

My final output for module YXM830 is a proposal for doctoral research with The Open University. I have followed the PhD research proposal guidance for submission to the Faculty of Wellbeing, Education and Language Studies, and used the Harvard (Cite Them Right) referencing format.

Name:

Title: Empowering autistic students to thrive in higher education: an investigation into stakeholder participation in redefining the barriers to inclusivity and improve the relevance of accessibility policy and procedures.

Importance and context of project

In my doctoral research I shall explore the current state of support provision for autistic students and investigate the value of a participatory approach to consider and evaluate the identified gaps. Beyond my own chequered history of higher education (HE) attainment many fellow autistics find HE inaccessible or failing to meet their support needs. The 'Arriving at Thriving' report from the Higher Education Commission reported that in England HE students with a disability rose from 197,000 in 2014/15 to 272,000 in 2018/19. Over the same period the number of students who disclosed a 'social communication or autism spectrum disorder' increased by 90% (Hector, 2020, pp. 12-13).

The Office for Students noted disparity between undergraduates who continued to high skilled employment or post-graduate study:

<i>Non-disabled</i>	<i>Social or communication impairment (autism)</i>
73.3%	61.8% (-11.5%)

(Office for Students, 2019)

The All Party Parliamentary Group on Autism (APPGA) report 'The Autism Act, 10 Years On' states that the Government should:

"work with universities to gather and share best practice on supporting autistic people moving into higher education" (APPGA 2019, p. 38).

Despite the publishing of reports from public inquiries and papers from research into the student experience, advancement in knowledge and understanding of autistic support needs has been measured. I wish to investigate why this is, and how the situation may be redressed.

Review of the literature

Five studies carried out since 2009 afford a valuable synopsis of observed changes in the support provision for autistic students over a ten year period.

MacLeod and Green (2009) used case studies within a structured model of personalised support and concluded that:

“the needs of individuals with autism are highly variable. Support provision needs to be flexible enough to accommodate these needs, whilst recognising the core problems associated with the autism spectrum.” (p. 11)

This paper pre-dates the Equality Act (2010) that set down legislative obligations for HE Providers to make reasonable adjustments for students with recognised disabilities (Cameron *et al.*, 2019); the requirement for student disclosure was to be significant. In 2018 MacLeod, Allan, Lewis, and Robertson considered ‘the cost of success’ in HE for autistic students; participants stated that:

“having the diagnosis put this barrier there as they looked at the label instead of me” (p. 689)

“these accounts illustrate that the experience of an autism diagnosis involves, at least in part, facing new barriers – those imposed by the presumptions of others.” (p. 690)

The report of 2009 with its successful outcome and clear indications for improvement, the 2018 study suggests that there has been little progress.

Chown and Beavan (2012, p. 479) described autism as a socially disadvantageous ‘social learning disability’, that resulted in poorer performance in HE settings ‘despite intellectual parity’. They argued that autistic students may have superior thinking skills to their neurotypical peers and that the barriers to HE achievement were ‘due to a failure of the education system’ (p. 480). The report on the ‘High Achievers’ project Chown *et al.* (2018) focussed on specific support provision in HE. With 60% of UK universities responding to the study there was evidence of some improvements, but the final comment was that:

“most HE institutions are in breach of current UK disability discrimination law ... failing to adequately support many of their potentially high achieving students” (p. 850).

Chown *et al.* (2018, p. 845) found “strong indications that no respondent had a separate autism policy or had made provision specific to autism”.

In their report on 'The social and academic experiences of university in the UK', Gurbuz, Hanley, and Riby (2019) noted that it is 'crucial' to put in place adequate support provision for the growing number of autistic students. The findings of Vanbergeijk et al. (2008, cited in Gurbuz, Hanley, and Riby, 2019) and Newham et al. (2011, quoted in Gurbuz, Hanley, and Riby, 2019) that 'less than 40% of autistic students successfully complete their studies' indicate the importance of relevant support.

