

Asperger Syndrome Student Project, 2009-12: Final Project Report, June 2013

Authors: Joanna Hastwell, John Harding, Dr Nicola Martin, Professor Simon Baron-Cohen

Disability Resource Centre



UNIVERSITY OF
CAMBRIDGE



Table of Contents

1. Introduction.....	4
2. Outputs and Achievements.....	7
3. Longitudinal Study.....	11
4. Further Research Opportunities.....	23
5. Conclusions.....	24
6. References.....	25

Appendices

Appendix I: Guidance for Staff: Supporting Students with Asperger Syndrome/Autism	i
Appendix II: Role of the Project Partners	x
Appendix III: 'Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview-based study towards developing a model of best practice', <i>Good Autism Practice, (GAP, 13,1, 2012), pp 56-63</i>	xi
Appendix IV: Model of Best Practice: Developing Provision for Students with Asperger Syndrome.....	xxiii
Appendix V: Careers Service Annual Report Extract 2011-12, University of Cambridge	xxvi
Appendix VI: 'All graduates with autism need access to good careers advice', <i>Association of Graduate Careers Advisory Services (AGCAS) Phoenix Magazine, Oct 2012</i>	xxix
Appendix VII: Research Project Documentation.....	xxxi
Appendix VIII: Conferences, Seminars and Training	xxxiii

1. Introduction

The Asperger Syndrome Student Project at the University of Cambridge was funded initially from a grant from The Baily Thomas Charitable Trust. The project was a collaboration between the Disability Resource Centre (DRC) and Cambridge Lifespan Asperger Syndrome Service (CLASS), based at the Autism Research Centre (ARC). In late 2008 Professor Simon Baron-Cohen, Director of ARC and John Harding, Head of the DRC, developed the terms of reference and objectives of the project (based on an existing proposal) in response to the year on year increase of students with Asperger syndrome (AS) disclosing to the University of Cambridge and in recognition of the specific support requirements of this cohort of students. Joanna Hastwell was appointed as the Asperger Syndrome Project Officer in August 2009 and Dr Nicola Martin was invited to work with the project as an Honorary Visiting Fellow.

Nationally, the Higher Education Statistical Agency (HESA [1]) recorded 855 students who identified as having an 'autistic spectrum disorder' in UK Universities in 2008-09. By 2010-11 (the latest available data), this number had risen to 1515 (a 77% increase over three years).

At the University of Cambridge, applications from students with AS increased from 21 in 2008/09 to 67 in 2012/13 (an increase of 219% over five years). Over the lifetime of the project the number of students with a diagnosis of Asperger syndrome rose from 27 in August 2009 to 91 in Sept 2012 (an increase of 237% in three years). It should also be noted that it is likely that there are many undiagnosed individuals not included in this data, as well as students who were diagnosed in childhood and choose not to disclose to the university.

The National Audit Office (NAO [2]) identifies access to education as a key factor in improving the lives of adults with autism, stating that 'provided appropriate support was in place, retention and success rates for students identified with autismshould be good', but also that, 'university is a major step for young people with autism owing to the change of routine, location and social environment. Without appropriate support they may not fulfil their potential and complete their degree'.

Students with AS at university are by definition very high achievers and the NAO 2009 report recognises university as a desirable option for academically gifted students with AS. However, this fact is not reflected strongly in The Autism Act and Strategy 2009. Furthermore, despite a growing body of research into autism, few studies address the needs of adults and more specifically students with Asperger syndrome.

Equality Challenge Unit (ECU) data indicates that of all current UCAS classifications of disability, those with a disclosed autistic spectrum disorder have the lowest levels of achievement of first or upper second degree classifications. [3]

[1] <http://www.hesa.ac.uk/index.php/content/view/1973/239/>

[2] Supporting people with autism through adulthood, REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 556 Session 2008-2009 | 5 June 2009, <http://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>

[3] Equality in higher education: statistical report 2011, Equality Challenge Unit (2011). Data indicates that 51.6% of those with a disclosed autistic spectrum disorder achieved a 1st/2:1 compared to 63.4% of those with no disability.

1. Introduction (continued)

With this in mind, the Cambridge Asperger Syndrome Student Project aimed to develop a model of best practice to support students with AS in higher education and to raise awareness and develop understanding more broadly.

The original objectives of the project were to:

- review current levels of service provision for students with AS within the University of Cambridge;
- develop a model of best practice in line with other national initiatives, such as the '*Template for provision of support for students with AS in Further (FE) and Higher Education (HE)*' produced by the NADP and Sheffield Hallam University [4];
- track the experiences of a group of students with AS in a longitudinal study, in order to identify what works and where improvements are needed;
- raise awareness of the support available across the University;
- strengthen and build effective links between the DRC and external services such as 'Prospects' (the employment agency for people with AS, run by the National Autistic Society) or the University Counselling Service, in order to ensure a coherent and effective support network for students with AS;
- follow the principles of 'emancipatory research' which ensure that the student's voice is centre stage and that the outcomes of the project are of practical benefit to students with AS;
- fast track students who are seeking a diagnosis of AS while at University, which can then unlock support from the Disabled Students' Allowances (DSAs).

The Project included a longitudinal study of the experiences of Cambridge students with AS over three academic years (from Oct 2009 to June 2012). The study involved 28 students across the University, who participated in one-to-one interviews, focus groups and completed questionnaires. As a result a wealth of data has been collected and key themes have been identified. Initial insights from participant comments on different aspects of university life suggest that simple and inexpensive changes could benefit students with AS, and those staff supporting them, as well as students in general. A list of ten student-generated recommendations is included within this report.

A model of best practice in supporting students with AS/autism in higher education has been developed (see Appendix IV), including identified transferable practice to apply in other contexts, such as further education and the employment sector. This model has been achieved through an 'emancipatory' study with a central focus on the student voice. At the time of the publication of this report, the model is in the form of a diagram and funding is being sought to allow the model to be developed as an on-line resource .

The project also enabled students at Cambridge requiring diagnosis to be fast-tracked to the Cambridge Lifespan Asperger Syndrome Service (CLASS). Once diagnosed these students were then able to receive a package of support (including the opportunity to reflect on their diagnosis) from the Disability Resource Centre (DRC) in collaboration with colleges, departments/faculties and other student services across the University.

[4] NADP Template 1/2008: A template for improving provision for students with Asperger Syndrome in further and higher education, <http://www.nadp-uk.org/resources/publications.php>.

1. Introduction (continued)

Key recommendations of the study (detailed later in this report) include the need for the continued development of specialist advice and guidance for students and staff with Asperger syndrome, and of inclusive practice across the entire student life-cycle, including transition into university, transition between levels of study and graduate transition into employment.

Equality Challenge Unit research [5] shows that in 2011 24.7% of UK-domiciled graduates with an Autism Spectrum Disorder (including Asperger Syndrome) were unemployed, the highest proportion out of all disability categories (the next closest being blind/visually impaired graduates at 13.4%). The project enabled highly effective and nationally recognised collaborative work with the University Careers Service in developing services for students with AS. The results of this collaborative work have been cited by the National Autistic Society (NAS) as good practice in their training sessions for other HEIs.

The Project Steering Group membership comprised Joanna Hastwell (Project Officer, University of Cambridge), Dr Nicola Martin (Chair of NADP and Head of Disability and Wellbeing, LSE), Professor Simon Baron-Cohen (Director of the ARC, University of Cambridge), John Harding (Head of the Disability Resource Centre, University of Cambridge) and one student with AS from the University of Cambridge (recruited in the final year).

[5] <http://www.ecu.ac.uk/publications> (Equality in Higher Education: Statistical Report 2011, Part 2: Students).

2. Outputs and Achievements

Findings and outputs are broken down below into two phases, 2009-10 and 2010-12. The project originally had funding for one year, and then was extended after a successful bid for additional funds from the Baily Thomas Charitable Trust. The findings include ten points of best practice developed from feedback from students with AS. This is followed by recommendations from the study's findings. Recommendations aim to follow the student life cycle from pre-entry to progression from University.

Phase I: 2009-2010

Outputs:

AS Social Group.

A social group for Cambridge students with a diagnosis of AS (or who feel they have AS but have chosen not to get a diagnosis) was established in January 2010 and as of Sept 2012 had 15 members. The group developed its own terms of reference and ways of working with a view to developing a sustainable model. This included the group facilitator role transferring from the Project Officer to a current student supported by the Cambridge University Student Union and Graduate Union (CUSU/GU) following the completion of the AS Project. An online networking group has also been established to ensure wider access to the group for prospective and current students of the University.

Longitudinal study.

28 student participants were identified and the methodology for the study established. The study continued for the lifetime of the project.

Transitional Support Events.

Specialist Autism organisations (such as the Autism Educational Trust) recognise that the process of transition into higher education is one of the key transition phases for individuals with AS, and often extremely challenging[6]. Appropriate support at this stage can be crucial to making this transition a success and in reducing drop out rates. In recognition of this, transitional events for incoming students with AS were developed. These now annual events, coordinated by the DRC, include planning transitional support such as pre-entry visits to allow incoming students to familiarise themselves with the collegiate university environment; meetings with key academic staff, and with non-medical support staff (such as 1-1 specialist mentors); and support discussions with Disability Advisers. All staff involved are appropriately briefed.

Student Support Documents (SSDs).

SSDs are clear, concise and consistent documents which communicate support needs and 'reasonable adjustment' recommendations in line with disability equality legislation (*Equality Act 2010*) for individual students with AS. Student feedback strongly supported the implementation of such documents. These were developed in collaboration with colleges and departments and designed to ensure that essential information, advice and guidance is available to staff and others with 'a need to know' when teaching and supporting a disabled student.

[6] <http://www.autismeducationtrust.org.uk/good-practice/written%20for%20you/parents-and-cares/pc%20transitions.aspx>

2. Outputs and Achievements (continued)

(Confidentiality protocols are explicit). A Student Support Document is produced in consultation with the individual student, supported by their medical or specialist evidence and often their Disabled Students' Allowances (DSAs) Needs Assessment Report. A Student Support Document is now produced for all students with a diagnosis of AS via the DRC.

Developing effective networks.

During the first year of the project networks and working relationships were established between the Cambridge AS Project and the following departments, institutions and professional bodies: the Cambridge University Student Union (CUSU), the Graduate Union (GU), the University of Cambridge Counselling Service, University of Cambridge Careers Service, Senior Tutors, college staff, a range of University of Cambridge departments and faculties, the Cambridge Lifespan Asperger Syndrome Service (CLASS), National Autistic Society (NAS), The National Association of Disability Practitioners (NADP) and Disability Support Services at other national and international universities (such as the University of Oxford, the LSE, Imperial College London, University of Strathclyde, Glasgow Caledonian University, Sheffield Hallam University, University of Canterbury, New Zealand, University of Leuven, Belgium and the University of Toyama, Japan).

Conferences.

Best practice examples and initial outcomes were shared via conference papers and presentations at 7 national and international conferences in 2009-10.

Phase II: 2010-2012

Outputs:

Careers Transition Programme for students with AS.

The programme was the output of a collaborative project by the AS Project and the University Careers Service. A series of three workshops were developed and offered to a group of students with AS over two academic terms. The pilot ran during the 2010/11 academic year and continued successfully in 2011/12. The workshops included topics such as '*disclosure and interview, dispelling myths about autism and careers, skills and presenting them, and career planning*'. The programme is being continued by the Careers Service in 2012/13 with support from the DRC. Further information is available on the DRC website. [7]

Specialist training for Careers Advisers.

Facilitated by the Prospects Service, part of the National Autistic Society (NAS), a pilot training course was run at the University of Cambridge and has now been rolled out nationally focusing on AS awareness training for HE Careers Advisers.

Review of careers services for students with AS.

A review of collaborative projects and a development plan were produced, including recommendations for on-going student support. This is included in Appendix V, along with an extract from the Careers Service annual report 2011-12.

