## Title: Misperceptions and realities: listening to autistic students on their online Higher Education experience.

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## Introduction

There are recognised challenges for autistic people in higher education (HE), but a lack of first hand reports of their experiences.[[1]](#endnote-1),[[2]](#endnote-2) In particular, online study may enable autistic persons to have better experiences of HE, but research to understand this is particularly limited.[[3]](#endnote-3) Bias against autistic persons is demonstrated when their observed behaviours are viewed less favourably than that of their neurotypical (NT) peers. In video-call employment interviews, even when all candidates are considered equally qualified, autistic interviewees are less likely to be successful as they are judged on ‘trustworthiness, likeability, and straightforwardness’[[4]](#endnote-4) whereas the NT applicants are judged on their qualifications. Failure by employers to address their obligations on ‘reasonable adjustments’[[5]](#endnote-5) for autistic employees and facing barriers to social acceptance with their NT peers, further limits their access to employment.[[6]](#endnote-6) Judgements made on initial impressions is reiterated in NT perceptions of autistic students who they observe as having unusual behaviours that make them ‘targets for misunderstanding, avoidance, ridicule, or worse’.[[7]](#endnote-7)

Online learning can be an attractive mode of study as it offers greater flexibility and control over most aspects of the learning experience. Research focused on autistic students’ experiences during the pivot to online learning caused by the Covid-19 pandemic suggest distinct benefits and challenges. Students mentioned the advantages of self-directed study and having flexibility and choice over when and where to learn; for others, problems with technology and contacting instructors, and having greater responsibility for self-management created major challenges.[[8]](#endnote-8) However there is little research to understand the current experiences of autistic students in online learning contexts, or the ways in which this mode of study may be designed to be appropriate for them. Given most staff and educators will be NT, understanding the autistic student is likely to be limited without further research and action.

It is detrimental to achieving a genuine understanding of the autistic student experience by attempting to identify complex autistic presentations within the narrow boundaries of an NT perception. Yet the separate observations of Kanner and Asperger that formulated the unique autistic profile of atypical behaviours have largely directed a common view of autism that pervades the literature: in 1944 Asperger recorded an inherent social difference in the children he observed; in 1957 Kanner recorded an attention to detail, preference for sameness, and a complete disregard for people as the defining characteristics in the children he observed.[[9]](#endnote-9) A general acceptance of these historic definitions can perpetuate a simplistic understanding of what it is like to be autistic and create a societal expertise that tolerates “those toxic words, ‘you don’t seem autistic’”.[[10]](#endnote-10)

The National Institute of Health and Care Excellence (NICE),[[11]](#endnote-11) a public body in England, describes the atypical features of autism that are necessary for diagnosis as:

• ‘persistent difficulties in social interaction and communication’.

• ‘stereotypic (rigid and repetitive) behaviours’.

• ‘resistance to change or restricted interests’.

Although not necessary for a diagnosis, the academic achievement of autistic students may also be impacted by extreme sensitivity to sensory input and difficulty with sensory processing.[[12]](#endnote-12) Over the past decade research has continued to evidence poor understanding of the specific challenges of autistic students,[[13]](#endnote-13),[[14]](#endnote-14),[[15]](#endnote-15) and they can feel unsupported and excluded from an HE system where too many are still being failed.[[16]](#endnote-16) These challenges can be compounded where educators have a poor knowledge and understanding about the condition, or lack confidence to support those students.[[17]](#endnote-17) Yet HE providers appear reluctant to address staff training needs, and relevant support provision remains inadequate.[[18]](#endnote-18),[[19]](#endnote-19)

NTs are as likely to misjudge autistic behaviours as autistic persons are to have difficulties interpreting NT social expectations, and it is problematic to explain the autistic experience in purely behavioural terms.[[20]](#endnote-20) Difficulty with social interaction and a reluctance of NTs to engage with autistic persons may be relational,[[21]](#endnote-21) or imposed by conflicting yet equally relevant normative social understanding.[[22]](#endnote-22) Targeted staff training is key to addressing problems inherent in the system but when based on misperceptions about the disadvantages faced by autistic students it can fail to prepare educators to fulfil their responsibility according to student support statements.[[23]](#endnote-23)

