

Towards an inclusive environment for university students who have Asperger syndrome (AS)

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Abstract

This paper is informed by a range of studies in which students that have Asperger syndrome (AS) have described the sort of backup they would like to have at university. Madriaga (working with Goodley, Hodge and Martin) systematically followed eight learners during their first year in various UK universities. Beardon and Edmonds co-ordinated a study in which over 200 people with AS shared ideas about a range of contexts, including higher education (HE). Martin drew on the practitioner, student and parental perspective in an attempt to identify what good support at university might look like.

The studies have revealed that students with AS commonly experience stereotyping and lack of empathy from other people, often arriving at university with previous experience of exclusion, and staff feel underprepared and uncertain about how to help. In reality, students often reinvent themselves at university, are euphoric about their achievements, and become increasingly independent and socially included, over time. Services can help or hinder this learning process. Insights presented here suggest that reliable, empathic, anticipatory and logical approaches, which respect the individuality of every student, are most likely to be effective.

Introduction

The number of students declaring that they have AS when they enter UK universities is increasing. In 2003-04, 80 disclosed. By 2005-06 the number had risen to 475. These figures only refer to those who made the decision to declare at the point of application, and are recorded by The Higher Education Statistical Agency (HESA). Martin (2008) found the majority to be young males, typically around twenty years old, studying science based undergraduate courses, having achieved good A level grades, mainly in school or sixth form college. However, the authors of this paper are aware that there are students with AS of all genders and ages in UK universities, at every level, from first degree to post doc. Some have part time jobs or caring responsibilities; some live with their parents; some are parents themselves, and others are a long way from the family home. It is important not to stereotype. The following comment, from a person with AS, illustrates the point that, if you have met one person with AS, you have met one person with AS.

- 'Realise that autism is ongoing and not all students with AS present in the same way'. (Beardon and Edmonds 2007 :156)

Madriaga et al (2008) quote one participant who likened the diversity amongst those with the label with the variety of dishes called 'chicken tikka masala', which are notionally the same, but very different from each other in real life.

While acknowledging individuality, common themes have emerged in relation to the sort of challenges university is likely to present and the type of services which students with AS have found to be useful. This paper draws together comments from people with AS who describe experiences of HE and suggest ideas for effective provision. The authors urge practitioners to use the information presented here with

sensitivity and respect for individuality. There is no such thing as a one size fits all solution.

The Studies That Underpin This Paper/ Student Voices

Martin (2008) researched the experience of 117 practitioners in 17 UK universities working with 110 students with AS, in order to ascertain what sort of staff development would assist practitioners to deliver appropriate services. Madriaga et al's (2008) study is far more student focussed and follows eight students with AS through their first year at a range of UK universities. Beardon and Edmonds (2007) survey enabled 217 people with AS to describe their experiences of a range of services, including those available (or required) in HE. The findings of all three works generated common themes which are presented here, along with additional ideas directly from people with AS, gathered mainly from the internet, and findings from a recent National Autistic Society report which focussed on the experiences of adults, but did not cover HE specifically. (Rosenblatt 2008)

As previously stated, Martin's (2008) study is weak on student voices. Although 8 students and 3 mothers contributed, the responses of practitioners informed the vast majority of the data used to underpin the development of the resulting good practice guidelines. Beardon and Edmonds (2007) Madriaga et al (2008), and others quoted here, who have shared their experiences (mainly on line) however, provide precious seams of commentary directly from students. Illustrative comments are quoted throughout this paper, mainly from the unpublished transcripts from Madriaga et al's (2008) study, referred to as 'the Madriaga transcripts', and from Beardon and Edmonds (2007), cited for ease as 'ASPECT(2007)'. (All necessary permission has been obtained and anonymity is protected).

_Characteristics Of As

A health warning about individuality and avoiding stereotyping is reiterated at the start of this section, which provides some useful background information for those not familiar with working with students who have AS. Writings on diagnosis explain that people who have AS are of at least average intelligence (Gillberg 1992). Examples of very able people thought to have AS pepper the literature (Frith 1989, Grandin 1996, Murray, 2008), but exceptional achievement can be due to interest, focus, motivation and application, as Arnold (2005) reflects, from his own experience.

