

Gathering autistic children's views on their educational experiences: A systematic review of methods

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Abstract

Children should be heard on matters that impact their educational lives. However, meaningfully engaging autistic children can be difficult for researchers and policymakers. Therefore, this systematic review aimed to summarise methods used to gather the views of autistic¹ children on their primary educational experiences. Database searches identified 34 peer-reviewed articles, which met the inclusion criteria. Analyses showed that semi-structured interviews were the most frequently used practice, and a variety of visual and technology-based activities were used as part of the interviews to support participants' expression. A key consideration for future research and practice is that as researchers, it is our responsibility to co-produce methods with autistic children, to allow them to express their views, both in research and real life.

Keywords: Autism, Children, Views, Systematic Review, Best Methods

¹ The identity-first term 'autistic' is used throughout this study based on internationally reported preferences from autistic adults (e.g., Keating et al., 2023).

Plain Language Summary

Children deserve to be listened to when it comes to their educational experiences. Therefore, consideration should be given to how best to facilitate autistic children to express themselves. The purpose of this review was to summarise the methods that have been used in previous studies and highlight good practice. The results of the review showed that most studies use semi-structured interviews. Many of these studies also used visual and technology-based activities to support the children to express themselves during the interviews (e.g., photographs, scrapbooking, digital storytelling, drawing). However, only two studies consulted with the children ahead of time to determine what they thought the best way would be to allow them to express their views.

Introduction

The advent of the internet led to significant growth in the autistic self-advocacy movement, providing an accessible, text-based means of communication, which empowered many autistic people to connect and share ideas (Dekker, 2020). The neurodiversity paradigm emerged from this self-advocacy movement and its core assertion is that variation in human development and functioning reflects normal variation in genetic expression (Leadbitter et al., 2021, p.2). The impact of this paradigm is becoming evident (Leadbitter et al., 2021), with some recent research seeking to identify key priorities of the adult autistic community (e.g., Pellicano et al., 2014; Roche et al., 2021) and elevate the perspectives of those with first-hand lived experience of the research topic.

However, despite progress, the effect of ableism is persistent. Ableism is any bias or discrimination directed towards people living with disabilities and subtly or directly implies that these people are inferior to their non-disabled counterparts (Smith, n.d.). Ableism also intersects with other systems of prejudice and discrimination, including ageism. These types of prejudices and associated limiting beliefs are part of the reason that much research in autism is still carried out on autistic children, rather than with them, and focuses on causes of autism, cures for autism and interventions to remedy autistic traits, instead of improving their quality of life (Chown et al., 2017).

The United Nations Convention on the Rights of the Child (United Nations, 1989) sets out the requirement that children and young people be heard on matters that impact their lives, including their educational lives, and that their views are not simply listened to but are given due weight (UN Committee on the Rights of the Child, 2009). It is also widely acknowledged that research capturing the views and opinions of children and young people is of significant value and importance (Graham et al., 2013). However, the major challenge faced by researchers and stakeholders is how to facilitate meaningful engagement with

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children and young people, on topics that affect their daily lives, while operating within time and resource constraints (Flynn, 2017).

This dilemma is exacerbated when it comes to research involving autistic children and young people. Autistic expression, understanding and social interaction often differs from the non-autistic, neuromajority norms (American Psychiatric Association, 2013) and it is estimated that approximately one-third of autistic children and adults are minimally speaking or non-speaking, relying instead on a small number of utterances or alternative communication systems (DiStefano et al., 2016; Jaswal et al., 2020). Therefore, where research solely relies on the spoken word, the voices of many autistic children may go unheard because of the perceived challenges associated with engaging those with communication differences (Dee-Price et al., 2021). Given the significant role that education plays in the lives of children and young people, the lived experiences of autistic children and young people need to be readily available to educators and policy makers, to establish a clear sense of what constitutes effective, meaningful, and enjoyable educational experiences for this group (Billington, 2006; Hebron & Humphrey, 2014). So, how do researchers ensure that communication differences are acknowledged and facilitated to ensure that autistic voices are “authentically rather than tokenistically heard” (Flynn, 2017, p.28)?

Two systematic reviews, which investigated how the views of autistic children and young people can be gathered, have been published since 2018 (Fayette & Bond, 2018; Tyrrell & Woods, 2020). Fayette and Bond (2018) reviewed the qualitative research methods used to gather the views of young people, aged 11 years and older, about their educational experience. While this review gave insight into how researchers have engaged autistic young people in educational research, the overarching finding was that this type of research is still in its infancy; only 12 studies met the inclusion criteria and only four of these were judged to have high methodological quality. In their subsequent review, Tyrrell and Woods (2020)

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sought to extend the findings of Fayette and Bond (2018) by focusing on quantitative and qualitative research, as well as studies involving children younger than 11 years. Like Fayette and Bond (2018), Tyrrell and Woods (2020) found that semi-structured interviews (SSIs) were frequently used to gather views and opinions and could be successful when accompanied by visual supports and suitable changes to abstract questions. However, there was tentative evidence that SSIs are better suited to autistic participants, who are older and more academically proficient.

In their review, Tyrrell and Woods (2020) focused on school-age children and young people who they categorised as being “at the ‘high functioning’ end of the autistic spectrum” (p.379). Their rationale for this was that “the methods used to gather the views of those towards the ‘lower functioning’ end successfully may be significantly different, particularly for participants with little speech” (p.379). Given that Fayette and Bond (2018) focused on autistic young people, aged 11 years and older and Tyrrell and Woods (2020) focused on children and young people, at the ‘high functioning’ end of the autistic spectrum, the current review aimed to address a gap in the literature pertaining to the methods used to gather the views of primary-age autistic children (4-12 years), regardless of verbal or academic ability. In addition, the two previous reviews ended their literature searches in 2016, so the current view extended the literature search by analysing studies published up until October 2020 and included two databases not previously searched by Fayette and Bond (2018) or Tyrrell and Woods (2020). Through this analysis, the review aimed to answer the following research questions:

1. What methods have been used in research designed to gather the views of autistic children’s views, regardless of verbal or academic ability, on their primary education experience (from 4-12 years)?
2. What key factors should be considered when carrying out this type of research?

