Frontiers in Education

TYPE Systematic Review
PUBLISHED 09 January 2024
DOI 10.3389/feduc.2023.1308664

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OPEN ACCESS

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RECEIVED 06 October 2023
ACCEPTED 18 December 2023
PUBLISHED 09 January 2024

CITATION
Newson A, Quinn S and Nese RNT (2024) Examining the utilization of participatory research with autistic youth in mainstream/public schools: a scoping review.
Front. Educ. 8:1308664.
doi: 10.3389/feduc.2023.1308664

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Examining the utilization of participatory research with autistic youth in mainstream/public schools: a scoping review

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Purpose: This scoping review explores the utilization of participatory research with autistic youth in K-12 public/mainstream school settings.

Methods: A scoping review was performed to identify how often participatory research methodologies are used in K-12 public/mainstream school settings with autistic students, what researchers report are the strengths, barriers, and recommendations in using participatory research methodologies with autistic students in K-12 public school settings and what type of demographic information is included in the studies.

Results: Five studies were included for review focusing on participatory research with autistic youth in K-12 public or mainstream school settings. The studies used a range of participatory research methodologies to explore the experiences of mainly male autistic youth in the UK and Australia. Strengths, challenges, and recommendations noted included opportunities for empowerment, increased ownership, issues with teachers, thinking critically about communication, and collaboration with partners.

Conclusion: Participatory research with autistic school-aged youth is an emerging practice. This is evidenced by the small number of studies included in this review. The findings highlight concerns about the lack of representation of autistic females and students with historically marginalized racial identities in autism research. Recommendations for including these groups in autism research, implications, and limitations are discussed.

KEYWORDS

autism (ASC), participatory research, public school, youth, methods

1 Introduction

Several studies have documented the harm experienced by members of the autistic community at the hands of autism research (Rosenblatt, 2018; McGill and Robinson, 2020; Pukki et al., 2022). Autistic[1] individuals have reported feeling tokenized or undervalued (Pellicano et al., 2014), being surrounded by dehumanizing, deficit, and stigmatizing language (Botha, 2021; Botha et al., 2021), feeling pathologized or "normalized" (Ashworth et al., 2020), and receiving lower ethical standards producing experiences of coercion, discomfort, and disempowerment (Cascio et al., 2020). This has led to general distrust between the autistic community and researchers and the perpetuation of harmful practices on autistic people (den Houting et al., 2021). Researchers have reported that autistic individuals have negative experiences when participating in research creating adverse outcomes and interactions (Ashworth et al., 2020). This includes research outcomes not being aligned with community priorities, dehumanizing interactions between researchers and participants, and little opportunity for feedback on research processes or outcomes (Ashworth et al., 2020; Cascio et al., 2021; den Houting et al., 2021).

Autistic advocates and autistic researchers have expressed that participatory methodologies are more effective at including autistic voices and perspectives in the research process (Jivraj et al., 2014; Frazier et al., 2018; Nicolaidis et al., 2019; Gillespie-Lynch et al., 2020; Cascio et al., 2021; Roche et al., 2021). Participatory methods in autism research are defined as "incorporating the views of autistic people and their allies about what research gets done, how it is done, and how it is implemented" (Fletcher-Watson et al., 2019, p. 1). Researchers have noted that participatory methods create opportunities for increased inclusion, accessibility, and meaningful input from autistic individuals (Fletcher-Watson et al., 2019; den Houting et al., 2021; Pickard et al., 2022). Autistic individuals have stated that they favor participatory methods, especially when conducted by autistic researchers, as they feel more acknowledged, understood, and supported as compared to traditional methods (Pellicano et al., 2021). Additionally, participatory methods have been shown to improve contextual fit, relevance, and increase the effectiveness of translating ideas into practice (Fletcher-Watson et al., 2019; Forsythe et al., 2019; Nicolaidis et al., 2019; Warner et al., 2019; Ashworth et al., 2020; Gillespie-Lynch et al., 2020; Pellicano, 2020).

There are three main types of participatory methods: (1) consultation, (2) co-production, and (3) equal power sharing. Each type comprises of different levels of participation and power-sharing, as defined by the Ladder of Public or Citizen Participation (Arnstein, 1969). Power-sharing can be defined as how power is distributed or balanced between key partners within the research project, program, or intervention (Mason and Boutilier, 1996; Lake and Wendland, 2018).

The first main type of participatory research is consultation which includes advisory boards, panels, or focus groups. Consultation can fall within what Arnstein (1969) describes as the tokenism group and what den Houting et al. (2021) frame as "doing for" (p. 149). This means that autistic community partners provide feedback and consultation services that may influence decision-making, however, the power ultimately lies with the researcher to make the final decisions. While consultation with the autistic community is important, power imbalances and lack of meaningful participation can create spaces where autistic individuals do not have a say or control over the methods being used, the goals of the intervention or study, and how their perspective will be utilized in the short-term and long-term (Cascio et al., 2020; den Houting et al., 2021).

The second major type of participatory research is co-production of research. This is seen as more authentic inclusion moving toward what Arnstein (1969) labels as the citizen control group. As seen in Patient Centered Outcome Research (Forsythe et al., 2019) or Design Based Implementation Research (Fishman et al., 2013), the autistic community partners get to have an active part in contributing ideas to the design, methods, and overall structure of the project, with the researcher still maintaining status as the expert. Oftentimes, research questions are initially created by the researchers. Once the community and key partners are on board with the research, co-production and inclusion begin.

The third major type of participatory research is called equal power sharing and can broadly include Participatory Action Research (PAR), or more specifically, Community Based Participatory Action Research (CBPR, Wallerstein et al., 2017; Nicolaidis et al., 2019) and Youth Based Participatory Action Research (YPAR, Caraballo et al., 2017). Both follow participatory and emancipatory approaches to research, with CBPR focusing on community, and YPAR focusing on youth as agents of change. Additionally, these types of research ask the community or group to define the problem and areas of research, rather than research questions being developed solely by the researchers. This level is seen as providing the most power to the community in what den Houting et al. (2021) categorize as "doing with" (p. 149). Researchers and autistic community members share power equally by working in collaboration to iteratively co-design, co-learn, and co-create sustainable socially valid research that is of benefit to the group.

