

'Everybody needs to learn more': A thematic synthesis of the first-hand experiences of autistic students in primary schools

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Abstract

Autistic students are more likely to experience mental health difficulties and have poorer academic outcomes than their non-autistic peers. However, most research into school experiences has focussed on secondary-aged students, or parents and school staff's perceptions of the primary school experiences of autistic students. The current systematic literature review explores the experiences of autistic students in primary school. Databases (PsycInfo, ERIC, SCOPUS and CINAHL) and hand searching were utilised to identify qualitative research. The research was included if it explored current and retrospective accounts of autistic people, internationally. Studies were excluded if they did not include the voice of at least one autistic person. Twenty-two studies met the inclusion criteria and were analysed using thematic synthesis. Four analytical themes ('We all have different experiences of school', 'We don't do things wrong we do them differently, and I need you to understand', 'Good relationships make it better' and 'Success matters but the environment is key') were generated. There were both positive and negative accounts, with some students detailing the long-term negative effects of primary schooling on their mental health. Overall, students in the review felt everybody needed to learn more about autism, as well as provide specific and subtle support based on individual needs. Strengths, limitations and implications for practice are discussed.

Lay abstract

The school environment can be a difficult place for autistic children which impacts their well-being and academic performance. Most research into school experiences has looked at the experiences of students at secondary schools or at adults who support autistic students. In this research we used a set of keywords to search for studies that included the voices of autistic students (both current and past) about what primary school was like for them. After a detailed search process, 22 studies from a range of countries were located. The results from each of these studies were analysed and sorted into themes: 'We all have different experiences of school', 'We don't do things wrong we do them differently, and I need you to understand', 'Good relationships make it better', and 'Success matters but the environment is key'. The results highlighted that although primary school was a positive for some students, for many it was a time of stress, with the negative impact lasting a long time. The participants felt that everybody needs to learn more about autism and that school staff should provide support that is based on their needs but does not make them stand out as different.

Keywords

autism, school experiences, thematic synthesis

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The number of autistic children and young people being diagnosed as autistic is increasing; however, exact prevalence figures are hard to quantify given differences in awareness, diagnosis and potential resourcing across countries (Fletcher-Watson & Happé, 2019). Each autistic child has a unique set of strengths, which may include loyalty, honesty, and attention to detail (Fletcher-Watson & Happé, 2019). Despite this, the differences associated with autism (including social communication and sensory

processing) can make navigating the school environment and communicating with non-autistic people challenging

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(Cunningham, 2022; Mesa & Hamilton, 2022). In a recent survey of over 600 autistic students, only 26% felt happy at school, and just 24% felt included (National Autistic Society, 2021). This may be partly attributed to non-autistic staff and peers misunderstanding autistic communication styles, as proposed by the Double Empathy Theory (Milton, 2012). Furthermore, autistic children are at high risk of exclusions (Ambitious about Autism, 2018), poor academic results (Keen et al., 2016) and high levels of distress (Guldberg et al., 2019). Given the range of differences that autistic individuals present with, and the potential impact of unmet or misunderstood needs, it is important that schools are well-equipped to support them.

Previous research has found that a sense of belonging, school culture, flexibility, and available resources are some of the key influences on the participation of autistic children in primary schools (Ballantyne et al., 2022; Hodges et al., 2020; Reupert et al., 2015). While interesting, this research prioritised the voices of teachers and parents, rather than including autistic children. If autistic people are not included in research, there is a risk that inaccurate experiences and knowledge will be attributed to them, potentially leading to incorrect support (Milton, 2012). According to the United Nations Convention on the Rights of the Child (UNCRC, 1989), children have a right to be heard (Article 9) and to engage in decisions which affect them (Article 12). This means all children should have the opportunity to share their perspectives about the support they receive. Beyond this, autistic individuals are experts of their own experiences, who hold valuable insights into simple changes that could make a significant difference to their schooling (Davidson, 2010; Gillespie-Lynch et al., 2017). Rather than providing education 'to' autistic students, they should be recognised as a valued resource to guide practice (Cunningham, 2022; Fayette & Bond, 2018; Sciotto et al., 2012).

There has been a recent push to gather autistic voices about school experiences. However, most research has focussed on secondary-aged pupils (Fayette & Bond, 2018), possibly due to the additional challenge of designing developmentally appropriate research studies for this group (e.g., methods less reliant on language). In a recent review, Horgan et al. (2022) used thematic synthesis based on 33 qualitative papers, internationally, to explore the perspectives of autistic pupils in mainstream post-primary (secondary) schools. Within the research, students voiced that they struggled with the transition from primary school to mainstream secondary school, and that the environment placed a high level of demand on them both academically and sensorially (Horgan et al., 2022). Students in 19 of the 33 studies cited experiences of bullying, both verbal and physical. Relationships with peers and staff were shared to be protective factors, however, overall, the researchers concluded that

secondary school was a challenging experience for autistic students that impacted their identity, well-being, and mental health.

Primary school (also referred to as elementary and first school) is the first phase of basic education. The age, and duration that children attend primary school differs internationally, although is typically from 5–7 to 10–12 (UNESCO, 2012). The International Standard Classification of Education cites that the purpose of primary school is to 'provide students with fundamental skills in reading, writing and mathematics (i.e., literacy and numeracy) and establish a solid foundation for learning and understanding core areas of knowledge, personal and social development, in preparation for lower secondary education' (UNESCO, 2012, p. 32). In many countries including the UK and Ireland, the majority of autistic students attend mainstream primary schools (Department for Education, 2021; Horgan et al., 2022). Some mainstream schools have resource bases where children can still benefit from inclusion in mainstream, but have access to additional staffing, individualised support, and environmental changes (Hebron & Bond, 2017). Specialist settings, including those exclusively for autistic pupils, are also available. The primary school context is significantly different from secondary school, with different opportunities and barriers (Jindal-Snape et al., 2020). At primary school, children typically receive teaching with the same group of peers, and a familiar teacher, in a consistent room (Mandy et al., 2016). It is possible that this consistency has resulted in autistic students perceiving that primary teachers have better autism understanding (National Autistic Society, 2021). Secondary schools demand a higher level of independence from learners who are required to move between different rooms and teachers (Mandy et al., 2016). However, it could be argued that the wider curriculum and diverse opportunities for social connection that secondary schools provide may be beneficial for autistic students (Hebron, 2018; Jindal-Snape et al., 2020; Stack et al., 2020). Given these differences, there are risks in using secondary school accounts to guide understanding and practice in primary schools (Cunningham, 2022). Therefore, the current review aims to foreground the voices of primary-aged autistic students in a range of settings, to understand their unique experiences and the environment that supports them best.

