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A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences

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ABSTRACT

Recent systematic reviews have found that the participation of adolescents and young people with Autism Spectrum Disorder (ASD) within research is limited despite an increasing international recognition of the importance of incorporating the views of all children and young people on matters that affect their lives. The purpose of this current systematic review was to explore the mechanisms, processes and perceived effectiveness of the methods used to elicit the views of young people with ASD about their educational experiences within qualitative research studies. Databases such as Applied Social Science Index and Abstract, web of knowledge, PsychInfo and web pages were searched for relevant studies between November 2015 and January 2016. Twelve identified studies were then screened using a trialled evaluation checklist and synthesised using the PRISMA guidelines. The current review identified data collection methods that were perceived to be useful in eliciting the views of young people with ASD about their educational experiences. Limitations such as the over-representation of participants who were able to engage in verbal discussion and the lack of detailed description of data collection and evaluation were also identified. Practical and research implications are also discussed.

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Introduction

All young people have the right to be included in making informed decisions on matters that will affect their lives (United Nations Convention on the Rights of the Child 1989). This has been highlighted in government guidelines and legislation in many countries, for example New Zealand (Youth Participation Guide; Ministry of Youth Affairs 2008), the USA (Individuals with Disabilities Education Act 2004) and England (Special Educational Needs Code of Practice; DfE 2014). Although views about the importance of the child's voice and how this can be ethically elicited to inform provision has changed over time, their contribution continues to be essential. As such, professionals have an obligation to develop and use appropriate means of gaining the views of all participants regardless of their abilities. However, individuals with Autism Spectrum Disorder (ASD) are still being excluded in decision-making, consultations and research (Pellicano, Dinsmore, and Charman 2014).

Specific supports such as Talking Mats (Cameron and Murphy 2002) and inferential approaches (Ware 2004) have been developed and used in research contexts to support pupils who struggle to communicate. However, such papers consider children and young people with (Special Educational Needs and Disabilities) SEND as a homogeneous group and consequently overlook the effects of specific difficulties relating to social interaction which are experienced particularly by individuals with ASD (Norwich & Lewis 2001). However, there is still uncertainty surrounding effective methods for eliciting the views of children and young people who have ASD (Whyte 2006) and research into the perceptions of educational support for these students predominantly involves gathering the views of their parents, and not enough efforts are made to include the views of the students themselves (Baric et al. 2015). The absence of the views and perceptions of individuals with ASD within the literature is well documented, and as Milton (2012) stated, this has created a knowledge-base about ASD which is informed by non-autistic others and imposed upon people with ASD. Milton (2012) therefore questioned the reliability of this knowledge-base and called for an increase in the inclusion of individuals with ASD in the knowledge-construction about their experiences as well as the support they need.

Potential issues in gathering and representing the voice of children and young people with ASD

ASD is characterised by impairments in social communication and interaction skills, as well as having restricted, repetitive and stereotyped behaviour and interests (American Psychiatric Association 2013). Lewis (2009) proposed that ASD's diagnostic criteria could influence the assumptions of researchers regarding the individuals' ability to participate, which in turn limited their inclusion in research. In a study by Haas et al. (2016), adults with high-functioning Autism (HFA) and Asperger's Syndrome (AS) reported that the major deterrents for their participation in research include practical issues such as travel time and time required to complete activities, perceived 'tokenism', insensitivity of researchers, lack of opportunities to decline aspects of the research and a limited choice of modes of participation.

Within education, Norwich (1996) proposed that pupils have needs that are common to all, needs that are shared with some others and needs that are unique to each individual. This applies to individuals with ASD who as a group share some common characteristics but as individuals possess their own unique set of limitations and strengths (Wing 1993). This, in addition to the changes in the definition of autism and the increasing heterogeneity of this population makes understanding the individual's perspective and needs crucial (Runswick-Cole, Mallett, and Timimi 2016). Research should therefore take into account common needs of those with ASD, for instance their right to have their views heard, as well as their individual needs, such as specific accommodations they require to communicate.

Previous studies identified potential difficulties when eliciting the views of children with ASD. Preece and Jordan (2010) reported that the children and young people with ASD were less likely to initiate interactions used language in an idiosyncratic way and struggled to identify and express emotions. Other barriers include young people's concrete thinking, reluctance to change and ability to access abstract or future questions (Beresford et al. 2004). Lastly, Winstone et al. (2014) warn that due to the power imbalance between participants and researcher, some children and young people with ASD may think that there is a single right answer to every question that researchers ask. Consideration of these potential

limitations is therefore crucial when developing methods to actively engage individuals with ASD in research.