A prime example of CBPR includes Nicolaidis et al. (2019) work creating the AASPIRE practice-based guidelines to include autistic adults as study participants and co-researchers. The guidelines were created utilizing CBPR with autistic adults, academic partners, and community members through an iterative multi-year process. The guidelines for autistic co-researchers detail how to be transparent about goals, how to clearly define roles and partners, ways to effectively communicate and share power, ways to focus on building trust, how to collaborate on dissemination, ways to encourage community capital, and how to fairly compensate partners and participants. The guidelines for the inclusion of autistic study participants include how to avoid exploitation and support autonomy, making accessible consent processes, offering multiple modes of participation, being critical of survey validity, creating accessible interview guides, and ways to use proxy reporters.

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[1] The first author has chosen identity-first language throughout the manuscript to acknowledge research and lived experiences that affirm this language is preferred by most individuals within the Autistic community. As an autistic autism researcher, the first author respects, honors, and appreciates the on-going conversation around language within autism research.

Both guidelines provide practical and essential recommendations to autism researchers hoping to provide a more inclusive and participatory environment in their studies.

Each level of participatory research methods emphasizes the need for autistic individuals to be involved members in practices or interventions to reduce tokenization, manipulation, and marginalization (den Houting et al., 2021; Pickard et al., 2022). Unfortunately, autistic student and community member voices have been routinely ignored, especially for individuals who also have communication difficulties (Pellicano and Stears, 2011; Chown et al., 2017; Fayette and Bond, 2017; Bastable et al., 2021; den Houting et al., 2021). To combat this, Cascio et al. (2020) organized ethics for autism research that include five big ideas: (1) Tailor the research process to each person (2) Think about the world in which the participants live (3) Make it easy for people to make their own choices (4) Value what people share in research and consider their needs and strengths (5) Think about how researchers and people work together. This aligns with the three core principles outlined by Hobson et al. (2023) that focus on fostering trusting relationships between researchers and the Autistic community, allowing for higher levels of accessibility throughout the research process, and developing the infrastructure and expertise to enable high-quality research to be conducted with the Autistic community.

These methods promote lived experiences, shared decision-making, equal power sharing, and socially valid outcomes. While PAR and CBPR are being used more often with the autistic community, YPAR is not (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019; Rudd and Hwang, 2021; Poulsen et al., 2022). Autistic and other students with disabilities are not often in YPAR efforts, with disability rarely mentioned or described in research demographics (Anyon et al., 2018).

This lack of inclusion of autistic student perspective is troubling, but not uncommon. In a review of social validation and inclusion of autistic perspectives in Augmentative and Alternative Communication (AAC) research, Bastable et al. (2021) found zero articles that included the direct voices of autistic students, but rather indirect perspectives from caregivers and related service providers. The authors note that autistic individuals with complex communication needs, which include those who use AAC strategies or who are non-speaking, are excluded from the research. This is problematic as it does not recognize the heterogeneity of the autistic community and creates further misunderstandings and marginalization (Woodfield and Ashby, 2016; Capozzi et al., 2019). Autistic students, no matter their strengths or level of support needs, should have the opportunity to be involved in their educational process as seen in the mentorship provided in Capozzi et al.'s (2019) work. They found that, although there were challenges with having non-speaking mentors and non-speaking youth involved in the program, there were opportunities to build community, increase visibility, and provide needed solidarity and support (Capozzi et al., 2019).

More recently, Zanuttini (2023) conducted a review that extended the literature on how autistic students' perspectives of their educational experiences are elicited and what are the outcomes. Their findings support other reviews discussing the need for participant evaluation of methods and the desire for researchers to use flexible, inclusive methodologies that support autistic student voice (Fayette and Bond, 2017; Tyrrell and Woods, 2018; Carroll and Twomey, 2021). These reviews recruited autistic student voices in a variety of settings, including mainstream or public[2] schools, segregated settings, and transition programs.

Autistic advocates and researchers have provided guidelines for including autistic adults throughout the research process as participants and co-researchers, but this process has yet to be tailored to fit the experiences of autistic students in K-12 mainstream public school settings (Nicolaidis et al., 2019, 2020; Benevides et al., 2020; Gillespie-Lynch et al., 2020). During the school year, autistic students spend much of their day in school alongside their non-disabled peers in, ideally, the least restrictive environment. While their peers are often included in research, interventions, and school programs, autistic students are often excluded from the process (Schuck et al., 2022; Monahan et al., 2023). This can further invalidate their experiences in schools and may contribute to feelings of deeper exclusion from the school community (Danker et al., 2016; Goodall and MacKenzie, 2019; Goodall, 2020).

Student voice can be defined as an expression of values, opinions, beliefs, and perspectives of an individual student or group of students which may be used to inform policy, instruction, or practices (Gonzalez et al., 2017; Cook-Sather, 2018). There are a variety of models for including the continuum of student voice, as noted in Hart's Ladder of Participation (Hart, 1992) and Mitra and Gross' pyramid of student voice (Mitra and Gross, 2009). Although the organization of each model differs, they highlight the need for students to be active participants in interventions and practices to reduce tokenization and marginalization.

