

Autistic pupils' experiences in primary and post-primary schools: A scoping review and consultation with autistic pupils in Ireland

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Abstract

Background and aims: Autistic pupils have the right to be heard in matters concerning their education and to be active agents in shaping their school experiences. Despite this, educational policies and research have rarely included the voices of autistic children, failing to identify what they consider to be beneficial and meaningful in their own education. This study aimed to (i) summarise existing literature exploring autistic pupils' experiences at school from their own perspectives and (ii) identify gaps for future research through a consultation with autistic pupils.

Methods: A scoping review was conducted to identify studies exploring first-person accounts of autistic pupils' school experiences (primary and secondary; aged 4–18 years) published between 2005 and 2023. Thematic analysis was conducted to identify overarching thematic categories across the included studies. Review findings were discussed through a consultation with a Child and Youth Advisory Group (CYAG) comprised of autistic pupils in Ireland ($N = 3$), to seek feedback and inform a future research agenda.

Main contribution: Thirty-six studies were included in the review and six themes were identified: Experiences of feeling misunderstood, of bullying and masking, of feeling excluded, of anxiety, of sensory needs in school, and of being overwhelmed during transitions. Consultation with the CYAG highlighted that these six themes were consistent with autistic pupils' experiences but that reports of positive experiences were missing in the literature.

Conclusions: This study identified several gaps in the literature on the school experiences of autistic pupils, based on both the scoping review and consultation with the CYAG. While the CYAG validated the themes identified in existing literature, there is a need for greater diversity in the samples included and increased focus on the potential positive aspects of the school experience. Implications. These findings have important research implications. In particular, further studies are needed with autistic pupils at primary school level, including those who are minimally or non-speaking, as well as ensuring pupils with positive school experiences are also represented. Findings also highlight the need for continued collaboration with autistic pupils themselves in matters concerning their education.

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Keywords

Autism, child voice, lived experience, scoping review, school-age children

Introduction

Autism is a neurodevelopmental condition characterised by differences in social skills, repetitive behaviours, speech, and non-speaking communication (Davidson & Orsini, 2013). A recent systematic review on the global prevalence of autism indicated that approximately one in 100 children are identified as autistic (Zeidan et al., 2022), but this estimate is considerably higher in certain countries, from one in 36 children in the United States (Maenner et al., 2023) to one in 20 children in Northern Ireland (Rodgers & McCluney, 2023). There has been a fundamental shift in how autism is conceptualised in recent years, from the traditional medical model (defining autism by its deficits) towards a neuro-affirmative approach which is more in line with the social model of disability (Pellicano & Houting, 2022). Within the social model of disability, autistic people are disabled by ‘correctible mismatches between autistic needs and societal accommodations’ (Walker, 2021, p. 49). In an educational context, autistic pupils may require a range of individualised supports and accommodations to meet their needs.

Informed by the United Nations Convention on the Rights of the Child (UNCRC; United Nations, 1989) and the Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006), inclusive education for autistic children is increasingly the goal of educational policies worldwide (Buchner et al., 2021). Under Article 24 of the UNCRPD, autistic children have the right to an inclusive education with accommodations and individualised supports. Under Articles 12 and 23 of the UNCRC, autistic children have the right to receive appropriate special education, to freely express their views, have a voice in relevant legal or administrative matters, and to have their views considered in decisions which impact them. In an educational context, autistic children therefore have the right to be heard in matters concerning their education and be active agents in the shaping of their school experiences. Despite this, educational policies and research to date have rarely included the voices of autistic children, failing to identify what they consider to be beneficial and meaningful in their own education (Lundy & Kilpatrick, 2006). This lack of consultation with autistic children in the shaping of educational policy and research is important to address, given that autistic children are particularly vulnerable to adverse school experiences (Horgan et al., 2023) and have historically been excluded from many opportunities in wider society (Pellicano et al., 2018).

Lundy and Kilpatrick (2006) highlighted that the rights of children with special educational needs have often been ignored or underplayed due to a reported lack of resources and capacity in schools to provide adequate provision. Over 30 years has passed since Article 12 of the UNCRC was established, yet issues continue to be cited in the translation of its principles into practice, including limited opportunities for children to express themselves through non-verbal modes of communication (Robinson et al., 2020). Neglecting to include autistic children’s voices in research is also in conflict with Article 7 of the UNCRPD, which affords children the right to freely express their views in matters that concern them and to receive disability-appropriate assistance when doing so.

Case example: the Irish context

The 2001 report from the Irish Task Force on autism examined the provision of education and support for autistic pupils in Ireland (Government of Ireland, 2001). It emphasised the importance of inclusion by fostering a ‘whole-school’ collaborative ethos and mandated schools to provide individualised support to autistic pupils. MacGiolla Phádraig (2007) later described challenges in translating this report into practice in Irish schools, including teachers’ attitudes towards inclusion and systemic issues. Winter and O’Raw (2010) concluded that in order to implement these best practices in Ireland, a significant shift was needed in the culture, organisation, and expectations of the Irish education system. Almost 15 years later, recent research with primary and secondary teachers in Ireland indicates that best practices are not being properly implemented in Irish school settings due to several systemic issues that remain to be addressed (Barry et al., 2023; Leonard & Smyth, 2022).