Method

Community involvement statement

This piece of research was conducted as part of the primary authors (EA) Doctorate in Educational Psychology. It did not include direct involvement from the autism community or policy group stakeholders.

Aims

The aim of this systematic literature review is to synthesise qualitative research that foregrounds the voices of autistic people to answer the question: *What are the first-hand experiences of autistic pupils during their time at primary school?* The scope of the question was kept wide to ensure that a range of autistic experiences were captured and valuable insight was not ignored. We included both current and retrospective accounts, and research exploring a range of settings (mainstream, special school and resource base).

Synthesis methodology

The research question was explored through a constructivist lens, recognising that we, as researchers, play a unique role in synthesising and interpreting data to construct new knowledge (Lewis-Beck et al., 2004). None of the authors identify as autistic. All have experience working with autistic young people and gaining their voice in both educational and research contexts. We acknowledge that this will impact our perspective, understanding and ultimately the quotes prioritised. Particularly using the approach as outlined by Thomas and Harden (2008) which facilitates in-depth analysis of the existing research, by going beyond the data to generate new understandings to inform practice and policy in a transparent way (Drisko, 2020; Thomas & Harden, 2008; Thorne et al., 2004). Part of this transparency is the recognition of the positionality of the authors, both of the original papers and the synthesis.

Prior to conducting the review, PROSPERO was checked to ensure that a similar review was not being conducted. The review was registered on PROSPERO, in accordance with PRISMA guidelines (PROSPERO CRD42022306156; Page et al., 2021).

Search and retrieval of qualitative studies

Following an initial scoping search, we refined the inclusion criteria (see Table 1). There were no conditions placed on the date of publication or location of research. While it would have been preferable to include papers published in all languages, the scope and time-limited nature of this research made this challenging, and papers were limited to those published in English. Furthermore, research has found that excluding non-English studies in systematic reviews has minimal impact on overall conclusions (Nussbaumer-Streit et al., 2020).

Search terms

The search strategy was constructed in collaboration with the University Information Specialist (as recommended by Boland et al., 2017). The SPIDER tool (Cooke et al.,

Table 1. Inclusion and exclusion criteria.

Inclusion	Exclusion
Informants are autistic or identify as autistic	Participants are not autistic
Reflections on primary education	Pre-school, middle-school, secondary school, university experiences, home education, online learning or not based in the school setting
Papers to include at least 1 autistic voice	Interventions
First-hand (including retrospective or current accounts)	Books or overview articles
In English	Unclear whether reflections relate to primary or secondary
Peer-reviewed journal article or dissertation	The aim of the study is to explore factors that support or hinder primary to secondary transition
Mainstream or special school or resource unit	Quantitative
Qualitative or mixed methods	

2012) aided in the development of search strategy and terms. Subject headings were adapted according to the database, and the comprehensive search strategy is detailed in Appendix A in the online supplemental materials.

Searches of PsycInfo, ERIC, SCOPUS and CINAHL took place in September 2022 (an updated search in April 2024 found no new articles). Grey literature was searched for using the Proquest dissertation and Theses. The initial database search produced 2,759 results, with an additional eight being located through other methods. Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart (PRISMA; Page et al., 2021; Figure 1), 22 studies were deemed eligible for inclusion.

Screening

A two-stage review process for screening articles was adopted (Boland et al., 2017). First, articles were screened by title/abstract by the first author (EA). To ensure reliability, another member of the research team screened a random sample (10%) of papers at this stage, and Cohen's Kappa indicated strong agreement ($k = 0.82$; McHugh, 2012). In