Student voice can be elicited through informal interviews or observations, or more formal social validity measures. Social validity, as described by Kazdin (1977), Wolf (1978), and Horner et al. (2005), is an important part of accessing the dimensions of an intervention in terms of feasibility, acceptability, and sustainability for interested parties. Wolf (1978) focused on the impact of the socially significant goals, socially acceptable procedures, and socially important outcomes produced by the intervention. Horner et al. (2005) extended these features by including quality indicators to better document the magnitude of change, cost-effectiveness, and intervention sustainability. To access social validity, researchers have used interviews, questionnaires, and rating scales, or have conducted maintenance and sustainability measures. Measures like the Primary Intervention Rating Scale (PIRS) and Intervention Rating Profile (IRP) have been evaluated and validated by research; however, it is not guaranteed that when used the intervention will center student voice in the process (Lane et al., 2009; Carter and Wheeler, 2019). Although there have been recent efforts in research, particularly single case design, to include and meaningfully incorporate autistic student perspectives during and after intervention, recent reviews have found that social validity measures are often not reported and do not meet quality standards (Hanley, 2010; Snodgrass et al., 2018; Ferguson et al., 2019). In a recent review of social validation procedures

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[2] The authors use mainstream and public school interchangeably to describe any country's freely and publicly available school system (e.g., public schools in US, mainstream schools in UK).

in interventions with transition-age youth, Bottema-Beutel et al. (2023) found that only 43% of studies assessed all three dimensions of social validity, and nearly all studies had issues with describing procedures and interpretations. The use of participatory methods in schools with autistic students will assist the field in moving away from interventions being done on students and instead have activities being done with students.

Participatory research methodologies are becoming increasingly utilized with autistic individuals in autism research. However, little is known about the use of these methods with autistic students in kindergarten through twelfth grade (K-12) mainstream public schools. Based on a review of the literature, there has not been a systematic literature review completed on this specific topic and population. A scoping review was chosen to offer an exploratory review of the larger body of literature about autistic students in mainstream K-12 schools and to gain an understanding of the topic. Thus, the purpose of this scoping review is to provide a synthesis of participatory methodologies used with autistic students in K-12 mainstream public school settings by answering the following questions:

1. What types of participatory methods and level of participation, based on Arnstein's Classification, were used in the participatory research conducted in K-12 mainstream public school settings with autistic students?
2. What do researchers report are the strengths, barriers, and recommendations in using participatory research methodologies with autistic students in K-12 mainstream public school settings?
3. What type of demographic information (location, race, age, gender, etc.) is included (and excluded) in the studies?

2 Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018) and the 27-item PRISMA reporting guidelines (Page et al., 2021) were followed for this scoping review. A scoping review was chosen as the goal was to synthesize and assess the scope of the literature. An electronic search was conducted from September to October 2022 and updated in July 2023 using four academic databases: (1) ERIC, (2) APA PsycNet, (3) Education Abstracts, and (4) PubMed. The terms used in the search were related to the type of methodology (Participatory Research OR Participatory action research OR PAR OR Participatory OR community-based participatory research OR CBPR OR Youth Participatory Action Research OR YPAR), the population of interest (Autis* OR ASD OR ASC), and the location of interest (k-12 OR k12 OR primary school OR elementary school OR middle school OR high school OR secondary school). Filters were used to include only peer-reviewed journal articles and articles published in English. Studies that were conducted in "special schools" or "alternative education programs" were not included in this review. There was no limitation on the year published. Search and screening procedures are summarized in **Figure 1**.

2.1 Article selection

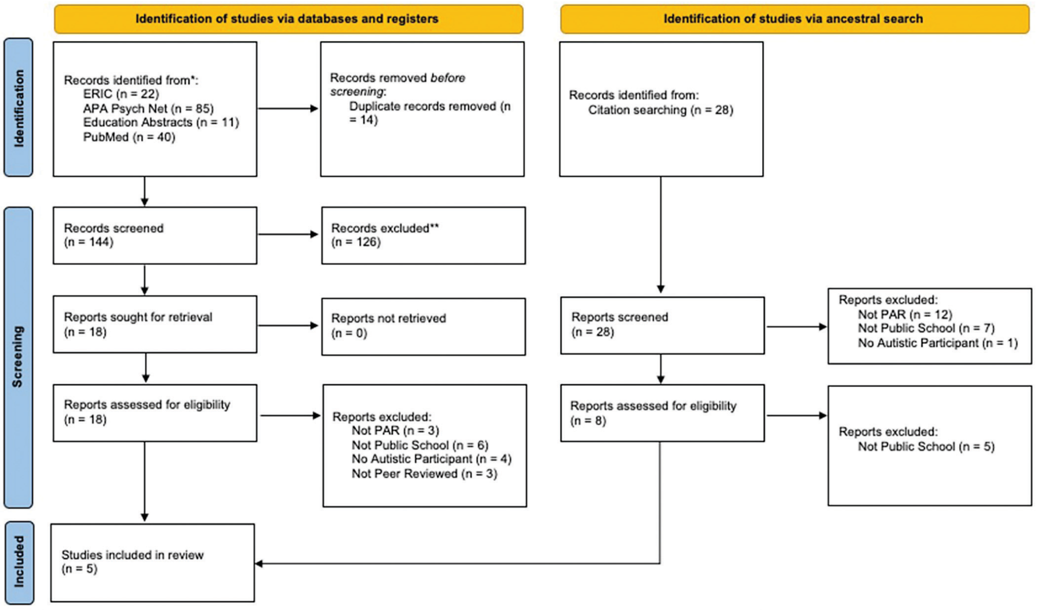
The author and a Special Education doctoral student independently screened title and abstract coding with the following five criteria: (1) peer-reviewed articles, (2) written in English, (3) located in mainstream public, K-12 schools, (4) pertained to participatory methodologies, and (5) pertained to autistic students. A total of 144 articles were initially screened using the criteria. This resulted in the removal of 127 records. From the 18 articles that met the criteria, an ancestral review (i.e., a review of citations) was completed using the Web of Science database. Twenty-eight additional articles were found from the ancestral review. They were then screened for title and abstract coding by both the author and doctoral student. This resulted in the exclusion of 20 articles. Eight articles were then screened in full text to ensure that they met the full inclusion and exclusion criteria. Common reasons for exclusion were studies that did not occur in a public/mainstream school, did not use participatory methods, and did not include autistic participants. The remaining eight ancestral and 18 original articles were assessed for eligibility in a full-text review. Following the final review, 21 articles were removed because they did not use participatory methods ($n = 3$), were not in public schools ($n = 11$), had no autistic participants ($n = 4$), and were not peer-reviewed ($n = 3$). A total of five articles were included for analysis. See **Figure 1** for a summary of the search.

