Messiers et al. (2007) observed that dialogue flows when individuals talk enthusiastically about their special interest, where motivation levels are highest. Support to help students get to know their academic peers faster via small informal structured social initiatives, utilising social media (Carpio 2012) might provide a mechanism for gaining informal network members. Since one to one relationships appeared to work particularly well for this study sample of people with AS, a peer support system in which NT and AS students who are both interested in the same topics are introduced (Gardiner and Iarocci 2013) as well as other self-initiated AS student interventions could be considered and supported, acting as a valuable link and introduction to the wider student community.

Acceptance of difference is also vital if these students are to feel socially included. The authors therefore recommend an approach which focuses on the variable and seemingly idiosyncratic needs of different types of students (not just those with AS). For example, designated 'quiet' zones across campus including student accommodation would benefit all those students who wish to be quiet, not just those with the label of AS. This moves away from current ableist

notions (e.g. that adaptations need to be made for people with AS rather than 'normal' students who supposedly now wish to verbally discuss their work in libraries). Programs promoting peer acceptance, as used by Bearden, Martin and Woolsey (2009) and Ranson and Byrne (2014) but extended to staff, would also be beneficial. In the long run, such interventions lead to less demands on staff time and cost whilst at the same time enabling students with AS to reach their full potential.

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