What do students with Asperger syndrome or high-functioning autism want at college and university? (in their own words)

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Editorial comment

Historically, there have been very few mid- or large-scale emancipatory studies in the United Kingdom (or elsewhere) which place the views of individuals with Asperger syndrome/high-functioning autism (AS/HFA) centre stage. Consequently, knowledge of best practice in further and higher education for learners with AS/HFA, which is directly informed by the student voice, remains limited. This study by staff at Sheffield Hallam University, explored the perceptions of 238 adults with AS/HFA about challenges and support at college and university. Difficulties relating to social interaction, the social environment, other people's understanding of AS/HFA, and course structure and curriculum requirements were cited most frequently. Good practice suggestions are made arising from data providing evidence on which to base provision.

What is Asperger syndrome/high-functioning autism?

Individuality

If you have met one person who has Asperger syndrome/high-functioning autism (AS/HFA), you have simply met *one* person who has AS/HFA (Shore, 2003). Over-generalising can lead to stereotyping, 'othering', and a 'them and us' mentality which can, in itself, create barriers to social inclusion (Barnes, 2008; Haller et al, 2006; Richards, 2008). This section describes characteristics which are fairly typical for people with AS/HFA, but the reader is invited to remember to respect individuality and to avoid thinking of people who have AS/HFA as an homogeneous group.

Asperger syndrome compared to high-functioning autism

The *suggested* essential difference between AS and HFA relates to the absence of early language delay in individuals with a diagnosis of AS (Attwood, 2000; Nesbitt, 2000). Blackburn (2000) believes that people with AS have a greater requirement for friendship than she does as an individual with a diagnosis of HFA. While the edges can be rather blurred, it is critical to respect the identity of the individual (Banton and Singh, 2004; Fletcher, 2006),

and the ASPECT methodology was sensitive about not using the terms interchangeably. Arguably, intervention, particularly in relation to socialisation, may well be different for someone with HFA if they wish to pursue solitary interests, than for a person with AS who may be more motivated to make friends. (The authors caution, however, against stereotyping and urge the reader to look beyond the terminology and engage with the individual; experience suggests that differing diagnostic terms do little to aid practitioners in understanding the actual needs of any given individual).

Intelligence and application

Being of at least average intelligence is a common diagnostic indicator (Gillberg, 1992) but it is not necessary to be 'a genius' to fulfil the clinical criteria for a diagnosis of AS or HFA (nor, indeed, is it statistically likely). Possibly unhelpfully, examples of the posthumously diagnosed historic geniuses (including Einstein, Newton, Mozart, Wittgenstein) are common enough throughout the literature and the Internet (Frith, 1989; Grandin, 1996; Murray, 2008). *The Curious Incident of The Dog in the Night* novel (Haddon, 2003) may also feed into the genius pressure which students with AS/HFA sometimes describe (Martin, 2008). Application, in-depth

interest, focus and motivation are also often positive characteristics of AS/HFA which may, at least in part, explain high levels of success (Dobbs, 2006). Arnold (2005) shares his take on this, from an insider perspective:

> '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, p 2)

What traditionally have been termed 'impairments' are, more recently by some authors, deemed as strengths in certain contexts (Baron-Cohen, 2000; Beardon, 2008). Such authors have urged a move away from a deficit/impairment-based model towards a more individual, strength-based perspective.

The social context
Issues around social inclusion, communication and flexibility are cited within the 'triad of impairments' which is used to describe 'differences' associated with the autism spectrum (Wing, 1996). Although students with AS/HFA may take exception to this negative terminology, along with the word 'disorder' (Hughes, 2006; Beardon, 2008), considering the three areas of socialisation, communication and flexibility provides a starting point, presented with caution and against a backdrop of respect, for neurodiversity and individuality.

