‘I felt closed in and like I couldn’t breathe’: A qualitative study exploring the mainstream educational experiences of autistic young people

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Abstract

Background and aim: More autistic young people are being educated in mainstream schools. While existing research suggests that the outcomes of mainstream inclusion are mixed for autistic young people, few studies have examined their views and experiences directly. This article discusses the educational experiences of 12 autistic young people (aged 11–17 years) from their perspectives and how education could be improved to better support the others with autism.

Methods: A flexible qualitative participatory approach was used which incorporated a range of methods, including individual semi-structured interviews, diamond ranking activities and draw-and-tell activities. A Children’s Research Advisory Group (CRAG) advised on the methods used and matters to be explored.

Results: The young people offered insights into how education has been for them in mainstream school, mostly negative, but with islets of positive experience. Several described themselves as being socially, emotionally and physically isolated from peers, with loneliness and bullying experienced by some. Participants felt unsupported and misunderstood by teachers within a social and sensory environment that was antithetical to their needs. Some spoke of the dread they felt before and during school and the negative impact their experiences in mainstream has had on their wellbeing. Many participants suggested simple strategies and curriculum adaptations that they felt would have helped make their time at mainstream more successful. These include having more breaks, smaller class sizes, less homework, instructions broken down, safe places to use when anxious and teachers who listen to their concerns and take account of their needs. In short they want to be understood, supported and included.

Conclusions: There exists scope to better support autistic young people in mainstream education, as evidenced by the literature and the participants in this paper. The participants demonstrate that mainstream is not working for all and that changes, such as smaller class sizes, flexible pedagogy and understanding could improve education for autistic learners.

Implications: Autistic young people can and should be central to the discussion on school improvement. They also show that being academically able for mainstream school should not be the only aspect when deciding on the suitability of mainstream school for meeting their needs. The young person’s social and emotional wellbeing must be considered to ensure they can flourish, and not flounder.

Keywords

Autism, mainstream, experience, support, inclusion, qualitative, isolation, bullying

Introduction

More autistic young people are being placed in mainstream school, particularly those who are more academically able, yet research indicates that not all are able to cope there (for example, Conn, 2014; Humphrey & Symes, 2010; McGillicuddy & O’Donnell, 2014). Research to date has focused mainly on the perspectives of adult stakeholders such as parents, teachers and classroom assistants on the efficacy of mainstream inclusion, the educational experiences of autistic young people and...
what is best for improving their educational outcomes. This paper presents some of the young people’s educational experiences and how education could be improved for them, from their perspectives. The findings presented below were collected as part of a larger study.

There is concern amongst parents and educators about the effectiveness of mainstream inclusion for all autistic children (Eldar, Talmor, & Wolf-Zukerman, 2010). Research indicates that mainstream has been a mixed experience for many autistic children and reveals a disconnect between the mainstream school environment, practice and their needs (Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; McGillicuddy & O’Donnell, 2014). As such, mainstream is not meeting the needs of every child. There is also a misconception that because many autistic children have academic ability – such as those with Asperger Syndrome (AS) – that they are automatically capable of coping in a mainstream school environment (Morewood, Humphrey, & Symes, 2011). Wing (2007, p. 32) notes that ‘even the most able children with autistic disorders may find mainstream school intolerable’.

Difficulties with mainstream inclusion arise from the interaction between the autistic child’s intrinsic characteristics and factors within the school environment, including teacher understanding, teacher knowledge and sensory, social and geographical aspects of the school environment (Eldar et al., 2010; Keane, Aldridge, Costley, & Clark, 2012). The unpredictable and intensely social nature of education, alongside sensory aspects of the school environment, can be overwhelming (McGregor & Campbell, 2001; Sproston, Sedgewick, & Crane, 2017; Wing, 2007).

Undoubtedly, mainstream inclusion can be enabling and beneficial, and benefits include displaying more social behaviour and increased social skills (Reiter & Vitani, 2007), as well as having more advanced educational goals (Eldar et al., 2010; Lindsay, Prouix, Thomson, & Scott, 2013). Interestingly, other studies have found that in the presence of mainstream peers, autistic children displayed less ‘autistic’ behaviour (Garrison-Harrell & Kamps, 1997), and develop coping strategies for times of transition and change (Eldar et al., 2010).

However, the mismatch between mainstream and many autistic children may result in challenging behaviour. Challenging behaviour, outbursts of aggression and anxiety are thought of as linked due to neurobiological predisposition and the interplay with environmental stressors (Mazefsky et al., 2013). Anxiety in autistic children, according to White, Oswald, Ollendick, and Scahill (2009), is more likely to be externalised through acting out behaviours, such as aggression, compared to non-autistic children. This is more so for boys, but less so for autistic girls who exhibit less externalisation of frustration and anxiety (see Moyse and Porter, 2015). Nonetheless, the consequence challenging behaviour is demonstrated by reports of a disproportionate number of mainstream school exclusions.

Autistic children are reported as 8 to 20 times more likely to be permanently excluded from school than pupils with no Special Educational Needs (SEN) (Department for Education, 2010; Humphrey & Lewis, 2008a). Sproston et al. (2017, p. 1) from exploring the perspective of eight autistic girls excluded from mainstream suggest that more needs to be done to ‘positively influence the direction of the girls’ educational journeys’ before they reach the point of exclusion. Brede, Remington, Kenny, Warren, and Pellicano (2017), like Sproston et al. (2017), identified similar factors precipitating exclusion, including inappropriate school environments, quarrelsome relationships with peers and teachers, limited understanding of, and support for, their specific needs.