- 'Obsessive narrow interests can be valuable. Take computers for instance. Most people can just use them, but I can strip down and rebuild mine'. (Arnold 2005 :2)

It is not necessary to be a genius to have a diagnosis of AS and 'The Curious Incident of The Dog in the Night' stereotype (Haddon 2003) can be unhelpful (Martin 2008, Murray 2008).

Challenges typically experienced relate to the areas of social inclusion, communication and flexibility of imagination (Wing 1996).

Students with AS may lack social experience when they start university, having previously been bullied and left out by their peers (Beardon and Edmonds 2007).

- 'People have to bear in mind that if you have AS you have probably been bullied for most of your life'. (ASPECT 2007:243)

The subtleties of communication can be elusive.

- 'Part of the pattern of AS is not being able to read or reciprocate non verbal communication. In fact, I do not seem to understand it, nor do I fit in well in conventional social situations'. (Arnold 2005:4).

Seeing the world from the perspective of another person may not come easily (Baron-Cohen and Sweetham 1997).

- ...I need help to read people' (ASPECT 2007:240).
Empathy from peers, teachers, and others, towards people who have AS, can not be guaranteed either.

'People need to get over the idea that the 'neuro typical 'way is right and any other way is wrong. The AS way is just as valid - in fact better in some respects. We should be accepted in our own right, and the emphasis should be on education NT's not to be so discriminatory, and to get over the absurd and offensive idea that they are better than anyone else. People with AS don't need to be cured or trained as to how to pretend to be 'normal'- it's the 'normal' people who need to learn that, contrary to what they think, they are not the pinnacle of God's creation and that there is, in fact, a lot they could learn from Aspies. They need to be taught not to be prejudiced and discriminatory and to accept and accommodate us for who we are' (ASPECT 2007:64)

Difficulty with the imagination, organisational skills and problem solving required to cope easily in a new environment, see the big picture, predict likely outcomes and understand other people's motivation are characteristics of AS (Beaumont and Newcombe 2007, Bogdashina 2003 and 2005, Frith 1989, Happe et al 2006). Anxiety about coping in unpredictable contexts, depression, often relating to feelings of isolation and previous negative experiences, and issues with the sensory environment can add further levels of complexity (Attwood 2007), as illustrated by the following excerpts from the Madriaga transcripts.

- 'I get very confused with people...I don't know what they meant...should I apologise or whatever?'
- 'Students are ok. I just wish there was a way I could blend in with them more'.
- 'I went through a low dip recently...I had a week at home and it was just being back here, back to the isolation'.
- 'There are some mornings when you think, bloody hell, do I really have to face the day? I could just stay here and wouldn't have to deal with any of it, wouldn't have to deal with people, with places, with work, with any of it'.
- 'I can't possibly decide how on earth I'm going to start a conversation'
- 'I didn't really want to work with anyone in particular, because I don't trust anyone really'

- 'It (the whole social setup) is really important to me but I don't really take part in it. I wish I could, so I just stand and observe almost'.
- 'I don't really know what I'm going to do this summer actually. What I would like to do is something that would get me out of the house'.
- 'Trying to survive in social situations with people with AS is a bit like trying to get upstairs with a broken leg - they can just about crawl themselves up if they were lucky' .

There is no doubt the experience of university represents a series of huge academic, social, emotional and practical challenges, but students own testimonies indicate that these are faced with great determination, and success often results.

Pre Entry Support and Early Assistance

It is extremely easy to put potential students off by not encouraging them to apply. Madriaga (2006) found this to be the first barrier, closely followed, inevitably, by lack of information (Jackson and Martin 2007). ASPECT (2007) participants put forward the following suggestions to address this concern.

