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The lived experiences of primary and secondary education for autistic university students

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ABSTRACT

Policy calls for inclusive practices to facilitate the integration of diverse autistic school students into mainstream education. This poses challenges for teachers and autistic students and retrospective accounts can make sense of the experiences of autistic. This study explored experiences of mainstream education in six autistic university students through semi-structured interviews facilitated by images chosen by participants. Three themes and four subthemes were identified through thematic analysis of the data: 1) Inaccessibility; 2) Support (Subthemes: Supportive Teachers; Inadequate Support Provision) and 3) Challenging Peer Relationships (Subthemes: Social Interaction Challenges; Isolation and Difference). Recommendations for improving inclusive support provision for autistic students in mainstream education included appropriate support and training for teachers, reasonable adjustments to the physical environment and inclusion of lived experiences when developing related future policies. Future research should consider a multi-informant approach and other groups such as those who do not progress to higher education for a more holistic understanding of the inclusion of autistic students in mainstream education.

Introduction

The Diagnostic Statistical Manual-5 defines autism as a neurodevelopmental condition that involves impairments in social communication, interaction, and restrictive and repetitive behavioural patterns (American Psychiatric Association (APA) 2013). Autistic people are reported to often experience challenges with executive function, or 'thinking skills that assist with reasoning, planning, problem-solving, and managing one's life' (Blair 2016, 1; Pellicano 2012). Autistic children and young people (CYP) are more likely to experience bullying, difficulties forming and maintaining friendships and lower academic attainment (Park et al. 2020; APA 2013; Department for Education (DfE) 2020; Locke et al. 2010). Without suitable teacher training, autistic students are two times more likely to be excluded from school than students without additional needs (DfE 2023). Only 26% of autistic CYP

report feeling happy at school and 75% of parents state their autistic child's needs are not met at school (National Autistic Society 2023). Therefore it is essential to gain insight into the experiences of autistic CYP, to help identify strategies to address and reduce these unacceptable educational inequalities (Saggers, Hwang, and Mercer 2011).

Policy: CYP with SEND in mainstream education

The *SEND Code of Practice* states that CYP with Special Educational needs and Disabilities (SEND), including autism, should have the opportunity to attend mainstream schools and be involved in discussions surrounding their support and educational provision (DfE, 2014; National Autistic Society, 2024). Effective inclusion is argued to benefit all students within the classroom with research suggesting it provides greater opportunities to develop social skills and diverse peer relationships, as well as improving attitudes towards neurodiversity (Beghin, 2021).

However, this is not straightforward and reports show that autistic CYP's needs are often unmet in mainstream education as they are frequently isolated, spend more time outside the classroom with support staff, away from their peers (Ofsted, 2021). Expectations to integrate students with SEND into mainstream education have also been criticised for placing excessive pressure on teachers who often lack sufficient training and resources to support them (Hellawell, 2015; Nilsen, 2018). Relatedly, teaching assistants are integral to enabling many students with SEND to access the curriculum; however, lack of funding and subsequent shortage of teaching assistants poses a threat to such support provision (Hughes, 2024). Relatedly, the DfE (2024) pledged additional funds to support children with SEND in mainstream schools. However, reports still show that the policy is failing CYP with SEND and reports a 'postcode lottery' of support (Azpitarte and Holte, 2023).

The combination of the integration of students with SEND and the lack of sufficient staff training has led to a more medical model approach to autism whereby additional needs are viewed as problematic. The absence of such training therefore means that autistic students are viewed as possessing deficits rather than cognitive differences. This lack of training and understanding therefore means that staff are unable to provide inclusive mainstream education environments that celebrate and harnesses individual differences, something that in recent years has been described as adopting a neurodiversity-affirming approach (Pellicano & den Houting, 2021).