Howlin (1997, p. 143) asserts that ‘for the majority of high functioning children with autism, their chances of living a full and independent life will be dependent on whether they are able to obtain academic qualifications at school’. Statistics obtained from the Department of Education for Northern Ireland statistics branch (February and May 2016; June 2017) indicate an achievement gap: in 2015/16 81.7% of the general school population obtained five GCSE A*-C grades compared to 62.8% of autistic school leavers. Perhaps the discussion above and that which follows helps to explain this.

Child perspectives

The existing research demonstrates that autistic children and young people themselves can find inclusion in mainstream schools stressful, marked by experiences of bullying, isolation and anxiety (Browning, Osborne, & Reed, 2009; Hebron & Humphrey, 2014; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2011; Poon et al., 2014; Sproston et al., 2017; Sreckovic, Brunsting, & Able, 2014).

Bullying was a major concern for the four students with AS interviewed by Hebron and Humphrey (2014); mirroring findings in other studies (see Humphrey & Symes, 2010). One such study by Northern Ireland Commissioner for Children and Young People (NICCY, 2007) explored the views of 35 children and found that while 50% were quite or very satisfied with their school experience, 57% want teachers to have greater understanding of AS and provide better support. Further, 66% would like their school experience...
to be significantly different particularly with respect to bullying and the need for safe learning environments.

Despite these experiences, autistic children express the same desire to be included and develop peer friendships as non-autistics (Dillon & Underwood, 2012; O'Hagan & Hebron, 2017). Three adolescents in a study of friendship by O'Hagan and Hebron (2017) expressed a desire for friendship, yet experienced loneliness. Similarly, a study of adolescents (seven autistic and 13 non-autistic) revealed that despite being involved in the social structure of their classroom, the autistic children experienced more loneliness than their non-autistic peers (Locke, Ishijima, Kasari, & London, 2010).

Gibb, Tunbridge, Chua, and Frederickson (2007) contend that both social and academic inclusions are important aspects of a child's educational experience. However, Saggars, Hwang, and Mercer (2011) who interviewed nine students with Autistic Spectrum Disorders (ASD), and Sciutto, Richwine, Mentrikoski, and Niedzwiecki (2012) who carried out an online survey with 27 adults with AS who retrospectively commented on education, discuss mixed attitudes of autistic students to socialising with peers; some prefer time alone and others like engaging in conversations centred on their interest, while others found the social (and academic) aspect of school stressful. Harrington, Cohn, and Orsmond (2006) describe the understanding and want for friendship of one adolescent with AS. They conclude that we ought to separate the difficulties autistics have with social interaction from the (misconceived) notion that they lack interest in developing friendship.

Ambler, Eidels, and Gregory (2015) used two psychometric assessments and found that autistic high school students \( n = 52 \) in Australia self-reported more symptoms of anxiety and feelings of anger than non-autistic peers \( n = 52 \). For autistic children anxiety can stem from the need for predictability and routine (Connor, 2000). Humphrey and Lewis (2008a, p. 38) explored the experiences of autistic young people and conclude that the ‘chaos of the corridor’ experienced in mainstream schools opposes this need for predictability and routine. Safe havens or quiet refuges are discussed as important in the literature to allow time away from it all in an environment considered safe and more predictable (see Parsons et al., 2011; Safran, 2002).

Teacher understanding was important for two adults with Asperger’s in a study of school experience by Sciutto et al. (2012); they spoke of how their behaviour in school was misunderstood and that a lack of autism knowledge underpinned this. Students with autism viewed teacher flexibility as an enabler of inclusive practices and want support to be unobtrusive to avoid differences being highlighted (Saggars et al., 2011; Sciutto et al., 2012). Similarly, understanding was a recurring theme in Sproston et al. (2017). Further, Dillon, Underwood, and Freemantle (2016) reported how 14 autistic secondary school students (11 boys, 3 girls) appreciated good relationships with staff, reiterating how positive staff–pupil relationships are potentially crucial to inclusion (Brede et al., 2017; Makin, Hill, & Pellicano, 2017).

**Methodology**

**Rationale**

As this was an exploratory study concerned with the lived educational experiences of autistic young people, their thoughts for educational improvement and their understanding of inclusion, a qualitative and participatory approach was most appropriate to garner rich, in-depth data. Humphrey and Parkinson (2006) suggest that autistic people can be marginalised within educational contexts with research conducted on rather than with them. ‘Autistic voice’ is made invisible in the current culture of how knowledge is produced about ‘autistic people’ (Milton, 2012, p. 885). Their voices, however, have been largely missing from this conversation, despite calls for gathering their experiences and views on education to better inform policy and practice (Harrington, Foster, Rodger, & Ashburner, 2013; Parsons, 2015).

Therefore, in order for educators and policy makers to change educational practice, and create a complete picture, the ‘insider accounts’ of autistic young people (Billington, 2006) need to be central to the discussion of what enables (or disables) their access to development through and enjoyment in education (Hebron & Humphrey, 2014).

**Participants and research setting**

Purposive convenience sampling was used. All 15 autistic young people within the Alternative Education Provision (AEP) (13 male and two female) where the author teaches, and all seven children of the ‘voluntary group’ (name of group removed) committee members were invited to participate (four male and three female). Twelve participants aged 11–17 years took part in this study (10 boys and two girls). Seven attend the Alternative Education Provision (having come from mainstream schools): Jim (aged 14.1), Joe (aged 15.2), Lee (aged 13.10), Robert (aged 16.4), Stephen (aged 15.5), Thomas (aged 15.4) and Timmy (aged 15.7). Five were home schooled as a result of struggling with attendng mainstream provision even on a part-time basis: these children attend a study hub set up by the ‘voluntary group’. These are Dan (aged 11.3), Jack (aged 12.3), Ro (aged 16.1), Sarah-Jane (aged
17.0) and Wade (aged 13.11). Data collection took place in these two settings.