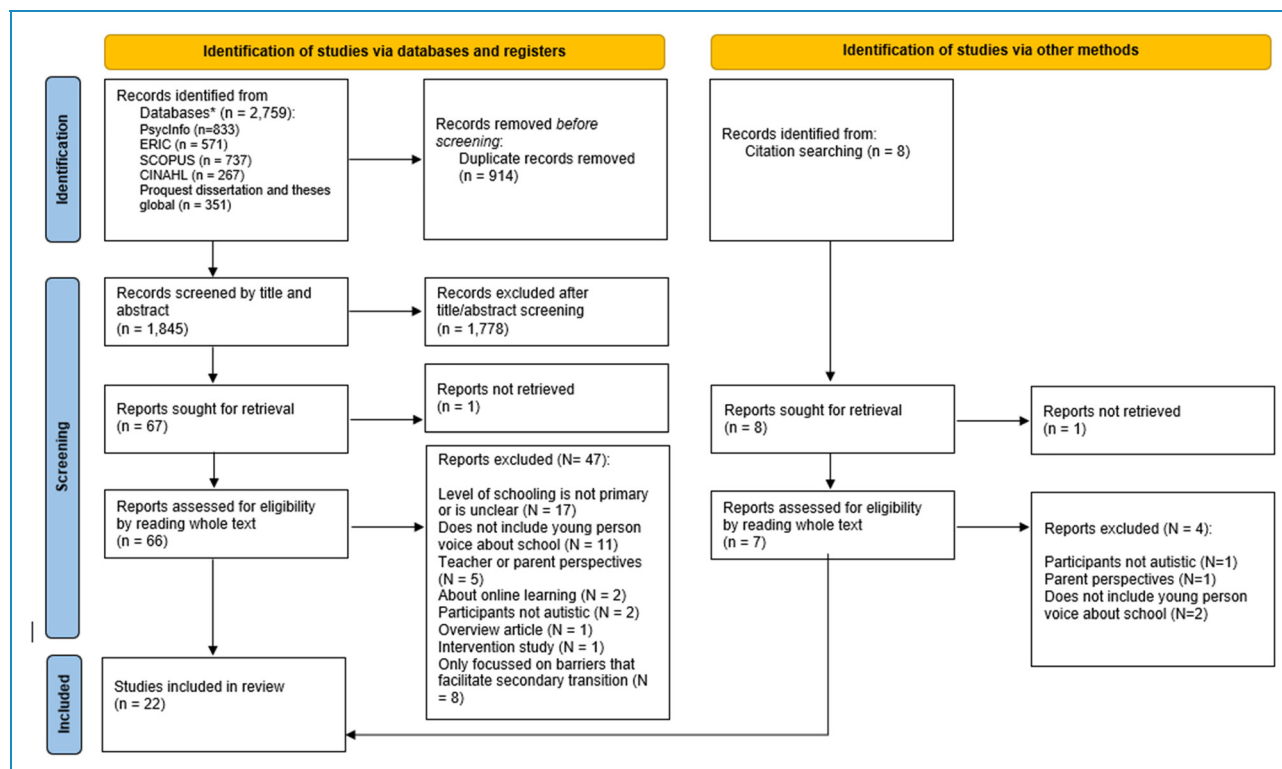


Figure 1. Prisma flowchart of the search process.

addition, a different member of the research team screened a further 10% of the studies, with Cohen's Kappa also indicating strong agreement ($k=0.82$). We discussed any papers that we disagreed with until we reached a consensus. Next, the first author screened the papers at the full text stage before a different member of the research teams screened 20% of these, with a perfect agreement (i.e., $k = 1$).

Quality assessment

The Critical Appraisal Skills Programme Qualitative research checklist was chosen (CASP, 2018) because it has been reported as a good measure of transparency, design, and reporting standards (Long et al., 2020). It was often unclear whether papers had met the CASP criteria or if this information had been omitted due to word count limitations. Thomas and Harden (2008, p. 4), suggested that quality assurance is important to avoid 'drawing unreliable conclusions' rather than to exclude papers (Long et al., 2020; Thomas & Harden, 2008). We were particularly interested in the extent to which the relationship between researchers and participants had been adequately considered (Q6) as this provided some indication that the researchers had ensured that they had considered barriers to accessing meaningful participant voice and therefore answered the research question; 59% had considered this,

but in the remainder it was either unclear (32%) or not addressed (9%). Additionally, it was not clear that data had been sufficiently analysed ($n=6$) or that ethical issues had been considered ($n=6$). All papers were included, see Appendix B in the online supplemental materials for full CASP scoring.

Data extraction

22 studies were analysed using the process of thematic synthesis as explained by Thomas and Harden (2008); a process of three iterative and overlapping stages. All three stages were primarily conducted by the primary author (EA). This was an immersive process that involved regular reflections with the research team.

1. *Line-by-line coding* – All data that answered the research question and were under the title of findings or results were line-by-line coded using NVivo for Windows (Version 12 for Windows). Data were coded if it represented the direct voice of the young person, through interviews or adapted methods. Interpretations of young people's experiences (from other participants) and observations were not coded. Instances where it was not clear that the participant is discussing primary school were excluded. Where possible, studies were coded into pre-existing codes, with

new codes being created if necessary. After all papers had been coded the number of codes was refined to avoid duplication.

2. *Developing descriptive themes* – Initial codes were then grouped into descriptive themes.
3. *Generating analytical themes* – Analytical themes were generated and interpreted from the descriptive themes. This interpretation was influenced by the authors' experience of working with autistic young people, and the successes and challenges they faced. It is important to note that autistic researchers may have prioritised different quotes and had different interpretations.

Results

Synthesis overview

A total of 22 studies were included in the review, published between 2012 and 2022. Sixteen studies included the voices of children currently attending and just left primary school ($n = 83$), aged 4–11. Over half of the papers were based in the United Kingdom and the Republic of Ireland ($n = 15$), with additional studies from the USA ($n = 4$), Australia ($n = 1$), Israel ($n = 1$), and Hong Kong ($n = 1$). Six studies included retrospective accounts of participants ($n = 89$), aged 11–67. A formal diagnosis of autism was a requirement for all studies in which participants currently were attending primary school. Within retrospective accounts (where data were available) 27 participants self-identified them as autistic and did not have a formal diagnosis. Data about the age of diagnosis were provided by three retrospective studies (Brownlow et al., 2021; Weiss, 2021; Zakai-Mashiach, 2022). Of these 44 participants, just over half (55%) were identified after their primary school years, meaning that they and the adults who supported them did not know they were autistic during the time discussed. Two participants were identified as having learning difficulties (with this information not available in most papers). The majority of participants communicated verbally, with this being within the inclusion criteria for some studies. One participant identified as non-speaking, and children who used augmented and alternative communication ($n = 13$) and who did not yet have an established communication method ($n = 2$) were also represented.

Studies represented a range of settings including mainstream ($n = 14$), resource provisions ($n = 4$) and satellite provision ($n = 1$). The remainder of the studies included participants from both mainstream and special settings. It is hard to draw reliable conclusions about gender because five studies did not include this information. It is also not possible to report accurate information about the ethnicity of participants because only six of 22 studies shared this information. Interviews were the predominant method of data collection ($n = 18$). Seven studies used adapted

methods for children and young people (e.g., picture board activities). Thematic analysis was used by over half of the studies ($n = 12$). See Appendix C in the online supplemental materials for a full breakdown.