The school environment

Despite barriers to accessing mainstream education such as executive function challenges and co-occurring mental health challenges, the mainstream school environment is criticised for creating further barriers for autistic CYP (Kose, Fox and Storch, 2018; DeFilippis, 2018; McKinlay et al., 2024). As the current stance in English education is to include students with SEND in mainstream schools, the school environment must be inclusive of these students and their needs (DfE, 2024). Such inclusive classroom environments can benefit autistic and other students with SEND without detriment to their neurotypical peers. For example, systematic review evidence (McKinlay et al., 2024) and workshops with autistic adolescents (McAllister and Sloan, 2016) assert the importance of designing classrooms that consider the auditory and visual sensory effects on autistic students to

enable them to focus. However, many classroom environments are deemed unsuitable for autistic pupils (Horgan et al., 2022) and create unnecessary education attainment barriers such as heightened noise levels, crowded areas and harsh lighting (Saggers et al., 2011; Gardiner, 2018). Further, Gardiner (2018) argues that exam invigilators must understand the needs of autistic students, including communication differences which could create barriers to understanding instructions. She posits that examinations should be more accessible without reducing the overall difficulty.

Peer relationships

Autistic students are reported to experience challenges with peer relationships such as peer rejection (Locke et al, 2010; Feldman et al., 2022). Despite earlier assumptions that this causes autistic CYP to not want to engage in peer relationships, it is now known that this is often not the case. Relatedly, autistic students are more likely to encounter bullying, which negatively impacts school attendance, social participation, mental health, self-esteem and academic performance (Ashburner et al., 2008; Park et al., 2020) thus creating further inequalities within mainstream schools. Explanations for these challenges include the 'double empathy problem' (Milton et al., 2023) that reframes challenges with peer relationships as a difference, not deficit, in communication styles and preferences of autistic and non-autistic individuals.

Student-teacher relationships

Student-teacher relationships impact academic performance and social development (Feldman et al., 2019). Although autistic students' perspectives of their teacher relationships are scarcely explored, Bolourian, Stavropoulos and Blacher (2019) found autistic students reported more conflict with teachers than their peers. Furthermore, Losh et al (2022) explored autistic students' interpretations of their student-teacher relationships and uncovered that although 80.7% of students reported liking their teachers, 14.7% reported anger towards them. Additionally, Feldman et al (2019) found that teachers with more experience working with autistic students reported closer relationships than their less experienced colleagues. These findings suggest that autistic students have varied relationships with teachers, which may impact their academic performance. Consequently, it may be important for teachers to have greater training or experience in working with autistic students to improve relationships.

Summary

Evidence indicates that autistic students experience challenges and educational inequalities in mainstream schools. Therefore, there is a clear need to increase the inclusivity of mainstream schools. However, existing research is often based on the views of individuals who are *currently* experiencing these challenges. Although this is valuable, evidence demonstrates the value of supplementing this evidence with retrospective accounts (Haegele and Zhu, 2017). This can help to make sense of previous life experiences (Huws and Jones, 2008), including experiences of autistic students in mainstream education, which is currently lacking. Retrospective accounts could therefore add richness to the current evidence and inform recommendations for policymakers and mainstream

education professionals to ensure inclusivity in mainstream schools (Zakai-Mashiach, 2022). Therefore this study aims to explore the lived experiences of mainstream primary and secondary education in autistic university students aged 18–25 years,

Methods

Positionality

Transparency of author positionality is essential as it can impact approaches to data collection and interpretation. Author MW has worked with families of autistic young people and has professional experience of how autism can impact young people at school. Author LP was late diagnosed with attention deficit hyperactivity disorder (ADHD) and autism in adulthood and therefore navigated education without the diagnoses and relevant support. These positionalities are deemed a strength of this work as they enable unique insights into data analysis and interpretation (Braun & Clarke, 2006).

Participants and recruitment

To recruit autistic University students aged 18–25 years, convenience sampling was adopted (Saunders et al., 2018). Students who met the inclusion criteria were recruited via a university-wide email and social media posts. Inclusion criteria were that individuals must report that they have a formal or self-diagnosis of autism, are 18–25 years old; are a university student in England and educated within a mainstream school before University.