From an Irish policy perspective, van Kessel and colleagues (2021) identified that of the ten special education policies in Ireland, none directly addressed autism. In April 2022, the Irish Department of Education published its ‘Autism Good Practice Guidance for Schools’ (Government of Ireland, 2001), providing detailed guidelines and practical recommendations for schools. However, there did not appear to be any meaningful consultations with autistic pupils in the drafting of this report and the language used throughout reflects a medical model of disability (e.g., ‘severe’, ‘person with autism’, ‘symptoms’), which is not in line with current preferences within the autism community and wider neurodiversity movement (Natri et al., 2023).

While preferences differ on an individual level, there is relative consensus across English-speaking countries (including Ireland) that identity-first language and conceptualising autism in the social model of disability is preferred by the majority of autistic adults (Keating et al., 2023). The use of language that does not conform to these preferences in Irish policy documents may therefore be further indication of a lack of meaningful engagement and consultation with the autism community.

However, there is evidence of positive change in the future educational provision of autistic pupils in Ireland, with the establishment of an Autism Innovation Strategy by the Department of Children, Equality, Disability, Integration and Youth. The Department held an open public consultation, actively seeking to incorporate the needs and views of autistic individuals and other stakeholders (e.g., parents, organisations). The initial report was published in April 2023 (Government of Ireland, 2021). Several educational barriers were identified, including an insufficient number of autism classes and a lack of autism-specific training for teachers. Adverse school experiences were also described by respondents, including children being placed on reduced school timetables and children being secluded, suspended, or expelled from school. Regarding autism classes, one organisation contributed that ‘There is an absence of evidence available to either support or refute the position that Autistic children have better social and education outcomes in mainstream or special classes’ (p. 33). Despite this finding, there is an increasing reliance on special classes in Ireland, of which over 85% are designated for autistic children (Shevlin & Banks, 2021). The extent to which this shift supports or conflicts with inclusive educational policy is a significant question for educational research and practice (Travers, 2023) and recent research highlighted both benefits and limitations of autism classes in mainstream schools (Sweeney & Fitzgerald, 2023).

Current study

In order to draft effective policies, information is needed on the educational experiences, needs, and wants of autistic pupils. Previous systematic reviews have provided important insights into the experiences of autistic pupils in different school contexts. For example, a recent systematic review involved a comprehensive synthesis of the research on autistic pupils’ experiences in mainstream secondary schools, including 33 studies from 2005 to 2022 (Horgan et al., 2023). The review identified several common challenges experienced by autistic pupils in mainstream secondary schools relating to the sensory environment, social participation, and academic expectations. Previous reviews have also examined specific research questions relating to autistic pupils’ school experiences, such as school transitions (Nuske et al., 2019). However, to the

best of our knowledge, no previous reviews have sought to capture the early school experiences of autistic children from primary school through to secondary school. Previous reviews are also missing a formal consultation phase with autistic pupils, which is a key step in ensuring reviews elicit valid contributions on matters within the literature that are relevant and significant to autistic children and young people. Further, we have an ethical obligation to ‘place children’s voices and experiences at the centre of enquiry’ as to exclude them is discriminating and disempowering (Taneja-Johansson, 2023). We therefore conducted a two-stage study involving a scoping review and consultation with autistic pupils in Ireland.

Our scoping review explored international literature on school experiences based on first-person accounts from autistic pupils attending either primary school (aged approximately 4 to 12 years) or secondary school (aged approximately 12 to 18 years). The wider purpose of this paper was to inform the design of future research studies on the educational experiences of autistic pupils in Ireland, given the limited research available in an Irish context despite ongoing policy changes of direct relevance to autistic pupils. The second stage of this study included active consultation with a group of autistic pupils ($N=3$) to seek their perspectives on scoping review findings and to identify future directions for research based on their interpretation of the findings.

The review aims were to: i) summarise the educational experiences of autistic pupils in primary and secondary schools and ii) identify gaps in our knowledge and understanding of the educational experiences of autistic pupils from the perspective of autistic children and young people.

Methods

Overview

A scoping review methodology was selected in order to summarise data in the research literature regarding the educational experiences of autistic pupils attending primary and secondary school (Levac et al., 2010). The PRISMA guidelines for conducting and reporting scoping reviews (Tricco et al., 2016) were followed by the research team.

Search strategy

The three concepts to encapsulate the current research that were used in our search strategy were ‘Autism’, ‘Experience’, and ‘School’ and a number of related terms were identified. The search terms were refined with the assistance of a university subject librarian to add rigour and expand the comprehensiveness of resulting materials. The finalised search string can be seen in Table 1.

