

## **The Cambridge Project: reflections on a university-based AS social group**

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### **Editorial comment**

University can be a challenging social environment for students on the autism spectrum. The Cambridge Asperger Syndrome Project was set up in 2009 to draw on insider perspectives to provide guidance on supporting individuals on the autism spectrum at university. This paper focuses on a social group set up over the course of the project. It provides background on why this group might be needed, and reflects on the outcomes of the group. The authors found that taking part in this group served as a social confidence booster and a safe space for some students on the autism spectrum at Cambridge. Students particularly valued the opportunity to spend time with peers. The

authors of this paper are particularly interested in collaborating with other colleagues to develop this work further.

### **Note on terminology**

In this paper, the authors have used the term 'students with AS', which includes those who identify with High Functioning Autism (HFA) and Asperger syndrome (AS). The majority of participants in this study came with a clinical diagnosis of AS, a smaller number were clinically diagnosed with HFA, and 10 self-identified initially and accessed a clinical diagnosis during the course of The Cambridge Project.

### **Introduction**

The Cambridge Project provided Cambridge University students with AS with a range of opportunities to identify positives and negatives about their university experiences and share ideas for good practice likely to maximise their chances of success.

The project was developed to ensure that the real experts (students with AS at Cambridge) could provide the University with access to their expertise and was guided by the principles highlighted in 'Nothing About Us Without Us' (Charlton, 1998). Ongoing changes in university policy, practice and procedure and continuous evaluation and development ensure that the impact of The Cambridge Project continues to be felt. The results of the project were translated into a number of staff-facing initiatives designed to develop best practice and will be the focus of a range of papers each concentrating on a particular aspect of the findings. This paper describes the development of the AS Social Group which emerged from The Cambridge Project.

Alongside the academic aspects of university life, students with AS may also experience emotional, practical, social, communicative and sensory barriers (Ames et al, 2016; Gelbar et al, 2014). Often these challenges are faced with great determination and many succeed and

have described conditions which are conducive to success (Beardon et al, 2009; Hastwell et al, 2012; Madriaga et al, 2008).

When asked about challenges, recurrent themes include: social exclusion and awkwardness, confusion and anxiety and challenging encounters with individuals, groups, and systems (invented and administered by people). In fact, it seems that many of the difficulties experienced are around social interaction and could, with some minor adjustments, be avoided (Beardon et al, 2009; Hendrickx and Martin, 2011; Perner 2008). Few attempts have been made to research social aspects of the university experience from the perspectives of individuals with AS. The lack of 'autistic expertise' in autism research is highlighted by Milton (2014). With the exception of Beardon and Edmonds (2007), Beardon et al (2009) and Hastwell et al (2012), the evidence base consists mostly of small scale studies (of less than twenty) alongside internet-based individual testimonies. Insider perspectives come inevitably from those prepared to share and views may not be representative of people who remain silent, including those who do not identify with AS despite having a diagnosis (Martin 2008).

The ASPECT study by Beardon and Edmonds (2007) thematically analysed insights about daily life from 237 adults with AS. The study found difficulties with social mixing with other people, education, housing, employment and criminal justice. Furthermore, 135 participants discussed college and university experiences, referring frequently to social encounters (Beardon et al, 2009).

## **Aims**

Due to the recurring theme of difficulties with social aspects of university, this paper aims to provide information (from The Cambridge Project and other sources) to assist university staff to understand why this is so and how the situation might be improved.

While the focus is on social groups, students also accessed other social opportunities successfully, including clubs and societies and activities in halls of residence. Practitioners

are encouraged to think about ways in which the university as a whole could be as socially welcoming as possible. Reflections from participants and others on the spectrum provide insider perspectives on why and how social groups may be beneficial and the practicalities of making them work effectively.

## **Methods**

### ***Participants***

The study was designed to achieve a systemic approach to capturing insider perspectives with a view to instigating and sustaining positive change. The focus of this paper reflects the concerns of the majority of participants who found the social aspects of university more challenging than anything else. Based on the principle, 'nothing about us without us' and as advocated by The Equality Act (2010), it was only the views of 'stakeholders' with the lived experience of studying at Cambridge with AS which were of interest.