**Children’s Research Advisory Group (CRAG)**

A CRAG of three young people advised on the initial research design, specifically the methods used and provided clarification on the aspects of educational experience that should be explored. The CRAG affirmed issues, such as teacher characteristics and peer relations that, from the authors experience and the literature, were already considered important. The CRAG helped the author develop research methods and instruments that were authentic, applicable, engaging, and ultimately able to support the research aim and questions.

**Data collection**

_Semi-structured interviews_. One-to-one semi-structured interviews were preferred by the CRAG to a structured or unstructured approach. This format provided structure and routine expressed as supportive by some autistic individuals (Attwood, 2007), yet allowed the author to accommodate the needs of each participant while being mindful of the potential communication and emotional demands placed on them (Preece, 2002). Pass and break cards were available for the participant to use, if required.

**Participatory methods**

Participatory methods were used to support the participants in expressing their experiences by providing them appropriate and engaging opportunities in a safe and inclusive environment (Lundy & McEvoy, 2012); and, to maximise research accessibility and ensure children’s participatory rights could be exercised by offering multiple means of representation. Offering participatory methods helped mitigate anxiety associated with expressing experiences verbally, and supported participants ‘to access and represent different levels of experience’ (Bagnoli, 2009, p. 547).

**Beans and pots activity.** Participants chose ‘true’, ‘not true’ or ‘unsure’ in response to 17 statements (see Figure 1) by placing a personalised polystyrene ball in one of three pots. These options were visually supported with thumbs up, thumbs down and a question mark (see Figure 2).

**Diamond ranking.** Three diamond ranking activities were used: the first acted as a capacity building exercise – as agreed by the CRAG – and involved ranking different foods into levels of preference; the second focused on ranking nine aspects of school and how supportive and enabling these are; and, the third sought information on potential worries about school that could act as barriers to accessing education in mainstream school (see Figure 3). All features to be ranked were felt to be important by the author and were reflective of the reviewed literature.

**Good teacher, bad teacher.** Participants were given two generic outlines of a figure and were invited to draw, add words, feelings and descriptions to these to describe the characteristics of a good and a bad teacher.

**Me at school.** Participants were invited to produce a drawing of themselves at school. They were encouraged
to add written descriptors and were asked to orally describe the drawing.

**Design your own school activity.** This activity allowed participants to freely express, through drawing, what kind of school they would like (the ideal school).

### Data analysis

A six phase process for thematic analysis was used (Braun & Clarke, 2014).

- **Phase 1:** Becoming familiar with the data.
- **Phase 2:** Generating initial codes (by adding comments to each dataset in Microsoft Word).
- **Phase 3:** Searching for themes – After the initial coding the author moved to identify themes within the data by grouping codes under descriptive headings.
- **Phase 4:** Reviewing themes – the author checked the themes in relation to the coded data and the entire data set to start building up a web of themes and identifying how they interconnect.
- **Phase 5:** Defining and naming themes – Three themes, with subthemes became apparent from the analysis of the data: ‘Exclusion in Inclusion’, ‘Supporting Me’ and ‘Inclusion and Me’ (see Figure 4) – the former two being the focus of this paper.
- **Phase 6:** Producing the report.

### Ethical considerations

Ethical approval was granted by the university. The ethical considerations most pertinent to this research are: power relations between the researcher and participant; researcher bias; voluntarily participation; informed consent; anonymity; confidentiality and protection from harm.

#### Protection from harm, gaining access and voluntary participation

Participants were given informed choice to exercise their right to participate – being assured of their right to information and guidance – and, once participating, they were aided in forming their experiences. At every stage they were protected from harm (the right to protection) with methods designed that would contribute to participants’ wellbeing.

Although the participants were capable of safeguarding their own interests as self-gatekeepers, in line with ethical guidelines, written institutional consent from the Principal of the AEP was sought and granted prior to seeking written parental consent for all participants. Following this, children were approached by a colleague with information sheets and consent letters to decide for themselves whether or not they wished to volunteer to take part in the study. Participants were informed of their right to withdraw up to the point when the data were made anonymous, emphasising that consent was renegotiable (Alderson & Morrow, 2011).

#### Informed consent

Steps were taken to ensure that informed consent was obtained from each participant. This encompassed four elements: having understanding of the research; voluntary participation; explicit written consent; and renegotiable participation. The latter – the right to withdraw – was discussed at the start of each data collection session.

#### Anonymity and confidentiality

Participants chose a pseudonym, which was then applied to their data. This helped to ensure anonymity, yet allowed each participant to identify their data.

Participants were informed of the boundaries of confidentiality at the beginning of data collection. If they gave information that indicated they or another person had come to harm, or were at risk of harm, then they would be told that this ‘would not just be between us’, this would then be passed on to the relevant people (such as the head of pastoral care in the AEP and parents of those participants outside the AEP).

#### Power relations

The power differential that exists between practitioner-researcher and participant can be difficult to overcome. As a practitioner-researcher, the author acknowledged the power status and potential influence of being a teacher may have on those in the AEP where the school, as a social setting, is organised around the power of the adults. The author recognised that working with the young people in the AEP could influence their participation, and as highlighted, a colleague approached the
young people on my behalf. Punch (2002) indicates that children often feel they should please adults and may fear reactions to what they say. For those young people outside the AEP it was recognised that the author’s position as a teacher could potentially evoke negative feelings due to past experiences within education, hence why a ‘get to know you’ session took place to build rapport and trust.

The author positioned themselves as a knowing adult, but also as a learner keen to learn from the young people’s experiences and reiterated that they (the young person) was the expert and that, therefore, there were no correct or incorrect responses (see Punch, 2002). The author’s experience working with autistic young people provided invaluable insight and knowledge that has helped with designing research materials for the participants in this study and outweighed the potential conflict of interest inherent in being a teacher; and ultimately allowed the author to build research relationships with them.