Social difficulties may be viewed from the social model perspective (Oliver, 2004) which poses the question as to whether the difficulties experienced are within-person (as in the medical model), or with others and social conventions (ie society), or both (Martin, 2008a; Shakespeare, 2006). Students with AS/HFA may have limited social experience when they first begin university (Martin, 2008; Madriaga et al, 2008). Experiences of social exclusion, including being bullied and left out by their peers, especially during the teenage years, could provide at least a partial explanation as to why socialising at university may be particularly emotionally charged for someone with multiple, negative peer group interactions (Beardon and Edmonds, 2007). The reader is invited to spend a minute remembering an incident of being left out, to concentrate on the emotions and physical feelings this brings up, and to reflect on how conducive to future social engagement this past experience may be. For students with AS/HFA these sort of incidents may well be multiple rather than singular (Attwood, 2008).

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

> 'I got bullied like hell when I was at school.' (Madriaga et al, 2008, p 19)

> 'They are quite awful to me sometimes at the halls but it is all in jest.' (Madriaga et al, 2008, p 20)

It may be argued that those with HFA might care less than those with AS about what other people think, but this has not been tested. In keeping with the ASPECT methodology, the voice of the insider is more useful and illuminating than any assumption which might be made by the authors. Bullying takes many forms and social exclusion is but one of these.

Communication
As with socialisation, communication is also a two-way street. People with AS/HFA may find some of the more subtle aspects of social communication difficult, but this is compounded by limited social experiences, and made emotionally complex by previous negative social experiences. A degree of empathy is necessary to appreciate the social components of communication challenges.

> '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, p 4)

> '... I need help to read people.' (ASPECT, 2007, p 240)

> 'I am terrible at body language.' (Madriaga et al, 2008, p 19)

Flexible imagination, organisation, anxiety and sensory sensitivities
Beaumont and Newcombe (2007), Bogdashina (2003; 2005), Frith (1989), Happe et al (2006) amongst others, cite evidence which identifies challenges in using imagination, in organisational skills and in problem solving. People with AS/HFA may therefore struggle to identify salient aspects of 'the big picture', to project forward to predict likely outcomes in unfamiliar contexts, and/or to understand the behaviour and motivation of unfamiliar individuals It does not take a massive leap of empathy to work out that heightened levels of anxiety about coping in unpredictable contexts

may result. Depression is often the unsurprising companion of anxiety and can also arise from the experience of social isolation and memories of unpleasant experiences with peers, especially in school (Attwood, 2007). Sensory sensitivities can compound feelings of anxiety. If an environment is noisy, busy, confusing, and alienating it may well be anxiety-provoking (Bogdashina, 2006). The full ASPECT survey supplies insider commentary on challenges students describe (see www.shu.ac.uk /theautismcentre). Madriaga et al (2008) provide further insights from transcripts in which eight first-year students talk about their experiences.

'Trying to survive in social situations for 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.' (2008, p 26)

'I don't think people get on with me for some reason.' (2008, p 22)

'For me it takes quite a bit of effort to get to know the person.' (2008, p 27)

'We don't know what to say really.' (2008, p 26)

'I just felt really bad that I was asking so many questions, getting in their way, annoying them.' (2008, p 31)

Empathy and self-esteem
Communication, social interaction and flexibility are two-way streets, as is empathy. Seeing the world from the perspective of another person may not come easily to someone with AS/HFA (Baron-Cohen and Swettenham, 1997). In particular, understanding the perspective of the NT peer may prove problematic. Locating difficulties with empathy solely with people who have AS or HFA is ignoring an important dimension which represents a potential harm factor in relation to self esteem. Empathy from peers, teachers, and others, towards people who have AS/HFA, cannot be guaranteed, and multiple experiences of being misunderstood, positioned as 'other', humiliated and excluded may be the consequence for people with AS/HFA who have not experienced empathic and humane responses from others.