Searches were conducted in January 2023 in five databases: Education Research Complete (ERC); Education

Resources Information Centre (ERIC); PsycINFO; Web of Science; and CINAHL as these databases were identified as most relevant to the topic under investigation. In order to adapt to the different databases and ensure the inclusion of relevant studies, the syntax and arrangement of the search string was slightly altered for each database, where necessary. A final search was conducted in June 2023 to identify any eligible studies published since January 2023.

Screening procedure

A rigorous screening procedure was followed: articles identified through the database searches were imported to *Covidence* software where duplications were first removed before screening of all titles by the first and second authors, according to pre-defined inclusion and exclusion criteria (see Table 2). The first and second authors then screened abstracts with 90% of agreement. The first author screened the full texts of remaining articles and any issues during this final phase of screening were discussed with all authors. The screening procedure was tracked using the PRISMA flowchart (see Figure 1).

Summarising the data

Only articles published between 2005 and 2023 were included to capture research conducted after the publication

of the UNESCO (2005) policy on inclusive education. The original searches took place in January 2023 and were updated in June 2023. A numerical analysis of the characteristics of included studies was performed. The first author then conducted thematic analysis to identify overarching thematic categories across studies (Braun & Clarke, 2022), which were further refined following input from the second and third authors.

Consultation with autistic pupils in Ireland

A consultation with autistic pupils attending mainstream secondary schools in Ireland was conducted once data extraction was complete and preliminary review findings were available. The group comprised three autistic young people who self-selected (with parental consent and child assent) to join a Child and Youth Advisory Group (CYAG) as part of a larger research project. Consultation involved an online focus group discussion lasting approximately one hour. As this was a consultation rather than a formal research study, the purpose of the discussion was to seek the expertise and guidance of the CYAG rather than to gain insights into members' individual school experiences.

The first author presented the initial themes emerging from the scoping review and facilitated a group discussion to seek feedback. The CYAG were then asked to identify any missing themes that they would have expected to

Table 1. Search string used in database searching.

Search string
("autis*" or "asd*" or "autism spectrum disorder*" or "asperger*" or "autistic*" or "pervasive developmental disorder*" or "PDD-NOS*") AND ("experiences*" or "perceptions*" or "attitude*" or "view*" or "feeling*" or "belief*" or "perspective*" or "voice*") AND ("primary school*" or "elementary school*" or "education*" or "secondary school*" or "high school*" or "secondary education*" or "middle school*") AND ("Mainstream*" OR "inclusion" or "inclusive education" OR "school integration" OR "inclusive education") AND ("children*" or "adolescents*" or "youth*" or "child*" or "teenager*" or "kids*" or "childhood*" OR pupil* OR "young pe*" or "adolescent*" or "teenager*" or "young adults*" or "teen*" or "youth*")

Table 2. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Must include data from autistic children. • Peer-reviewed published articles • Primary Research Study or review • Published articles from 2005-2022 to reflect UNESCO (2005) policy on inclusive education. • All retrieved articles must be published in the English language due to budgetary and time restraints. • Articles referring to autistic school-aged children approximately 4–18 years. • Articles that have included the views of at least one autistic person about their experiences in education. • Originating in a country with social or cultural similarities to Ireland. 	<ul style="list-style-type: none"> • Systematic literature reviews or scoping reviews were excluded if they did not include the voice of autistic children.

Table 3. Characteristics of included studies.

#	First author (Year)	Location	Setting	Ages	N	M:F	Focus	Methods
1	Waldman et al. (2022)	Scotland, UK	Transitions Primary	16–18	22	13:9	Transition-related anxiety	Interviews, questionnaire, pictures
2	Cunningham (2022)	UK	Primary	8–12	11	8:3	Creating an autism-friendly school	Interviews, focus groups, participatory methods
3	Stack et al. (2020)	Ireland	Transitions	12–12	6	5:1	Transition from primary to post-primary school	Interviews pre- and post-transition
4	Goodall (2018a)	Northern Ireland, UK	Both	11–17	12	10:2	Mainstream school experiences	Interviews, activities (draw-and-tell, diamond ranking), Children's Research Advisory Group
5	Calder et al. (2013)	UK	Primary	9–11	12	8:4	Friendships at school	Social network methods
6	Aubineau and Blicharska (2020)	France, Canada	Post-primary	12–16	26	24:2	School inclusion	Interviews
7	Croydon et al. (2019)	UK	Transitions	8–17	19	17:2	Transition from special to mainstream school	Interviews
8	Cullinan (2017)	Ireland	Primary	7–13	25	25:0	Social inclusion at school	Surveys (SIS, Guess Who Behaviour; Bullying Measure)
9	Dann (2011)	UK	Transitions	10–11	6	5:1	Transition from primary to post-primary school	Interviews pre- and post-transition
10	Dillon et al. (2016)	UK	Post-primary	13–13	14	11:3	Mainstream post-primary school experiences	Self-report questionnaires; semi-structured interviews.
11	Dixon and Tanner, (2013)	Australia	Transitions	14–15	2	2:0	Transition from primary to post-primary school	Interviews
12	Goodall (2020)	Northern Ireland, UK	Both	11–17	12	10:2	School Inclusion	Interviews, activities (draw-and-tell, diamond ranking)
13	Goodall (2019)	Northern Ireland, UK	Both	13–16	7	7:0	Mainstream and alternative school experiences	Interviews; participatory methods
14	Goodall (2018b)	Northern Ireland, UK	Both	11–17	12	10:2	School experiences	Interviews; participatory methods
15	Goodall (2019)	Northern Ireland, UK	Both	16–17	2	0:2	Girls' mainstream school experiences	Interviews; participatory methods
16	Haegele and Maher (2022)	USA	Post-primary	13–18	8	8:0	Experiences of belonging in PE	Interviews
17	Halsall et al. (2021)	UK	Post-primary	12–15	8	0:8	Camouflaging of autistic girls in mainstream and specialist provision	Interviews
18	Hebron and Bond (2017)	UK	Both	8–15	9	7:2	Developing mainstream resource provision	Interviews
19	Hill (2014)	UK	Post-primary	11–16	6	6:0	School experiences	Interviews
20	Hoy et al. (2018)	UK	Transitions	12–16	5	4:1	Inclusive practices to support transition from primary to post-primary	Photovoice; interviews
21	Hummerstone and Parsons (2021)	UK	Post-primary	11–15	12	11:1	Pupils' perspectives on what makes a good teacher	Photovoice; interviews