Researchers such as Lewis (2009) propose that using statements as opposed to questions; including more closed rather than open-ended questions and repeating questions may help increase understanding and engagement of individuals with ASD. Morris (2003) suggested that researchers should include pupils with ASD in the development of their interview schedules through piloting and adjusting following their feedback. Lastly, most individuals with ASD are motivated using technology devices as they are easy to control and explore in their own terms (Porayska-Pomsta et al. 2012). There is also growing evidence that indicates that technology-aided instruction and intervention produce positive outcomes across key areas of functioning and is likely to have potential for communicating views both in education and in research contexts (see Bond et al. [2016] and Parsons et al. [2011] for detailed reviews of ASD interventions, including those that are technology-based).

Lloyd (2013) cautioned that obtaining informed consent from children and young people with ASD needs to be carefully planned. She proposed that doing so should entail an individualised approach which includes providing information to participants through the means within which they communicate such as through Widgit literacy symbols (Detheridge, Whittle, and Detheridge 2002) and/or Social Stories (Gray 1998); ensuring on-going assent, and allowing each participant to speak with the researchers at any point during the study to discuss what their participation entails (BPS, 2010).

McLaughlin and Rafferty (2014) found that there is still a tendency for researchers' analyses and interpretations of the views of individuals with ASD to be influenced by diagnostic criteria, for instance presenting findings under headings that relate to characteristics that define diagnoses. McLaughlin and Rafferty (2014) and Milton (2012) suggested that researchers should aim to accept the views of their participants as truth since they are the experts in knowing about their own experiences instead of interpreting them as confirmation of their diagnostic criteria. However, changing researchers' preferred means of analysis can be challenging since choices of methodology and conceptualisations of knowledge stem from individuals' ontological and epistemological positions (Scotland 2012). At the very least, researchers should acknowledge and report these biases and the limitations they present.

The current study's rationale and literature review questions

As McLaughlin and Rafferty (2014) pointed out, there is a wealth of literature about the experiences of younger children with ASD but not so with adolescents and young adults. Furthermore, the majority of the existing literature that focuses on the perspectives of children and young people with ASD neither describes nor evaluates their data collection tools, which limits the likelihood of replication and/or further refinements of their methods. This paper therefore aimed to build on McLaughlin and Rafferty's efforts to highlight the experiences of adolescents and young people with autism. While McLaughlin and Rafferty's review focused mainly on researchers' analyses and interpretations of the views of adolescents with AS, the current paper adopts a broader focus as it provides a systematic review of qualitative studies that elicited the views of young people with ASD about their experiences in education to answer the following questions:

- (1) What qualitative methods have researchers adopted to elicit the views of young people with ASD about their experiences in education?
- (2) To what extent were these methods evaluated?

Methods

The researchers adopted an evaluative approach, which was derived from their critical realist epistemological position in order to understand the processes and mechanisms that enable the participation of young people with ASD in research. Initial scoping of the literature revealed that quantitative studies (for instance Locke et al. 2010; Van Roekel, Scholte, and Didden 2010) describe and explore the process of participation much less than qualitative studies. In addition, while the authors acknowledge the potential contribution of studies that adopted a mixed-method approach to this review, none were identified during the initial screening phase. The authors therefore focus on qualitative research studies to illuminate how emerging methods might enable participants with a range of needs to convey their experiences and engage in the research process (Milton 2012). This focus also enabled consideration of perceived effectiveness of each method, and implications for practice as it was anticipated that this review will be of use to practitioners given the increase in policy guidance stressing the importance of gaining the views of young people with ASD.

Literature search strategy

The current review adopted a systematic and rigorous search strategy that was guided by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA), a 27-item checklist for identifying empirical studies (Moher et al. 2009). Although quantitative studies were excluded at several points during the process the checklist provides an overview of the range of work in the field and outlines the transparent process for identifying included studies. Figure 1 outlines each stage of the literature search process.

