Creative methods developed to facilitate the voices of children and young people with complex needs about their education: a systematic review and conceptual analysis of 'voice'

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Abstract

A range of methods has been applied in research to enable children and young people with special educational needs and / or disabilities to share their views about educational experiences. However, methods tend to be targeted at older children and those who can communicate verbally and so there remains an important gap in knowledge about the methods used to support children with complex needs to share their views. This systematic literature review addresses this gap by exploring the creative methods that have been developed and used to facilitate the voices of children and young people with complex needs about their educational experiences and preferences. Additionally, methods were analysed conceptually in relation to Lundy's (2007) framework of Space, Voice, Audience and Influence to examine where, how and whose voices are heard, and what happens as a result. Fourteen qualitative papers published between 2003 and 2021 were included and synthesised according to PRISMA guidelines. Findings emphasise how it is possible to access the views of children and young people with complex needs using multi-modal, flexible approaches that require spending time with children, families, and practitioners to co-construct knowledge. The importance of a toolbox approach to enabling voice and participation challenges more orthodox and standardised methods of data collection. However, more needs to be done to ensure that children's views are acted upon, given due weight, and influence change.

Keywords: complex needs, education, experiences, voice, methods

1. Introduction

Over 30 years ago, the United Nations Convention of the Rights of the Child (UNCRC, 1989) stated, amongst other fundamental rights, that children and young people (hereinafter abbreviated to 'children') have a right to be listened to and for their views to be given due weight (Article 12) i.e., to have a 'voice'. Since its publication, the UNCRC has been ratified in 168 countries and implemented in many policy and practice arenas, so this is a topic that has wide international significance and implications for educational policy and practice. However, despite this international commitment, the way that voice is conceptualised frequently results in the exclusion of children from being actively involved in matters that affect their lives, including within educational decision-making (Davis & Watson, 2000; Hesjedal, 2021; Lundy, 2007). Children with special educational needs and / or disabilities are particularly vulnerable to marginalisation (Cascio et al., 2021; Courchesne et al., 2021; Fayette & Bond, 2018; Flutter & Rudduck, 2004; Pellicano, Hill & Croydon, 2014; Pellicano, Dinsmore & Charman, 2014) and are frequently denied participation in decision-making due to a "double denial" (Lundy, 2007, p.935) of their voice; i.e. doubts about their competence to form and express a view because of being: (a) a child and (b) a disabled child. Additionally, it is suggested that professionals working with children are unaware of the existence and scope of Article 12, and even when there is an awareness of children's right to have a voice, the requirement to consider the "age and maturity of the child" is often used as a caveat to exclude them or overlook their inclusion (Bloom et al., 2020a; Gersch et al., 2014; Lundy, 2007).

Within this context, children with more complex needs[1], are even more likely to be denied the right to be agentic and to have a voice (Morris, 2003), and are often "multiply

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[1] Children and young people with significant communication and/or cognitive disabilities: a subgroup who are identified as those most commonly excluded and marginalised within research and practice.

marginalised" (Parsons et al., 2021, p.163) within formal processes of educational review and decision-making. For example, Ashby (2011) discusses the marginalisation of children who type to communicate: "We have to remember how often these voices that do not speak have been overlooked, dismissed or even discounted as valid" (n.p.n). Ashby (2011) refers to these children as "individuals who challenge normative constructions of typical speech and voice" and argues for a broader conceptualisation of voice that includes the "unvoiced and differently voiced" (n.p.n.). This very much aligns with Doak's (2018) argument that children with complex needs communicate in a range of different ways and so creating opportunities for facilitating their voices must consider multi-modal expression and, therefore, methods that are tailored accordingly. Importantly, there is a need when critically reflecting on voice and what it means for different children for researchers to focus on the "de-privileging of [spoken] language" (Doak, 2018, p.37). Consequently, efforts need to be made to value all forms of expression so that barriers to the voices of *all* children being represented and facilitated can be removed (Ashby, 2011; Ellis, 2017).

This issue emphasises how crucial it is for research to explore the methods that can be used to successfully facilitate children's voices within processes for making decisions impacting their education. Although there are examples of more inclusive methods being used for gathering the views of children, there is an overreliance on methods which privilege the spoken word. For example, Fayette and Bond (2018) conducted a systematic review to identify the qualitative methods used in research for facilitating the views of autistic young people about their educational experiences. The main conclusion was that only a relatively narrow range of methods were used and, therefore, voices heard. Indeed, autistic young people who had a "high level of language ability" (Browning et al., 2009, p.38) and "no diagnosed intellectual ability" (Van Hees et al., 2015, p. 1675) were purposefully selected to ensure data could be analysed. Moreover, where children's voices were gathered to develop

an understanding of their educational experiences, the voices represented were much more likely to derive from older children (adolescents) and those who communicated using speech (Fayette & Bond, 2018).

Tyrrell and Woods (2018) drew similar conclusions in their systematic review of methods used to facilitate the views of autistic children and summarised that traditional methods, such as semi-structured interviews and focus groups, were "common place" and favoured "older" or "more able" young people (p. 320). Nicholas et al. (2019) reported very similar findings in their review that included methods for gathering first-person perspectives from people with different diagnoses including autism and dementia. Likewise, DePape and Lindsay's (2016) meta-synthesis of lived experiences of autistic children, adolescents and adults concluded that "the majority of samples involved individuals with high-functioning ASD who were able to verbally report their experiences" (p.69). In aiming to take a broader look at the methods used to include "the diverse voices of youth with ASD" (p.1883) in research, Tesfaye et al. (2019) conducted a wide-ranging scoping review across different disability and age groups, sectors/disciplines, and topics (i.e., not focused on autism or education) and synthesised findings from 284 articles. They identified that in-person, oral interviews were the most frequently used method across the papers and concluded that "…individuals with speech and language impairments and complex communication needs tend to be the least represented in research capturing first-person perspectives compared to youth with well-developed verbal abilities" (p.1891).

Moreover, while there was recognition of the importance of taking flexible, multi-modal approaches to obtain the voices of young people based on the findings from their synthesis (Tesfaye et al., 2019), the experiences of children with more complex needs were still side-lined in the review through being included and discussed alongside the overwhelming dominance of interview methods used with verbal participants. Similarly,

Bloom et al. (2020a) conducted a narrative review of methods for eliciting the voices of children with speech, language, and communication needs. However, their search was not conducted systematically, and their focus was not on the most marginalised children with complex needs. Thus, the voices of children with complex needs, and the methods used to facilitate them, remain under-explored, and this is identified as a major gap in research that needs to be addressed (Cascio et al., 2021). Therefore, the first research question for this review was: What methods have been developed and used to facilitate the voices of children and young people with complex needs about their educational experiences and preferences?