'People need to get over the idea that the "neurotypical" 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

educating NTs 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, p 64)

The challenge
While stereotyping is to be avoided, the reality for many students with AS/HFA, is that college or university presents a vast tapestry of emotional, practical, social, communicative and sensory challenges. The ASPECT report illustrates that these are often faced with a great deal of determination and many students with AS/HFA do succeed. However, conditions could be more conducive to achievement with a greater degree of empathic understanding of AS/HFA from NT people. The ASPECT survey aims to add to this understanding.

The ASPECT methodology
Emancipatory research methodology
The ASPECT Consultancy study (2007) explored Local Authority service provision for 238 adults with AS or HFA in the United Kingdom. Participants who self identified included some people who had not gone through a formal diagnosis, inclusion of whom added to the data. The study which was conducted between 2006–2007 had three main aims:

1 Allow individuals to voice their opinions
2 Highlight challenges experienced by students with AS/HFA
3 Establish an evidence base on which to improve services.

The ASPECT Consultancy questionnaire was devised by Luke Beardon, a Senior Lecturer from Sheffield Hallam University Autism Centre and the late Genevieve Edmonds, an author and activist who had AS, in consultation with the ASPECT Committee which was made up of people with AS/HFA, a professional in the field of autism, and a parent of an adult with AS. The questionnaire included a mixture of closed and open-ended questions. These were distributed at an ASPECT consultation day attended by 100 individuals and also sent electronically to individuals and AS groups. Ethical clearance was obtained from participants who agreed to their

anonymised comments being used in publications and presentations. A total of 238 responses was received. Of these, 135 students identified challenges at college or university.

Data analysis

Responses to the *open-ended* question, 'List the problems, if any, that you have encountered at college/university were coded and grouped into four categories:

1   Social interaction
2   Course structure/curriculum requirements
3   College or university social environment
4   Understanding of AS or HFA (self and other).

These categories were then cross-checked with personal information regarding the support that students had received to understand:

•   Social situations
•   Neuro-typical behaviour
•   Friendships/relationships,
•   AS or HFA.

Limitations of the study

The implications of the findings remain unclear due to the complexity of the data and the potential for multiple interpretations. The trends in service provision identified could be attributed to several factors, ranging from student refusal, or non-recognition of support which had been received,

through to the non-existence of social and educational support services. Moreover, a causal relationship between support relating to a specific difficulty and perceived improvement in the situation could not necessarily be assumed, as factors such as increased familiarisation and confidence may have played a part. Further qualitative research could be undertaken to explore the subtleties of these relationships and their implications for future strategic initiatives. Additional quantitative analysis of the perceptions of students reluctant to access services would prove interesting. Not all students with AS or HFA will willingly disclose their diagnosis and it is currently not possible to know what sort of services students who fall into this category want or need (Martin, 2008). Obviously, practical and ethical dilemmas surround this and pragmatism would suggest that easily accessible services not badged as being for disabled students or students with autism or Asperger syndrome might hold the key.

The percentages included in this report should be read in tandem with the actual numbers (n) that constitute these, as several of the latter are relatively small in statistical terms. It is also important to note that the percentages and numbers included in this paper are based on valid responses only and do not include responses which have been classified as missing eg variable numbers of students who identified a challenge in a particular area, or gave a valid response to questions regarding different types support received (see *Table 1*).

Table 1: Number of respondents by type of support received

	Type of support received	Number of valid responses
Challenges at college or university	Support at college or university	118
	Neurotypical behaviour	133
	Friendships and relationships	129
	Social situations	132
Diagnosis of AS	Support/counselling to understand the diagnosis	97
Diagnosis of HFA	Support/counselling to understand the diagnosis	11
Social interaction	Support at college or university	46
	Neuro-typical behaviour	53
	Social situations	52
	Friendships and relationships	51
Social environment	Neuro-typical behaviour	28
	Social situations	28
Course structure	Support at college or university	30

Findings

Levels of support received by students who had experienced challenges whilst at college or university

A total of 135 respondents (based upon 229 valid responses) said that they had experienced difficulties. Of these, 54 of the valid respondents (46 per cent) had received some sort of support. About a quarter had been helped to understand neurotypical behaviour (28 per cent, n = 37), friendships and relationships (32 per cent, n = 41), and social situations (37 per cent, n = 49). Only 12 per cent (n = 12) of the 97 'valid' students with a diagnosis of AS felt that they had received adequate post-diagnostic support/counselling to understand the diagnosis. Rather worryingly, none of those with HFA (11 students) felt that they had received *adequate* support/counselling for this area.