Identification of studies

Five databases (Applied Social Science Index and Abstract, Web of Knowledge, PsychInfo and Education Resources Information Centre and, Google Scholar) were systematically searched from November 2015 until January 2016 to gather relevant studies. Terms for communication, autism, means of gathering the young people's views, study participants, education and experience were combined to systematically search for papers (see Table 1). This stage also involved searching for relevant references from the studies identified through searching the databases (reference harvesting) and consultations with colleagues.

The database search yielded 695 studies while reference harvesting and consultations returned 32 studies, which resulted in a total of 727 studies. A total of 588 studies were identified once duplicates were removed. Five hundred and forty studies were excluded as most of them were opinion pieces (non-empirical papers), meta-analyses or systematic reviews. The abstracts of the remaining 48 studies were examined which led to a further 25 studies being excluded as the majority solely collected quantitative data, while others focused on the participants' experiences outside of education. This in turn yielded 23 studies to be examined by reading full texts.

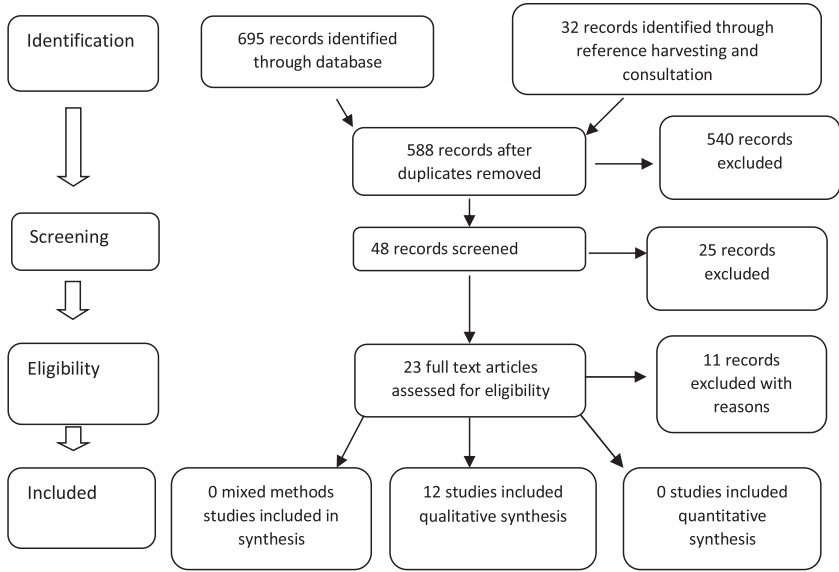


Figure 1. The PRISMA framework.

Table 1. Literature review search terms.

Terms related to communication	Terms related to ASC	Terms related to means of gathering pupils' voice	Terms related to participants	Terms related to education	Terms related to experience
Communicat*	Autis*	Facilitat*	Student*	School	Experienc*
Participat*	ASD	Gather*	Pupil*	Education	Evaluation
View*	ASC	Collect*	Child*	College	Perception*
Voice	PDD-NOS	Elicit*	Young		
Perspective	Asperger*		Person		
Consult*			Adult		
			Teen*		

Note: Asterisks act as a 'wildcard symbol' which broadens a search by finding words that start with the same letters.

Screening and inclusion criteria

The 23 included studies were screened using the following inclusion criteria:

- (1) Published in a peer reviewed academic journal.
- (2) Written in English.
- (3) Reported primary data.
- (4) Includes qualitative data.
- (5) Published from 2000 onwards.
- (6) Includes at least one young person with ASD aged between 11 and 25 years. This age range was chosen as it reflects the changes in the UK's SEN Code of Practice which state that pupils with SEND should begin planning for transition to adulthood at age 11 and because most young people with SEND transition to adult services after the age of 25 (DfE 2014).

A total of 11 studies were excluded as they failed to meet the inclusion criteria. The remaining 12 studies that met the inclusion criteria were subjected to the next stage which involved the assessment of eligibility.

Assessment of quality

Gough's (2007) process for assessing research quality (Weight of Evidence A) and focus (Weight of Evidence C) was followed. As this was an investigative review, only Weight of Evidence A (WoE A) and WoE C were adopted. Methodological quality (WoE A) was assessed using the scoring framework developed by Bond et al. (2013). This framework was adopted as it provides an indicator of research quality based on an integration of the criteria set by two established frameworks for evaluating qualitative studies (Henwood and Pidgeon 1992; Spencer et al. 2003). While the current authors acknowledge that the criteria are open to researcher interpretation, this limitation is addressed through inter-rater checking.