Additionally, while it is important to identify *what* methods are used in research to enable very marginalised voices to be included, it is also crucial to move beyond a descriptive account to examine *how* they are used and for *what purpose*. As Lundy (2007) makes clear, Article 12 of the UNCRC cannot be fully understood in isolation and should be considered collectively with other relevant articles, particularly Article 13, which states when seeking ways to support children with complex communication needs to form a view, they must have the "freedom to seek, receive and impart information…either orally, in writing or in print, in the form of art, or through any other media of the child's choice" (p.935). Lundy (2007) also acknowledged the importance of using a range of support methods and tools to enable children's voices to be heard, describing how "children may need practical assistance to communicate their views" (p. 936). This observation also aligns with Article 7 of the UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) which requires that:

> States parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

This emphasis on a range of approaches highlights the importance of developing person-centred, individualised methods and adapting "research tools to suit each child or young person" (Morris, 2003, p.344). Moreover, there is very little value in developing methods to enable children's voices unless these views are "seen to be integral and embedded within decision-making" (Lundy, 2007, p. 939). Therefore, as argued by Lundy (2007) "voice [by itself] is not enough" (p.927). Similarly, Ashby (2011) argues that it is vital to not only consider the methods used in research to facilitate the voices of those with complex needs but also how the "hierarchies of power and privilege are re-inscribed when the researcher presumes to give voice to someone else" (n.p.n). Ashby (2011) suggests that rather than researchers claiming they are "giving voice" to children, we should instead aim to "facilitate voice and agency" (n.p.n.). This means not only providing the means to support children to be heard, but also for those perspectives to be "available to others" (Ashby, 2011; n.p.n.) and for them to influence changes in perceptions and practice (Lundy, 2007).

To help interrogate practices and methods designed to enable children to have a voice, Lundy (2007) provided a framework for informing understanding, aiding policy development, and for auditing current practice about children's voice and participation based on the tenets of Article 12 of the UNCRC. There are four key elements of the framework: *Space, Voice, Audience and Influence*, and although these are presented as four distinct elements, they are interrelated and are intended to reflect the full scope and meaning of Article 12. Specifically, the framework explores the extent to which a child is given the right to express a view (*Space and Voice*) and for their view to be given due weight (*Audience and Influence*). According to Lundy (2007), to successfully implement Article 12 and enable children's views, perspectives, and experiences to be authentically represented, all four elements are necessary for children's views to be heard, actively listened to, and taken seriously. This framework therefore provided the foundation for a conceptual analysis of the

data derived from the current review to address the second research question (with sub-questions based on Lundy, 2007): How have the voices of children and young people with complex needs been authentically represented in the methods identified in the review? Specifically:

- Has the child or young person been invited and encouraged to express their views, safely and inclusively? (Space)

- Has the child or young person been given the opportunity to 'freely' express their views and, where appropriate, facilitated to form their views? (Voice)

- Has the child or young person's views (both verbal and non-verbal expression) been listened to and given due weight? (Audience)

- Has the child or young person's views been acted upon, as appropriate? (Influence)

2. Method

2.1 Search Strategy

A systematic search of the literature was carried out using eight bibliographic databases: Australian Education Index, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Education Resources Information Centre (ERIC), International Bibliography of the Social Sciences (IBSS), Medline, PsycINFO, Scopus and Web of Science. These databases were chosen to reflect the range of professionals and professions who may be involved in facilitating children's views within education (e.g., speech and language therapists, social workers, teachers, psychologists). Synonyms for 'voice', 'facilitate', 'child', 'education' and 'experience' were taken from Fayette and Bond's (2018) systematic literature review to provide initial search terms, which were further refined during scoping searches. Two additional terms central to the first research question were also included: 'complex needs' and 'method'. To ensure that the main search was comprehensive

and yielded relevant evidence i.e., balanced in terms of specificity and sensitivity (Boland et al., 2017), several iterations of the search using different terms was conducted. Table 1 details the final search terms and search syntax, which were adapted as required for each bibliographic database. The search was conducted in February 2022.

Due to the number of papers retrieved, articles published pre-1989 were not included in the final search as this date accords with the publication of the UNCRC (1989). Subsequently, there has been a greater focus on facilitating children's voices to develop educational practices (Noyes, 2005) and therefore this period was anticipated to yield articles of most relevance. Limiters were applied to exclude articles that were unpublished theses and book chapters. Articles not published in English were also excluded from the search.

This search produced a return of 3549 papers across the eight databases, which were collated in Mendeley where duplicates of articles were automatically removed, leaving 1978 papers to be screened. The papers were initially screened for relevance by reading the title and abstract only, and a further 1911 papers were excluded leaving 67 papers to be assessed for eligibility against the inclusion and exclusion criteria through full text reading (Table 2). Fifty-three papers were excluded, leaving 14 papers in the current review. Most papers were excluded due to not developing an inclusive methodology to facilitate children's views, verbal communication being a pre-requisite for inclusion in the study, and the research being carried out in a non-educational context. Each stage of the search and the process of paper selection is displayed in the PRISMA flow diagram (Moher et al., 2009) shown in Figure 1.

2.2 Quality Assessment

Once papers were identified for inclusion, the methodological strengths and limitations for each study were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (CASP, 2022). As suggested by Long et al. (2020), to determine methodological rigour of each qualitative study, the CASP tool was adapted to

include a question exploring the clarity and appropriateness of a study's qualitative paradigm. This question appraised the study's theoretical underpinnings and explored whether the guiding theoretical framework was "clear, consistent and conceptually coherent" (Long, et al., 2020, p.35). In addition to the three original response options within the CASP ('yes', 'no' and 'can't tell') a 'somewhat' response was added. The inclusion of this fourth response option allowed for a distinction between a reporting issue, where there is limited information within the paper to fairly appraise against the criteria and a methodological issue, where authors had partially fulfilled a specific quality domain (Long et al., 2020). The CASP discourages numerical scoring of quality domains and calculating total quality scores. Therefore, as suggested by Noyes et al. (2018), qualitative information was recorded against the quality criteria outlined in the CASP, to determine each study's methodological strengths and limitations. Although the CASP does not provide thresholds regarding assessing overall study quality, the overall quality was subjectively guided by the criteria within the CASP quality assessment and decided by the first author.

Most papers included had clearly described research aims and a qualitative methodology and design was deemed appropriate for addressing the aims of the research. For nine of the papers, the recruitment strategy was not explicitly stated or not included and, therefore, it was unclear how and why the participants were selected. Eleven studies provided sufficient detail about ethical considerations (e.g., consent and assent procedures). An in-depth description of the data analysis process was missing from most studies, with only four studies providing a thorough description of the analysis process i.e., description of steps taken within the analysis and how the themes were generated from the data. See Table 3 for the full quality assessment data.