Procedures

This study gained ethical approval from the authors' University's ethical procedure (Reference: 050120). Data collection was carried out either remotely or in person. Participants were asked to provide 1–3 images reflecting their school experience to aid discussion during semi-structured interviews. This visual method is considered useful for lived experience research (Pope et al., 2019) and has been shown to facilitate rapport-building and communication between interviewer and participant and enhance data quality (Glegg, 2018). Interview questions included asking participants to tell the interviewer about their chosen image(s), their experiences of peer relationships at school, the school environment, if they were included in discussions about their support provision and what they think could improve support provision in mainstream education.

Data analysis

A Reflexive Thematic Analysis (RTA) was undertaken as it is deemed an appropriate method to explore the experiences and perceptions of marginalised groups (Braun and Clarke, 2022a, 2022b). The RTA searched for patterns across the data through six iterative stages:

1) Data familiarisation: Listening to audio recordings re-reading transcripts making detailed notes;

2) Generating initial codes: Author MW added short phrases to data that are relevant to the research question. It is typical for there to be a single coder for a reflective thematic analysis as it acknowledges that themes do not pre exist within the data and are identified and interpreted by the individual undertaking the analysis, hence the importance of being transparent about author positionality.

3) Searching for themes: Combining codes from the previous step;

4) Reviewing themes: Checking group codes represent the dataset;

5) Defining and naming themes: Discussions with author LP to deepen MW's understanding of the data (not to check accuracy);

6) Producing the report: Including carefully selected quotations to ensure they represent the data (Braun and Clarke, 2022a).

Results

Participants (n = 6) completed semi-structured interviews. All of the participants had a formal diagnosis of autism. Five of the six participants reported co-occurring conditions (See Table 1). Three themes and four sub-themes were identified (See Figure 1). The participants discussed primary and secondary school experiences simultaneously and did not specify which experiences related to which school stage.

Four participants' images reflected feelings of isolation and difference at school (see Table 2) and are discussed in further depth below.

Inaccessibility

Participants shared how the inaccessibility of classrooms impacted their learning negatively. They reported that the 'classroom was not accessible … just the number of people was so overwhelming' (P.D). P.A shared that he was often unable to complete his work due to the 'overwhelming environment' which made him feel like 'a failure'. He suggested that to improve access to education for autistic individuals, educators should use 'small rooms and softer lighting.' P.E described how moving classrooms was 'really loud' which often made them late to lessons. Another participant shared that inaccessibility impacted her attendance:

My attendance in actual lessons was like 50% … I have no idea how I passed my GCSEs. P.D

Table 1. Participant demographic information.

| Participant	Gender	Age	Age at Diagnosis	Self-reported Diagnoses	Country of Education
P. A	Male	22	21	Autism; Attention Deficit Hyperactivity Disorder (ADHD)	Kuwait
P. B	Female	19	16	Autism	England
P. C	Male	20	16	Autism; Poor Working Memory; Slow Processing Speed	England
P. D	Female	18	16	Autism; Anxiety	England
P. E	Female	21	17	Autism; Dyslexia	England
P. F	Male	21	16	Autism; Anxiety	England
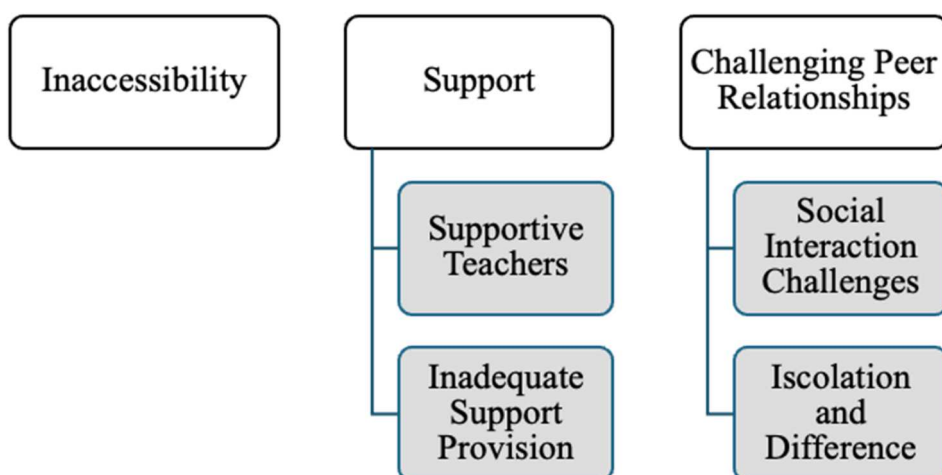
Figure 1. Summary of themes.