(continued)

Table 3. Continued.

#	First author (Year)	Location	Setting	Ages	N	M:F	Focus	Methods
22	Humphrey and Lewis (2008)	UK	Post-primary	11–17	20	Unspecified	School experiences	Interviews; pupil diaries
23	Locke et al. (2010)	USA	Post-primary	14–14	7	4:3	Loneliness, friendship and social networks	Loneliness Scale; Friendship Quality Scale; Friendship Survey; School Activities Questionnaire
24	McAllister and Sloan (2016)	Northern Ireland, UK	Post-primary	13–18	17	13:4	Designing and creating an autism-friendly school	Design workshops
25	McCorkell and Lobo (2021)	UK	Post-primary	12–16	7	2:5	Remote learning experiences during lockdown	Interviews
26	McNerney et al. (2015)	UK	Transitions	10–11	6	6:0	Choosing a post-primary school	Interviews
27	Mesa and Hamilton (2022)	UK	Both	10–14	13	12:1	Autism identity	Interviews
28	Miles (2019)	UK	Post-primary	12–17	8	0:8	Social experiences and sense of belonging in mainstream school	Interviews
29	Neal and Frederickson (2016)	UK	Transitions	11–12	6	5:1	Transition to mainstream post-primary	Interviews
30	Saggers (2015)	Australia	Post-primary	13–18	9	7:2	Improving pupils' educational experiences	Interviews
31	Skafle et al. (2020)	Norway	Post-primary	16–18	5	4:1	Social perception of pupils	Interviews
32	Tomlinson et al. (2022)	UK	Post-primary	14–16	3	0:3	Mainstream school experiences	Interviews
33	Warren et al. (2021)	UK	Primary	9–11	5	5:0	Everyday experiences of inclusion	Visual storyboards
34	Cook et al. (2016)	UK	Post-primary	11–17	11	11:0	Learning, friendship and bullying of boys in mainstream and special settings	Interviews
35	Tobias (2009)	UK	Post-primary	14–16	10	Unspecified	Supporting students at school	Focus groups
36	Richter et al. (2020)	France	Transitions	10–12	6	6:0	Transition from primary to post-primary school	Interviews