3. Findings

3.1 Overview of Studies

A summary of the study context and location, participant information and data collection methods of the final 14 studies is provided in Table 4. These articles are marked with * in the references list. The participant information column describes information on the participant characteristics including number of children with complex needs included in the study, age, gender, known diagnoses and verbal communication skills, where provided. The data collection method column includes information on the method(s) that were developed and used within the study, how the children's voices were represented in the method and the authors' aims for developing the method. All the research included was published between 2003 and 2021 and reported qualitative studies. Nine studies were conducted in England, one in Northern Ireland, one in the Republic of Ireland, one in Greece, one in Canada and one in New Zealand.

3.2 Participant Characteristics

Studies included children aged three to 25 years, with the sample size ranging from one to 60. Collectively, the voices of 98 children with complex needs were represented across the 14 studies. Eight studies reported the views of only male participants, while two included males and females (Gray & Winter, 2011; Loyd, 2013), and Rouvali and Riga (2020) included one female participant only. The gender of participants was not given in three studies (Fitzgerald et al., 2003; O'Leary & Moloney, 2020; Whitehurst, 2007). Research was conducted within a broad range of education settings, which included mainstream, special schools, and residential special schools, across each stage of education from nursery through to further (post-compulsory) education.

All studies included participant information regarding known diagnoses, with many studies including children with multiple needs and co-occurring conditions. Most (11 of the 14) papers explicitly included autistic children and young people, some exclusively so (e.g., Bradley & Male, 2017; O'Leary & Moloney, 2020). The expressive language skills of

participants were reported in 10 studies, apart from Bradley and Male (2017), Hill et al. (2016), Gray and Winter (2011) and Fitzgerald et al. (2003). From the ten studies that reported children's verbal communication profile or characteristics (Ajodhia-Andrews & Berman, 2009; Bloom et al., 2020b; Hart, 2021; Loyd, 2013; O'Leary & Moloney, 2020; Parsons et al., 2021; Richards & Crane, 2020; Rouvali & Riga, 2021; Simmons & Watson, 2015; Whitehurst, 2003), 10 children were reported as 'non-verbal', 13 were referred to as having 'limited verbal skills', six were considered 'pre-verbal'; and six were reported as having 'limited or no verbal communication'.

3.3. The Methods Used to Facilitate Views

The range of data collection methods used to facilitate the voices of children with complex needs is briefly described in Table 4. Five studies specifically developed an inclusive methodology (Bloom et al., 2020b; Hill et al., 2016; Parsons, Ivil et al., 2021; Richards & Crane, 2020; Simmons & Watson, 2015); six studies combined elements from existing methods to create a novel methodology to be used inclusively with children with complex needs (Ajodhia-Andrews & Berman, 2009; Bradley & Male, 2017; Gray & Winter, 2011; Loyd, 2013; Rouvali & Riga, 2021; Whitehurst, 2007); two studies adapted traditional data collection methods, i.e., interviews and observation (Hart, 2021; O'Leary & Moloney, 2020); and one study identified the child's preferred communication method and used a total communication approach to facilitate their views (Fitzgerald et al., 2003).

The views of participants across all the studies were predominantly accessed through creative, usually visual, methods. Overall, the number of methods used in each study ranged from at least two to six, with 12 of the 14 papers using three or more. Photographs were used in ten of the studies in a variety of ways: to indicate preferences on a visual scale (Bloom et al., 2020b; Hill et al., 2016), within a structured 'Talking Mat' activity (Ajodhia-Andrews & Berman, 2009; Loyd, 2013; Whitehurst, 2007), to capture experiences (Gray & Winter, 2011;

Hart, 2021; Rouvali & Riga, 2021), to supplement parental narratives (O'Leary & Moloney, 2020), and for children to use directly to capture their own experiences (Richards & Crane, 2020). Within these studies, observational methods, or adapted interviews were frequently used alongside creative methods to make meaning and to assist with interpreting children's views. Four studies used videos to capture children's experiences, interactions, and preferences. Two of these studies used video footage to create movies, which were used as a stimulus within adapted interviews (Bradley & Male, 2017; Whitehurst, 2007). Parsons et al., (2021) co-created 'I am…' Digital Stories with practitioners and families to represent preschool aged children's perspectives and unique insights. Similarly, Simmons and Watson (2015) used a participatory approach by co-constructing vignettes with familiar adults following participatory and non-participatory observations of the child over time.

3.4 Purpose of the Methods Developed and Used to Facilitate Voice

All studies aimed to facilitate the voices of children with complex needs regarding their experiences within education settings and developed and/or used a novel methodology. Three studies focussed on facilitating the voices of children with complex needs to explore their experiences, perspectives and interactions within their education setting generally (Ajodhia-Andrews & Berman, 2009; Bradley & Male, 2017; Gray & Winter, 2011). Other studies focused on transition planning (Hart, 2021; O'Leary & Moloney, 2020; Parsons et al., 2021), individualised learning plans (Rouvali & Riga, 2021), and understanding children's feelings and experiences within specific subjects, including drama (Loyd, 2013) and physical education (Fitzgerald et al., 2003). Whitehurst's (2007) study aimed to explore children's retrospective views about their inclusion within an inclusive drama performance.

Five studies also facilitated children to share their views of their experiences in their education setting. However, the focus was on developing the use of a specific methodology to enable children's voices, namely 'I am…' Digital Stories (Parsons et al., 2021), 'Multimodal

Talking Wall' (Richards & Crane, 2020), 'Your Voice, Your Choice Toolbox' (Bloom et al., 2020b) and 'School Preference Cards' and 'Ethnographic approach using SCERTS' (Hill et al., 2016), which were two methods developed specifically for children with limited verbal communication. Simmons and Watson (2015) developed a multi-modal approach to interpret the actions and behaviours of a child with Profound and Multiple Learning Disability (PMLD) within both mainstream and special school settings. Participatory observations were used to 'get to know' the child, followed by the creation of first-person narratives and a 'behaviour state ethogram' to interpret the child's behaviour (a list of behaviour states and their meaning for the individual child).

3.5 Representation of Voice

All 14 articles are discussed in the following sections to explore how children's voices were represented according to Lundy's (2007) framework of Space, Voice, Audience, and Influence.

3.5.1 Space: Has the Child or Young Person Been Invited and Encouraged to Express their Views?

We have interpreted *space* as meaning whether and how children were asked if they wished to participate through inclusive and accessible assent/consent procedures and how ongoing assent to participate was considered throughout research projects. Additionally, *space* considers whether children's views were safely sought i.e., that there was no fear of reprisal, that children were comfortable with the adults supporting them, and these adults were familiar with, and attuned to, children's needs.