2.2 Data extraction

The first author coded all five articles included to synthesize the data required to answer the research questions. The articles were first reviewed to distill the following demographic information: Country, type of participatory research methodology, the study focus, number of participants, grade level, gender of participants, and race or ethnicity of participants. See a summary of the results in **Table 1** for more detail about each article. Next, the author analyzed each article to determine the strengths, challenges, and recommendations of the study, which will be discussed in the Results section. See results and **Table 2** for more information about specific data extracted from each article.

2.3 Interrater reliability

For initial inclusion and exclusion, the first author independently read and coded all 144 articles and the doctoral student independently coded 30% of the total articles through each phase. Interrater reliability was calculated as the total number of agreements minus the total number of disagreements divided by the total number of articles coded, for an initial IRR percentage of 97% agreement. Cohen's Kappa score was also calculated using an online kappa calculator. Kappa is used to evaluate the degree of agreement between choices made by two or more independent raters. The initial Kappa scores were 0.87, which can be interpreted as near-perfect agreement. Any differences were discussed and resolved based on a review of the five criteria mentioned in the article selection section. The first author and doctoral student met via Zoom and reviewed the criteria together while discussing



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

FIGURE 1
PRISMA Flowchart for Scoping Review.

the independent rationale for each code until a final agreement of 100% was unanimously reached. For the ancestral review, the author and doctoral student reviewed all reports, with an IRR percentage of 90% and Kappa of 0.74 or substantial agreement. Any disagreements were discussed and resolved for a final agreement of 100%. For the full-text coding, the author and doctoral student independently reviewed and coded all six articles for final inclusion. The IRR percentage agreement was 96% with a Kappa score of 0.898 or near perfect agreement. Any differences were reviewed and discussed until agreement was reached with a final agreement of 100%.

3 Results

The five studies included in this review utilized three different types of participatory research methodologies. All the studies were published after 2010, demonstrating that the use of participatory methods with autistic youth in mainstream schools is an emerging practice with promising potential. The following sections describe the setting, type of participatory methods used, study focus, and participant demographics including gender and race/ethnicity in addition to common strengths, challenges, and recommendations from each study. See Table 1 for more information about demographic information and Table 2 for study strengths, challenges, and recommendations for participatory research methods.

3.1 Study settings

All five articles selected were conducted in either the United Kingdom or Australia. None of the articles selected were from the United States. One of the studies was in an elementary school setting, three in secondary school/high school settings, and one study did not report the grade level/setting (i.e., Kindergarten through twelfth grade or elementary/middle/secondary school type). All studies were conducted in or at mainstream school settings.

3.2 Participatory method and level of participation

Studies ranged on the continuum of participatory research methods, with 40% utilizing Participant Driven Photo Elicitation (PDPE) also called Photovoice, one using phenomenological participatory design with an advisory panel, and one using a PAR workshop. PDPE or Photovoice is a form of PAR that allows people to record their perspectives of an issue using photos or images that are individually chosen by the participant (Wang, 1999; Suprapto et al., 2020). Those images are then used to gain insight and understanding of the topic from the participants' point of view which allows for power-sharing and exchanging of ideas. Phenomenological participatory design utilizes the philosophical framework of phenomenology to explore the experiences, context, interactions, and processes of individuals in PAR (Frauenberger et al., 2010). The PAR workshop implemented a participatory design that included power-sharing and high participation from autistic youth and their families. No studies specifically indicated the use of CBPR or YPAR in their methodology.

When accessed for the level of participation using Arnstein's Ladder of participation, most articles were at the consultation stage or placation stage of the "tokenistic" group. Lamb et al. (2016),

TABLE 1 Included study characteristics and demographic information.

References	Country	Type of PAR	Study focus	Participants	Grade level	Gender	Race/ethnicity
Danker et al., 2017	Australia	PDPE (Participant Driven Photo Elicitation)	Student perspective of school	10 students	Secondary/High School	All male	Not reported
Danker et al., 2019	Australia	PDPE (Participant Driven Photo Elicitation)	Student perspective of wellbeing	15 students	Secondary/High School	All male	Not reported
Frauenberger et al., 2011	UK	Phenomenological Participatory Design; Advisory Panel	Social skills	2 students *30 neurotypical and 1 undiagnosed	Elementary Schools	All male*	Not reported
Lamb et al., 2016	UK	PDPE (Participant Driven Photo Elicitation)	Student perspective of PE	5 students	Secondary/High School	4 male, 1 female	Not reported
McAllister and Sloan, 2016	UK	Participatory Action Research Workshop	Creating autism friendly school	5 students	Not reported	Not reported	Not reported

The asterisk denotes that the 30 neurotypical students gender was not reported.

McAllister and Sloan (2016), Danker et al. (2017), and Danker et al. (2019), all focused on capturing the perspectives of students rather than including them as collaborators. Frauenberger et al. (2011) was the closest to co-production or partnership as students were engaged in co-designing with autistic students. No included studies allowed for equal power sharing "doing with" as stated in den Houting's model.

3.3 Focus of the studies

Each of the five studies included had a different specific study focus or objective. Three of the five focused on student perspective with Danker et al. (2017) examining the perspective of school, Danker et al. (2019) studying perspectives of wellbeing, and Lamb et al. (2016) observing perspectives of physical education. Each of those studies used the similar PDPE or Photovoice methodologies as described above. Frauenberger et al. (2011) looked at the broad idea of social skills for autistic youth. McAllister and Sloan (2016) were also broad in their review of creating an autism friendly school for autistic youth.

3.4 Demographics

The number of participants included in each study ranged from two to fifteen autistic students. Demographic data from the studies showed that all but one of the thirty-seven participants were male with one study not reporting gender (Lamb et al., 2016). No studies reported or mentioned ethnicity/race and did. Not specifically indicated the level of support needs or communication abilities, beyond general descriptions of accommodations and flexibility in communication styles. This included needing breaks, being explicit in directions, and allowing processing time. There was no discussion of AAC devices or other means of communication (i.e., signing) as most students verbally responded to the prompts provided by researchers. No information related to LGBTQIA + status was mentioned or reported; however, this was not detailed in the table provided for this review.

