

## **Enabling transition into higher education for students with asperger syndrome**

MADRIAGA, M. <<http://orcid.org/0000-0003-2725-1718>>, GOODLEY, D., HODGE, N. <<http://orcid.org/0000-0001-5706-1865>> and MARTIN, N.

Available from Sheffield Hallam University Research Archive (SHURA) at:  
<http://shura.shu.ac.uk/1004/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

### **Published version**

MADRIAGA, M., GOODLEY, D., HODGE, N. and MARTIN, N. (2008). Enabling transition into higher education for students with asperger syndrome. Project Report. Higher Education Academy.

---

### **Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>



---

## **Enabling transition into higher education for students with Asperger Syndrome**

Manuel Madriaga, Sheffield Hallam University

Dan Goodley, Manchester Metropolitan University

Nick Hodge, Sheffield Hallam University

Nicola Martin, Sheffield Hallam University

---

## **Contents**

Acknowledgements	<b>3</b>
Executive Summary	<b>4</b>
1. Background	<b>11</b>
2. Aims	<b>12</b>
2.1. What is Asperger Syndrome?	<b>12</b>
3. Methods	<b>15</b>
3.1. About the respondents	<b>17</b>
4. Results	<b>18</b>
4.1. 'Intro' weeks	<b>19</b>
4.2. Engaging academically	<b>24</b>
4.3. Accommodation	<b>34</b>
4.4. The role of disabled student support teams in HE	<b>40</b>
5. Conclusion	<b>49</b>
6. Recommendations	<b>53</b>
References	<b>57</b>
Appendices	<b>62</b>

## **Acknowledgements**

We would like to say thank you to all students who participated in this project. Moreover, we would also like to thank their respective HEI disabled student support teams for their support.

Assistance from the National Association of Disability Practitioners early on in the project was greatly appreciated.

Special thanks goes to Sheffield Hallam University's Disabled Student Support Team, The Autism Centre, Widening Participation Policy Unit and the Manchester Metropolitan University's Research Institute for Health and Social Change. Also, a special thanks goes out to Rachel Madriaga for her input and comments to the project.

## **Executive Summary**

### Abstract

This project report provides an insight into the lives of students with Asperger Syndrome (AS) during their transition into higher education. It details the experiences of eight students with AS. Students were interviewed multiple times at various junctures throughout their first academic year. Although they told stories of everyday disabling barriers, they also shared experiences of academic and social successes. The project was primarily focused on students with AS; however, its findings will hopefully help inform inclusive policy and practice within higher education institutions.

### 1. Background

Much of the previous work examining transition issues and support for disabled students in higher education has too wide a focus, and the variety of differences existing underneath the umbrella of disability, such as AS, is often discounted. Traditional research in AS has pathologised the individual, focusing on the problematic nature of the condition. This report seeks to address this imbalance by placing students with AS at the centre of the process, helping to identify enabling and disabling practices found within their universities. As a result, the findings will inform and identify ways to ease the transition of students with AS into higher education.

### 2. Aims

The aims of the study were to:

- enhance the widening participation agenda by seeking to enable a group, currently with restricted access to higher education, to claim their entitlement to study in higher education
- raise the profile of students with AS in higher education
- acquire a better understanding of the societal barriers that disabled students, in general, encounter during their transitions into higher education institutions
- help promote issues of disability equality awareness among higher education staff.

### 3. Methods

The project entailed a longitudinal study, interviewing eight students with AS during their first year at a higher education institution. Students were recruited from various areas of the country, and interviews took place in their local area. All eight respondents were interviewed three times throughout the academic year of 2006-07: the beginning of Autumn semester; during Christmas break; and the end of Spring

semester. These junctures were significant because they showed the extent of university support offered to students at the beginning of the year and how universities administered alternative assessments and examination arrangements after the first and second semesters. It was envisioned at the beginning of project that data extracted at these particular junctures would offer valuable insight to universities and disabled student support teams in their service provision.

#### 4. Results

The majority of respondents (five out of eight) experienced euphoria upon entering their respective higher education institutions. This finding has not been evident, or discussed, within previous practitioner-focused literature about supporting students with AS in higher education. A possible reason for this absence is the result of practitioners pathologising individuals with AS, rather than allowing students with AS to make their voices heard. With their narratives at the centre of this study, respondents spoke about opportunities for invention. Attending university gave them a chance to place negative experiences of school, such as social isolation and bullying, behind them. Of course, this may be the case for many students, disabled or non-disabled. However, for students with AS, this has particular resonance as the everyday barriers they confront are 'unwittingly' taken for granted by a non-disabled, neuro-typical world.

Much of the literature regarding the experiences of individuals with AS discuss difficulties in communication and social interaction. As a result, it is argued that people with AS experience social isolation more frequently. This was confirmed in a few of the narratives. For instance, one respondent declared: 'My whole life has been spent worrying about isolation and essays, both together.' However, difficulty in interacting with others was not experienced by some respondents. A couple of them talked about having chats and drinks with friends in pubs. For instance, when asked about organising any events in his student society, one respondent replied: 'We did have one social, which was getting drunk.' All respondent stories were indicative of the diversity existing underneath the category of AS. Understanding the variability of AS is essential, especially in teaching and tailoring support for individuals in higher education.

There is also an assumption within the literature that people with AS need to partake in social activities to remedy bouts of social isolation. However, the findings show that those who live in student accommodation do not necessarily have more opportunities to develop a social timetable than those who live in the parental home.

Anxiety stems from confronting barriers in attending fresher's fairs, accessing information in lectures, working in seminar groups, disclosing their AS condition, gaining friendships and having support arrangements in place. Although much of the evidence may support a medical model view of AS, the barriers faced by many respondents were social. Thus, difficulties faced by many respondents were not principally the result of the impairment effects of AS. These difficulties can also be

credited to a lack of good practice and disability awareness among teaching and student support staff.

As respondents described disabling moments, they also told of instances of good practice. These instances revolved around accessible learning and teaching methods, as well as working with mentors appointed to them by their respective university disabled student support teams. In regards to the latter, half of the respondents viewed their mentors positively as mediators, counsellors or people who are just there to help.

## 5. Conclusions

With the recent Disability Discrimination Act amendment, the Disability Equality Duty (2006), higher education institutions have to make 'positive' steps in ensuring disability equality for all staff and students. This means disability issues are university-wide issues. These issues should not be considered the reserve of student services departments. The evidence presented here shows there still remains a significant gap between policy and practice in these public institutions. It is hoped the recommendations below may help inform ways to narrow this gap, ensuring equality for all students.

## 6. Recommendations

All recommendations were derived from the research. Underlying these recommendations was the recognition that higher education institutions (HEIs) have a legal duty to take positive steps in ensuring disability equality.

Recommendations for Government and HEIs:

- The Disability Equality Duty (2006) needs to be recognised as a legal duty in instilling a culture of valuing diversity within HEIs.
- The notion that confronting disablism is a university-wide issue, not just an issue reserved for student services, needs to be reinforced. This means academic faculties and departments should be held more accountable in curtailing disabling practices.
- Teaching staff should be enabled to achieve good practice in teaching, learning and assessment for all students. For instance, resources should be made available for teaching staff to develop professionally and acquire knowledge on alternative assessments and working with disabled students in accessible ways.

- Disability awareness training should be made compulsory for all staff in light of recent changes in the Disability Discrimination Act, in line with other mandatory training courses (e.g. fire safety).
- It should be recognised that students with AS are entering into HEIs in increasing numbers. According to HESA online data ([www.hesa.ac.uk](http://www.hesa.ac.uk)), the number students with AS entering into their first year of HE in the UK has been increasing each year: 80 in 2003-04; 295 in 2004-05; and 475 in 2005-06. Therefore, institutions will need to accommodate students with AS and ensure that they have positive learning and social experiences.
- Prospective disabled students, who are interested in attending their preferred institutions, should be made aware of early Disabled Students' Allowances needs assessment opportunities. This should be considered as an essential element of pre-entry activities, such as a taster courses. It will help a student to know what kind of support can be expected on year of entry. This may also be supported through the development and input of disabled student groups.
- An early Disabled Students' Allowances needs assessment for students with AS is strongly encouraged due to the multifaceted aspects of the condition as evident in this study. This diversity requires diverse support needs. Thus, having a pre-set support package for students with AS may not be the best way forward. Supporting students with AS requires creative thinking as well as the student's input on what he or she may require.
- Schools and colleges should be reminded that attending higher education is a viable option for disabled learners, particularly learners with AS.
- The successes of disabled students should be celebrated and publicised, if the student wishes, as an example to younger disabled people. Moreover, having success stories of students with specific impairments, like AS, will be beneficial to others who have similar conditions.

#### Recommendations for lecturers teaching in HE:

- Lecturers should make every effort to keep track of disabled students who have been made known to them by their respective institution's disabled student support teams. However, if a student is placed in an anxiety-ridden situation to disclose his/her impairment, then this may be an issue of discrimination according to the Disability Discrimination Act and SENDA.
- Due to the stigma associated with AS as a condition, some respondents in this study were more likely to disclose other conditions such as epilepsy and dyslexia rather than their AS. Lecturers must be aware that students with AS recognise a hierarchy of impairments and are less likely to disclose the AS itself.



- Lecturers should make clear in advance of lectures the availability of electronic versions of handouts. As recognised by respondents in the study, having handouts, visual aids or even music can aid *all* students in assessing information conveyed to them in classes. Good, inclusive practice for students with AS will benefit all students, disabled or non-disabled.
- Several of the respondents expressed discomfort in working with other students in group settings. This reflects what has been said about people with AS having social communication difficulties. So, at the beginning of a term, instead of immediately placing students in groups that number more than three, lecturers may want to consider pairing students up to help facilitate students in 'getting to know each other'. However, this may also be problematical for some students. Disabled student support teams may need to discuss this with a student to identify benefits of group work on learning.

#### Recommendations for HEI disabled student support teams:

- There should be increased awareness of the fact that Disabled Students' Allowances needs assessments can be conducted as early as April on the year of entry. This will help ensure that students with AS will have necessary support in place by the beginning of the academic year. If there is a delay in being able to offer support, practitioners should keep students informed.
- Disabled student support teams should consider that parents of students with AS are likely to be playing a large role in enabling their son or daughter practically, socially and emotionally, and can be an excellent source of advice, if appropriate permission is sought from the student. However, sensitivity is required because parents' views may differ from those of their offspring.
- Disabled student support teams should consider working with their student unions in planning alternative ways to increase student participation in student-led societies. For instance, in addition to having a fresher's fair, students with sensory impairments should have the opportunity to attend a similar event without 'the noise and the crowds', or receive buddy/mentor support in attending such fairs.
- AS-friendly activities should be identified in areas that might include people with AS.
- Disability practitioners in higher education should ensure that teaching staff are taking account of confidential information about disabled students within their classes. This will help ensure that lecturers are aware of a student's difference without them having to disclose or remind staff of their needs.
- Confidential channels must be maintained between disabled student support teams and academic faculties when conveying information regarding students.

- Disability practitioners in higher education should reinforce the notion that student support packages are not etched in stone. Support arrangements should be reviewed regularly and amended if necessary.
- Mentoring support recommended to students with AS should be flexible and consistent as students have varying support needs. Disability officers should initially meet with both mentor and student to lay ground rules and agree the support package.
- Considering the social isolation issues that many respondents experienced in their first year of higher education and the difficulties transition can present, assessors and disability officers should make students aware of the counselling support available within higher education student support services.
- Ensure that support arrangements (e.g., notetaking and examinations) are consistent. For instance, when a student's notetaker does not show up for a lecture, this may cause undue stress and anxiety.

#### Recommendations for disability researchers:

- Closer examination of the heterogeneity of disabled people would prove valuable in informing sociological understandings of impairments.
- Awareness of autism and AS within the social model of disability literature should be increased.
- More focused research into specific impairments and higher education transitions is necessary to better inform policy and practice.
- The extent of transition as a re-engagement, renegotiation and reconstruction of the label/ontology of autism should be examined.

#### Recommendations for Disabled Peoples' Movement:

- Differences and voices of people with autism and AS should be represented and taken into account within the Disabled Peoples' Movement.
- The extent of AS as a productive impairment should be highlighted.
- The Government and HEIs must be held more accountable to the aims of the DED.

## 1. Background

Disabled students are under-represented in higher education (National Disability Team and Skill, 2004). According to the National Audit Office (2002), an 18-year-old with an impairment is 40% less likely to enter higher education than a non-disabled 18-year-old (National Audit Office, 2002 as cited in Adams and Brown, 2006, p. 10). Riddell *et al.* (2004, p. 5) also indicated that disabled students continue to be under-represented in further education colleges and higher education, 'making up about 5% of home students, well below the proportion of disabled people in the population' (about 16%).

With this background, there have been many who have discussed and explored ways to ease disabled students' transitions into higher education (HE) (Hurst, 1996; Holloway, 2001; National Disability Team and Skill, 2004; Fuller *et al.*, 2004a, 2004b; Riddell *et al.*, 2005). Stemming from recent changes in disability discrimination legislation, the need to examine disabled students' transitions into HE has become significant. Particularly, with the introduction of the Disability Discrimination Act (DDA) amendment, the Disability Equality Duty (DED) (2006), there has been increased attention paid as to how higher education institutions (HEIs) are making 'positive' steps to ensure equal opportunity for disabled students.

However, most studies that have examined support for disabled students in HE have too wide a focus (Borland and James, 1999; Holloway, 2001; National Disability Team and Skill, 2004; Fuller *et al.*, 2005; Riddell *et al.*, 2005; Goode, 2007; Jacklin *et al.*, 2007). They discount the variety of *differences* that exist underneath the umbrella of disability (Barnes, 2003). To counter this, studies are now emerging about students with specific impairments (e.g. dyslexia and Asperger Syndrome) and their experiences in HE (Blamires and Gee, 2002; Martin, 2005; Taylor, 2005; Madriaga, 2007). This 'new' emphasis is in response to recent changes in disability legislation. As recognised by Fuller *et al.* (2004a, p. 467); 'There is now a need to move beyond single institution studies and a focus on specific impairment towards a more extensive and integrated approach.' Although this call for a specific impairment focus may appear to reaffirm divisions within the Disabled Peoples' Movement (Humphrey, 1999), it does bring attention to the particularities of impairments, such as Asperger Syndrome, which have often been ignored in the social model of disability literature.