Twelve studies that included participants under the age of 16 reported that informed consent had been gained from the child's parents and from relevant adults within the participating setting. Many studies also reported accessible assent/consent procedures, which were created specifically for the children. In three studies the authors described approaches

using a variety of visual tools and support. Bradley and Male (2017) created a "visual consent/information form" (p.83) using Communicate in Print, which is a programme for creating symbol-based resources familiar to the children. Similarly, Loyd (2013) sought consent from the children through "dedicated approaches devised specifically for the research" (p. 10), and Whitehurst (2007) collaborated with the school's Speech and Language Therapist to develop individualised assent procedures, which were adapted to each child's communication skills using a total communication approach. Three studies (Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021) described how they sought assent from children using Social Stories (Gray, 2010). Although Ajodhia-Andrews and Berman (2009) reported that they gained child assent, no information was provided about how this was adapted and individualised to the child's complex needs.

Many researchers described the challenges of gaining meaningful assent from children who do not have the expressive language skills to assent to their participation. Indeed, many ethical considerations were raised relating to this issue. However, where assent was not possible, many authors described the importance of a familiar, attuned adult (e.g., class teacher, teaching assistant, parent) who was responsible for monitoring the child during the time of their involvement for any indications that they no longer wished to participate (Gray & Winter, 2011; Hill et al., 2016; Parsons et al., 2021; Richards & Crane, 2020; Simmons & Watson, 2015). Many studies also reported additional measures that were put in place to support children to communicate their wish to withdrawal or end their involvement within the study. Within three studies, a red 'stop' symbol was made available so children had the opportunity to non-verbally communicate their wish to end their participation and actively dissent (Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021).

For studies that included young people over the age of 16, gaining informed consent was reported as more challenging. Hart (2021) described how consent was creatively sought

and adapted to the communication preferences of the young adults. However, Hill et al. (2016) excluded young people over age 16 from the research process, deeming them as not having "the capacity to consent for themselves' using 'standard procedures'" (p. 28). Despite efforts made to adapt assent forms for children under 16 included in the same study, no adaptations to consent processes were made for young people over 16 years, nor any Mental Capacity Assessment (MCA), or best interest decisions made for their voices to be included. Hill et al. (2016) recognised this as a limitation and suggested future researchers should ensure a "careful process of securing permission" (p.29) is outlined within ethics applications, so this does not present a barrier to accessing the voices of this group. In two studies it was not clear how children were made aware of their choice to participate and the reasons why their views were being sought. Fitzgerald et al. (2003) did not provide a description of consent/assent procedures within the study and although Bloom et al. (2020b) described how parental consent was gained, the authors did not provide details on child consent/assent procedures.

To ensure that children felt safe and comfortable with the adults who were seeking to ascertain their views, eight of the fourteen studies described methods to ensure threat was reduced and children's views safely sought. Children were supported to feel safe and comfortable through the availability and presence of familiar adults who already had an established rapport with them (Bradley & Male, 2017; Richards & Crane, 2020; Whitehurst, 2007). Where the authors were unfamiliar to the children, specific rapport building activities were carried out to support the child to feel comfortable in the presence of the researcher. Parsons et al. (2021) and Simmons and Watson (2015) described that an in-situ researcher spent time in the settings building rapport with the child; Rouvali and Riga (2021) carried out daily intensive interaction sessions with the child for one week prior to data collection; Loyd (2013) carried out observations of the children; and Ajodhia-Andrews and Berman (2009)

stated that 30 minutes of playing and reading together prior to carrying out the adapted interview with the child helped establish rapport. In the remaining studies, it was not clear what measures, if any, were put in place to establish rapport and familiarity between the children and the researcher(s).

3.5.2 Voice: Has the Child or Young Person Been Given the Opportunity to 'Freely' Express their Views and where Appropriate, Facilitated to Form their Views?

This second element within Lundy's (2007) model, *voice*, explores the opportunities children are given to express their views. Understandably, and as acknowledged by Lundy (2007), children with complex needs may need support or "practical assistance" (p. 936) to form their views and for their voice to be expressed using any "media of the child's choice" (p. 935). Therefore, the freedom with which children have been enabled to express their views, and the facilitation provided, are analysed in this section.

3.5.2.2 Freedom: The Agency of Children to Express their Views.

An important consideration when exploring how children's voices have been enabled, is to explore *how* and *to what extent* the child's views, preferences and experiences have been represented in the methods used; in other words, the extent to which children had freedom and agency in sharing their views. Researchers who used more directive, adult-led activities, such as symbol or photo-based communication (e.g., Talking Mats, symbol or photo sorting tasks, cue cards) expressed limitations with these methods. For example, several studies (e.g., Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021) suggested that the child's voice was limited by the number of symbols that were available to them within the activity, whether the symbols used were familiar and meaningful to the young person and to what extent they responded to them with "representational intent" (Hill et al., 2016, p. 35). Similarly, Richards and Crane (2020) reported that support staff found it difficult to ascertain whether the children were demonstrating communicative intent when using the 'Multimodal

Talking Wall' and, therefore, questioned the authenticity of children's voices represented. Accordingly, Richards and Crane (2020) highlighted the importance of triangulation and the use of multiple methods.

Photography was used as a method within ten studies. Four of these enabled children to be agentic by supporting the child to take the photographs themselves (Gray & Winter, 2011; Hart, 2021; Richards & Crane, 2020; Rouvali & Riga, 2021). Young adults in Hart's (2021) study co-created a 'participatory photographic interview', which involved the young people taking photographs as a methodological tool. This was found to be the most inclusive and "influential in the agentic production of knowledge without the need for verbal communication" (Hart, 2021, p.11). However, it was reported that this method included a discussion during and after the photographs were taken, and therefore it is unclear to what extent this method relied on discussion to make meaning. Very few methods were identified in this review as requiring minimal interpretation from adults. Although Parsons et al. (2021) described and acknowledged the centrality of adults in the co-creation of 'I am' Digital Stories, the authors suggested the Digital Stories themselves required little interpretation from adults to understand the experiences of young children. Within this methodology children were positioned as "knowers in their lives" (p.165) and, therefore, the Digital Stories provided a lens into the child's world, independent of adult influence or direction. Digital Stories captured children's experiences and interactions in ways that did not rely on expressive communication skills; rather, children's experiences from their point of view were accessed and jointly witnessed (by families and practitioners) via video clips.