3.5 Strengths of participatory research

Each of the five studies reported multiple strengths of using participatory research methods with autistic students. Four out of five studies (80%) detailed opportunities for empowerment, increased engagement and feedback, and increased opportunities for individuals to communicate their perspectives or experiences. Other common themes included accessibility, enhanced communication, opportunities for relationship building, increased autonomy, ownership or choice of participants, and the ability to use flexible, creative, or versatile methods. Lamb et al. (2016) specifically mentioned how participatory research gave voice to historically marginalized groups and fostered deep meaningful reflection and connection. Frauenberger et al. (2011) had the most strengths to report ranging from broad ideas about bridging theory to practice to more specifics relating to reducing restrictions on autistic students.

TABLE 2 Included study strengths, challenges and recommendations for PAR.

References	Strengths	Challenges	Recommendations
Danker et al., 2017	• Opportunities for empowerment, • Accessibility, • Development of skills, • Increased engagement and feedback, • Enhanced communication	• Collaboration with teachers, • Outside influence of teachers, • Time, • Flexibility, • Effort, • Resources	• Use with autistic students to promote authentic voices and include disabled perspectives
Danker et al., 2019	• Increased engagement and feedback, • Decreased anxiety of participants, • Enhanced communication, • Increased individual perspectives and experiences	• Collaboration with teachers, • Teachers as "gatekeepers," • Exclusion of those unable to participate, • Lack of adherence to method due to locations	• Identify advocates within organization that are invested to reduce gatekeeping • Share findings with teachers and other partners • Collaborate with teachers and parents to garner more support • Provide examples and non-examples of photos
Frauenberger et al., 2011	• Bridge theory to practice, • Opportunities for empowerment, • Increased acceptance/ownership and success of design, • Increased individual perspectives and experiences, • Less restrictive, • Creativity, • Opportunities for student empowerment and control, • Accessibility, • Versatile, • Increased relationship building	• Outcomes can be less quantifiable, • Arguments against validity, • Issues with groups leading to less participants, • Time, • Mismatch in communication between researchers and students, • Building relationships, • Communicating information to partners	• Build trust and manage expectations • Keep inclusion and ethics in mind around development of goals and outcomes • Provide options for low- and high-tech communication • Consider monotropic preferences and preferred ways of communicating • Be conscious of power dynamic. Give students control and choice • Consider theory and theoretical perspective that shape design, results, and implementation • Use pragmatic approach to difficulties with rigor and validity
Lamb et al., 2016	• Increased communication and meaningful conversations, • Foster deep reflection, • Gave voice to historically marginalized groups	• Understanding that photos are personal and up for interpretation, • Accommodations for students who do not want to verbally share • Relationships with teacher	• None provided related to method
McAllister and Sloan, 2016	• Increased choice, • Increased engagement and feedback, • Opportunities for empowerment, • Enhanced communication, • Increased individual perspectives	• None reported	• Allow options for participants to opt out throughout process • Start off slow and make people feel welcome and part of group • Allow for opportunities for anonymous submissions of information • Provide reference sheet with questions asked/posed to group

3.6 Barriers to using participatory research

Four out of the five articles included reported challenges to participatory methods with autistic students. Three out of the five studies detailed that collaboration and communication with the teachers proved to be a barrier to success. Danker et al. (2019) detailed how teachers proved to be "gatekeepers" of information that influenced the results of the study. Other common challenges reported were time, issues with communication, resources, issues with location or groups, providing accommodations for students, and communicating information to partners. Frauenberger et al. (2011) noted that participatory methodologies, especially those utilizing qualitative data collection, can create outcomes that are less quantifiable and bring into question ideas of validity due to the nuance of findings. It is important to note this observation can be true to qualitative research in general rather than being a specific barrier to participatory research with Autistic youth.

3.7 Recommendations

Four out of the five studies included recommendations related to participatory methods with autistic youth. Frauenberger et al. (2011) provided the most detailed list of recommendations, which included building trust and managing expectations, considering monotropic[3] preferences and ways of communicating, being conscious of power dynamics in the study, and considering how the theory and theoretical perspective shape the design, results, and implementation. The other studies included calls for collaborating with teachers and community partners to share findings, support the projects, and promote authentic autistic voices. Other recommendations were specific to participation and organization of studies with McAllister and Sloan (2016) providing examples of how students can opt out of participating or submit responses anonymously and Danker et al. (2019) describing the need for examples and non-examples to promote clarity of work.

4 Discussion

This scoping review aimed to focus broadly on the use of participatory research methods with autistic students in K-12 mainstream public school settings. The goal was to identify participatory research methods implementation in K-12 mainstream public schools by answering questions about what type of participatory methods are used, the level of participation, common strengths, challenges, and recommendations provided by researchers, and information around reported demographic data. As previously stated, participatory methodologies are an emerging trend in autism research with autistic participants and researchers reporting positive and socially valid outcomes. However, this research is not commonly being conducted in mainstream public schools with disabled or autistic youth, leading to questions of equity and access for these populations. The conclusions of this review provide evidence that participatory research methods in K-12 mainstream public school settings with autistic youth are feasible and more effort must be put into implementing participatory research with students with intersecting marginalized identities.