- 'College, schools and Connexions to have more knowledge about Asperger's': 153
- 'As long as I am guided before the start of term, I feel I will be able to cope': 156
- '...support and advice with applications': 150
- 'Having someone specific to deal with who knows about AS so that they could tell you about more relevant things and how things work and so that you could ask things that others may find odd without feeling stupid ':150
- 'Someone to help with the process of applying, filling in forms, sorting money, accompaniment to any interview' :151
- 'People ...aware of AS...available at open evenings...': 152

Evaluations indicate that a co-ordinated pre-entry events provided annually by the Sheffield universities have been found to be extremely helpful. Potential students who have AS are told, in the presence of supporters, including teachers, parents, and Connexions personal advisors, about the services available to them. This is followed up by familiarisation activities and the opportunity to access a pre-entry Disabled Student Allowance (DSA) assessment, to determine individualised service requirements. Goode (2007) reported that many disabled students start university without appropriate support in place, and the Sheffield approach is an attempt to address this concern. The DSA system is not without its student critics.

- 'I need help with all the bloody forms. Of course, I need to do them in order to get help, which is a bit ironic. I think it is absurd that they don't put the DSA forms out until after Easter and then they take so long to get support in place that they aren't usually ready by the time classes start in September. How am I meant to cope without support?' (ASPECT 2007): 150

- 'I think the support has met my needs, apart from the (DSA) assessment. That's a stupid system - having to go round the entire of London'. (Madriaga transcripts).

Reliable backup in the early days has often proved to be critical. The following extracts from the Madriaga transcripts illustrate the value students place on pre entry activities.

- 'During a week in January 2005 I undertook one week's tasting course where I actually got some experience into this art course that I was considering doing, just to get the feel of what sort of things I'd be going through. Even though it only lasted for about five days, it actually proved to work well, even though I didn't exactly get on with it actually. Yes, and then before I started in September 2006, I wanted to make sure that I really did get on well with this, and amazingly within just two weeks I had settled in'.
- 'They need to have the experience you see. They must go on a taster'.
- 'Pre-entry information and assistance is a starting point'.

ASPECT (2007) participants were quick to make it clear that early support is essential, but not enough by itself. Assistance may be required at any point from pre entry to post exit, for example to cope with changes such as going on placement, and major life events, like trying to find a job.

- 'I think you need not just to be supported to get to uni. ...you have to be supported to stay there' :151
- 'Help in place at the very start of the year as initial weeks are most stressful of all-took too long to be put in place' :173
- 'Be consistent with support and not drop off when things are going well' :156

Practical Help

Previous comments from students have illustrated that it is not always the lectures which are the biggest challenge. Perner (2002) articulates this point eloquently in the following two comments:

- 'What was the most dreadful was probably what other students looked forward to....the breaks between lessons'.
- 'Problems included handling pragmatics such as time management, budget and transportation'.

ASPECT (2007) participants provide useful advice about the sort of backup they require

- 'support with getting there' :153
- '...sorting money'...: 151.
- 'help with life skills, timekeeping and organisation' :156
- '...day to day living, having to do everything for myself without support or help (i.e. eating, getting dressed, washed etc)...':166
- '...crossing the road safely...': 150

The sensory environment posed particular challenges for some of ASPECT (2007) and Madriaga et al's (2008) participants,

- '... the college library is too noisy...' :157
- '... social noise in accommodation...' : 158
- '...social aspect problems, lighting...noise...' : 168
- '... I need a quiet study area...' : 157
- 'I don't like students, they're too loud' Madriaga transcripts.

_Social-Emotional Support

ASPECT (2007) participants explained the sort of social and emotional issues which arise for them, and the type of backup they would like. The number of comments (which are only edited highlights) is indicative of this being the area which was cited most frequently.