In responding to the call made by Fuller *et al.* (2004a), this report details a year-long, longitudinal study (2006-07) examining the HE experiences of first-year students with Asperger Syndrome. The study entailed following the lives of eight students from six different universities across the country. This report will consist of the following sections: aims; methods; results; conclusions; and recommendations.

## 2. Aims

The purpose of this report is to highlight the diversity of students with Asperger Syndrome (AS) so that the university experience, from their perspective, can be identified and understood. This report will identify strategies that students themselves identify as being enabling. It will also highlight attitudes and practices experienced by students as disabling. From responses below, students are aware of how AS may impact their studies; however, there is a sense of resilience (Goodley, 2000) among them that is often left unheard. An aim of this report is to raise their voice, not focusing on the 'pathological' nature of AS of previous studies (e.g. Taylor, 2005). This is not to dismantle the notion that students with AS have difficulties living in a disabling society: they do. Experiences and meanings attached to the social category of AS should not go unrecognised. At the same time, it should be noted how respondents' lives have been impacted positively in making the transition into university.

Thus, the aims of the study were to:

- enhance the widening participation agenda by seeking to enable a group, currently with restricted access to HE, to claim their entitlement to study in HE
- raise profile of students with AS in HE
- acquire a better understanding of societal barriers disabled students encounter during their transitions from schools and further education colleges into HEIs and
- help promote issues of disability equality awareness among HE staff.

## **2.1 What is Asperger Syndrome?**

Asperger Syndrome (AS), together with autism, forms one out of the many UCAS disability categories that students may tick when applying for a university place. According to Blamires and Gee (2002), the incidence of students with these impairments appears to be on the increase. This is evident in recent UCAS data that show that in 2005 there were 356 applicants who disclosed they had AS, as opposed to 165 in 2003 (source: UCAS website, accessed on 2 July 2007).

There are two competing views of AS, firstly, an 'official' view of the condition based on a medical model of disability; and secondly, an alternative, 'vernacular' view of the condition based on the social model of disability. The distinction between the two models of disability is a matter of ontology, epistemology and politics. The medical model view of AS considers the condition within the autistic spectrum. It is believed to be a 'devastating developmental disorder' (Williams, 2004, p. 704), or a 'neurological abnormality' (Frith, 2003, p. 1), 'due to a physical dysfunction of the brain' (National Autistic Society, 1998, p. 26). This 'dysfunction' results in a triad of qualitative impairments in social interaction, social communication and imaginative thought (Wing, 1991). The main clinical features, as noted by Wing (Burgoine and Wing, 1983) include: lack of empathy, one-sided interaction, little or no ability to form friendships, pedantic speech, poor non-verbal communication, intense absorption in certain subjects and odd postures. This perspective is considered an 'official' view

because individuals with AS will not be able to access specialist funding without an 'official' medical diagnosis.

Recognising and rejecting 'official' notions of power assumed by medical professionals in categorising disabled people with 'disorders' and 'dysfunctions', disabled people have reacted collectively and politically by offering an alternative view of disability (Oliver, 1990). Instead of viewing disability as an indicator of individual failing and stigmatisation, the social model of disability comprehends disability as purely social phenomena. This means that disabled people are not disabled due to their impairments. They are disabled due to dominant societal attitudes that are perpetuated by taken-for-granted notions of non-disabled people as 'normal'. Molloy and Vasil (2002) have expanded on the social model of disability in relation to AS. They believe the way AS is classified, treated and interpreted is socially constructed. Thus, they have argued, 'that AS is never simply located within the individual: no gene or discovery of different neurological "wiring" arrangements will wholly explain AS' (2002, p. 662). For them, it is not a disorder: it is a social *difference*.

Adopting Goodley's (2000) theoretical framework on the social construction of impairment, Molloy and Vasil (2002) contend that AS has been readily adopted as a category because of its value in the area of special education. The category functions 'as a convenient common category' because practitioners are able 'to communicate with one another about the peculiarities of [a] child's personality, behaviour, learning achievements and needs' (2002, p. 666). They believe the category, although convenient, is problematic within a medical paradigm. They recognise a variance in interpretations of diagnostic criteria of AS among practitioners. Citing Singer's work (1998), they recognised there is little consensus in clinical practice on 'patterns of symptoms being referred to as AS, High-Functioning Autism and Autism Spectrum [condition], to name a few' (2002, p. 661). The harm in this lack of consensus is that children are receiving this 'label' more frequently (Blamires and Gee, 2002). In some respects, this may be viewed as positive as it enables a child to obtain specialist funding. However, it also sets a child 'on the road to specialist – and mostly segregated – provision and ultimately moving towards an excluded future' (Hodge, 2005, p. 348).

This report reflects the 'vernacular' – the resistance to the medical model of disability and the oppression of disabled people (Gabel and Peters, 2004) - like other recent writings that have explored issues in supporting students with AS in HE (Blamires and Gee, 2002; Howley, 2004; Martin, 2005; Taylor, 2005; Birnie, 2006). However, in reading these works, two contentious issues have become apparent: firstly, there is a tendency to pathologise the differences of AS and secondly, a practitioner, rather than a student focus is often adopted. The first issue stems mostly from a disabling canon (e.g. Harpur *et al.*, 2003, Taylor, 2005), where a student's behaviour, or how one should behave, is emphasised. This emphasis on behaviour resembles a cautious attitude among HE staff in preparing for a worst-case scenario. Because of this tendency to pathologise AS, there have been a few studies within UK HEIs that have painted a more positive portrayal of students with AS (e.g. Blamires and

Gee, 2002; Howley, 2004; Martin, 2005). For instance, in Blamires and Gee's work (2002, p. 9), they stated:

The academic ability of this identified group spans the full range and certainly includes people of outstanding ability. Those who achieve their potential have overcome many difficulties. Such students have a tendency to over-formalise speech and monologue with limited turn-taking in conversation. In some academic settings this may be seen as an ability rather than a disability.

Although making an excellent point, they presented this positive portrayal as *practitioners* in order to inform good practice to other practitioners. They did not place voices of students with AS in the foreground. Adams and Holland (2006, p. 21) have encouraged HE providers 'to undertake research to provide a sound evidence base to inform future interventions. This should focus on the impact of existing activities but also include greater opportunities for the student voice to be heard.' This thinking reflects the legislative demands of the DED, where disabled people are to be consulted in formulating disability equality policies within public organisations. Traditional research has pathologised the individual by focusing on the problematic nature of AS. This study seeks to address this imbalance by placing the student with AS at the centre of the process. It is they who can best identify enabling and disabling attitudes and practices found within their university. They are experts in recognising barriers within universities that a non-disabled, neuro-typical world 'unwittingly' take for granted (Deal, 2006; Madriaga, 2007). Being experts, we felt students with AS would be best suited in helping to address the following questions:

- What do you have to say about your experiences in HE?
- What have you found helpful in achieving and succeeding in HE?
- What barriers do you identify and mark out in your transitions into HE?
- How have you negotiated barriers throughout the duration of your first year?

It is important to note that research into lived experience needs to be driven by issues raised by students with AS. As will be discussed below, the aim of this study was to identify issues the respondents raised concerning their experiences.

### **3. Methods**

To address the research aims, a longitudinal study was planned, which entailed following the lives of five to ten students with AS throughout their first academic year within a HE setting. Having a small sample size was considered ideal in providing a snapshot into the everyday lives of university students with AS. Moreover, the planned sample size was based upon the small sample sizes of existing qualitative work on disabled student experiences in HE (Parker, 1999; Holloway, 2001; Taylor, 2005). Recruiting respondents to the study from across the country was eased by Sheffield Hallam University's Disabled Student Support Team links with The Autism Centre and the National Association of Disability Officers (NADO). Sending out an email via the NADO email list of practitioners proved to be the most successful

means of recruiting respondents. Practitioners were asked in an email to forward a letter (see Appendix A) to first-year students with AS within their institutions. Within this letter, it stated that those who participated in the study would receive a £60 voucher for a national bookstore chain.

Eight students were recruited from various areas of the country. This meant a researcher travelling throughout country to meet students. Through good fortune, one of the eight students who agreed to take part happened to be a first-year MA student. Although his status as a postgraduate student was not part of the original remit of the study, his story added to the diversity of experiences that all respondents confronted in new environments. All eight respondents were interviewed three times throughout the academic year of 2006-07: the beginning of Autumn semester; during Christmas break; and the end of Spring semester. These junctures were significant because they showed the extent of university support offered to students at the beginning of the year and how universities administered alternative assessments and exam arrangements after the first and second semesters. It was envisioned at the beginning of project that data extracted at these particular junctures would offer valuable insight to universities and disabled student support teams in their service provision. While this longitudinal study required much travel, it offered exceptional opportunities for respondents to become more acquainted with the researcher. This was positive as respondents appeared more open, wanting to divulge more about themselves and their experiences in later interviews; a sense of trust was nurtured over time. Another positive aspect of this research approach was the opportunities for respondents to reflect on questions and statements made in prior interviews. In addition, it allowed the researcher to re-ask certain questions to respondents in later interviews. Interviews were not structured. Research was driven by the issues raised by the participants. Although having this aim, the research team employed some prompts to understand their lives before university and examine how they engaged with classroom activities, assessment and support arrangements. These prompts were conjured and informed by previous work on disabled learner transitions into HE (Goode, 2007; Madriaga, 2007).

Several parents, more specifically four mothers, and two 'mentors' (support workers) of student respondents were also interviewed. Unlike student respondents, they were only interviewed once during the project. Perspectives were acquired from these respondents to gain a better understanding of the barriers student respondents face in their everyday lives from the perspectives of those close to them. Their views were only sought to accompany narratives of student respondents. This has been done in previous studies (Riddell *et al.*, 2004; Fife and Tayside Wider Access Forum, 2005; Madriaga, 2007) that focused on disabled learner transitions into HE. Moreover, in a literature review of student first-year transitions conducted by Harvey *et al.* (2006), it was suggested that family members can impact significantly on adjustment in a student's first year of HE. Being members of a disabled family, the role of parents cannot be discounted. They will have experienced disabling attitudes as well (Hodge, 2008). Many parents have had a history of advocacy on behalf of their sons/daughters with AS, particularly in dealings with educational authorities (Gray, 2002). However, university practice, particularly in regards to the Data

Protection Act, prevents a parent’s advocate role being carried out. For instance, with students most likely having adult status, parents have restricted access to any information or correspondence between university and their child. Thus it was necessary to gather information from carers and how they understood these practices to be impacting on their son or daughter. They were all pleased to share their experiences.

Much was done to make sure the project was ethically sound and addressed, as far as possible within the resources of the project, emancipatory principles for those who participated in the project (Mercer, 2002; Barnes, 2003). Transcripts of interviews were always sent back to respondents for their review. This provided them with opportunities to make amendments and clarify what was said.

In working with all respondents, informed consent (see Appendix B and Appendix C), ensuring confidentiality and transparency were always pursued. Hence, throughout this report, the names of respondent and even their universities appear as pseudonyms. Moreover, the titles of their courses have been altered. This was done for confidentiality reasons and to ensure respondents of their anonymity. Although respondents understood they would be anonymous, some of them expressed a willingness to help out with dissemination of report findings, in the form of presenting their stories of HE at conferences or writing up their experiences in professional publications. In fact, one of the respondents has already shared his story at a conference this year. Another respondent agreed to co-write a paper to inform disability practitioners how to support students with AS in HE.

Although ensuring confidentiality was a formal process of the research, the form and style of the interviews were informal. The researcher let his subjectivities come across to the interviewees as he reflected upon his own beliefs. In giving information about himself, the researcher made the interviews more personable and supportive. This informality led to opportunities for celebrating interviewees' achievements.

### 3.1 About the respondents

Although respondents share in the experience of being diagnosed with AS, they are all very different. They originate from different parts of the country, study a diverse range of courses, attend different types of universities and receive an assortment of academic support from their respective disabled student support teams.

Respondent	Age	Course	University type	Type of support they receive	Age of diagnosis
Alan	30	BA in Social Sciences	Pre-1992	<ul style="list-style-type: none"> <li>○ notetaker</li> <li>○ exam arrangements</li> </ul>	29
Cathy	18	BA in Humanities	Post-1992	<ul style="list-style-type: none"> <li>○ notetaker</li> <li>○ mentor</li> <li>○ exam (e.g. extra time)/coursework arrangements</li> </ul>	4
Karen	18	BSc in Social	Pre-1992	<ul style="list-style-type: none"> <li>○ mentor</li> </ul>	15



		Sciences		<ul style="list-style-type: none"> <li>○ exam (e.g. extra time)/coursework arrangements</li> <li>○ tutorial support</li> </ul>	
Len	18	BSc Biology	Pre-1992	<ul style="list-style-type: none"> <li>○ mentor</li> <li>○ exam (e.g. extra time)/coursework arrangements</li> </ul>	9
Lisa	18	BA in Social Sciences	Pre-1992	<ul style="list-style-type: none"> <li>○ mentor</li> <li>○ exam (e.g. extra time)/coursework arrangements</li> </ul>	18
Louis	22	BA in Arts	Post-1992	<ul style="list-style-type: none"> <li>○ mentor</li> </ul>	13
Mark	23	MA in Social Sciences	Pre-1992	<ul style="list-style-type: none"> <li>○ mentor</li> </ul>	12
Ray	22	BSc in Computer Science	Pre-1992	<ul style="list-style-type: none"> <li>○ tutorial support</li> <li>○ exam (e.g. extra time)/coursework arrangements</li> <li>○ taxi costs to and from home to university</li> </ul>	15

#### 4. Results

The way AS impacts upon their lives varies as well. Some respondents feel the condition governs their lives. For instance, Mark credits being depressed to having AS: 'The depression is a response to how I deal with external factors, and how I deal with external factors will be governed by how I react to them as a person with Asperger's Syndrome.' In contrast, for other respondents, AS is just one of many things they have to contend with on a daily basis. Lisa ranks the seriousness of her food allergies ahead of having AS, depression and dyslexia because an allergic reaction, in her words, will 'kill me'. Of course, their views have a bearing on how they understand their diagnosis (Brady, 2007). Alan felt his late diagnosis of AS at the age of 29 had given him clarity in reflecting back on his own life. As he stated: 'I was almost in complete tears to be honest. It was like everything [the doctor] said was like "Oh my god! There it is! That's the reason why!"' In contrast, Louis had a less-than-positive view about his diagnosis:

Back in 1998 I believe, when I was about 13 or 14. I had to go to this psychiatrist. It was a hospital... I had to go to this lady. She was more or less a therapist. For about a couple of hours, she did some tests with me, which I must admit was incredibly humiliating. I was nearly 14 and I felt like I was being treated like a seven-year-old. I did not like that.