This framework gave credit in relation to the following 12 criteria:

- (1) Appropriateness of design.
- (2) Clear sampling rationale.
- (3) Well executed data collection.
- (4) Analysis that was close to the data.
- (5) Emergent theory related to the problem.
- (6) Evidence of explicit reflexivity.
- (7) Comprehensiveness of documentation.
- (8) Negative case analysis.
- (9) Clarity and coherence of reporting.
- (10) Evidence of researcher-participant negotiation.
- (11) Transferrable conclusions.
- (12) Evidence of attention to ethical issues.

Studies received scores of 1 (indicating full alignment), 0 (indicating no alignment) and 0.5 (indicating partial alignment) for each criterion. Since the studies included in this review were conducted with community samples, similar to those reviewed by Bond et al. (2013), their 'cut off' scores were adopted in this study. As such the studies that received a total score between 0–4 were considered 'low quality', 5–8 'medium quality', and 9–12 'high quality'.

Inter-rater reliability

A Cohen's kappa inter-rater reliability score of 0.94 was achieved following an independent scoring and moderation of three out of the 12 studies included in this review by both authors. This high level of inter-rater agreement (Robson and McCartan 2015) allowed the first author to score the remaining eight papers independently.

Appropriateness of focus

All of the included studies were also evaluated for their 'appropriateness of focus' in relation to the research questions posed for this review (Weight of Evidence C; Gough 2007). Since individuals with ASD are a heterogeneous group and that previous research suggest there

is not a single 'gold standard' method of data collection (Lewis 2009; Wing 1993), the authors decided to review studies in relation to the following criteria:

- (1) The extent to which the researchers described the participants' characteristics beyond their age (e.g. participants' language abilities, social interaction and cognitive skills).
- (2) An explicit evaluation of the data collection methods used.

Clear descriptions of the studies' sample, as well as evaluation of the methods used are important for the advancement of knowledge through replicating the studies and applying the research findings into practice (Robson and McCartan 2015). Studies that met both criteria were evaluated as having 'high methodological appropriateness', whereas those that met only one were evaluated as having 'medium methodological appropriateness'. Studies that did not meet any of the criteria were evaluated as having 'low methodological appropriateness'. The studies were scored after an agreement was reached between both authors regarding their interpretation of the criteria through discussions during on-going supervision.

Findings

Overview of the studies

All 12 studies were deemed eligible for the review, due to the small number of studies that met the inclusion criteria; the exploratory nature of this literature review (see Table 2 for descriptive summaries of each study) and the variability in scores for methodological quality and appropriateness. The studies were all published in peer reviewed journals between 2007 and 2015. Eight studies were conducted in the United Kingdom, two in Australia (Harrington et al. 2013; Saggars, Hwang, and Mercer 2011), one in Singapore (Poon et al. 2014) and one in Belgium (Van Hees, Moyson, and Roeyers 2015). One study was conducted by a practising social worker (Harrington et al. 2013) two by educational psychologists (EPs; McLaughlin and Rafferty 2014; Williams and Hanke 2007) and the rest of the studies were conducted by academic researchers.

Quality appraisal (Weight of Evidence A and C)

Table 2 shows that four of the studies were judged as being of 'low methodological quality', five were judged as 'medium methodological quality' while only McLaughlin and Rafferty (2014), Saggars, Hwang, and Mercer (2011) and Humphrey and Lewis (2008) were judged as 'high methodological quality'. Only three studies were evaluated as having 'high appropriateness of focus' (Harrington et al. 2013; Loyd 2015; Shepherd 2015); four were evaluated as 'medium', while another five were deemed 'low'. It is important to note that the studies of Barrow and Hannah (2012), McLaughlin and Rafferty (2014), Mitchell and Beresford (2014) and Saggars, Hwang, and Mercer (2011) did not include descriptions of their participants' levels of language, social interaction and cognitive skills, and preferred communication medium, which affected the evaluation of their 'appropriateness of focus'.

The replicability of the studies is limited due to the way in which they were reported. Only five studies (Barrow and Hannah 2012; Harrington et al. 2013; Loyd 2015; Shepherd 2015;

Table 2. Descriptive summaries of included studies.