[7] http://www.admin.cam.ac.uk/univ/disability/asperger/news_events.html

2. Outputs and Achievements (continued)

Association of Graduate Careers Advisory Services (AGCAS) article.

In Oct 2012 AGCAS's Phoenix magazine published an article written in collaboration between the DRC, the University of Cambridge Careers Service and NAS Prospects, entitled '*All graduates with autism need access to good careers advice*'; it is available in Appendix VI.

Development of an initial screening process.

The AS Project developed a fast-track for diagnostic referral for students seeking a diagnostic assessment for AS/autism in liaison with the CLASS clinic and Prof. Simon Baron Cohen. Pre-screening appointments are now available at the DRC for students to discuss their experiences, challenges faced and routes to support. Dealing with the paperwork and completing screening tools in a supportive environment has reduced the time between referral and diagnosis, on average, from eight to three months.

Increased access to diagnosis.

Over the duration of the project 56 students at the University of Cambridge who were seeking a diagnosis of AS/autism were fast-tracked to the Cambridge Lifespan Asperger Syndrome Service (CLASS) clinic. Early access to diagnostic services can contribute to the reduction of drop out rates. [8] Post diagnostic support is picked up by the DRC as appropriate.

Specialist training and awareness-raising for staff.

Training was delivered at the University of Cambridge and at other HEIs, including Imperial College, London. 'How to work effectively with students who identify with AS/autism' was delivered to DRC Disability Advisers and 1-1 mentors. Specialist training has also been identified as useful for specialist 1-1 study skills tutors, due in part to the growing number of students being recommended such support. 'Teaching students with Asperger syndrome', a training course for academic staff, delivered by the DRC, was also developed with input from the AS project officer.

Project Steering Group.

A current student with AS was recruited to the AS Project steering group, joining the other 4 members.

Good Autism Practice (GAP) paper.

Publication in the journal, May 2012. Paper titled; *Giving Cambridge University students with Asperger syndrome a voice: A qualitative, interview-based study towards developing a model of best practice for students with Asperger syndrome/autism in higher education*. [9] The paper is available from the Autism Research Centre (ARC) website publications list and the DRC website (also see Appendix III).

[8] *Compendium of effective practice in higher education retention and success*, Higher Education Academy (2012); *Students with Asperger's syndrome: a pre-entry induction programme*, Rob Fidler and Jan Britton, University of Surrey.

[9] www.bild.org.uk

[10] <http://network.autism.org.uk>

2. Outputs and Achievements (continued)

Network Autism interview.

A feature article and video interview introducing the Cambridge AS Project was published on the Network Autism website [10] in August 2012. The network is aimed at professionals across all sectors including health, social services, education, public sector, and academic and professional bodies.

Increase in the number of students with AS at the University.

Over the duration of the project the number of students, who are diagnosed at the University of Cambridge has increased from 27 in August 2009 to 91 in Sept 2012, an increase of 237% in three years.

Conference presentations/papers.

Good practice examples and initial outcomes from the study were shared nationally and internationally via conference papers and presentations across 17 conferences in 2010-12, totalling 24 over the duration of the project. See Appendix VIII for full details.

Materials and resources.

Revised DRC publications and guidelines relating to support for students with AS. Appendix I details the Information for Staff document. This document will be made available via the DRC website in 2013. The collection of books relating to autism/AS and Neuro-diversity has been expanded and updated. These books are available on loan from the DRC.

Student Experience Film [11].

As part of a wider project to produce films promoting the positive experiences of disabled students at the University of Cambridge, the Asperger Syndrome Student Project funded the film '*Alison's experience*'. Alison is a student with Asperger syndrome studying Natural Sciences. In the film, she talks about the things she loves about studying at Cambridge, her diagnosis of Asperger Syndrome, the support she has received, and choosing her College.

[11] Alison's Experience: <http://www.youtube.com/watch?v=C3bquIXKu3Y>

3. Longitudinal Study, 2009—2012

The longitudinal study builds on previous ‘student voice’ work by Beardon et al. (2009), Beardon and Edmond (2007), Madriaga et al. (2008), Martin (2008). Cambridge students with AS were asked to reflect on their experience of University and to identify conditions likely to maximise their chances of academic achievement and improve the quality of their university experience. The project utilised the findings of this research to inform best practice guidelines for the University of Cambridge in conjunction with the project’s own recommendations. It is planned that recommendations, materials, training courses and guidance become a sustainable resource for future students.

The Cambridge AS Project was an example of a systemic approach to capturing insider perspectives with a view to achieving positive change, as advocated by The Equality Act (2010). [12] ‘*Nothing about us without us*’ [13], an expression borrowed from The Disabled People’s Movement, resonated with participants. Significant data have been generated from the 21 interviews, 17 questionnaires, a focus group with 8 students and email correspondence with the researcher over the study period. Presentation of the findings aims to be mindful of the impact and practical value to both staff and students.

Following ethical clearance, qualitative and quantitative data were collected from focus groups, one to one interviews and questionnaires, in order to track the experience of 28 students (23 undergraduate (UG) and 5 post-graduate (PG)) with AS, over a three year longitudinal study. The study had 10 female and 18 male participants. Female participants made up 36% of the total participant figure, representing a larger than average balance of female to male perspective in the study. In epidemiological research Wing (1981) found that among people with high functioning autism or AS there were as many as fifteen times as many males as females. In Sweden, Ehlers and Gillberg (1993) found a similar male to female ratio of 4:1. [14]

At the start of the study all students with AS who had disclosed to the DRC were invited to participate via email or letter. Further opportunities for students to participate in the study were available during 2009-11. The range of data gathering methods was determined by participant preferences and included structured interviews at fixed intervals and regular email contact with the researcher. Given the difficulty of obtaining a clinical diagnosis of AS in adulthood [15] having a formal diagnosis was not a requirement to participate. During the project, seven participants without a diagnosis at the start were clinically diagnosed at the Cambridge Lifespan Asperger Syndrome Service (CLASS).

In line with ethical research practice, students were informed of expectations of them as study participants. Anonymity was assured, no pressure was exerted and it was explicit that anyone could withdraw at any point without explanation. Forms were signed and taken away by the participants (Appendix VII). Diverse methods to participate were set up and the purpose of each engagement was clear and transparent and the researcher was supportive and mindful of doing no harm.

[12] The Equality Duty says that ‘public bodies must ensure that disabled people are treated fairly. By working with disabled people when designing policies, services or communications, and understanding the perspective, needs and priorities of disabled people will develop better policy and deliver successful public services’ .

[13] Charlton, 1998.

[14] NAS, www.autism.org.uk.

[15] Beardon and Edmonds, 2007.

3. Longitudinal Study, 2009—2012 (continued)

Thematic Analysis of Longitudinal study findings

This thematic analysis divides responses into four main categories:

1. Social interaction
2. The University environment
3. Understanding of AS or High Functioning Autism (HFA)
4. Engaging academically

Two pieces of research, the 'ASPECT' report [16] and 'Enabling Transition into HE for students with AS' [17], also identified similar themes in their work. Throughout subsequent sections comments *in italics*, unless otherwise attributed, are direct quotes from the student participants. All are reproduced anonymously with necessary permissions.

1. Social interaction

35% of respondents found social situations at University 'very' stressful.

Pertinent quotes:

"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"

"My hopes for the future are to do further study, a job in scientific research, maybe even having friends someday"

"Am fine most times; am not fine when there's a reason to find fault with myself"

"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."

Student recommendations:

"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"

[16] Beardon, L, Edmonds, G (2007) 'The ASPECT report. A national report on the needs of adults with Asperger syndrome'.

[17] Madriaga, M, Goodley, D, Hodge, N, Martin, N (2008) 'Enabling transition into higher education for students with Asperger syndrome' HEA.

3. Longitudinal Study, 2009—2012 (continued)

2. The University environment

73% of respondents identified challenges related to the University environment, with a particular focus on issues of access related to sensory overload, lack of structure and predictability.

Pertinent quotations:

“What I found difficult was being completely alone, and worse the lack of external structure and order”

“I find it stressful having a room that is in the middle of a noisy environment and studying in my room”.

“When I first started I had a lot of trouble adjusting to being away from home, spent all my time studying and did not make many friends. This led to severe depression and having to take time out from my course”.

Student recommendations:

“If supervising a student more than once try to schedule supervisions at the same time and on the same day of the week as each other”.

“Buy earplugs. Lots of them”.

3. Understanding of Asperger syndrome or High Functioning Autism

A lack of empathy from others was widely reported as well as a stereotypical approach by many towards AS/Autism.

Pertinent quotations:

“Do not assume AS is something ‘wrong’ with someone. A lot of the problems are caused by a lack of empathy from others”

“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”.

“From a superficial understanding, autistic people would look like a machine, not interested in the other people, which was actually my first impression of what autism would be like (I think this is mainly the reason why I never speculated I might be autistic). I think this actually shows how subtle AS really is, and indeed, one autistic person will be entirely different to another.”

“It explains how my brain works, and how other people behave in weird ways”.

“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”.

3. Longitudinal Study, 2009—2012 (continued)

Student recommendations:

“What I wish for would be understanding rather than specific actions”

“Assume nothing. If I am anything to go by”

“Remember empathy goes two ways”

4. Engaging academically

Participants related their experiences and difficulties concerning transition between levels of study, pedagogy, assessment, teaching and learning.

Pertinent quotations:

“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 can result in tasks taking longer than would normally be expected.”

“I want to understand everything on a topic so I need to read every book that I can find that's got something on it. I suppose that it is not a bad thing to read lots of stuff but this has caused me difficulties and taken up more time.”

‘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.’

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

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

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

‘Student recommendations:

“It helps to have a mentor who is knowledgeable in my subject, having an understanding Director of Studies, having a contact at the Disability Resource Centre 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 counterproductive.”

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

3. Longitudinal Study, 2009—2012 (continued)

Ten points of good practice

Study participants were asked to build on their observations, comments and initial recommendations by contributing to the creation of a ten point good practice document for higher education institutions (HEIs). 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 following recommendations for HEIs are presented here:

- 1 Provide opportunities for students to discuss what would be helpful to them before starting University and establish support arrangements as early as possible.
- 2 Prospective students should be encouraged to attend open days and transitional support events to familiarise themselves with the collegiate university environment, in order to aid transition into Higher Education.
- 3 Provide support to identify and secure appropriate accommodation for the duration of the course.
- 4 Aim to schedule all regular teaching/supervisions at the same time/day each week to create structure and routine.
- 5 Provide access to quieter and less sensory overwhelming careers events and ensure access to specialist careers advice that provides practical advice for disabled students regarding sustainable employment.
- 6 Ensure that supervision/tutorial groups are as small as possible. Large groups are hard to socially navigate and become overwhelming and unproductive.
- 7 Advise lecturers and other staff that ambiguous language can hinder effective communication. Metaphors, humour, irony may not be understood. Where possible, use clear language with concrete examples.
- 8 Arrange living accommodation to minimize noise and social intrusion whilst avoiding isolation by matching student interests or preferences.
- 9 Use explicit written feedback. Provide constructive criticism and examples where possible.
- 10 Ensure advice is consistent.

3. Longitudinal Study, 2009—2012 (continued)

Recommendations

The following recommendations were recorded and developed by the AS Project Officer and steering group members from study participant feedback concerning the challenging aspects of the student lifecycle from pre-entry to graduate progression.

It is acknowledged that some of the support and adjustments recommended herein may already be part of existing policy and practice. However, the feedback from study participants suggested that individual experiences differed radically depending on the specific academic context within which they found themselves. Further guidance for staff supporting students with Asperger syndrome is also included in Appendix I.

Many of the recommendations are very straightforward and describe inclusive practice which would benefit all students, not only students with Asperger syndrome.