### The purpose of the current study

The rationale behind this research is to investigate the online experience of HE autistic students and to examine the barriers and enablers that shape that experience. The hypothesis is that the barriers to learning created by negative assumptions and attitudes held by NT students and staff may be mitigated by digital pedagogical practice that develops autonomy and agency through flexibility, choice, and relevant support provision. The study examines how interacting with a majority NT learning community might impact the motivation and well-being of students who need to be understood and accepted by the society in which they are judged and stigmatised.[[24]](#endnote-24) The core feature of ‘persistent difficulties in social interaction and communication’ is likely to be more problematic for autistic students when faced with learning activities that require collaboration and negotiation.[[25]](#endnote-25)

## Method

Data are collected on the social and learning experience of autistic students to examine whether studying within an NT majority impacts the quality of their engagement and wellbeing. A focus on investigating the *how* and *why* of the autistic experience through narrative input situates the research within a qualitative approach that considers autistic participants’ perception of NT assumptions and attitudes about the ways autism as a condition impacts this student group. To further contextualise the narratives, prior to thematic coding, the two forms of interaction are defined:

* a learning situation may be asynchronous group work with other students, sharing or responding on a course-based forum page, using onscreen text or audio-visual input, or taking responsibility for time management and assignment targets.
* a social situation may involve synchronous onscreen interaction in tutorials or group tasks.
* using a university social media page is not included.

Responses from autistic students to open-ended questions in the context of online learning is to provide rich data on student and tutor online interactions and highlight key areas for reflection and further exploration*.*

The decision to use three online surveys over a four-week period is to avoid possible information overload and thereby support participant well-being. The short timeframe commitment alleviates any potential stress for students already balancing study and personal responsibilities. The choice of an online platform for data collection avoids the stress that direct, face-to-face interaction may trigger for some autistic students. Both timeframe and online platform are appropriate for the needs of the project and addressing the research questions.

### Data collection

Each questionnaire is designed to address issues pertaining to the research hypothesis. Questionnaire 1 collects data on whether negative assumptions and attitudes held by NT students and staff create barriers to fulfilment for autistic students. The themes examine the autistic participants’ experience of non-autistic persons using labels, based on misperceptions of autistic features and behaviours, to describe them. Questions also explore the social and learning situations of online study, whether they make a difference to the HE experience, and whether any event has triggered shutdown or meltdown.

Questionnaires 2 and 2a examine the quality of academic engagement and explore online course-related experiences and autistic student reactions to those experiences. Questionnaire 3 includes an opportunity to reflect on the survey activities and the usefulness of taking part in the research.

All research questionnaires include closed and open questions, introduced sequentially, and are designed and distributed using the JISC Online Survey Program. Quantitative data is collected from responses to 5-point Likert scale or multiple-choice questions (MCQ) to investigate the theory that NT assumptions, based on stereotypical understanding, have a bearing on the autistic experience. Qualitative data is captured from participants’ narrative accounts of their perspectives on the HE experience, their reactions to online pedagogy and support practice, and the effect it has on their wellbeing. Optional comment boxes are included in the surveys for descriptive accounts of HE experiences outside the current online engagement, and for reflecting on shared collective responses. Without restriction on individual input this data is detailed and when collated generates rich data.

### Participant demographics and recruitment

The criteria for the research participant demographic was pre-determined by the research focus and the specific characteristics of the subject group. The decision to specifically include only those students who had disclosed a diagnosis of autism is to achieve an authentic representation to enrich the ‘information power’ of a limited target group that is not achievable from a broad-based participant group.[[26]](#endnote-26) The decision not to narrow the group demographic by specifying ‘age’, ‘gender’, or ‘level of study’ is to broaden the representation of experience. Inquiry on the impact that NT misperceptions may have on autistic student engagement and well-being demands that we listen to autistic students; focus on the benefits and challenges of online learning requires the participants to be studying online. Potential participants were sent an email invitation, followed by information sheets on the research process to those who expressed their interest in taking part.