Method

Search Procedure

In October 2020, comprehensive literature searches were conducted across four electronic databases: 1) Education Research Complete (ERC); 2) SAGE Research Methods; 3) Education Resources Information Centre (ERIC), and 4) PsycINFO. The search strategy employed is as follows: (child OR pupil OR learner OR student) AND (voice OR experience OR attitude OR perspective OR view or belief) AND (autis* OR autism OR ASD OR Asperger's syndrome) AND (primary school OR elementary school OR primary education OR elementary education).

Peer-reviewed articles, published in the English language, between January 2004 and October 2020, were included. This covers the period immediately before and after the international adoption of the United Nations Convention on the Rights of Persons with Disabilities (2006). Included articles were also restricted to those studies that:

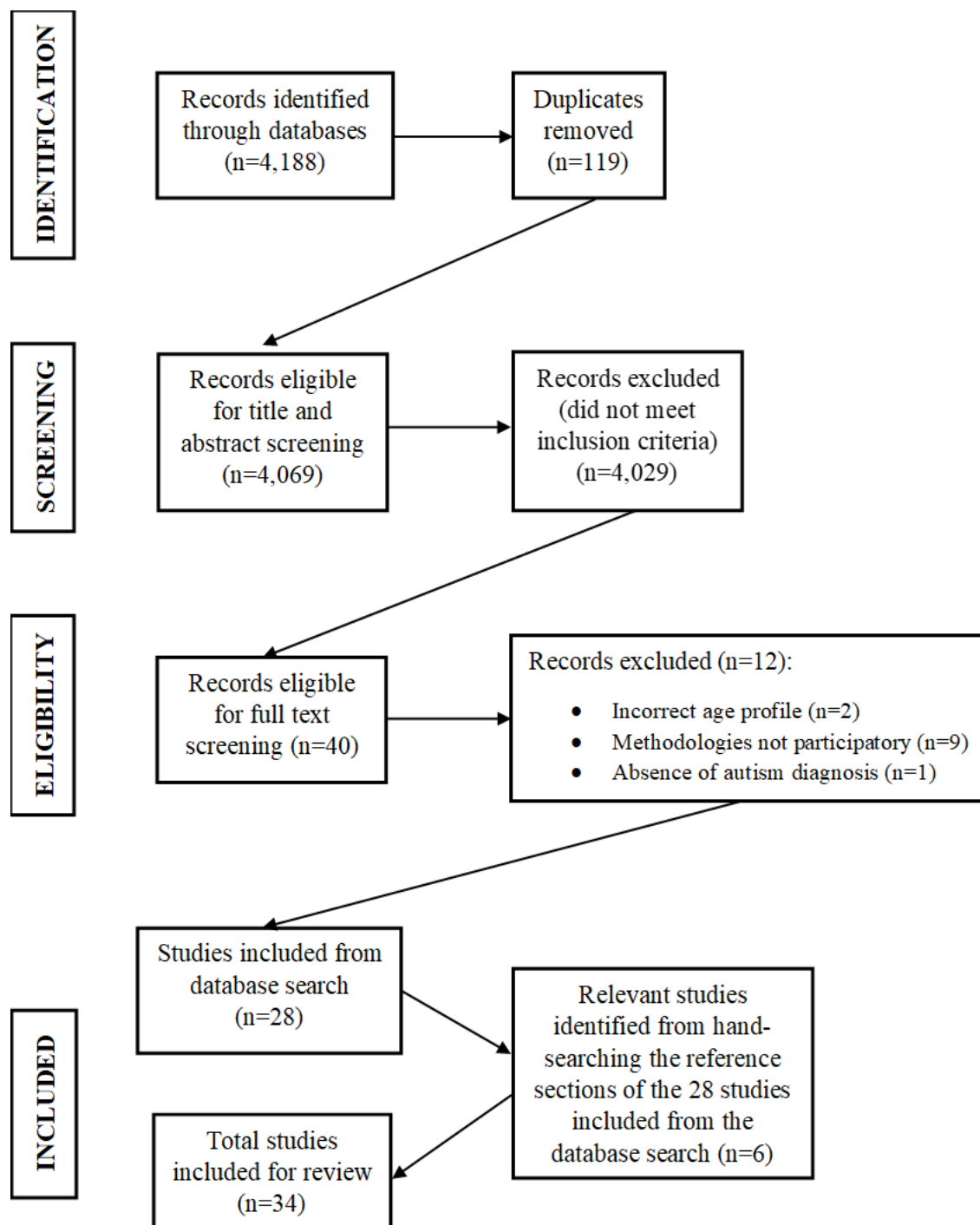
- Involved at least one autistic child of primary school going age (4-12 years). Articles involving both autistic and non-autistic children were included. Studies that included participants of primary school age, as well as participants older than this (i.e., 12+ years), were also included.
- Used methods that enabled autistic children to express their views on their educational experiences. Autistic children must have actively provided information on their own experiences, as part of the research.

Comprehensive searches identified 4188 articles, with 4069 remaining after duplicates were removed. Title and abstract screening eliminated an additional 4024 studies. The remaining 45 studies underwent full-text screening, with 28 of these studies meeting the inclusion criteria for this review. The reference sections of these 28 articles were manually

searched, resulting in a further six studies to be included in the current review (i.e., a total of 34 articles). The screening process is depicted in Figure 1.

Figure 1

Flowchart of study selection process



Data Extraction

Data were extracted onto a single coding sheet (see ‘Supplementary Material’) as follows: 1) year of publication; 2) location of study; 3) participant characteristics (number, age, gender, diagnosis); 4) research objectives; 5) methods used to gather the autistic children’s views, 6) consultation with key stakeholders during research process (e.g., children themselves, parents, educators), and 7) consideration of children’s preferred communication mode. For those studies that provided sufficient information, only data pertaining to the autistic children, aged 4-12 years, was extracted. However, for studies where this was not possible, procedures were consistent across all participants.