Contrastingly, P.F. suggested that the environment was largely accessible for his sensory challenges. He stated that 'I didn't have any issues with it, except sometimes it might be a bit loud' and the main challenge was the 'fire alarm.'

Four participants deemed assessment processes as inaccessible, uncomfortable and distracting. For example, P.E described her experience of examinations as 'awful' and shared that 'it was really really hard and I was extremely stressed'. P.C shared his difficulties with essay writing, 'I never used to like essays and I always thought it was because I

Table 2. Images shared by participants.

Participant	Description of image(s) shared	Meaning attributed to image(s) by participant
P.A	Image 1: Student who appeared sad sitting at a desk in a classroom. Image 2: Words 'I was bullied. This is my story'	Image 1: Feeling isolated at school. Image 2: Experiences of bullying
P.B	Image 1: Image of a dull empty classroom with rows of desks	Poor lighting and classroom appearance.
P.C	Image 1: Man sitting alone by a lake. Image 2: Rubber duck surrounded by swans.	Images 1 and 2: Feeling lonely and isolated at school.
P.D	Image 1: Green robot in a crown of red robots. Image 2: Girl screaming with fingers in her ears Image 3: Person staring at a wall of different facial expressions	Image 1: Feeling different to her peers. Image 2: Represented the challenges with noise and sensory overload. Image 3: Represented her experiences of masking her emotions at school.
P.E	Image 1: Girl staring at a laptop with head in her hands with to-do lists, papers, envelopes and music notes swirling around. Image 2: A maze without an exit. Image 3: A child drowning/falling into the water. Image 4: Carrying a weight Image 5: Person with head in hands Image 6: Outline of a profile with brightly coloured flowers and vines emerging from top of the head.	Images 1, 3, 4, and 5: Represented the overwhelming demands of school. Image 2: Trying to navigate social situations with difficulty. Image 6: Representing creativity associated with being autistic and having ADHD.
P.F	Image 1: Student appearing sad and isolated near a group of peers Image 2: White egg in a box with brown eggs	Image 1: He felt lonely at school. Image 2: He felt different to his peers at school.

was unintelligent.' However, he revealed that examinations were a particular struggle for him. 'When it came to exams … I could come out with the worst grades or the best grades … I grew up with this prevailing feeling that I'm stupid, or inadequate'

Three participants shared how examinations were anxiety-provoking for them:

> I would have a lot of panic attacks when I would go into the exam room. P.E

> Every little noise I hear, I'm listening to that instead … suddenly my time for the paper was up. P.D

> Exam condition assessments are just a real sensory overload environment. P.C

Support

Supportive teachers

All participants indicated that they had some positive relationships with teachers and three participants additionally reported variability in the relationships with teachers: P.B said they were 'really close' to some teachers and 'really clashed with' others. Two participants (P.D and P.F) noted that spending time with their teacher helped facilitate a more positive relationship:

> the ones who actually taught the subjects and knew me … They were good … were trying to be helpful. P.D

Further, one participant shared a preference for communicating with teachers over their peers:

> I would say I always got along with teachers because I felt more able to relate to them than the kids. P.C

Inadequate support provision

Participants described a lack of support, such as strategies, provision of resources, adaptation of teaching methods or pastoral care, for challenges they experienced at school that they attributed to their autism and also uncertainty around where to access support. They shared that this lack of support may have been due to a lack of teacher understanding of autism and in some instances, teachers' offending ableist language.