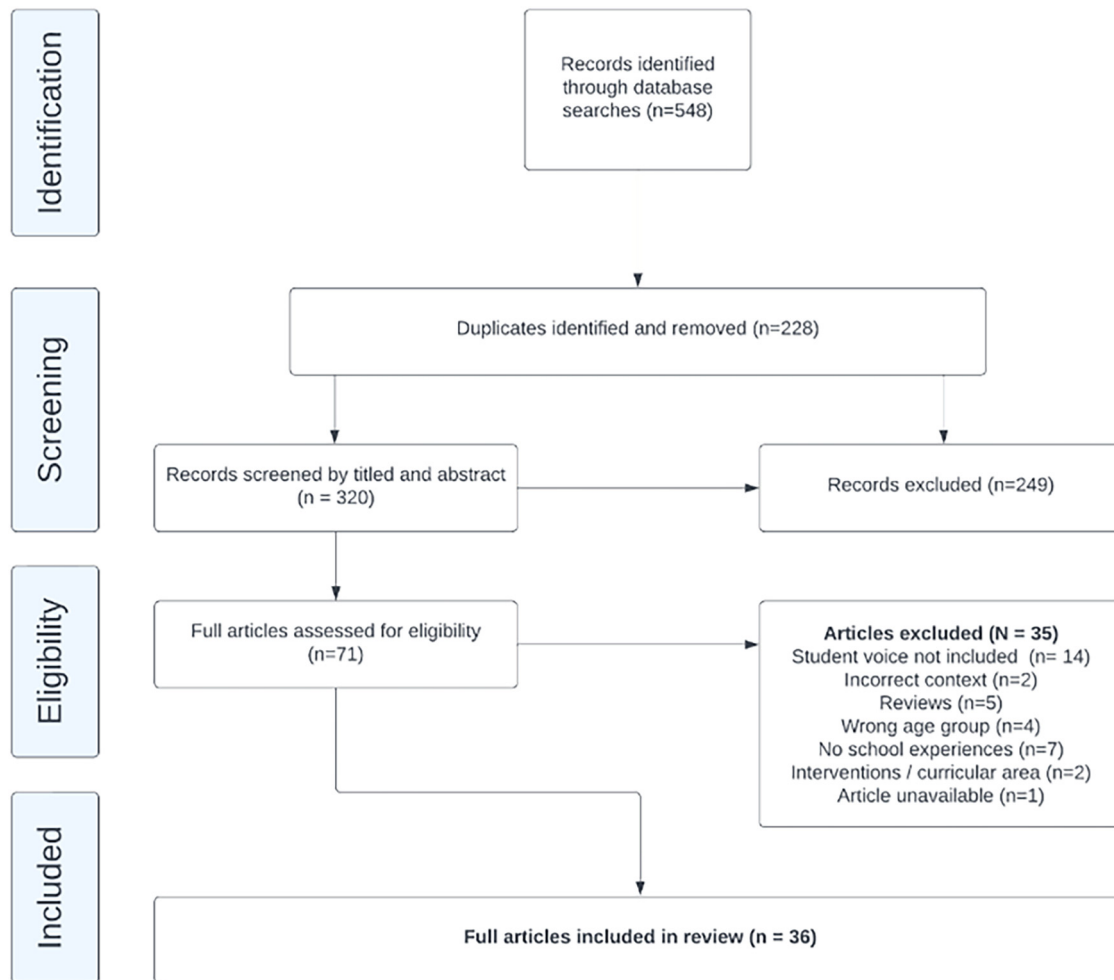


Figure 1. Prisma flow diagram.

have emerged from the literature. Following this consultation, anonymised feedback from the group was collated. We used this feedback to validate the themes from the literature and to report missing themes and gaps in research on the school experiences of autistic children, thus adding further methodological rigour to our findings (Levac et al., 2010). In line with recommendations by Lundy (2007), we provided the CYAG with the final scoping review findings which incorporated their feedback, showing the impact that members' contributions had on the research and to ensure that we had captured what had been discussed with us authentically and accurately.

This consultation phase of the review was also an important first knowledge exchange as part of a larger project on the school experiences of primary and secondary school children in Ireland. As such, including this stage in our review enhanced the value of its findings and supported the dissemination of preliminary results with autistic pupils (as advised by Levac et al., 2010 in their discussion on the added value of including a consultation phase in scoping reviews).

Community involvement statement

As described above, three autistic young people who were members of a research CYAG were consulted in the penultimate phase of the scoping review. The feedback which they provided on the themes identified by the research team was used to revise the initial themes and to help identify gaps in the research literature.

Results

The systematic search yielded 548 publications, resulting in 320 original studies following the removal of duplicates. Thirty-six articles met the criteria for inclusion.

Characteristics of included studies

Of the 36 articles included, 14 articles were from the year 2020 onwards: this is noteworthy given the impact of the COVID-19 pandemic between 2020 and 2022 on the delivery of both primary and secondary education globally (e.g.,

Daniel, 2020; anonymised for review) (see Table 3 for characteristics of included studies).

The majority of studies were conducted in the UK ($k=27$); the remaining nine studies took place in Ireland ($k=2$; Cullinan, 2017; Stack et al., 2020), the USA ($k=2$; Haegele & Maher, 2022; Locke et al., 2010), Australia ($k=2$; Dixon & Tanner, 2013; Saggars, 2015), Norway ($k=1$; Skafle et al., 2020), France (Aubineau & Blicharska, 2020 [dual-site study]; $k=2$; Richter et al., 2020), and Canada ($k=1$; Aubineau & Blicharska, 2020 [dual-site study]).

Across the included studies, a total of 369 autistic children provided first-person accounts on their school-related experiences, with an average of ten children per study ($M=10.30 \pm 6.07$ participants). Children ranged in age from 7 years (average lower age across studies $M=11.61 \pm 2.26$ years) to 18 years (average upper age across studies $M=15.11 \pm 2.35$ years). The vast majority of participating autistic children were male. The most common methodology used across the included studies was semi-structured interview ($k=30$). Eleven studies used alternative methods of qualitative data collection such as photo elicitation and diamond ranking (e.g., Goodall, 2020). Other methods included focus group discussions ($k=2$) and surveys ($k=2$). Twelve studies used a combination of both interview and non-interview methods.