- 'Social isolation, depression, anxiety' :158
- 'Some more people to go out with would have been good, someone to call by once in a while' :172
- 'Loneliness':166
- '...needed something to replace the routine during breaks and summer - always got depressed' :178
- 'depression... severe stress' :167
- '...raised self esteem, defence from depression' :241
- '...anxiety. Panic attacks...' :163
- '...the psychologist helped me with anxiety...' :55
- '...I would like to be able to understand NT's more' :235
- 'I find it extremely hard to cope with changes' :158
- 'I struggle to recognise non verbal communication and when people are being sarcastic'. :235
- '...Help understanding social expectations...' :165
- 'never part of any social group' :162
- '...open to exploitation from men...be able to spot those just using me' :240
- '...serious bullying, inability to cope with unstructured workload, clinical depression /self harm /eating disorders and social isolation ':159
- '...cyber bullying..' :163
- '...talking more with others who are AS aware' :231
- '...how to recognise a proper friend' :230
- 'If there was a way of explaining to potential friends, what AS is, without putting them off' :243
- '...I have good friends who accept my quirky ways...' : 232
- '...small groups who have similar likes to me...places where it's not rowdy...' : 233
- 'I do have a small group of friends. I tell them if I am struggling to understand something, and they help me out' :242
- 'Some kind of mentor system...someone I can meet with and chat to, who can show me around and tell me things, and who can help me to integrate socially a bit more' :154

The Madriaga transcripts also included positive stories of people who found friendship at university.

- 'I think sometimes you arrive somewhere and sometimes you feel comfortable. I sort of like it here. I like the people who I have met. Everyone else I have spoken to through emails, like my friends who complain about being homesick, and I am like, I am not feeling remotely homesick. What's wrong with me?'
- 'I have been here three weeks. I sort of come to realise that students here are very welcoming indeed. Though in a way, I am part of a fictional family in this case.'

Academic Support

The nature of academic difficulties described by ASPECT (2007) participants is quite specific, and relates closely to the challenges of organisation and requirement for clarity

- '...unstructured work load...': 159
- 'I find criticism difficult and have issues with failure' :159
- 'Difficulty with presentations/ group work' :159
- 'I felt that I did not understand some of the instructions I was given and just remained silent rather than asking for help time and time again...': 161
- '...help to find a suitable placement' :152
- 'Getting copies of all the required notes as I can not write and listen at the same time'. :154
- '...essay planning, preparing and grammar' :154
- 'Failing to start assignments in good time' :164
- '...individualised communication agreement between tutor and myself, e.g. prefer email to phone'. :156
- 'Tutors not doing what they say they will' :164
- '...getting lost in detail...': 165
- 'No explanation of how university works. The need to organise ones own time for study, the need to 'network' in the department in order to get on in one's field' :165
- '...expectations made clear....': 156
- '...If I had a tutor that was able to detect my confusion and explain things to me, it would have helped' :161
- 'The social interaction was very difficult for me. Studies were easy, but the Open University would have suited me better'. :161
- '...a mentor who knows about course material...': 157
- 'Clearer worksheets, targets and timetable for assignments'. :157
- 'Highly structured learning suits me best'. :158
- 'Once I was diagnosed with AS, I had some study skills tuition, as I had difficulty being able to grasp the necessary study skills, and extra time for exams, as I had much difficulty working under pressure. After I had this support, my work became comparable with others and I got better marks than other students, who said that I wasn't good enough' :11
- 'I went to university and it was the worst time of my life. I had not expected the change to freak me out so much. I also didn't realise that I could not learn from the lectures, so avoided lectures and social contact. I did a psychology degree, but clearly, my issues were not obvious to anyone at the time'. :11

The Madriaga (2008) transcripts echo similar concerns:

- “They know someone in their class has it, but they don’t know who the person is. It is because they just don’t know who I am’
- ‘...for this semester, there have been some problem organising note takers. She missed out on at least two of my seminars...the first time was because she went to the wrong room’
- ‘I’m waiting for him (academic mentor) and most of the time he is outside on the phone. Last week he didn’t turn up. He didn’t ring me or anything’
- ‘...it went chaotic last term because they couldn’t work out what I needed. They were trying to give me things I did not need’.
- ‘I’d rather the teachers were to explain. If they want students to do good work, it would be better to explain it to them and show them good examples of how to...’

Backup from Parents

ASPECT (2007) participants illustrate that a high level of parental support with dealing with the practicalities of daily life, as well as coping with emotional upsets is common.