Results of synthesis

Through line-by-line coding, 63 codes were generated, which were sorted into 14 descriptive themes. The descriptive themes were developed into four analytical themes that went 'beyond' the data (Thomas & Harden, 2008, p. 9) to explore the experiences of autistic students in primary school. This approach to the analysis regarded data meanings as open to multiple interpretations by researchers who played a key role in interpreting and synthesising these data, creating a synthesis which went beyond the findings of the individual studies to create a new set of themes which answered the review research. The four themes were: 'We all have different experiences of school', 'We don't do things wrong we do them differently, and I need you to understand', 'Good relationships make it better' and 'Success matters but the environment is key'. These overarching themes, descriptive themes, and example quotations can be found in Table 2.

For some included studies a small amount of text was coded, and for others all data were pertinent. The weight given to each paper within the synthesis reflected the relevance of each paper; studies that more accurately answered the research question had higher representation within analytical themes. It has been argued that the overall synthesis is of more importance to the research question than how many themes were present in each paper (Markland et al., 2022). Despite this, to keep the process transparent, details of which descriptive themes arose in each paper are highlighted in Appendix D in the online supplemental materials.

Analytical themes

We All Have Different Experiences of School. As is to be expected from such a heterogeneous sample, participants¹ shared a range of individual experiences of their time at primary school. This was reflected in simple preferences, such as whether maths (Cunningham, 2022) or science (Moyses & Porter, 2015) was their favourite subject, as well as their feelings towards school.

For some children, school was seen positively, and their accounts used terms such as 'perfect' (Hebron & Bond, 2017, p. 563) and 'fun' (Hebron & Bond, 2017, p. 565; Stack et al., 2020, p. 6). Additionally, according to O'Leary & Moloney (2020), pre-verbal children reacted positively to photos of their school during adapted tasks. Often, current school placement (resource base or satellite provision), which included specialised support, was perceived as preferable to previous negative experiences

Table 2. Analytical themes, descriptive themes, and example quotations.

Analytical theme	Descriptive theme	Example Quotes
<i>We all have different experiences of school</i>	Contrasting perceptions of school: enjoyment vs dislike	I just don't like going to school. (Howard et al., 2019) From Brian's perspective, however, the same empty classroom was simply "his school" and invoked only positive reactions within him. (O'Leary & Moloney, 2020, p. 7)
	Preference for different subjects	PE is not for me. (Gray & Donnelly, 2013, p. 21) Three students liked Art, PE and Science. (Stack et al., 2020, p. 6)
	School impacts my well-being	I feel scared and I feel embarrassed. (Cunningham, 2022, p. 8) I'd struggle with doing the homework and sometimes when I'm in school I'd worry so much that I'd forget a book in school. (Stack et al., 2020, p. 7)
<i>We don't do things wrong we do them differently, and I need you to understand</i>	I hold my emotions in	They hit me. I told no one about it, even my mother. (Yi & Siu, 2021, p. 243) I was quiet and reserved in school, my anxiety was rarely visible so teachers thought I as wilful and rude. (Sciutto et al., 2012, p. 181)
	We don't do things wrong we do them differently	Also, just because you don't hear the lights, doesn't mean that we don't. We don't do things wrong, we do them different (sic) and that is not bad. (Sciutto et al., 2012, p. 181) I want to say just because I can be a little weird; it doesn't make me less human. (Holmes, 2022, p.10)
	Understand and listen to me	Four pupils felt that it was important that they and their peers understood more about autism so that their behaviour was not viewed as "weird". (Cunningham, 2022, p. 8) 'Interested, his mother asked him, "Why's she nice?" Barney answered', "She listens to me. She listens". (Gray & Donnelly, 2013, p. 20)
<i>Good relationships make it better</i>	What friendship means to me	(P) My best part is with [friend] *points to poster*. (I) Playtime with [friend]? Why do you like that part? (P) Because it's good. (I) Yeah. What do you do with [friend]? (P) Run around. (I) Anything else? (P) Skipping. (I) Is it just [friend] you play with at break time? (P) *nods* (I) Yeah? Would you say he's your best friend? (P) Yeah. (Warren et al., 2021, p. 8) David used to be good friends with me...he's not anymore. why did he used to be good friends with me? (Potter, 2015, p. 213)
	Supportive teachers make me happy	CYP1: When I'm stuck on my work...They explain it to me. Interviewer: Who explains it to you? CYP1: My teacher, and then my teacher assistant...they help me figure out what I'm meant to do. (Hasson et al., 2022, p. 8) Typically, I would have a para that went with me to classes. I also had additional kinds of support classes in elementary school...I think either reading and writing class to help with the speech confidence. I had an adaptive gym ed class. (Weiss, 2021, p. 130)

(continued)

Table 2. Continued.

Analytical theme	Descriptive theme	Example Quotes
	I'm often alone	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. (Goodall, 2018, p. 8)
		Samuel, however, appeared to have been isolated from his peers throughout much of his time at school and he was acutely aware of this. (Hebron et al., 2015, p. 189)
	I'm treated badly by others	I find it very different from the other school there was all the bullies. (Hebron & Bond, 2017)
		There are two whom I do not like because I was beaten by them. They are boys who are taller than me. Others said I should hit them back, but I did not. There was only me surrounded by others. (Yi & Siu, 2021, p. 243)
<i>Success matters but the environment is key</i>	I am keen to learn and succeed	Keep thinking, keep thinking, and then, have a question. Then there's a light. So thinking, then a light. There's a light here [gestures with hand] and it means "I got it". (Howard et al., 2019, p. 13)
		'I was wondering why people still go to Egypt if we know what's there already,' demonstrating strong reflective thinking skills in his desire to acquire more knowledge. (Wu et al., 2019)
	The language used is important	Participants indicated that the significant memory they had from this period was that there were many misunderstandings and a great deal of confusion, which caused emotional stress. (Zakai-Mashiach, 2022)
		I could accept that because she talked to me like a reasonable adult. She treated me like a sensible person, and it was a perfectly reasonable excuse. (Brownlow et al., 2021, p. 4)
	The right sensory environment is key	Caroline, an autistic adult participant, stated that when at primary school, she used a lot of her energy "just coping with the noise". (Wood, 2020, p. 118)
		While these issues were fairly short-lived, certain aspects of the transition were a continued challenge. For young people, these aspects centred on the sensory environment. (Croydon et al., 2019, p. 10)
	Make changes for me and my learning	'She also said that whilst fiddling helped her to concentrate and made her "happier," "It doesn't make the teacher very happy! It makes the teacher shout at me."' (Moyses & Porter, 2015, p. 16)
		'I like working in a three because 3's my favourite number' (Wood, 2021, p. 42)