Sixteen studies examined experiences at secondary school, four studies examined experiences at primary school, and seven studies examined experiences at both primary and secondary school. Eight studies were focused on school transitions from primary to secondary school and one study focused on school transitions from special educational settings into a mainstream school.

Study themes

Six themes were identified in the included studies: experiences of (1) being misunderstood – ‘By the way they act they just don’t know enough at all’; (2) bullying and masking – ‘They call me names like weirdo and stuff like that’; (3) being excluded – ‘I felt very lonely’; (4) school anxiety – ‘I feel scared and I feel embarrassed’; (5) sensory needs not being met – ‘Too much noise and too many people’; and (6) transitions as overwhelming – ‘I might be shy about meeting new people’. The themes are presented with an emphasis on listening to autistic children’s reports of experiences in school. Thus, direct quotes are threaded through the narrative to give prominence to the perspectives of autistic children.

Feeling misunderstood – ‘by the way they act they just don’t know enough at all’. There was a strong theme in 34 of the 36 articles that autistic children often felt misunderstood by teachers and peers (e.g., Aubineau & Blicharska, 2020; Calder et al., 2013; Cook et al., 2016; Dann, 2011), as well

as feeling that those in school had a limited understanding of autism: ‘By the way they act they just don’t know enough at all’ (Cunningham, 2022). Mainstream school was considered less supportive with pupil reports of teachers not knowing how to support autistic children (Dillon et al., 2016; Goodall, 2020). Strategies and teaching methods that teachers used were often challenging for autistic children with pupils reporting a need for clear and explicit instruction (Dixon & Tanner, 2013). Communication between teachers and autistic pupils was often mentioned as challenging (Goodall, 2018a, 2019, 2020), particularly in relation to lesson directives: ‘I need it like broken down a bit’ (McCorkell & Lobo, 2021, p. 81). However, the variety of teachers in secondary school was seen as positive by some children (Stack et al., 2020, p. 6).

Bullying and masking – ‘they call me names like weirdo and stuff like that’. Autistic pupils across 22 of the 36 included studies spoke about their bullying experiences in school. Bullying was viewed by autistic pupils as occurring as a direct result of their autism (e.g., Cook et al., 2016), or due to a lack of autism awareness by peers (Goodall, 2020, p. 1302). Some experiences involved physical or sexual abuse: ‘I was bullied when I was younger ... verbal physical and there was once ... sexual ... which is bad. It was a pupil’ (Goodall & MacKenzie, 2019, p. 507).

Bullying and teasing were experienced at varying levels of severity and frequency by most participants (Humphrey & Lewis, 2008; Mesa & Hamilton, 2022) and as something that could lead to self-harm: ‘I started choking myself with my thumbs’ (Haegele & Maher, 2022, p. 55). Autistic children, often girls, reported ‘masking’ (e.g., hiding their authentic self) in order to avoid being bullied, and were motivated to develop these strategies to avoid bullying or humiliation: ‘I smile and nod, like I know what they’re talking about, but I really don’t ... (Halsall et al., 2021, p. 2078). The bullying could occur over a long time (Haegele & Maher, 2022, p. 55), and could intensify as pupils progressed through school (Mesa & Hamilton, 2022) and when teachers were not around (Aubineau & Blicharska, 2020). However, bullying was also counteracted by support from, and enduring friendships with, classmates (Humphrey & Lewis, 2008). Some autistic pupils in primary school also reported satisfaction with their friendships though these were rated to be of poorer quality than their neurotypical peers (Calder et al., 2013).

Feeling excluded – ‘I felt very lonely’. Reports of feeling excluded as a result of being autistic were found in 33 of the 36 included studies. One child mentioned that feeling different had begun from a young age: ‘[...] it was like I had germs and they weren’t to go near me’ (Goodall & MacKenzie, 2019, p. 507). In the same study, autistic pupils reported feeling that they had no one to talk to and that no one wanted to team up with them: ‘...I had no

one. It was awful' (Goodall & MacKenzie, 2019, p. 508). Among reports of exclusion autistic children shared a desire to be treated equally: 'They treat us like we're not human, like we're less. . .' (Mesa & Hamilton, 2022, p. 224); '...we are different, that's a fact, but they treat us like we're different-er' (Mesa & Hamilton, 2022, p. 225). In a study of loneliness, Locke et al. (2010) found significant difference in feelings of loneliness among autistic adolescents compared to their neurotypical classmates, with autistic adolescents reporting significantly more loneliness (Locke et al., 2010).

School anxiety – 'I feel scared and I feel embarrassed'. School was a place where many autistic children identified feelings of anxiety and stress, with 32 of the 36 included studies referring to this (e.g., Siggers, 2015; Tobias, 2009; Tomlinson et al., 2022; Warren et al., 2021). Children reported experiences of significant stress ('I always felt very stressed, anxious and out of place', Goodall & MacKenzie, 2019, p. 508), and a negative impact of mainstream school on their mental health: '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' (Goodall, 2018b, p. 1662). Participants reported feeling emotionally drained from school (Goodall & MacKenzie, 2019) and highlighted homework often added to this stress (Richter et al., 2020).

