

Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview-based study towards developing a model of best practice

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Editorial comment

This paper has been written jointly by staff at the Disability Resource Centre, University of Cambridge¹, the Disability and Wellbeing Team at the London School of Economics² and the Autism Research Centre at the University of Cambridge.³ Twenty-eight Cambridge University students who identified with Asperger syndrome (AS) or High Functioning Autism (HFA) considered the question, 'What would improve your university experience and increase your chances of success?'. Findings have been fed back to staff at the University with a view to developing best practice. Qualitative methods sensitive to individual preferences were used for capturing student views. These included focus groups, one-to-one interviews and e-mail contact with the researchers. Broad themes are presented in this paper. Initial insights from their comments on different aspects of University life suggest that simple and inexpensive changes could benefit students with AS. A list of ten recommendations generated by the students is provided within the paper.

Note on terminology

Students who identify with Asperger syndrome (AS) or High Functioning Autism (HFA) are referred to as 'students with AS' for the purpose of this study. The term encompasses the majority of students with a formal clinical diagnosis of AS, a smaller number formally diagnosed with HFA, and seven who self-identified initially and were formally diagnosed during the course of this study.

Introduction

This study builds on previous 'student voice' work by Beardon et al (2009); Beardon and Edmond (2007); Madriaga et al (2008) and Martin (2008). It asked Cambridge students with AS to reflect on their

experience of the university and to consider conditions likely to maximise their chances of success. The number of students disclosing AS at the University of Cambridge is rising annually. In August 2009, 27 students disclosed and by August 2011 this had risen to 70. This represents a three-fold increase. This study had ten female and 18 male participants. The Higher Education Statistical Agency (HESA) recorded 615 (585 UG and 30 PG) students who identified as having an 'autistic spectrum disorder' in UK universities in 2007–08. By 2009–10, this number had risen to 990 (845 UG and 145 PG) (www.hesa.ac.uk). These figures only include those students who are prepared to disclose their diagnosis, so will not be the true figure of the numbers of students diagnosed with AS in higher education (Martin, 2008).

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There will be other students at university who meet the criteria for diagnosis, but who have not been diagnosed as it is well established that in the adult population, autism is often missed.

Existing evidence base

With the exception of the ASPECT survey (Beardon and Edmonds, 2007), small-scale studies and individual accounts provide most of the available insider perspectives on experiences of higher education from students with AS (Hendrickx and Martin, 2011). ASPECT thematically analysed insights about daily life from 237 people with AS with a view to influencing the development of effective services. Areas including housing, education, employment and criminal justice emerged. A total of 135 people discussed challenges at college or university (Beardon et al, 2009). Principles of emancipatory research (Oliver, 1997) were followed in the ASPECT survey which was controlled by a Steering Group in which four of seven members identified with AS. This Cambridge study holds the same values, although participant involvement in the steering group, was only accomplished in 2011. This is acknowledged as a limitation.

Methodology and ethics

Steering Group membership comprised Joanna Hastwell, Dr Nicola Martin, Professor Simon Baron-Cohen, John Harding and two students with AS. A total of 28 current students with AS (23 undergraduate (UG) and five post-graduate (PG)) known to the Disability Resource Centre (DRC) participated in a range of activities between 2009–12. At the start of the study all students with AS who had disclosed to the DRC were invited to participate via e-mail or letter. Further opportunities for students to participate in the study were available during 2009–11. Given the difficulty of obtaining a clinical diagnosis of AS in adulthood (Beardon and Edmonds, 2007) having a firm diagnosis was not a requirement to participate. During the project, seven students without a diagnosis at the start were clinically diagnosed at the Cambridge Lifespan Asperger Syndrome Service (CLASS). The range of data gathering methods was determined by participant preferences and included focus groups, questionnaires, structured interviews at fixed intervals and regular email contact with the researchers. Ethical approval was given by the Psychology Research Ethics Committee.

Participants were asked to contribute ideas about anything they felt might improve their university experience. Ethical concerns were addressed in discussion with the students themselves. Anonymity was assured, no pressure was exerted and it was made explicit that anyone could withdraw at any point without explanation. Diverse methods to participate were set up, including individual meetings, focus groups, email contact and questionnaires. The purpose of each engagement was clear and transparent and the researcher was supportive and mindful of doing no harm.

The Cambridge project is an example of a systemic approach to capturing insider perspectives with a view to achieving positive change, as advocated by The Equality Act (2010). ‘Nothing about us without us’ (Charlton, 1998) – an expression borrowed from The Disabled People’s Movement – resonates with participants. Very rich data has been generated from the 21 interviews, 17 questionnaires, a focus group with eight students and e-mail correspondence with the researcher over the past two and a half years. Detailed thematic analysis will take place during the next phase. Presentation of the findings will be mindful of the impact and practical value to staff and students. Contributions from participants are woven into the literature review which follows in order to provide a flavour of emerging themes.