Not only did respondents have varying views on their diagnosis, they had contrasting views on the effects of having an impairment. For example, Karen and Alan both saw it as a matter of having social communication difficulties and not being able to read social cues, Mark has credited his social isolation to it and Len has indicated that it has not hindered him in anyway (except when it comes to having to take in information from 'badly written' books).

The variability of AS does not go unnoticed. Bogdashina (2006) captured 'internal' views of those who can attach themselves to the autistic/AS category (e.g. Williams, 1996; Grandin, 2000). She argued: 'As autistic individuals differ from each other as much as their non-autistic peers, there are as many "autistic" definitions as there are autistic individuals' (Bogdashina, 2006, p. 81). The respondent Mark understands the diversity existing underneath the category of AS and parallels the condition to chicken tikka masala:

I guess the important thing to remember is that [definitions of AS] are very much generalisations. There is nothing more annoying than reading a book by someone who says AS is this, this and this and they got AS and present it as the definitive article, or present themselves as the definitive article. As with everyone, everyone is an individual, and AS adds and subtracts from certain aspects of that... it is a bit like chicken tikka masala really. There are really all sorts of tasty things underneath the label of chicken tikka masala, but it is exactly how you mix up the ingredients that determine the exact taste. But, it is still all chicken tikka masala though.

This is only a snapshot of the diversity of respondents and the contrasting meanings they attach to the category of AS in their lives. Understanding the variability of AS is essential, especially in teaching and tailoring support for individual students through HE. As Howlin (2004, p. 4) has recognised, 'some of these students will need minimal, if any, additional support, while others may need a comprehensive support service both for academic and social needs'.

This part of the report attempts to break down findings from what respondents stated about their transitions into HE. The analytical approach taken was informed by grounded theory. The hallmark of grounded theory, according to Charmaz (1995, p. 32), consists of the researcher deriving his or her analytic categories directly from the culture under investigation, not from preconceived concepts or hypotheses. Each member of the research team analysed transcripts of all interviews. When meeting as a group, the research team discussed and highlighted common themes that emerged from the narratives of student respondents. Nvivo software was invaluable during this process in organising the discussed themes. Twenty categories were initially identified and were subsequently collapsed into four: 'intro' weeks; academic studies; accommodation; and the role of the disabled student support teams. These themes form the following sections of this report. The analysis begins with a section (4.1) where respondents retell their experiences of their first weeks of university life. This provides some insight into how they perceive their transition. Then a section (4.2) follows on how respondents coped with the rigours of academic study, such as working with tutors and other students within the classroom. Since university life is much more than what happens within the classroom, the next section (4.3) will draw attention to their social lives, with specific attention to their home lives (or student accommodation). Lastly, a section (4.4) focuses on student perspectives of the role of the disabled student support team within their respective institutions.

#### **4.1 'Intro' weeks**

Five out of the eight respondents expressed euphoria upon entering their respective HE institutions. This euphoria has never been touched upon before, since previous literature (e.g. Taylor, 2005) focused on the pathological nature of AS. With the prospect of meeting new people through their courses, accommodation and student societies, respondents embraced the opportunity for reinvention. This was echoed in Karen's reflections:

In the same way, I have come here and normally I am not a very chatty person. At home, I am a very quiet and I just sort of sit there. I come here. I introduce myself to people. I have been talking. And, I am like where does that come from? This is isn't me. Or maybe this is me? It is just a *me* that could not exist where I was before. Coming here without anybody's preconceptions and there is nobody going 'you got Asperger's so therefore you are going to be freaking out at every opportunity'. I have been a different person.

Like other respondents, Karen readily embraced this 'different person' in university because of the adversity she confronted when in school:

My skills with friendship have come and gone over the years. My friendship group for a few years was great. It was absolutely great and I loved it and I thought I was getting the hang of it now. I can make friends and have fun. Then, suddenly, in year 13, the moment I hit serious problems I found a lot of them were not there for me... They are not friends. Coming here and making new friends was good.

Alan, in a similar way, talked about university being a more inviting environment when compared to the difficulties he experienced back in school:

When I look back, the fights that I used to get into and the scrapes that I used to get into, it was all because I said the wrong thing or having the wrong behaviour. Kids pick up on it. I got bullied like hell when I was at school.

Now, in university, he feels more confident to the point of even disclosing that he has AS to his peers:

...whether you want to disclose your disability or actually tell somebody. I find with most university students, they are a bit more intelligent and most willing to understand. Like I told some of the lads in my halls, they were quite interested actually. It was not an issue.

This same respondent held this positive attitude towards disclosing his AS throughout the study, to the extent of stating: 'My best advice is not to hide it.'

#### **4.1.1 Fresher's week**

Engaging socially with others has been noted to be problematic for individuals with AS due to impairments in communication and interaction (Wing, 1991; Happe, 1994; Attwood, 1998, 2006; Howlin, 1998; Gillberg, 2002; Frith, 2003; Harpur *et al.*, 2003). Five out of the eight respondents have explicitly recognised how these impairments impact on their lives. For example, Karen explained her difficulties of reading social cues, especially when it comes to interacting with the opposite sex:

I actually thought he did not like me, because obviously I am terrible at body language. I got no idea unless somebody is being really overt with me... And then someone said 'do you realise that you two are just flirting?' And, I am like 'we are flirting?' (laughing) If somebody did not point that out to me, I would not have realised. That was obviously a very Asperger thing.

In addition to admitting he has difficulty reading social cues, Alan recognised he sometimes says the most inappropriate things when in conversation with others:

Society expects you to act in a certain way... I think a lot of AS children have difficulty learning it. It is a learning disability itself because it takes you longer to learn skills. Some people never learn them. People like me do a pretty good job, but there are just tiny, little things that I still get wrong. I will give you a typical example. A few weeks ago I was sitting in the pub, there's a bloke there. He is a nice guy and he was about 33-years-old, I think he was. He looked really old. He got grey hair. He was on ship. He was in the Navy. It just happens that he was on a ship which I went to visit while I was in school. He would have been 18 and I was about 15. We went to this ship and he was obviously on this ship, which was a total coincidence. I asked, 'How old are you?' He says he was 33. I said, 'What? Are you 33? You look really old for 33!' I said, 'fuck, I don't believe I just said that', the look on his face. Oh! It was time for a sharp exit. He was cool about it. I just thought, 'you twat, why did you say that for? [sic]'

The inability to read social cues and the paranoia of saying something 'wrong' to others has a negative impact for respondents' confidence to socially engage with others. It is due to being aware of their impairments that some of them just avoid people altogether, to the extent of isolating themselves. Mark, for instance, was very open about his bouts with isolation in his first interview:

My whole life has been spent worrying about isolation and essays, both together... It is an absolutely foul thing for someone with AS to have to do in [sic] any kind of further education. I suppose I am just a glutton for punishment (laughing). 'I say is that a nearly insurmountable challenge? Right-o, I am on it!' (laughing)

He recognised that he is 'not particularly confident' in keeping a conversation going on with others. One of the ways he has been able to cope with his social isolation was having passion for British television dramas. As he stated: 'All I ever do is go back to my room. My specialty in film was British television drama. I just sit there watching DVD after DVD. I lead a very, very dull life you know.'

The loneliness an individual with AS experiences has been widely recognised (Gillberg, 2002; Frith, 2003; Harpur *et al.*, 2003; Attwood, 2006). Thus, it has been no surprise that half of respondents in this study had been in one time or another diagnosed with depression (Gillberg, 2002). To remedy this isolation, Blamires and Gee (2002) and Martin (2005, 2006) have drawn attention to the idea that the social demands of student life should be recognised by HEIs. While not specifically focusing on students with AS, the Higher Education Academy-funded study by Jacklin *et al.* (2007) has also highlighted the social experiences of disabled students as a matter of concern. The authors advised that HEIs must give equal weight to social spaces as they do learning spaces (Jacklin *et al.*, 2007, p. 50).

Leaving their experiences of school behind them, respondents were challenged within their first weeks of university life by the fresher's fair. Six out of eight

respondents indicated they attended this event within their respective institutions. This event provided them with the opportunity to enlist themselves into various student societies and develop a social timetable (Martin, 2006). Out of all respondents, Cathy took full advantage of what was on offer during her fresher's week. Accompanied by a disabled student support mentor, she joined five student societies: the drama society; Christian union; tennis; netball and the video gaming society. Fresher's week also helped facilitate Len joining the reptile society and Ray enlisting into a martial arts society. In contrast to the experiences of Cathy, Len and Ray, both Mark and Alan found fresher's week was not to their liking. The latter attributed their distaste for fresher's week to the sensory and hypersensitivity aspects of their condition. As Mark explained: '[Fresher week events] are completely and utterly, unsuitable for someone who does not like noise and crowds. I avoid them like the plague.' Alan described what he saw after walking into his university's fresher's fair, and then immediately walking out:

I walk into the society fair and they crammed all these societies in a little room... I walked in. Oh fucking hell, I got to get out of here! There was [sic] all these mad people in there. It was like students bouncing off the walls. I felt like I could hit somebody in a minute. I cannot be dealing with this! I don't like big crowds of people... I think it is part of the condition. I have always been the same. I never liked loud noises. I don't like arguments. What is that called when you need plenty of space around you? Claustrophobia! You get all these people there. I get quite stressed out when there is a lot of people around me.

Unlike Cathy, Len and Ray, Mark was able to enlist himself into social activities without having to partake in fresher's fair. He joined the university's wind orchestra and clarinet choir just by getting in touch with the music department. As he stated: 'Well, nearly every university has that, a wind orchestra. So, I got in touch with the wind orchestra here and I went for an audition and they put me in first clarinet!' For him, being a part of these activities has been 'a godsend' in coping with isolation issues:

It is going to be even more useful this [Spring] term because every lecture I have with the department is condensed into an extraordinarily busy Monday and a rather busy Tuesday. The rest of the week is essentially doing coursework. So, that was going to present some isolation issues. So, having the clarinet choir and the wind instrument orchestra on two separate days is going to be an absolute godsend.

Being a part of student societies was also positive for Cathy and Len. Both of these respondents were able to gain friendships through their societies. For instance, Len was able to befriend coursemates, as well as find drinking partners, through the reptile society:

*Have you guys organised any events since you joined?*

We got a lecture theatre booked out soon for people who worked at reptile parks and things like that to do lectures. We did have one social, which was just getting drunk.

*What did that social entail?*

We had an inflatable crocodile and a few beers. Generally, most people cannot remember what happened.

In his third interview, Len stated that he had been appointed secretary for the reptile society. He already envisioned what will be needed to recruit more students into his society at next year's fresher's fair: 'So we've got to get more snakes in, stick them on a table and attract everyone to us.'

Although active in different social activities around their universities, both Mark and Ray still experienced difficulties engaging with other students. For instance, Mark has not been able to socialise with other members of the wind orchestra as they go to the pub immediately after rehearsals. He does not like pubs due to 'the crowd and the noise'. Ray, on the other hand, has not been able to befriend anyone in his martial arts society for reasons unknown to him. He was asked in his second interview if he was still partaking in the society:

Sometimes but...

*Are you busy?*

Well it is just... I don't think people get on with me for some reason.

*Why's that?*

I don't know. Some people are okay with me, but some don't like me for some reason. Well that's how I feel.

*...Is it just personality and stuff?*

Probably. 'Cos like after each martial arts [class] that I'd be doing then we'd swap with another person. I'd be trying to look to see who'd want to go with me and they're all looking away.

In some respects, participating in student activities was positive and aided the transition into HEIs for a few respondents. For Cathy and Len, their participation in student societies helped facilitate friendships with their coursemates. However, this was not the case for others, providing evidence that partaking in student societies can never guarantee full immersion into university life or gaining friendships. The reason for highlighting fresher's week experiences and student society participation is to present, not only the diversity of AS, but also the barriers some students face in participating and engaging socially in university life. Dismantling some of these

barriers may mean universities, particularly student unions, can create spaces for students with AS where their differences are accepted and recognised (Ryan, 2005).

## 4.2 Engaging academically

This section of the report will be subdivided into themes revolving around notions of pedagogy, curriculum, assessment, teaching and learning.

### 4.2.1 Lectures

Half the respondents (four out of eight) had expressed some dismay with some of the teaching methods being employed by their lecturers. A point of commonality among them was their desire to actually comprehend the information conveyed from their 'teachers'. Perhaps having handouts of lecture notes prior to lectures will make information presented more accessible for students (Healey *et al.*, 2006). However, some respondents have indicated they have not been informed of lecture notes being made available before or after their lectures. One respondent even commented that her university has a policy that lecture notes and handouts should not be available beforehand as they think it 'induces laziness in students in that they don't take their own notes and interpret in their own words'. This kind of policy presents difficulties for some respondents who have indicated that they have issues retaining information:

Sometimes, I can only understand things when it makes sense. Sometimes, they say something, and everything goes around in my head and I am thinking does it mean that? Does it mean that? I only get it when they explain it properly in the way I need to go in my head. (Ray)

I would probably have managed on my own with a few teachers who are actually helpful. If I had problems with coursework with that teacher, I would go to them and they would explain it to me again in a slightly different way that I would understand... My dad used to try and help me with coursework, but he is not great at explaining things himself. He was like: 'How come you don't understand this? It is simple.' I am like: 'I don't understand it.' He can't put it in any other way. At some things, he could explain. But other things, he should never become a teacher. (Len)

Alan, who is perhaps the most critical of all respondents on this issue, credits poor teaching practice to explain why some students have not been retaining information in their lectures. He gave an example:

I mean [the lecturer] just stands at the front of class and he'd be talking down a microphone and he couldn't seem to get the distance right – so it was going ooh-aah-ooh-aah, and people were sitting there just basically falling asleep...