### Ethical considerations

A sample of students were identified and contacted through the support of the Distance Learning University’s Student Research Project Panel, thus avoiding any ethical concerns about recruiting via personal contact.[[27]](#endnote-27) Working with autistic students to investigate the impact of online social and academic interactions on their current HE experience may carry a risk for potentially vulnerable individuals. The lead researcher’s positionality as an autistic researcher requires a critical reflexivity on the outsider role as researcher, on the insider position with the subject community, and as collator of the disclosed experiences. This requires the researcher to bracket off expectations inherent in shared understandings prior to assuming the role of reflective commentator.[[28]](#endnote-28) However, maintaining transparency about the lead researcher’s personal experience as part of the autistic community places her effectively as both support and guide. The consent forms are clear as to the rights of participants and each survey has reminders that taking part is optional. The lead researcher assumes responsibility as both data collector and analyst.

### Positionality of the lead researcher

As an autistic autism researcher it is imperative that I counter my own understanding of autism and of being an autistic student by placing it within a larger dynamic of experiences.[[29]](#endnote-29) As a researcher collecting qualitative data from autistic participants it is equally vital that I reflect on the interactions and acknowledge my own concerns and perceptions.[[30]](#endnote-30) Having the support of NT co-researchers balances the inherent bias of a singular autistic outlook.

### Participant feedback

Gaining participant feedback on the research process is as important as the essential purpose of data collection and analysis. Email comments from potential participants indicated that this research being conducted by an autistic researcher is welcomed:

‘any research into autism by an autistic person is long overdue!!’

‘more than willing to contribute to autistic voices and perception being heard and recognised.’

The participants received interim reports on the analysed data from Questionnaire 1 and from the preliminary findings commentary with a request to read the reports for accuracy and for comment feedback. The final survey includes an opportunity to reflect on the overall process and the value of taking part. From 14 participant responses

* 79% said it was a positive experience and felt it offered a positive step forward.
* 100% felt involved with the survey process.
* 57% felt that their input was useful and valued.

### Data analysis

The data analysis is guided by the core aims of this research:

1. To examine stereotypical concepts of autism held by NTs and the impact on HE engagement and well-being from the perspective of the autistic student.
2. To collect authentic autistic student narratives from social and learning HE experiences.
3. To investigate whether online HE enables or creates barriers for autistic students.

The narrative answers to open-ended questions and key extracts from the optional comments are grouped and listed using the JISC survey response analysis function, and the raw data collated in an Excel workbook and imported into NVivo. Responses to the surveys introduced a range of issues and the researcher coded both quantitative and qualitative data within the sub-groups of ‘learning aspects’, ‘social aspects’, and ‘general aspects’ of HE. These sub-groups direct the coding attributes for analysis of the thematic content. Following a systematic thematic analysis approach,[[31]](#endnote-31) the data from quantitative surveys and from qualitative narrative responses create a rich data-base for deeper interpretation and reflection on the findings.

## Results

*[Extracts from the research participants’ comments are referenced as [Sn.n]. The format represents a student comment, a questionnaire, + a response number, for example [S2.07] is a student comment, in response to Q2, that is the 7th received.]*

### Theme 1: Stereotyped behaviours and autistic realities

This investigation seeks to understand the learning and social dynamic for autistic students who may be defined by a label that places them outside an NT contrived norm.[[32]](#endnote-32) Distinct themes around social interaction and engagement with learning emerge from the coded and analysed data, and underpinning these themes is the mismatch between perceptions of autism and the reality for autistic students. For Questionnaire 1 the study participants rate 14 stereotypical labels that reflect misperceptions of autistic characteristics or behaviours, based on their perception of NT views about autism. A 5-point Likert scale of ‘always’, ‘often’, ‘sometimes’, ‘not often’ or ‘never’ is used. The analysed response data is represented on a stacked bar chart (see Fig. 1) as ‘always/often’, ‘sometimes’, and ‘not often/never’ for clarity.

*Figure 1*

The findings in figure 1 display the proportional value of response sub-sets within the total responses for each label, and in relation to the response values for all labels. The participant responses indicate that they are less like to be thought of as ‘caring’ and ‘friendly’, and more likely to be considered ‘antisocial’ and ‘weird’. The disparity between NT perception and autistic reality is strengthened by further analysis of the participant demographic. I compared the participants’ responses to the issue of ‘caring’ with the range of their subject choices (Fig.2).