3.5.2.3. Facilitation: How Children Were Supported to Share Views.

Eleven studies sought the involvement of familiar adults to facilitate children to form their views, though these approaches varied considerably. Rouvali and Riga (2021) stated that parents and the child's class teacher helped triangulate responses to assist with interpretation

of the child's views. A questionnaire was given to the parents and the class teacher, and the answers were compared against the child's responses. Although Rouvali and Riga (2021) stated this member checking procedure was "not a means to overpower" (p. 471) the child's voice, it is not clear whose voice was given more weight, should the responses from the adults not have aligned with those of the child. Two studies also collaborated with parents and school staff to co-construct children's views. Familiar adults within these studies provided a lens through which to understand and interpret the children's responses (O'Leary & Moloney, 2020; Simmons & Watson, 2015). Three studies were conducted by at least one researcher who worked within the participating education setting. This was reported as beneficial to supporting the facilitation of children's views due to the researchers being familiar with the child's communication style and having an established relationship with them, thus contributing to them being able to safely express their views (Bradley & Male, 2017; Parsons et al., 2021; Rouvali & Riga, 2021).

Speech and Language Therapists who were familiar with the children, were also identified as key adults who were consulted to support with the development of methods to enable children to express their views (Loyd, 2013; Whitehurst, 2007). Their involvement was also reported to increase understanding about how each pupil communicated i.e., through identification of their preferred communication method and to individualise and personalised the methods specific to each child (Loyd, 2013). Parsons et al. (2021) collaborated with parents and nursery staff to ensure that the children's experiences were accurately represented in their Digital Stories and therefore played a central role in their construction. Hill et al. (2016) developed a Young Researchers group who, amongst other tasks, were responsible for providing feedback on accessibility and appropriateness of the methods developed to facilitate the children's views. Finally, Hart (2021) involved young people as research

partners. This enabled them to be agentic in their involvement in the research and were directly involved in the co-creation of inclusive interviews.

3.5.3 Audience and Influence: Has the Child or Young Person's Views Been Listened to and Has the Child or Young Person's Views Been Acted Upon, as Appropriate?

The third and fourth elements within Lundy's (2007) model are *audience* and *influence*, and these were combined due to the degree of overlap. This means considering how children's views are listened to, not just heard by those involved in decision-making, and whether children's views have been given due weight. These elements are also concerned with whether children's views have been taken seriously and whether they influenced change.

Very few studies reported whether the children's views influenced change within the education setting. Only three studies described, albeit in varying detail, how children's views had been acted upon and led to changes. Parsons et al. (2021) described how the Digital Stories were shown and jointly witnessed by families, nursery staff and, crucially, the primary school to which the child was transitioning. Watching the Digital Story enabled the receiving school to plan activities and adapt the environment to ensure that the children were included and transitioned successfully. Rouvali and Riga (2021) used multiple methods to facilitate the wishes, preferences, and experiences of their child, which shaped the development of their new Individual Learning Plans (ILP). Encouragingly, Rouvali and Riga (2021) reported a "significant decrease" (p. 475) in the child's challenging behaviour following the implementation of the new ILP. However, it was not reported how this reduction in behaviour was measured, how significance was determined, or who had reported this. Gray and Winter (2011) made changes within the classroom environment in response to the children's views (e.g., removed smelly rubbish bins) and provided the children with opportunities to share their views within their pre-school graduation, by presenting their photographs, drawings, and collages of their school preferences. Nevertheless, it is unclear

whether the children's preferences reflected the voices of children with complex needs since children with and without a known disability were matched into pairs to collaborate and form a shared view. Gray and Winter (2011) reported that "not every dyad was a success" (p. 319), especially where children in dyads had different communication skills. Therefore, it is unclear how much influence the non-disabled peer had over the construction of those views.

The remaining studies did not provide details on how the children's views were acted upon, if at all. Some studies reported that more time was needed to embed the method within the school, acknowledging that the method developed was in its infancy (e.g., Richards & Crane, 2020). Bradley and Male (2017) described that on completion of the study, all children were sent a personalised letter stating that their voices had been heard and views valued. However, within the research it was not stated how these views were acted upon. Similarly, Loyd (2013) shared that the views of the young person would guide future lesson planning, but it was not stated whether this happened and if the young person's views affected change within drama lessons. Finally, within Hart's (2021) study, it was not explicitly stated whether the views of the young adults influenced decision-making within their transition planning to adulthood.

4. Discussion

This systematic literature review aimed to identify the current research on the development and use of methods which have been designed to facilitate sharing the voices of children and young people with complex needs about their educational experiences and preferences. Additionally, and unique to this review, identified methods were considered in relation to Lundy's (2007) conceptual framework of *Space, Voice, Audience,* and *Influence*. In alignment with Fayette and Bond (2018), the findings highlight that research exploring the development and use of methods for voice remains in its infancy, with only fourteen studies across eight bibliographic databases meeting the inclusion criteria. Therefore, while this

review identified creative methods that have been used to facilitate the voices of children with complex needs, far more needs to be done to enable the voices of this frequently marginalised group to be meaningfully heard within research and practice.

Notwithstanding the relatively small number of studies identified, there are some clear messages for research and practice that follow from this review. First is the importance of using a "toolbox" (Gray & Winter, 2011, p.313) of methods for enabling children to participate in different ways, over several sessions, over time. None of the papers used only one method or a single encounter with participants, choosing multi-modal approaches that included photographs, symbols, video, observations, sign language, and adapted questionnaires. These methods were often deployed flexibly and shaped to meet the communication needs and preferences of the young people. The research teams understood that time is needed with children with complex needs (usually over weeks and months) to build relationships and understanding of the person and their context before making meaning or interpreting preferences. Moreover, many approaches included the creation of visual artifacts that were amenable for sharing and display, such as Digital Stories, posters, and graffiti walls. Such public displays move beyond the collation of data for research purposes to position the child's creativity and contributions – their voice – as important, and worthy of expressing meaning in its own right (Ashby, 2011). Such participatory and celebratory approaches stand in contrast to more extractive approaches to data collection that aim for standardisation of questions and are based on single sessions (cf. Courchesne et al., 2021).

Taking a toolbox approach highlights the importance of creating "non-orthodox" methods (Parsons et al., 2022, p.1072), which include those that do not rely on verbal communication or discussion to make meaning. Although the use of symbols can helpfully be used to make choices and state preferences, in some studies it was suggested that children responded to these visuals (e.g., cue cards, symbols) without representational intent (Hill et al., 2016;

Richards & Crane, 2020). It is well documented that visual systems such as Talking Mats can provide an understanding on preferences i.e., what the child 'likes' and 'does not like'. However, there is a concern whether the child's voice is limited by the symbols available or the number which hold representational value for them (Brewster, 2004). This suggests the value of symbol or photo-based communication when used alongside other methods to facilitate the views of children. Indeed, no studies used symbols in isolation, and symbols were combined with other communication strategies to make meaning. For children who may express little spoken language, it is especially important to consider a range of methods, including more embodied approaches, that do not require verbal discussion or understanding and presentation of propositional knowledge (Parsons et al., 2021; Simmons & Watson, 2015). The findings overwhelmingly agree with Lewis and Porter (2007) that children's views should be explored "flexibly, collaboratively and variously" (p. 229).