P.A. who studied in a school in Kuwait, claimed 'there was nothing in place' in terms of supportive strategies and inclusion within his school. Contrastingly, other participants who studied in England, said that they were aware of some supportive measures, but still identified significant failings:

> … generally, there is a lack of awareness of what to do … it sometimes feels like they (teachers) just go 'Oh they need quote unquote support so let's do XYZ and rubber stamp it' and don't really know what else to do. P.C

Similarly, experiences were shared around not knowing where to seek support. P.B shared that she was told there was a 'liaison person' but she 'didn't even know who she was' and felt she couldn't ask due to her social anxiety. Additionally, P.E discussed

the lack of support for her challenges with friendships, and anxiety, stating ' … there wasn't really much like extra help … I only really got things (support) for dyslexia.'

One participant described feeling unsure of what he needed when he was first diagnosed with autism and another participant (P.E) felt that support around 'social issues' was lacking:

> I don't really know who I am or what I need … I didn't feel able to say with authority 'Oh yes this is what I need' … . P.C

Four participants (P.E, P.D, P.C and P.F) suggested that improving teachers' and students' understanding of autism may have improved support provision for them:

> If the teachers were more open and understanding then that would hopefully naturally trickle down to the students. P.E.

Further, it was argued if teachers spent more 1–1 time with autistic students, this could help improve their awareness and understanding of autism and individual needs because 'Every single autistic person is different' (P.D):

> I would probably say more one-to-one/relational because I think that is so important. P.C

> (teachers should) talk to the autistic people … and like see what they need. P.D

P.D. described one of her coping strategies as sitting by the door, away from crowds, with friends to feel more comfortable in the canteen. However, she shared how teachers teased her and her friends for this and stated that a solution would be 'from (teachers) being more educated' about autism:

> We don't need the extra judgement from the teachers that we feel like we are already receiving from the students.

P.D and P.F shared concerns around the ableist and offensive language directed towards them from other students, the lack of consequences for this and the discomfort it caused during lessons:

> The number of times I heard the 'R' word ('retard') is ridiculous … … Every time someone would use it I would be put on high alert. There was no real punishment or anything to stop … deter them from saying it. P.F

P.D shared how the impact this language had on her sometimes went beyond feelings of discomfort:

> I just spiralled from there and that was it for me for the day … There was no intervention from teachers. P.D

P. F argued that the only solution he felt would help the issue was 'making proper awareness' of autism and neurodiversity among teachers and students.

Participants were asked if they were included in conversations regarding the inclusion of autistic students within mainstream school settings. Three participants discussed finding this challenging and felt they were not supported or informed enough to meaningfully contribute to these conversations:

> They would ask me like what I wanted, like what accommodations I felt like I wanted, but I had absolutely no idea because no one ever explained to me what I could have. P.B

Challenging peer relationships

Participants shared that they often found peer relationships challenging as they found social interaction challenging and felt different and isolated.

Social interaction challenges

Challenges with social interaction were deemed to have a detrimental impact on participants' peer relationships:

> 'I hated social interaction' and it was not until towards the end of high school that 'I found people I connected with who were also heavily interested in my special interests'. P.D

> I didn't interact with people who weren't my friends very well. P.B

P. E. shared that, although she was able to form initial relationships easily, she struggled to maintain them and then felt blame for this was placed on her by her teachers:

> I could make friends quite easily because I was fun, bubbly … but maintaining them and managing them was tricky … … It felt like I was the one that was being told off … I was the one who was not understanding enough. P.E

Isolation and difference

Two participants shared experiences of bullying at school, which they explained had a serious impact on their self-esteem and mental well-being.