**Trustworthiness and authenticity**

Due to the subjective, constructivist nature of this research study, principles of reliability, validity and generalisation were not of concern. Evidently, scholars debate the relevancy and accuracy of the terminology used to describe validity in qualitative research (see Hammersley, 2007). These are paralleled with the terms ‘trustworthiness’ and ‘authenticity’ (Guba, 1981; Lincoln & Guba, 1985). Trustworthiness is the goal rather than the concept of validity to establish confidence in the findings (Lincoln & Guba, 1985) and is achieved by demonstrating credibility, transformability, dependability and confirmability. Checklists exist to guide researchers in reaching these four tenets of trustworthiness. One proposed by McMillan and Schumacher (2006) was used within this study: the use of multi-method strategies to allow for data triangulation in collection and analysis; verbatim accounts of experiences given by participants; precise detailed descriptions recorded; and, informal accuracy checks with participants during data collection (participant verification). The author tried to ensure that he was accessing precisely what the participants actually meant to say.

Table 1 provides a key to identifying extracts of data, the activity these came from and to which participant the data belong.

**Results**

The author now presents the findings, framed as responses to two key questions, ‘What experiences have autistic young people had during their education?’ and ‘How would autistic young people like school to be?’, along with the subthemes found to be pertinent. The subthemes presented beneath question one are: feelings of dread (including the sensory environment and unpredictability, loneliness and bullying); feelings of isolation, feeling misunderstood; and, feeling unsupported. The subthemes presented beneath question two are: supportive teachers, curricula and environments.

**What experiences have autistic young people had during their education?**

**Feelings of dread.** Several participants described the negative impact of mainstream school on their well-being and difficulties that they experienced in getting through the school day, as the following extracts illustrate, the first three from Sarah Jane and then Dan:

‘My time at primary school was very stressful. At secondary school, the difficulties got worse.’ (I/SJa/p1)

‘“You know what? I am not doing this [secondary school] anymore. I am physically, mentally and emotionally drained ... I am done with this”. Talking about it [mainstream school] makes me angry ... very angry and upset.’ (I/SJb/p9)

‘School was always awful. I went through a bit of severe depression. I kept on saying, every time bad things happened, that I wished I was dead. I was always dreading it.’ (I/D/p4)

Several spoke of apprehension, dread and the despair they felt before going to school, with Jack suggesting that he was on the ‘roadway to hell’. Dan and Ro gave insight into their coping strategies:

‘I never felt excited, always dread. I would not want to get up, I wouldn’t want to open my eyes. I would wish I was still asleep.’ (I/D/p4)

‘It was a never ending cycle, every day ... I dreaded the repeat of that cycle.’ (I/D/p5)

‘The night before school I would put off going to sleep to put off school as much as possible ... staying in bed as long as possible and getting up at the last minute.’ (I/ Ro/p3)

**Sensory environment and unpredictability.** Young people elaborated on the sources of their stress and dread. These include the school environment, such as auditory sensory overload, social anxiety and social pressure, arising from the unpredictability and intensely social
nature of the mainstream environment. Overall, in the ‘diamond sort activity’, participants ranked ‘the class environment being too noisy and busy’ and ‘being in school for the whole day’ as top worries. Participants discussed the difficulties they had with the overwhelming impact of the sensory and intensely social environment.

‘I was stressed trying to cope with the noise, the large class sizes, the constant changing of classrooms.’ (I/SJa/p1)

‘Secondary school was very large with lots of corridors.’ (I/SJa/p5)

‘Asperger’s made it very difficult for me to cope with life in a large secondary school; there was too much noise and too many people to deal with. It was awful moving to the next class. Everyone was coming out and it was just swarmed with people pushing, running, shoving.’ (I/SJa/p8)

‘I felt closed in and like I couldn’t breathe as there were so many people. It was so difficult being in there all day.’ (I/SJb/p6)

Wade echoed this feeling of being closed in and being overwhelmed by the noise and number of people. It was, he said:

‘Too crowded, too noisy, the corridors were too small, the classrooms were too noisy.’ (I/W/p6)

Thomas drew an image of himself at school to illustrate his frustration, and offered further insight into his experience (see Figure 5):

‘This is me pulling my hair out as I am so stressed at teachers, the work and being suspended.’ (MeAtSch/Th)

‘I felt really annoyed … the stress of the day had built up.’ (I/Th/p4)

‘It was too overwhelming and every single class was really noisy.’ (I/Th/p3)

‘It is too crowded.’ (I/Th/p11)

Participants also discussed loneliness, isolation, being bullied and experiences of anxiety in mainstream.

| Code | Meaning |
|------|---------|
| I    | Semi-structured interview |
| p    | Page number of semi-structured interview transcript |
| C    | Sheet C – ‘more children with autism are being made to go to mainstream school’ – what do you think about this? |
| D    | Sheet D – What does school ‘inclusion’ mean to you? |
| MeAtSch | Me At School activity |
| MyIdSch | My Ideal School activity |
| GtBt | Good Teacher, Bad Teacher activity |
| W    | Wade |
| SJ   | Sarah Jane (female) (SJa indicates transcript ‘a’ and Sjb indicates transcript ‘b’) |
| Ro   | Ro (female) |
| D    | Dan |
| J    | Jack |
| Jo   | Joe |
| Ji   | Jim |
| Ti   | Timmy |
| Th   | Thomas |
| L    | Lee |
| S    | Stephen |
| R    | Robert |
| Examples | I/D/p1 = Semi-structured interview, Dan, page 1 of transcriptionis |
|        | MeAtSch/Ji = Me at school activity, Jim |
|        | C/SJ = Sheet C, Sarah-Jane |
Loneliness. In the second ‘diamond ranking’ activity participants, overall, ranked ‘having friends’ as the second most important supportive and enabling factor. For some, social isolation and loneliness arose from having no close friends or no one to relate to despite making efforts to build relationships. The following extracts from Sarah Jane and Ro describe their experiences of isolation and loneliness.