(Croydon et al., 2019; Hebron & Bond, 2017; Warren et al., 2021). Despite this, positive experiences were not typical. Some children showed apathy towards school, stating that they had nothing positive to share (Howard et al., 2019; Stack et al., 2020). Others were resentful of the time they had to spend at school, describing it as 'too long' (Hebron et al., 2015, p. 18; Howard et al., 2019), and the pressure of completing homework caused a high level of stress that built throughout the week (Cunningham, 2022; Stack et al., 2020).

Many accounts were underscored by acute and extreme difficulties that impacted the well-being of pupils. Two children shared how they spent a lot of time crying (Cunningham, 2022; Moyses & Porter, 2015), and others used terms such as 'scared' (Cunningham, 2022, p. 8), 'worry' (Stack et al., 2020, p. 7) and 'panic mode' (Howard et al., 2019, p. 15) to describe their feelings. Retrospective accounts from adults and young people offered more insight into the detrimental impact of the primary school environment on the mental health of some

autistic people (Goodall, 2018; Zakai-Mashiach, 2022). For example, in Zakai-Mashiach (2022), Jasmine, an autistic adult, shared that school had led her to have suicidal thoughts, and Sapir highlighted that the impact was long-term: ‘I have scars in my soul from that time’ (Zakai-Mashiach, 2022, p. 6). Although researchers frequently used the term ‘anxiety’ to describe these emotions and behaviours, children did not typically use this language. It is possible that time and understanding are needed for the impact to be realised, for example Sophia, an adult, shared: ‘I had a lot of anxiety attacks [at] that time, and no one knew what it was’ (Zakai-Mashiach, 2022, p. 6).

We don't do things wrong we do them differently, and I need you to understand. Children shared the importance of both peers and staff understanding autism, so that their behaviour was not perceived as ‘weird’ (Cunningham, 2022, p. 8; Stack et al., 2020). In Cunningham (2022), children were able to identify teachers who had taken the time to understand autism. However, both current and retrospective accounts highlighted that teachers have a lot to learn: ‘They just don’t know enough at all’ (Cunningham, 2022, p. 8; Zakai-Mashiach, 2022). In a retrospective account, Ella reflected ‘they [the teachers] could not understand how I could be so smart and so socially clueless at the same time’ (Zakai-Mashiach, 2022, p. 6). Another autistic adult shared a wish that ‘they understood my behaviour is not intentional’ (Sciutto et al., 2012, p. 181). Peer understanding was also highly valued, yet despite some positive accounts (Hebron & Bond, 2017; Holmes, 2022), the consensus was that ‘everyone needs to learn more’ (Cunningham, 2022, p. 8). There were examples given when others showed they had understood, demonstrated through actions such as giving space (Stack et al., 2020), or modifying tasks (Goodall, 2018). The level of understanding shown by teachers could negatively or positively impact well-being and overall school experiences (Stack et al., 2020; Cunningham, 2022). Indeed, according to Goodall (2018), Sarah Jane (aged 17 and now home-schooled) shared that primary school was her happiest placement, due to the understanding and adaptations made by teachers. Other children felt ignored by their peers (Howard et al., 2019) and not ‘believed’ by school staff which meant they were reluctant to share their difficulties (Stack et al., 2020, p. 9).

It was common for participants to hold in or hide their true feelings (Cunningham, 2022; Sciutto et al., 2012; Stack et al., 2020; Yi & Siu, 2021), need for support (Cunningham, 2022; Moyses & Porter, 2015), and even autistic diagnosis (Brownlow et al., 2021) during their time at primary school: ‘I just muscled through it and acted like I was neurotypical’ (Brownlow et al., 2021, p. 5). In Gray and Donnelly (2013, p. 21), Elle (aged 7) wrote a poem about her experiences, which included the line ‘I am seen, but I am not me’, when further questioned, she stated ‘I

would like to be Elle all the time’ but felt that people did not know her.

Children reported feeling ‘embarrassed’ (Cunningham, 2022, p. 9) to use supportive strategies or seek help, and one feared sharing their emotions may get them into trouble (Stack et al., 2020). In some cases, participants shared that adults or school culture had led them to feel ashamed of their autism, further causing them to hold it in (Brownlow et al., 2021; Howard et al., 2019; Yi & Siu, 2021), or mask difficulties (Sciutto et al., 2012).

Children developed strategies such as getting something from their bag (Cunningham, 2022), looking busy, or copying peers (Moyse & Porter, 2015), to help them get through the day. These findings highlight the importance of staff understanding, knowing, and being attuned to their students because this ‘hiding’ often causes distress (Brownlow et al., 2021; Cunningham, 2022; Moyses & Porter, 2015; Sciutto et al., 2012; Zakai-Mashiach, 2022).