Throughout subsequent sections comments in italics, unless otherwise attributed, are direct quotes from the student participants. All are reproduced anonymously with necessary permissions.

The label

Respect for individuality is a key principle of the project. Participants are all unique individuals who share common ground. They are all high achievers who have gained access to an elite university and all identify with AS. Members of the growing online autism community problematise portrayal as a homogeneous ‘other’ (Arnold, 2003; Beardon and Edmonds, 2007). A ‘them and us binary’ is central to the notion of ‘othering’ (Foucault, 1967) in which diagnostic labels are used pejoratively (Barnes, 2008; Goodley, 2011; Haller et al, 2006; Richards, 2008). Use of negative terminology (like disorder and impairment) is criticised by insiders such as Hughes (2006) who favour the notion of neurological difference.

'People do not know much about Asperger's and they don't know how to handle it or treat me.'

'It is a very misunderstood, generalised and stereotyped condition.'

'It explains how my brain works, and how other people behave in weird ways'

'It enables a greater self understanding allowing better decision making.'

'It means there is a reason for all the pain and suffering I've endured, albeit not a fair one.'

'It's the only way I know to stop someone trying to convince you that you have enjoyed x y or z, or to stop arrogant bastards telling you how you just need to come out of your shell or just need to mature.'

'(It means) totally different things to different people; a very misunderstood, generalised and stereotyped condition; a blessing and a real debilitating disability by turns.'

'I so often suffered from depression and suicidal urges before I got the diagnosis, as I thought my social difficulties (were) all due to myself being bad or mad. It didn't even occur to me that I just don't understand people rather than that I am terrible. I feel much easier after the diagnosis.'

Blackburn (2000) suggests that people with HFA (like her) do not crave friendship as a means of social validation. She describes being content with her own company and observes that people with AS rarely are. Absence of early language delay currently differentiates AS from HFA diagnostically (Attwood, 2000; Banton and Singh, 2004; Fletcher, 2006; Nesbitt, 2000). Proposals to absorb separate labels and subgroups into a generic descriptor 'Autism Spectrum Disorder' in the 2013 revision of DSM are currently under discussion (www.dsm5.org). This is causing some disquiet amongst individuals who identify strongly with one label or another (www.wrongplanet.net) but was not raised as a concern by project participants.

Individuality, context, personality, intelligence, life experiences and many other factors impact upon how

someone with AS manages the social world (Beardon et al, 2009; Madriaga et al, 2008; Shore, 2003).

'AS means to me; organisation, directness, sense of purpose, being dependable and wanting others to be as dependable as I am, lacking confidence with everyday tasks.'

Communication, social inclusion and flexibility

Difficulty with social inclusion, communication and flexibility are central to the 'triad of impairments' associated with the autism spectrum as described by Wing and Gould, (1979) and Wing (1996). Indicators include literal interpretation of language, unusual eye contact, bodily awkwardness, limited conversation and adherence to routines. Such characteristics can become less obvious with age and because of the strenuous efforts of individuals to disguise these (Beardon, 2009).

'The supervisions were stressful as I do not like talking to people. Especially strangers.'

'When talking to someone or engaging in a conversation I feel that not talking for an extended period after being presented with a question causes a problem.'

'I find it difficult, dealing with unexpected questions in a formal verbal environment.'

'I have difficulty with being completely alone, and worse the lack of external structure and order.'

'If I am fixed on something, for example, anxious about something that I need to do, I will be totally focused on thinking about that. This means I can sometimes forget things or make mistakes.'

'This is somewhat unclear to me, as it (AS) appears to vary wildly across individuals. I understand the areas of impairments are to do with Social, Communication, and Sensory areas, however.'

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

'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)

People with AS have described difficulties arising in social contexts seemingly because of misunderstanding arbitrary social conventions and unpleasant interactions. Exclusion and bullying are frequently associated with unhappy adolescent years (Attwood, 2008; Lawson, 2005). The impact of others who create a hostile environment for people with autism feeds the notion that problems are, to an extent, socially constructed. Emphasis is placed on the interplay between environmental factors, such as bullying and exclusion, and in-person characteristics (including degree of impairment) (Arnold, 2003; Beardon, 2008; Shakespeare, 2006). The convention of imitating neurotypical (NT) behaviour in order to fit in is increasingly contested by people with AS (Arnold, 2004; Beardon, 2009).

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

'When someone with AS does something that seems totally ludicrous, they always have a reason which, in their own mind, is perfectly logical. It may be a good idea to ask them what this reason is.'