‘I found that I had no close friends and no one to talk to. I felt very lonely and often found myself without anyone to play with.’ (I/SJa/p1)

‘I was often excluded by the girls in my class. I spent break and lunchtime wandering around on my own. I had no one to sit with in class.’ (I/SJa/p3)

‘Despite making the effort to be friendly with the ones in my class, I was always left out and on my own.’ (I/SJa/p4)

‘I didn’t really have anyone to hang out with.’ (I/Ro/p3)

‘I was isolated and separate, in like a bubble of depression and anxiety . . . but, I still felt the centre of attention with others looking at me and judging.’ (MeAtSch/Ro)

The following extract from Sarah-Jane highlights a lack of friendship, but also demonstrate the impact of a seemingly harmless classroom practice – being asked to ‘find a partner’:

‘As usual, I had no one and I was made to pair up with the teacher. I felt so little having to stand there waiting to pair up with the teacher. It scars you. Mentally it didn’t help me. It was awful being left out and not having a partner to be with.’ (I/SJb/p10)

Bullying. Only four participants in the ‘beans and pots’ activity selected ‘true’ to the statement ‘people are friendly to me in school’. Unsurprisingly therefore, several of the participants who chose ‘untrue’ or ‘unsure’ discussed being bullied by peers at mainstream. Jim said ‘people are friendly to me in school’, yet was scared of being physically bullied by others.

Wade discusses his peers being the worst aspect of mainstream:

‘The children were probably one of the worst things there. They would constantly bully you. There was physical harassment . . . I got kicked in the private areas, pushed and punched. I have also had pupils make verbal sexual comments towards me.’ (I/W/p2)

Wade illustrated his experiences and supplemented this with a short verbal description (see Figure 6):

‘There was a weight on my shoulders all the time. Other pupils are shouting kill yourself, the most common slur. This made me suicidal and teachers tried to help but it got too much.’ (MeAtSch/W)

Ro experienced bullying in primary and secondary school.

‘I was bullied when I was younger . . . verbal physical and there was once . . . sexual . . . which is bad. It was a pupil. [Short silence and closed body language — squeezing her arms in]. Some bullies followed me to secondary school which made me feel I couldn’t answer any questions or talk out . . . it wasn’t just specific bullies. When I was younger it was as if it was okay for everyone to be like that to me . . . you know germs . . . if kids have germs . . . it was like I had germs and they weren’t to go near me.’ (I/Ro/p4)

Sarah Jane highlighted that peers do not wish to befriend her because of her disability:
'It is all about themselves and if you have a disability they don’t want to know, they look down at you and think “no, I am not going to be with her’.” (I/SJb/p5)

Despite experiencing difficulties with social interaction, participants, in the main, expressed a desire for friendship and want to be with, and included by, peers – albeit this should not be forced as some prefer time on their own, as suggested by Timmy.

**Feelings of isolation.** Participants experienced isolation by peers, but were also isolated physically and academically by some of the teaching practices and approaches used for curriculum delivery. For instance, opportunities for social interaction and friendship building were curtailed for four, by having to catch up on missed homework during break time, or by being physically isolated from peers. Sarah Jane describes her experiences:

‘At primary school I was often kept in at lunchtime to complete my work and this meant that I was even more isolated as I missed out on the chance to play with anyone at lunchtime.’ (I/SJa/p2)

These practices exacerbate isolation, loneliness and feelings of being an outsider looking in – as documented by Sarah Jane who felt isolated academically from peers within the classroom, left outside the learning of the classroom by teaching practices and by a lack of support, and by Dan who was taught on his own away from peers:

‘I didn’t get to see my friends at all. I wasn’t able to see anyone.’ (I/D/p1)

‘I was always stuck in there [the classroom] and I was only ever let out for a small time.’ (I/D/p2)

‘It was a nice classroom, but you can’t enjoy a nice room if you are locked in it all the time I was isolated from everything.’ (I/D/p3)

‘I was always much slower to understand any new topic and always found that I was slower to finish my work.’ (I/SJa/p2)

‘I found it difficult to follow the lessons.’ (I/SJa/p3)

‘I was switched off. If the support was there I could have accessed the curriculum.’ (I/SJb/p9)

‘There was no differentiation in classwork or at home.’ (I/SJb/p4)

**Feeling misunderstood.** In the main, the young people feel unsupported and misunderstood by teachers in mainstream schools. Eleven spoke of teachers not understanding them, as Thomas attests:

‘They [mainstream teachers] are not understanding of certain individuals and their needs.’ (I/Th/p11)

Dan expressed a lack of understanding of his behaviour manifesting in feeling judged by teachers:

‘Every time I felt I couldn’t keep myself together properly I felt like they were just looking down at me.’ (I/D/p4)

‘Teachers make it [school] worse, they don’t understand what I am going through.’ (I/D/p5)

**Feeling unsupported.** The impact of being unsupported is perhaps why most of the young people (nine) stated that mainstream school had failed them. The following quotes provide a vivid insight into these young people’s lived experiences.

Wade suggests, that ‘there was close to no support in my opinion.’ (I/W/p1)

Sarah-Jane felt mainstream schools are not being flexible to meet individual needs, but young people to adapt to their practices. She states:

‘It [mainstream school] is not about them adapting to you, but you adapting to them.’ (I/SJb/p3)

Jim experienced similar, which resulted in him truanting school:

‘I walked in and walked out half an hour later.’ (I/Ji/p3)

‘They didn’t try and change anything to help you out.’ (I/Ji/p4)

Several participants (Sarah Jane, Ro, Stephen, Thomas and Wade) felt teachers simply did not care enough about them, or children who had in additional needs. They felt abandoned and unnoticed. They felt less important than other children who did not face the same challenges. The following excerpts from the data exemplify this.