I mean he obviously knows his stuff, don't get me wrong, and he's a bloody nice gentleman but he's just not a natural communicator.

It may not even be a matter of talking through the microphone correctly. It can also just be a lack of consideration of students placed within the teaching room, as Karen explained:

Our table was in the wrong side of the room and all the other tables in the other side of the room. So, whenever the lecturer is pointing at stuff, we couldn't see where he was pointing. He kept forgetting on coming to our side of the room and pointing on the screen on our side of the room. So, we did not know what we were doing.

Alan believed this poor practice is attributed to the 'snobbery' of lecturers who have the attitude of 'I don't really want to be here [lecturing]'. He described his solution:

Seriously, what you have to do is have a big room, two hundred students, you got a lecture. Get rid of the lecturer. Find somebody who can actually teach. What does the lecturer do? He just stands in the front and goes blah, blah, blah and that's it. A lot of them just stand in the front and have this spiel for an hour. 'There you are. I shared my knowledge. Go away. Read the books. Then, come back to me with an assignment or whatever.' If a lecturer can't lecture, get somebody who can actually teach, just a qualified teacher, not an academic, a teacher. All you have to do is supply that teacher with the relevant information – 'Right then Mrs. so-and-so. I am the lecturer and I want you to cover this, this and this.' Get somebody with a bit of talent to get it across. They don't have to know the subject inside and out. All they got to do is get the information across.

*So, you don't need someone who has a PhD?*

Well, a bit of background. There was this one lad, who was a PhD student, and he is doing something with world politics. He got a bit of flair. He could actually teach, and he was able to engage the class. You get a lot more out of the class if you can engage and actually have the crack, and a bit of laugh and a joke.

His suggestion for a change can be paralleled with the call for a change in pedagogy, particularly in relation to marginal groups (Giroux, 2003; Nind, 2005; Goodley, 2007). The current pedagogy perpetuates disabling barriers as 'educational environments, curricula content, teacher identities are all normatively associated with environments, standards and achievements that are at odds with the quirkiness of disabled learners' (Goodley, 2007, p. 319). This call for a pedagogical change can be supported with comments made by other respondents, such as Karen, on the topic of favourite lecturers:

They are the ones who make people laugh and are entertaining. We just finished with one of them now. He has been teaching us since the semester began on brain and behaviour. I think it was the first time since we had our introduction talk that we actually gave our lecturer a round of applause. He actually got one at the end. He said that this was our last lecture. We have a seminar tomorrow, so this is basically the last lecture. He got a big applause from everybody. I think he is very well-loved.

By enjoying humour from a lecturer, the previous respondent challenges current thinking about people with AS. According to Gillberg (2002, p. 101), some people with AS 'appear to be devoid of humour, always serious and may be thought of as "deep", "moody", "dysphoric", or constantly "brooding"'. This certainly was not the case for the previous respondent, or Len when describing the colourfulness of one of his lecturer's teaching style. Not only was humour exhibited in the following passage, but also empathy (understanding thoughts and feelings of others or seeing the world from someone else's perspective), which people with AS supposedly lack (Baron-Cohen, 1995; Attwood, 1998, 2006; Gillberg, 2002):

We were laughing, wondering what we were actually gonna do on the course after the first lecture cause it seemed just a bit random, like about trees and stuff, and then we had a break to drink fair trade coffee with him, and we were like laughing, saying that he was gonna teach us to dig tunnels under motorways and stuff to make them collapse, cause he protects the forest basically. We were laughing about all the things he was going to do.

*Did he know you guys were joking?*

He probably did. He probably wouldn't care. At one point he had about 15 jumpers on and stood on the thing at the front that he's supposed to lecture on, and he stood on it and was showing all the different colours on his jumper to trees at different stages in the year. He's taking off jumpers and throwing them about.

*Hey it's the best way to learn. It's visual isn't it?*

He was also playing the keyboard at one point as well

*So he brought a keyboard?*

He brought a little electric keyboard in and started playing a song he wrote.

For the likes of Alan, Len's description of his lecturer taking off jumpers and playing a keyboard in front of class would be a good example of good practice:

Going back to disability, whether you have a disability or not, most people learn from a combination at looking things, listening to things, touching things,

etc, etc. We got all this wonderful equipment – overhead projectors, overhead screens.

These technologies are placed in university lecture halls to aid a lecturer in engaging students, so Alan begs the question: 'How come lecturers do not use them more often?' His attitude is that lecturers 'are not interested'. Their lack of interest is a barrier for him to achieve a sense of inclusion.

The responses above show that students desire their lecturers to enjoy being with them and to be *interested* in them. Lecturers were able to engage the respondents with humour, props and technology in their teaching. They made an effort in breaking down the barriers of communication and the students recognised it. Alan is expecting more lecturers to modify their teaching methods with inclusion in mind. This expectation comes from his awareness of widening participation issues and recent increases in tuition fees:

My biggest problem is boredom. It has always been my problem. If I get bored, forget it. You can make any subject interesting if you put your mind to it. I don't care what anybody says... The problem is the elitism coming through – 'We have always done it this way. This is the way we will always going to do it.' Well, times are changing mate! Times are changing! ... Let's face it. If you got a son or daughter, you are paying to send them to university and you are earning a fair few quid so you have to pay top wack. I think you will be suddenly asking, 'What am I getting for my money?'

#### 4.2.2 Group work/seminars

Having to work with another student or in groups with other students placed many respondents (six out of eight) in anxiety-ridden scenarios. Martin (2006) credits the anxiety of students with AS to communication *differences* and limited social interaction prior to university life. Respondents were cognisant of these difficulties in their own lives:

...trying to survive in social situations with people with AS is a bit like trying to get someone with a broken leg to walk upstairs – they can just about crawl themselves up it if they're lucky. (Mark)

Well essentially, Asperger's Syndrome means that a person has low communication and social skills, meaning that they don't talk to people much or they're shy, like myself... They often prefer to work independently rather than in groups. They're not really outgoing people, like myself, because... well, we don't know what to say really. (Cathy)

These worries about what to say may stem from social isolation that some students with AS may have experienced while in school (Harpur *et al.*, 2003). This preference for being alone (Attwood, 2006), or being social phobic (Gillberg, 2002), will limit a

student's experience to socially engage with others, restricting the development of knowing the social rules when interacting with others. This may help to explain why some students found their initial meetings with their respective working groups difficult:

I don't get on with people in my tutor group. They are not very 'me'. One of them has their dad's Land Rover, that they borrowed, and they pay the congestion charge everyday. Or, 'oh no, I broke a nail!' Or, 'the hair straighteners have not gone right today!' It is like my god, there are more important things. (Lisa)

I don't like my group (chuckle)... I think I just took an instant dislike to one of the other girls... There was just something about her. When I am around someone whom I feel uncomfortable with, then I just go quiet. I will just sit there and look at the ceiling. (Karen)

In his initial weeks on his arts course, Louis was paired off with another student to work on a project. Although not placed in a tutorial group like Lisa and Karen, Louis' story of working with a 'stranger' provided him with a sense of unease:

When I was first paired off with a total stranger, I was not very content of working [sic]. I would have preferred working with a girl actually, because I know they are a bit more enthusiastic. Unfortunately, it took quite a lot of time for me to be able to work with this boy on my own accord [sic]. So, therefore, I had to make the effort with this boy even if I knew nothing about him. Therefore, I had to get to know this boy and prove to myself that he is not such a bad person, which he isn't. He is all right now, so that's good. For me, it takes quite a bit of effort to get to know the person in a way.

None of the respondents above attributed their anxieties towards working with other students to having AS. However, a few of them did link their anxieties to being shy. For instance, Ray explained during his first interview that he was very shy and did not know any of his coursemates. He stated: 'If it is one-to-one, I am okay. But, if there are a lot of people around, I just get too shy.' This is not too different from Louis' explanation of his anxiety in getting to know others on his course:

They talk about social life which I suppose is not too bad. For me though, I like to talk about my subject of art all the same. I don't mind talking about that, but to actually start a conversation is one of my greatest difficulties because I am rather a shy person.

Cathy also described a similar experience on the initial days on her course:

Well, I am rather a shy person when it comes to seminars. Most people speak before me... I do like working in groups. Although, most of the time, I try to get to know a person a bit and the people in my group. Well, I try to focus on the task. I try to put in ideas as much as I can.

The commonality running in the narratives of Ray, Louis and Cathy is not only an awareness of their shyness, but their desire to get to know a person on a one-to-one basis. This is best stated in Louis' assessment of being paired up with a stranger: 'It takes quite a bit of effort to get to know [a] person in a way.' This finding is consistent with Attwood's (2006, p. 56) observations when he recognised that the 'phrase "two's company, three's a crowd" is very appropriate for someone with AS'. Thus, in some respects, working in groups may be a barrier to their learning and compounds difficulties in engaging socially with peers. Also, there seems to be a real focus on trust among respondents. They want to know who is 'good' or who is 'bad'.

As Lisa, Karen, Ray, Louis and Cathy expressed their anxieties working with other students, Len and Alan had contrary experiences. Asked about any issues in working with others in a group during the initial weeks of the course, Len expressed not having difficulties:

We do our own group work, but then we write it up on our own or we supposedly write it up on our own. Basically, if one of us comes across a problem, it is probably going to be all of us, we got the same data and see if there are any errors. As soon as someone comes across an error, the person will ring up everybody else and say 'we took this measurement wrong' or something like that. So, we pretty much have to figure it out altogether. We just write it up in our own words.

Alan expressed an ease with working with groups as well. However, he realised there was a problem when other students in his politics seminar were not as keen as him in partaking in group discussions:

It is just seems to be me and the lecturer talking, that's it. Everyone sits there and bloody listens. So, there is no debate!

*Are you the only one who raises a hand?*

There is me; the one who can't do social things.

The experiences of Len and Alan are highlighted because they show the diversity of AS. While confirmation was given to the notion that students with AS may experience some difficulty working with other students (Attwood, 1998, 2006; Gillberg, 2002; Harpur *et al.*, 2003), there was also contrary evidence to suggest that some experience this with ease.

#### **4.2.3 Disclosing AS to other students and lecturers**

The diversity of the respondents was also reflected in their decisions to disclose to others. While a couple of respondents felt free to disclose they had AS, the majority

of them (five out of eight) were not keen. A commonality shared between respondents who did not disclose was that they saw AS more or less in a negative light. They perhaps did not want to be perceived as being unusual (Gillberg, 2002). This is not the fault of respondents. It is a reflection of how embedded negative stereotypes of disabled people are in wider society (Madriaga, 2007). This was certainly echoed in Ray's first interview when he stated that: '[My former school] sent me to a school (in another area) which had to do with AS. People there were a bit funny, because of the way they act innit?'

It is perhaps for this reason that respondents, like Karen, did not feel confident in disclosing her AS. She refused her impairment to the extent of not disclosing on a job application. She stated: '[The employer] asked, "Do you consider yourself to have a disability that could affect your work?" No!' Leaving an exam room reserved for students with special arrangements, she bumped into other students on her course. She approached their queries in an indirect fashion:

I just told them that I am special. And they are like okay, but I think they assume that I am dyslexic. I remember speaking to some people before the mid-term exams and the couple of people who came out the exam early, like I did, and we were talking about it. They just assumed that I was dyslexic. So, I just go with that. It is far easier than explaining anything else.

*That's cool. So, then, you are known as the student with dyslexia on your course?*

Yeah. I think my friend on the course is getting a bit worried that I seem to disappear every time there is an exam. It is like *no* I am just in a different room.

Karen's response provides some credence to Deal's (2006) notion of a hierarchy of impairments, where some impairments appear more socially acceptable than others. For instance, there may be fewer stigmas associated with dyslexia than AS. Her response was also indicative of the burdensome nature of disclosing. With dyslexia being more widely known, it may not require as lengthy an explanation as would AS. There remains a lack of awareness of AS. As Cathy had found when disclosing to her friends at university: 'I have told my friends, but I'm not sure if they understand it.'

Mark, like Karen, also experienced some anxieties over the issue of disclosure. However, at the beginning of his postgraduate degree, he approached the issue differently from previous personal experiences. Instead of refuting his impairment like Karen, he used it to inform those he lived with to explain his 'quiet' behaviour:

This year is quite a landmark. My last university I never really let on to anyone about my condition. In many ways, I still don't. It is a privacy that I guard really highly. My mother after many years of persuasion finally persuaded me to write an introductory letter to other members of the flat, stating who I am and this condition, whilst I may seem quiet and non-talkative and aloof, please don't take

it as being rude or anything. That was a very big breakthrough for me. It has had mixed success. For a start, there are two or three people in the flat of six who are less communicative than I am. Other ones are international students, so half of them did not understand the letter to begin with. The success has been that there is one person who understands the gist of the letter. We talk occasionally. But, he is Chinese with a strong accent. It is actually quite difficult to keep a conversation going there. But, it is more than it would have been otherwise.

What stands out from his narrative was that he was in control. He did not have to disclose, but he did willingly. Although this method of disclosure was somewhat successful for him, it may not prove successful for others.

In contrast to Karen and Mark, Alan did not see disclosing as an issue. However, like Mark, Alan shared his impairment, disclosing to students living in his accommodation: 'Like I told some of the lads in my halls, they were quite interested actually. It was not an issue.' He also felt comfortable disclosing his condition to one of his lecturers, although he indicated it may have been a bit pointless:

Yes, I did tell him about it... I mean my (disability co-ordinator) has sent him a email just to say, 'this chap in your tutor group has a learning disability, in inverted commas, and he says, 'oh I do remember seeing something about that' and I thought 'well did you ever look into it?' 'Well, no.' Well, surely the idea is, if you've got... I don't know... 15 students in your care that you should at least read up on it.