Quality Appraisal

To systematically assess the trustworthiness and relevance of the included articles, the Weight of Evidence Framework (Gough, 2007) was applied. This tool, specifically designed to assess the quality of qualitative, quantitative and mixed-methods studies, consists of three distinct aspects: 1) research quality (Weight of Evidence A – WoE A); 2) the appropriateness of the evidence (WoE B), and 3) the appropriateness of the research focus (WoE C). Scores across all three aspects combine to produce an overall assessment of study quality (WoE D). In this review, the Weight of Evidence Framework (Gough, 2007) was applied by primarily focusing on the methodology of each study, as per the research questions.

Research quality of included studies (WoE A) was assessed using the established framework developed by (Spencer et al., 2003). Studies received scores of 1 (full alignment), 0.5 (partial alignment) and 0 (no alignment) for each criterion appraising research quality (WoE A) and were rated as low quality (scored 0-6), medium quality (scored 6.5-12) and high quality (scored 12.5-18), accordingly. Given the aims of this review, the research

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evidence (WoE B) aspect was assessed according to the following criteria: 1) Transparency in communicating methods; 2) appraisal of the methods used (advantages and limitations); 3) communication of findings, and 4) detail provided on participant sample. The appropriateness of the research focus (WoE C) was appraised according to 1) the ethical considerations given designing the study, and 2) the relevancy of the data collected and resulting findings to the research focus. Studies received scores of 1 (full alignment across both criteria), 0.5 (full alignment for one criterion) and 0 (no alignment for both criteria) across both criteria assessing the appropriateness of the research focus (WoE C). Studies were then rated as low (scored 0), medium (0.5) or high (1), accordingly. Finally, ratings for WoE A, WoE B and WoE C were combined and averaged to produce an overall assessment for study quality (WoE D).

Synthesis of Results

Extracted data were summarised as follows: 1) autistic participant characteristics; 2) research methods used to gather autistic children's views; 3) securing assent, and 4) consultation with stakeholders during the research process.

Reliability

A second rater independently 1) evaluated whether the included studies met the inclusion criteria, 2) extracted data from 12 of the 34 (35%) included studies, and 3) implemented the quality appraisal protocol on these 12 studies. Reliability for 1) and 2) was calculated by dividing the number of agreements by the number of disagreements and multiplying by 100. Interrater agreement was 100% for 1) and 2). A Cohen's kappa interrater reliability score of 0.65 (or 75%) was achieved following the independent quality appraisal conducted by the lead author and second rater on 12 studies. Disagreements were resolved by consensus. Cohen's kappa of 0.65 indicates a substantial level of agreement (McHugh, 2012)

and provided confidence in the lead author's implementation of the quality appraisal framework.

Results

Quality Appraisal

Table 1 shows that of the 34 studies included in this review, 25 were characterised as high quality overall (WoE D), eight were deemed to be of medium quality (Altomare et al., 2017; Hsu & Teoh, 2017; Humphrey & Symes, 2010; Turner et al., 2017; Whalon & Hart, 2011; Wood, 2020; Wu et al., 2019; Yi & Siu, 2020) and one study was classified as low overall quality (Carnahan, 2006). Research quality (WoE A) was high across 31 of the 34 studies, medium across two studies (Wu et al., 2019; Wood, 2020) and low for one study (Carnahan, 2006). Ratings for the appropriateness of research evidence (WoE B) and research focus (WoE C) were substantially more mixed, with 18 studies rated as high for WoE B and 14 for WoE C. Apart from the Carnahan (2006) study, all remaining studies received a medium rating on WoE B and WoE C, respectively. Given its quality rating and the limited procedural information provided, the Carnahan (2006) study was deemed unsuitable for inclusion in the subsequent data analysis phase of this review. This left 33 studies for further analysis.

Table 1

Summary of methods used and quality appraisal across included studies (n=34)

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Study	WoE A	WoE B	WoE C	WoE D
Altomare, McCrimmon, Cappadocia, Weiss, Beran & Smith-Demers (2017)	High	Medium	Medium	Medium
Barrow & Hannah (2012)	High	Medium	High	High
Beresford, Tozer, Rabiee & Sloper (2004)	High	High	Medium	High
Bradley & Male (2017)	High	Medium/High	Medium/High	High
Brede, Remington, Kenny & Warren (2017)	High	Medium	High	High
Calder, Hill & Pellicano (2012)	High	Medium	High	High
Carnahan (2006)	Low	Low	Low/Medium	Low
Conn, Lewis & Matthews (2020)	High	Medium	High	High
Croydon, Remington, Kenny & Pellicano (2019)	High	Medium	High	High
Daniel & Billingsley (2010)	High	High	Medium	High
Dickerson (2012)	High	High	Medium	High
Ezzamel & Bond (2017)	High	High	Medium	High
Foulder-Hughes & Prior (2014)	High	High	Medium	High
Goodall (2018)	High	Medium	High	High
Harrington, Foster, Rodger & Ashburner (2013)	High	High	High	High
Hebron & Bond (2017)	High	High	Medium	High
Holt, Bowlby & Lea (2017)	High	High	Medium	High
Hsu & Teoh (2017)	High	Medium	Medium	Medium
Humphrey & Symes (2010)	High	Medium	Medium	Medium
Lindblom (2017)	High	High	Medium	High
Moyse & Porter (2015)	High	High	High	High