4.1 Countries included

The present review examined five studies that implemented participatory methodologies with a total of 37 autistic students in K-12 public school settings located in the United Kingdom, and Australia. Australia and the UK have made an impact in the field of participatory research methods in autism research with organizations like Autism CRC in Australia providing "Participatory and Inclusive Autism Research Practice Guides," the Participatory Autism Research Collective (PARC) led by Dr. Damian Milton, and the University of Edinburgh's Salvesen Mindroom Research Centre's Learning About Neurodiversity in School (LEANS) project. These centers and organizations provide robust training, information, and support for involving autistic individuals in research through participatory and neuroinclusive research methodologies. While the United States has organizations like the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) and the Autistic Self Advocacy Network (ASAN), a recent review completed by Anyon et al. (2018) shows how disability is often omitted when describing the implementation of youth participatory research in the United States. Moreover, a review of K-12 student voice research from the past decade shows that students with disabilities are rarely included in the literature (Gonzalez et al., 2017). These findings display the large gap in including disabled and autistic youth perspectives in research in the United States. The field of participatory research methods with youth is an emerging practice in the U.S. that could provide increased opportunities for meaningful student voice and choice from autistic youth in school settings. More needs to be done to ensure that autistic student voices are included in research in mainstream schools, rather than relying on information solely from their neurotypical peers.

4.2 Level of participation

The majority of articles in this review focused on capturing the experiences, perceptions, and thoughts of autistic youth rather than including them as co-producers or collaborators in the overall research process. This firmly places the studies in the consultation type of participatory research as described by Arnstein (1969), where autistic students were able to provide feedback and suggestions based on their lived experiences, but the researchers maintained power over decision-making, research questions, methods, and goals of the study. As mentioned by den Houting et al. (2021), consulting can be a useful method for researchers who are first learning how to complete participatory research studies or when community members do not have

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[3] Monotropism, as originally defined by Murray et al. (2005), is the theory that autistic minds can focus their attention on a smaller range of interests with a higher level of intensity. This can lead to experiences of hyperfocus where autistic individuals can experience a flow state as they are highly engaged in activity or interest, making it difficult to switch tasks or reallocate attention.

experience or time to be fully involved in the process (pg. 12). Utilizing participatory methods in mainstream schools with autistic youth is a beginning practice, as evidenced by the limited number of studies included in this scoping review. As researchers learn more about how to effectively work with autistic youth in mainstream school settings, there may be an increase in funding and research opportunities that see autistic youth as partners in the process rather than merely participants. Frauenberger et al. (2011) touched on the co-creation of research in their study and was the closest to co-production. They did not include autistic students at the beginning of the research process, but asked students, autistic and non-autistic, to co-design technology related to social skills interventions. By doing so the author noted that "it is clear that the effort required... is far outweighed by the benefits of co-creation and the increased likelihood of a resulting end product that is useful, usable, and desirable" (pg. 26). This is supported by participatory research done with autistic adults which has shown outcomes that higher levels contextual fit and relevance to the autism community (Fletcher-Watson et al., 2019; Forsythe et al., 2019; Nicolaidis et al., 2019; Warner et al., 2019; Ashworth et al., 2020; Gillespie-Lynch et al., 2020; Pellicano, 2020).

4.3 Consideration of the double empathy problem

A variety of experiences of including autistic students were present in the reported strengths, challenges, and recommendations from the five included studies. The most reported strengths were related to opportunities for empowerment, increased engagement and feedback, and increased opportunities for individuals to communicate their perspectives or experiences. Each of the studies noted that participatory research methods create meaningful opportunities for students to share their voices and perspectives while allowing students to have ownership and autonomy over the study focus. Frauenberger et al. (2011) acknowledged in the recommendations that autistic communication can look and feel different than what is "traditional" in research. For example, "traditional" can rely solely on neurotypical communication styles (i.e., verbal responses) and disregard autistic individuals who use AAC devices, stimming, and echolalia to share their thoughts, feelings, or ideas (Sterponi and Shankey, 2014; Kapp et al., 2019; Cummins et al., 2020; Howard and Sedgewick, 2021). For instance, autistic adults have stated that stimming can allow them to share both positive and negative "uncontainable emotions" (Kapp et al., 2019, pg. 1786), and can be seen as an integral part of autistic identity and culture (Felepchuk, 2021). This is seen in the video titled "In My Language" by advocate Mel Baggs as they describe how we force autistic folks to use normative ways of communication but rarely take time to understand a person's way of communicating. Rather, we intervene or try to force these "traditional" neuronormative communication styles on autistic people without regard for autonomy, preference, or choice (Catala et al., 2021). Frauenberger et al. (2011) goes on to describe how if researchers allowed for monotropic preferences and recognized preferred ways of communicating, there would be increased instances of meaningful and honest conversations between researchers and autistic students. Deeper conversations with autistic students could impact research outcomes, validity, and generalizability. These types of considerations are necessary when thinking about what communication and participation mean for autistic students in research, especially for those with high levels of support needs or those using AAC devices and strategies. Studies have shown that autistic individuals feel more comfortable, at ease, and can communicate more freely with those with the same neurotype (Crompton et al., 2020a,b). Mutual disconnect and frustration can happen when autistic individuals are asked to communicate with neurotypical people, in a phenomenon called the double empathy problem (Milton, 2012; Mitchell et al., 2021). As described originally by Milton (2012), the double empathy problem states that the onus for miscommunication does not solely lie on the autistic person. Rather, it is like a bad game of Telephone where both parties, autistic and non-autistic, are misinterpreting and misunderstanding the communicational cues of each other. This tension can lead to some of the challenges explained in the studies, including issues with communicating with students, teachers, and community partners. For example, researchers may not be able to misinterpret what an autistic student is saying about their experience in school due to difficulty understanding the way students are describing their stories, or teachers may see a student stimming and see it as not paying attention when the stimming allows the student to focus on the directions provided by the teacher.

4.4 Working with teachers

Communication and collaboration with teachers proved to be a common challenge for the five studies in this review. Danker et al. (2019) labeled teachers as "gatekeepers" who influenced results and information from students. Lamb et al. (2016) wrote that building relationships with the teachers was difficult and they would have benefited from their insight when working with students. Frauenberger et al. (2011) again provides recommendations about the need to build trust and manage expectations with community partners, like teachers. Danker et al. (2019) also propose a set of solutions that include identifying advocates within the organization to reduce gatekeeping, collaborating early and often with teachers, and sharing findings with teachers to improve buy-in. These recommendations signal that participatory methods in schools need to think about all those in the environment, not just the autistic students in the space. Each person within the school community must be given the opportunity to engage in this work, while still creating chances for autistic students to be the focus.