The work of Richardson (2017) and Scott and Sedgewick (2021) found that many autistic students did thrive in higher education and gave positive feedback about their experience. Richardson (2017, p. 81) investigated attainment in online learning and found that students with autism at The Open University "who had no additional disabilities were as likely as non-disabled students to complete the modules ... to pass the modules ... and to obtain good grades". Despite arguing that autistic students are not disadvantaged by the condition the study concludes that given the supportive learning environment advocated by Chown and Beavan (2012) they will achieve academic success. Scott and Sedgewick also evidenced a high incidence of disengagement for autistic students, and Lipson *et al.* (2020, cited in Scott and Sedgewick, 2021) argued that this was due in part to lack of understanding by staff and peers, with recommendations for more specific staff training on relevant support strategies. Taylor (2005, cited in Knott and Taylor, 2014) argued that a lack of knowledge about the condition underpinned a lack of understanding of appropriate adjustments. I suggest in figure 1 how the interrelated, but often separated, concepts need to be considered in relationship to the others.

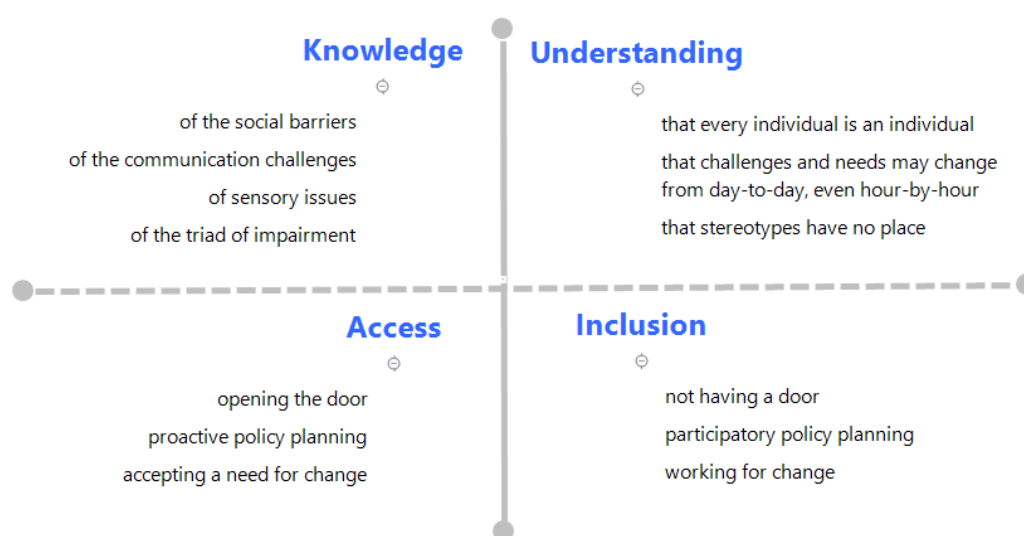


Figure 1, The correlation between 'knowledge / access' and 'understanding / inclusion'

The cited government reports into higher education point to inadequate understanding of autism in many institutions. The misunderstanding can be perpetuated when research is

directed toward areas like ‘autism’ and ‘perceived support needs’ in isolation. These focus areas need to be joined up to address the challenges specific to autistic persons and how, and whether, they can achieve. Without stakeholder involvement, open dialogue, and a sense of ownership an effective support system is not achievable. This investigation seeks to address this gap between the research and reports and the lived experience for autistic students and potential students.

Research questions

Do university accessibility policies reflect knowledge and understanding of the academic and social barriers faced by autistic students as a distinct group?

Do autism accessibility policies focus on the barriers created by the diagnostic triad of impairment (*figure 2, below*)? Are the challenges beyond the triad also considered?

Is the knowledge and understanding of specific barriers disseminated clearly to educators and support staff? Is there evidence that stakeholders would benefit from greater participation in the decision-making? Would participatory decision-making enfranchise autistic persons currently outside the higher education system?

Methodology:

The DSM-III (1980) introduced the ‘triad of impairment’ (*figure 2, below*) to establish the diagnosis of autism (O’Reilly, Lester, and Kiyimba 2020, p. 143).