> I was picked on for acting out in different ways … I had songs made about me; I had people call me names behind my back; people insult me and my family. P.A

P. A reflected on the impact his experience of being bullied at school has on his adult life and stated that he has undiagnosed 'complex PTSD' because of it. Further, P.C shared that he believed differences led to his experiences of bullying, arguing by being different:

> … you get picked on a lot more, you get hurt a lot more and you get penalised. P.C

Three participants (P.C, P.A, P.F) stated that they experienced loneliness and felt isolated at school. When referring to the image he shared of a man sitting alone by a lake, P.C shared that it:

> encapsulates loneliness because I remember spending a long time in secondary school primarily feeling totally isolated … I felt like I never had friends. P.C

P.A. shared that the image he brought to the interview of a student appearing sad sitting at a desk in a classroom also referred to as 'feeling isolated.' This was also reflected in P.F's discussion of his image which depicted a student appearing sad and isolated near a group of friends. He shared that it reflected how he 'was quite lonely' in school.

These feelings of isolation were also linked to a feeling of being different to other students. P.D. shared that her image of a green robot in a crowd of red robots reflected 'not being the same as normal people.' P.C shared 'There was something different about me and I wasn't like other kids' and this was reflected in the image he shared of a rubber duck surrounded by swans. Feelings of difference were also expressed by P.F, who shared that

despite having a group of friends, 'I didn't feel like one of them,' which he expressed with an image of a white egg in a box of brown eggs. He further articulated 'I felt othered by everyone in the school by all like the other students' and 'I was like the weird one.'

Discussion

Retrospective accounts of autistic young adults support existing evidence that argues mainstream education is largely inaccessible to autistic students, who often encounter challenges with peer interactions and isolation. Teachers and staff also lack appropriate training and resources to support autistic students.

Inaccessibility

Despite a plethora of evidence reporting sensory sensitives in autistic individuals (e.g. Ashburner et al., 2008) evidence reports mainstream education often not meeting their sensory needs and creating barriers to their learning (e.g., Saggers et al., 2011; Gardiner 2018). Unfortunately, this was also a finding of the present study with reports of sensory barriers such as noise levels and crowds, distractions during examinations such as invigilators pacing and other students writing and conversely particularly quiet environments can amplify more subtle noises such as their own heartbeat or ticking clocks which was reported to be unsettling. Therefore, it is crucial that mainstream staff, including exam invigilators receive sufficient training to ensure examination environments are accessible for autistic students (Gardiner, 2018).

A possible barrier to such provision may be the medicalised deficit approach to disability that is often adopted in schools whereby challenges are attributed to individual deficits and individual strengths are overlooked. Purely strengths-based approaches have similarly been criticised for omitting recognition of important challenges experienced by neurodivergent individuals (Sonuga-Barke & Thapar, 2021). Therefore, the adoption of a neurodiversity-affirming approach may be more suitable for schools where *differences* are celebrated, which recognise individual strengths *and* challenges, not deficits (Pellicano & den Houting, 2021; Wright, Spikins and Pearson, 2020).

Policy translating to practice

The SEND Code of Practice calls for the voices of autistic CYP to be heard when designing inclusive mainstream school provisions (DfE, 2014). However, participants in this study indicated that it is more complex than this as although they were invited to partake in such discussions,they felt uncomfortable and unable to contribute as they often lacked suggestions to improve inclusion as they often did not know what reasonable adjustments were possible. Therefore it is important to consider the approach to and coordination of such discussions to ensure autistic students feel able to meaningfully contribute (Hellawell, 2015). This could be achieved through sufficient training of staff leading these activities which could draw on existing successful examples such work by McAllister and Sloan (2016) who conducted workshops with autistic students and a 'jigsaw kit' to help them communicate their needs when designing their perfect school.

Results included positioning noisier areas away from support areas showing their need for quiet, support spaces.

The role of support provision for autistic CYP in mainstream education

Evidence shows the importance of student-teacher relationships in classroom engagement for autistic students (Losh et al., 2022), something that participants in the present study reported was positively impacted by spending more time with their teachers. Quality of student-teachers relationships was varied amongst participants in this study, potentially reflecting the reported postcode lottery of support (Azpitarte and Holte, 2023). Another explanation could be the varied experiences of teachers as evidence does suggest more experienced teachers form more meaningful relationships with autistic students than their less experienced colleagues (Feldman et al. 2019). Such evidence is however based on teachers accounts therefore there is potential for responder bias as teachers may not choose to share more negative experiences. Further, perceptions of relationships may also vary between teachers and autistic students (Losh et al., 2022) therefore it is important to acknowledge the absence of autistic students' voices in the latter work.