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Parsons, Ivil, Kovshoff & Karakosta (2020)	High	High	Medium	High
Peters, Forlin, McInerney & Maclean (2013)	High	High	High	High
Potter (2015)	High	High	High	High
Preece & Jordan (2010)	High	High	High	High
Ronksley-Pavia, Grootenboer & Pendergast, (2019).	High	High	High	High
Turner, Remington & Hill (2017)	High	Medium	Medium	Medium
Ware, Ohrt & Swank (2012)	High	High	Medium	High
Whanlon & Hart (2011)	High	Medium	Medium	Medium
Winstone, Huntington, Goldsack, Kyrrou & Millward (2014)	High	High	High	High
Wood (2020)	Medium	Medium	Medium	Medium
Wu, Lo and Tsai (2019)	Medium	Medium	Medium	Medium
Yi & Siu (2020)	High	Medium	Medium	Medium
Zilli, Parsons & Kovshoff (2020)	High	High	High	High

Autistic Participants' Characteristics

In total, 387 children participated in the 33 studies remaining in this review and as per the inclusion criteria, at least one autistic child, of primary school age, participated in each of these studies. Analyses showed that 312 of the 387 children had an autism diagnosis (81%) and the number of autistic participants in the studies ranged from 1 to 38. Thirteen of the included studies focused exclusively on children aged 4-12 years. Nineteen of the twenty remaining studies included participants under and over 12 years of age, and the final study did not specify ages (Yi & Siu, 2020). However, it was possible to ascertain that participants in this study fell inside the desired age range, given that the setting was described as a mainstream primary school in Hong Kong.

Twenty-nine studies provided information on the gender of the autistic children; 17 studies included boys and girls, 10 studies included boys only, and 2 studies included girls only. Four studies did not provide any information on the gender of participating children (Barrow & Hannah, 2012; Beresford et al., 2004; Wood, 2008; Yi and Siu, 2020). Information on the autistic children's educational placements were available in 27 studies, with settings including special classes, special schools, and mainstream classes.

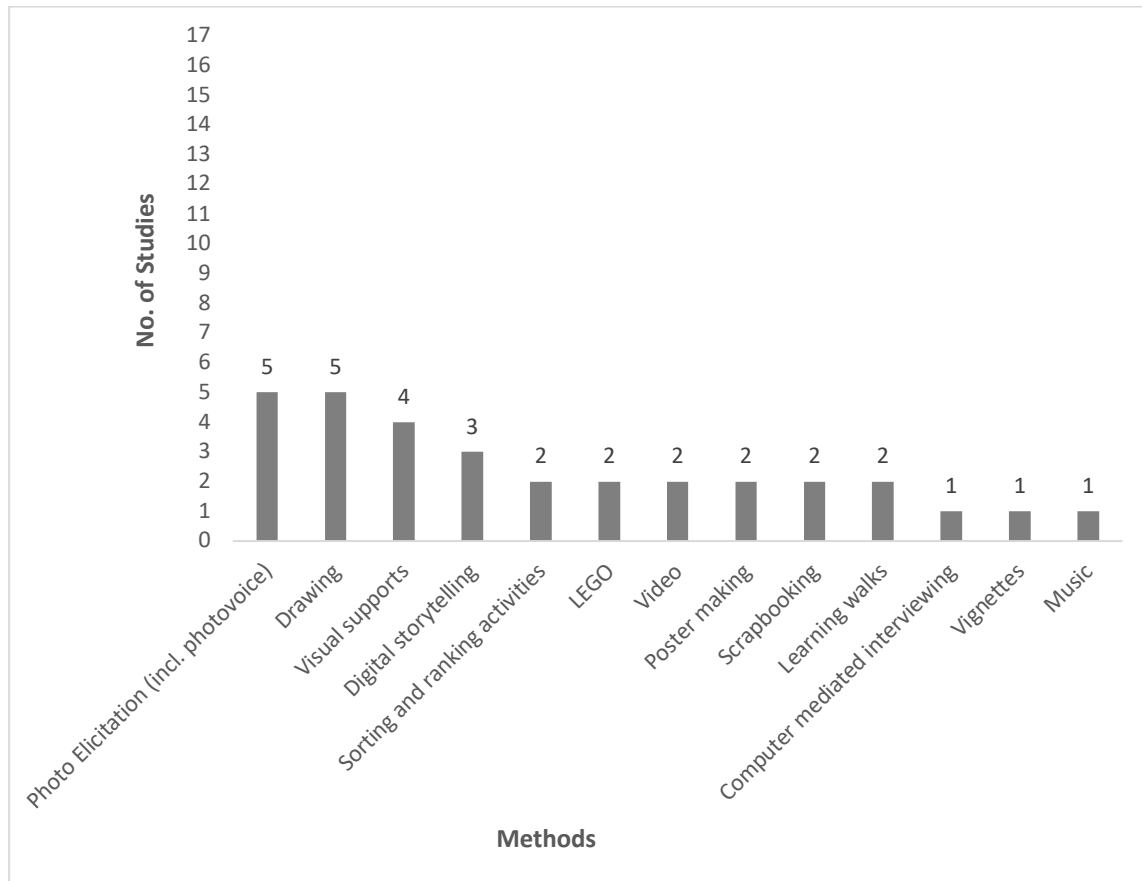
Seventeen of the 33 studies reported that their autistic participants were speakers, while four studies included a mixture of speakers and non-speakers (i.e., Croydon et al., 2019; Preece and Jordan, 2010; Peters et al., 2013; Wood, 2020). The twelve remaining studies did not provide explicit detail on whether their participants were speakers or non-speakers.

Research Methods

In most studies (n=28; 85%), the views of autistic participants were gathered using semi-structured interviews, carried out in the child's home or school setting. Across 17 of these studies, engagement in interviews was supported through a range of strategies (see Figure 2 and Supplemental Material), including photographs (photo elicitation), drawing, visual supports, digital storytelling, sorting and ranking activities, LEGO, videos or vignettes following ethnographic observation, poster making, scrapbooking, computer mediated interviewing, and scrapbooking. Some studies engaged participants using multiple supporting methods.