Social interaction

Fifty-four students reported difficulties with social interaction, defined in the questionnaire as challenges relating to the need to communicate with others (eg in group-work). Eighteen of the valid respondents (39 per cent) had received some form of support at college or university. Eleven of the 54 students had received support to understand neurotypical behaviour (see *Table 2*), 16 students had had help to understand social situations and friendships and relationships.

It is important to note that the authors begin from the standpoint that people with a diagnosis of AS/HFA do not need to be 'cured' or trained in how to pretend to be 'normal'. However, experience would suggest that for some individuals, support to understand neurotypical behaviour might help to reduce some of the challenges. Equally important is the authors' belief that responsibility for inter-subjective understanding is a two-way process. That is to say, support to understand AS or HFA might benefit neurotypical individuals. As noted earlier, from these data alone, it is not possible to discern the reasons why levels of support to understand neurotypical behaviour have remained so limited for students who have experienced difficulties with social interaction. It is possible that for at least some students, a lack of provision is the problem, rather than a refusal to engage with a particular support service.

Social environment

Twenty-nine students identified challenges related to the social environment of the college or university. These are defined as those arising from the activities, expectations, or presence of others (eg the physical proximity of others or sensory distractions caused by others which are not primarily based upon the need to interact socially). Nine (32 per cent) of the valid respondents had received support to understand neurotypical behaviour. Eleven (39 per cent) had received support to understand social situations.

Assistance to understand neurotypical behaviour could be an important precursor to the avoidance of potentially challenging situations. For example, an individual with AS who expresses irritation at the manner in which a fellow student is tapping their pen, might be supported to understand that the NT 'offender' does not intend to cause annoyance, but rather, has a lower sensitivity to sensory-stimuli and/or is engaging in a repetitive activity which aids concentration or serves some other function! In addition, the neurotypical student might be informed about the emotions aroused by their seemingly 'innocuous' activity.

Understanding of AS/HFA (self and other)

Thirty-two students identified challenges which were related to their own or other people's understanding of AS or HFA. All but three of these students had a diagnosis of AS, the others considering themselves to have either AS/ or HFA, but they had no formal diagnosis.

Course structure and curriculum demands

Thirty-five students identified challenges with their course structure or curriculum demands. These related to practical activities, rigid assessment

Table 2: **Percentage of students with AS/HFA who received support to understand neuro-typical behaviour**

	Had received support to understand NT behaviour	Had NOT received support to understand NT behaviour
Challenges at college or university included social interaction of integration	21% (n = 11)	79% (n = 42)

criteria, organisational requirements and flexible programmes of study. Seventeen (57 per cent) of the valid respondents had received support at college or university.

Support received

Half the students with a diagnosis of AS (n = 44) and 60 per cent (n = 6) with a diagnosis of HFA, who had problems at college or university had received support (see *Table 3*). The comparative figure for students who were not formally diagnosed was considerably less at 19 per cent (n = 4). An 'official' label is often the gateway to accessing the Disabled Student Allowance at University and this may well be problematic, particularly as effective services for adult diagnosis are scarce and so there will be many students at universities and colleges with AS or HFA who are undiagnosed (Martin, 2008b). This is not to say that all students with AS or HFA require or welcome additional support at college or university. It would be a positive move, however, for effective intervention to be available when required with or without a diagnosis, either via mechanisms like the Disabled Student Allowance, or as part of sound inclusive practice which respects, values and facilitates diversity.