A further strength identified within many of the studies was the importance of including familiar adults within the research who have an established relationship and, therefore, an in-depth understanding of the child to enable methods to be personalised to the child's unique strengths and needs (see also Tesfaye et al., 2019). Three studies highlighted the value of co-constructed methods to facilitate voice, and how co-construction with key personnel who know the child well can support these methodologies being used within practice (Hart, 2021; Parsons et al., 2021; Simmons & Watson, 2015). Crucially, such co-construction of knowledge should include the child (e.g., Parsons et al., 2021; Simmons & Watson, 2015), but Fayette and Bond (2018) found that many studies failed to engage children within research, therefore impacting how person-centred and individualised the methods developed were. Concerns continue to exist in the literature about research being carried out *on* people rather than *with* people (Morris, 2003; Parsons et al., 2021). This observation further

highlights the need for participatory approaches that not only include adults, but also the children themselves.

Indeed, the conceptual analysis of the identified literature according to Lundy's (2007) framework highlighted that most studies failed to demonstrate how children's views were given due weight in the research or how the findings influenced practice and understanding. Several studies reported that understanding children's perspectives had led to changes in practice but failed to describe how the child's views had been acted upon and, specifically, the impact children's voices had on educational decision-making processes. Concerningly, even when this was addressed as a specific aim or research question within the study, there was no discussion within the findings about how the child's views were taken seriously and acted upon (Fitzgerald, 2003; Richards & Crane, 2020). These findings are a good reminder about the importance of retaining a critically evaluative lens on the purpose for facilitating voices in research, since so often it is the researcher or research team who benefits the most rather than the young people whose voices have been 'given' (Ashby, 2011).

Thus, while researchers have demonstrated a commitment to developing and evaluating the impact of the methods they design and use in research, crucially, these methods also need to be accessible and replicable so that they can be applied in education settings and embedded in practice. Ultimately, this impacts on the extent to which children's voices are not only heard, but actively listened to, acted upon, and taken seriously. A more holistic conceptualisation of voice needs to be embraced in research, policy and within practice to enable children's inclusion with educational decision-making on matters which affect their lives. Voice needs to be understood and valued as more than spoken words to incorporate the many ways in which *all* children communicate and express themselves (Ashby, 2011; Doak, 2018). The lack of inclusive methods developed in research, and successfully embedded in practice, further marginalises children's voices and perpetuates the dominant deficit-based

narrative about them i.e., that children with the most complex needs are not capable of forming and expressing a view (Bloom et al., 2020a; Hill et al., 2016). This assumption needs to be continually challenged by encompassing and embracing the many ways in which children and young people can express their views.

Researchers also need to ensure inclusivity is embedded within their methodology at the earliest stages of research design by developing accessible consent or assent procedures for children with complex needs. Many researchers included within the findings of this review described the challenges of gaining consent or assent from children with learning and communication difficulties. Indeed, in one study young people over the age of 16 who were considered as lacking capacity to consent to participate in the research were excluded (Hill et al., 2016). These difficulties are commonly reported in the literature with some authors suggesting that "obtaining informed consent may be a considerable undertaking and daunting to achieve" (Lewis, 2002, p.111). However, boundaries must be pushed and, as identified in this review, flexible individualised and multimodal (predominantly visual) approaches must be developed to obtain meaningful consent or assent from children with complex needs (e.g., Loyd, 2012). Additionally, for children under 16 where this is not possible, their continued assent to participation must be monitored on an ongoing basis via familiar staff. Therefore, a key implication of these findings is the importance of researchers developing accessible assent and consent procedures to enable all children and young people to participate, so that the continued marginalisation of voices and experiences can be actively addressed in research rather than passively accepted as an insurmountable challenge.

In line with this observation, many researchers suggested that their methods were "promising" and "worthy of further development" (Richards & Crane, 2020, p.4276) or had "considerable potential for providing greater insight" (Hill et al., 2016, p.30). These statements reinforce that research remains at the early stages of developing inclusive

methodologies for children with complex needs, and it is not clear whether and how such further developments are taking place. Moreover, efforts to facilitate children's views should not stop with the researcher developing the method/the research, and more needs to be done to embed these methods in practice where they have the potential to make a meaningful impact on children's lives (Bloom et al., 2020b). Indeed, as argued by Prout (2003) "...too often children are expected to fit into adult ways of participating when what is needed is institutional and organisational change that encourages and facilitates children's voices" (p. 32). It is through researchers working *with* children and families and practitioners in context where such institutional and organisational changes can be made (Parsons, 2022; Parsons et al., 2022).

4.1 Strengths and limitations of the review

These findings address a significant gap in the literature by identifying methods developed and used to enable children with complex needs to have a voice about different aspects of their education. Only one article (Loyd, 2013) was also included in Tesfaye et al.'s (2019) review, thereby validating the need for our more specific and focused search and highlighting the novelty of our contribution. Lundy's (2007) model was also uniquely applied as a framework for critically reviewing how voice was enacted in the identified papers. Crucially, the findings challenge the dominant view that the voices of children with complex needs are too difficult to access (also Hill et al., 2016). An additional strength is the wide range of databases searched which reflected the range of professionals and professions who are involved in facilitating children's views within education. However, pre-defined inclusion and exclusion criteria may have missed or excluded some studies e.g., if not conducted within education settings (such as Carroll & Sixsmith, 2016; Stafford, 2017). Additionally, grey literature was not searched, and dissertations / theses were excluded.

A further strength is that identified papers were qualitatively assessed using the CASP (2018) to explore their methodological strengths and limitations. A key finding about study quality was the absence of transparency within data analysis, with ten of the fourteen studies either failing to analyse their data e.g., by presenting themes in their findings without providing detail about how these themes were generated or providing insufficient information about how their data was analysed. Additionally, the guiding qualitative paradigm in several studies was either not described or was expressed with poor clarity and conceptual confusion (see Bloom et al., 2020b and Simmons & Watson, 2015 for exceptions). The theoretical or epistemological underpinnings or assumptions of the researchers must be made explicit within qualitative research and is integral to understanding how methodologies and methods are understood. Therefore, it is important that future research is conducted in a way that is theoretically and methodologically coherent and researchers are clear about *how* they are analysing their data.

It is also important to consider *what* is analysed as well as how it is analysed. Doak's (2018, 2020) research is a powerful reminder that if we accept that children with complex needs communicate their voices in multi-modal ways, including non-verbally and through typing and gestures, then the analysis of their voice must also be multi-modal to adequately represent the variety and complexity of communication. This is another major challenge that remains to be adequately taken up by researchers in this field.