Figure 2

Frequency breakdown of supporting strategies used alongside semi-structured interviews (n=17 studies)



Five of the 33 studies (15%) did not use semi-structured interviews to gather the children's views. Conn et al. (2020) provided the children with an iPad and a list of prompts to guide their photographs (e.g., 'What makes you happy?'). Similarly, Moyse and Porter (2015) facilitated learning walks, during which the children were invited to take photos of places they liked in school. Afterwards, sorting activities were used to identify and prioritise the children's key observations and these were subsequently displayed to the children as symbols or simple text. Video was used by Parsons et al. (2020) and Peters et al. (2013) to capture the autistic children's experiences. Footage of the children interacting with others in

the school setting was recorded and then analysed. Finally, Dickerson (2012) carried out a conversational analysis on conversations between an autistic child and their teacher.

Securing Assent

Based on our analyses, only 22 studies (67%) secured the children's assent to conduct the research. In some studies, the children were given an information letter, written in accessible language, and were then required to provide written assent if they wanted to be involved (e.g., Foulder-Hughes & Prior, 2014; Lindblom, 2017). Other studies used social stories to communicate the research details to the children in an accessible way (i.e., Beresford et al., 2004; Harrington et al., 2013). Potter (2015) stressed the importance of simplifying the information provided to facilitate the children's understanding, while maintaining full transparency.

Consistent with this approach, seven studies conceptualised assent as an ongoing, interactive, and respectful process (i.e., Goodall, 2018; Harrington et al., 2013; Moyse & Porter, 2015; Croydon et al., 2019; Beresford et al., 2004; Barrow & Hannah, 2012; Preece & Jordan, 2010). In these studies, the children were aware that they could withdraw from the research at any point and were frequently given the opportunity to do so, in an explicit way. For example, Goodall (2018) and Croydon et al. (2019) sought assent from participants at the beginning of every data collection session, with Croydon et al. (2019) facilitating this through PECS. During their sessions, Harrington et al. (2013) provided the children with 'stop' cards, which they could use to end a research session at any time. 'Signal' cards were used in several studies to communicate the children's willingness to continue to engage with the research session (e.g., Brede et al., 2017; Dickerson, 2012; Moyse & Porter, 2015). For instance, Moyse and Porter (2015) employed a traffic light system. The children could communicate that they were happy to continue by using the green card, that they were

somewhat uncomfortable by showing the amber card, and that they wanted to stop by using the red card.

Consultation with Stakeholders During the Research Process

Five of the 33 included studies (15%) consulted with autistic children, their caregivers, or educators, prior to data collection, to determine methods that would facilitate the children to comfortably communicate with the researchers. Three of these studies consulted with the caregivers or educators (Conn et al., 2018; Hebron and Bond, 2017; Preece & Jordan, 2010), one consulted with a group of children (Goodall, 2018), and one consulted with the children and adults (Lindblom, 2017). For example, Harrington et al. (2013) worked with parents, proactively, to identify each participating child's preferred communication mode and used this information to facilitate the children to express their views. In their study, Goodall (2018) hosted Children's Research Advisory Groups (CRAGs) with three young people, to explain what the research was about and to identify methods for gathering their views, which they deemed most suitable and enabling. It should be noted that none of the studies in this review offered the children a choice in how they wished to communicate once the study began. In studies where multiple methods were available, the children were expected to engage with all methods.

Almost 40% of the included studies (n=13) interviewed adults (e.g., parents, teachers, teaching assistants), to further inform and validate the information provided by the children, while seven studies (21%) followed up with the children, after the first interaction, to provide additional 'thinking' time (Preece & Jordan, 2010), to achieve data saturation (Croydon et al., 2019; Daniel & Billingsley, 2010; Hebron & Bond, 2017; Ronksley-Pavia et al., 2019), and to check interpretations of the collected data (Goodall, 2018; Lindblom, 2017). It was noted by Harrington et al. (2013) and Preece and Jordan (2010) that having parents or teachers

present during the children's interviews impacted the scope of the interview, as unsolicited prompts tended to shape the children's responses and direction of the conversation.

Discussion

The 'voices' of autistic children and young people are often absent in educational research due to the perceived challenges in facilitating them to communicate their views, opinions, and perspectives. Therefore, the current systematic review sought to summarise the methods used to gather the views of primary-age autistic children, regardless of verbal or academic ability, regarding their educational experiences. We were also interested in identifying key factors that should be considered when conducting this type of research. As such, this review extended previous reviews, which focused exclusively on older children (Fayette & Bond, 2018) or those characterised as being "at the 'high functioning' end of the autism spectrum" (Tyrell & Woods, 2020, p. 379).

Following systematic searches of the literature, 34 studies were originally included in this review. However, due to scoring on the Weight of Evidence Framework (Gough, 2007), one study, Carnahan (2006), was excluded from analysis of the extracted data. Consistent with findings from the Fayette and Bond (2018) and Tyrell and Woods (2020) reviews, semi-structured interviews were the most frequently cited practice. In addition, a variety of supporting tools were used alongside this traditional method to engage the children and support them to express their views. These strategies typically involved visually oriented activities (e.g., Beresford et al., 2004; Bradley & Male, 2017), technology (e.g., Barrow & Hannah, 2012; Hsu and Teoh, 2017) or a combination of both (e.g., Conn et al., 2020).

However, only three studies consulted with the autistic children's caregivers or educators when developing tools to gather the children's views (Conn et al., 2018; Hebron and Bond, 2017; Preece and Jordan, 2010) and only two studies consulted directly with the

children (Goodall, 2018; Lindholm, 2017). It may be the case that researchers consider Children's Research Advisory Groups (CRAGs) to be better suited to older children or those proficient in verbal communication. However, given that approximately one-third of autistic children and adults are minimally speaking or non-speaking (DiStefano et al., 2016), the responsibility lies on us as researchers work with children, their caregivers, and their educators, to identify our participants' preferred modes of communication and use this information to carry out age-appropriate CRAGs.