It was rare for autism to be viewed positively by participants (Brownlow et al., 2021; Howard et al., 2019), and in some extreme accounts it was seen as an illness: ‘this illness is troubling me’ (Yi & Siu, 2021, p. 243). It is possible that this perception of autism is related to cultural differences, as the research was conducted in Hong Kong. When children had been taught a positive narrative, they could see their strengths ‘you know more stuff about what you like than most people’ (Howard et al., 2019, p. 13), and autism as a ‘special thing to have’ (Cunningham, 2022, p. 8). Adults reflected that during primary school they did not understand their own autism and would have liked support in understanding themselves better, and a desire for autism to be seen as a difference not a disability (Sciutto et al., 2012; Zakai-Mashiach, 2022).

Good relationships make it better. The importance of social connection was a prevalent theme in the experiences of autistic students in primary school. Relationships with school staff were shared by many participants as influential during their primary school years (Goodall, 2018; Gray & Donnelly, 2013; Hasson et al., 2022; Hebron & Bond, 2017; Stack et al., 2020; O’Leary & Moloney, 2020). Supportive relationships were characterised by trust (Stack et al., 2020), mutual respect (Sciutto et al., 2012), and support with problem solving (Stack et al., 2020; Weiss, 2021). Often it was the support staff, rather than the teacher, that made the difference (Stack et al., 2020; Weiss, 2021; Hasson et al., 2022).

Friendship appeared to be one of the most important factors contributing to the enjoyment participants placed in school (Warren et al., 2021; Wu et al., 2019; Yi & Siu, 2021; Zakai-Mashiach, 2022). For Scarlett (a year 6 pupil), enjoyment of school ‘appeared to be directly linked to the quality of her social interactions’ (Moyse & Porter, 2015, p. 18) and autistic adults reflected that they tried hard to form social connections. ‘It’s not that I

didn't try to befriend them, I really tried, like I was playing their games and even talking about their interests' (Goodall, 2018; Zakai-Mashiach, 2022, p. 6). The importance of friendship is demonstrated in Weiss (2021), who details the difficulty Rick had choosing between joining a gifted and talented school or staying at his current placement where he had finally made a friend. Children currently attending a resource base in a mainstream school valued social learning opportunities, as a positive way to 'navigate the non-autistic social world' (Cunningham, 2022, p. 8). In several retrospective accounts, adults reflected that they wished that they had experienced support with the social aspect of school: 'you mean I could have had that?, well that would have been helpful' (Holmes, 2022, p. 8; Scitutto et al., 2012; Weiss, 2021).

Many children felt positive about their experience of friendship at primary school. They valued friendships with people with whom they shared common interests including football (Hebron et al., 2015), basketball (Croydon et al., 2019), and video games (Howard et al., 2019). In some instances, they were happy with the way their friendships were, even if these would not be considered the norm: 'one pupil explained that "I don't have a best friend" but didn't see this as a problem' (Cunningham, 2022, p. 8; Warren et al., 2021).

Despite craving connection, autistic children experienced much of their time alone during primary school. For participants in some studies (Moyses & Porter, 2015; Weiss, 2021; Zakai-Mashiach, 2022) solitude was a choice with which they were happy: 'Sometimes I am by myself, but I like this' (Cunningham, 2022, p. 8). However, others felt intentionally isolated by peers, which caused feelings of loneliness (Goodall, 2018; Holmes, 2022; Potter, 2015; Warren et al., 2021).

Often, playtimes were the most difficult part of school. Indeed, for Scarlett, lessons provided a distraction from feeling left out (Moyses & Porter, 2015). Participants recalled trying but struggling to understand games (Yi & Siu, 2021), or the unwritten social rules: 'I never understood the children around me, their conversations, or their behaviours' (Howard et al., 2019; Zakai-Mashiach, 2022, p. 6). Consequently, they reported feeling unwanted 'they don't want me they want someone else' (Moyses & Porter, 2015, p. 13), and eventually choose to be alone: 'they don't really like my ideas, so I like working on my own most of the time' (Moyses & Porter, 2015, p. 11).

At times, school practices served to further isolate participants, for example being asked to complete their work at lunchtime (Goodall, 2018). Other times non-autistic peers interpreted coping mechanisms negatively; withdrawal was interpreted as rude (Moyses & Porter, 2015; Zakai-Mashiach, 2022), or emotional outbursts and interests were deemed annoying (Gray & Donnelly, 2013; Warren et al., 2021): 'So, I lost a lot of my friends that I

had in elementary school just because of outbursts' (Weiss, 2021, p. 143).

In addition to being isolated, many students recalled instances of significant bullying during their primary school years. Despite wanting to be treated like people (Goodall, 2018; Holmes, 2022), they had experiences of feeling like freaks, aliens, and monsters (Holmes, 2022), and as if they had germs (Goodall, 2018). They recalled experiences of teasing (Stack et al., 2020), physical abuse, (Yi & Siu, 2021), and even sexual assault (Goodall, 2018). Often, participants felt that they were being treated badly because they were different, or due to the stigma of their diagnosis (Holmes, 2022; Stack et al., 2020; Weiss, 2021). They did not retaliate or tell anybody as they assumed they would be ignored (Stack et al., 2020; Yi & Siu, 2021).

Success matters but the environment is key. Children demonstrated a motivation to succeed and be challenged in school: 'The best part is learning new stuff every time' (Wu et al., 2019, p. 229). They were often aware of the gaps in their knowledge (Croydon et al., 2019; Moyses & Porter, 2015) but at the same time discussed the importance of persevering, and learning from their mistakes (Howard et al., 2019). Children in autism specialist classes reported feeling held back academically and wanting to spend more time in the mainstream classroom (Stack et al., 2020). In two papers, students who had moved from specialist settings to mainstream resource bases appeared to value, and feel empowered by, the higher academic expectations of mainstream, 'It's time for me to change now... and learn some harder things' (Croydon et al., 2019, p. 9; Hebron & Bond, 2017). However, not all participants shared this motivation (Howard et al., 2019; Stack et al., 2020), demonstrating both individual differences and environmental factors that can foster or hinder the desire to do well academically.