Having to disclose to others was a scenario that the majority of respondents aimed to avoid. However, for a couple of respondents disclosure was deemed necessary. Mark, although hesitant, disclosed to his flatmates so they would not perceive him to be rude. Alan disclosed to make sure that his lecturer knew of his 'learning disability'. These two respondents wanted their AS *difference* to be recognised by others, so they can socially engage with other students and staff. Disclosing, not refusing impairment, worked extremely well for Alan and had mixed success for Mark.

#### **4.2.4 Students with AS disclosing other impairments (and illnesses)**

Mark is one of three respondents in this study who indicated that they have mental health difficulties, more specifically depression. While Mark indicated that depression is attributed to the social isolation brought forth from communication and sensory difficulties of AS, Karen believed her depression is mutually exclusive of her AS. She associated her depression with failed friendships back 'home'. Although Mark and Karen have contrasting views of the link between depression and AS, they both comprehend AS to be a very significant part of their lives. This differs from Lisa and Ray who both rank AS as a low priority in relation to their other impairments.

Lisa is the third respondent who disclosed in her interviews that she has depression. Not only this, she also has a diagnosis of dyslexia and severe food allergies. It is the food allergies that she has determined to be the most important out of all her impairments because, as she stated: 'The others won't kill me.' She established a hierarchy of impairments in her own mind according to the severity of consequences. For instance, she can see herself dying from her food allergies, not from having dyslexia. It is for this reason that she felt compelled to disclose her food allergies to lecturers and other students on her course, especially when they had to go on field trips. It is on field trips where environments were new and provoked fear:

I mean that was a major worry that I discussed for many weeks with my mentor before going on the field trip was the fact that I told these people that I can't eat food and I'd got so many questions like what's the room layout cause I like to know where my room is in association to the level I'm working at. So I can just map everything in my head and like, what's the actual timetable. What are we doing in that week, just so I can prepare for it, so it wouldn't become such a big change to my timetable. I just felt really bad that I was asking all these questions that I was getting in their way, annoying them, stopping them from doing their work.

Though worried about what others might think of her upon disclosing, she had a very supportive lecturer who helped make a field trip inclusive for her:

Yeah, he was understanding and like he sent me a map of the room lay out. He did what he could. He's never heard of what I had, he was like, aren't you just allergic to nuts? What is this ulcer thing? But I find that quite a few people just don't even know what it is. So he was like, give us a list of what you feel needs to be put into place and we'll put it in place. So I had freewill to go, 'okay I want this, this, this and this'.

Ray ranks having epilepsy ahead of having AS. The severity of his epilepsy is to the extent that he needs a taxi to and from university because, as he stated: 'I just suffer from a fit and walk into the road and get run over.' With regard to disclosing, he understood his disability co-ordinator had made his lecturers aware of his epilepsy. However, it became clear that his lecturers and other students may not be aware of his condition. This leaves him feeling embarrassed whenever he has a fit in a lecture:

'Cos in one (lecture), we have like, tests on Friday and I had a fit then and I was sitting at one of the long desks and like I'm off moving to the other side (laughs). I didn't know what to do. When I came out of it and I was on the other side I was like, 'what the hell am I doing?' And after I've had a fit, my mind is dead for an hour.

*Right, of course, because you'd need loads of time to recover. Did the students around there, or the lecturers know what to do?*



Not too sure, I don't know what I was doing.

The reason for highlighting respondents' 'other' impairments is to emphasise once again the diversity of these respondents and how they see AS in their lives. As Lisa and Ray have shown in their narratives, they do not regard AS highly in relation to their other impairments. Moreover, by highlighting their other impairments, this report helps present the additional barriers they face on a daily basis.

### **4.3 Accommodation**

Given the social aspects of university life, this section draws attention to the living arrangements of respondents. Four out of the eight respondents resided in university-owned, shared student accommodation. The other half of respondents lived with their parents, commuting to university. Their experiences will be detailed below.

#### **4.3.1 Living at home with parents**

The close proximity of university to parental home and the issue of finances were two reasons behind half the respondents choosing to remain living at home. While explanations of finance have confirmed existing evidence of why students, in general, choose to live at home (Patiniotis and Holdsworth, 2005), there is very little attention paid to the disabled student experience. Grewal *et al.* (2004, p. 55) have suggested that disabled people tend to go to their local HEI or college rather than move away from home because they believe they will be losing an existing or required service. Help with coursework from parents is an example of this 'existing' service. However, this suggestion does not reflect the data presented here. For instance, Louis factored in the proximity of a railway station in deciding where he would pursue HE studies. He lived 26 miles away from his institution. He did not mind his daily commute and said his parents were 'happy about it'. He also envisioned he would be doing it for the next three years. Cathy was another respondent who chose to pursue HE study near her parental home. She indicated that the 'accessibility' of the university from her village was a big factor in her decision. Asked what she meant by 'accessibility', her response was:

Well, essentially, to get to [university city] from [village], I could either go by car or by train or by bus. Now, by car, it takes about a half-hour to get here. By train, it takes a half-hour as well. By bus, it takes an hour. But, the bus is cheaper than the train really.

When questioned about how she found the commute, she stated: 'Well, going on the bus or train, is quite relaxing to me really. Although at times, the train can get crowded. Yes, especially in the morning before nine.' Her one-hour commute from her parental home to university was not an obstacle in participating in five different student societies. So, although living at 'home', she was making an effort in

immersing herself into university social life (Holdsworth, 2006). Cathy is one of the increasing numbers of students being recruited from 'non-traditional' backgrounds into HE who are staying at home for their duration of their studies (Patinoitis and Holdsworth, 2005).

In addition to proximity of family home to university, two other respondents also discussed the financial benefits of living at home. For Ray, finances were a big issue. He expressed frustration that tuition costs were £3,000 a year after being told by the university that if he 'done well' in college he could be awarded with £800. He stated that he 'got all distinctions' in college and was upset to find out that he could not get the £800 award due to his parents' income:

I came here and they said that my parents have to be earning less than £33,000, people who you are living with. They don't even give me anything. So, it doesn't matter really if your parents are only earning so much.

He decided to live at home after learning it would cost him £5,500 a year if he were to live in student accommodation. As he stated: 'I did not think I was going to stay here [university]. £5,500 is a lot!' He said in a later interview that 'If you live near university you can save a lot.' His decision to remain at home was to the dismay of his parents. He explained: 'I think they are getting a bit annoyed at the moment... They wanted me to stay at the university. They need a break.'

Like Ray, Lisa also cited finances in her reasons for remaining at home and commuting to university. However, she was preoccupied about her initial decision throughout the year, eventually expressing interest in moving into student accommodation the following academic year. In her first interview, she said: 'I am used to [commuting]. It does not bother me at all. I prefer to commute than have to live up here.' Her two-hour commute to university entailed 'a bus, two trains, the [tram] and short walks'. She said the travel was 'fun' and described: 'On the way in, I just kind of sit there with my diary, thinking what do I have to hand in today? What's in tomorrow? What do I need to read? So, I use the time to organise and plan.' Her views of commuting from the first interview contrasted with what she said later in a second interview. She said of commuting: 'After doing it for some time and having to sit through delays, then you realise. I think during the first few weeks, you are like "Wow, I am commuting." Afterwards, like six months, this is not interesting at all!' Working with the disability student centre, she was able to get a place in student accommodation for the following year. She expressed her rationale for this move:

I feel like I am a step behind everyone else. I feel like a little baby who still lives at home. I would like to have some sort of independence. I mean I don't really do much socially anyway. But, I would feel at least that I have had the chance to.

Seeking independence and engaging socially with other students fuelled her desire to move into student accommodation. This, she said, would be a 'positive move' as her social life has gone downhill:

I think it has gone downhill because I used to be members of stage crews and first aid courses. But, of course, I have to go home and have my dinner then I commute back up to join the clubs. So, that made it into a six-hour commute every day.

In the third interview, she gave up on the idea of moving into student accommodation. She said her decision to remain at home was influenced by her parents' negative reaction of the idea, as she explained:

Well actually it wasn't really me who changed my mind. It was my parents. I'd discussed it with my parents and they were really negative, and I feel like as soon as you've lost the support it puts such an onus, I don't feel confident anymore. And even though I know that they will support me, I know that their hearts are not truly in it. So it's put a lot of worry in me and I've backed out of it and I'm staying at home.

Although she was frustrated with her parents' decision, she was able to have a positive attitude as she has recognised that she will not feel like the only one living at home next year:

I can see the logic behind staying at home but I do feel disappointed that no one has supported me and the fact that I'm not up here [living nearer to university]. I'm still gonna be stuck in the same situation. Although it's slightly better cause everyone that's been living in halls this year are moving back to their houses next year because they can't afford to live in [the city]. So instead of being the only one at home I'm now gonna be just one of the many.

#### **4.3.1.1 Parental role**

Lisa's story shows the influence parents have on many of the respondents. Although Lisa expressed disappointment at her parents' negative reaction to her desire to move from home, she does recognise the support and concern her parents have for her. Confirming Gray's (2002) findings, many of the respondents in this study found their parents, most specifically their mothers, to be the most supportive people in their lives. For instance, Lisa has found bringing her mum to doctor's appointments very helpful. Asked about this, she responded:

Because I had to talk to a new person that I didn't know and it would be scary, and [they would] ask me complicated questions I didn't know the answer to. Then I'm like, do you understand, and apparently I just sit there and stare blankly at people and then they looked at my mother and she says, 'don't worry, she understands, she normally stares like that'.

*Have you always brought your mum, when you get to these different scenarios, like the assessment of need?*

I take my mum even if I'm going to a doctor's appointment, 'cos the doctor's like 'do you understand when you have to take your medication?' to my mum 'does she actually know?' 'Yes, she does.' 'Cos like people can't interpret what I mean or say so my mum's like an interpreter.

Other respondents expressed similar sentiments about the practical, as well as emotional support, they get from their parents:

My mother is an absolute rock. I would have not got anywhere without her. I just wouldn't be able to do it. I wouldn't have been able to get my first degree. I have an absolute mad passionate hate for forms. So, every time I get a form, I just throw it to her direction and say: 'Here you are, there is another one.' And, she fills them in. Without her, I just couldn't do it. I never get passed filling in the forms, never mind doing the courses. (Mark)

I talked to my parents about the many problems that I had. It is my mother, mostly, who tries to tell me about what I should do in a situation where I am shy. She tells me sort of the things I should be looking out for and how to communicate with people properly. I often dislike listening to all of this. But, it is normally after she has finished talking I consider what she said. Her voice is going through my mind about the sort of things she tells me about. If I don't talk to people enough or don't talk at all, they will not know what sort of person I am. (Louis)

Parents also recognised their role in their son or daughter's lives. As the mother of one of the respondents stated: 'I don't think [parents] should let their youngsters go it alone as 18- or 19-year-olds are expected to do. They definitely need the support... [My son] has taking a lot longer to mature and a lot longer to grow up.'

While several respondents expressed encouragement from support they received from their parents, there were a couple of respondents who desired some independence from them. This is consistent with findings from other studies (e.g. Parker, 1999). Karen was one of the respondents who desired independence:

I always wanted more independence. My mum is a bit clingy. I think that it has made me more determined to be independent than everything else. She perceives me as not being able to cope, whereas I can. I generally don't cope when she is being clingy.

It is this desire of independence that resonated in Len's advice to parents of students with AS: 'You don't have to do too much worrying or helping, because the person at university has to find out what to do themselves, but always be ready to help if you need to be.'

#### **4.3.2 Living in student accommodation**

The other half of the respondents were able to gain a sense of independence via living in student accommodation. While Mark and Alan had previous experience of living away from their respective parental homes, Len and Karen did not. They not only had to contend with absorbing the rigours of HE study, but also had to learn to live independently in shared accommodation. Both Len and Karen generally spoke of positive experiences of living away from home. However, when asked about living on his own during the initial interview, Len responded:

It was extremely boring and depressing at first, because the room was just brick and painted white. It was like living in a white box. In the end, I was able to get some posters and books from home and stick them around the room. So, now it does not actually look so boring and depressing everywhere. Now, when I look at places, I have got something to look at instead of the white wall. It makes it a lot better.

Despite the drawback of moving into a 'boring and depressing' room, Len indicated that he got on well with his housemates. The kitchen was the meeting place, where they would sit around and talk. Sometimes, he and his housemates would collaborate on meals together, as he described: 'Normally it works out that only one of us has chicken, one of us has sauce, and one of us has rice so we just cook a big curry.' This finding reflects previous literature suggesting that living in student residence enhances a sense of social integration (Harvey *et al.*, 2006) Although the respondent described a harmonious living arrangement in first interview, he stated in second interview that he will be not be living with any of his first-year flatmates next year:

*How's living with your housemates?*

I don't see any of them much, because they seem to sleep all day and be out all night. There's one I've only seen three times since Christmas, and all three times he was on his way out to get drunk. I don't know how he's been going in his exams. He seems just to be drunk every single night...

*Will [next year's accommodation] mostly be comprised of your coursemates then?*

Yeah I think there's three or four of my coursemates, three or four other people from the flats of my friends who I'd go over to see and I'd see their flatmates more than I'd see mine, 'cos they don't seem to be asleep all day and out all night. So I talk to them much more.

Like Len, Karen readily embraced university life. She recognised that moving into student accommodation was not as big a transition for her as it would be for other students with AS:

Because Dad is away a lot and he has been away a lot for most of my life. I am used to not seeing him for long stretches of time. So, I am more used to it than anybody else. I think a lot of people with Asperger's who I have spoke with in uni, their main problem is that their family has always been there for their entire lives and a lot of them have been overly-supported and they have gone to uni and like aaaaarrgh (frightened) – 'I need to try to do things for myself!' And, I am just like yeah, I can do this (laughing). I'm fine.

Since moving to university, she has also acknowledged she never once felt homesick. This may be attributed to associating university life with a renewed sense of self, while her ties to friendships back 'home' equated to stress and anxiety. Her new friendships at university revolved around relationships with her first-year flatmates. A sense of trust was able to grow between her and several of her flatmates, which resulted in them deciding to move into a shared house together for the following year.