Such variable teacher-student relationships could be explained by the resultant challenges of the SEND Code of Practice (2014) which is widely criticised for its disregard for and lack of training and resources teachers require to provide inclusive education and environments in mainstream settings (Vorlíček, R., & Kollerová, 2024), something that was also a concern of participants in this study. I.e. It may be that teachers lack the time and resources to nurture important relationships with autistic students. Such training needs must therefore be created *with* families and teachers *and* for teachers to ensure the suitability of content and delivery (N8 Research Partnership, 2024; Powell et al., 2024), something that is also indicated to be wanted by teachers (Chow et al. 2023).

Challenging peer relationships

Positive peer relationships are essential for school attendance, self-esteem, mental health and academic attainment (Ashburner et al., 2008; Park et al., 2020). However, participants in this study described challenges around forming and maintaining peer relationships at school including two participants reporting that they were bullied. This is also widely reported in the literature, including in a review of 23 studies that described this as a primary concern for autistic CYP (Roberts and Simpson, 2016).

In favour of a neurodiversity-affirming approach (Pellicano & den Houting, 2021), participants in this study attributed these challenges to feeling different, rather than presenting deficits, and reported an overwhelming sense of loneliness. This has been mirrored in other evidence such as through questionnaires with 20 adolescents (Locke et al., 2010) and is also reported in autistic adults (Grace et al., 2022). This supports the need for schools to advocate for individual differences and move away from a medical model approach whereby differences are viewed as deficits.

To achieve this, mainstream schools could work towards normalising a narrative around communication differences, not deficits, and support autistic and non-autistic students to understand these communication differences. This is supported by the double empathy problem that posits there is no communication deficit in autism, but a difference in communication styles and preferences (Milton et al. 2023).

Strengths and limitations of this study

This study contributes to current understanding of inclusivity provision for autistic students in mainstream schools, placing the voices of autistic individuals at the centre of the work. Findings have the potential to inform discussions around inclusive mainstream education, which could benefit thousands of autistic CYP in England.

Results also solely relied on information from autistic young adults to gain a deeper understanding of their experiences of mainstream education and how inclusivity could be ensured in the future. We did not however seek experiences from other groups such as parents/carers, teachers or policy makers which may have provided a more holistic data set.

Further, we relied on retrospective accounts, of which evidencedemonstrates the value of these techniques (Haegele and Zhu, 2017), including the ability to make sense of previous life experiences (Huws and Jones, 2008). However, this may also mean that the data may have been subject to recall bias (Zakai-Mashiach, 2022).

The sample may also be biased for several reasons: 1) As the study was interview-based, this may have led to the underrepresentation of autistic individuals with alternative communication needs (Zakai-Mashiach, 2022). 2) The sample consisted of university students, indicating a competent level of academic abilities which is not the case for many autistic students, who were not represented in this study (Ashburner, Ziviani, and Rodger 2008). However, it is impossible to represent all groups in the present study and attempts to do so would have reduced the richness of the data. Therefore the aim was not to represent all groups but to gain further insight into the lived experiences of autistic students in mainstream school settings.

Lastly, the use of the images during interviews proved fruitful in facilitating conversations with participants and provided a focal point for potentially difficult conversations. This added depth to the data, something that is reflected in existing evidence (Glegg, 2018).

Summary of recommendations for practitioners

– Policymakers must meaningfully incorporate the voices of autistic individuals and CYP and teachers when developing policies around the provision of autistic students and students with SEND to ensure they are suitable, feasible and clear in terms of what they aim to achieve and how to ascertain what success looks like.
– Continued Professional Development (CPD) for teachers: This should include how to support autistic students in mainstream classrooms and should be co-produced with teachers to ensure the content and delivery of the CPD is suitable and accepted by teachers.
– Examination environments: Should be adjusted to be less distracting for autistic students. For example, invigilators do not pace up and down, to provide quieter clocks and smaller rooms for autistic students where practicable.