‘I would ask them for help and they wouldn’t care.’ (I/W/p5)

‘I feel if I had had been taken care in the right way I could have done something good.’ (I/W/p7)
‘They [mainstream teachers] just kind of abandoned people who had problems.’ (I/SJb/p1)

‘They [teachers] didn’t care.’ (I/SJb/p8)

‘I never felt supported.’ (I/SJb/p7)

‘It makes me feel pissed off at them, really pissed off and they did nothing to help me. They made me feel worse. I was so unhappy.’ (I/SJb/p9)

Participants used the ‘good teacher, bad teacher’ activity to indicate further thoughts on their experience of unsupportive (or bad) teachers, with three mentioning that they felt teachers judged them based on past experiences with autistic young people. Ro, Joe and Wade explain:

‘A bad teacher has preconceptions which impacts on how they treat pupils – judging all autistic children the same based on past experiences. They are inconsistent, for example, being flexible and ok about homework one day and then not the next. This makes it hard to understand what is expected. Each day starts of worrying about how I will be treated or spoken too, making me scared of being shouted at.’ (GtBt/Ro)

‘Stereotypes me based on past experiences with other children with autism.’ (GtBt/Jo)

‘They use past experiences to judge current children.’ (GtBt/W)

Sarah Jane offered a comprehensive description of a good supportive teacher – encapsulating elements of data from other participants – and how they would support an autistic young person:

- A good teacher is someone who takes time to listen.
- They understand the difficulties and problems that a young person with AS/autism faces in a school.
- They realise that a person with ASD has sensory issues with noise, crowds, etc. and provides support and help when necessary.
- A good teacher realises that it can be difficult for someone with ASD to make friends.
- Provides an alternative to playground activities such as a quiet, reading/games room.
- A good teacher understands how to provide social activities to try to help the person with ASD to be an accepted member of the class/year group.
- They understand that planned activities might need changed to meet the particular needs of someone with ASD.
- A good teacher would provide a quiet area in class for those with ASD who need some time out.
- A good teacher takes time to explain activities.
- Listens to parental concerns.
- I think a good teacher is someone who is patient, kind understanding, helpful, considerate, calm and above all doesn’t shout a lot.

Only three young people referred to a lack of ASD training as a characteristic of a bad, or unsupportive teacher in the ‘good teacher, bad teacher’ activity.

‘[Bad teachers] Not trained in autism/ADHD, but even worse if they are trained but do not use the information.’ (GtBt/J)

‘[Bad teachers] Don’t use training they have to help.’ (GtBt/S)

‘Training can make them bad as they use it to treat kids as thick.’ (GtBt/Ti)

For Ro, ASD training was considered neither a good or bad aspect of a teacher, with Joe indicating ‘training doesn’t necessarily matter’ (GtBt/Jo). Ro expanded on this in the semi-structured interview:

‘It [teacher training] makes some of the difference but it depends how it is used. It is a matter of taking the training and using it seriously and understanding that the child is their own person.’ (I/Ro/p8)
Ro wants teachers to care about more than just academic results:

‘Actually start caring about the students rather than the results they give you. It is about teaching the children and not only caring for the results. Really knowing and paying attention to the children... each child has their own individual needs.’ (I/Ro/p7)

Three participants drew upon islets of support they experienced from mainstream teachers. These highlight the significance of the relational aspects of education. For instance, Sarah Jane, whom had four negative educational placements, spoke of supportive teachers in a primary school where she felt happiest. Here, teachers understood her needs and demonstrated this through the kindness they showed and the adaptations they made to the curriculum. Sarah Jane gave this school a score of nine out of 10 compared to much lower scores for her other school placements. She explains:

‘They [teachers] were firm but kind and took their time to explain things that I didn’t understand. They understood that I had some sort of learning difficulty and they would give me work that I was able to understand and complete.’ (I/SJa/p3)

Ro spoke of two supportive teachers, one whom had high expectations of her:

‘She [Art teacher] was also one of the more down to earth teachers. She expected a higher standard from me. It made me feel I had something to work for.’ (I/Ro/p1)

Wade also spoke of a teacher he liked:

‘Out of everyone there I felt he [teacher] was the one who understood me the most. I didn’t get to see him often ... once bi-weekly for an hour. He got to know me and showed an interest.’ (I/W/p4)

Participants highlighted simple, reasonable strategies, some of which are pertinent to one participant, while others suggested several. These include: breaking work and instructions down into more manageable chunks (Stephen); supporting instructions visually; being able to use ICT more often to present work (Jack, as he found writing uncomfortable); having alternatives to auditory mental mathematics due to processing difficulties (Sarah-Jane); using a child’s interest to engage them (Dan); being given time to socialise with peers (Jack); showing flexibility in the amount and content of homework (Jack); and, providing homework in written form rather than relying on the young person having to block out the noise of others to write down the task that is being given orally (Sarah-Jane).

Supportive environments. In the ‘diamond ranking’ activity, not having a quiet space to go to when stressed was ranked as the third biggest worry by the participants. Likewise ‘having a space to go to when feeling anxious or stressed’ was ranked fourth of nine possible supportive aspects of school. Outside of these activities 11 participants specifically spoke of wanting a safe space to distress, relax and socialise with similar young people. Six participants want more breaks for the same reasons. Jim summarised why to ‘get away from it all for a bit.’ (IdSch/Ji)

However any areas of support need positioned for easy access to negate the need to navigate complex busy corridors. Robert caveats the use of safe spaces by saying:

‘If you were anxious and nervous and then had a room to go to but you didn’t know who was there it would also make you nervous.’ (I/Rob/p3)

All participants believe that smaller class sizes would improve mainstream education, allowing their teachers to support them more as they would have more time to give to each child.