In summer 2009, any student who had informed Cambridge University's Disability Resource Centre (DRC) that they identified with autism was invited via email or letter to participate and given explicit guidance about what would be involved. All were told clearly that they could contribute any ideas about anything they felt might improve their university experience. The original invitation was followed up at least every three months between 2009 and 2011. As adult diagnostic services are limited (Beardon and Edmonds, 2007; Hastwell et al, 2012), the study was open to people who identified with AS but were not formally diagnosed. During the project, seven participants out of 28 had their AS confirmed at the Cambridge Lifespan Asperger Syndrome Service (CLASS). All found this beneficial.

The number of students disclosing AS at the University of Cambridge increased from 27 in 2009, to 70 in 2011, to 153 in April 2016. Participants in this study included 10 female and 18 male students (self-identified).

## ***Ethics***

Anonymity, non-coercion, withdrawal without explanation, transparency and usefulness were guiding ethical principles. The large scale ASPECT study (Beardon and Edmonds, 2007) was controlled by a Steering Group in which four of seven members identified with AS. The Cambridge Project shared the same emancipatory values (Barnes 2003, Oliver 2009, Milton 2014), but most participants were clear that they were simply too busy with studying to join the steering group and this is acknowledged as a limitation. The Steering Group included the Principal Investigator (Professor of Developmental Psychopathology, Director Autism Research Centre, University of Cambridge), Project Supervisor (Head of Research, Higher Degrees and Student Experience in the Division of Education, London South Bank University), the Head of the Disability Resource Centre (University of Cambridge), the Project Co-ordinator (Disability Adviser, University of Cambridge) and two student participants with Asperger syndrome. Each student participant gave whatever time they could as part of the Steering Group.

## ***Gathering data and reporting results***

28 students with AS (23 undergraduates and 5 postgraduates) known to the DRC participated in a range of activities during the three year project which formally ended in 2012, although research activity is still ongoing.

Data was gathered using focus groups, questionnaires and structured interviews at fixed intervals and regular email contact with the researchers was used in order to appeal to a range of participant preferences. This resulted in 21 interviews, 17 questionnaires, a focus group with 8 students and email correspondence with the researcher over the course of two and a half years. Detailed thematic analysis revealed a range of categories including social groups, ... . Social groups were a particularly important theme, given the frequency with which social aspects of university life were highlighted as problematic by participants. The

findings were presented in such a way as to be useful as a resource to enable the AS Social Group to flourish after the project formally finished.

## **The AS Social Group at Cambridge**

### ***Advertising***

Advertising of the group took place via the DRC, Student Union and colleges via email, websites, posters, bulletins and flyers. The text on the posters read as follows:

*AS Social Group. The group is for anyone who considers themselves to be on the Autistic Spectrum and is studying at Cambridge University. We meet as a small group and chat about a variety of interesting topics. We meet other students from across the university, organise activities, attend events and contribute to improving the student experience. Everyone is welcome, please come along when you can.*

The following quote from the project was boldly displayed *'I like attending the group as it's a place I can be myself'*.

### ***Organisation***

Sessions took place weekly at the same time in the same room. Participants were told that the group would not provide formal counselling and no one was under any obligation to attend regularly or disclose personal information. Sessions were started off by the Project Officer and soon moved to a user-led model often around a theme decided by the group. A Facebook Group was established but was not particularly successful as concerns were raised by participants about confidentiality, which was a core principle of the meetings. Fifteen participants attended sporadically but a small number of students attended every week. Eight was the maximum number in a single session.

In an early session group rules were established by participants. These were: Listen to others, confidentiality, respect other views, try not to make assumptions, be honest, use plain English, avoid acronyms/jargon, be open about sensitive subjects, share experiences of good practice and strategies that have worked well.

### ***What worked well?***

Having regular free meetings in the same quiet comfortable place, facilitated by a key contact from the Disability Resource Centre, minimised anxiety which could arise from confusing arrangements. Targeted emails supplemented other forms of advertising. Refreshments helped to create a welcoming atmosphere and experience of sharing refreshments with others. A fluid meeting structure allowed participants space and themed discussions gave the group momentum. A range of activities, some of which took place outside the university, were organised at the suggestion of participants. Activities included origami and board games, guest speakers, sharing hobbies and discussing university life. Trips included bike rides, cinema and theatre, archery, climbing, visiting the observatory and science festival. Initiatives which began within the Social Group served as a catalyst to wider opportunities and gave participants the confidence to join in socially.

Participants enjoyed the peer support, advice and understanding they received from other students with AS. The Social Group was experienced as a place where participants could be themselves and would not be required to fit in with neurotypicals, something which was experienced as exhausting and stressful. Silences and the gaps in conversations, which no one felt pressured to fill with small talk, were viewed as a refreshing change.