No autistic educators were mentioned in the five included articles; however, this could be due to fear of disclosing, stigma, or fear of losing their job (Wood, 2023). It would be interesting to see how dynamics and procedures would shift with the clear inclusion of autistic or disabled educators. In a survey completed Wood and Happé (2020), results indicate that autistic students benefit from autistic educators as they serve as a role model and advocate. In a review of autistic teachers lived experiences, StEvens (2022) found teachers with disabilities foster inclusion and can counteract deficit narratives toward disability, which can be useful for neurotypical and autistic students. Further research could delve into the interaction between autistic educators and autistic students to see how communication and collaboration would be impacted. Additionally, it could be fascinating to see if the "gatekeeping" would occur as often with autistic educators as compared to those who identify as non-autistic.

5 Limitations and recommendations for future research

There are several limitations of this study that are worth mentioning. First, the articles included in this review were restricted to peer-reviewed to provide a clear understanding of what was currently happening in the peer-reviewed literature. Dissertations like Snow (2011) and Ajodhia-Andrews (2015) met other aspects of the review, but were not included for this reason. The exclusion of gray literature may create a less balanced and comprehensive picture (Paez, 2017), Procedures, strengths, and recommendations from these findings could be used in future reviews to create a more robust literature base for participatory research methods in public or mainstream K-12 schools. Future research should include white papers, dissertations, and other sources of information to take a broader look at the inclusion of autistic students in participatory methods in public schools.

5.1 Lack of global perspective

Second, the review was limited to only articles published in English due to the first author only speaking and reading English. This may have excluded articles from researchers in countries that do not speak English and contributes to the marginalization of researchers who are not Western, Educated, Industrialized, Rich, and Democratic (WEIRD). Autism research is primarily completed in WEIRD countries, creating a large gap in understanding the autistic perspective on a global level (Jones and Mandell, 2020). Kassous (2023) describes this large widening research gap in the Global South due to lack of funding, lack of opportunity, and lack of access to Western research. The Global South refers to countries outside of Europe and North America, including Latin America, Asia, Africa, and Oceania (Dados and Connell, 2012). This affects the amount of research coming from these regions, which stifles knowledge creation based on diverse and different contexts, cultures, and lived experiences. Future reviews should include various languages to reduce exclusion and promote the lived experience and culture of autistics beyond predominately white countries. Moreover, reviews specifically focusing on research from the Global South and other overlooked countries would bring to light studies that are often discounted or underutilized and attune to some of the intersectionality that students can bring.

5.2 Gap in gender representation

Third, just like in most literature about autistic youth, the participants in the five studies were mostly male, with only one female reported (Loomes et al., 2017). As Lamb et al. (2016) did not report the gender of the autistic students, this number could be higher. However, the number does highlight the gap in identifying autistic females also called the "leak" in the recruitment to research pipeline (D'Mello et al., 2022). Researchers have postulated that the underrepresentation of autistic females could be due to clinical bias of male presentations of autism, confirmatory diagnostic measures, camouflaging of autistic traits by females, and misinterpretation of female social behavior (Kirkovski et al., 2013; Jamison et al., 2017; Hull et al., 2020; D'Mello et al., 2022). This gender imbalance between male and female autistics within the larger literature, and this review, could impact the perceived challenges, strengths, and recommendations from researchers around participatory methods. Researchers may play into what Botha and Gillespie-Lynch describe as the "pervasive and persisting whiteness, cisgender, middle-class, straight maleness" narrative that creates stereotypes of who autistic people are in the world and how they are perceived (pg. 96). Moreover, recent surveys uncover that a large number of autistic individuals in Western countries identify as LGBTQIA + and may not conform to binary gender norms (George and Stokes, 2018; Hillier et al., 2020; Koffer Miller et al., 2022; Mallipeddi and VanDaalen, 2022; McAuliffe et al., 2022). This further creates opportunities for disproportionate identification of autistic youth and adults who could benefit from support and positive identity building. Future research should seek to deliberately collaborate and recruit from gender-diverse groups and spaces to be more representative of the autistic community's multiple gender identities. Additionally, researchers should seek out counter-narratives of those beyond the traditional middle-class white male autistic boy narrative to counteract the stereotypes perpetuated by media and research.

5.3 Reporting and including intersecting identities

Fourth, the racial and ethnic identities of the autistic students in this review were not reported or discussed in any of the studies. This lack of demographic information is problematic as it supports the continued marginalization of disabled individuals with intersecting identities. Data shows that students who identify as Black, Latino/a/x, Indigenous, and Pacific Islander are less likely to receive autism diagnoses and more likely to receive identifications of learning disabilities, emotional disturbance, or mental health challenges (Mandell et al., 2009; Durkin et al., 2017; Wiggins et al., 2020). As these children grow up, these mislabels and diagnoses follow them making it increasing difficult to access autism diagnoses later in life (Wiggins et al., 2020; Maye et al., 2021). The lack of supports can also lead to mental health needs, lack of positive identity creation, a weakened sense of belonging, and increased minority stress (Milton and Sims, 2016; Botha and Frost, 2020; Mitchell et al., 2021; Malone et al., 2022). Malone et al. (2022) describes how Black autistic individuals have been overlooked, neglected, and excluded from autism research leading to systemic disparities in services and supports. They call for increased partnerships with Black autistic adults, for researchers to inspect their own biases, values, and experiences, and the need for cultural reciprocity in research methods. The sentiment of reciprocity, intersectionality, and intentional collaboration with historically unrepresented intersectional autistic groups has been shared by other researchers in a 2022 edition of Autism in

Adulthood (Ames et al., 2022; Cohen et al., 2022; Davis et al., 2022; Doyle et al., 2022; Lopez, 2022; Lopez et al., 2022). However, these articles mainly provide recommendations for autistic adults, further showcasing that continued work must be done to include autistic youth in the conversation. Future research, at minimum, must report the identities of their participants or collaborators. Including this information can lead to more inclusive research that can have an impact on policy and practice for autistic youth with intersecting identities and who experience marginalization and erasure.