‘Smaller classes and just time for teachers to be aware that certain students have certain difficulties.’ (I/Ro/p2)

‘... you [teacher] could notice more if a child is doing well or not and encourage them. Smaller schools would be more suitable for children with autism.’ (I/Ro/p9)

For Ro, the school ethos holds greater importance than physical features of the school environment. She explains:

‘It is not the building which matters, it’s the attitude and atmosphere inside it.’ (MyIdSch/Ro)

Discussion

The discussion is organised as answers to the same two questions in the findings section, ‘What experiences have autistic young people had during their education?’ and ‘How would autistic young people like school to be?’

What experiences have autistic young people had during their education?

The 12 autistic young people have shared experiences that are many and varied. In the main, they spoke of the challenges they faced in mainstream schooling and the negative impact these had on their wellbeing and
enjoyment of education. Most felt excluded; some by peers and others by teachers. They also discussed the stress, anxiety, dread and despair they felt before, during and after school. Failure to support young people is likely to have consequences for their behaviour and psychological wellbeing (Goodall, 2015), as attested by participants in this study.

The unpredictability and overwhelming impact of the sensory and social environment – the ‘chaos of the corridor’ (Humphrey & Lewis, 2008a, p. 38) – and the teachers (for some) underpin these negative feelings. As Connor (2000) expressed, anxiety can stem from an autistic person’s need for predictability and routine. They often need to feel that they have control within their environment. Some participants noted that school was a place of control, with Timmy equating mainstream to jail. Most young people spoke of how they failed at mainstream school, and the young people were of the opinion that mainstream school had failed them. In the main, the young people feel unsupported and misunderstood by teachers in mainstream schools as highlighted in Sproston et al. (2017), some in the current study also spoke of being unnoticed or being unwanted.

Participants also discussed loneliness, isolation, being bullied and experiences of anxiety in mainstream; all of which are experiences congruent with the literature (Browning et al., 2009; Hebron & Humphrey, 2014; Humphrey & Symes, 2008a, 2008b; Humphrey & Symes, 2011; Poon et al., 2014; Sreckovic et al., 2014). Chamberlain, Kasari, and Rotheram-Fuller (2007), however, found that autistic children did not indicate they are lonely despite their peers indicated that they are less socially accepted.

Several participants in this study provided instances of when they experienced bullying (Hebron & Humphrey, 2014; Humphrey & Symes, 2010; National Autistic Society, 2006; NICCY, 2007). NICCY (2007) found that 66% of young people with Asperger’s (n = 35) in their survey would like school to be different, particularly in respect of bullying. Despite experiencing difficulties with social interaction, participants, in the main, expressed a desire for friendship and want to be with, and included by, peers – albeit this should not be forced as some prefer time on their own. Other research studies also reflect this (Harrington et al., 2006; O’Hagan & Hebron, 2017).

Sarah Jane feels that her disability underpinned why others did not wish to befriend her. The importance of peer education and awareness is widely cited as underpinning acceptance (Morewood et al., 2011; Tonnsen & Hahn, 2015; Williams, Gleeson, & Jones, 2017). Joe, Wade and Ro also felt that teachers judged and stigmatised them based on previous experiences with autistic pupils. As attested by Florian (2010, p. 65) judgements are often made about learners based on assumptions that they possess all the characteristics to the same degree’ Autistic young people in Jones, Gallus, Viering, and Oseland (2015) discuss the social stigma misunderstanding they experience by being autistic. However, as outlined in Huws and Robert (2015), and although autism is a disability, participants in both studies viewed it as more favourable than the term disability.

Participants experienced isolation by peers, but are also isolated physically and academically by some of the teaching practices and approaches used for curriculum delivery, such as being educated in isolation and being kept inside during break time to complete missed homework. Jack suggested this practice isolated him further from peers. Although this link between homework difficulties and subsequent social and physical isolation was not evident within the reviewed literature, Gibb et al. (2007) contend that both social and academic inclusion are important aspects of a child’s educational experience. These practices exacerbate isolation, loneliness and feelings of being an outsider looking in – as documented by Sarah Jane who was regularly left alone when asked to find a partner in class. Inflexible teacher pedagogy is expressed by seven participants as a worry about school – a barrier to accessing the curriculum and to experiencing enjoyment of education. For Sarah Jane, being treated the same as her peers through the use of auditory mental maths as a means of assessment proved exclusionary as she had auditory processing difficulties. Participants did note that teachers lack time and training to be able to give the required support to them; an aspect considered a major factor for successful inclusion of autistic young people (for example, Hayes, Baylot Casey, Williamson, Black, & Winsor, 2013; Kidd & Kaczmarek, 2010).

How would autistic young people like school to be?

Participants explored several aspects of school they would like to change. As with the literature (such as NICCY, 2007; Sciutto et al., 2012; Sproston et al., 2017) participants want teachers to be more understanding of them, of autism and of their individual needs. They want teachers to adopt a flexible pedagogical approach and implement strategies carefully and not assume that a strategy, such as visual schedules, should be used ubiquitously with every autistic young person. They also want teachers to be mindful of the implications of how they deliver the curriculum and of each child’s circumstances. Above all, they want to be listened to – a characteristic highlighted when participants spoke of positive teachers they had.

Teacher training is described as an enabler of inclusion in the literature (for example, Morewood et al.,
and is often advocated as the invariable solution (see Hayes et al., 2013; Kidd & Kaczmarek, 2010). However the young people (such as Ro) want training to be used flexibly, and not wedded to a ‘one size fits all’ approach – this perspective is not evident from young people within the reviewed literature and offers us further insight into the complexity faced in achieving successful ASD inclusion.