Across twelve studies, there was a noticeable lack of information pertaining to the children's communication abilities. This raises the concern of whether these factors were actively considered and planned for by researchers. This has an impact at every stage of the research process, including assent, participation, and validation of findings. Findings from this review showed that only 22 studies (67%) secured assent from the children themselves. Potter (2015) emphasised the importance of delivering information on the study to the children in an accessible and transparent way. In line with this, seven studies approached assent as an ongoing, interactive, and respectful process, giving the children frequent, explicit opportunities to withdraw from the research process (Goodall, 2018; Harrington et al., 2013; Moyse & Porter, 2015; Croydon et al., 2019; Beresford et al., 2004; Barrow & Hannah, 2012; Preece & Jordan, 2010). These studies typically included alternative systems of communication (e.g., picture exchange) to facilitate this (e.g., Croydon et al., 2019).

Similarly, findings revealed that the children did not have a choice in how they engaged or participated in any of the studies. Methods for participation were predetermined and in studies where multiple methods were used, the children needed to engage in all methods available. It is acknowledged that autistic children express themselves in diverse ways and therefore it is critical to have multiple options and choices available to the children, to support meaningful engagement (Ware et al., 2012). Taking this approach might reduce the

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reliance on adults as additional informants in research exploring the views of autistic children. For instance, Parsons et al. (2020) acknowledged that the adult contributions likely led to an 'over-interpretation' of their findings (p.15). Similarly, Lindblom (2017) claimed that the child and adult input was necessary to confirm interpretations and make changes as needed. However, as researchers, we need to be aware that adult input could encroach on the children's contribution, distorting their intended meaning and elevating the adult voice. Having several means of communication/engagement available to the children, alongside multiple interviews, and follow-up meetings, should enhance the likelihood that the children can carefully consider the topics, meaningfully express their views, and ensure that the researcher's interpretation is correct.

While all studies included in the synthesis stage of this review were of medium to high quality, vital details relating to participant profiles, ethical considerations and the effectiveness of the methods used, were lacking in some instances. Information on the communication and cognitive abilities of participants was missing in most studies, many did not provide sufficient detail on key ethical considerations, including the acquisition of consent and assent and only eight studies (24%) explicitly evaluated their research methods. These omissions negatively impact on the replicability of the methods used. Delivering sufficient detail to allow for replication and interrogation is critical to facilitating the use of these methods in future consultations with autistic children, as well as helping to further improve processes designed to gather the views of autistic children and young people.

Although this review was open to appraising quantitative, qualitative, and mixed methods studies, all articles were predominantly qualitative in their approach. There were several established tools for evaluating the quality of quantitative research (e.g., Scientific Merit Rating Scale) and given the nature of quantitative research, the criteria on these tools were relatively objective. On the other hand, the tools available to appraise qualitative

research were more limited. While the Weight of Evidence Framework (Gough, 2007) was well established for assessing the trustworthiness and relevance of research, criteria, particularly for WoE B and WoE C, were quite subjective, influenced by researcher intention, and open to researcher interpretation. We recognised that this was one of the limitations of this review. However, we attempted to mitigate this by having a second rater independently appraise 12 of the studies but it should be noted that there were disagreements, which needed to be resolved through consensus. When conducting research in this area, it is likely that researchers choose a qualitative approach, given its inherent flexibility and the facility to explore topics in-depth. However, future research must be cognisant of the need for transparency and the provision of sufficient to allow for replication of their methods.

Some of the main limitations of this review relate to the search strategy. For example, plurals and alternative endings were not included in some of the terms used (e.g., child/pupil/learner/student) and the inclusion criteria only allowed for peer-reviewed articles, thereby excluding dissertations and other types of grey literature. Furthermore, only those articles written in the English language were included in the review, which may account for the fact that the majority of studies were based in the United Kingdom (n=21). A final shortcoming was the absence of reliability checks on the literature search itself, meaning there was no secondary oversight on the studies deemed eligible for inclusion in the review.

Notwithstanding these limitations, the findings of this review complement and extend those of the previous systematic reviews on this topic. Semi-structured interviews remain the predominant approach to gathering the views of autistic children and studies appear biased towards older children and those who use speech as a primary means of communication. Nonetheless, consistent with Tyrell and Woods (2020), many studies in the current review used visual supports to help the children express their opinions. However, more recently, there appears to be an increased use of technology to support meaningful engagement and

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one recent study purposefully involved the children in the development of the data collection methods (Goodall, 2018). The absence of this involvement had been a limitation highlighted in the Fayette and Bond (2018) review.

The current review set out to determine the types of methods used to gather the views of autistic children on their educational experience, as well as the critical factors to be considered. Findings have shown that semi-structured interviews can be successfully used when supported by additional methods, including visual and technology-based activities. However, consultation with the children before and during the research process was a consistent issue across studies. Children need to be consulted about their preferred means of communication and this needs to be factored into all aspects of the research process, including rapport building, balancing of power dynamics, assent provision and method of engagement. Semi-structured interviews and the associated support methods might be more effective, by adopting an individualised approach based on participants' communication preferences. This individualised approach could be facilitated by having a suite of options available to participants, based on the methods identified in this review and informed by parents and educators, where appropriate.

Following on from this, it is imperative that the adult views are not permitted to overshadow those of the children or unnecessarily shape the interpretation of the views expressed by the children. Furthermore, interpretations should be checked and validated with the children, in the same way it would be in qualitative research with members of the neuromajority population. As researchers, it is our responsibility to co-produce methods with autistic children and young people, to allow them to express their views, both in research and real life.