'Do not assume AS is something "wrong" with someone. A lot of the problems are caused by a lack of empathy from others'

Ability and interest

Contrary to stereotypes, including 'Rain Man' (Morrow and Bass, 1988) and 'The Curious Incident of the Dog in the Night-Time' (Haddon, 2003), AS does not necessarily equate to genius. Gillberg's (1992) diagnostic criteria specify 'at least average intelligence'. Einstein, Mozart, Newton, Wittgenstein and others (predominately male, white and deceased) are identified posthumously with AS and brilliance (Frith, 1989; Grandin, 1996; Murray, 2008). Application, in-depth interest, focus and motivation are conducive to academic success and associated with AS. 'Genius pressure' however can be unhelpful (Baron-Cohen, 2000; Beardon, 2008; Dobbs, 2006). Fulfilling in-depth interests are often pejoratively described as obsessions by outsiders (Arnold, 2003; Baron-Cohen, 2000; Grandin, 2003). Clearly Cambridge participants are academically gifted, but this relates to

their status as Cambridge students, rather as individuals with AS.

'And then the supervision itself was not so useful for me because I'd already worked it all out in doing the work.'

'I'm entitled to pursue what I'm interested in. I also appreciate the intellectual stimuli I get from teachers and friends.'

'Obviously university is also a great place for pursuing one's interest in great depth and meeting other people who are equally enthusiastic about their subject.'

'Performing with loads of ensembles. Being known as a committed/enthusiastic percussionist/drummer. Studying the subject I want to. Random conversations with people I know.'

'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)

Mental health and well-being

Secondary mental health issues, mainly anxiety and depression, are common and often precipitated by ambiguity, unpredictable change, bullying, humiliation and loneliness in people with AS (Attwood, 2006; Beardon and Edmonds, 2008). Sartre famously said, 'Hell is other people'.

'Depression. In fact, I've been having it as my "constant background" since I was 15 years old or so.'

'If I see someone being socially successful, or if I commit a social faux-pas which "nobody else would have done", I get depressed and behave awkwardly. I beat myself up excessively, self-deprecate, lose all self-confidence and get depressed.'

'I suffered due to anxiety, depression. I'm OK now and have been improving steadily since I first sought a diagnosis of AS.'

'Mainly anxiety attacks that appear/get worse with heightened stress.'

'Trying to survive in social situations for people with AS is a bit like trying to get upstairs with a broken leg – they could just about crawl themselves up if they were lucky.' (Madriaga, 2008:26)

Organisational skills and prioritising

Attempts at organising and problem-solving can cause anxiety. Recall of negative experiences and difficulty with imagination and predicting what other people might be expecting can make novel situations terrifying (Baron-Cohen and Swettenham, 1997; Beaumont and Newcombe, 2007; Bogdashina, 2003, 2005; Frith, 1989; Happe, 1994; Happe et al, 2006; Hughes, 2007; South et al, 2007).

'I often need to take time to calm myself. This can result in tasks taking longer than would normally be expected.'

'My ability to learn the presented material and get enough out of supervisions in the time available and/or avoid running out of supervision time have all come under pressure. This in turn means that I am perpetually stressed and fairly unhappy, which leads to secondary problems – tiredness, depression, negative interaction with people, to name but a few.'

'... high pressure, having to cope on your own with everyday tasks, eg eating, travelling etc.'

Sensory challenges

Noisy, over lit, chaotic crowded unpredictable places can trigger sensory overload (Bogdashina, 2006; ECU, 2009). The proposed 2013 revision of DSM is likely to include 'sensory behaviours' as part of the diagnostic criteria. Given these factors, and a preference for systems, often as a way to maintain a level of predictability (Baron-Cohen, 2003), it is unsurprising that spontaneity is seldom associated with AS.

'Taste and smell sensitivity cause nutritional issues.'

'I have trouble following lectures in overcrowded lecture theatres and I can't work in my room if people are loud in the corridor.'

'I don't like loud or sudden sounds. I don't like people talking to each other when I'm working. I

don't like bright lights either, but I can deal with that better than the noise.'

'I don't like people touching me but that doesn't usually happen at work.'

Self-esteem and empathy

Much has been written about the development of 'Theory of Mind' in relation to autism and AS that suggests that the ability to empathise with other people may well develop later or differently (Baron-Cohen, 2011). Less has been discussed about the way it might feel to be identified as someone who is lacking in empathy. Although the Cambridge students did not focus on this concern specifically, other people with AS have found their depiction as individuals lacking in empathy disturbing. Baron-Cohen (in press) has clarified that people with AS tend to have most of their difficulties in 'cognitive' empathy (eg imagining other people's thoughts and feelings, including decoding complex facial, vocal, and bodily expressions), whilst they can be intact in 'affective' empathy (eg, feeling concern for other people's suffering) (Dziobek et al, 2008).