- Inclusive environment recommendations: Where required, adjustments can be made that benefit autistic students without detriment to other students. This can include softer lighting, quiet spaces, and noise levels (e.g., quiet spaces situated away from busier areas like the playground or lunchrooms).
- Inclusive environments built with and for autistic students: To Include autistic students in the design of the school environment. This can include larger projects at a school or academy level to build inclusive environments or smaller conversations around adapting existing environments at an individual level.
- To ensure those facilitating these discussions are adequately trained to do so to ensure autistic CYP feel comfortable and able to share their thoughts.

Policymakers should consider the voices of current and former autistic students when reviewing inclusive education policies.

Future research directions and implications for practice

Future research should additionally explore the lived experiences of other groups of autistic students. Other groups should include those with unique support needs such as 1) Autistic students who did not progress to University; 2) Autistic students from ethnic minority groups (N8 Research Partnership, 2024); and 3) Autistic girls and women (Happe and Frith, 2020). Inclusion of these groups in future research can ensure that their voices contribute to discussions around what constitutes inclusive mainstream education for *all* autistic students.

Future work would also benefit from a multi-informant approach whereby in addition to autistic individuals, other groups are also included such as education professionals, parents/carers and policy makers. This would provide a more holistic understanding and support recent recommendations for the joining up of services in support provision for autistic students in education settings (N8 Research Partnership, 2024). Additionally, further work may wish to explore whether or not differences in experiences between primary and secondary education exist as this may inform more tailored future inclusive practices.

Findings from this study have important implications for multiple stakeholders, including teachers, support staff, policymakers, parents/carers and autistic CYP. It is hoped that these findings will stimulate further research, and encourage and contribute towards important conversations around increasing inclusivity and accessibility of mainstream education for autistic students, that aim to achieve positive change and improved outcomes for autistic students.

Conclusions

This research explored the lived experiences of primary and secondary mainstream schools in six autistic University students. Participants reported that they found mainstream education largely inaccessible, including loneliness and isolation and non-inclusive school environments. Reasons for this included non-inclusive physical school environments, loneliness, isolation challenges with peer and teacher relationships, and feelings that their teachers lacked an appropriate understanding of autism and associated

support needs, indicating an urgent need for appropriate training for teachers in mainstream education.

This study also highlights the importance of centring the voices of autistic CYP in the development of inclusive school environments and additionally teachers in the development or refinement of policies around integrating autistic students and students with SEND into mainstream education. This is vital to ensure appropriate support and implementation of such policies in practice.

It is hoped that findings from this study will encourage future work with other groups such as those who do not progress to higher education, girls and women and those from ethnic minority groups, and will encourage and inform discussions around inclusive mainstream education, which could benefit thousands of autistic CYP in England.

Ethics approval statement

Acknowledgements

Disclosure statement

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Notes on contributors

M. Ward is a current Social Policy and Social Work PhD student at the University of York completing an NIHR-funded project surrounding the co-design of an intervention for homecare workers supporting people with dementia struggling to engage with social care. She holds a BA (hons) in Education, Culture and Childhood and an MSc (Conversion) in Psychology and Education. She is passionate about amplifying the voices of marginalised groups, including autistic children and young people, through research, as well as ensuring research has practical application. She has also been involved in digital storytelling projects to explore the mental health and well-being of family carers and adults with learning disabilities.

Dr. L. Powell is a Lecturer in Psychology and Education, with a BSc (Hons) in Psychology, an MSc in Psychological Research and a PhD in Health Psychology. As a late-diagnosed autistic woman with ADHD, Dr Powell brings both personal insight and professional expertise to her work. Her research focuses on centring the voices of young people, particularly through the use of innovative participatory methods. She has contributed to several parliamentary reports in England, offering recommendations to improve support for autistic children and young people, those with special educational needs and preschool-aged children.

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