5.4 Heterogeneity of autism

Fifth, autistic youth represent a wide constellation of individuals with a variety of support needs, strengths, and areas of growth. This includes autistic individuals who are speaking, non-speaking, have co-occurring mental health needs or co-occurring disabilities, require at-home care, or are more independent in day-to-day life. Autism is not a linear range of abilities, but a profile of features and characteristics that can fluctuate depending on the environment, experiences of trauma, and individual mental health, among other factors (Bury et al., 2020; Botha et al., 2021; Faccini and Allely, 2021; Phung et al., 2021). The articles in this review may not represent all autistic students, as communication and level of support needs were not reported in demographic information. Research has shown that autistic individuals with intellectual disabilities, those with high levels of support needs, and those who are non-speaking are often excluded from participatory methods and research (Capozzi et al., 2019; Nicolaidis et al., 2020; Bastable et al., 2021; Maye et al., 2021). More studies need to be conducted that specifically state that they are working alongside these marginalized populations within the autistic community to promote participation across the range of autistic experiences. This can include creating more accessible and inclusive research opportunities for autistic participants or creating intentional spaces for autistic people with co-occurring needs and disabilities to be research partners.

5.5 Need for robust coding

Lastly, the intercoder agreement was not completed for all articles in all stages due to time and resource commitments by both the first author and second author. The intercoder agreement did meet standard criteria; however, a more complete review could have been useful to strengthen the findings. Additional reviews utilizing more robust methods can be completed in the future to ensure higher levels of agreement and continue to reduce the gap in understanding the research questions posed. Moreover, future reviews may include more than two coding individuals to allow for triangulation of findings and coding agreements.

5.6 Implications for practice

As seen in the included studies, practitioners are key partners that can facilitate or impede participatory research methods with autistic youth in public or mainstream schools. Practitioners, like educators and school staff, may not be aware of how to be involved and contribute to the research, while still maintaining their status with students. They also may subscribe to the medical model of disability that views autism as a deficiency residing within the individual that must be fixed or cured (Shyman, 2016). This can reinforce ableist and discriminatory practices, that undermine the purpose of participatory designs and contribute to issues of collaboration and communication that were present in the studies. To prevent this from happening, a clear list of expectations needs to be co-created with key partners to ensure that aspects of participatory research, like power sharing and shared decision-making, are supported throughout projects.

This could be accomplished by extending the work of Nicolaidis et al. (2019) and others who provide recommendations for how to include autistic adults as co-researchers and participants to students in K-12 school settings. Such guidelines would have explicit expectations for the participation of autistic youth, practitioners (i.e., educators, related service providers, and school staff), and families in each step of the research process. Guidelines for including autistic students in research would need to be cognizant of the spectrum of neurocognitive abilities, communication and language differences, historically marginalized identities, and preferences of youth populations. Additionally, the guidelines could incorporate the YPAR literature that centers on youth knowledge, voice, and partnership (Shamrova and Cummings, 2017). This would allow autistic students to remain key partners in the research design and process but leverage the skills of those in schools to promote their ideas and perspectives.

To further leverage the skills of practitioners and decrease issues with communication, researchers could provide research training to educators and service providers who themselves would like to conduct participatory research methods or are involved in participatory research with autistic youth. While Chown et al. (2023) have found that common ground may not be found between individuals with opposing beliefs on autism due to what they call the autism worldview dilemma, there is hope in providing training directly to autistic individuals and practitioners on research practices. Research trainings have been co-created by autistic and neurodivergent researchers and advocates to better inform autistic participants and collaborators of what to expect in participatory research. These trainings include Learning About Research[4] led by Dr. Jackie Ryan and Dr. Sue Fletcher Watson and Autism Intervention Research Network on Physical Health Research Basics Training. Each training has open-access materials and manuals that can be used to empower autistic collaborators and provide information to practitioners on how to meaningfully complete community-based participatory research or other participatory research methodologies.

Future iterations of these trainings could incorporate the findings from this review to tailor participatory research methods to K-12 mainstream school settings. Specific attention could go toward ways to sustainably develop participatory research

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[4] https://dart.ed.ac.uk/research/learning-about-research/

alongside autistic students and teachers to reduce instances of gatekeeping and to bring research closer to YPAR or co-creation of the overall process. Additionally, training could highlight the importance of providing support to students with diverse racial and gender identities, communication needs, and cognitive needs to ensure that research is inclusive and engaging to all students. Concrete examples of this could include specific courses on universal design, positionality, intersectionality, the double empathy problem, the theory of monotropism, ways to incorporate AAC into the classroom, and more. This would allow autistic students and school staff to work together as partners to promote the trust, community-building, and power-sharing necessary for many of the participatory research methods discussed in this review.

6 Conclusion

Participatory research methodologies are a budding practice that is not only useful in amplifying autistic perspectives and voices but can provide opportunities to understand an individual's values, needs, and culture. Autistic youth, especially those with intersecting identities, should be recognized as key partners in participatory methods in K-12 public schools instead of being excluded from the conversation. Autism research is gaining momentum toward accepting, acknowledging, and honoring the lived experiences of autistic participants, but there is more that needs to be done to ensure the continued safety of the autistic community. This safety must extend to autistic students in mainstream schools and those engaged in participatory research. The findings from this review can be a starting point for future research to create increased opportunities for autistic students to be included in participatory research in their schools and ways to work collaboratively with the school community to reduce harm and provide spaces that affirm, welcome, and honor autistic student perspectives.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

AN: Conceptualization, Formal analysis, Investigation, Methodology, Writing—original draft, Writing—review and editing. SQ: Formal analysis, Investigation, Writing—review and editing. RN: Writing—review and editing.

Funding

The author(s) declare that no financial support was received for the research, authorship, and/or publication of this article.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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