Author(s) and country	Aim/focus	Sample (who and how many)	Data collection method(s)	Selected themes/findings	Quality assessment score (WoE A)	Appropriateness of focus (WoE C)
Barrow and Hannah (2012) United Kingdom	Evaluated In My Shoes to consult young people with autism	8 pupils; 9–15 years old; diagnosed with ASD (gender not specified)	1 semi-structured interview assisted by 'In My Shoes'	<i>Advantages</i> - Positively received; enabled three-way interaction allowed participants to take control and use their own vocabulary <i>Limitations</i> - IMS computerised guide (Mary) was deemed irritating - Distracting - Difference between pupils with ASD and those without regarding their sources of stress, perceptions of their abilities to cope with stress, and their concerns about the future	4.5; Low	Medium
Browning, Osborne, and Reed (2009) United Kingdom	Post-school transition experiences of young people with and without ASD	7 participants without ASD 10 had ASD, 6 male and 2 females had Asperger's; mean age = 15y/o	1 standard semi-structured interview	- Identified likes, dislikes and contributions in drama lesson - Reflected on their performance - Pupils with ASD were able to participate meaningfully	4.5; Low	Low
Harrington et al. (2013) Australia	Interview strategies to enhance engagement in research	8 young people with ASD (3 with PDD-NOS; 5 with AS) aged 12–15 (gender not specified)	1 semi-structured interview (30–70 min) with visual support	<i>Facilitators identified</i> - Visuals - Extra time to process and respond to questions - Closed questions	6; Medium	High
Humphrey and Lewis (2008) United Kingdom	Views of pupils about mainstream education	20 pupils with AS aged 11–17 (gender not specified)	1 standard semi-structured - Diaries - Pupil drawings	- Different constructions of AS label - Relationships with peers - Need for predictability - Some able to cope; some are very anxious - Support from adults - Negotiating difference	10; High	Medium
Lloyd (2015) United Kingdom	Teaching approaches that facilitated drama outcomes	10 pupils aged 16–18 diagnosed with autism - An autism unit at an FE college 6 female; 4 male	- Observation in lessons for 34 weeks 4-Part interview – individualised	- Identified likes, dislikes and contributions in drama lesson - Reflected on their performance - Pupils with ASD were able to participate meaningfully	6; Medium	High

McLaughlin and Rafferty (2014) United Kingdom	Explore the lived experiences of young people with AS	1 female and 5 male pupils in years 10–13 (ages not specified) diagnosed with AS	1 semi-structured interview	(Having AS feels like) something has been taken away from me – participants expressed anger for having AS; felt regret for their past behaviours (Having AS) does something to me – academic benefit; the possibility to change behaviour; AS is a part of their identities - A desire to be normal – to have a choice on how they let other perceive them; the usefulness of others' support - Fitting in – effects on relationships	9; High	Low
Mitchell and Beresford (2014) United Kingdom	Views of young people regarding post-16 transition	- Sample- 18 YP aged 15–25 with HFA/AS 4 female; 14 male	1 Standard semi-structured interview	- Need for a lead coordinator and emotional support - Different stages = different needs - Parents important role - Learning support not always available/matched to the level available in school - Need to develop social skills - Travel training - Practitioner needs to be known and reliable	6.5; Medium	Low
Poon et al. (2014) Singapore	Perspectives of students with HFA attending mainstream secondary school	4 students aged 12–16 1 female; 3 male 2 Asperger's Syndrome; 2 HFA	- Standard semi-structured interview - Observation in school before the interviews	- Negative, neutral, positive constructions of the HFA label - Description of an ideal friend - Difficulties with classmates - Bullying - Fear of failure – but not all	7; Medium	Medium
Saggers, Hwang, and Mercer (2011) Australia	Educational experiences of adolescents with autism	9 high school students aged 13–16 7 male; 2 female 7 Asperger's Syndrome; 2 ASD	2 standard semi-structured interviews	- Teacher, curriculum, support and environmental characteristics - Friendships/relationships with peers - Teasing and bullying	9; High	Low
Shepherd (2015) United Kingdom	Evaluation of methodological approaches used in listening to the views of pupils with ASC	1 male pupil, with HFA and MLD, final year of secondary schooling	- Semi-structured interview with practical activities 30-min interview at home - Walking interview at college	- Use of tablet was helpful - Walking interview helped take the pressure off the social interaction - Participant led	3; Low	High

(Continued)



Table 2. (Continued).