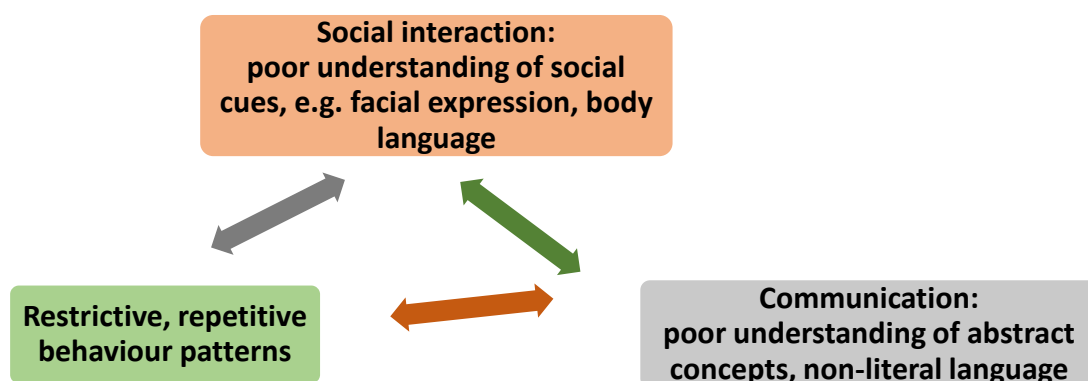


Figure 2, Triad of impairment characteristics cited from O’Reilly, Lester, and Kiyimba 2020, p.143

The DSM-5 (2013) conflated social interaction and communication into one diagnostic criterion, establishing a dyad of impairment and the OpenLearn course ‘Understanding autism’ (n.d.) reiterates this dyad of ‘social’ and ‘non-social’ characteristics. I would argue that the communication and social interactions of autistic persons are different sides of the same coin, and I support the argument of Wing *et al.* (2011, cited in O’Reilly, Lester, and Kiyimba,

2020) that as these are clinically discrete areas it is inappropriate to combine them. My investigation will adopt the DSM-III diagnostic triad of impairment.

A significant failing of higher education support policies is that they are based on misconceptions about the core difficulties for autistic persons. It is central to the solution to re-articulate the autistic experience, away from co-occurring mental health and specific learning difficulties. To the triad of difficulties that impact on learning and community life, sensory issues can be justifiably added. Sensory overload can lead to autistic shutdowns or meltdowns. Gurbuz, Hanley, and Riby (2019, p. 625) found that 'more than half of the autistic students reported issues with sensory overload ... [that] affected both their academic performance and their motivation to participate in social events'.

Knott and Taylor (2014)'s research into staff and student perspectives of the autistic experience was conducted with three focus groups (two staff and one student) and considered ten discussion topics. The results were positive in terms of greater staff understanding of the autistic experience, and increased student confidence in receiving relevant support. For the purposes of my investigation, where face-to-face groups are not appropriate, I propose to create scenarios based on academic, social, and sensory challenges. These will form part of a supplementary questionnaire for graded responses and optional comment. Analysis of data from these stakeholder groups should also have a significant impact on the collective understanding of autism as a condition and how it may impact on the learning experience.

Research into the higher education experience of autistic students is, by default, conducted with the participation of students who have successfully navigated the system. I would argue that these were also the students who were thriving and enjoying the academic life. The issue I wish to address is that of how to support academically capable students who find the barriers to access insurmountable, or who need reliable and relevant support to engage. The investigation would fail to answer the questions on how to improve the relevance of support, and inspire and promote engagement if there was no input from autistic persons who have either not been successful or who have not found HE accessible. To be relevant, robust, and reliable, all directly impacted stakeholders should be invited to participate at all levels. Nelson and Wright (1995, quoted in Fletcher-Watson *et al.*, 2019) argued that 'participatory research is the recognition, and undermining, of the traditional power imbalance between researcher

and participant'. As an autistic person I maintain that the only effective method for meaningful research is to engage with groups on both sides of the barrier.

From the premise that it can be education systems and academic communities that are the agencies by which autistic students will have a positive or negative experience of higher education (Chown and Beavan, 2012, p. 480), a social model of disability will be assumed throughout the investigation.