Narratives that characterise people with autism as 'laced with strangeness' (Stevenson, 2008:201) and emphasise 'deficits' potentially severely damage self-esteem (Haller et al, 2006; Hendrickx and Martin, 2011; Molloy and Vasil, 2002; Murray, 2006; Peeters, 2000; Valentine, 2002). Goffman (1969) described the notion of 'spoiled identity'. Absence of a sense of being 'good enough' (despite having gained entry to an elite institution) is evident in the following comments.

'Being awkward in front of people – easily feeling embarrassed or inferior.'

'I am afraid I honestly cannot think of any strengths.'

'... neurotypicals demand an empathy in us which is lacking in them.' (ASPECT 2007, p 14)

The University environment

University presents students with many challenges – emotional, practical, social, communicative and sensory, which are often faced with great determination by those with AS. Many succeed and have described conditions that are conducive to success (ASPECT, 2007; Beardon et al, 2009; Madriaga et al, 2008), as follows:

'Try to have well structured conversations, for example, keep sentences short and clear.'

'An AS social group might well have helped in terms of providing an opportunity to make friends and do something other than just study all the time.'

'Say exactly what you mean. Do not exaggerate or try to put something such that it sounds less or more than what it is.'

'Buy earplugs. Lots of them.'

'It helps to have a mentor who is knowledgeable in my subject, having an understanding Director of Studies, having a contact at the Disability Support Team who is receptive to my particular needs.'

'It helps if I'm given lots of praise and encouragement – for me too much emphasis on mistakes and shortcomings can be counter-productive.'

'Avoid giving too much information at once, orally. Having it written down, or letting the person take notes, could be useful.'

'Assume nothing. If I am anything to go by.'

A reductionist definition of inclusive practice is provided by Martin (2008) using the word 'belonging'. A culture which facilitates belonging amongst diverse students is arguably the antithesis of that which creates 'othering' (Richards, 2008). Inclusion involves embedding services which have been traditionally badged as specifically for an identified group to create a sense of ordinariness (May and Bridger, 2010). Connotations of 'othering' (Richards, 2008) may be reinforced within segregated disability specific services that are counter to the notion of inclusion. Inclusion implies acceptance of the ordinariness of difference (Cameron, 2011).

Interim findings

A significant quantity of qualitative data is currently being thematically analysed with a view to capturing key messages about conditions conducive to success from the perspective of Cambridge students with AS. The interim report presented here aims to provide a flavour of some of the ideas that have emerged. In the final report it will be possible to quantify to an extent the frequency

with which particular concerns are raised. The emancipatory principles which underpin the Cambridge project require that findings are communicated in ways which are useful to students with AS. Once an evidence base has been developed, which can be used to inform and facilitate positive change, the main task will be to ensure that key messages reach key people. In the final phase of the project effectiveness and impact will be tested.

At this interim stage, participants were asked, for example, to work together as a focus group to create a ten point, generic good practice document. Sixteen students worked on the task in one-to-one interviews with the researcher, and eight as a focus group. A further 18 contributions came via email (six students participated in two ways). The nature of the project requires flexibility and responsiveness to the agenda of the participants and it may ultimately be impossible to condense suggestions to ten points. The following are presented at this interim stage.

Ten points of best practice as described by students with AS

1. Provide opportunities for students to talk to people about what would be helpful to them before they start university and make arrangements that meet the student's needs early on.
2. Prospective students should go to open days and transitional support events to have a look around. This will make the transition more familiar and therefore a lot easier.
3. Have people at universities who help disabled students find appropriate accommodation for the duration of their course.
4. Try to schedule all regular teaching/supervision sessions at the same time/day each week to create structure and routine.
5. Have access to quieter and less sensory overwhelming careers events and specialist careers advice that provides practical advice or tips about how to find, get and maintain successful employment.
6. Supervise/tutor in groups that are as small as possible. Large groups are hard to socially navigate and become overwhelming and unproductive.

7. Lecturers and other university staff should avoid ambiguous communication. Stick to factual communication rather than using words (including emotion words) that are vague.
8. Arrange living accommodation to minimise noise and social intrusion whilst avoiding isolation by matching student interests or preferences.
9. Use explicit written feedback. Constructive criticism alone should be given.
10. If advice is going to be given, it must be consistent.

Concluding comments

The project is moving into a phase of translating data into helpful information for staff who have the potential to influence the life chances of students with AS. Participants will be asked to contribute and comment on the extent to which they feel what is produced is of value. Student voice will resonate throughout and underpin all outcomes. In the final stage of the project the methodology will be critiqued and limitations will be identified. Future avenues for research will be considered and the potential application of findings beyond the Cambridge context will be identified.

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