As stated earlier, Alan and Mark have both lived independently prior to moving into student accommodation. As a mature student, Alan chose student living arrangements. Asked why, his response was:

I couldn't do it when I was 18, when I should have done it, because I did not have the skills to do it. I thought I want to say that I spent a year in halls, having a crack and getting pissed. That's why I did it! This is my 18 now! I am 30, yes. I get called the old man or the old bastard at the end. They are quite awful to me sometimes at the halls, but it is all in jest.

While Alan enjoyed the 'crack' of living in student accommodation, Mark spoke of having a difficult time. Social isolation gets the best of him, as he explained: 'Well, I could always wish for more. But, you know there are no answers. Believe me, I have looked (chuckle). The only thing that I found I can do is just grit my teeth and get on with it.' It is this isolation that Harpur *et al.* (2003) finds problematic for students with AS living in shared accommodation. This isolation can lead feelings of exclusion as well as depression. However, Attwood (2006) argued that being alone can be considered a comfort for some individuals with AS. Reflecting upon responses given for not attending fresher's week, Attwood's argument is very pertinent.

Karen was the only one out of the four respondents living in student accommodation who actually established close friendships with her flatmates. Thus, from the evidence presented here, living in student accommodation may increase opportunities for students with AS to interact socially with other students. However, it may not aid one to develop a social timetable, which was desired by many of the respondents.

#### **4.4 The role of disabled student support teams in HE**

In concluding their report, Blamires and Gee (2002, p. 22) indicated that there were three areas to focus on in raising aspirations of students with autistic spectrum 'disorders' in HE:

- academic
- social
- notetakers/enablers.

The *academic* suggestions included raising AS awareness among teaching staff and providing lecturers with resources to teach students with 'social and communication needs' (ibid). The *social* suggestions included the provision of buddy/mentor systems for students with AS. The *notetaker/enabler* suggestion dealt with everyday practical support of notetakers/enablers for the benefit of students with AS. All three areas listed by Blamires and Gee (2002) lay in the remit of many disabled student support teams in UK HE. This should come as no surprise, as disability issues have been usually confined within the student services arena rather than academic departments (Adams and Brown, 2000; Fuller *et al.*, 2004). Thus, disabled student support teams have a pivotal role in ensuring that students with AS do not encounter barriers, both in and outside the classroom, within their institutions.

It must be reiterated that there is a wide range of *differences* underneath the 'label' of AS (Bogdashina, 2006; Howley, 2004). As a result, disabled student support teams have to be flexible and offer a variety of support. Only with permission from the student may helpful advice come from a parent (Martin, 2006). As one parent commented: 'I always meet with the "head honcho" on the disabled student support team.' Much of the support a disabled student support team can offer is dependent on resources, with a huge proportion of funding deriving from Disabled Students' Allowances (DSA). DSAs are awarded by local education authorities (LEAs) to students who can provide medical evidence that they have a disability, a medical condition or a specific learning difficulty that affects their ability to study. This allowance is not means tested, and it pays for any extra costs that a student may incur as a direct result of being disabled while attending an HE course.

All respondents in the study received DSAs. These allowances helped resource specific support many of them received such as a mentor/buddy, a notetaker/enabler or tutorial support.

#### **4.4.1 Mentor/buddy support**

Appointing a mentor, or 'buddy', to a student with AS in HE is perceived as a way forward in breaking down social barriers with peers (Blamires and Gee, 2002; Martin, 2005) and academic staff (Howley, 2004). In contrast to Blamires and Gee (2002), Howley (2004, p. 10) makes a distinction between mentor support and peer support through buddy schemes. The former is usually composed of non-students who work on an hourly rate, while the latter support is driven by student participation:

Peer support may promote collaborative interaction, co-operation and negotiation. Peer support through 'buddy' schemes can be provided by understanding, supportive peers and can be particularly successful in helping the Aspie student to participate; for example a buddy may be helpful in providing orientation around a campus, aid use of library facilities or provide support during a field trip... The use of academic and peer mentors for Aspies may be helpful in two key ways: firstly an academic mentor can mediate between a student and tutors, particularly when misunderstandings arise; secondly, a mentor can provide information for the student to explain social/academic etiquette.

Six out of eight respondents stated they had mentors at one point or another during the study. Their mentors were not 'buddies' in the Howley (2004) sense, however they did do 'buddy'-type tasks, such as providing orientation around campus. For instance, both Cathy and Karen were accompanied by their mentors during their respective fresher's fairs. Cathy's mentor stated that she was more intimidated about the event than her mentee:

It was incredibly noisy and incredibly busy. There were bodies everywhere and I found it quite intimidating, but she was really confident. We went, talked to people. I sometimes initiated conversations but then she would continue. So I think really she just needed someone to be there to part the people and just be there.

Half of the respondents saw their mentors as mediators, counsellors or people who are just there to help. Len explained how he worked with his mentor:

*Before you said you were seeing a mentor from the Disabled Student Support Team. How was that?*

That was okay. I just went and spoke every week to make sure I was getting on okay really.

*And what sort of things did you discuss?*

Pretty much anything general really, whether I was having any trouble in lectures or anything like that...

*I think that's quite cool, and you say you get on with her?*

Yes. So I think just knowing there's a mentor there and knowing I can use her if I need to get my work sorted and stuff like that...

*Out of curiosity, what other things does she do to help you out?*

Mostly just talks to me, asks how things are, if I need any help, but it's been a fairly easy year this year...



*Do you recommend other students with Asperger's having a mentor?*

Yes I think so. Like, it probably doesn't have to be every week. You could talk to them every fortnight and look through your notes. Spend an hour or so just to make sure everything's going okay.

*Does your mentor liaise with any of your lecturers?*

I think she can do if she needed to, if I was having trouble accessing lecturers' notes she could go to the lecturer and get the notes on my behalf, but I never had to use that 'cos I managed to get all the notes fine.

Karen talked about her mentor in a similar same way:

I meet her once a week and we talk for about an hour. She will sort out anything that I have major problems with. I don't like calling people, particularly anything that has to do with my personal tutors. I don't like calling them. So, she will do that for me. She will make sure that I am getting on okay. She will write a list of things for me to do, like by next week, so that she keeps tabs on me. I need someone to remind me that I do need to do these things.

As respondents remarked of the benefits of working with a mentor, a couple of them wanted to become less dependent upon them (Parker, 1999). Cathy and Louis were two respondents who found their mentors quite helpful towards the beginning of the year; however, they eventually sought independence from them as they became more settled. Cathy explained why she did not require mentoring support:

Yes, I guess it's down to confidence.

*So, is that something that can be counted as gaining success – being independent?*

Not always. Working independently is an important skill, yes, but asking for help about things that you don't understand, a text or work, can help.

*Would you agree that you have become more independent this year?*

A bit more, yes.

*Is that something you're trying to aim for?*

Well, essentially I do want to work hard on my own.

Establishing a sense of interdependence was also important for Louis. His mentor, or 'student support worker', observed this as well. She has found that Louis has

become more confident since his first days at the institution. In addition, she has said that he likes to do things alone, which requires less time from her. Instead of working with his mentor on an essay, Louis wanted to try it on his own as he explained:

I didn't get any help because I didn't want any help. I wanted to do the project by myself and I did a very good job actually. It was the very first time and I was very proud of it. I felt while I was doing the project, I didn't want to go and ask for any help because I wanted to show people that I can do something by myself. I wanted to show people that I have got the ability. I just need the chance to prove myself.

While the likes of Karen, Len, Mark, Cathy and Louis found their mentors very supportive and encouraging, Lisa and Alan saw mentors as not being qualified to meet their needs. Lisa indicated that she saw her mentor for practical help, but not for emotional help: 'my mentor is not a trained counsellor, so, she can't.' Having a mentor who can help with depression, like a counsellor, was the kind of support she had sought throughout the year. Unfortunately, she was not able to access a counsellor during her first year. Alan made a similar comment about mentors not being qualified:

They have this mentor scheme which is, who's my mentor? [Names person] She's just like a... a Masters student. So she's already done her degree and she's doing a further year for her Masters, and she was doing the mentor scheme, but to be honest with you, they're not really, they're not qualified or anything. They... ah... it's just a cheap method to be honest. That's the impression I got.

Although respondents' attitude towards mentoring support may appear mixed, half of the respondents found their mentors to be helpful and supportive. This positive feedback may stem from the variety of support respondents expect from their mentors such as: accompanying them to the fresher's fair; helping them with the organisation of their lecture notes; and liaising with tutors on their behalf. One mentor commented on the support she has been expected to offer as 'making it up as you go along' depending on what the student requires. Thus, mentoring support has to reflect the diversity of students with AS.

#### **4.4.2 Notetaker support**

Only two respondents, Cathy and Alan, have indicated that they have notetaking support. Having this support has been beneficial for them, as Cathy explained:

... it makes things a whole lot easier for me, because I can get things, like more information and details about the history, that background behind set texts for the module. Well, sometimes, the speed of the speakers in the lectures is a bit overwhelming to me.

While Cathy and Alan herald their notetaking support, the majority of respondents indicated that they do not feel it is necessary for them. This, of course, reflects the diversity of the respondents. Perhaps, a reason for the low take-up rate may be the result of the stigma attached to having this support. Ray explained this stigma: 'At college, I found it a bit embarrassing. There would be a 40-year-old lady with me, taking notes. My mates would be having a laugh there sometimes. She is like being my mother (chuckle).' In contrast to Ray, Alan did not seem too concerned about how he may be perceived in having this notetaking support:

(My disability advisor) asked me if I wanted [staff and other student] to know. I said do you want them to sit by me? Of course, really! If I was to turn up to the lecture hall and they were there before me, just tell them to sit down and just write it. It doesn't bother me. I will take my own notes as well for what they are worth. In the classes, I will let the teacher know.

Despite explaining the positives of having this support, respondents did expose the negative aspects. Alan did not like the delay in getting his support at the beginning of the year: 'I only just had notetakers three or four weeks into the course, that all should have been sorted before.' Cathy mentioned that there have been times when she did not have notetaking support consistently. She explained: 'There have been some problems with organising notetakers. She missed out on at least two of my seminars on Tuesday mornings. The first time was because she went to the wrong room.'

#### **4.4.3 Tutorial support**

Two respondents, Karen and Ray, have claimed they receive tutorial support funded through DSA. However, getting this support has not been easy for them. They had to take the initiative and lobby their respective disabled student support to get specific tutorial support. For instance, Karen had asked for tutoring support in statistics for her psychology course throughout her first semester. She had to work with her disabled student support team to negotiate with her LEA in getting this specific support:

I was supposed to originally have notetaking and essay writing skills classes. But, we exchanged that for some statistics time instead. They had to apply for more because I needed more statistics help. It all went chaotic last term, because they couldn't work out what I needed. They were trying to give me things that I did not need.

It was not until her second semester that she was able to get the statistics support she desperately wanted. Of course, the support offered to Karen initially was contrary to what she needed, thus producing a negative scenario. The issue was rectified because she was able to negotiate her needs with the disabled student support team. This negotiation took time and produced anxious moments for Karen.

This problem may have been prevented if Karen was informed of the flexible nature of her support, during her initial meetings with her disabled student support team, rather than feeling it was etched in stone.

Unlike Karen, Ray was able to convince his disabled student support team early on to provide tutorial support for web programming. However, the downside was that his tutor was not very co-operative or knowledgeable, leaving Ray fuming:

I'm waiting for him, and most of the time he's outside on the phone. Last week he didn't turn up. He didn't ring me or anything... There's no point in being there. I think they earn about 25 pounds an hour.

*That's true and you're supposed to meet him once a week, isn't it?*

Yeah, well I could get two hours a week.

*So did you tell this to [disability co-ordinator], or somebody over there about that?*

Sometimes, but I just can't be arsed now. I've said it once or twice now and I just gave up.

*Were there advantages of having him?*

Not really because he didn't understand the questions either.

In a later interview, Ray explained how he was able to get the support entitled to him:

I spoke to someone else, who the disabled student support team talk to, to give me my support. I told him that I knew some students who would be happy to go through my work and help me out. I gave them their names. In the last couple of weeks, they were going over my work with me. That was better as well. It is better when students do it, because they got more experience [sic]. It felt like I knew more than that other bloke. These students went through the first year.

Receiving tutorial support was a difficult matter for these two respondents. For Karen, it was a matter of amending her disabled student allowances to free up resources to pay for tutorial help. For Ray, the difficulty arose from initially being appointed an uninspiring tutor.

In addition to receiving DSA, all respondents may also be offered alternative or flexible assessment arrangements, such as having extended deadlines on coursework or extra time on exams.

#### **4.4.4 Coursework/exam arrangements**

Although having allowances in place, all respondents surveyed did not ask for extensions in submitting their coursework. This may be related to earlier comments by Cathy and Louis regarding independence and wanting to prove to people 'that they have the ability'. Mark elaborated on this position in responding to a question about coursework extensions:

...throughout all of my academic career I've never wanted special consideration to be taken for me in the sense of when the work's been marked, I've always wanted my work to be marked in the same way and at the same level as my peers, and I've never wanted consideration given to the fact that I'm disabled or extended deadlines because other people wouldn't necessarily have that option, and while I understand why it's available for people like us, and it's a good thing that it is, I've never wanted to cross that line where I've needed that kind of special consideration. I've wanted to be marked in the same way as my peers.

While all respondents did not take up the offer of coursework extensions, seven out of the eight respondents, however, did see the benefits of taking their exams in separate accommodation from their peers. One of the benefits was being allowed extra time on exams. Lisa embraced this allowance having had prior difficulties taking exams:

I wanted to get some more time 'cos of the stress things and anxiety, and also I always have a problem with exam scripts. Like one of the A-level ones was like 'name this part of the cell' and I was like, well, the common name or the scientific name? It was a two-mark question and I spent a half-an-hour thinking and interpreting what the damn question wants me to answer. I know the answer, but I don't know what answer you want.