### ***The reliability, empathy, anticipation and logic (REAL) approach***

The Cambridge Project refers to the REAL approach, first described by Martin (2008). REAL stands for: reliability, empathy, anticipation and logic and is designed to distil a set of overarching themes relevant to working effectively with students with AS in every aspect of university life, in its broadest sense. This approach underpins the social group model and all aspects of The Cambridge Project. The acronym has the advantage of serving as an aide memoire for anyone trying to set something up with an eye to AS friendliness.

Confusion can be diminished if people do what they say they are going to do and reliability needs to extend to students as well as all staff. If, for example, a Social Group is organised for a given time and place, this needs to happen. Exceptionally, if plans have to change, students need to know in advance. Similarly academic arrangements need to be reliable.

If staff and peers use empathy they will look at any given situation through the eyes of other people. Ideally this would result on their reflecting on, for example, the use of deficit language or stereotyped images of autism (such as Rain Man) which may impact negatively on self-esteem. Everyone wants to be treated as an individual and homogeneity by impairment (or any other) label is offensive.

Anticipating (empathically) that unpredictable change may well cause anxiety and sensory overload will be an issue in some venues for example, should prompt the organisers of events to find a suitable space, make reliable arrangements and advise in advance if these have to be revised. Depression and anxiety can arise as a result of social isolation and fresher's week may be an excellent opportunity to join in. Anticipating that Fresher's week could be a sensory nightmare and understanding the importance of taking proactive steps to promote wellbeing may precipitate a more empathic approach to organising social activities.

Clear logical communication makes life more predictable and it is important to say what you mean and mean what you say and to avoid emotional overload which can muddy the message.

## **Key themes raised by the social group**

### ***The label***

Although this was not everyone's experience, some students spoke about the potential for the AS label to create social difficulties by setting them apart from their non-AS peers. Many Cambridge participants felt that mixing socially with other autistic people was important

because they felt tired of having to explain themselves to non-autistic peers or not feeling like they fit in. Some talked about the impact of negative stereotyping via media portrayals including *The Curious Incident of the Dog in the Night Time* (Haddon, 2003), and *Rain Man* (Morrow and Bass, 1988). Furthermore, despite Gillberg's (1992) diagnostic criteria for AS specify 'at least average intelligence', Einstein, Mozart, Newton, Wittgenstein, and others are posthumously associated with AS by Fitzgerald and O'Brien (2007), Frith (1989), Grandin (1996) and Murray (2008). This 'genius pressure' can create pressure and self-consciousness in itself and can be unhelpful (Baron-Cohen, 2000; Beardon, 2008; Martin 2008).

In recent studies, Brosnan and Mills (2015) and Matthews et al (2015) found that other students tended to respond positively when told that a peer was on the autism spectrum. Nevertheless 'disclosure' is still perceived by insiders to carry an ontological risk (Roulstone and Williams, 2014).

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

Some expressed concerns (echoed by the growing online autism community) about portrayals of people on the spectrum as a negatively constructed stereotypical homogeneous 'other' (Arnold, 2005; Beardon and Edmonds, 2007; Madriaga et al 2008).

On the other hand, those whose diagnosis was confirmed at Cambridge were positive about the experience and attributed some of their prior difficulties with social interactions partly to lack of confirmation of their AS.

*'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.'*

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

It is worth bearing in mind that some students with an AS label may choose not to access university disability services or anything associated with the label (Martin 2008), including an AS specific social group. Students who feel negative or conflicted about having ever been labelled with autism are also unlikely to participate in research like this. Practitioners are advised to anticipate that this may be the case and foster an institutional culture which makes all social opportunities accessible, from the start.

### ***Ability and interest***

In order to be academically successful at Cambridge, intelligence, application, in-depth focus and motivation are essential. Many people on the autism spectrum have in-depth interests. However, others sometimes describe these interests as ‘obsessions’ (Arnold, 2005; Baron-Cohen, 2000), a pejorative term which does not do justice to the positive experiences these interests bring. Participants described deriving joy from their interests while experiencing negativity from others, and expressed the hope of finding like-minded people at Cambridge.