Ten common topics emerged from the student responses:

1. Transition and Planning
2. Accommodation
3. Institutional Communication
4. Role of Student Services (including Disability Services)
5. Mentoring (including Peer mentoring) and Study Skills
6. Learning and Teaching
7. Diagnosis
8. Mental health
9. Socialising
10. Transition into employment

Recommendations reflect the student life cycle from pre-entry to post exit and are underpinned by the understanding that all individual students with AS at Cambridge are necessarily high achievers (even though many do not see themselves in such a positive light). There is no such thing as a one size fits all approach and student requirements may well change over time as the demands of the course alter and as things become more familiar and settled.

All recommendations made here presume open discussion with the student concerned and a commitment to sensitive delivery of services which are reliable, empathic, anticipatory and logical. Reliability is the corner stone of all services as students with AS often find unpredictable change difficult to navigate. Empathising with the way the student is experiencing the university is necessary in order to understand and anticipate their concerns. Anticipating, for example, that the social environment may well cause anxiety can lead to subtle and helpful changes to promote social inclusion. Logical clear and positive communication helps students to understand what is expected and therefore to be able to engage more productively. The acronym REAL (reliable, empathic, anticipatory, logical) is applicable throughout all the following recommendations.

3. Longitudinal Study, 2009—2012 (continued)

1. Transition and Planning

- The pre entry phase can feel extremely lengthy to incoming students with AS and this can lead to increased anxiety. Keeping in touch with students, or giving them an easy way to reach a member of DRC/College contact to ask any questions once they have been offered a place can help alleviate this anxiety. It is helpful to tell the student that they can ask about anything.
- Widening participation activities should be mindful of and positive towards the requirements of disabled students. Disabled student ambassadors could help to communicate this message. It is impossible to know how many prospective students are put off at an early age because they have never felt 'good enough' to think about Oxbridge.
- It is easy to celebrate diversity and give the impression of problematising disability at the same time. Students with AS often have low self esteem, even if they are very high achievers. It is very important to acknowledge success and make them feel extremely welcome.
- Students who had to unravel early negative experiences suggested that getting it right early on can set the tone for on-going productive engagement.
- A positive welcoming approach, reflected in university literature and interactions with people can set the tone for developing a sense of belonging.
- Provide taster days for prospective students across all subjects, with current students having a key role.
- Ensure explicit pre-entry information is widely available, and includes clear guidance on all relevant services which explains what each can provide and how to access the key contact. (Services should not be limited to those aimed at disabled students.)
- Offer meetings between new students with AS and their college tutor and/or Director of Studies before the start of term. (Ensure that staff are adequately briefed in advance.)
- Establish guidance appointments with a Disability Adviser as early as possible, to discuss support requirements and set up services accordingly.
- Encourage students to apply for DSA as early as possible, e.g. 6 months before their university start date. Provide easily accessible clear information about DSA.
- Understand that Fresher's Fair is an opportunity to join in with a wide range of activities but may well be inaccessible to students with AS because it is usually too noisy and crowded. Implement a quiet hour at the start of each day of Fresher's Fair. For example, turn down/off the music, and/or limit the number of people in at one time.
- Offer to provide a Fresher's buddy who can help navigate Fresher's Fair (including a pre-planning session if required). Understand that some students with AS have experienced bullying and social exclusion in the past and may well be nervous about social contact.
- Provide a wide variety of induction and fresher's activities, for example, include some activities that don't involve crowded chaotic venues, or alcohol.
- Clubs and societies provide valuable opportunities to interact around a theme (e.g. chess).
- Activities such as swimming or rowing can provide opportunities to interact socially within very clear parameters and can be helpful. Exercise promotes wellbeing.
- Don't wait until later in the programme to introduce available services from beyond DRC. Make information about all services easily available.
- Provide, from an early stage, specialist advice and guidance for students with AS and disabled students as part of the Careers Service.

3. Longitudinal Study, 2009—2012 (continued)

- Raise awareness of disabled graduates' experiences. Connect with students and graduates nationally, as well as employers and professional bodies who are already active in this area, for example, the Institute of Physics, Barclays, Goldman Sachs. Provide case studies of graduates' experiences.
- 2. Accommodation**
- Ensure clear application processes for student accommodation. Include information on how rooms are allocated and opportunities for students to discuss access requirements at an early stage.
 - Provide visual information, such as a virtual tour, about accommodation so the student can get a sense of how it looks.
 - Consider favourably requests from students with AS to keep the same room for the duration of their course.
 - Recognise when determining room allocation that en-suite rooms and rooms on quieter corridors/halls of residence can be of benefit to students with AS.
 - Ensure the annual allocation of suitable student rooms provides equal opportunities for all students. Some systems can favour students already in friendship groups and not those who apply independently, for example.
 - Be mindful that some students with AS, while being academically brilliant, may not have excellent life skills such as cooking, shopping etc. Provide clear, non patronising, advice and guidance as necessary. (This may well be helpful to other students who are away from home for the first time.)
- 3. Institutional Communication**
- Link from all college and department webpages to the DRC under the list of student services. Avoid contradictory information in different parts of the website.
 - Ensure that the University prospectus and other guidance documents, for example the Parent Guide, include information informed by recognised good practice in respect of disabled students. All information should be positive about disability as a valued diversity characteristic.
 - Information about the university should include practical advice about, for example, registering with a GP and dentist.
 - Establish a forum for staff and students conducting disability related research to network and share professional expertise across the institution and nationally with the Disabled Education Research Network (DERN).
 - Ensure key contacts' roles are clearly defined for new students, including student roles like 'college parent', for example.
 - Develop close communication between the DRC, Admissions and Widening Participation teams to facilitate useful information reaching the widest pool of talented applicants, including those with AS. Emphasise a positive attitude towards students with AS.

3. Longitudinal Study, 2009—2012 (continued)

- Develop close working relationships between Disability Advisers and academic departments. Focus on sharing information, developing knowledge between departments and the disability service, and maintaining effective student focussed working relationships
 - Ensure that all forms and documents are relevant, inclusive clear, explicit and logical.
- 4. Role of Student Services (including Disability Services)**
- Establish and maintain clear lines of communication between Disability Advisers and colleges/ departments for the discussion of student support requirements. Make confidentiality protocols clear.
 - Establish a working group to continue to implement recommendations and build upon the work of the Cambridge AS project.
 - Continue to promote understanding of the Social Model of Disability.
 - Provide a clearly signposted welcoming and open entrance to student services. Ensure that the layout is designed to avoid confusion and maximise clarity about what to do when entering the department.
 - Consider informative, inclusive and non stigmatising alternatives to current departmental names. Feedback highlighted that many students experience discomfort (therefore avoid) or simply don't identify with the current terminology, i.e. 'Disability Resource Centre'.
 - Employ a specialist Adviser for students with Asperger syndrome/autism.
 - When students book guidance appointments via reception record pertinent information about the reason for booking and ensure that Advisers have relevant background information in preparation for an appointment.
 - Provide a two-tier advice service.
 - * Offer speedy initial advice and guidance to students making enquiries at the DRC.
 - * Provide on-going advice and guidance appointments as a key second tier.
 - Assess and anticipate support requirements and provide clear and pragmatic advice and guidance in order to reduce the likelihood of future crisis or difficulties.
 - Advertise and provide regular focussed drop-in in sessions on relevant topics such as applying for DSA or exam access arrangements.
 - A student's support recommendations need to be clearly and explicitly communicated to academic staff. Open lines of communication for liaison between student services and academic staff need to be maintained. A widely used method for communication support recommendations is a Student Support Document produced by University Disability Advisers. Revisions should be updated on the student's support document with their approval at any point during their course. Confidentiality needs to be explicit.
 - Ensure the case management database of student records is easy to navigate and aids the Student Advisers to access information and data efficiently and effectively. Required information should include individual appointment logs recording the date and purpose off all appointments booked/attended.
 - Missed appointments should be recorded and trigger an invitation to rebook.

3. Longitudinal Study, 2009—2012 (continued)

- Establish key DRC team contacts for work relating to different stages of the student life cycle, including pre-entry, graduate transition/careers, and placements/internships. Enabling close working relationships with other services and sharing of information/expertise, which respects boundaries of confidentiality.

5. Mentoring (including Peer mentoring) and Study Skills

- Provide peer mentoring schemes for new students with mentors from years above within the same college and/or department. Enable contact before the start of term.
- Make online mentoring available for students who prefer this form of communication.
- Provide clearly defined role (task) descriptions for non-medical assistants (NMAs).
- Provide information explaining how and why mentoring and study skills tuition can support a student with AS. Emphasise individuality.
- Consider individual students' support requirements as part of the NMA matching process. Feedback from students often indicated a preference for someone close in age who looks more like a peer than an assistant.
- Ensure there is a mechanism to record and regularly feedback details of mentoring support sessions to the DRC from the student and mentor.
- Recruit mentors and study skills tutors with knowledge and experience of working with students with Asperger syndrome, an understanding of the social model of disability, and a commitment to being reliable.
- Advertise for new mentors via local NAS services, autism specialists and possibly universities that offer courses on autism from a social model perspective (e.g. Birmingham, Sheffield Hallam, Strathclyde, IOE).
- Share resources between HEIs relating to non-medical helpers (NMH) schemes. Including examples of mentor handbooks, NMH policy, role descriptions, student feedback, duty of care policy, guidance on boundaries and research into good practice.

6. Learning and Teaching

- Understand the various roles and local systems particular to your institution and their boundaries.
- Provide timetables as far in advance as possible.
- Allow online sign up to course modules/sessions.
- Make available where possible drop in locations for students that are calm and provide minimal sensory stimulation. This could possibly include a room in the department, tutorial or college nurse's room.
- Utilise specialist services within your institution, i.e. Disability Advisers, guidance documents, on-line training.
- Try and ensure that supervisions/tutorials/lectures are scheduled at the same time and day and location, where possible, and if not possible ensure this has been clearly communicated. Avoid 'special' communication—the whole student body needs routine access to this sort of information.

3. Longitudinal Study, 2009—2012 (continued)

- Do not assume that everyone with AS is the same – if you have met one person with AS you have met one person with AS. Women may present differently from men (and within genders differences are also to be expected).
- Describe clear boundaries around roles and be reliable and consistent.
- Advise in advance of any changes to any sort of arrangements in anticipation that unpredictable change causes distress. Communicate clearly.
- Further recommendations related to learning and teaching can be found in the Guidance document in Appendix I.

7. **Diagnosis**

- Be very clear about availability and cost of diagnostic resources (including post diagnostic support) in your area before making any promises to students.
- Be aware that some students may have had a diagnosis in childhood that they may not longer feel comfortable with.
- Take your lead from the student when approaching discussions about the AS label and diagnosis.
- Students without a formal diagnosis (or who do not wish to pursue diagnosis) can still be supported effectively.
- Monitor referrals for diagnosis of autism/AS for students at university, including numbers and waiting times
- Train Disability Advisers to enable them to make referrals for diagnosis to specialist clinics or GPs as appropriate.
- Diagnosis is a process not an event. Be aware that initial relief at a formal diagnosis can give way to anxiety. Post diagnostic support is necessary as questions/concerns can emerge at any time.
- Incorporate the views and support requirements of HE students in the local/national development of post-diagnostic support. Work with local diagnostic clinics (e.g. CLASS) and NAS services to ensure students' views are represented.

8. **Mental health**

- AS is not a mental health difficulty but secondary mental health problems such as anxiety and depression can occur. These secondary problems can be largely avoided through anticipatory adjustments and inclusive practice (while acknowledging that academic life of itself can be inherently stressful).
- In-depth interests are common and can be highly motivating. The in-depth interests of people with AS should not be confused with OCD.
- Adherence to 'sameness', i.e. resistance to change and perfectionism can be an anxiety response. Much anxiety is avoidable in a reliable, empathic, anticipatory and logical environment.
- Solution-focussed counselling such as CBT may be more appropriate than psychodynamic counselling. Social isolation can be a cause of depression which can be addressed through social inclusion.