Children valued having access to a broad curriculum (Hebron & Bond, 2017), but had not always experienced learning that was meaningful to them: 'I don't learn, they don't teach what I want to know' (Gray & Donnelly, 2013, p. 21). They shared that they benefited from adaptations including videos and technology (Howard et al., 2019); hands-on activities (Wu et al., 2019), and an adapted physical layout (Howard et al., 2019), yet it was important that support was subtle and did not make them stand out as different (Cunningham, 2022; Hebron & Bond, 2017). Peers were valued as tools that support classroom learning and academic success (Howard et al., 2019; Stack et al., 2020; Wu et al., 2019). In some cases, children had experienced teachers who allowed them to incorporate their interests in learning, which allowed them to show their strengths (Howard et al., 2019; Wood, 2021; Wu et al., 2019).

One important contributing factor to students' experience of primary school was the language used. Often, participants reported not liking lessons where there was a heavy application of language skills (Cunningham, 2022; Howard et al., 2019; Stack et al., 2020). More generally, difficulty understanding teacher instruction or intent caused anxiety (Cunningham, 2022; Hasson et al., 2022; Goodall, 2018; Zakai-Mashiach, 2022). This was particularly pertinent when language was abstract or social, as demonstrated in the following quote from an autistic adult:

The question to answer is, what did you do this summer? And I was terrified... It's like, well, the summer is a really big thing. I don't know what to say... I don't know what the expectation is and also what the question means. (Weiss, 2021, p. 133)

Children in Cunningham (2022) shared that their experience was more positive when they were provided with specific rules, and clear, concise instructions. Additionally, simple changes, such as having extra time to formulate a response (Howard et al., 2019; Wu et al., 2019), and teachers who explain concepts (Brownlow et al., 2021; Goodall, 2018; Hasson et al., 2022), were greatly appreciated.

For some participants the sensory environment of primary school was difficult to manage. In particular, noises were reported to affect engagement, cause anxiety, and take up a lot of energy to manage (Croydon et al., 2019; Weiss, 2021; Howard et al., 2019; Scitutto et al., 2012; Warren et al., 2021; Wood, 2020). In some cases, this aversion led to further exclusion. For example, in Wood (2020, p. 118), Michael did not join PE, assembly, or lunch in the hall because 'noises make (sic) my ears bleed'. Children found it difficult to engage in learning until their anxiety had subsided (Howard et al., 2019; Stack et al., 2020), and reported that smaller class sizes (Warren et al., 2021), being able to take a sensory break without any questions being asked (Stack et al., 2020), and extra play time (Howard et al., 2019), would help them to manage the sensory environment. Despite this, it could sometimes feel difficult to use this support. For example, one child reflected on learning breaks: 'Sometimes, I don't want to do it, but I know I need to do it' (Cunningham, 2022, p. 9).

Discussion

Summary

The aim of the current review was to answer the question: *what are the first-hand experiences of autistic pupils during their time at primary school?* The qualitative

research in the synthesis included retrospective and current accounts from children in a range of educational settings (mainstream, special needs, resource base), and countries (although the majority UK and Ireland). The synthesis highlights four themes, that are pertinent to the experience of autistic children during the primary school years: we all have different experiences; being understood; relationships, and the role of the environment. A summary of themes, links to literature, and key implications are presented below.

We all have different experiences of school

Children recalled differing and unique stories of their primary school years, with a range of factors influencing this. This is consistent with the findings of teachers who support autistic students, many of whom reported a range of factors which impact their learning (McDougal et al., 2020). Although there were some positive accounts, many participants told tales of feeling stressed, sad, and overwhelmed. While children did not typically use the word 'anxiety', retrospective accounts emphasised the impact the environment had on their mental health later in life, supporting research that if children are not adequately supported early on, more severe mental health difficulties can develop (Mesa & Hamilton, 2022). It is therefore crucial to implement a child-centred approach, based on gathering voices about unique experiences. Resources such as *The Ideal School* (adapted from Moran, 2001) and *Mapping the Landscape of Fear* (Ripley, 2015) may be helpful, as well as adopting a genuinely curious approach through all interactions with students and their families, using their preferred communication method.

We don't do things wrong we do them differently, and I need you to understand

Due to societal ignorance, autistic people are at risk of being dehumanised and treated like non-sentient beings (Botha et al., 2021). Indeed, despite desperately craving connections, children in the current review experienced social isolation and bullying, which they often attributed to the stigma of their diagnosis. Understanding from staff, peers and themselves was often make or break for the experiences of participants. They knew they could be perceived as 'weird' and wanted autism to be viewed as a difference, not a disability. When school staff showed their understanding through small gestures, it had a big impact on the well-being of the children in the current study. Despite increases in autism awareness, it is well documented that many teachers are underprepared to recognise and support autistic students, and some teaching assistants have received no training at all (Gómez-Marí et al., 2021; Mesa &

Hamilton, 2022; Ravet, 2018; Whitlock et al., 2020). This lack of understanding means that children are not getting appropriate support and can impact teacher motivation, representing the experiences of some children in the review (APPGA, 2019; Busby et al., 2012).

Whole school approaches that support understanding of neurodiversity (e.g., Learning about Neurodiversity at School; Alcorn et al., 2021) can help all staff and children to develop their knowledge of autism. This may help those who have not yet received a diagnosis, to understand that everybody is different. Additionally, autistic children should be encouraged to explore autism in a neuro-affirming way, such as considering their individual strengths (Landells, 2016), or reading books by autistic authors. It is possible that supporting this understanding earlier in their education could counteract some of the difficulties with identity experienced at secondary school (Horgan et al., 2022).

