Enhancing Outcomes for Autistic Students
Executive Summary of the AuVision Project

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1. Overview of the project

The ‘AuVision’ project was a peer-to-peer project co-ordinated by academic staff and an independent mentor from Student Support Services from the University of Birmingham. It was designed as far as possible to be a user-led project. Autistic students and alumni from the University of Birmingham (UoB) were employed as Project Assistants and consulted with their peers and alumni via one to one interviews and focus groups over one academic year from 2015-2016.

2. Aims

The overall aims of the project were:

1. To enhance understanding of the autistic student experience and current barriers to achieving best outcomes at the University of Birmingham, through peer-to-peer consultation.

2. To enable autistic students at the University of Birmingham to have a meaningful voice in their educational experience, and be part of a community of learners.

3. For the student group to consult with the other autistic students and alumni population at the University of Birmingham in order to develop a set of recommendations for practice.

4. For the student group to use the information collected to develop an educational resource on autism for the use of students and staff at the University of Birmingham.

5. For the student group consultation process to input into the development of a model for peer-to-peer consultation.

6. To develop a report of recommendations on participatory, user-led consultations for groups with specific needs that can be replicated with other student groups at the University of Birmingham, including user groups with other types of disability or disadvantage, across the wider higher education (HE) environment.

This executive summary presents key findings, outcomes and recommendations from the project. Detailed information on data and analysis can be found in the full report, available from the Autism Centre for Education and Research (ACER) via a.g.macleod@bham.ac.uk
3. Credits

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Grateful thanks also go to the students and alumni who participated in the project and, in giving it their time and attention, greatly furthered the university’s understandings of the student experience for autistic individuals at UoB. We would also like to thank Julie Foster, Dr Nicola Gale, Neil Hall and Dr Kerstin Wittemeyer for their support in developing the resource.

4. Citation guidance

To cite this report:

5. AuVision: Contextualising the project

In recent years, both in the UK and more widely, the emerging widening participation agenda has led to changes in policy to address the needs of ‘non-traditional’ students (Adams and Brown, 2006). This focus has included disabled students, although arguably they have been given relatively low priority compared to other disadvantaged groups (Barer, 2007). However, since it was not until 2001 that disability discrimination against students in higher education institutions (HEIs) became illegal in the UK, there has remained the potential for greater discrimination within higher education than in other sectors. Disabled students have tended to be under-represented within higher education (Hopkins, 2011).

The higher education climate is also increasingly challenging and competitive. In their report on support for students with mental health difficulties, Riddell, Tinklin and Wilson (2005) discussed the impact of increasing student numbers, pressure to prioritise research above teaching, and modularisation of the curriculum, as factors that have impacted on the student experience to the detriment of more vulnerable students. These are the additional, and growing, pressures to be negotiated by students entering higher education. Globally and nationally, higher education is defined by the enormous change taking place within the sector (Outhred, 2012).
This is not least demonstrated by the ways in which the sector is being called upon to be more inclusive, both in its strategies and its processes. The number of disabled students entering higher education, whilst still disproportionately low, is growing fast. Autistic students make up an increasingly significant proportion of this number (HESA, 2017). However the sector is ‘playing catch-up’, being a relative latecomer in terms of legislative imperatives.

The implications for individual students with additional needs who choose to enter higher education have been enormous. They have often been the pioneers, and consequently cornered into being educators on disability rights within their institutions – an additional stress on top of the existing pressures of studying (Hopkins, 2011). A recurring theme in the accounts of disabled students has been that they, as individuals, bore personal responsibility to educate tutors about their disability, and in these ways were forced to publically disclose, and to become ‘extra-visible’ (Goode, 2007; Fuller, 2008; Vickerman and Blundell, 2010). Additionally, the tendency for individual tutors to be held accountable, rather than institutions, was highlighted (Madriaga, 2007; Lang, 2015). A lack of strategic or joined-up thinking has been apparent. Institutions have tended to respond to individual need, rather than pro-actively adapt their processes to be more inclusive, and in this way have been more closely aligned to an individualised model of disability that overlooks the structural and cultural barriers that confront disabled students (Holloway, 2001).