*Fig. 2*

|  |  |  |
| --- | --- | --- |
| **'Caring' behaviour label** | | |
| always + often | 6 | 32% |
| sometimes | 4 | 21% |
| not often + never | 9 | 47% |
|  | **19** | **100%** |

|  |  |  |
| --- | --- | --- |
| **Students' current courses:** | | |
| Creativity / Humanity | 3 | 16% |
| Society / Social Systems | 7 | 37% |
| Healthcare | 2 | 11% |
| Social Sciences | 5 | 26% |
| STEM | 2 | 11% |
|  | **19** | **100%** |

The participants’ current courses include ‘Introduction to social sciences’ [2], ‘Exploring psychological worlds: thinking, feeling, doing’ [2], ‘Issues in research with children and young people’ [1], ‘Introducing health and social care’ [1], ‘Introduction to healthcare practice’ [1], and ‘People, work and society’ [3]. Proposing that these study choices are proof of a caring disposition is unsound, but to assume that students who are naturally drawn toward these courses are ‘always + often’ and ‘sometimes’ considered to demonstrate caring behaviour is also unjustified. That the views are presupposed and judgemental is backed by participant comment,

‘the stereotypical idea of how an autistic person presents is what most people think of, so are unaware of the wider range of experiences autistic people have’ [S1.14]

‘labels make people make judgements before knowing a person.  
‘You wouldn’t go up to a non-autistic person with a pre-judgement however people do with autistic individuals.’ [S1.13]

The frequency of negative inference as indication that ‘autism’ and ‘autistic’ continue to be associated with historic and media stereotypes,[[33]](#endnote-33) is upheld.

The image of outlier group identities are often at odds with the individual’s personal reality and inner view of themselves. The negative interpretation of such value judgements impact the autistic students’ ability to develop any sense of belonging and may place them outside their comfort zone while within the predominant group space.[[34]](#endnote-34) The narrative evidence from the survey participants illustrate how upsetting and unsettling this can be for autistic students who are already well aware of these common perceptions:

‘people think I’m rude when I’m really not trying to be’ [S1.02]

‘I was afraid of offending someone by being too honest or not understanding some social rules’ [S1.10]

These autistic student accounts of attempting to fit in with the majority group suggest that they take responsibility for the problem, having tried and failed before. Other participants explained the problem by attributing it to a natural unease on the part of NTs who ‘are reserved and cautious about interacting with someone they know is autistic’ [S1.09].

### Theme 2: Recognizing autistic student needs and preferences as enablers for HE engagement

Identifying the barriers to access for autistic students, to prioritise their needs and preferences, and to liberate them from the constraints of NT norms[[35]](#endnote-35) is also a priority for this investigation. The course structure and learning situation sub-themes from the quantitative data are enriched by the student narratives.

#### Sub-theme: Preferred learning situations [% of participants choosing option]

* Working with other students, [0%]

‘When everyone is talking at once I find it very overwhelming and exhausting.’ [S1.02]

* Taking part in online tutor groups, [45.5%]

‘Online tutorials are sometimes a little difficult and I feel my comments are not always picked up as other people’s comments are.’ [S1.09]

* Being able to study at home, [85.7%]

‘I love learning at home by myself without having to speak or see people.’ [S1.05]

*Sub-theme: Preferred support provision [% of participants choosing option]*

* Knowing that support with study skills is available, [50%]

‘Having to be responsible for all of my organisation stresses me out a bit as I prefer already being given a scheduled to work with.’ [S1.03]

* Having a supportive course tutor or mentor, [78.6%]

‘My tutor is open to email conversations instead of over the phone which has helped me communicate anything I need on the course more effectively.’ [S1.13]

* Being provided with course materials, [92.9%]

‘Having study materials provided for the whole module is really useful for managing my expectations of what's coming up.’ [S2.09]

[I need guidance to help make] ‘clear what I need to be doing all the time’ [S1.09]