Respondents were comforted with the knowledge that they had extra time, although some did not practically need it:

I didn't actually use the extra time, but it was a lot of comfort knowing it was there... 'cos I didn't have to rush at all. I finished within all the preset time zones. (Len)

...in the two exams that I did, I finished early. In fact, I finished ridiculously early even with extra time. I think I finished the first one in a half-hour of an hour and a bit including extra time... From speaking to people online, the main reason why people with Asperger's need extra time is to not have stress. They don't necessarily need extra time. They just need to know that they got the time [sic]. That is the important bit! (Karen)

Another benefit in taking exams in separate accommodation for some respondents was being cut off from a big group:

To be honest with you, for myself, it is not too much having extra time. I don't think the extra time benefits me that much. It might benefit other people, but not myself personally. It is more about being in a big room with a lot of people. I can't do exams in big rooms with lines of chairs and tables. (Alan)

Ray believed it was necessary to be in an exam room alone because of his epilepsy:

I wanted to be in a separate room, on my own, just in case I have a fit. When there are other people, I will be making noises. It will be distracting for everyone else there. That would really embarrass me as well.

Although many respondents found alternative exam arrangements helpful, providing them a relief from anxiety and stress, a couple of them did experience bad practice in their institution's implementation of this allowance:

The rooms was a bit of a stress because half the time, they put me in a room with no computers for a computer exam, which I had to go and I realised the day before because I had an exam in there that day and I looked around and there were no computers in there, and tomorrow I'd got a computer exam... so I had to go and sort that out myself. (Len)

I didn't get extra time on this last exam and I didn't actually need it – I finished before the end of the exam anyway. I was a bit like, what happened? Normally I have an email that says, 'you need to go through this person and arrange it' and then I'll get an email some days later saying 'you have extra time'. I didn't have anything. I didn't have an email saying go through this person, I didn't have an email saying you have extra time. The first time round I was actually in the same room as everybody else, but it was just more slightly annoying than anything else. If I needed it, it would have been worse, but as I finished before the end anyway so it was okay [sic]. (Karen)

Overall, respondents were quite pleased with the support they received from their respective disabled student support teams. Because of the positive support she received, Lisa argued that a meeting between a disabled student and a disabled student support staff member should be made 'compulsory' at the beginning of the year:

You know there's people to talk to and report back on and will listen, and then it's not up to you, 'cos I think making the first move is pretty much the hardest thing to do. I can't make a first move.

Although there was much praise for the work of disabled student support teams, there was also some evidence showing that support must be improved to ensure inclusivity.

## 5. Conclusions

This report has attempted to increase awareness of the *differences* of students with AS by representing their voices. In doing so, there was no attempt to pathologise and perpetuate 'official', medical model conceptions of AS. Hence, in addition to raising awareness of the barriers students with AS face in HE, this report also set out to represent the diverse voices of students with AS that have often been left unheard throughout the literature. Of course, a few findings reported here confirm existing ideas about the 'medical' nature of AS, such as students having difficulties processing information in lectures, working in groups and disclosing their condition (Attwood, 1998, 2006; Blamires and Gee, 2002; Harpur *et al.* 2003). However, from the evidence presented here, it would be incorrect to conclude that these difficulties were primarily the result of the impairment effects of AS. These difficulties can also be credited to a lack of good practice in teaching as well as lack of awareness of disability issues.

Yes, in a medical model view, this report confirms the notion that individuals with AS have differences processing information in a learning context (Attwood, 1998, 2006; Blamires and Gee, 2002; Harpur *et al.*, 2003). Several of the respondents described their difficulties in ascertaining information from lectures. It is for this reason that students with AS are recommended notetaking support from their respective disabled student support teams. However, the difficulties these respondents described may be more the result of teaching methods employed rather than on their so-called individual 'deficits'. Half of respondents (four out of eight) did not appreciate some of the teaching methods employed by many of their lecturers. They expected more than a lecturer talking for an hour without making an effort to entice them. Karen, Alan and Len remarked that their favourite lecturers were those who made them laugh, as well as those who employed visual aids or music to enhance their learning experience.

The report also confirms that students with AS have difficulties working in groups. Six out of eight respondents frowned upon group work. Working in groups may be a barrier to both learning and engaging socially with their peers. A more ideal situation for at least three of the students was getting to know another on a one-to-one basis rather than in a group setting. Although this finding confirms existing knowledge of individuals with AS (Attwood, 2006; Blamires and Gee, 2002; Harpur *et al.*, 2003), there was some contrary evidence as well. Two respondents experienced ease in working in groups. Thus, this finding suggests that not all students with AS experience anxiety in group settings.

The report also confirms evidence that universities fail to disseminate confidential information to lecturers about students with AS in their classes effectively (Borland and James, 1999; Madriaga, 2007). Of course, there is a data protection issue. Transferring confidential information from central services to academic departments has to be handled with care. However, this sensitive information is not being transferred to those working with students. This has led to a majority of

respondents being placed in anxiety-ridden scenarios. Five out of eight respondents expressed discomfort in disclosing their AS to lecturers and other students. This finding should come as no surprise considering the stigma associated with AS (Attwood, 2006), or any other impairment (Deal, 2006). Not only were respondents hesitant in disclosing AS, they were also anxious about disclosing other impairments. For a couple of respondents, other impairments were rated more significantly than AS. It is this diversity that presents new challenges in supporting students with AS in HE. Instead of seeing students on a spectrum, HE teaching and support staff should look at students with AS holistically. As respondent Karen argued, a person with AS 'is more than their diagnosis. Diagnosis comes second. They will always be themselves first.'

Another new challenge is that all practitioners must accept the idea that students with AS are happy about being an HE student. In previous literature, this euphoria has not been discussed. This is perhaps the result of having a practitioner-focus, where the voices of students are in the background. Arriving at university is a time for reinvention, as it would be for all students, disabled and non-disabled. However, this moment in life has particular importance for students with AS, especially when respondents, like Alan and Karen, remarked on how their impairment has hindered them in forming friendships in previous school/college experiences. Of course, these difficulties have been well documented (Attwood, 1998, 2006; Gillberg, 2002; Harpur *et al.*, 2003; Molloy and Vasil, 2004). An encouraging finding was how euphoria spilled over towards attending social events. Although respondents recognised and understood that they may have communicative and sensory impairments, six out of eight respondents attended their institution's fresher's week fair. Three of them enlisted themselves into student societies during this event. Although attending the fresher's fair posed no issues for half of the respondents, this was not the case for two respondents. Alan and Mark did not want to engage with the noise, the crowd and the claustrophobia that accompanied the fresher's week fair.

Another challenge is that not all respondents were able to overcome issues of social isolation by living in student-shared accommodation. To some writers (Harpur *et al.*, 2003), this may be seen as problematical for individuals with AS. In contrast, Attwood (2006) argued that being alone can be considered a comfort for some. Four out of eight respondents lived in shared student accommodation, placing them in an ideal setting to develop a social timetable. However, out of those four respondents, only one respondent actually established close friendships with flatmates. Thus, living in student accommodation may not aid a student with AS to develop a social timetable. The other half of respondents continued to live in the parental home. Although financially feasible to live at home, it prevented Lisa from partaking in student union activities. While living at home posed a barrier for a few respondents to socially engage with other students, it did not pose a barrier for Cathy, who was able to participate in five different student union societies.

As living in student-shared accommodation cannot guarantee success over social isolation, the same can be said of participation in student union activities. There was evidence to show that partaking in student union activities was positive for a few



respondents in making a successful transition into university. However, it was not the case for others, providing evidence that joining in student societies can never guarantee full immersion into university life or friendship.

From the evidence provided, many of the challenges facing disabled student support teams are not new (Madriaga, 2007). There continues to be poor practice in implementing notetaking and tutorial support for students. For instance, Cathy was left without a notetaker in her lectures in some instances and Alan had to wait almost a month for notetaking support to be arranged. Of course, these are matters of resource and timing, as students may have to wait for LEA approval in order to fund necessary support. This wait may take up to several months. To remedy this issue, Martin (2006) has suggested that DSA needs assessment could be conducted as early as April in the year of entry, which will assist in ensuring that support will be in place at the beginning of the year. Having an early DSA assessment should be considered a pre-entry activity in the same vein as HE taster event courses, as they both inform student expectations upon arrival into HE.

Respondents have also observed a need for improved alternative exam arrangements. All respondents listed and identified benefits in being placed in a separate room for exams. However, some respondents experienced disappointments. Len was scheduled to take a computer exam in a room without a computer. He had to take the initiative and ensure that the necessary arrangements were made. In another instance of poor practice, Karen was not placed in separate accommodation for one of her exams in the second semester. She did not expect this, as she had been in separate accommodation in the first semester. Lack of consistency in support arrangements constitutes poor practice and institutions are at fault here.

The only challenge that was not new for disabled student support teams was the ambiguity of mentoring support for students with AS. Six out of eight respondents had mentoring support and held it in high regard. The ambiguity of this support was viewed positively as it allowed for flexible, multifaceted support. Since students with AS have varying needs, they expect mentors to offer a variety of support, such as organising notes, liaising with academic staff on their behalf, or keeping them accountable to a weekly routine. The extent of this flexibility allowed students like Cathy and Louis to become more confident about working independently from their support workers.

Many of the barriers faced by respondents were not the result of their condition. They were and are perpetuated by poor practice and lack of disability awareness within HEIs. With evidence presented here, there still remains a significant gap between policy and practice in these public institutions. It is hoped that the recommendations below may help inform ways to narrow this gap, ensuring equality for all students.

## 6. Recommendations (to break down barriers of exclusion)

All recommendations were derived from the research. Underlying these recommendations was the recognition that higher education institutions (HEIs) have a legal duty to take positive steps in ensuring disability equality.

Recommendations for Government and HEIs:

- The Disability Equality Duty (2006) needs to be recognised as a legal duty in instilling a culture of valuing diversity within HEIs.
- The notion that confronting disablism is a university-wide issue, not just an issue reserved for student services, needs to be reinforced. This means academic faculties and departments should be held more accountable in curtailing disabling practices.
- Teaching staff should be enabled to achieve good practice in teaching, learning and assessment for all students. For instance, resources should be made available for teaching staff to develop professionally and acquire knowledge on alternative assessments and working with disabled students in accessible ways.
- Disability awareness training should be made compulsory for all staff in light of recent changes in the Disability Discrimination Act, in line with other mandatory training courses (e.g. fire safety).
- It should be recognised that students with AS are entering into HEIs in increasing numbers. According to HESA online data ([www.hesa.ac.uk](http://www.hesa.ac.uk)), the number students with AS entering into their first year of HE in the UK has been increasing each year: 80 in 2003-04; 295 in 2004-05; and 475 in 2005-06. Therefore, institutions will need to accommodate students with AS and ensure that they have positive learning and social experiences.
- Prospective disabled students, who are interested in attending their preferred institutions, should be made aware of early Disabled Students' Allowances needs assessment opportunities. This should be considered as an essential element of pre-entry activities, such as a taster courses. It will help a student to know what kind of support can be expected on year of entry. This may also be supported through the development and input of disabled student groups.
- An early Disabled Students' Allowances needs assessment for students with AS is strongly encouraged due to the multifaceted aspects of the condition as evident in this study. This diversity requires diverse support needs. Thus, having a pre-set support package for students with AS may not be the best way forward. Supporting students with AS requires creative thinking as well as the student's input on what he or she may require.

- Schools and colleges should be reminded that attending higher education is a viable option for disabled learners, particularly learners with AS.
- The successes of disabled students should be celebrated and publicised, if the student wishes, as an example to younger disabled people. Moreover, having success stories of students with specific impairments, like AS, will be beneficial to others who have similar conditions.

#### Recommendations for lecturers teaching in HE:

- Lecturers should make every effort to keep track of disabled students who have been made known to them by their respective institution's disabled student support teams. However, if a student is placed in an anxiety-ridden situation to disclose his/her impairment, then this may be an issue of discrimination according to the Disability Discrimination Act and SENDA.
- Due to the stigma associated with AS as a condition, some respondents in this study were more likely to disclose other conditions such as epilepsy and dyslexia rather than their AS. Lecturers must be aware that students with AS recognise a hierarchy of impairments and are less likely to disclose the AS itself.
- Lecturers should make clear in advance of lectures the availability of electronic versions of handouts. As recognised by respondents in the study, having handouts, visual aids or even music can aid *all* students in assessing information conveyed to them in classes. Good, inclusive practice for students with AS will benefit all students, disabled or non-disabled.
- Several of the respondents expressed discomfort in working with other students in group settings. This reflects what has been said about people with AS having social communication difficulties. So, at the beginning of a term, instead of immediately placing students in groups that number more than three, lecturers may want to consider pairing students up to help facilitate students in 'getting to know each other'. However, this may also be problematical for some students. Disabled student support teams may need to discuss this with a student to identify benefits of group work on learning.

#### Recommendations for HEI disabled student support teams:

- There should be increased awareness of the fact that Disabled Students' Allowances needs assessments can be conducted as early as April on the year of entry. This will help ensure that students with AS will have necessary support in place by the beginning of the academic year. If there is a delay in being able to offer support, practitioners should keep students informed.

- Disabled student support teams should consider that parents of students with AS are likely to be playing a large role in enabling their son or daughter practically, socially and emotionally, and can be an excellent source of advice, if appropriate permission is sought from the student. However, sensitivity is required because parents' views may differ from those of their offspring.
- Disabled student support teams should consider working with their student unions in planning alternative ways to increase student participation in student-led societies. For instance, in addition to having a fresher's fair, students with sensory impairments should have the opportunity to attend a similar event without 'the noise and the crowds', or receive buddy/mentor support in attending such fairs.
- AS-friendly activities should be identified in areas that might include people with AS.
- Disability practitioners in higher education should ensure that teaching staff are taking account of confidential information about disabled students within their classes. This will help ensure that lecturers are aware of a student's difference without them having to disclose or remind staff of their needs.
- Confidential channels must be maintained between disabled student support teams and academic faculties when conveying information regarding students.
- Disability practitioners in higher education should reinforce the notion that student support packages are not etched in stone. Support arrangements should be reviewed regularly and amended if necessary.
- Mentoring support recommended to students with AS should be flexible and consistent as students have varying support needs. Disability officers should initially meet with both mentor and student to lay ground rules and agree the support package.
- Considering the social isolation issues that many respondents experienced in their first year of higher education and the difficulties transition can present, assessors and disability officers should make students aware of the counselling support available within higher education student support services.
- It should be ensured that support arrangements (e.g. notetaking and examinations) are consistent. For instance, when a student's notetaker does not show up for a lecture, this may cause undue stress and anxiety.