3. Longitudinal Study, 2009—2012 (continued)

- Periods of high anxiety will fluctuate and change in reaction to circumstances. Anxiety around transition is to be expected but can be minimised.
- Do not assume that appropriate and effective services are available beyond the university, or that interventions within university need to be complex and costly.

9. Socialising

- Be aware that some people like their own company and prefer interacting on-line rather than face-to-face (also that this can change over time).
- Not all social experiences need to revolve around drinking and noise – provide alternative events/opportunities, e.g. socialising around exercising.
- Freshers' Fair can present extreme sensory overload and help to access clubs and societies via a calmer entry point may be required.
- Previous experience of bullying is common and has a long term effect.
- Structured opportunities to socialise around a theme (clubs, societies) can be very helpful.
- Social groups around a theme, such as chess or swimming, provide opportunities for interactions which are structured and unambiguous.
- The sensory environment is important – pubs and clubs for example may be too crowded and noisy.
- Training and information for student peers acting in supporting roles needs to emphasise individuality of people with AS and the requirement for peers to be reliable (e.g. College parents, peer mentoring).

10. Transition into employment

- Start to plan early. Introduce students to careers services early in their programme.
- Provide a 10 point guide to actions a student should take before they leave university, made available to all final year students. Ensure students are clear about additional tasks including leaving a forwarding address or email address.
- Collaborate with Careers Service to develop careers module for students with AS (see Cambridge example, appendices III, V, VI).
- Address gaps in CVs by looking at internships (employability) – linking to specialist services e.g. Prospects. Identify and emphasise strengths.
- Assist graduates with AS to identify relevant experiences and skills to include within CV.
- Provide assistance in preparation for interviews, and explore alternatives to interviews such as work trials where appropriate.
- Ensure that support provision in HE is mirrored in employment (e.g. Access to Work, Prospects) – do not assume support will be automatic – plan and prepare.
- Think creatively about employment options, e.g. self-employment.
- Help the student to negotiate the social environment of work, e.g. via personal statements / mentor support.
- Facilitate work trials/placements, where appropriate.

4. Further Research Opportunities

Further opportunities for research have been identified by the study, including an exploration of:

- The impact of early and anticipatory support in relation to student crisis/drop-out rates.
- The value of a gap year in gaining employability skills and experience of team/group work.
- Disabled graduate transition, tracking progression, developing good practice and how expertise from HE disabled student support can be transferred into employment.
- What are the influencing factors in decisions concerning disclosure; what gives students with AS the incentive to disclose?
- An analysis of the reported low employment and under-employment figures for graduates with AS/autism.
- Post diagnostic support. What do adults with a recent diagnosis of AS/autism want in terms of service and support. What are their experiences of receiving a diagnosis in adulthood?
- Gender and Asperger syndrome.
- The impact of the changes to autism and Asperger syndrome diagnostic criteria in The American Psychiatric Association (APA) Diagnostic and Statistical Manual (DSMV).

5. Conclusions

The University of Cambridge Asperger Syndrome Student Project came to an end in September 2012. Over the lifetime of the project significant developments to services available to students with AS, or those seeking diagnosis were made. (Examples include development of Student Support Documents, running of Transitional Events for incoming students, and establishment of a fast-track diagnostic route to CLASS.) Resources, materials and training courses were developed (such as the highly successful and nationally recognised careers training course for student with AS). A successful AS Social Group was established.

Other in-house outcomes included the development of resources for staff supporting students with AS, including a film entitled '*Alison's experience*' highlighting the experiences of a Cambridge student with AS, '*Teaching students with Asperger syndrome*', a training course for academic staff delivered by the DRC, and specific training for the Disability Advisers at the Disability Resource Centre. Other materials and resources developed during the project will be made available on the DRC website during 2013.

The project also developed a model of best practice and through the contributions of its student participants an important series of observations and recommendations from those with direct experience of being a student with Asperger syndrome. Innovations from Cambridge have exerted influence across the sector leading to national and international work aiming to improve the university experience of students with AS.

The challenge now is to continue and sustain the work started by the project, to implement the recommendations effectively, secure funding to produce the on-line model of best practice tool, and to continue to promote an inclusive agenda, challenging current thinking and identifying and overcoming barriers for students with AS/Autism. Transforming evidence-based research into practice is essential. Good practice for students with AS is often straight forward and logical, therefore it could be considered as good practice for all.

As Beardon, Martin and Woolsey put it, 'valuing diversity necessarily involves a degree of sensitivity from individuals and a cultural shift from the top away from tolerating, to facilitating, towards valuing' [18].

[18] Beardon, L, Martin, N, Woolsey, I (2009) 'What do students with AS and HFA want at college or university –in their own words'. GAP.10-2. 35-43

6. References

- Beardon L, Edmonds G (2007) 'The ASPECT report. A national report on the needs of adults with Asperger syndrome'. www.shu.ac.uk/theautismcentre
- Beardon L, Martin N, Woolsey I (2009) 'What do students with AS and HFA want at college or university –in their own words'. Good Autism Practice (GAP) .10-2. 35-43
- Ehlers and Gillberg (1993) 'The epidemiology of Asperger syndrome. A total population study.' J Child Psychol Psychiatry. 1993 Nov;34(8):1327-50.
- Fidler and Britton: Compendium of effective practice in higher education retention and success, Higher Education Academy (2012), Students with Asperger's syndrome: a pre-entry induction programme—Rob Fidler and Jan Britton, University of Surrey
- Hastwell, Harding, Baron Cohen and Martin. 'Giving Cambridge University students with Asperger syndrome a voice. A qualitative, interview-based study towards developing a model of best practice for students with Asperger syndrome/autism in higher education'. Good Autism Practice (GAP, 13,1, 2012), p 56-63.
- Madriaga M, Goodley D, Hodge, N, Martin N (2008) 'Enabling transition into higher education for students with Asperger syndrome' HEA www.heacademy.ac.uk
- Martin N.(2008) 'REAL services to assist university students who have AS'. NADP 4/2008
- Martin N (92010) 'Minimising the stress of the PhD viva for students with Asperger syndrome'. GAP.11 -1.52-58

Web Resources and data

- The Autism Act 2009: www.legislation.gov.uk/ukpga/2009/15/contents
- Autism Education Trust: <http://www.autismeducationtrust.org.uk/good-practice/written%20for%20you/parents-and-cares/pc%20transitions.aspx>
- The Autism Strategy: www.autism.org.uk/working-with/autism-strategy.aspx
- Equality Challenge Unit. Equality in higher education: statistical report 2011, Equality Challenge Unit (2011): <http://www.ecu.ac.uk/publications/>
- The Government Equalities Office: 'Equality Act 2010: What do I need to know? Disability Quick Guide' http://sta.geo.useconnect.co.uk/equality_act_2010/equality_act_2010_what_do_i_n.aspx
- The Higher Education Academy: The Higher Education Academy, Psychology Network, Inclusive Practice, 2011 e-bulletin <http://www.psychology.heacademy.ac.uk/networks/sig/>
- Higher Education Statistics Agency: <http://www.hesa.ac.uk/index.php/content/view/1973/239/>
- National Audit Office. Supporting people with autism through adulthood, REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 556 Session 2008-2009 | 5 June 2009, <http://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>
- NADP Template 1/2008: A template for improving provision for students with Asperger Syndrome in further and higher education, <http://www.nadp-uk.org/resources/publications.php/>
- Proposed changes to diagnostic criteria: <http://www.autism.org.uk/about-autism/all-about-diagnosis/proposed-changes-to-autism-and-as-diagnostic-criteria.aspx>

Visual resources

- Interview with Joanna Hastwell, Asperger Syndrome Project Officer: Available on line via membership of Network Autism, <http://network.autism.org.uk> , or via http://www.youtube.com/watch?v=L6MvbH9cpbY&feature=player_embeddedhttp://network.autism.org.uk
- Alison's Experience: <http://www.youtube.com/watch?v=C3bqulXKu3Y>

Appendix I: Guidance for staff: Supporting Students with Asperger Syndrome / Autism

This guidance document contains information on the best ways to support a student who has disclosed Asperger syndrome (AS) / autism.

Key support actions

Students with AS are better able to study in an environment which is an enabling social and educational one, where the barriers to access and achievement are removed. By observing the following principles when working with students with AS/autism, students are more likely to succeed.

Be:

Reliable
Empathic
Anticipatory
Logical

REAL (*Martin, 2008*)

Be Reliable, avoid over-promising and therefore under-delivering, say what you mean, and mean what you say.

Empathise with the individual's perspective in order to understand the person and avoid reacting to preconceived or stereotyped ideas.

Anticipate that new situations and unpredictable changes, and previous negative experiences, may cause increased anxiety.

Be Logical. Use unambiguous and explicit detail when communicating and don't expect the unsaid to be known. Inferred meanings or understanding can often be missed altogether or misinterpreted.

What is Asperger syndrome / autism?

Asperger syndrome (AS) and autism are known as autistic spectrum conditions (ASC). 'Autistic symptoms' were described by the Austrian paediatrician, Hans Asperger, in a landmark paper published in 1944. People with AS have average or above average intelligence. AS is considered a Neuro-Diverse profile categorised by differences to the Neuro-Typical (NT) profile, occurring in the following areas:

- social communication and interaction
- verbal and non-verbal communication
- imagination and flexibility of thought
- sensory - hyper or hypo sensitivity

Appendix I (continued)

Students with AS/autism often come into higher education having exceeded other people's expectations. They often come with some negative experiences arising from barriers they have encountered and possibly some trepidation about being viewed as a stereotype or being socially isolated. When discussing stereotypes of people with Asperger syndrome a student explains that;

“From a superficial understanding, autistic people would look like a machine, not interested in the other people, which was actually my first impression of what autism would be like (I think this is mainly the reason why I never speculated I might be autistic). I think this actually shows how subtle AS really is, and indeed, one autistic person will be entirely different to another.” [1]

Communication

A person with AS/autism may process language literally and may have difficulties interpreting non-verbal forms of communication such as facial expression, body language and tone of voice. It is helpful not to presume that a person knows what is unsaid.

For someone with AS, being able to understand accurately interactions that have many layers of meaning, such as metaphor or sarcasm, maybe difficult. For example, saying sarcastically 'this is a really good book', when it isn't, may be confusing for some people. Ambiguous information, for example, giving an assignment brief which is not expressed clearly, could cause confusion and be a barrier to demonstrating their full potential.

A person with AS/autism may have difficulty with cognitive empathy, identifying another person's state of mind, their thoughts and feelings or seeing the world from someone else's perspective. As a result of this, a person with AS/autism may have to make assumptions or may say things that appear strange, rude or insensitive. It is very likely that it is not their intention to cause offence, and considering the intention of the person is helpful before reacting or responding.

People with AS/autism, as people without autism, are all profoundly different from one another in terms of their sensory and emotional responses. People with AS/autism are often very motivated to want to help or offer comfort to another person. A growing number of studies suggest that a person with AS/autism, is likely to have good affective empathy. This refers to the drive to respond with an appropriate emotion to another person's state of mind, and people with AS/autism will often feel upset themselves if they're told they have upset or hurt someone, unintentionally.

Experiencing confusion due to different social interaction and communication can mean that forming and maintaining relationships can be challenging. For example, going for coffee with the rest of a peer group may be difficult the first time, despite the student really wanting to join in and fit in. Help in developing social networks, particularly with people with similar interests, is often welcomed. Online interaction can be a more comfortable starting point for some individuals with AS/autism.

[1] Cambridge AS Project, 2013.