‘Not having a printed booklet played a big part’ [in misunderstanding an assessment question] [S1.07]

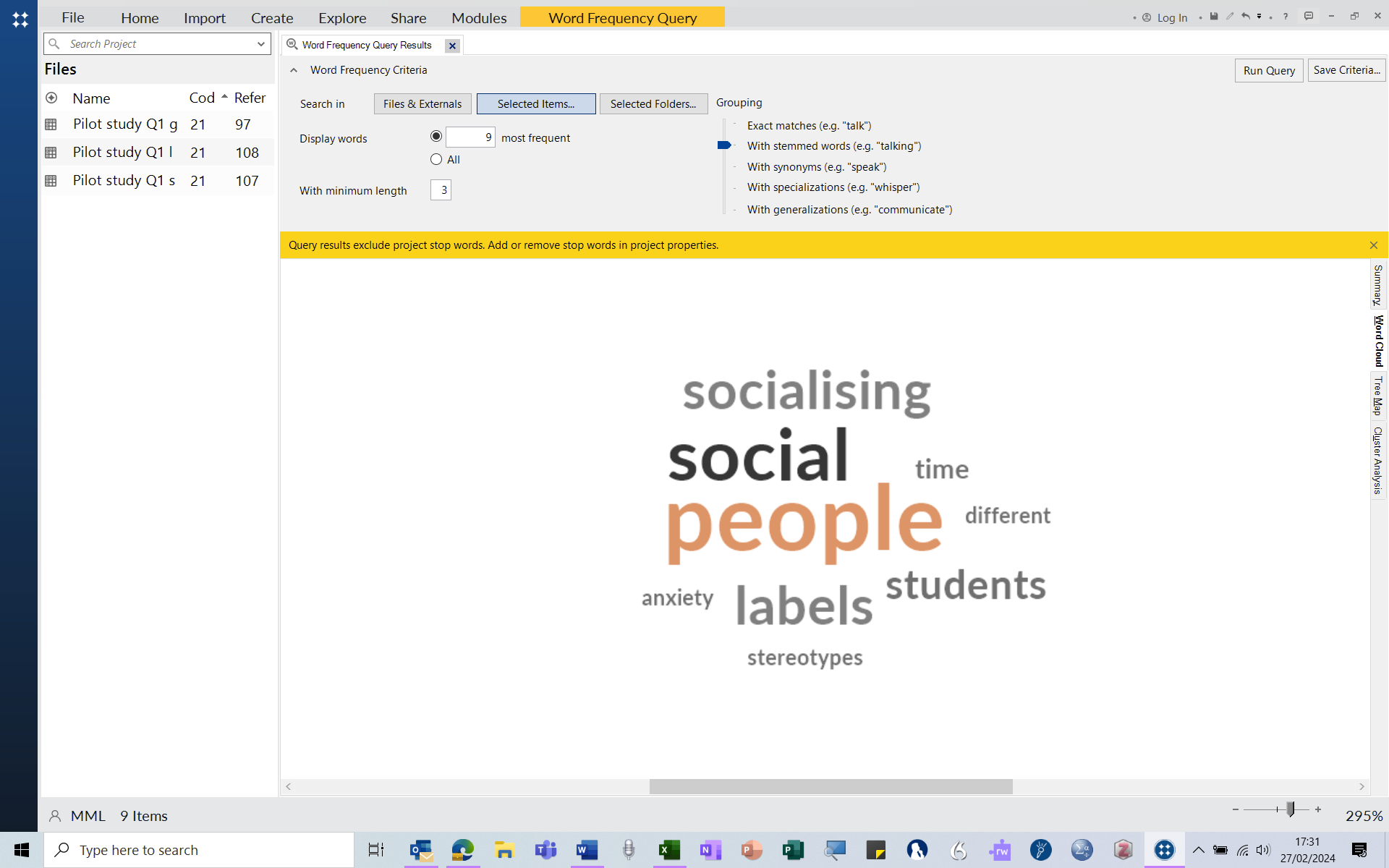
One student explained different strategies they employed for coping in diverse situations:

‘I have techniques to avoid being overwhelmed and I don’t socialise so mostly my learning is within my control.