References

- Altomare, A. A., McCrimmon, A. W., Cappadocia, M.C., Weiss, J. A., Beran, T. & Smith-Demers, A. D. (2017). When push comes to shove: How are students with Autism Spectrum Disorder coping with bullying? *Canadian Journal of School Psychology*, 32(3–4), 209–227. <https://doi.org/10.1177/0829573516683068>
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* (5th ed.). American Psychiatric Association.
- Barrow, W. & Hannah, E. F. (2012). Using computer-assisted interviewing to consult with children with Autism Spectrum Disorders: An exploratory study. *School Psychology International*, 33(4), 450–464. <https://doi.org/10.1177/0143034311429167>.
- Beresford, B., Tozer, R., Raibee, P. & Sloper, P. (2004). Developing an approach to involving children with autistic spectrum disorders in a social care research project. *British Journal of Learning Disabilities*, 32, 180-185. <https://doi.org/10.1111/j.1468-3156.2004.00318>.
- Billington, T. (2006). Working with autistic children and young people: Sense, experience and the challenges for services, policies and practices. *Disability and Society* 21 (3), 1–13. <https://doi.org/10.1080/09687590500373627>
- Bradley, K. & Male, D. B. (2017). ‘Forest School is muddy and I like it’: Perspectives of young children with Autism Spectrum Disorders, their parents and educational professionals. *Educational and Child Psychology*, 34(2), 80–93. <https://doi.org/10.1080/03004279.2023.2183081>.

Brede, J., Remington, A., Kenny, L. & Warren, K. (2017). Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school.

Autism & Developmental Language Impairments, 2, 1-20.

<https://doi.org/10.1177/2396941517737511>.

Calder, L., Hill, V. & Pellicano, E. (2012). 'Sometimes I want to play by myself':

Understanding what friendship means to children with autism in mainstream primary schools. *Autism*, 17(3), 296–316. <https://doi.org/10.1177/1362361312467866>.

Carnahan, C. R. (2006). Photovoice: Engaging children with autism and their teachers.

Teaching Exceptional Children, 39(2), 44–50.

<https://doi.org/10.1177/004005990603900208>.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K.,

Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society*, 32(5), 720–734.

<https://doi.org/10.1080/09687599.2017.1320273>

Conn, C., Lewis, M. & Matthews, S. (2020). An analysis of educational dialogue as support for learning for young pupils with autism in mainstream schools. *International*

Journal of Inclusive Education, 24(3), 251–

265. <https://doi.org/10.1080/13603116.2018.1458254>.

Croydon, A., Remington, A., Kenny, L., & Pellicano, E. (2019) 'This is what we've always

wanted': Perspectives on young autistic people's transition from special school to mainstream satellite classes'. *Autism and Developmental Language Impairments*, 4, 1-

16. <https://doi.org/10.1177/2396941519886475>

Daniel, L. S. & Billingsley, B. S. (2010). What boys with an Autism Spectrum Disorder say about establishing and maintaining friendships. *Focus on Autism and other Developmental Disabilities*, 25(4), 220-229. <https://doi.org/10.1177/10883576103782>

Dee-Price, B.J., Hallahan, L., Nelson Bryen, D & Watson, J.M. (2021) Every voice counts: exploring communication accessible research methods. *Disability & Society*, 36(2), 240-264. <https://doi.org/10.1080/09687599.2020.1715924>

Dekker, M. (2020). From exclusion to acceptance: Independent living on the Autistic Spectrum. In S. K. Kapp (Ed.), *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* (pp. 41–49). Springer Singapore. https://doi.org/10.1007/978-981-13-8437-0_3

Dickerson, P. (2012). The interactional work of repeated talk between a teacher and a child with autism. *Journal of Interactional Research in Communication Disorders*. 3(1), 1-25. <https://doi.org/10.1558/jircd.v3i1.1>

DiStefano, C., Shih, W., Kaiser, A., Landa, R. and Kasari, C. (2016). Communication growth in minimally verbal children with ASD: The importance of interaction. *Autism Research*, 9, 1093-1102. <https://doi.org/10.1002/aur.1594>

Ezzamel, N. & Bond, C. (2017). The use of a peer-mediated intervention for a pupil with Autism Spectrum Disorder: Pupil, peer and staff perceptions. *Educational & Child Psychology*, 34(2), 27–39. DOI: <https://doi.org/10.53841/bpsecp.2017.34.2.27>

Fayette, R., & Bond, C. (2018). A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational

experiences. *European Journal of Special Needs Education*, 33(3), 349–365.

<https://doi.org/10.1080/08856257.2017.1314111>

Flynn, P. (2017). *The learner voice research study: Research report*. National Council for Curriculum and Assessment.

Foulder-Hughes, L. & Prior, C. (2014). Supporting pupils with DCD and ASD with the transition to secondary school. *Research in Education*, 92, 79–92.

<https://doi.org/doi/10.7227/RIE.0011>.

Goodall, C. (2018). 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people'. *Autism & Developmental Language Impairments*, 3, 1-

16. <https://doi.org/10.1177/2396941518804407>.

Gough, D. (2007). Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, 22(2), 213–228.

<https://doi.org/10.1080/02671520701296189>

Graham, A., Powell, M., Taylor, N., Anderson, D., & Fitzgerald, R. (2013). *Ethical Research Involving Children*. UNICEF Office of Research - Innocenti.

Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2013). Engaging young people with Autism Spectrum Disorder in research interviews. *British Journal of Learning Disabilities*, 42, 153-161. <https://doi.org/10.1111/bid.12037>.

Hebron, J. & Bond, C. (2017). Developing mainstream resource provision for pupils with autism spectrum disorder: parent and pupil perceptions. *European Journal of Special Needs Education*, 32(4), 556–571. <https://doi.org/10.1080/08856257.2017.1297569>.