Appendix I (continued)

Flexibility of thought

A person with AS/autism may work best when thinking in concrete ways and may find it harder to imagine abstract ideas. For example, imagining new situations such as starting university, moving year groups, going on placement, or life after university can be difficult without knowing what to expect and therefore can be anxiety provoking. Planning for periods of transition is advisable and considered good practice.

A person with AS/autism may have particularly narrow or specialist interests. Such interests can be for subject areas that a student is reading at university, and therefore can enable a high level of knowledge and achievement in higher education.

Due to repetitive behaviour or a possible preference for structure or predictability, a person with AS/autism may appear rigid and inflexible. Therefore, they may be particularly unsettled by sudden and unexpected changes to familiar routines (a timetable change for example), or changes in their environment or by people being unreliable or thoughtless (e.g. not letting them know that arrangements have been altered). They may have an unusual and interesting learning style which will really add something to group interaction and work.

How does Asperger syndrome / autism impact on study?

Each person with AS/autism is different and should be treated as an individual. Support is put into place for students depending on their areas of strength/ability and the barriers that exist in their environment.

The impact of AS/autism will vary from individual to individual and will depend on a range of factors, including: the time since diagnosis, the range of strategies that they have developed, the environment the person is in and the support that is available to them.

Some students with Asperger syndrome/autism may:

- be highly motivated and conscientious
- be extremely interested in their chosen subject or hobbies
- be socially inexperienced or feel isolated from peers
- lack knowledge about how to manage away from home and in a new environment
- have poor co-ordination or fine motor skills
- use very precise, literal language
- find people who are unclear with their use of language confusing
- show a lack of facial expressions, avoid eye contact and/or speak in a monotone manner
- experience sensory overload on a daily basis
- experience difficulties when faced with too many choices
- develop individual coping strategies over time
- find it hard to manage multiple demands at once
- not infer meaning or misinterpret communication that is ambiguous
- find socializing in groups anxiety provoking and/or uncomfortable
- find it hard to adjust to unexpected changes
- find it hard to accept there may be more than one perspective

Appendix I (continued)

Supporting and teaching students with Asperger syndrome/Autism

The guidance below aims to avoid a single prescriptive approach, and instead offers a student-centred, flexible range of strategies to explore. When working with a student with AS/autism it is important to remember that every student is different, and the best approach is to speak directly with the individual in order to get to know them, communicate effectively, and not to let assumptions get in the way:

- Appreciate that having AS/autism can make life a lot more challenging. Be reliable, clear, sympathetic and encouraging
- Speak clearly, using concrete rather than abstract terms; fact as opposed to fiction. Check understanding. Avoid metaphors, double-meanings, sarcasm and irony if these seem confusing to the student. Avoid being patronising. Say what you mean and mean what you say
- A person with AS/autism may not pick up on non-verbal cues, such as looking at the clock or shuffling. Therefore it is important to be straightforward; e.g. 'I am busy now, could you come back at 2pm?'
- Be aware of distracting external stimuli, such as people talking and buzzing or humming machines. Speak to the student in a quiet environment, or a place the student chooses, wherever possible
- A student with AS/autism may assume that you know what they know, for example, that they were sick and thus did not hand their work in. They may not offer an explanation. Empathise and anticipate.
- If you need to cancel an appointment or make a change to their schedule in any way, ensure that the person is aware of this. Preferably do this in writing or by email. Even if it seems minor to you, unpredictable change can be very upsetting.
- If a student with autism or AS is exhibiting behaviours that you find challenging, be aware that it is very unlikely that their intention is to be challenging. It is more likely to be a manifestation of social awkwardness, stress anxiety and confusion.

Inclusive Practice

What do we mean by Inclusive Practice?

'Focusing on an inclusive approach means that student entitlements have been designed into plans and activities from the outset. As opposed to integration which applies to the assimilation of students into a pre-existing arrangement' [2]

'Integrating disabled students / students with neuro-diverse profiles involves for example; making ad hoc changes to teaching so that they can access what has not been designed from the outset with their needs in mind' [3].

'The diversity of the student population is increasing, with greater proportions of disabled students,

[2] HEA, 2011.

[3] Ibid.

Appendix I (continued)

mature students and international students entering higher education each year. *HEA, Psychology Network* suggests this increasingly diverse student population ‘calls for the adaptation of our teaching, learning, curriculum and assessment methods in order to ensure that all students are able to experience success in HE and achieve their full potential.’ [4]

Many principles of inclusive practice are beneficial for students with AS/autism. Inclusive practice means consideration will have been given to the impact of teaching activities on disabled students and will aim to reduce the number of needless barriers they encounter.

By identifying and using evidence-based good practice guidance for students with AS/autism we are able to consider current practice and a wider application of this evidence base.

Students with AS are better able to study and to achieve if they are enabled to work in an organised and well planned way, where teaching expectations are clear and well defined, and where the student is enabled to manage and organise their work load and their leisure time effectively and predictably. An environment which does not enable a student in this way will become stressful and will cause anxiety which will in turn have a negative impact on the student’s retention and attainment at university.

Below are some examples of teaching and learning practice which is considered as good practice and inclusive of students with AS/autism:

Supervisions, Tutorials, Seminars

In supervisions, consider the following:

- Expectations need to be clear and well defined, e.g. what is expected from a piece of work in terms of the level of detail and expected focus or route to take
- Provide directed reading lists in advance, i.e. with the most relevant/essential texts identified at the top of the list for each assignment/essay/ or /module to avoid reading of the entire list in great detail
- Written (typed if possible) feedback detailing what the student has done well and why, as well as what he/she needs to develop and how
- Anticipate that students who identify with AS/autism work best in a structured environment
- When setting a new task, modelling the task by giving detailed instructions about how to approach it, what is involved and using examples helps to make expectations clear and reduce anxiety of the unknown
- Providing a mark (e.g. out of 10, a class mark or percentage) can be helpful as it is measureable, whereas ‘good’ can result in uncertainty
- Regular meetings with staff, including supervisory or teaching staff/Director of Studies at the same time each week/fortnight/month, helps to establish a manageable and predictable routine and to enable difficulties to be addressed prior to them reaching a crisis

[4] *The Higher Education Academy, Psychology Network, Inclusive Practice*, 2011 e-bulletin <http://www.psychology.heacademy.ac.uk/networks/sig/>

Appendix I (continued)

Lectures

In lectures consider the following:

- Students will benefit from copies of PowerPoints/hand-outs in advance, preferably via email or accessible online. This will provide an opportunity for prior reading and assimilation, enabling the student to become more familiar with the content of the lecture in advance, support their note taking strategies and organisation of material
- Key terms/information should be clearly identified e.g. via hand-outs or signposted in lectures. This will ensure such information is not missed due to difficulties reading non-verbal communication and ambiguous verbal communication
- The use of unambiguous and explicit carrier language is essential to avoid misinterpretation or confusion in lectures and examination papers. If examples are expected to be included in a student's exam answer then explicit language to make this expectation clear for each exam question it applies to, should be included. For example 'use examples to explain your answer'. This will help avoid questions being taken literally and therefore answers being too short to demonstrate full knowledge.

Practical sessions

In practical sessions consider the following:

- Written instructions about practical activities are helpful to support verbal instructions and working memory
- Clear ground rules or an agreed way of working when in a group situation. These should be established as ground rules for all members and not single anyone out.

Transitional support

During times of transition, e.g. pre-entry, changing year groups and graduate transition, consider the following:

- Timetables available in advance of the start of term whenever possible
- An opportunity to meet key members of college, faculty or department staff before the start of term may help to reduce anxiety about getting to know and interacting with many new people
- Clarity about the different roles staff, students and professionals have, so it is clear who to approach and how can they help/advise
- A tour of the key locations relevant to the student, before the start of the year is recommended to help with orientation and familiarisation. This helps to build confidence in what to expect when a student starts.

Appendix I (continued)

Libraries

Consider the following:

- Making it clear and explicit who is available to contact for support within the library and what services are available to the student. This will reduce anxiety regarding meeting new people and working in this setting
- Providing assistance to locate and retrieve required books and resources

Examinations and assessments

In examinations students with AS/autism may benefit from the following:

- Extra Time
- Use of a word processor
- Use of a separate room with fewer/no other people and therefore less distraction and sensory overload
- Alternative modes of assessment

Accommodation

In relation to a student accommodation, consider the following:

- An en-suite room where the student is able to manage his/her own sensory and social environment
- A quieter room, but still with the student's peer group is often preferred by a student with AS due to hypo or hyper sensitivity. Sensory overload can increase anxiety and make it very hard for the student to study or relax
- The option of staying in the same room for the duration of the student's course to reduce change related anxiety can be beneficial

Reasonable adjustments

To ensure disabled students have equal opportunities to non-disabled students, higher education institutions (HEIs) have a duty make any additional 'reasonable adjustments' for an individual as required by the Equality Act (2010).

People with AS/autism are better able to study in an environment which is enabling socially and academically, where the barriers to access and achievement are removed. Adjustments are recommended by higher education Disability Practitioners and Disabled Students' Allowances' Needs Assessors.

Appendix I (continued)

Reasonable adjustments for students with AS/autism may include the provision of specialist mentoring and/or study skills support (also known as specialist 1-1 support by Student Finance). A mentor or study skills tutor should be someone who has relevant experience to assist the student in coping with the academic and social demands of university life, while promoting learner autonomy and respecting individuality. Student involvement in the matching process is important.

For example, mentoring and study skills support can be beneficial in the following ways:

- Encouraging and developing learner autonomy
- Identifying periods of stress and developing problem solving strategies
- Developing strategies to help manage workload and organise academic, social and personal tasks/event
- Creating predictability and structure in the daily environment
- Assistance to join in socially and engage with one's interests/hobbies without increasing social anxiety. Positive social experience can increase feelings of acceptance, inclusion and enjoyment of university life. Creating opportunities for 'down time' and having fun or enjoying an interest, can combat loneliness and issues that can occur if a student with AS is constantly studying. This can also help to manage a student's mental health and wellbeing.

The Equality Act (2010) – 'a framework for a fairer future'

The Equality Act (2010) protects people from discrimination and inequality on the basis of 'protected characteristics' which include disability. People with AS/autism are protected under the Equality Act (2010) under the legal definition of disability. There is a legal obligation to make *reasonable adjustments* and not to treat individuals with AS/autism unfavourably.

The act brings together previously separate equalities dimensions and incorporates new strands, recognising multiple identities. It replaces the Disability Discrimination Act (1995), (2006).

The Home Office guidance titled, 'Equality Act 2010: What do I need to know? Disability Quick Guide' provides more information about what to do in order to prevent and address disability discrimination and disability-related harassment when you provide goods, facilities and services. Link: http://sta.geo.useconnect.co.uk/equality_act_2010/equality_act_2010_what_do_i_n.aspx

For more information you can also visit The Equality and Human Rights Commission website for guidance focusing on HEI and the Equality Act (2010) Link: <http://www.equalityhumanrights.com/>.

Appendix I (continued)

The Autism Act 2009

Thanks to a huge campaigner effort and cross-party support in Parliament, in November 2009 the Autism Act 2009 was passed. The act committed the Government to publishing an adult autism strategy to transform services for adults with autism. This commitment was met on 3 March 2010, with the publication of the first ever strategy for improving the lives of adults with autism in England.

The Autism Strategy sets out key actions and recommendations for central Government, local authorities, NHS and Jobcentre Plus, focusing on five key goals:

- increase awareness and understanding of autism
- develop a clear and consistent pathway for diagnosis
- improve access to the services and support people need to live independently within the community
- secure accessible employment opportunities
- enable local partners to develop relevant services to meet identified needs and priorities

In response to the Autism Strategy, the National Audit Office also highlighted education as a key factor in improving the lives of adults with autism. The NAO report (Supporting People with Autism through Adulthood, June 2010), made the following key points in relation to higher education for people with autism:

- University is a major step for young people with autism owing to the change of routine, location and social environment. Without appropriate support they may not fulfil their potential and complete their degree. Between 2003-2008, the number of accepted applicants to higher education with declared autism has risen by 408%, from 139 to 706
- HESA data shows that over half the 1,455 students with autism in 2007-08 received DSA, and students receiving the Allowance are more likely to continue their course. [5]

Students with Asperger Syndrome at elite universities are by definition very high achievers. The NAO report recognises university as a desirable option but this is not currently reflected strongly in The Autism Act and Strategy.