‘I have attended tutorials online without camera or need to speak. They have been ok although they are always delivered too fast and occasionally I have had to walk away.

‘I have chosen modules without exams because I would not be able to take an exam due to having to work to a short timescale from memory.’ [S1.05]

The challenging situations described by individual participants are not uncommon and underpin a deeper chasm between the experience of autistic students and that of the majority NT community.[[36]](#endnote-36) A high frequency word (HFW) thematic analysis of narrative responses clearly indicates that interaction with others is a primary barrier to HE inclusion and wellbeing, and negatively affects learning. The HFW include ‘people’ [21 counts], ‘social’ and ‘socialising’ [21 counts], and ‘labels’ [8]; ‘anxiety’, ‘stereotypes’, and ‘different’ [5 counts each].



The results of a HFW query to identify ‘what makes a learning situation easier’ highlight the autistic student need for control over how and where they learn, their preference for having access to printed materials, and for developing independence through relevant and reliable support:

control – resources - online, independent - tutor, choice

### Theme 3: Online HE as enabler or creator of barriers for autistic students

This investigation’s premise is that online learning may provide an optimal HE platform for students facing the challenges of being autistic in a space of NT norms and expectations. Those participants with campus-based experience related the medically-recognised autism feature of ‘challenges in social interaction’ as problems in particular contexts. HE staff may not know of the autistic student’s preference for autonomy, and how this can positively impact other aspects of their experience. By having choice over their learning environment and being able to control the extent and quality of online course interactions students had ‘time to think about my responses before I send them’ [S1.08] and minimised difficulties associated with social interaction.

Online learning may not be an unqualified panacea for the engagement and well-being of any student group, but it is the quality of the online experience for autistic students that this study examines. Some participants had previously studied in campus-based HE Institutions and made comparison between the two experiences. They describe ‘a lot of stress and pressure’ [S2.11] and ‘just not being able to cope with being around people’ [S1.13] that caused them to drop out of college. Conversely, for the majority of participants positive feelings about their online experience exceeded the negative. They describe the freedom of online learning, of being able ‘to learn at my own pace’ [S1.13], to allow ‘myself the freedom to work when I felt in the right mind’ [S2.11], and how ‘minimal interaction with other students has helped me not to worry [and to] just get on with learning.’ [S1.14].

The accepted figure for autistic persons as part of the population worldwide is 1%.[[37]](#endnote-37) With education design and support provision focussed on the demands of the predominant group, the needs of minority groups can be further marginalised.[[38]](#endnote-38) The chasm created between an accepted NT norm and a disparaged autistic norm creates a ‘social learning disability’ that intensifies any potential HE disadvantage.Judging a person’s merit on how well they conform to a mythical stereotype can also determine whether they are found socially acceptable, but a need to conform may push autistic persons toward masking as a survival or avoidance strategy.[[39]](#endnote-39)

Research in this area suggests that the reasons for, and the effects of masking may be negatively associated with stigma and attempts to suppress unusual behaviours.[[40]](#endnote-40) However, the argument in favour of supporting autistic persons toward a state of not needing to mask, or toward recovery from the distress of masking, appears to assume that for autistic persons the act of masking is distressing and requires controlling. The result from the survey on situations that make it easier to study online suggests that for autistic students the freedom to mask is regarded as a positive, with 63.6% selecting this option. The learning contexts most highly valued, provision of course study materials [92.9%] and the flexibility of being able to study at home [85.7%] have been discussed. The learning contexts valued less highly than masking include having a course tutor or mentor [57.1%] and knowing study skills support is available [50.0%].

Another flawed NT perception of autistic persons struggling to cope aligns with the diagnostic feature of ‘extreme reactions to change’ that may lead to difficulty in re-adjusting to a sudden change of circumstance. When online learning offers the flexibility of asynchronous presentations this is not problematic. However, one student describes a state of panic in an online tutorial following a sudden, unexpected request for everyone

‘to have their mics/cameras on - it had always been optional before - I had to come out of the [online] tutorial as it panicked me’ [S1.14]

The actual root of the panic is not stated: it may have resulted from a fear of having to speak or of being triggered by lots of voices. Another participant comment on the difficulty of taking part in forums ‘as I don't know what's expected of me fully’ [S1.02] suggests the possibility for panic is an awareness that an expectation to interact is fraught with difficulty and uncertainty. This absence of background information to clarify the meaning behind the comment is a problem inherent in balancing ethical considerations within an e-research context.[[41]](#endnote-41) Introducing opportunities for individual, pseudonymised clarifications may mitigate this dichotomy in future research projects.