Participants alluded to concepts of personhood and social justice. They want and need to be respected and valued as an individual person and not viewed as part of a homogenous group because of the shared autistic label (see Florian, 2010). Jim described his ideal school as very relaxed and called this the ‘school of identity’ – where people can be themselves. They want – and need – the necessary, and not just equal, supports to be implemented to ensure they can not only access the curriculum, but be included in the learning and community of the classroom. Participants highlighted simple strategies, some of which are pertinent to one participant, while others suggested several. These include: breaking work and instructions down into more manageable chunks; supporting instructions visually; being able to use ICT more often to present work; having alternatives to auditory mental mathematics due to processing difficulties; using a child’s interest to engage them; being given time to socialise with peers; showing flexibility in the amount and content of homework; and, providing homework in written form rather than relying on the young person having to block out the noise of others to write down the task that is being given orally. The young people want teachers to be mindful of the implications of how they deliver the curriculum and of each child’s circumstances.

Support can come from the school environment itself. As noted in the literature (such as Humphrey & Lewis, 2008b), participants want safe havens, or places to go to de-stress within school – to get away from it all – and to recalibrate and refocus. They also want more breaks for the same reasons. This aligns to literature that emphasises safe havens – or spaces to go – when feeling overwhelmed. However any areas of support, such as ‘quiet refuges’ (Parsons et al., 2011) need positioned for easy access to negate the need to navigate complex busy corridors, as Robert indicated earlier.

All participants believe that smaller class sizes would improve mainstream education, allowing their teachers to support them more as they would have more time to give to each child. Smaller class sizes and a smaller pupil population (with a high staff to pupil ratio) would also reduce social anxiety and sensory overload. Several young people outlined that their ideal school would feel more relaxed and safe if classrooms were large open spaces with sofas and, again, areas to take breaks and relax. This would help remove the feeling of being trapped. Further, it would also be reasonable to suggest that smaller class sizes would reduce social anxiety and feelings of being judged – an issue mentioned by Ro when entering social spaces (bus and cafeteria). One girl within Sproston et al. (2017) spoke of how reduced class sizes help reduce the feeling of being judged.

For some, such as Ro, teacher mentality and school ethos are more important than aesthetics or location. Positive relationships, underpinned by understanding, as discussed in Brede et al. (2017) are of fundamental importance for those in this study. The young people want something to strive for with teachers who have high expectations of their ability and without fear of repercussion for not knowing. This is consistent with Sproston et al. (2017); although one autistic girl cautions against unrealistic expectations. Teachers hold a variety of attitudes to the inclusion of autistic young people in mainstream schools, with several writers describing teachers attitudes as influential in the inclusion of autistic young people (see Glazzard, 2011; Lee, Young, Tracey, & Barker, 2015; McGregor & Campbell, 2001).

How participants would like school to be mirrors some of the aspects to successful ASD inclusion outlined by Morewood et al. (2011) whom advocate a saturation model underpinned by: staff training; peer awareness education; school environment modification; flexible provision; a positive ethos of autism acceptance and suitable policy. Findings in my study align to these suggestions by Morewood et al. (2011), but provide deep insights into individual experiences that result in the absence of these tenets of successful ASD inclusion.

Limitations and future research

The 12 participants in this study were, in part, chosen for convenience and to avoid the need to approach the Principals (or gatekeepers) of several mainstream schools directly. The sample was therefore limited to those young people for whom mainstream was, or is, challenging. Including several participants who solely attend mainstream school could have added further richness to the data. Hearing these experiences could have added to the discussion on educational improvement and what is working to create autism friendly environments.

The sample size was small, but not uncommon for such in-depth qualitative research (for instance, Sproston et al., 2017 worked with eight autistic females). There is gender bias within the small sample, although this imbalance is reflective of the male dominated nature of autism and is not dissimilar to reported gender ratios. The Department for Health, Social Services and Public Safety Northern Ireland
(DHSSPSNI, 2016) indicate that 3.7% of male school children have autism compared to 0.9% of females in NI in 2015/2016, a ratio of 4.1:1. This reflects the predominantly cited ratio of 4:1 (Kreis & White, 2014), with Kim et al. (2011) citing a ratio of 5.1:1, almost matching that of the sample in this study. The experiences of the females within this study are easily identified (see Table 1).

Exploring the positive aspects of primary versus secondary education could provide further insights into how a young person’s educational journey can be such that it is as supportive as possible throughout. Having primary aged children would have perhaps enhanced understanding of the enablers and barriers to education and whether the structures and practices within primary settings are more suitable for supporting autistic learners, such as a child having fewer teachers and less need for movement around the school environment.

Conclusion

This study provides a vivid insight into the educational experiences of an under-represented group in the literature. The autistic young people have shared their many and varied educational experiences and reflected on aspects of education which hinder and support access to and enjoyment in education. For them, attempts at inclusion in mainstream resulted in exclusion, feelings of dread and isolation, and for some, impacted on their wellbeing. The participants demonstrate that mainstream education is not meeting the needs of all with autism deemed mainstream able; a gap exists between inclusion rhetoric and their lived realities in the classroom.

They offered advice on how education could be improved to make it more enjoyable, supportive and enabling. The person the teacher is, their ability to show genuine interest in, and understanding of, the individual is of utmost importance to these young people. It goes beyond having training or implementing specific strategies, to showing a genuine interest in them as a person.

This study demonstrates that autistic young people can – and should – contribute to the discussion on the educational provision and change. Pellicano, Bölte, and Stahmer (2018, p. 387) contend that ‘autistic children and young people are already excluded from many opportunities simply because society does not understand what is like to be autistic’, therefore learning from them, using their experiences to develop our understanding will hopefully, in turn, inform educational practice and policy. They are the experts on their lives and what works best for them. Without their individual perspectives educators and policy makers will always remain as outsiders looking in trying to judge what is best.

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