[5] NAO: <http://www.nao.org.uk/publications/0809/autism.aspx>

Appendix II: Role of the project partners

The Disability Resource Centre (DRC)

The University's DRC offers advice, guidance and support to disabled students, and guidance and training to those staff supporting them. In addition, the DRC develops University disability policy and practice in conjunction with the University's Academic Division and promotes disability awareness in conjunction with the University's Equality and Diversity team. Sharing good practice with other Higher Education Institutions (HEIs) and national professional bodies is also an important element of the work of the DRC. This includes close working relationships with The Autism Centre and Disabled Student Support Team at Sheffield Hallam University, The National Association of Disability Practitioners (NADP), the National Autistic Society (NAS) Cambridge branch, the London School of Economics Disability & Wellbeing Service and the University of Oxford.

Cambridge Lifespan Asperger Syndrome Service (CLASS)

The CLASS clinic was established in 1999 at the University of Cambridge with the support of the Three Guineas Trust, one of the Sainsbury Family Trusts, and pioneered 'late' diagnosis of suspected Asperger Syndrome in adults. CLASS is linked to but is independent of the Autism Research Centre (ARC) at Cambridge [1]. In 2012 CLASS was taken over by the NHS Cambridgeshire and Peterborough Foundation Trust and no longer has charitable funding.

The need for a specialist clinic for adults with suspected Asperger Syndrome arose because this condition was only recognized internationally in the 1990s, and thus there is a generation of individuals who may have had Asperger Syndrome that went undiagnosed during their childhood and can only seek a diagnosis for the first time in adulthood. CLASS has developed specialist screening and diagnostic methods (the Autism Spectrum Quotient (AQ), the Empathy Quotient (EQ), and the Adult Asperger Assessment (AAA) to meet this need, all of which have been fully validated and published in peer-reviewed scientific journals.

[1] www.autismresearchcentre.com.

Appendix III: Giving Cambridge University students with Asperger syndrome a voice

Acknowledgements

Funding for this study came from a grant from the Baily Thomas Charitable Fund to the Cambridge Lifespan Asperger Syndrome Service (CLASS) and the Disability Resource Centre (DRC). We are also grateful to the Three Guineas Trust for its support of the CLASS diagnostic clinic in Cambridge, which has had close links with the DRC in Cambridge. Finally, we thank Richard Mills at Research Autism/National Autistic Society for advice and discussions.

‘Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview-based study towards developing a model of best practice’, Good Autism Practice, (GAP, 13,1, 2012), p 56-63.

Joanna Hastwell, Nicola Martin, Simon Baron-Cohen and John Harding, Cambridge UK

Editorial comment

This paper has been written jointly by staff at the Disability Resource Centre, University of Cambridge, the Disability and Wellbeing Team at the London School of Economics and the Autism Research Centre at the University of Cambridge. 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.

Appendix III (continued)

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) [1]. 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 [2]. 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 [3], small-scale studies and individual accounts provide most of the available insider perspectives on experiences of higher education from students with AS [4]. 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 [5]. Principles of emancipatory research [6] 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

- [1] www.hesa.ac.uk
- [2] Martin, 2008.
- [3] Beardon and Edmonds, 2007
- [4] Hendrickx and Martin, 2011.
- [5] Beardon et al., 2009.
- [6] Oliver, 1997.

Appendix III (continued)

obtaining a clinical diagnosis of AS in adulthood [7] 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’ [8] – 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’ [9]. A ‘them and us binary’ is central to the notion of ‘othering’ [10] in which diagnostic labels are used pejoratively [11]. 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.’

[7] Beardon and Edmonds, 2007.

[8] Charlton, 1998.

[9] Arnold, 2003; Beardon and Edmonds, 2007.

[10] Foucault, 1967.

[11] Barnes, 2008; Goodley, 2011; Haller et al., 2006; Richards, 2008.

Appendix III (continued)

'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 [12]. Proposals to absorb separate labels and subgroups into a generic descriptor 'Autism Spectrum Disorder' in the 2013 revision of DSM are currently under discussion [13]. This is causing some disquiet amongst individuals who identify strongly with one label or another [14] 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 [15].

'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

[12] Attwood, 2000; Banton and Singh, 2004; Fletcher, 2006; Nesbitt, 2000.

[13] www.dsm5.org.

[14] www.wrongplanet.net.

[15] Beardon et al., 2009; Madriaga et al., 2008; Shore, 2003.

Appendix III (continued)

age and because of the strenuous efforts of individuals to disguise these [16].

'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.' [17]

'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.' [18]

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 [19]. 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) [20]. The convention of imitating neurotypical (NT) behaviour in order to fit in is increasingly contested by people with AS [21].

'People have to bear in mind that if you have AS you have probably been bullied for most of your life.' [22]

'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.'

[16] Beardon, 2009.

[17] Madriaga et al., 2008, p. 19.

[18] Arnold, 2005, p. 4.

[19] Attwood, 2008; Lawson, 2005.

[20] Arnold, 2003; Beardon, 2008; Shakespeare, 2006.

[21] Arnold, 2004; Beardon, 2009.

[22] ASPECT, 2007:243.

Appendix III (continued)

Ability and interest

Contrary to stereotypes, including ‘Rain Man’ [23] and ‘The Curious Incident of the Dog in the Night-Time’ [24], 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 [25]. Application, in-depth interest, focus and motivation are conducive to academic success and associated with AS. ‘Genius pressure’ however can be unhelpful [26]. Fulfilling in-depth interests are often pejoratively described as obsessions by outsiders [27]. 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.’ [28]

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 [29]. 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.’

[23] Morrow and Bass, 1988.

[24] Haddon, 2003.

[25] Frith, 1989; Grandin, 1996; Murray, 2008.

[26] Baron-Cohen, 2000; Beardon, 2008; Dobbs, 2006.

[27] Arnold, 2003; Baron-Cohen, 2000; Grandin, 2003.

[28] Arnold, 2005, p. 2.

[29] Attwood, 2006; Beardon and Edmonds, 2008.

Appendix III (continued)

'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.' [30]

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 [31].

'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, e.g. eating, travelling etc.'

Sensory challenges

Noisy, over lit, chaotic crowded unpredictable places can trigger sensory overload [32]. 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 [33], 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.'

[30] Madriaga, 2008:26.

[31] 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.

[32] Bogdashina, 2006; ECU, 2009.

[33] Baron-Cohen, 2003.

Appendix III (continued)

'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 [34]. 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 (e.g. imagining other people's thoughts and feelings, including decoding complex facial, vocal, and bodily expressions), whilst they can be intact in 'affective' empathy (e.g., feeling concern for other people's suffering) [35].

Narratives that characterise people with autism as 'laced with strangeness' [36] and emphasise 'deficits' potentially severely damage self-esteem [37]. 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.' [38]

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 [39], 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.'

[34] Baron-Cohen, 2011.

[35] Dziobek et al., 2008.

[36] Stevenson, 2008:201.

[37] Haller et al, 2006; Hendrickx and Martin, 2011; Molloy and Vasil, 2002; Murray, 2006; Peeters, 2000; Valentine, 2002.

[38] ASPECT 2007, p. 14.

[39] ASPECT, 2007; Beardon et al., 2009; Madriaga et al., 2008.

Appendix III (continued)

'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, there are no/few attributes of someone with AS.'

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' [40]. Inclusion involves embedding services which have been traditionally badged as specifically for an identified group to create a sense of ordinariness [41]. Connotations of 'othering' [42] may be reinforced within segregated disability specific services that are counter to the notion of inclusion. Inclusion implies acceptance of the ordinariness of difference [43].

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

[40] Richards, 2008.

[41] May and Bridger, 2010.

[42] Richards, 2008.

[43] Cameron, 2011.

Appendix III (continued)

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.

References

- Arnold, L (2005) *Neurological Difference Page* available from www.larry-arnold.info/neurodiversity/index.htm (accessed 18 April 2012).
- Asperger, H (1944) *Autistic psychopath in childhood*, a translation of the paper by U Frith (1991) (Ed) *Autism and Asperger syndrome* Cambridge: Cambridge University Press.
- Attwood, T (2008) *The complete guide to Asperger's syndrome* London: Jessica Kingsley Publishers.

Appendix III (continued)

- Barnes (2008) Generating change, disability culture and art *Journal of disability and international development* 1, 4–13.
- Baron-Cohen, S (2000) Is Asperger's syndrome/High Functioning Autism necessarily a disability? *Development and Psychopathology Millennium Edition* 489.
- Baron-Cohen, S and Swettenham, J (1997) Theory of mind in autism: Its relationship to central coherence, in D Cohen and F Volkmar (Eds *Handbook of autism and pervasive developmental disorders* (2nd Edition) Chichester: John Wiley and Sons.
- Beardon, L, Martin, N and Woolsey, I (2009) *What do students with Asperger syndrome or High Functioning Autism want at college and university?* Sheffield: Sheffield Hallam University.
- Beardon, L (2008) Is Autism really a disorder part two – theory of mind? Rethink how we think *Journal of Inclusive Practice in Further and Higher Education* 1, 19–21.
- Beardon, L and Edmonds, G (2007) *ASPECT consultancy report: a national report on the needs of adults with Asperger syndrome* available from www.shu.ac.uk/theautismcentre (accessed 18 April 2012).
- Beaumont, R and Newcombe, P (2006) Theory of Mind and central coherence in adults with High Functioning Autism and Asperger syndrome *Autism* 10 (4), 365–382.
- Bogdashina, O (2003) *Sensory perceptual issues in autism and Asperger syndrome: Different sensory experiences: Different perceptual worlds* London: Jessica Kingsley Publishers.
- Bogdashina, O (2005) *Communication issues in autism and Asperger syndrome: Do we speak the same language?* London: Jessica Kingsley Publishers.
- Edmond, G and Worton, D (2005) *The Asperger love guide: A practical guide for adults with Asperger's syndrome to seeking, establishing and maintaining successful relationships* London: Jessica Kingsley Publishers.
- Equality and Human Rights Commission (2006) *Disability Equality Duty* available from www.drc-gb.org (accessed 18 April 2012).
- Frith, U (1989) *Autism: Explaining the enigma* Oxford: Blackwell Publishers.
- Gillberg, C (1989) in L Wing (Ed) *Diagnosis and treatment of autism* New York: Plenum Publishing.
- Grandin, T (1996) *Thinking in pictures and other reports on my life* New York: Vintage.
- Goode, J (2007) Managing Disability: Early experiences of university students with disabilities *Disability and Society* 22 (1), 35–49.
- Goodley, D (2010) *Disability studies: An interdisciplinary approach* London: Sage Publications.
- Haddon, M (2003) *The curious incident of the dog in the night-time* Oxford: David Ficking Books.
- Happe, F, Booth, R, Charlton, R and Hughes, C (2006) Executive function deficits in ASD and AD/HD: Examining profiles across domains and ages *Brain and Cognition* 61 (1), 25–39.
- Haller, B, Dorries, B and Rhan, J (2006) Media labelling versus the US disability community identity: A study of shifting cultural language *Disability and Society* 21 (1), 61–75.
- Hughes, P J (2007) *Reflections: Me and planet weirdo* London: Chipmunka Publishing.
- Jackson, V and Martin, N (2007) Towards a smooth transition into higher education for disabled students in South Yorkshire *NADP News* 13, 23–25.
- Lawson, W (2001) *Understanding and working with the spectrum of autism: An insider's view* London: Jessica Kingsley Publishers.
- Madriaga (2006) *Research report on transition of disabled learners from further to higher education* European Access Network Newsletter 3 available from www.ean-edu.org/news.