Difficulties with adjusting to sudden change is believed to stem from a methodical way of thinking that influences academic strengths, makes autistic students thrive in subjects that require systematic logic, but views them as being unsuited to creative activities.[[42]](#endnote-42) In this either-or reasoning the research that feeds society’s knowledge needs to reject the stereotypes and adopt an approach that celebrates autistic individuality and the potential for creativity. One participant’s account of the surprise voiced by their support teacher that ‘I could write so well about literature seeing as I’m autistic’ [S1.01] confirms a lack of appreciation that autistic individuals are ‘individual’.

The findings suggest that the element of the HE experience that creates the greatest inconsistency between barrier and enabler is the autistic students’ personal interaction with their tutors. Some students describe a relationship with their tutor that fully supports their individual challenges. For others their tutor’s commitment to fulfil their responsibilities to support each student to reach their potential is absent, and one participant describes being told ‘in my learning plan I shouldn’t use the word autism as my tutors wouldn’t treat me the same/fairly’ [S1.02]. Another student with a tutor who only made contact ‘when I’ve emailed him first’ [S2.07] describes having difficulty with motivation. Such experiences impact the autistic student’s sense of belonging and well-being and can have significant implications for the student’s ability to progress.

## Discussion

Of the 20 students who signed a Consent Form 19 took part in Questionnaire 1, but the response rate for completing all other surveys is 74%. The increased time commitment for Questionnaire 2 may be a factor in attracting fewer responses, but a 55% completion rate for the self-directed activity appears to be at odds with an autistic preference for having individual control over learning,[[43]](#endnote-43) and with the overall positive verdict on participating in the study. This situation suggests that future investigation into autonomy as a preference and as a process could be beneficial.

The research findings support this study’s hypothesis that NT assumptions and misperceptions about autistic behaviours negatively impact the autistic student experience of HE. Additionally, the findings suggest the most significant factor for an optimum learning environment is working online without the need to interact with other students. However, the benefits of distance learning are balanced against the challenges that studying online can create for autistic students in terms of self-management and inadequate resources, and this requires further exploration.

## Limitations and future directions

The key themes in participant responses informs the comment coding, but it became apparent that the wording of open questions influences the usefulness of the subsequent analysis. Questions such as “Do you have examples of situations that made it difficult for you to complete any of OU learning activities?” will always elicit a richer, descriptive response, whereas “Do any labels or attitudes make it easier for you to join in social situations?” could be answered with ‘yes’ or ‘no’.

## Conclusions

A roadmap for a 10-year strategy for working toward ‘lifelong learning’ for autistic persons through staff training programmes and standard qualifications was published by Autism Europe.[[44]](#endnote-44) Educating neurotypical persons in awareness and acceptance of divergence from arbitrary norms and committing to research that directs inclusion from engagement toward empowerment should be the goal. This is as important, arguably more so, that reprogramming neurodivergent brains to fit inside an alien paradigm. Logistically and economically there may be higher benefits: offering quiet spaces, reducing sensory input, and allowing for flexibility will be less intrusive than dealing with emotional shutdowns and course disengagement. Ethically there is greater justification for educating a predominant group to be more accommodating of myriad minorities than to maintain a belief that a group’s size equates to the value of its experience and the merit of its expectations.

Research benefits from listening to authentic voices. But an investigation into the autistic student experience will ultimately fail when it does not involve the autistic community as participants rather than as subjects in an NT process,[[45]](#endnote-45),[[46]](#endnote-46) or is conducted by non-autistic researchers.[[47]](#endnote-47) Achieving these goals is the researchers’ justification for conducting this research and by listening to authentic narratives the way forward becomes more clearly defined.

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