Author(s) and country	Aim/focus	Sample (who and how many)	Data collection method(s)	Selected themes/findings	Quality assessment score (WoE A)	Appropriateness of focus (WoE C)
Van Hees, Moyson, and Roeyers (2015) Belgium	Challenges for students with ASD during transition to HE	• 17 men; 6 women aged 18 and over who have attended HE for at least one year • Diagnosed with ASD; no intellectual disability	• 1 standardised semi-structured interview	• Importance of individualised support effects of transition and college on mental health and educational and daily living challenges	7; Medium	Low
Williams and Hanke (2007) United Kingdom	Views about the important features of school provision	• 15 participants with ASD – 8 Primary; 7 secondary (gender not specified) • Aged 6–14	Interviewed using the 'ideal self/school' technique	• Ideal school environment; staff characteristics and Pupils' activities and feelings • Non ideal school feelings	4.5; Low	Medium

Williams and Hanke (2007) included detailed descriptions and evaluations of their methods of data collection while the other seven focused mainly on reporting their research findings but did not evaluate the process of collecting the pupils' views.

The presentation of the findings relates to the categories in Table 2, with particular focus on the key areas of the literature review questions, namely participants, methods of data collection, focus of the studies and summary of findings.

Participants

While all studies included at least one pupil aged 11–25, the studies of Barrow and Hannah (2012) and Williams and Hanke (2007) included participants below the age of 11. Seven studies were conducted with pupils who were attending mainstream secondary schools; two included a combination of Primary and Secondary school pupils; two included pupils from both secondary and further education; one included only college students (Van Hees, Moyson, and Roeyers 2015) and one included pupils who were attending an ASD unit in a further education (FE) college which provides education for pupils between the ages of 16–19 (Loyd 2015). The number of participants in the studies ranged from 1 to 23, with males outnumbering the females in all studies except than of Loyd (2015) where there were 6 girls and 4 boys.

It is important to note that the heterogeneity of ASD was not represented in the included studies as the majority of participants were diagnosed with AS or HFA and were able to engage in verbal communication. Browning, Osborne, and Reed (2009) purposely selected participants with 'high language abilities' as they deemed that doing so would ensure that the data they collect could be analysed, while Van Hees, Moyson, and Roeyers (2015) included only those without intellectual disabilities but gave no reasons for doing so. Only Loyd's (2015) study was found to include pupils who communicated in ways other than speech (for instance, through symbols or Makaton). Furthermore, only one study (Poon et al. 2014) provided information about their participants' cognitive abilities and academic performance. Two studies (Loyd 2015; Shepherd 2015) provided descriptions of their participants' social and communication functioning, as well as preferred method of communication. Half of the studies provided no such information (Barrow and Hannah 2012; Humphrey and Lewis 2008; McLaughlin and Rafferty 2014; Mitchell and Beresford 2014; Saggars, Hwang, and Mercer 2011; Williams and Hanke 2007). The studies that included participants below the age of 18 gained informed consent from their participants' parents and from relevant staff from the participants' schools, as well as informed assent from the young people but only Harrington et al. (2013), Humphrey and Lewis (2008) and McLaughlin and Rafferty (2014) described how assent was sought.

Overall, the majority of the studies appeared to focus only on representing the views of individuals with AS and HFA as opposed to the wider autism spectrum. The majority of the research also did not include information about their participants' cognitive and communication abilities, as well as the ways in which they sought participants' assent.

Methods of data collection

The views of the participants in all of the studies were predominantly collected through semi-structured interviews, the length of which varied between 5 and 147 min. Shepherd (2015) conducted an interview while walking around the participant's college, while in the rest of the studies; the interviews took place in a quiet room either at the participants' school

or home, depending on the participants' preference. Participants in three studies (Barrow and Hannah 2012; Mitchell and Beresford 2014; Poon et al. 2014) were given the option of having a familiar adult present during the interview to reduce possible anxieties.

Even though the interview schedules in each of the studies were developed by the researchers, only Harrington et al. (2013), and Loyd (2015) sought advice and support during their development from other professionals such as Speech and Language Therapists, teachers and psychologists. Humphrey and Lewis (2008) asked for feedback from the participating schools' staff about the appropriateness of their interview questions before conducting the interviews. In addition, only Poon et al. (2014) piloted their interview schedule. These four studies were the only ones where researchers engaged in activities such as classroom observations and spending time with participants in their homes prior to any interviews due to the researchers' aim of getting to know each individual participant and building rapport with them.