Appendix III (continued)

- Madriaga, M, Goodley, D, Hodge N and Martin, N (2008) *Experiences and identities of UK students with Asperger syndrome* available from www.heacademy.ac.uk/events/detail.researchseminar/07feb08.
- Martin, N (2008) *REAL services to assist students who have Asperger syndrome* Northampton: National Association of Disability Practitioners.
- Martin, N (2008) *A template for improving provision for students with Asperger syndrome in further and higher education* Northampton: National Association of Disability Practitioners.
- Murray, S (2008) *Representing Autism: Culture, narrative and fascination* Liverpool: Liverpool University Press.
- Perner, L (2008) *Autism and Asperger syndrome: Personal reflections* available from www.asper.org.
- Purdam, K, Afkhami, R, Olsen, W and Thornton, P (2008) Disability in the UK: Measuring equality *Disability and Society* 23, 1, 53–65.
- Richards, R (2008) Writing the Othered Self: Autoethnography and the problem of objectification in writing about disability and illness *Journal of Qualitative Health Research*, 1717–1728.
- Rosenblatt, M (2008) *I exist: The message from adults with autism in England* London: National Autistic Society.
- Shore, S (2003) *Beyond the wall: personal experiences with autism and Asperger syndrome* Overland Park, KS: Autism Asperger Publishing Company.

Appendix IV: Model of Best Practice: Developing Provision for Students with Asperger Syndrome

Model of Best Practice: Developing Provision for Students with Asperger Syndrome (Cambridge AS Project 2012)

The following model identifies 8 key areas of focus for institutional initiatives concerning the development of effective provision for students with Asperger syndrome. At the time of writing, funding is being sought to develop the model into an interactive on-line resource.

Research

Ensure any research captures the student voice, and tracks the student experience, with a focus on a) what students with AS feel has been positive/helpful, b) negative/unhelpful and c) what would have been helpful/effective practice. Analyse data thematically to inform outcomes and recommendations.

Student Engagement

Ensure student involvement as part of any project or service development steering group. Work with Student Union/student representatives to develop AS social groups or support schemes.

Suggested objectives for support groups or schemes include: improving the student experience; raising the student voice; participation in social activities; sharing interests and hobbies; inviting speakers to the group meetings; meeting other students from a variety of subject areas; developing friendships and support networks.

Develop department/faculty/college voluntary Peer Mentoring (for example matching small groups of students with similar interests or subject areas or postgraduates working with undergraduates).

Training

Provide AS specific training including bespoke support for academic staff, bookable training for academic staff, and specialist input into programmes for new academic staff.

Develop online training materials for key support staff including Mentors and specialist 1-1 study skills tutors, Disability Practitioners, University Counsellors, College Nurses, Supervisors/Tutors.

Develop Inclusive Practice

Develop recommendations which inform and develop policy in relation to inclusive learning and teaching practice. From research, put forward recommendations concerning learning, teaching and services for students in HE.

Develop policy and practice in collaboration with other student services, departments and professional bodies. For example: Admissions and Widening Participation teams, Student Unions, Careers Service, Counselling, Libraries, General Study Skills/Education Advisers, Placement Officers, Academic administration and support services, professional bodies (e.g. NADP), specialist organisations, (e.g. NAS Prospects, Employability).

Appendix IV (continued)

Specialist Information, Advice and Guidance

Enable Disability Advisers to provide specialist information, advice and guidance to staff across the University / Institution about supporting students with Asperger syndrome, including staff involved with the transition into and progression from H.E: admissions, accommodation, freshers' week, graduate transition, the Careers Service and alumni.

Ensure Disability Advisers provide specialist information, advice and guidance for prospective, undergraduate and graduate students and that recommendations for support are made following an assessment of the individual student's requirements.

As standard practice, where resources allow, Disability Advisers are assigned responsibility for work with certain colleges, departments or faculties. This enables understanding and knowledge in that subject area/location and helps academic staff to develop awareness and understanding of disability related matters.

Ensure efficient referrals by enabling Disability Advisers to screen and make referrals for diagnosis, either via the students' GPs or develop working relationships with local clinics/centres.

External Liaison

Share good practice and research finding between Higher Education Institutions. Present at national and international conferences, training events, and work closely with professional bodies across the sector.

Develop external networks between University support services and Schools, FE Colleges and graduate recruiters and employers.

Develop Policy and Procedures

Areas of Focus: admissions, graduate transition, transition between year groups, disclosure, screening, diagnosis, post diagnostic support, mentoring, core information, advice and guidance services, assessment and dissemination of students' support requirements, examinations and assessment, and inclusive teaching and learning practice.

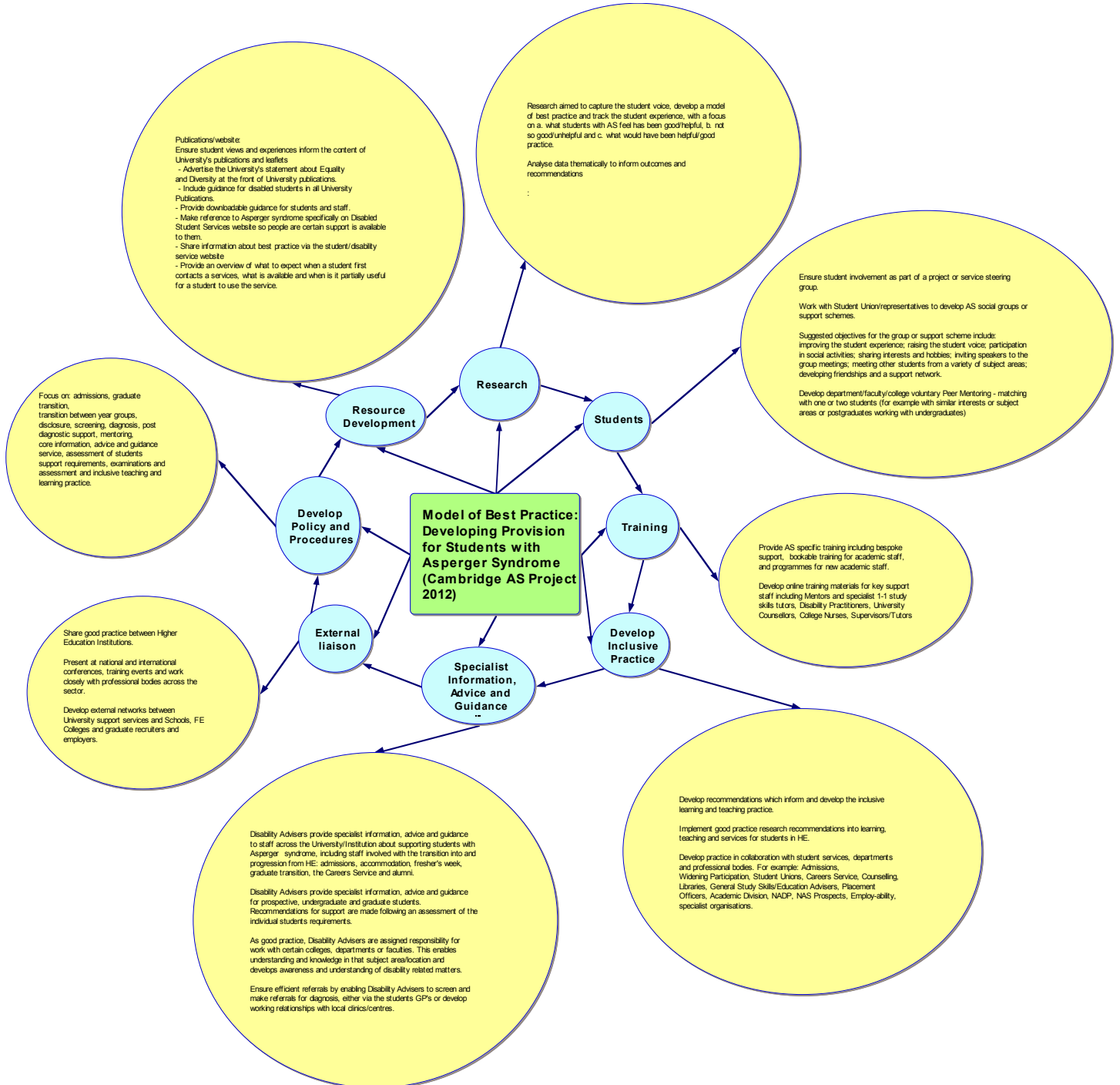
Resource Development

Publications/website:

- Ensure student views and experiences inform the content of University's publications and leaflets.
- Advertise the University's statement about Equality and Diversity at the front of University publications.
- Include guidance for disabled students in all University publications.
- Provide downloadable guidance for students and staff.
- Make reference to Asperger syndrome specifically on Disabled Student Services website so people are certain support is available to them.
- Share information about best practice via the student/disability service website.
- Provide an overview of what to expect when a student first contacts a service, what is available and when is it particularly useful for a student to use the service.

Appendix IV (continued)

Model of Best Practice Diagram.



Appendix V: Careers Service Annual Report Extract 2011-12, University of Cambridge

Our provision for students with disability and long term illness has developed in the past year. In the summer of 2011 we worked on a project to generate case studies representing successful and positive experiences of the transition to the workplace by disabled graduates. These provide positive role models and motivation for this group of students whose anxiety about the move into the workplace can be far greater than for their peers.

In the 2010/11 academic year a series of workshops was initiated, for students with Asperger Syndrome, in collaboration with Joanna Hastwell at the Disability Resource Centre. This has been further developed in response to feedback from that pilot and a series of three workshops is now an established part of the Careers calendar. This is particularly important as numbers of students with Asperger Syndrome disclosed to the DRC has more than tripled in the past three years.

Our work with students with ASD is now used as an example of best practice and the National Autistic Society recently piloted their workshop for Careers Advisers working with Asperger/Autism with our service for this reason.

Currently, when a student discloses to the University on application this is not shared with the Careers Service. We have liaised with the DRC to facilitate the sharing of such information (with the relevant permissions) about new students joining the University and the nature of their disabilities. This knowledge will help us develop our service further e.g. we will know a particular client needs a ground floor meeting room or large print materials for workshops in advance without them having to disclose repeatedly. We will also use this information to encourage early engagement with the Careers Service and, to a certain extent, tailor information they may need e.g. careers opportunities for students with specific kinds of disability.

Many students with disability reach their final year without having accessed the necessary support to get vacation work experiences or internships and so are further disadvantaged in the competition for jobs. In time we will then follow them into the workplace and they may become the role models for future students.

Appendix V (continued)

Review of the Careers Service and AS Student Project, University of Cambridge 2009-12

Key achievements/service development:

- Following the 2010 pilot and the AS Career Transition Programme for students with AS at Cambridge was run for a second year in 2011/12 and be will continued by the Careers Service with support from the DRC from 2012-13.
- Summary of the developments to practice between the Careers Service and DRC have been included in each departments Annual Reports 2011-12.
- Bespoke training – pilot of a national programme run by the NAS Prospects, ‘Understanding Autism Spectrum for Careers Advisers’ was held at the Careers Service in April 2012. This has now been rolled out by the NAS nationally.
- Personal Professional Development (PPD) delivered by the DRC Training Consultant was attended by several Careers Advisers between 2009-12
- Development of close working relationships across departments – acknowledged as good practice by NAS, 2012
- University Careers Advisers have joined the NAS Network Autism, Careers and Employment network group
- Increased the provision of specialist AS advice available to colleagues across the Careers Service by the DRC
- Case work - clear referral routes have been developed between the Careers Advisers and DRC Disability Advisers
- Links with DSA mentors, as well as other professional bodies including Employ-ability, MyPlus consulting and NAS Prospects have been well established for on-going student support and a close working relationship
- Downloadable resources have been developed - including best practice for Interviews, Managing Staff and Transition for Graduates with AS. Case Studies including students with AS have also been collected by the Careers Service and are available on their website
- Key outcome - increased awareness across the Careers Service about the barriers students with AS face and best practice in relation to transition for graduates
- Data sharing between the two services relating to disabled student disclosure has been developed by the DRC and Careers Service to ensure a record of disabled graduates can be accessed in the future. This will start from 2012-13.