Sensory needs in school – 'too much noise and too many people'. Sensory needs were identified in 20 of the 36 included studies, where pupils reported becoming overwhelmed by noise (Cook et al., 2016; Goodall, 2019; Hill, 2014; McAllister & Sloan, 2016), lack of space and overcrowding (e.g., Aubineau & Blicharska, 2020; Skafle et al., 2020); and teachers shouting (Hummerstone & Parsons, 2021). Some children found the school bell distressing and had to leave the classroom before class ended in order to avoid it (Hill, 2014). In particular, the secondary school environment and regular movement between classes was seen by some as challenging: '...I felt closed in and like I couldn't breathe' (Goodall, 2018b, p. 1662). As a result, many autistic children sought out quiet spaces to decompress (Goodall, 2019). When asked what they disliked about school, four autistic children took pictures of communal areas, describing them as 'noisy' with some pupils disliking how busy school gets during break times, and preferred stay inside where it is quieter (Hoy et al., 2018, p. 188).

6. Transitions as overwhelming – 'I might be shy about meeting new people'

In terms of transitions (identified as a theme in 21 of the 36 articles), many studies explored this in relation to moving from one school to another, or from moving from one classroom lesson to another physical classroom and different teacher (e.g., in secondary school) (e.g., Myles et al.,

2019; Richter et al., 2020). One pupil identified the move as positive, and identified better relationships with peers (Dann, 2011) following the transition to secondary school: 'My friends in my primary ...made fun of me ... nobody does it in my school now so it's really good' (Stack et al., 2020, p. 7), whereas another pupil found it challenging to build new friendships (Stack et al., 2020). Many autistic children expressed apprehension about interacting with people at their new school, whereas others were anxious about achieving academically when they transitioned to secondary school: 'I don't know whether I'm going to be able to keep up' (McNerney et al., 2015, p. 1109). However, some children were looking forward to interesting academic areas (Hebron & Bond, 2017).

Findings from consultation with autistic pupils

Consultation with autistic pupils in the study's CYAG confirmed the themes as reflective of pupils' own personal school experiences. While some pupils had good relationships with their teachers, the CYAG felt that generally, teachers do not have a good understanding of autism (Theme 1), unless they have direct experience of autism. The CYAG was generally in agreement in viewing teachers as wanting to help but highlighted that they could say the wrong things due to a lack of understanding.

Similarly, in relation to the theme of bullying (Theme 2), the CYAG felt that this was an expected theme and that bullying happens regularly, though not everyone experiences this. The CYAG felt that autistic children regularly feel isolation (Theme 3) but can often end up having friends outside of school during their extracurricular activities where they have shared interests. The CYAG highlighted a potential for 'collective ignoring' of autistic classmates by neurotypical peers in secondary school and that 'masking' to fit in is common (Theme 2). The social side of school was identified as particularly difficult to engage in and often resulted in autistic children feeling excluded. The CYAG concurred that anxiety and stress was also a likely common experience for autistic pupils (Theme 4), though they felt that school could also be a safe environment as it can give structure and routine. Finally, sensory needs within busy and boisterous classroom environments (Theme 5) were highlighted as an important part of the school experiences of autistic pupils that the wider school needs to be aware of.

Consultation highlighted a potentially significant gap in the literature around likely differences between experiences in primary and secondary school. The CYAG highlighted that autistic pupils' experiences of secondary schools had the potential to be more positive than their experiences of primary school as autistic pupils were more likely to have opportunities to pursue interests and to find pupils who shared similar interests. They also pointed to increased

autism awareness and better supports in some schools that are not yet captured in the literature.

Discussion

This two-stage study aimed to summarise the primary and secondary school experiences of autistic pupils through first-person accounts in the literature and through consultation with autistic pupils regarding research gaps and future directions. Through a scoping review, six overarching themes were identified as common school experiences. These findings are consistent with a recent systematic review exploring autistic pupils' perspectives of mainstream secondary school placement (Horgan et al., 2023) and previous reviews highlighting specific difficulties autistic pupils can encounter during school transitions (Nuske et al., 2019), as well as a high risk of experiencing bullying at school (Maiano et al., 2016). It is unsurprising, therefore, that these themes were also deemed relevant by autistic pupils in Ireland in the consultation phase of this study.