Autistic students occupy a distinct place within this landscape. There is a high co-morbidity associated with autism, particularly in relation to mental health and dyslexia, so that autistic students represent a significant and complex group. Given the poor outcomes associated even with the most intellectually gifted (Billsted, Gillberg and Gillberg, 2011) and reports from autistic adults that autism should be regarded as a different “way of being” (Sinclair, 1993, page unknown), there is a pressing need to take account of their first-hand perspectives. Studies which have done so have revealed important discrepancies between student and staff perceptions. Knott and Taylor (2014) conducted focus groups with both autistic students and staff members, finding that staff were aware of incidences of severe depression, but missed potential opportunities to prevent it by recognising the impact of daily anxieties and stresses. Other studies have discussed the tendency for staff to pathologise autism and in doing do, overlook the social needs of their students (Madriaga and Goodley, 2009; VanBergeijk, Klin and Volkmar, 2008).

The available literature highlights the need for HEIs to better understand this marginalised group in order to effectively anticipate adjustments as they enter higher education. Moreover, with recent changes in legislation, including in particular Disabled Students’ Allowance (DSA) reforms, the sector is called upon to adapt its support services from helping students: “deemed entitled...by virtue of a diagnosis to one which empowers the learner, is accessible to and benefits all students.” (Department for Education, 2017, p. 11)
The overlapping concepts of Universal Design and an Inclusive Curriculum are useful to consider here, in the potential that they offer institutions to create accessible and inclusive educational environments.

Universal Design “favours educational strategies that are proactively designed to support multiple paths through learning, rather than focusing on retroactively altering existing material to fit the needs of a specific group.” (Fabri, et al., 2016, p. 21). A range of assessment options to suit different learning styles is one example, and this approach can be beneficial not just to students with additional support needs, but to other groups such as international students (Thoma, et al., 2010) and minimise the need for (more expensive) individualised support (Bublitz et al., 2015).

Likewise, an Inclusive Curriculum approach “takes into account students’ educational, cultural and social background and experience as well as the presence of any physical or sensory impairment and their mental well-being” (Morgan & Houghton, 2011, p. 5) Thus it considers the needs of a diverse student cohort, reflecting a typical higher education classroom, and takes an approach that is sensitive to difference, whether disclosed or not.

Both of these approaches suggest a fundamental change in the approach of the institution, from responding to the additional needs of individuals as these are presented, to an awareness of the diversity of the student body as whole and changes
to what students are offered, in anticipation of these diverse needs. It can be achieved with relatively little resource, and is likely to result in fewer individual support needs and better outcomes. For example, a fresher’s option that takes place in a quiet space and without alcohol might appeal not only to students with sensory needs or social anxieties, but also to students from different cultures or faiths.

This short review of the literature serves to contextualise the AuVision project. Within a challenging HEI environment, the project has sought to not only develop understanding of our autistic students, but also explore how more inclusive approaches within UoB can serve the needs of our whole student body and the institution alike.

6. Recommendations

Our findings indicate some recommendations that are specific to the needs of autistic students. However, many recommendations have broader relevance and so these are reported first, as points to consider for an Inclusive Curriculum/Universal Design approach that seeks to benefit a diverse student group.

<table>
<thead>
<tr>
<th>RECOMMENDATIONS SPECIFIC TO AUTISTIC STUDENTS</th>
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Autistic students often put unreasonable pressure on themselves, so support to understand expectations (e.g. Interpreting reading lists and assessment protocols) can mediate this.

### INCLUSIVE CURRICULUM RECOMMENDATIONS

1. Importance of clarity of communication – uncertainty is a primary cause of anxiety. Communication needs to be more consistent, led by systems rather than individuals. Ensure the effective sharing and use of Reasonable Adjustment Plan (RAP) information.

2. Students tend to be passive and ill-informed about their rights and responsibilities when they disclose. Better support to understand the systems would result in better use of them by students.

3. Need for support and to anticipate and respond to students’ needs from start of the course and beyond – transitions into, and out of, the University.


5. Anticipate the needs of students – ‘check-in’ with students as those struggling the most may not be able to flag it up.

6. Recognition of students’ diverse ways of learning and consequently a need to respond with diverse methods of assessment.

7. Participatory consultation with hard-to-reach groups requires careful planning and resourcing. However, the benefits include a more accessible model of consultation and important opportunities for networking and development of skills for the student participants.

8. Distance and part-time students have different experiences and needs and tend to be more isolated than full-time campus students.

9. Being a student with additional needs within higher education causes the student extra workload to get support set up and extra stress in ensuring this is managed. The sector needs to find ways to minimise this workload.