- ‘If I didn’t have a mother willing to fight my cause, I wouldn’t have been where I am now’ :177
- ‘...I have no friends, only my parents and brothers...’ :243
Many students with AS live with their parents, or go home when the going gets tough. (Martin 2008).

The following comment illustrates a situation in which a student was put off the idea of living in halls by parents who felt that she would not be able to cope. While empathising with this view, perhaps university staff also have a role in reassuring parents that reliable assistance is available.

- ‘Well actually, it wasn’t me who changed my mind (about moving into halls of residence) It was my parents. I’d discussed it with my parents and they were really negative...I don’t feel confident any more...I’ve backed out of it and I’m staying at home’. (Madriaga transcripts).

_Staff and Student Awareness

Useful insights into the level of preparedness practitioners felt when they first encountered a student with AS, their sources of prior knowledge, first impressions, and revision of these perspectives over time are gained from Martin’s (2008) paper. ASPECT (2007) cite participants who are very clear about the requirement for staff and students to be AS aware.

- Staff need awareness training in AS...’: 151
- Staff to be familiar with ASD with leaflets’ :152
- Staff could be taught what AS is and that I am not just bad tempered’:155
- ...explaining to other students about my difficulties...’: 160

Martin (2008) found that staff development opportunities often excluded front line personnel, who came into frequent contact with students, such as library workers or residential services practitioners. Given that social, emotional and practical concerns are often played out outside lectures, this is potentially a serious omission. Many academic and support staff had no prior training before working with people with AS and often drew on their personal experience of family members with the condition, the internet or Mark Haddon's (2003) novel 'The Curious Incident of the Dog in the Night'.

Silent Voices

For every student prepared to access services, there may well be others who will not go near anything badged as 'disabled student support' because they are not comfortable to acknowledge that they ever had the AS label. Anecdotal evidence, and the experience of the authors, supports this view, but it is ethically and practically difficult to research.

- 'Having had a diagnosis of Asperger's syndrome in school, as an adult you feel like you can never actually participate normally in everything with everyone else. If you think I am going to go and get any more special needs help, you can get lost. I don't need it. I work it out for myself and I had enough of that at school and it ruined school for me; it was demeaning and it was no use anyway. That's why I will never be happy doing anything like that again. Having a label like that is really terrible. If anyone here found out, I'd just have to leave straight away. I am worried it's on my record somewhere and I want that record to be destroyed' (Personal contact of authors reported with permission).

Sensitive awareness about alternative ways to help students is required. Publicising a range of services as being generally available (rather than specific to disabled students) may be a way forward. Many, particularly in the first year, would benefit from having some help to join in socially, cope practically and integrate academically.

- 'I find it hard to ask for help...almost as if I've failed' (Madriaga transcripts).

Lack of Clinical Diagnosis

Limited opportunities to progress to free of charge clinical diagnosis in adulthood (ASPECT 2007) is another factor which disenfranchises students from services.

- 'It has been horrendous. I tried everyone-education, psychology, social services, adult services, doctor. No diagnosis - no help. How do I get a diagnosis? Will it take attempted suicide before anyone acts?' Rosenblatt (2008):18.

The Disabled Student Allowance (DSA) is the vehicle through which individualised HE support services are funded. Without a diagnosis, this is a closed door. Baron-Cohen (2000) comments that the requirement for a label is often resource driven. While being very clear that a diagnosis was a positive thing in his case, a view echoed by many people with AS (Arnold 2005, Lawson 2001), Hughes 2007 laments the use of the value laden term 'disorder' rather than the more neutral 'condition'.

The requirement for post diagnostic support was highlighted by several of the ASPECT (2007) participants.

Real Services

The Disabled Student Support Team at Sheffield Hallam University came up with the acronym 'REAL' which captures the essence of effective services to assist university students who have AS. REAL stands for Reliable, Empathic, Anticipatory and Logical.

Reliability

Reliability is the corner stone of effective services. Over promising and under delivering is not an option. A student with AS will not be interested in why someone let them down, but will be less confident about being able to rely on a service in the future. Provision dependant on a single individual has the potential for being unreliable built in. Staff leave, have crisis of their own and get sick, therefore, building a service around a small team is often more effective.

