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Abstract.

Purpose:

Research has consistently shown that young people at the higher end of the autism spectrum (AS) are likely to experience increased anxiety during new social situations. 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 whether experiences of students with AS differed between the two countries as well as whether there were any interventions which students with AS from both countries considered might aid students' social integration and well-being at university.

Method

Nine students with AS were recruited to participate in a small-scale comparative exploratory study that incorporated life-history interviews. Face-to-face interviews with four students from the UK and five students from Spain were transcribed verbatim and subjected to Interpretative Phenomenological Analysis.

Findings

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'

Conclusion

Students with AS need and want clear, unambiguous and structured information from academics; support to get to know others in 'small networks' such as a special interest peer group, more designated 'quiet zones' across campuses and above all, a move away from ableist notions of AS.

Limitations.

The study was small-scale, a larger, quantitative random controlled trial would increase the reliability of the findings.

Introduction

Asperger's Syndrome (AS) (Asperger 1944) is a lifelong developmental Autistic Spectrum Condition (ASC), that affects how a person processes information, understands their environment and socially interacts (National Autistic Society UK 2015 (NAS)). Predominantly defined as a social impairment (Wing 1981;1996), the condition is diverse and on a continuum, with every person individually experiencing associated difficulties including communication deficits, repetitive or restrictive behaviours (see American Psychiatric Association, 2013) 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.

AS is generally diagnosed using the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and/or the International Classification of Diseases (ICD-10) which utilise interviews with the person themselves (as well as parents/carers) and observations of behaviours. The most commonly used assessment tools 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). Controversy surrounds diagnosis however, with Howlin (2000:127) and Leekam *et al.*, (2000) arguing that a diagnostic instrument designed for specifically testing for AS does not exist. 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, perpetuated by 'taken for granted' notions of non-disabled people as 'normal' (Davis 1995). Proponents of this idea posit 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).

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. 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. According to a study of 59 Spanish universities by Belinchón *et al.*, (2009), the total number of students with disabilities was 17,702, representing 1.3% of the university community. The same study did not report specific statistics for AS but it was supposed that AS was included in the category of "mental disability" (17.3%) or "other disabilities" (15.5%).

Policy and previous research

The UK Disability Discrimination Act (DDA) (1995) was followed by The Special Educational Needs and Disability Act (SENDA) (2001) which called for UK HE institutions to make reasonable adjustments so as to prevent a disabled person being placed at a substantial disadvantage. The Children and Families Act 2014 (C&FA) which extended educational support for young people with Special Educational Needs from 18 years to 25 years requires 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 *et al.*, (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. Refreshingly, Madriaga's (2010) qualitative study of eight UK HE students with AS who also suffered from hypersensitivities tried to negotiate inaccessible campus spaces. Using a life-history approach, Madriaga's study is one of very few studies focussing 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 concerning experiences of university life was developed by one of the authors (Casement 2012) using previous literature, and public and patient engagement (PPI). It 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.

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 (Patton 2002; 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 chose 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 at the request of the participant). 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.

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 et al. 2006) navigating social relationships proved to be one of the most difficult aspects of every day life for all of the study participants 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 P6:

"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 than me, than any other person did than me in school?"(P6, UK)

The difficulties encountered by P5 and P6 relate to what Rodriguez (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 & Wehman, 2009 cited in Fertig 2015 p12). For some participants, transition from home to University with all its new challenges triggered bouts of obsessive compulsive disorder, depression and paranoia, causing mental and physical exhaustion and feelings of inadequacy 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).

Sub-theme: 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. In general, all of the participants acknowledged that having a diagnosis of AS was preferable to no diagnosis 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 also 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)

Nevertheless, whilst individuals generally enjoyed meeting other students:

“The first good experience ... was talking to colleagues, on the way home” (P7 Spain)

getting to know people in smaller rather than larger groups appeared to be preferred, one participant reporting that they liked ‘one to one conversations’, finding these smaller interactions less stressful. Small groups invariably place less social demands on individuals with AS since the focus required as well as the incoming information to process is limited (Müller, Schuler and Yates 2008).

Most participants 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:

“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)

“I’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)

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 Madriga (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)

“Maybe they think we're retarded, that we are like fools...and they have to think just the opposite, people with disabilities are able to be in college. (P1, Spain)

“It's not something I blurt out all the time but when I get to know someone like pretty well, in order to allow them to know me better and understand why I act the way I do, I just feel it's like for the best to tell them the truth.”(P8, 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 themPreviously, 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 ILP [individual learning plan]...I think the worst thing that comes to everyone’s mind is that you're going to be stereotyped. Like people may not think that your suited to University or ...that you just be stereotyped as someone who is taking a notetaker, taking the easy way not having to write, but what they wouldn't understand is that when it came to the essays, I didn't have my notetakers write it for me or anything, and even when I had exams, even though I had a scribe they had to write down exactly word for word what I had said.”(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. Shtayermann’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). 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)

"Difficult at times and very lonely but it's got better as time [has] gone on." (P6, UK)

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 'home friends'. 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 P6, and P2, the well-being benefits of increased social interaction was tangible as they explain below:

"...I've got a number of people who would be, say happy to go and have a coffee with me" (P2, UK)

"... I don't want to let this good feeling go away you know, so I wanna yes, try and build it up."(P6, 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 'interests' (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 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 special 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 is doing much more what many people do...people who have no psychological problems and they are here anyway." (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:

"Its 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 an input. 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 Heitnetz 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 reenactment 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)

“I made friends with the chap in the room next door. And I would just go and sit in his room and discuss religion for hours on end” (P2, UK)

Winters-Messiers (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 multi-tracked, many individuals with AS are 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 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 new found 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 2002). 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 ableist physical environments of campus universities.

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) call for a critical pedagogy which embraces the needs of ‘quirky’ marginalised learners (see Giroux 2003; Nind 2005; Goodley (2007:317).

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 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. This support was highly valued, and appeared to be a lifeline for some:

“I still feel the need to umm, to just go and talk to someone for an hour or so every week just to get some things off my chest you know. (P6, UK)

“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 and P6 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 & 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 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, Cheung, Hickson, Xiang, Tsai (2012;2013), expectations of academic achievement as well as social participation is important to students with AS.

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 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). 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.

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 Thierfeld (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 which could be changed in order for students with AS to fully engage in what is 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 universities for providing academic support, their experiences suggest that there is still work to be done. 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 appear to work particularly well for 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 Larocci 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 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 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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