10. Recognition that an inclusive approach benefits a range of needs reflected in the UoB student population, including not just students with additional needs, but also students with different cultural/linguistic backgrounds.
7. AuVision resource

A key output of the project was the development of a multimedia staff information resource. The content of this resource was informed by the findings from interviews and focus groups. Participants contributed directly to the making of the resource and were consulted throughout the development stages. The resource is intended to make key information easily accessible, so that UoB staff can use it as a quick reference point or find more in-depth information as needed.

The AuVision resource for UoB Staff can be found at: https://auvisionsite.wordpress.com/
Appendix 1: Summary of Project Design & Findings

Recruitment:

Five autistic students from the University of Birmingham were employed as Project Assistants (PAs) to contribute to the development of the interview schedule and to conduct the interviews. A further two autistic alumni were employed to conduct focus groups and analyse the data. We interviewed the students in order to ensure that they had the necessary skills, or were able to develop them, and to ensure that they were fully aware of their responsibilities and the demands that would be placed upon them. Interviews were conducted face-to-face or online depending on applicant preference. The Project Assistant team of seven was larger than planned, due to the level and variety of relevant skills offer by individual applicants. This served to enhance the project in unforeseen ways, as PAs were able to contribute, for example, skills in art and design.

Participants:

Twenty autistic students were recruited and gave informed consent to take part in the research project. The students were undergraduates (from all years) and postgraduate students, studying a range of courses. Participants were each interviewed individually and asked to contribute to a focus group at three key points in the academic year, in order to develop an ongoing discussion with the students about the challenges that they faced as well as any positive experiences. This ‘snapshot’ design was intended to give an understanding of the particular challenges faced by students at key points in the year.

Summary of Findings:

The table below provides a brief summary of significant demographic characteristics that related to our participants. Although the data are relatively small, some clear trends emerged:

Figure 2: Demographic data from participants

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<th>AuVision respondents</th>
<th>UoB population as a whole</th>
</tr>
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<tbody>
<tr>
<td>Identifying LGBTQ</td>
<td>12.5%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Started course over 21 yrs</td>
<td>64.7%</td>
<td>14.5%(UG)</td>
</tr>
<tr>
<td>Distance Education</td>
<td>35.3%</td>
<td>7%</td>
</tr>
<tr>
<td>Have repeated a year</td>
<td>37.5%</td>
<td>17%</td>
</tr>
<tr>
<td>Other disabilities</td>
<td>58.8%</td>
<td>Data not available</td>
</tr>
<tr>
<td>In receipt of DSA</td>
<td>88.2%</td>
<td>Data not available</td>
</tr>
</tbody>
</table>
Our autistic participants were much more likely than the general population to identify as LGBTQ, which is in keeping with a growing body of literature indicating that autistic individuals are less likely to express binary gender identity (Glidden et al., 2016). A high proportion had repeated a year which echoes the situation for disabled students generally, who tend to take longer to complete academic courses. Over half disclosed two or more disabilities, reflecting co-morbidities commonly associated with autism. The data are small but nevertheless this gives a strong indication of important crossovers within this population. It would seem that many autistic students will be facing a number of other challenges that would cause them to be marginalised and disadvantaged. These are important factors in need of further exploration.

**Phase 1 (September 2015):**

Students reported much enthusiasm for their studies and appreciation for their learning experience.

- “Exploring topics I am really interested in and indulging in writing and producing pieces that are unique about women and autism.” (Max).
- “…academically things have been going quite well so far, both assignments I’ve had I got distinctions.” (Leslie).
- Support provided by the department was very positive, able to Skype with them over the holidays. (Leslie).

Managing workload was a common difficulty mentioned by nine of the participants.

- Difficulties pacing themselves, overworking and burning themselves out as a result. They also spoke of spending a lot of time to look for certain things, and find it difficult to switch off. (Julia).

The role of mentors was specifically identified by a number of participants, often highlighting the importance of having someone to assist with planning and organisation, or breaking tasks down, and providing additional support on things such as CVs and career advice.

- “Mentors are quite helpful in helping arrange and unpack essay tasks which is something [I] would neglect and let fall to the side otherwise.” (Max)
- “Having a mentor is really helpful and helps structure plans and adhere to them feel that they can confide in their mentor and they wouldn’t have a biased opinion.” (Mattieus).