#### Recommendations for disability researchers:

- Closer examination of the heterogeneity of disabled people would prove valuable in informing sociological understandings of impairments.

- Awareness of autism and AS within the social model of disability literature should be increased.
- More focused research into specific impairments and higher education transitions is necessary to better inform policy and practice.
- The extent of transition as a re-engagement, renegotiation and reconstruction of the label/ontology of autism should be examined.

#### Recommendations for Disabled Peoples' Movement:

- Differences and voices of people with autism and AS should be represented and taken into account within the Disabled Peoples' Movement.
- The extent of AS as a productive impairment should be highlighted.
- The Government and HEIs must be held more accountable to the aims of the DED.

## References

- Adams, M. and Brown, S. (2006) Improving access to higher education for disabled people. In: Adams, M. and Brown, S. (eds.) *Towards Inclusive Learning in higher education: Developing curricula for disabled students*. London: Routledge, pp. 10-22.
- Adams, M. and Brown, P. (2000) The times are a changing: developing disability provision in UK higher education. Paper presented to *Pathways 4 Conference, Canberra, Australia*, 6-8 December.
- Attwood, T. (1998) *Asperger's Syndrome: A guide for parents and professionals*. London: Jessica Kingsley.
- Attwood, T. (2006) *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley.
- Barnes, C. (2003) What a difference a decade makes: reflections on doing "emancipatory" research. *Disability and Society*. 18 (1), 3-17.
- Baron-Cohen, S. (1995) *Mind Blindness: An Essay on Autism and Theory of Mind*. Cambridge, MA: MIT Press.
- Birnie, J. (2006) Developing an inclusive curriculum for students with Asperger Syndrome. In: Leach, J. and Birnie, J., *Developing an inclusive curriculum for a) students with mental health issues b) students with Asperger Syndrome*. Cheltenham: Geography Discipline Network, University of Gloucestershire, pp. 85-107.
- Blamires, M. and Gee, S. (2002) Raising Aspirations: Increasing the Participation of Students with Autistic Spectrum Disorders (Social Communication Difficulties) in Higher Education. (Report of the HEFCE strand two disability ASPIHE) Available from: <http://education.cant.ac.uk/xplanatory/showref.asp?category=Autistic%20Spectrum> [24 July 2007]
- Bogdashina, O. (2006) *Theory of Mind and the Triad of Perspectives on Autism and Asperger Syndrome: A view from the bridge*. London: Jessica Kingsley
- Borland, J. and James, S. (1999) The learning experience of students with disabilities in higher education: A case study of a UK university. *Disability and Society*. 14 (1), 85-101.
- Brady, G. (2007) It's not the "real me": children's experiences of ADHD and medication. Paper presented at The 8th European Sociological Association Conference *Conflict, Citizenship and Civil Society*, Glasgow, 3-6 September.

Breakey, C. (2006) *The Autism Spectrum and Further Education: A Guide to Good Practice*. London: Jessica Kingsley.

Burgoine, E. and Wing, L. (1983) Identical triplets with Asperger's Syndrome. *British Journal of Psychiatry*. 143, 261-5.

Charmaz, K. (1995) Grounded Theory. In: Smith, J.A., Harré, R. and Langenhove, L.V. (eds.) *Rethinking Methods in Psychology*. London: Sage.

Deal, M. (2006) *Attitudes of Disabled People towards other Disabled People and Impairment Groups*. PhD. Thesis, City University, London.

Fife and Tayside Wider Access Forum (2005) *The experience of disabled students making the transition between institutions to begin or continue their higher education* (Project Report Transitions Project). Dundee: Fife and Tayside Wider Access Forum.

Frith, U. (2003) *Autism: Explaining the Enigma*, 2<sup>nd</sup> ed, Oxford: Blackwell Publishing.

Fuller, M., Bradley, A., and Healey, M. (2004a) Incorporating disabled students within an inclusive higher education environment. *Disability and Society*. 19 (5), 455-68.

Fuller, M., Healey, M., Bradley, A., and Hall, T. (2004b) Barriers to learning: a systematic study of the experience of disabled students in one university. *Studies in Higher Education*. 29 (3), 303-18.

Gabel, S. and Peters, S. (2004) Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability and Society*. 19 (6), 585-600.

Gillberg, C. (2002) *A Guide to Asperger Syndrome*. Cambridge: Cambridge University Press.

Giroux, H. A. (2003) Public Pedagogy and the Politics of Resistance: Notes on a critical theory of educational struggle. *Educational Philosophy and Theory*. 35 (1), 5-16.

Goode, J. (2007) "Managing" disability: early experiences of university students with disabilities. *Disability and Society*. 22 (1), 35-48.

Goodley, D. (2000) *Self-advocacy in the Lives of People with Learning Difficulties*. Buckingham: Open University Press.

Goodley, D. (2007) Towards socially just pedagogies: Deleuzoguattarian critical disability studies. *International Journal of Inclusive Education*. 11 (3), 317-34.

Grandin, T. (2000) My mind as a web browser: how people with Autism think. *Cerebrum*.2 (1), 13-22.

Gray, D. E. (2002) "Everybody just freezes. Everybody is just embarrassed": felt and enacted stigma among parents of children with high-functioning autism. *Sociology of Health and Illness*. 24 (6), 734-49.

Grewal, I., McManus, S., Arthur, S. and Reith, L. (2004) *Making the transition: Addressing barriers in services for disabled people* (Department for Work and Pensions, Research Report No. 204). Her Majesty's Stationery Office: Leeds.

Happé, F. (1994) *Autism: an introduction to psychological theory*. London: University College London.

Harvey, L., Drew, S. with Smith, M. (2006) *The first-year experience: a review of literature for the Higher Education Academy*. York: Higher Education Academy.

Harpur, J., Lawlor, M. and Fitzgerald, M. (2003) *Differing by degrees: a handbook for college students with Asperger Syndrome*. London: Jessica Kingsley.

Healey, M., Bradley, A., Fuller, M. and Hall, T. (2006) Listening to students: The experiences of disabled students of learning at university. In: Adams, M. and Brown, S. (eds.) *Towards Inclusive Learning in Higher Education*. Oxon: Routledge, pp. 32-43.

Hodge, N. (2005) Reflections on diagnosing autism spectrum disorders. *Disability and Society*. 20 (3), 345-9.

Hodge, N. (2008) Evaluating Lifeworld as an emancipatory methodology. *Disability and Society*. 23 (1), 29-40.

Holdsworth, Clare (2006) "Don't you think you're missing out, living at home?" Student experiences and residential transitions. *The Sociological Review*. 54 (3), 495-515.

Holloway, S. (2001) The experience of higher education from the perspective of disabled students. *Disability and Society*. 16 (4), 597-615.

Howley, M. (2004) Asperger's Syndrome in further and higher education students. Paper presented at *Specific Learning Differences in Higher Education and Further Education: dealing with diversity conference*, Leicester Student Services, De Montfort University.

Howlin, P. (1998) *Children with Autism and Asperger Syndrome*. Chichester: John Wiley & Sons.



Humphrey, J. C. (1999) Disabled People and the Politics of Difference. *Disability and Society*. 14 (2), 173-88.

Hurst, A. (1996) Reflecting on researching disability and higher education. In: Barton, L. (ed.) *Disability and Society: emerging issues and insights*. London: Longman.

Jacklin, A., Robinson, C., O'Meara, L. and Harris, A. (2007) *Improving the experiences of disabled students in higher education*. York: Higher Education Academy.

Madriaga, M. (2007) Enduring disablism: students with dyslexia and their pathways into UK higher education and beyond. *Disability and Society*. 22 (4), 399-412.

Martin, N. (2005) *Empowering Students with Asperger Syndrome to succeed in university*. PhD. Thesis, University of Derby.

Martin, N. (2006) Strategies which increase the likelihood of success at university of students with Asperger's Syndrome. *Good Autism Practice*. 7 (2), 51-60.

Mercer, G. (2002) Emancipatory Disability Research. In: Barnes, C., Oliver, M. and Barton, L. (eds.) *Disability Studies Today*. Cambridge: Polity Press, pp. 228-49.

Molloy, H. and Vasil, L. (2002) The social construction of Asperger Syndrome: the pathologising of difference. *Disability and Society*. 17 (6), 659-69.

Molloy, H. and Vasil, L. (2004) *Asperger Syndrome, adolescence, and identity*. London: Jessica Kingsley.

National Audit Office (2002) *Widening Participation in Higher Education in England*. London: National Audit Office.

National Autistic Society (1998) *The Autistic Spectrum - A Handbook 1999*. London: National Autistic Society.

National Disability Team and Skill (2004) *Aspiration raising and transition of disabled students from further education to higher education, Final Report*. Ormskirk, UK: National Disability Team. Available from:  
[http://www.actiononaccess.org/index.php?p=2\\_5\\_4\\_3\\_7](http://www.actiononaccess.org/index.php?p=2_5_4_3_7) [4 July 2007]

Nind, M. (2005) Inclusive education: discourse and action. *British Educational Research Journal*. 31 (2), 269-75.

Oliver, M. (1990) *The Politics of Disablement*. Houndsmill: Macmillan.

Parker, V. (1999) Personal Assistance for Students with Disabilities in HE: the experience of the University of East London. *Disability and Society*. 14 (4), 483-504.

Patiniotis, J. and Holdsworth, C. (2005) 'Seize that chance!' Leaving Home and Transitions to Higher Education. *Journal of Youth Studies*. 8 (1), 81-95.

Riddell, S., Tinklin, T., and Wilson, A. (2004) *Disabled Students and multiple policy innovations in higher education*. Glasgow: Centre for Educational Sociology and Strathclyde Centre for Disability Research.

Riddell, S., Tinklin, T. and Wilson, A. (2005) *Disabled Students in Higher Education*. London: Routledge.

Ryan, S. (2005) "Busy behaviour" in the "Land of the Golden M": mothers and children with learning difficulties in public places. *Journal of Applied Research in Intellectual Disabilities*. 18 (1), 65-74.

Shakespeare, T. (2006) *Disability rights and wrongs*. London: Routledge.

Singer, J. (1998) "Why can't you be normal for once in your life?" from a "problem with no name" to the emergence of a new category of difference. In: Corker, M. and French, S. (eds.) *Disability Discourse*. Buckingham: Open University Press, 59-67.

Taylor, M. J. (2005) Teaching students with autistic spectrum disorders in HE. *Education and Training*. 47 (6/7), 484-95.

Williams, D. (1996) *Autism, an inside-out approach: an innovative look at the mechanics of 'autism' and its developmental 'cousins'*. London: Jessica Kingsley.

Williams, E. (2004) Who Really Needs a "Theory" of Mind?: An interpretative phenomenological analysis of the autobiographical writings of ten high-functioning individuals with an Autism Spectrum Disorder. *Theory and Psychology*. 14 (5), 704-24.

Wing, L. (1991) The relationship between Asperger's syndrome and Kanner's autism. In Frith, U. (ed.) *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press, pp. 93-121.

## Appendices

### Appendix A



*Sheffield  
Hallam University*

Phone (0114) 225 4538

Minicom (0114) 225 3816

Email: [M.Madriaga@shu.ac.uk](mailto:M.Madriaga@shu.ac.uk)

22 August 2006

Dear student,

I am a researcher interested in how students with Asperger Syndrome will experience their first-year of higher education. I am writing to see if you may be interested in being a part of this project, as an informant.

My project will consist of me interviewing you on three occasions about your higher education experience. The first interview can be planned for sometime in October 2006, the second interview can be held in January 2007, and the third interview can be planned in May 2007. These interviews can take place at a convenient location of your choice within your college or university, such as a cafe, student union, library, etc. Each interview should last only an hour. In taking part in all three interviews, you will receive a £60 voucher from WH Smith.

At the end of the project, I will write a report. I hope my report will help raise awareness and aspirations of higher education to all young people with Asperger Syndrome. More information about my project can be found at <http://www.heacademy.ac.uk/4604.htm>

I hope for a positive response from you. If you have any questions or interested in taking part in my project, please get in touch by emailing me at [M.Madriaga@shu.ac.uk](mailto:M.Madriaga@shu.ac.uk) or by phone 0114 225 4538.

Thank you very much,  
Manuel Madriaga

### Appendix B



*Sheffield  
Hallam University*

10 October 2006

#### INFORMATION SHEET

#### RESEARCH PROJECT: ENABLING TRANSITION INTO HIGHER EDUCATION FOR STUDENTS WITH ASPERGER SYNDROME

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following.

This is a year-long project which seeks to gain insight into the lives of five-to-ten first-year students with Asperger Syndrome (AS) during their transition into higher education from around the country. The findings will be used to inform current higher education policies and practices in providing disabled student support. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

This project will consist of me interviewing you on three occasions throughout the academic year (sometime around October 2006, January 2007, and May 2007). Each interview should last only an hour. In taking part in all three interviews, you will help change and improve policies and practices in providing disabled student support in higher education. You will also receive a £60 voucher from WH Smith for participating in all three interviews.

All information collected in interviews 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. I hope my report will help raise awareness and aspirations of higher education to all young people with Asperger Syndrome. This report will be available to you at the end of the study.

This project is funded by The Higher Education Academy. More information about the project can be found at <http://www.heacademy.ac.uk/4604.htm>. If you have any questions, please get in touch by emailing me at [M.Madriaga@shu.ac.uk](mailto:M.Madriaga@shu.ac.uk) or by phone 0114 225 4538.

Thank you for reading this information sheet.

#### **Appendix C**

#### CONSENT FORM

Title of Project: Enabling transition into higher education for students with Asperger Syndrome

Please Initial Box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.
3. I agree to take part in the above study.
4. I agree to the interview being audio recorded
5. I agree to the use of anonymised quotes in publications

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

\_\_\_\_\_  
Name of participant                      Date                      Signature

\_\_\_\_\_  
Name of researcher                      Date                      Signature

Please keep copy of the consent form and the information sheet together. (name, address, contact number of investigator).