Data collection/analysis:

Data will be collected from a range of questionnaires that feature both 5-point Likert scale checkboxes and optional comment areas. The quantitative data from the survey and the qualitative data collected from the comments will be entered into Nvivo software for analysis. Comments will be cross-referenced using keywords and grouped into objective and subjective responses. Many autistic people are driven to follow rules and have difficulty identifying the crux of instructions. To mitigate any uncertainty or confusion over survey requirements the language will be unambiguous, instructions bullet-pointed, and completion require minimal inputs. Where appropriate there will be response examples for clarity.

Survey 1 (staff only): accessibility policy addressing the barriers faced by autistic students

Survey 2 (students and staff): knowledge and understanding of academic and social barriers

Data collection for the presence of identifiable features of the autism triad of impairment will use a 5-point Likert scale with an additional response option for "varies" as the impact of the condition can vary from day-to-day. This survey will include a series of created scenarios.

Survey 3 (students, non-students, and staff): opportunity to list questions (staff) or give suggestions for action (students and non-students)

I acknowledge that online discussion within and between groups would be appropriate for collecting responses to the activity. However, this is not the optimum way to interact with autistic persons and would impact negatively on the collection of data. I believe that an impersonal approach, with the option for discussion, will achieve more honest responses.

Survey 4 (students, non-students, and staff): importance of participation in decision-making

By its nature the data collection can only be a subjective exercise and will include input from and analysis by autistic and non-autistic persons.

Access to participants/recruitment:

I propose that distance learning may offer better access for autistic students challenged by building-based education. The Open University is the 'UK's largest provider of supported open and distance learning ... the largest provider of higher education for people with disabilities' (Slater, Pearson, Warren, and Forbes, 2015. p. 6). Staff and students will be invited to take part in the surveys after initial contact with the student support department, and social science and education research groups. I have been informed by my assigned education advisor that The Open University Students Association and the disabled students forum group may be contacted. I shall also use the university survey reports on staff and student responses for additional data. Permission to invite participants from two additional universities with autistic research centres will be made.

Autistic persons who are not OU students will be invited to take part through a research focus group that I contribute to. An initial request for permission to extend an invitation to fellow participants will be to the associate researchers.

Ethics:

The purpose and importance of the investigation to address the needs and realise the potential of autistic students, current and future, will be set out in clear language with an explanation of terminology as a preface to an invitation to take part. Assurance will be made that confidentiality will be safeguarded by requesting no personal information on the questionnaires except, where relevant to the survey, to indicate whether the participant is a current student / ex-student / never a student / educator / or support team member.

Human participants will be involved at all stages of the data collection. All involvement will be voluntary with the understanding that there is no commitment to complete any survey, either by individual questions, groups of questions, or the whole questionnaire. It will be stated clearly that if the survey causes stress at any point participation may be paused, or stopped.

A choice of contact will be offered: mail, online, or telephone. This will be flexible and initial choices will not need to be adhered to. Any survey-related questions or necessary support may be made online or by phone message. Any unavoidable changes to format or timescale will be explained clearly and in good time. For autistic individuals involved in distance research with an unfamiliar person, maintaining trust and confidence in the process will be the biggest issue. (Word count: 2402 (main text) + 91 (figures 1 and 2); total 2493)

PhD Research Project Timeframe																
	Year One				Year Two				Year Three				Year Four			
	1st quarter	2nd quarter	3rd quarter	4th quarter	1st quarter	2nd quarter	3rd quarter	4th quarter	1st quarter	2nd quarter	3rd quarter	4th quarter	1st quarter	2nd quarter	3rd quarter	4th quarter
Project																
Planning, initial																
Planning, interim																
Question, refining																
Literature																
Search, key sources																
Search, additional sources																
Critical reading																
Data Collection																
Survey plan + pilot study																
Data collection																
Data analysis																
Dissemination																
Report, initial																
Report, interim																
Literature review, draft 1																
Literature review, draft 2																
Methodology, draft																
Findings, write-up																
Thesis, draft																
Thesis, revision																
Thesis, final																

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