- Hebron, J. & N. Humphrey (2014). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs*, 14 (1), 22–32. <https://doi.org/10.1111/j.1471-3802.2012.01246.x>
- Holt, L., Bowlby, S. & Lea, J. (2017). “Everyone knows me I sort of like move about”: The friendships and encounters of young people with Special Educational Needs in different school settings. *Environment and Planning A: Economy and Space*, 49(6), 1361–1378. <https://doi.org/10.1177/0308518X17696317>.
- Hsu, C.W. & Teoh, Y.S. (2017). Investigating event memory in children with Autism Spectrum Disorder: Effects of a computer-mediated interview. *Journal of Autism & Developmental Disorders*, 47(2), 359–372. <https://doi.org/10.1007/s10803-016-2959-2>.
- Humphrey, N. & Symes, W. (2010). Responses to bullying and use of social support among pupils with Autism Spectrum Disorders (ASDs) in mainstream schools: A qualitative study., *Journal of Research in Special Educational Needs*, 10(2), 82–90. <https://doi.org/10.1111/j.1471-3802.2010.01146.x>
- Jaswal, V., Dinishak, J., Stephan, C., & Akhtar, N. (2020). Experiencing social connection: A qualitative study of mothers of nonspeaking autistic children. PLOS, <https://doi.org/10.1371/journal.pone.0242661>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406-428. <https://doi.org/10.1002/aur.2864>

- Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.635690>
- Lindblom, A. (2017). 'It gives them a place to be proud' – Music and social inclusion. Two diverse cases of young First Nations people diagnosed with autism in British Columbia, Canada. *Psychology of Music*, 45(2), 268–282.
<https://doi.org/10.1177/0305735616659553>.
- McHugh, M. L. (2012). Interrater reliability: The kappa statistic. *Biochemia Medica*, 22(3), 276–282.
- Moyse, R. & Porter, J. (2015). The experience of the hidden curriculum for autistic girls at mainstream primary schools. *European Journal of Special Needs Education*, 30(2), 187–201. <https://doi.org/10.1080/08856257.2014.986915>.
- Parsons, S., Ivil, K., Kovshoff, H and Karakosta., E. (2020). 'Seeing is believing': Exploring the perspectives of young autistic children through Digital Stories. *Journal of Early Childhood Research*, 1-18. <https://doi.org/10.1177/1476718X20951235>.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756–770. <https://doi.org/10.1177/1362361314529627>
- Peters, B., Forlin, C., McInerney, D. & Maclean, R. (2013). Social interaction and cooperative activities: Drawing plans as a means of increasing engagement for children with ASD. *International Journal of Whole Schooling*, 9(2), 61–86.

- Potter, C. (2015). 'I didn't used to have much friends': Exploring the friendship concepts and capabilities of a boy with autism and severe learning disabilities. *British Journal of Learning Disabilities*, 43(3), 208–218. <https://doi.org/10.1111/bld.12098>.
- Preece, D. & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support', *British Journal of Learning Disabilities*, 38, 10-20. <https://doi.org/10.1111/j.1468-3156.2009.00548.x>
- Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336–348.
<https://doi.org/10.1177/1362361320967790>
- Ronksley-Pavia, M., Grootenboer, P. & Pendergast, D. (2019). Bullying and the unique experiences of twice exceptional learners: Student perspective narratives. *Gifted Child Today*, 42(1), 19–35.<https://doi.org/10.1177/1076217518804856>.
- Smith, L. (n.d.). *Ableism*. Center for Disability Rights. Retrieved 20 September 2023, from <https://cdrnys.org/blog/uncategorized/ableism/>
- Spencer, L., Ritchie, J., Lewis, J., & Dillon L. (2003). *Quality in qualitative evaluation: A framework for assessing research evidence*. Government Chief Social Researcher's Office. <https://dera.ioe.ac.uk/id/eprint/21069/2/a-quality-framework-tcm6-38740.pdf>
- Turner, H., Remington, A. & Hill, V. (2017). Developing an intervention to improve reading comprehension for children and young people with Autism Spectrum Disorders. *Educational & Child Psychology*, 34(2), 13–26.
<https://doi.org/10.5555/AAI28197214>.

- Tyrrell, B., & Woods, K. (2020). Gathering the views of children and young people with ASD: a systematic literature review. *British Journal of Special Education*, 47(3), 376–398. <https://doi.org/10.1111/1467-8578.12311>
- UN Committee on the Rights of the Child. (2009). *General Comment No. 12 (2009): The right of the child to be heard*. Geneva: UN Committee on the Rights of the Child. <https://www2.ohchr.org/english/bodies/crc/docs/advanceversions/crc-c-gc-12.pdf>
- UN General Assembly. (2006). *Convention on the Rights of Persons with Disabilities*. <https://www.refworld.org/docid/4680cd212.html>
- United Nations. (1989). *Convention on the rights of the child*. New York: United Nations General Assembly. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
- Ware, J. N., Ohrt, J. H. and Swank, J. M. (2012). A phenomenological exploration of children's experiences in a social skills group. *Journal for Specialists in Group Work*, 37(2), 133–151. <https://doi.org/10.1080/01933922.2012.663862>.
- Whalon, K. J. & Hart, J. E. (2011). Children with Autism Spectrum Disorder and literacy instruction: An exploratory study of elementary inclusive settings. *Remedial and Special Education*, 32(3), 243–255. <https://doi.org/10.1177/0741932510362174>.
- Winstone, N., Huntington, C., Goldsack, L., Kyrou, E. & Millward, L. (2014). Eliciting rich dialogue through the use of activity-oriented interviews: Exploring self-identity in autistic young people. *Childhood*, 21(2), 190–206. <https://doi.org/10.1177/0907568213491771>.
- Wood, R. (2020), The wrong kind of noise: Understanding and valuing the communication of autistic children in schools. *Educational Review*, 72(1), 111–130. <https://doi.org/10.1080/00131911.2018.1483895>.

Wu, I.-C., Lo, C. O., & Tsai, K.-F. (2019). Learning Experiences of Highly Able Learners With ASD: Using a Success Case Method. *Journal for the Education of the Gifted*, 42(3), 216-242. <https://doi.org/10.1177/0162353219855681>

Yi, H. & Siu, Q. K. Y. (2020) 'His inner-self must be good': An ethnographic-vignette study of social interactions between children with Autism Spectrum Disorder and typically developing peers. *Journal of Social and Personal Relationships*, 1-24. <https://doi.org/10.1177/0265-407520959456>.

Zilli, C., Parsons, S., & Kovshoff, H. (2020). Keys to engagement: A case study exploring the participation of autistic pupils in educational decision-making at school. *The British Journal of Educational Psychology*, 90(3), 770–789.
<https://doi.org/10.1111/bjep.12331>