Empathy

Empathy is a two way street. The requirement for a level of acceptance on the part of peers and staff and an attempt to embrace the world view of the individual with AS was flagged up repeatedly as a requirement by students with AS. It would be empathic for example to ensure that Fresher's week includes activities for those who do not like noise and night clubs.

Anticipatory Planning

Being aware that anxiety can result in response to uncertainty is a starting point for staff to enable them to plan to make the environment as predictable as possible. Anticipating that a person with AS might find it hard to secure a place in a social or academic group, may not know which bus to catch, or might need to know where there is a quiet space to sit would be a start. Providing practical and emotional supporting accordingly, would be a way forward.

_Logical Approach

Asperger (Frith 1991) talked about teaching with the affect turned off. Clarity, predictability, logical explanations and tangible expectations contribute to security and underpin conditions for success.

Inclusive Practice

Rosenblatt (2008) quotes adults with AS who are not students, and are not enjoying life. The first condition to achieve inclusion is to ensure that people have the information necessary to enable them to consider whether they want to access HE. It is not clear whether the people quoted here had access to the support and encouragement necessary for them to consider university as an option.

- 'Neither health, education nor social services felt that my needs fell within their remit, and so consequently I didn't receive much in the way of services. Furthermore, they didn't work together and so my support was very disjointed and fragmented' :26
- 'Because of high IQ, I am not eligible and do not fit into any category for support. They do not recognise my disability and send me away. Even if I was eligible, there is no ASD support (here) for people like me' :22 (This is a comment from an adult with HFA, who is presumably not a student)

The Madriaga transcripts include examples of students with AS at university who talk positively about their experiences and their successes.

- 'For people who run the disability team, I wouldn't have any advice, except follow what they do here...They've really bent over backwards to help and it's very much appreciated'
- 'I find what makes a successful day is surviving it....success is getting to the end of the day having done what you needed to do and sticking with it'
- 'I feel modest pride'
- 'I felt the exams went very smoothly and they were not very stressful'
- 'My dream, for as long as I can remember, was to go to university'
- 'I wanted to do the project by myself and I did a very good job actually. It was the first time and I was very proud of it....I didn't want to go and ask for help because I wanted to show people that I can do something by myself'

Conclusion: Towards A Template For Assessing Inclusive Practice In Services For University Students Who Have As

'Belonging' is probably the single most useful word which captures the ethos of inclusion. The Disability Equality Duty (2006) describes the requirement for public bodies, including universities, to demonstrate a pro-active approach to fostering an inclusive atmosphere in which disabled student's feel that they belong and that their requirements, as individuals, are catered for, as an ordinary part of business as usual. Purdam et al (2008) describe 'a need to identify the ways in which the barriers society creates can be overcome and to understand what leads to positive change in peoples quality of life'. Asking the right questions, and listening to individuals with AS is an obvious way to understand the particular obstacles they face. The concept of inclusion as broader than a disability agenda may be more appealing to those people with AS who do not regard themselves as disabled. An ethos of valuing and celebrating diversity for the richness a multi faceted population brings to an institution may be most appropriate to fostering a feeling of belonging.

- 'It's a free country after all and thank goodness that some people don't follow the crowd, because the world would be very dull if no one was individual'. Edmonds and Worton (2007): 5

Martin (2008) found that students with AS frequently entered university with better A level grades than their peers, and certainly with a level of dedication to their chosen area of study. Celebrating the presence of intelligent motivated students and being open to finding ways to facilitate their success, rather than defining aspects of

their engagement with the academy as problematic behaviour, is a starting point. Listening to actual and potential students is vital in order to meet them where they are, as individuals, with a view to assisting them appropriately, so that they can get to where they want to be.

A template which is informed by the research cited here is currently being piloted (Martin 2008). It provides a coherent method for universities to consider every aspect of the journey of students who have AS, from pre entry to post exit, with a view to developing best practice.

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