Support from academic staff was valued however at times participants felt that it was often down to the goodwill of the staff, rather than any ‘official’ support that they might be entitled to. Specifically participants highlighted the need for better staff awareness of the needs of autistic students.

Often a student’s ‘success’ seemed to lie in negotiating the wealth of information that they were bombarded with, as well as the organisational challenges. Independent mentors were identified as providing appropriate support and there were individual examples of good practice from departments and members of staff. These initial findings echoed the findings from the alumni interviews.
Phase 2 (March 2016):
The second round of interviews gave a generally more positive picture, with most students reporting an improvement over time, both in their studies and extra-curricular opportunities.

- “I went to see my welfare tutor and I was able to get extensions on my essays for a month – because I had three essays to do and I was just completely overwhelmed”. (George).
- “There was an event I went to, a careers day and they were giving help with, like CVs and possible ways to look for people, and that gave me a lot of good ideas to help on my CV and that's made me feel happy.” (Angus).

Support provided by a mentor was frequently identified as an example of when the university provided effective support to students. Support from a mentor was flexible, providing assistance with personal and academic life and providing a link between the department and the student in the best way possible. The role of the mentor was highlighted as key to student success, and poor communication within and between university departments as a key barrier. Very positively, students indicated strong engagement with the academic aspect of their student experience. Students also continued to report difficulties with their Student Support Agreement (SSA) documents, and apparent lack of clarity regarding who had access to these and what adjustments ought to be available for students.

- “My mentor has been very helpful and comforting, as she helps proofread my essays and helps plan how to manage my time effectively. I also feel I can trust her with any personal problems I am facing.” (Nicola).
- So things haven't been that good mentally, so I decided to stay with my mum (not in Birmingham) as much as possible and do lectures via panopto and only come into uni on days when I had practical classes. So that meant I couldn't make mentoring appointments. So my mentor agreed to do Skype sessions in the evening instead. It's been really helpful because it has enabled me to stay at home while communicating with my mentor. She has been able to sort everything out with the department (so that they don't think that I'm just skipping lectures) and help me to deal with university pressures - keeping up with deadlines and staying organised away from campus. (Rowan).

Phase 3 (June 2016):
Students commented on their achievements during the year, many of which were very personal and unique to them. However, the challenge of getting through their exams was mentioned by a number of participants.

- “First of all, I've had an awful lot of 'real life' to contend with this year. Just dealing with that has been a major thing. […] That I have not completely flunked out of the course is an achievement!” (Frankie).
Students also reflected back on how they would like to have done things differently with better time management, improved organisational skills and revision tactics being mentioned

- “I think maybe planning my time better and earlier on in the things which I was doing academically would be one thing. For me it tends to be frantically doing an assignment for 2/3 weeks and then feeling completely exhausted and burnt out afterwards and unable to do much. During that time I tend to neglect things like cleaning the house, my own health, sleep etc. That’s been quite detrimental to me in the long run.” (Ben).

Participants also mentioned a desire to attend more social events or to be more sociable. This highlights a contentious area for autistic students, who are often perceived to have less need for social contact and who may need support to develop their social lives. Specific support to engage in extra-curricular activities as well as a greater understanding of the needs of autistic students by fellow students was mentioned by a number of participants.

- “…offering students information about the benefits of societies and clubs would be helpful, because those are the things that complement education”. (Mattieus).

Students also made recommendations as to what they wanted the University staff and students to know. Dealing with feelings of apprehension and uncertainty was mentioned by a number of people.

- “I stopped going to a whole module because I was told by someone that there was a presentation at the end which was compulsory and we couldn’t pass without it, and I found the idea so stressful I decided it was pointless going to the module…the unknown is terrifying/ stressful! So the more info they have that they can pass on the better, and as early as possible. e.g. with how groups are assigned, or, in terms of students, how many people will be at an event/ a rough schedule etc. Change can be very stressful, so a bit of info e.g. on how to find a different room if there is a room change.” (Joy).

Summary of participatory model:

To evaluate the impact of the participatory model on participants and Project Assistants, participants were asked to complete evaluations after each interview, and Project Assistants were asked to reflect on their role after each set of interviews (through group discussions on the online team area) and then at the very end of the project, through individual email responses to set questions. Additionally, Coordinators exchanged reflections and logged key points that arose.