*‘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.’*

*‘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)*

Remembering that AS-badged social groups are not for everyone, it is important to note that clubs and societies can be a great source of joy, interest and social connection with likeminded people. Cambridge participants accessed a wide range of such opportunities including societies and activities organised around chess, gaming in general, history, politics, debating, film and museum visits. Socialising via online activities around a particular interest was also something which participants valued. For some, the collegiate system helped at Cambridge because of its emphasis on community building around, for example, sharing meals. Some participants found activities around faith to be very welcoming. In Martin (2008) participants commented that Fresher’s week was a nightmare of sensory overload and

confusion which posed a barrier to joining clubs and societies. Many universities (including Cambridge) have since introduced a quiet time during Fresher's Fair and alternative ways to join groups and this has been well received by students with AS and others.

There is no one size fits all approach when working with unique individuals. Some participants loved the Christian Union, others the AS Social Group. Some attended a range of social activities, others stuck to one thing and some either wanted to be alone or chose to socialise in cyberspace. Therefore it is important to anticipate this and make varied social opportunities ordinary, of equal status and easy to access.

### ***Communication, social inclusion, flexibility and past experiences***

Participants talked about past experiences which have impacted negatively on their social confidence during childhood and adolescence and continued to do so, sometimes to a lesser extent, in adulthood. Joining in socially will inevitably be harder for people carrying the baggage of negative past experience alongside characteristics associated with AS. For some, planned social activities created a safer space.

In this study, 35% of participants found social situations at university very stressful:

*"My main barriers have been social and I find large groups of people I don't know intimidating. As a result I rarely attend lectures and often feel very alone."*

*"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."*

Challenges around social situations, aspects of communication and flexibility of thought are associated with the 'triad of impairments' identified by Wing and Gould (1979). Characteristics such as unusual eye contact, bodily awkwardness, literal interpretation of language, limited conversation and adherence to routines often appear less obvious with age. Beardon (2009) suggests that adults on the spectrum may well make deliberate

attempts to hide particular behaviours in order to try and fit in, often at great personal cost. Arnold (2005) and Milton (2012) are scathing about the notion that it is desirable to comply with seemingly arbitrary social conventions in order to pass as non-autistic.

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

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

*'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)

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

Adolescent years marred by social exclusion and bullying are all too common (Attwood, 2008; Edmonds and Worton, 2005; Lawson, 2005; Rosenblath, 2008). Students on the spectrum may begin university having had limited social experience outside of the family and their parents may also be anxious about the situation and reluctant to trust in the ability of the institution to provide appropriate support (Gelbar et al, 2014; Jackson and Martin, 2007; Madriaga et al, 2008; Martin 2008). In-person characteristics can work in tandem with environmental conditions, often created by other people (Arnold, 2005; Beardon, 2008; Milton, 2012; Shakespeare, 2013). The result of unhappy pre-university experiences can be a lack of confidence, fear and mistrust. The availability of safe social space is clearly important for promoting the wellbeing and confidence of students with AS.

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

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

### ***Mental health and well-being***

While personality, life experiences and many other factors impact how someone with AS manages the social world, there is much evidence to back up the logical assumption that

negative social interactions can be detrimental to personal well-being and mental health (Ames et al, 2015; Barnett, 2008; Beardon et al, 2009; Cameron, 2011; Hendrix and Martin, 2011; Madriaga et al, 2008; Shore, 2003).

*'I am fine most of the time; I am not fine when there's a reason to find fault with myself. I can be fine one second and then something triggers a sensation of awkwardness and lack of self-confidence.'*

Anxiety and depression are common secondary mental health concerns for people with AS and are often precipitated by bullying, humiliation, social exclusion, loneliness, ambiguity and unpredictable change (Attwood, 2008; Beardon and Edmonds, 2008). It is important to understand this and for staff to take proactive steps to address these external factors with the aim of avoiding conditions conducive to the development of anxiety and depression. Campbell (2009), Goodley (2014), and Goodley and Runswick-Cole (2011) highlight how ableist attitudes can lead to discriminatory and exclusionary behaviour which university staff have a duty to challenge.

Positive social interaction may be derived from social groups, clubs and societies and other organised attempts to create a supportive empathic community. Participants found the collegiate system at Cambridge useful in this respect.

Students may start university with high hopes of making friends. If Fresher's activities are not inclusive, the results are likely to be feelings of failure at the first hurdle, leading to loneliness, othering and depression. This was reported frequently in the Cambridge Project.

*'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.'*

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

*'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.'*

The Cambridge project provided clear evidence that social groups and easy access to other social activities relating to areas of particular interest contributed positively to student wellbeing, sense of belonging and confidence.