Appendix V (continued)

Future development and recommendations in relation to careers advice for students with AS/ disabled students:

- Further research into the experiences of graduates with AS when leaving University, finding work and their careers path. Exploring barriers, what helps and what changes need to be made to challenge stereotypes and ensure fair access to the employment markets for graduates with AS/autism.
- Joint article between NAS Prospects, Careers Service and DRC to be submitted to disability and careers journals (CIPD magazine, UK recruiter, NADP journal, Disability and Society) and other relevant journals
- Joint presentations relating to graduates with AS at national careers and disability conferences/ events
- Development of resources that include more specific details to improve the accessibility of careers advice. For example ‘marking criteria’ for students with AS when producing CV, cover letters, and applications.
- Verbal and written guidance that explains ‘how to apply’ the advice provided by the Careers Service to your situation. E.g. include the rationale, what to do (not just what *not* to do), what to expect when using the service, especially on first contact.
- Raise awareness of barriers and best practice for students with AS in relation to careers and employment, i.e. through case studies highlighting what helped and what the barriers were for each student. Include examples of unclear communication and examples of effective communication e.g. Interviewer asks; “have you got any questions, you can ask up to 3 questions if you would like to?”
- Further develop opportunities for work placements and internships to be secured by students with AS/disabled students
- Disability equality training to be offered to all careers advisers and training on specific learning difficulties, Neurodiversity, inclusive practice and the Social Model of Disability
- NAS Network Autism to share resources and details of recognised ‘autism friendly employers’ with University Careers Service’s and Disabled Student Support Teams
- Identify local employment support organisations to connect with
- Ensure the AS Careers Transition Programme is sustainable for future students
- Continue to collect and use destination data to record disabled students’ progression.

Appendix VI: All graduates with autism need access to good careers advice

Association of Graduate Careers Advisory Services (AGCAS) Phoenix Magazine, Oct 2012 All graduates with autism need access to good careers advice

Autism is a lifelong developmental disability affecting how a person communicates with, and relates to, other people. It is a spectrum condition, meaning that while all people with autism share certain difficulties, their condition will affect them in different ways. However, there are three main areas of difficulty that all people with autism experience – difficulty with social interaction, difficulty with social communication and difficulty with social imagination. Asperger syndrome is a form of autism; people with the condition have fewer problems with speaking than people with classic autism and are often of average, or above average, intelligence.

The difficulties that people with autism and Asperger syndrome face can be a barrier to employment, resulting in only 15% of adults with autism currently being in full-time paid jobs. Statistics for graduates with autism show that the transition between higher education and employment does not run as smoothly as it does for graduates without the condition:

- 26% of graduates with autism are unemployed 6 months after completing their course, compared with 8.8 per cent of non-disabled graduates and 11.4 per cent of disabled graduates as a whole [1]
- Graduates with autism who do find jobs are 7% less likely to end up in graduate level employment than others leaving university [2]

The University of Cambridge started a research project in 2009 to review services and develop a model of best practice for students with Asperger syndrome. Joanna Hastwell, Asperger Syndrome Project Officer said: “The project has enabled networks to be developed across the University, nationally and internationally, which has increased understanding and awareness of the needs of disabled students and graduates.”

Cambridge University currently has 91 students who have disclosed a diagnosis of Asperger syndrome or autism; a number which has more than trebled since 2009. From the 2012-13 intake, 30 new students have disclosed Asperger syndrome on their application and have been made an offer.

The University’s Careers Service (CUCS) works closely with the University’s Disability Resource Centre (DRC) to engage with students with Asperger Syndrome and work with them to help facilitate the transition from University to the workplace. CUCS and DRC have collaborated on a series of workshops which help students to recognise their strengths and skills and present them in applications; research different careers and decide which may suit them; decide whether and how to disclose their condition to employers and discuss reasonable adjustments as well as developing techniques for interview and assessment centres.

[1] AGCAS Disability Task group (2010 -2011). What happened next? A report on the first destinations of 2009/2010 disabled graduates. Sheffield: AGCAS.

[2] Ibid.

Appendix VI (continued)

Following these workshops students said they had 'more confidence to list experiences/skills that they previously thought irrelevant' and found 'the opportunity for discussion was a highlight, as this is something a written guide can't provide'. Students also found the following aspects particularly helpful; 'reassurance that requiring adjustments is not uncommon' and information about the Disability Two Ticks Symbol. Students said they would be happier to disclose to organisations that have the Two Ticks Symbol as well as 'employers who want to recruit people with Asperger syndrome'.

Careers Advisers from CUCS recently took part in a specialist training course with The National Autistic Society's (NAS) employment service Prospects to gain a greater understanding of autism and Asperger Syndrome.

Catherine Alexander, Careers Adviser at Cambridge University Careers Service, said: "We learned so much about the autism and Asperger syndrome that was directly relevant to our day to day work. Many of the techniques in communication and feedback would be helpful for ALL clients, not just those on the spectrum."

Prospects surveyed graduates with autism to find out what issues they had faced when using Careers Advisers. These included the Career Adviser having a lack of understanding of the condition; not being able to spend enough time with the Careers Adviser, and problems with the job match and recruitment process.

In light of this research, Prospects developed a training course focused on developing advisers' understanding of autism and Asperger syndrome and increasing their confidence in working with those with the conditions as well as discussing best practice examples of careers guidance for students with autism. The course also provided an opportunity to talk about some of the barriers to employment currently faced by people with autism and how best to overcome them.

David Perkins, Manager of Prospects, said: "We were delighted with how the course went and we hope that other Universities will be encouraged to take it up. It's essential that all Careers Advisers have a knowledge of autism and are able to provide students with the condition with access to the same level of information and guidance as non-disabled students, thus ensuring their transition between higher education and employment runs as smoothly as possible."

Prospects is running courses open to representatives from all Universities on the following dates:

October 10th 2012 - Manchester

October 17th 2012 - London

If you are interested in attending or would like more information on Prospects' Careers Advisers training course please contact **020 7704 7450** or email prospects@nas.org.uk

Appendix VII: Research project documentation

September 2009

Information Sheet

Research project: Support for students with Asperger syndrome (AS) in higher education

You are being invited to take part in a project co-ordinated by the Disability resource Centre at the University of Cambridge. It is important for you to understand why the research is being done and what it will involve. Please read the following.

Your involvement in this project will include meeting with me for between one to two hours several times in the next year. This interview will focus on your past and present experiences and support as well as your future plans relating to higher education and/or employment.

The aim of this project is to acquire a better understanding of the barriers faced by students with AS. This will therefore inform current practises and policies to support students with AS.

A key aim is to raise the profile of students with AS in higher education and promote disability equality awareness.

All information collected in the interview will be kept confidential. Your confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material. At the end of the project I will write a report. This report will be made available to you.

Because you have agreed to take part in the project please keep this information sheet and sign the attached Consent Form. You are free to withdraw from this project at any time and without divulging reason.

If you have any questions, please get in contact with me.
Email: jlh89@admin.cam.ac.uk Telephone: 01223 746508

Thank you for reading this information sheet.

Kind regards,

Joanna Hastwell

Appendix VII (continued)

Consent form

Research project:

Support for students with Asperger syndrome in higher education

Please initial each box...

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

I agree to take part in the above project.

I agree to the interview being audio recorded.

I agree to the use of anonymous quotes in publications.

Your signature will show that you have chosen to take part in this research project and that you have read and understood the information provided. It will also show that you have been able to talk about the study with the researcher and that you are happy that your questions have been answered.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Please keep copies of the consent form and the information sheet for your information.

Appendix VIII: Conferences, Seminars and Training

Conferences

AS Project steering group members have promoted the project across national and international education and employment conferences.

The project is seen as a model of good practice, receiving positive feedback from staff and students across the FE and HE sector, professional bodies including the National Autistic Society, and graduate recruiters.

Further details of presentations at 23 national and 5 international conferences and events:

2009

The 5th national conference, Autism Today organised by the British Journal of Hospital Medicine, Edinburgh, November 2009

European LINK Network and Skill annual higher education conference, Manchester, November 2009.

2009 annual Society for Disability Studies conference; Arizona University, USA, June 2009

Asperger Syndrome Post-Graduate Certificate course, NAS and The Autism Centre, Sheffield Hallam University, Nov 2009

NAS Scotland Conference, Edinburgh, 2009

UWIC, 2009

2010

Adult Autism Development Project Launch, Cambridge, May 2010

Welfare Seminar, Imperial College London, June 2010

2010 annual Society for Disability Studies conference; Disability in the Geo-Political Imagination, Temple University, USA, June 2010

National Association of Disability Practitioners (NADP) annual conference, Oxford, June 2010

Equality Challenge Unit Annual Conference, London, 2010

Lancaster University Disability Studies Conference, Lancaster, September 2010

7th International Conference on Higher Education and Disability, Organised by the University of Innsbruck and University of New Orleans. July 2010

Goldman Sachs Transition Conference, November 2010

Asperger Syndrome Post-Graduate Certificate course, NAS and The Autism Centre, Sheffield Hallam University, Glasgow, Nov 2010

Appendix VIII (continued)

2011

Asperger Syndrome Student Project Seminar May 2011

DRC and ARC hosted a highly successful and engaging seminar on initial findings of the University of Cambridge Asperger Syndrome (AS) Student Project.

It was attended by a wide range of delegates including staff from professional bodies, academics, HEI Disability Practitioners and those working in Widening Participation.

Keynote speakers:

Professor Simon Baron-Cohen, Director Autism Research Centre
Dr Nicola Martin, Head of Disability and Wellbeing Service, LSE and Chair National Association of Disability Practitioners

Annual Disability lecture, University of Cambridge, March 2011

Disability Identity Conference, LSE, March 2011

Employer Forum on Disability Conference, April 2011

SOAS transition Conference, London, September 2011

3rd National Conference Adolescence to Adulthood with Autism Conference- Making the transition from education to employment, Sept 2011, The Kings Fund, London. Supported by The National Autistic Society and Research Autism.

Seminar at the Hong Kong Institute of Education, Hong Kong, November 2011

2012

Accessing STEM subjects conference, Royal Holloway, University of London, Feb 2012

Seminar on Asperger Syndrome in Higher Education in the UK, Visitors from Hong Kong Institute of Education, hosted by SOAS and the Oxford University, March 2012

NAS training pilot for Careers Advisers, University of Cambridge Careers Service, Cambridge, April 2012

HEA National HE STEM Programme- Mathematics group work and Asperger Syndrome working group, University Birmingham, May 2012

ProgressAbility ASD Conference, Coventry and Warwickshire LLDD Network- formed out of Aimhigher, Coventry, June 2012

Graduate Recruiters Disability Café Club- hosted Lloyds Banking Group, London, June 2012

If you would like this report in an alternative format (such as Braille, large-font or an electronic version) please contact the Disability Resource Centre.

Address

Disability Resource Centre (DRC)
Keynes House
Trumpington Street
Cambridge
CB2 1QA

Telephone

01223 332301

Textphone

01223 764085

Fax

01223 766863

Email

disability@admin.cam.ac.uk

Website

<http://www.admin.cam.ac.uk/univ/disability/>

Twitter

http://www.twitter.com/Cambridge_DRC