Browning, Osborne, and Reed (2009), Mitchell and Beresford (2014), McLaughlin and Rafferty (2014), Poon et al. (2014) and Van Hees, Moyson, and Roeyers (2015) gathered their data exclusively by interviewing their participants only once, while Saggars, Hwang, and Mercer (2011) conducted two and Shepherd (2015) conducted three interviews. Saggars, Hwang, and Mercer (2011) did so to further explore the key themes they identified after the first interview, while Shepherd (2015) explored the lived experience of her participant before and after his transition to college.

The interview questions in 10 studies were delivered verbally and only 6 studies provided copies of their interview schedules in their research reports (Loyd 2015; McLaughlin and Rafferty 2014; Poon et al. 2014; Saggars, Hwang, and Mercer 2011; Van Hees, Moyson, and Roeyers 2015; Williams and Hanke 2007). Only Harrington et al. (2013) and Loyd (2015) presented interview questions verbally and with visual support such as Social Stories, Picture Communication Symbols, Widgit symbols, Talking Mats pictures, gestures or videos. The photographs and videos acted as prompts for Loyd's (2015) participants to remember what they did during the drama lessons.

The participants in most of the studies responded verbally – even in studies that were investigating specific techniques to gather pupil voice. For instance, although the participants in Williams and Hanke's study (2007) were encouraged to draw the components of their 'ideal' and 'non-ideal' schools, the data analysis still relied on recorded verbal responses. Similarly, the pupils in Barrow and Hannah's (2012) investigation of the use of the 'In My Shoes' (IMS) Computer Assisted Interview program, also responded verbally. Contrastingly, the participants in Loyd's (2015) responded to interview questions using their preferred means of communication which included varying levels of speech (full sentences, two-word and single-word responses), pointing to pictures, and the use of Widgit Symbols and Talking Mats (Murphy 1998). Shepherd's (2015) interviews, although predominantly verbal, were punctuated by activities such as card sorting and collage making on a tablet, as well as taking photographs of different areas of the participant's college.

Even though Humphrey and Lewis (2008) collected most of their data through semi-structured interviews, they triangulated these using the data from their participants' pupil diaries. They also decided to include one participant's drawings to supplement verbal answers, to take into account his social and communication difficulties. Humphrey and Lewis (2008) were also the only ones who invited their participants to provide comments on a 'pupil-friendly' summary of their findings before submitting their research for publication.

Taken altogether, the data in all of the studies were collected through semi-structured interviews with four that involved various modifications. The development of data collection methods in all of the studies included in this review did not involve any collaboration between researchers and their participants, although Harrington et al. (2013), Humphrey and Lewis (2008), Loyd (2015) and Poon et al. (2014) aimed to get to know their participants through engaging in various activities prior to interviews.

Focus of the studies

The majority of the studies gathered their participants' retrospective views of their experiences within educational settings. Three studies focused on pupils' general experiences of mainstream secondary education (Humphrey and Lewis 2008; Poon et al. 2014; Saggars, Hwang, and Mercer 2011). Loyd's (2015) study aimed to explore pupils' experiences that were specific to drama lessons delivered at an autism unit in a mainstream college. Van Hees, Moyson, and Roeyers (2015) focused on the challenges that pupils encountered during their transition from school to colleges and their academic support needs. Mitchell and Beresford (2014) reported the views of young people regarding good practice and further needs regarding transition from school to further education settings. Browning, Osborne, and Reed (2009) on the other hand compared pupils with ASD's perceptions of causes of stress and perceived coping ability to those of pupils without ASD. Lastly, while McLaughlin and Rafferty (2014) focused on their participants' lived experience of having AS, their participants predominantly discussed their experiences in school.

The four remaining studies also elicited the views of young people with ASD about their experiences in education. However, their focus was on exploring the use of different techniques to modify interviews to enhance the engagement of young people with ASD in research. Three studies described and evaluated specific methods namely 'Interrupted Interview' (Shepherd 2015), the 'Ideal School Technique' (Williams and Hanke 2007) and 'In My Shoes' (Barrow and Hannah 2012). Harrington et al. (2013) discussed various modifications to their interview approach such as the inclusion of closed questions, visual prompts and extra time for participants to process and respond to questions. It should be noted that even though Barrow and Hannah's (2012) and Williams and Hanke (2007) studies investigated the use of novel methods of eliciting views of individuals with ASD, their inclusion of participants below 11 years of age as well as the limited available quotes from individual participants warrants further research to explore specific facilitators and barriers to participation that apply to the application of these methods to this review's target age range.