### ***Organisational skills and prioritising***

Some people with AS may have difficulties with problem-solving and organisational skills and these may be exacerbated by unclear communication of expectations. Anxiety can arise as a consequence of the resulting confusion and recall of prior similar negative experiences is likely to add to the problem. Novel situations may be terrifying, which partly explains why individuals on the spectrum may appear to be 'resistant to change' (Barnett, 2008; Baron-Cohen and Swettenham, 1997; Beaumont and Newcombe, 2007, Bogdashina, 2003, 2005; Madriaga, 2006; Hughes, 2007). University staff need to take these factors into account and create an organised (academic and social) environment in which expectations are communicated clearly. These factors are important when planning social activities. Deviating from arrangements which are reliable, empathic, anticipatory and logical is likely to cause social stress.

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

*'High pressure, having to cope on your own with everyday tasks e.g. eating, travelling etc.'*

### ***Sensory challenges***

Busy, over-lit, noisy overcrowded chaotic unpredictable places can be intensely unpleasant for people with AS (Bogdashina, 2006; Beardon 2008; ECU, 2009). If seminar groups meet in a pub for example, some students may choose not to attend and will therefore miss out socially and academically.

*'Taste and smell sensitivity cause nutritional issues.'*

*'Buy earplugs. Lots of them.'*

*'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.'*

### **Self-esteem and empathy**

Social groups and social activities have the potential to make people feel good about themselves, to reduce social isolation and to increase social confidence in its broadest sense. It is necessary to empathise with students with AS in order to plan social activities which achieve this and help make university a place for personal development and fun, for all. The expression 'empathy is a two way street' (Martin, 2010) suggests that seeing the world through the eyes of individuals with AS would be a good starting point for creating autism friendly environments, a notion echoed by Arnold (2005) and Milton (2012, 2014). An ASPECT participant made the observation that *'Neurotypicals demand an empathy in us which is lacking in them'* (Beardon and Edmonds, 2007, p.14).

Baron-Cohen (2011) distinguishes between cognitive and affective empathy suggesting that difficulties in 'cognitive' empathy (e.g. imagining other people's thoughts and feelings, including decoding complex facial, vocal, and bodily expressions), are more common than problems with 'affective' empathy (e.g., feeling concern for other people's suffering). A useful exercise in empathy might be to consider how it might feel to be described as 'lacking in empathy'. Cambridge participants did not highlight this as a concern but the association between autism and limitations in empathy has been highlighted by Milton (2012).

Descriptors which emphasise 'deficits' (such as being un-empathic) and characterise people with autism as *'laced with strangeness'* (Stevenson, 2008:201) have the potential to harm self-esteem (Haller et al, 2006; Hendrickx and Martin, 2011; Murray, 2006). The following

comments suggest that participants did not necessarily start their Cambridge journey with a positive identity and high self-esteem (despite having gained entry to an elite institution).

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

*'I am afraid I honestly cannot think of any strength.'*

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

Social activities have the potential to enhance university life by offering fun and encouragement with a view to enhancing wellbeing and feelings of self-worth. The Cambridge Project did not lose sight of these possibilities and developed the AS Social Group and other social opportunities accordingly.

### **Concluding comments**

At the end of the project the Student Union and Graduate Union took on responsibility for oversight of The Social Group with The Welfare and Rights Officer acting as the main contact. In 2012, four student facilitators were also appointed and reliability was strongly emphasised in their training and is reinforced in ongoing supervision. The Disability Resource Centre kept a watching brief over the initiative and was able to partly resource with the Student Union, visiting speakers and consumables. A specific virtual support portal was set up based on participant's suggestion about being comfortable with communicating in this way. In 2014/15 a board games group started and in 2015/16 sessions with a pet assisted therapy (PAT) dog were introduced. These have been particularly appealing to people who don't necessarily want to talk to each other too much or find working with a pet relaxing.

In 2017 the group still is active and expanding and evaluations indicate that social aspects of university life still present significant challenges to students with AS and the AS Social Group is in part still appealing and useful to students.

The authors invite collaboration across diverse sectors in the ongoing positive development of the social aspect of education and work. While the focus here is on students who identify with AS, many of the considerations discussed have broader relevance. Future research may take characteristics such as gender and mental health and AS into account.

London South Bank University Centre for Education Research is currently working with Research Autism on an exploration of the value of mentoring to adults on the spectrum. The research includes mentors with autism and given the enthusiastic comments about peer empathy from Cambridge project participants this is potentially a very positive development.

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