Participant evaluations:
**Term 1**
Evaluations in the first term sought general feedback on accessibility of the interviews. All found the meaning of questions clear, and the environment and format accessible. Example comment:

*Being asked follow up questions, because it made me feel like I was being listened to. I also liked that I was asked what else I thought the university could have done because it meant I got to put forward some of my ideas.*

Only one person stated that they felt upset or negative and explained their reasons:

*When I was asked to compare this year with First year – that wasn’t down to the interviewer though, I had to take a leave of absence after first year due to depression and it’s still hard to think about. I was allowed to skip that question though which helped.*

**Term 2**
The evaluation for this term focused on the peer to peer aspect and asked (among other things) ‘Was it important to you that you were interviewed by an autistic, rather than non-autistic peer?’ Most participants found it to be important. For those that preferred an autistic interviewer, it was felt that there was a shared understanding that made disclosure and trust easier, for example:

*I felt more comfortable because I didn’t have to explain any of my quirks as they were accepted as part of my autism. I didn’t have to feel embarrassed about any of the support I needed or any of the difficulties I was having because the interviewer had that personal understanding.*

**Term 3**
Since this project was born in response to a potential demand for an autistic peer advocacy network, the evaluation also included questions relating to the peer contact that had been available during the project. Eight participants cited particular ways the interview had made them feel positive, and five of those attributed this to the interviewer style:

*I really appreciated the way that the interviewer helped me come up with better answers to my questions and helped me to expand on answers and it really helped me reflect on my time at university.*

It is not clear whether this was due to the interviewers themselves being autistic, but what is apparent is that the interview process was overwhelmingly a positive experience, and this is a useful finding in relation to peer interviews generally.

When asked whether there could have been more opportunities for peer contact within the project, participants were evenly split, with half wanting no more than they had and some saying they had no time due to other commitments.
Participants completed a survey towards the end of the project and 9 out of 11 respondents suggested that they would have found a peer mentor on the autism spectrum useful during their studies.

**Project Assistant (PA) reflections:**

The most common points arising from the group discussions were:

- Project Assistants feeling that their confidence and skills had grown (with impact beyond the immediate role) [cited 7 times]
- Interviews not going as planned (e.g. Late starts, need to reschedule due to non-attendance) [cited 7 times]

With the next most common being:

- The need to be sensitive to the needs and personal disclosures of their participants [cited 6 times]
- The usefulness of the prompt sheet in keeping the interviews on track [cited 6 times].

In response to the final evaluations, PAs highlighted:

Q. Anything that should have been done differently? – scheduling
Sample response: “I would be concerned if a similar project involved first years without allowing flexibility”

Q. Has the role influenced your attitude to autism? – yes
Sample response: “It has widened my view of autism, and I have come to realise that even autistic people are sometimes only limited to their personal experiences as something to judge autism.”

Q. Have you made peer contacts you will stay in touch with – yes
All respondents felt they had made new contacts from the project.

**Co-ordinator reflections:**

Co-ordinator reflections highlighted both the challenges and benefits of the project, which often went beyond those which had been anticipated:

- The need for significant time commitment for support and organisation, especially in the early stages.
- The need to be continuously flexible to accommodate the changing needs of both PAs and student participants.
- Recruiting to posts with fixed expectations were not necessarily the only method to determine an individual’s potential contribution. Working flexibly with differing skills and adapting accordingly was a very positive experience.
- Recruiting a larger team than first anticipated was beneficial as project assistants could provide cover for each other during periods of heavy...
workload or stress. It also meant that project assistants were able to be involved in many aspects of the project.

- Opportunities for project assistants and participants to have real input into the development of the project often need creative approaches which required a time commitment from all parties.

Benefits included:

- PAs brought a broad skill set to the project and were more involved than anticipated from the early stages; e.g. in training and induction.
- PAs brought important new ideas to the design and delivery. For example, they suggested a form of words to address the peer to peer element of the interview process:

  *I may empathise strongly with some of your responses (as an autistic student myself). However, during the interview I may appear neutral due to my role as an interviewer. However, we may talk about shared experiences off the record after the interview.*

- All project members learnt from each other – including specific skills relating to the project delivery but also about the ways they understood being on the autism spectrum.
- Students had the opportunity to take part in positive work experience and developed their skills in delivering presentations, record keeping, maintaining confidentiality, team work, working to deadlines and developing positive relationships in the workplace as examples.
Appendix 2: References