Discussion

Clearly, contexts which are unpredictable, chaotic, illogical, universally noisy and populated with people who communicate unclearly and are unreliable are not conducive to success – full stop. Limited friendly interactions and lack of appropriate socialising opportunities can create misery at college or university. For students with AS/HFA, ASPECT responses suggest that the challenges of 'chaotic contexts' can be extreme.

Getting it right for students with AS/HFA could enhance the comfort and confidence of other students too. Positioning neurodiverse students as 'other' in ways which are anxiety-provoking, and

concentrating support services on a group of labelled individuals is not necessarily cost effective or inclusive. The following suggestions are taken from the findings and the reader is invited to consider them from two perspectives. Firstly, what might students with AS/HFA find helpful and secondly, how far would these suggestions be good ideas to the student body as a whole.

The authors caution the readers once again against reading the suggestions which follow as if all of these apply in the same way to all students with AS/HFA, and with a little tweaking, to anyone else. Some people start college or university more socially naive or socially bruised than others. AS/HFA occurs in all areas of life, people have different personalities, and every individual has had their own unique life experiences, which is built upon every day. Consequently, the degree and nature of assistance required by students varies between individuals, and can change for any given individual, because people change and develop over time. In supportive institutions which offer a wide range of services for all students, the requirement for extensive, bespoke disability-related resources may possibly, but not necessarily, diminish. Providing an infrastructure in which everyone is empowered to develop as an autonomous learner and active citizen may well be the aim for all students. The degree to which individuals require assistance on this journey will vary.

Understanding self, others and context

ASPECT participants described finding it hard to make sense of other people, singularly, and in groups in the contexts of the social goings on around college and university, friendships, relationships and academic interactions, including group work and dealing with confusing lecturers. Nobody seemed to be around to help them through the social minefield and academic support was often not clear or reliable.

Table 3: **Percentage of students receiving support at college or university by diagnosis (number of students in brackets)**

	Received support at college or university	Did NOT receive support at college or university
Has a diagnosis of AS	51% (n = 44)	49% (n = 43)
Has a diagnosis of HFA	60% (n = 6)	40% (n = 4)
No diagnosis, but considers they have AS/HFA	19% (n = 4)	81 (n = 17)

Note: Seventeen students who described challenges at college or university gave no response to the question regarding the support they had received.

A sensitive response may prompt university and college personnel to consider the requirements of students who may be finding university or college confusing, lonely and anxiety-provoking. Clarity in communication in any context is necessary to alleviate the anxiety that can be produced when things just do not make sense.

Lecturers may wish to interrogate for clarity the instructions and assignment briefs they are producing. Rules for group work could be more clearly described and a careful eye on ensuring that everyone has a role within the group, no one is left out, and bullying is avoided may well be helpful. Students' commitments to inclusive behaviour may be enhanced if marks were awarded for team work. If it is not possible for a student to work comfortably in a group then academic staff should consider whether it is absolutely necessary to do so in order to fulfil the requirements of the course.

It is useful to consider what sort of opportunities exist to enable students to safely gauge social and academic elements that they find hard to understand on the basis of, 'What did that mean?' and 'Why did he say that?' Mentoring may play a role here, particularly if a climate is created between mentor and mentee in which confidentiality is articulated and respected and there is no such thing as a 'silly question'. Mentoring may not need to occur face to face as many students communicate electronically much of the time, as evidenced by the social networking Internet revolution.

Social opportunities which do not revolve around drinking may well be welcomed by students for whom alcohol is offensive on religious grounds, as well as to others who have non- alcohol-related hobbies. Diverse social opportunities reflecting a diverse student body, and easy ways to access a social life based on shared interests, may well enhance the college and university experience for many. Freshers' week is often the first step on the social ladder, so for students with AS/HFA, the sensory environment of the Freshers' Fair is important. It does not have to be really noisy all the time. Sheffield Hallam University, for example, has introduced a quieter time within Freshers' week which takes place mid morning, possibly before those with really bad hangovers are out of bed, allowing people the chance to check out things like the Chess Club. The Student Union is often potentially an excellent source of guidance and advice so working together between departments

may help to make the wider functions of the Union known and attractive to the wider student body.