4.2 Conclusions and implications for professionals

The findings of this review emphasize how it is possible to access the views of children and young people with the most complex needs. However, it requires researchers to push boundaries by developing inclusive methods which are novel, creative, and individualised to each young person and to be willing to spend time with young people and the adults who know them well. The time and resource implications of doing research in this way are

significant but it is increasingly indefensible to say that such approaches are too hard to do, or that they provide data that are too hard to analyse. All children and young people have the right to express a view and for that view to be taken seriously and these rights must not be contingent on their perceived capacity or skills to express one. Indeed, with 168 countries having ratified the UNCRC (1989) and 164 signing the UNCRPD (2006), there is both a legal and moral obligation to ensure all children's voices are heard and listened to. All forms of communication need to be valued and recognised for barriers to participation and expression to be removed.

The findings also show that girls are underrepresented relative to boys and, in some cases, the gender of the young people included in studies was not reported at all. The higher ratio of boys to girls amongst children with complex needs is well documented, especially in autism, which was the main diagnostic category reported for children in most of the studies (Loomes et al., 2017). However, there is increasing recognition of the many factors that may lead to the under-diagnosis of autism in females (Hull et al., 2020), which also impacts on their experiences of education and (lack of) support received (Goodall & MacKenzie, 2019). Research clearly needs to report the gender of participants and consider the role of gender as well as other intersectional characteristics (Cascio et al., 2021) on participation, methods and findings.

The findings also highlight that more needs to be done to ensure that children's views are acted upon and given due weight. This can be achieved through adopting participatory approaches that include not only adults, but also the children themselves. Ensuring that methods to facilitate voice are co-constructed with adults who know the child well and include the child is therefore vital. Future research could consider using Lundy's (2007) model of *Space, Voice, Audience* and *Influence* as a framework when developing and evaluating methods to facilitate the voices of children with complex needs to ensure that the

tenets of Article 12 are critically assessed, and stronger practices implemented. Overall, the most important implication from this review is that inclusive, person-centred methods must continue to be developed to enable children who are frequently marginalised and excluded to have a voice within decisions impacting their education, and that their views are taken seriously and influence change.

References

* denotes the papers identified through the systematic search

*Ajodhia-Andrews, A., & Berman, R. (2009). Exploring school life from the lens of a child who does not use speech to communicate. *Qualitative Inquiry*, *15*(5), 931-951. https://doi.org/10.1177/1077800408322789

Ashby, C. E. (2011). Whose" voice" is it anyway? Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly*, *31*(4). https://dsq-sds.org/article/download/1723/1771

Bloom, S., Critten, S., Johnson, H., & Wood, C. (2020a). A critical review of methods for eliciting voice from children with speech, language and communication needs. *Journal of Research in Special Educational Needs, 20*(4), 308-320. https://doi.org/10.1111/1471-3802.12491

*Bloom, S., Critten, S., Johnson, H., & Wood, C. (2020b). Evaluating a method for eliciting children's voice about educational support with children with speech, language and communication needs. *British Journal of Special Education, 47*(2), 170-207. https://doi.org/10.1111/1467-8578.12308

Boland, A., Cherry, G., & Dickson, R. (2017). *Doing a Systematic Review: A Student's Guide* (2nd ed.). Sage Publications.

*Bradley, K., & Male, D. (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, 43*(2), 80-93.

Browning, J., Osborne, L. A., & Reed, P. (2009). A qualitative comparison of stress in adolescents with and without autistic spectrum disorders as they approach leaving school. *British Journal of Special Education, 36*(1), 36–43. https://doi.org/10.1111/j.1467-8578.2008.00400.x

Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning

disabilities and little/no speech. *British Journal of Learning Disabilities*, *32*(4), 166-

169. https://doi.org/10.1111/j.1468-3156.2004.00319.x

Carroll. C., & Sixsmith. J. (2016). Exploring the facilitation of young children with

disabilities in research about their early intervention service. *Child Language*

Teaching and Therapy, 32(3), 313–325. https://doi.org/10.1177/0265659016638394

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making autism research inclusive by

attending to intersectionality: A review of the research ethics literature. *Review*

Journal of Autism and Developmental Disorders, 8, 22-36.

https://doi.org/10.1007/s40489-020-00204-z

Courchesne, V., Tesfaye, R., Mirenda, P., Nicholas, D., Mitchell, W., Singh, I.,

Zwaigenbaum, L., & Elsabbagh, M. (2021). Autism Voices: A novel method to access

first-person perspective of autistic youth. *Autism*, 1-14.

https://doi.org/10.1177/13623613211042128

Critical Appraisal Skills Programme. (2022)*. CASP Qualitative Studies Checklist.*

https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-

Checklist/CASP-Qualitative-Checklist-2018_fillable_form.pdf

Davis, J., & Watson, N. (2000). Disabled Children's Rights in Everyday Life: Problematising

Notions of Competency and Promoting Self-Empowerment. *The International Journal*

of Children's Rights, *8*(3), 211-228. https://doi.org/10.1163/15718180020494622

Department for Education (DfE) & Department of Health (DoH). (2015). *Special educational*

needs and disability code of practice: 0 to 25 years.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data

/file/398815/SEND_Code_of_Practice_January_2015.pdf

DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 60-71. https://doi.org/10.1177/1088357615587504

Doak, L. (2019). 'But I'd rather have raisins!': Exploring a hybridized approach to multimodal interaction in the case of a minimally verbal child with autism. *Qualitative Research*, *19*(1), 30-54. https://doi.org/10.1177/1468794117752115

Doak, L. (2020). Realising the 'right to play' in the special school playground. *International Journal of Play*, *9*(4), 414-438. https://doi.org/10.1080/21594937.2020.1843805

Ellis, J. (2017). Researching the social worlds of autistic children: An exploration of how an understanding of autistic children's social worlds is best achieved. *Children & Society*, *31*(1), 23–36. https://doi.org/10.1111/chso.12160

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

*Fitzgerald, H., Jobling, A., & Kirk, D. (2003). Physical education and pupil voice: Listening to the 'voices' of students with severe learning difficulties through a task-based approach to research and learning in physical education. *Support for Learning, 18*(3), 123–129. https://doi.org/10.1111/1467-9604.00294

Flutter, J., & Rudduck, J. (2004). *Consulting pupils: what's in it for schools?* Routledge.

Gersch, I. S., Lipscomb, A., Stoyles, G., & Caputi, P. (2014). Using philosophical and spiritual conversations with children and young people: A method for psychological

assessment, listening deeply and empowerment. *Educational and Child Psychology, 31*(1), 32–47.