Research gaps

Actively involving autistic pupils in the review of themes was a particularly novel aspect of the current study which added rigour to our scoping review findings (Levac et al., 2010) and supported autistic young people's rights to be heard in matters that concern them (UNCRC; United Nations, 1989). During this consultation, pupils discussed how findings did not appear to capture the potentially positive aspects of school. While some studies included reports of positive school experiences from autistic pupils (e.g., Neal & Frederickson, 2016), these were not included in a sufficient number of studies to form a theme when synthesising the findings of all studies included in this scoping review. There are several possible explanations for the limited reporting of positive school experiences amongst autistic pupils in the literature. This can happen when data collection is focused on particular categories of learners, which risks the promotion of deficit views of pupils who share certain characteristics (Ainscow, 2022). As the articles rarely included the interview schedule for interviewing autistic children or survey tools used, it is difficult to ascertain if results are due to questioning, or emerged unprompted. Our review therefore highlights the need for further methodological details to be included in future research papers that include the perspectives of autistic pupils.

In addition to the research gaps identified by autistic pupils described above, our scoping review also highlighted several issues which should inform future research. Firstly, the majority of studies that reported first-person school experiences have taken place in the UK. This is problematic as educational systems vary on an international basis, meaning that the drafting of national policies cannot be solely informed by studies specific to a given country.

Secondly, very few studies reported on children's primary school experiences. While there are recent exceptions of studies where autistic primary school pupils' perspectives have been sought (e.g., Cunningham, 2022), much of what is known about how autistic children experience primary school is based on parental insights (Warren et al., 2021). Thirdly, the voices of autistic pupils who communicate through speech were over-represented across the studies, with most research adopting a spoken interview methodology. It is essential to develop research methods which are tailored to meet all pupils' communication needs in order to diversify the voices being heard in this research area. This is also important under Article 7 of the UNCRPD (United Nations, 2006), which highlights children's right to receive disability-appropriate assistance to freely express their views in matters that concern them. Some studies included in the current review adopted participatory methods to allow autistic pupils to communicate through non-verbal methods, such as photo elicitation or diamond ranking (e.g., Hill, 2014). More widespread use of participatory methods is needed in the literature to support the inclusion of autistic pupils who are minimally or non-speaking. In order to ensure data collection methods are authentically inclusive, future researchers may consider co-production with autistic individuals (Stark et al., 2021) and adopting Universal Design for Learning (UDL) principles to individualise research methods (Kenny et al., 2023). Finally, like other areas of autism research, boys were over-represented in study samples (Morgan-Trimmer, 2022). Taneja-Johansson (2023) also noted how educational research involving first-person accounts from autistic children tend to under-report details such as ethnicity or socioeconomic status, meaning issues relating to intersectionality have not been addressed.

Implications of findings

The current findings indicate that many autistic children felt misunderstood by their teachers and peers, with many frequently experiencing bullying. A big part of a sense of belonging was intrinsically linked to being understood by peers and teachers. Supporting school relationships and fostering a sense of belonging is therefore a clear implication of these findings for inclusive educational policies for autistic pupils.

All children have the right to feel safe and receive an appropriate education (UNCRC; United Nations, 1989). The broadly negative school experiences described by autistic pupils in the current literature need to be addressed from a children's rights perspective and highlight the need for educational reform. For example, in the case of Ireland, the need to foster a whole-school collaborative ethos with individualised support has been recognised since the 2001 report from the Irish task force on autism (MacGiolla Phádraig, 2007). Now over 20 years later, it

is unclear how much has changed in everyday classroom practices to support the full inclusion of autistic pupils. The educational challenges described in the recent Autism Innovation Strategy (Government of Ireland, 2001) are consistent with those reflected in our review (e.g., lack of autism-specific training and adverse school experiences), but there was just one qualitative study eligible for inclusion in our review conducted in Ireland (Stack et al., 2020), which focused on the transition from primary to secondary school. This has implications for the educational provision of autistic pupils in Ireland, as policy recommendations and decisions which impact them are being made without their involvement. The ongoing changes to educational policy and practice in Ireland further underscores the need to actively seek input from and collaborate with autistic pupils themselves in matters concerning their education. Our consultation with autistic pupils in Ireland was therefore a key stage of this review and findings can inform the direction of future research.

This review adopted a robust methodology which was guided by a subject expert librarian, experienced researchers, and autistic pupils to ensure a rigorous search strategy and thematic analysis framework. A strength of the current scoping review is its focus on the literature that included the voices of autistic children in order to give prominence to their school experience and a consultation with autistic young people themselves on the findings and potential gaps in the literature. This is an important approach to scoping reviews on children's school experiences given that children's views can differ from those of other interested parties (Dann, 2011) and that children's voices can often be lost amongst adult perspectives (Richter et al., 2020).

Conclusion

This scoping review summarises literature on the experiences of autistic children in primary and secondary education. The themes, validated through consultation with autistic pupils in Ireland, were predominantly negative and focused on what did not work within schools. Additionally, autistic pupils at primary school level and autistic pupils who are minimally or non-speaking were under-represented in the literature. In order to achieve the Sustainable Development Goal of Education (SDG 4; UNESCO, 2018) 'To ensure inclusive and equitable quality education and promote lifelong learning opportunities for all', there needs to be collaborative efforts made to authentically listen to autistic pupils of all ages so that effective educational changes for autistic children can be made to enhance awareness, learning, and belonging in school.

Author's note

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