Discussion

In order to attain knowledge that would contribute to the development of practice and policies relating to individuals with ASD, they need to be included in research. This systematic literature review revealed that while efforts have been made to do so, research is still in its infancy. This is highlighted by the relatively sparse available literature as only 12 studies met the inclusion criteria. The quality of these exploratory studies was also relatively weak as only four studies were judged to have high methodological quality (WoE A; Gough 2007) and only three studies had high appropriateness of focus (WoE C; Gough 2007). Furthermore, this review found that the current available literature do not represent the heterogeneity of

the ASD population as it predominantly includes the views of young people with AS and HFA.

All of the studies were successful in gathering data through semi-structured interviews. However, caution should be exercised when adopting such an approach particularly with individuals across the autism spectrum in future since the studies reviewed do not represent the heterogeneity of the ASD population.

The lack of description of individual participants' cognitive and communication abilities in half of the studies begs the question of whether these were considered by the researchers at all. Since these affect the participants' likelihood to comprehend information that are relevant to their decision to provide informed consent, consideration of these factors can enhance the development of data collection methods and the way in which informed consent or assent are gained (Nind 2008). This is supported by the studies which did use individualised approaches in gaining assent.

Some studies highlighted the value of seeking the advice of relevant professionals, spending time to get to know the participants, and adopting a multi-modal approach to semi-structured interview that include the provision of visual supports such as videos and pictures, as well as Social Stories. However, the absence of detailed descriptions and evaluations of data collection methods in most of the studies limit their replicability as it is unclear which data collection methods facilitated the engagement of their participants and which aspects acted as barriers. This suggests that limited progress has been made since Preece and Jordan (2010) highlighted the negative impact this scarcity of such research has on the collective knowledge regarding effective methods of increasing the engagement of individuals from this population.

Furthermore, while the accessibility of the research for participants has been highlighted by previous research (Preece and Jordan 2009), none of the participants in all of the studies reviewed were actively involved in the development of the data collection methods. Similar to Hass et al.'s (2016) findings, the participants' choice of modes of participation in most of the included studies was limited.

Although the current systematic literature review is limited by its focus on only qualitative research studies it does highlight challenges for researchers. These relate to methods for eliciting the voice of young people with ASD and also to more fundamental issue about the way that people with ASD participate in research. This review highlights that research studies that attempted to elicit the views of young people with ASD about their experiences in education are still being conducted 'to' the participants and not 'with' them. This results in perceived power imbalance between the researchers and participants which influence the participants' engagement (Winstone et al. 2014) as well as the nature of knowledge produced (Milton 2012). One way to address this is to view individuals in the ASD community (including those with co-occurring learning and communication difficulties) as essential in producing knowledge and that they should be involved throughout all of the stages of research (Milton 2012). Collaboration with participants may increase the accessibility of the research as well as develop other modes of participation in future studies.

Researchers also need to describe the extent to which each aspect of their methodology were successful as this would contribute to replication, refinements of methods, and ultimately increase the participation of individuals with ASD in research (Beresford et al. 2004). Such detailed documentation could also provide a link between research and practice as it could serve as a framework for practitioners who are looking to improve their process of eliciting the views of this population.

The recognition of the importance of knowing each individual pupil's strengths, areas of needs and preferred means of communication in eliciting the pupils' views emphasises the importance of building a relationship which both researchers and practitioners must aim to do. Therefore, collaboration between researchers, practitioners and the individuals themselves can help improve the appropriateness of the questions and the methods as a whole as each of them possess knowledge about ways of building positive working relationships and effective means of communicating (Milton 2012; Morris 2003). This also suggests that in practice, young people should be actively involved in the development and evaluation of ways in which professionals such as teachers, careers advisors and educational psychologists elicit their views in matters that affect their lives.

Conclusions

This review highlighted that some researchers have recognised their responsibility to enable young people with ASD to express their views. However, the scarcity of qualitative research that elicited the views of young people with ASD about their educational experience reveal that this movement is still in its infancy and more needs to be done to actively push the boundaries of participation. While several methodological considerations that helped elicit the views of individuals with ASD have been identified, participants' involvement in all aspects of research must be actively encouraged to inform the future direction of research in this field.

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