Good relationships make it better

Children in the current review spent much of their time alone. While this was a choice for some, for many, isolation came from school practices and rejection from peers. Previous research has found that autistic children are motivated by friendships (Cook et al., 2018; Myles et al., 2019; Tierney et al., 2016). Despite this, teachers often incorrectly assume that autistic children want to be alone (Mesa & Hamilton, 2022), and this can lead to further unwanted seclusion. In the current research, children shared a wish for a form of social learning (to navigate the non-autistic social world), reflecting the thoughts of 50% of autistic children in a recent survey (National Autistic Society, 2021). It should be noted that the use of some social skills teaching has been criticised, with some opponents arguing that social skills programmes demand that autistic people fit into neurotypical moulds (Ai et al., 2022). It is important that any support provided is co-constructed, trauma-informed, and neuro-affirming (Ai et al., 2022) so that it does not encourage autistic students to act in non-authentic ways, and inadvertently encourage masking. We also recommend that support involves non-autistic students learning about the communication styles of their autistic peers, to foster bi-directional understanding, in accordance with the principles of the Double Empathy theory (Milton, 2012).

A more neuro-affirming approach would be to encourage involvement in clubs or activities based on interests, including both autistic and non-autistic students, where they can meet peers and develop friendships naturalistically (Cook et al., 2018; Mesa & Hamilton, 2022). Relationships with trusted adults were valued, and relationships can be utilised to allow talking through social situations. It is important that staff believe autistic children (and their parents) if they say they have struggled, as feeling that

they are not believed leads children to hide their need for support.

Some children, especially those who had specialist adaptations, reported positive relationships, and support attuned to their needs. However, often children were bullied, excluded, and stigmatised, which negatively impacted their sense of school belonging, reflecting what has been found in secondary schools (Horgan et al., 2022; Myles et al., 2019). Belonging is the fundamental human need to be accepted, respected, and included (Allen et al., 2021; Baumeister & Leary, 1995), and a sense of school belonging has been linked with positive educational and psychological outcomes (Allen et al., 2018; Arslan, 2018; Arslan et al., 2020). Feeling that they were not accepted, left children isolated, and often hid their true selves to fit in. There has been evidence that peer support programmes can support the sense of belonging in neurodivergent students at secondary school, and the efficacy of this for primary-aged students should be explored (Fotheringham et al., 2023).

Success matters but the environment is key

Most children were motivated to learn and succeed. In contrast to secondary school students who found the learning overwhelming (Horgan et al., 2022), children, especially at specialist primary schools, reported feeling held back academically. They valued being challenged and accessing meaningful learning. However, environmental influences such as the sensory environment, and language demands, impacted their engagement.

Children shared the importance of schools making seemingly small adaptations including regular breaks, quiet spaces, extra time to answer questions, and technology. It is vital that support is carefully adapted based on individual needs, for example through a sensory audit, leading to environmental changes (Guldborg et al., 2019). Further, many children were reluctant to access support if it would 'other' them, and general support that benefits all children is preferred (Mesa & Hamilton, 2022). As has been demonstrated in this review, some autistic children can provide meaningful information about their experiences, and it is up to schools and policy makers to listen.

Strengths and limitations

The current review is the first focussing on the voice of autistic primary-aged children, and is of wide scope, including a range of voices, internationally. The research methodology was intentionally wide in order to be inclusive, and amplify the voices of autistic students who may have previously been marginalised. The research highlighted the unique experiences and found some commonalities. Despite this, we acknowledge that some of the variation may be dependent on contextual factors (such as type of

setting, culture or geographical location). Future research may wish to focus more on the potential impact of these contextual factors (e.g., reviewing studies limited to one type of setting or culture). It provides further evidence of the importance of listening to unique autistic perspectives to further develop understanding. It should be noted that the extent to which implications can be implemented relies on the context and political climate, and limited resources can have a negative impact on attitudes towards autism (Leonard & Smyth, 2022).

The research included has taken positive steps to amplify the voices of a wide range of autistic students. Most of the included studies utilised semi-structured interviews, which excluded children with limited verbal communication (Fayette & Bond, 2018). Research that did use participatory methods and adapted resources yielded meaningful findings (e.g., Cunningham, 2022; Howard et al., 2019; Moysé & Porter, 2015; Warren et al., 2021). However, it could be argued that the level of interpretation required by the researcher could be an additional barrier to fully capturing the autistic persons' voice. Nevertheless, we maintain that participatory and creative approaches should be continued in research in order to capture a diverse range of voices conveyed in different ways. In addition, It should be noted that the authors of the paper do not openly identify as autistic, which may have impacted interpretation at different levels. Future syntheses, particularly those in relation to autistic voice, would be further enhanced by autistic representation within the research team.

Further groups of autistic voices that are missing are those specifically relating to race and gender. In a recent review of autism intervention studies, Steinbrenner et al. (2022) found that only 25% reported data on ethnicity, and of those that did, the majority were White. In the current review, just five of 22 studies reported ethnicity information. Additionally, many studies did not disclose gender or were predominantly male. Given the implications of intersectionality and the interest in gender differences in autism, it is important that future researchers gather comprehensive demographic information, and actively seek missing voices.

Conclusion

Previous research has excluded the voices of autistic children about their school experiences or primarily focussed on accounts of secondary-aged pupils. The current review explores the school experiences of autistic children in a range of primary school settings. This research highlights the importance of *everybody* developing their understanding of autism, both generally and specifically to the children with whom they are working. There are many examples of good practice, and schools should be encouraged to listen to their young people and work together to ensure that all autistic children, regardless of the setting, are challenged yet

experience a sense of school belonging. Supporting children to develop a sense of belonging in primary school may prevent 'cycles of restricted participation' which we know continue into adolescence (Hodges et al., 2020, p. 9).

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Note

1. A note on language: to clarify the positionality of accounts, the term 'participants' has been used when evidence and quotations came from both current and retrospective accounts (adults and young people). The term 'children' has been used to refer to participants who were currently attending primary school at the time of the research. 'young people' refers to secondary-aged pupils reflecting on primary school, 'adults' refers to people over the age of 18.

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