Different service providers make up the sort of package of support which could be available and it may be useful for a mentor to have a signposting role to an extent. Talking to a personal tutor about academic concerns, a dentist about worries about teeth and so on makes perfect sense to someone who is thinking things through calmly and logically and a mentor may be necessary to assist a student, in a non-patronising way, to come to this realisation.

Diagnostic issues

Some ASPECT participants were in the position of having recently acquired a diagnosis and were therefore struggling, without support, to work out what this meant in relation to sense of self. Others felt that neurotypical people made very little effort to understand, accept or value neurodiverse individuals and expressed some resentment about this given that 'neurotypicals' are allegedly blessed with the capacity for empathy should they choose to use it.

The fact that a diagnostic label is a gateway to services for university students via the Disabled Student Allowance and funding methodologies in further education was noted as a problem by ASPECT participants. The lack of post diagnostic support has already been identified and the lack of the opportunity for diagnosis within the current regime throws up a range of other problems. While services are dependent on a diagnosis, people are inevitably disenfranchised if the diagnosis is hard to come by. The issues of who pays for it and who is qualified to deliver a sensitive diagnosis form part of the story. Only providing a service to someone who has successfully gone down the diagnostic route arguably runs counter to an inclusive culture in which individual requirements are addressed within the context of ordinary diversity.

The opportunities for ongoing post diagnostic support were flagged up as necessary but lacking for ASPECT respondents. Therefore when searching out any sort of diagnostic service, it is important to ascertain the degree to which this is built in as part of the service. Because a diagnosis can be hard to come by, some sort of review of current provision is indicated. At university and college, diagnostic assessments for dyslexia are often funded and the fact that this is not so for AS/HFA raises some equity issues which requires consideration at a strategic level. Sheffield Hallam University's Disability

Equality Scheme Action Plan addresses this inequality and is striving for a solution.

In an ideal, inclusive world, services would be available to individuals on the basis of requirement, rather than entitlement via a diagnosis. Resource-led arguments could be evoked about why this would be impossible, but these have not really been tested. It is very likely that for every student with a diagnosis who is accessing label generated services, there is someone else for whom the door is closed, either through lack of diagnosis or unwillingness to associate with disability services (Martin, 2008b). The intention of the authors at this stage is to put this idea on the table. Further discussion is required.

A concern that diagnosis could lead to 'othering' and stereotyping prompted the suggestion from ASPECT participants that it would be helpful for neurotypical people to come to some understanding of the potential impact of the 'condition'. Very sensitive handling would be required to avoid stereotyping. Attempts to get across the value of AS/HFA as part of the human condition, within the context of valuing diversity could backfire badly if the idea of individuality somehow got lost in the mix. However valuing rather than problematising diversity is some sort of starting point. Consigning words like 'normalisation' to the history bin would be timely. The authors challenge readers to describe the mythical beast that is the typical or normal student in a diverse institution. It is, simply, not possible, in any accurate sense.

Concluding comments

The participants were very clear about wanting to be appreciated for themselves rather than modified in order to fit in and this is likely to apply to all students, including all 'non-traditional' students. Consigning expressions like 'non-traditional' to the bin of history alongside words like 'normalisation' feels like – and is – a good idea, because by definition, describing anyone as 'other' is 'othering'. Valuing diversity necessarily involves a degree of sensitivity from individuals and a cultural shift from the top away from tolerating, to facilitating, towards valuing. The contribution of ASPECT participants to the debate is of value beyond the immediate population of individuals with AS or HFA.

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