Goodall, C., & MacKenzie, A. (2019). What about my voice? Autistic young girls' experiences of mainstream school. *European journal of special needs education*, *34*(4), 499-513. https://doi.org/10.1080/08856257.2018.1553138

*Gray, C., & Winter, E. (2011). Hearing voices: participatory research with preschool children with and without disabilities. *European Early Childhood Education Research Journal*, *19*(3), 309-320. https://doi.org/10.1080/1350293X.2011.597963

Gray, C. (2010). *The new social story book (Revised and Expanded 10th Anniversary Edition.)*. Future Horizons.

*Hart, S. (2021). Agentic ethnography: inclusive interviews of young adults with significant disabilities on the transition from school. *International Journal of Research & Method in Education, 45*(1), 3-17. https://doi.org/10.1080/1743727X.2021.1881057

Hesjedal, E. (2021). Educational psychology counsellors' views about children's participation in educational decision-making: A thematic analysis. *The International Journal of Children's Rights*, *29*(3), 640-661. https://doi.org/10.1163/15718182-29030005

*Hill, V. C., Croydon, A., Greathead, S., Kenny, L., Yates, R., & Pellicano, E. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. *Educational and Child Psychology*, *33*(3), 26-43.

Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism and Developmental Disorders*, *7*, 306-317. https://doi.org/10.1007/s40489-020-00197-9

Lewis, A., & Porter, J. (2007). Research and pupil voice. In L. Florian (Ed.), *The SAGE handbook of special education* (pp. 222–232). Sage Publications.

Lewis, A. (2002). Accessing, through research interviews, the views of children with difficulties in learning. *Support for learning*, *17*(3), 111-116. https://doi.org/10.1111/1467-9604.00248

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), 31-42. https://doi.org/10.1177/2632084320947559

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466-474. https://doi.org/10.1016/j.jaac.2017.03.013

*Loyd, D. (2012). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities, 41*(2), 133–40. https://doi.org/10.1111/j.1468-3156.2012.00734.x

Loyd, D. (2013). Gaining views from pupils with autism about their participation in drama classes. *British Journal of Learning Disabilities, 43*(1), 8-15. https://doi.org/10.1111/bld.12078

Lundy, L. (2007). 'Voice' is not enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal, 33*(6), 927–942. https://doi.org/10.1080/01411920701657033

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *British Medical Journal, 339,* 1-8. https://doi.org/10.1136/bmj.b2535

Morris, J. (2003). Including all children: Finding out about the experiences of children with communication and/or cognitive impairments. *Children & Society, 17*(*5*), 337–348. https://doi.org/10.1002/CHI.754

Nicholas, D. B., Orjasaeter, J. D., & Zwaigenbaum, L. (2019). Considering methodological accommodation to the diversity of ASD: A realist synthesis review of data collection methods for examining first-person experiences. *Review Journal of Autism and Developmental Disorders*, *6*(2), 216-232. https://doi.org/10.1007/s40489-019-00164-z

Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series-paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology*, *97* (May 2018), 49–58. https://doi.org/10.1016/j.jclinepi.2017.06.020

Noyes, A. (2005). Pupil voice: Purpose, power and the possibilities for democratic schooling. *British Educational Research Journal, 31*(4), 533-540. https://doi.org/10.1080/01411920500153614

*O'Leary, S., & Moloney, M. (2020). Understanding the experiences of young children on the autism spectrum as they navigate the Irish early years' education system: Valuing voices in child-centered narratives. *International Journal of Qualitative Methods, 19,* 1-11. https://doi.org/10.1177/1609406920914696

Parsons, S. (2021). The importance of collaboration for knowledge co-construction in 'close-to-practice' research, *British Educational Research Journa*l, *47*(6), 1490-1499. https://doi.org/10.1002/berj.3714

*Parsons, S., Ivil, K., Kovshoff, H., & Karakosta, E. (2021). 'Seeing is believing': Exploring the perspectives of young autistic children through Digital Stories. *Journal of Early Childhood Research, 19*(2), 161-178. https://doi.org/10.1177/1476718x20951235

Parsons, S., Kovshoff, H., & Ivil, K. (2022). Digital stories for transition: co-constructing an evidence base in the early years with autistic children, families and practitioners. *Educational Review*, *74*(6), 1063-1081. https://doi.org/10.1080/00131911.2020.1816909

Pellicano, E., Hill, V., & Croydon, A. (2014). *My life at school: understanding the experiences of children and young people with special educational needs in residential special schools.* Office of the Children's Commissioner. http://www.childrenscommissioner.gov.uk/sites/default/files/publications/My_Life_at_School_.pdf

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

Prout, A. (2003). Participation, policy and the changing conditions of childhood. In C. Hallett & A. Prout (Eds.), *Hearing the voices of children: Social policy for a new century* (pp. 11-25). Routledge Falmer.

*Richards, N., & Crane, L. (2020). The development and feasibility study of a multimodal 'talking wall' to facilitate the voice of young people with autism and complex needs: A case study in a specialist residential school. *Journal of Autism and Developmental Disorders*, *50*(12), 4267-4279. https://doi.org/10.1007/s10803-020-04476-6

*Rouvali, A., & Riga, V. (2021). Listening to the voice of a pupil with autism spectrum condition in the educational design of a mainstream early years setting. *Education 3-13, 49*(4), 464 - 480. https://doi.org/10.1080/03004279.2020.1734042

*Simmons, B. R., & Watson, D. L. (2015). From individualism to co-construction and back again: Rethinking research methodology for children with profound and multiple learning disabilities. *Child Care in Practice, 21*(1), 50-66. https://doi.org/10.1080/13575279.2014.976179

Sinclair, R. (2004). Participation in practice: making it meaningful, effective and sustainable, *Children & Society, 18*(2), 106–118. https://doi.org/10.1002/chi.817

Stafford, L. (2017). 'What about my voice': Emancipating the voices of children with disabilities through participant-centred methods. *Children's Geographies, 15*(5), 600–613. https://doi.org/10.1080/14733285.2017.1295134

Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, I., Shikako-Thomas, K., Mirenda, P., Waddell, C., Smith, I.M., Nicholas, D., Szatmari, P., Bennett, T., Duku, E., Georgiades, S., Kerns, C., Vaillancourt, T., Zaidman-Zait, A., Zwaigenbaum, L., & Elsabbagh, M. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism*, *23*(8), 1882-1896. https://doi.org/10.1177/1362361319831487

Tyrrell, B., & Woods, K. (2018). Gathering the views of children and young people with ASD: a systematic literature review. *British Journal of Special Education*, *45*(3), 302-328. https://doi.org/10.1111/1467-8578.12235

United Nations Convention on the Rights of the Child, November 20, 1989, https://www.ohchr.org/en

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, *45*(6), 1673–1688. https://link.springer.com/article/10.1007/s10803-014-2324-2

*Whitehurst, T. (2007). Liberating silent voices? Perspectives of children with profound & complex learning needs on inclusion. *British Journal of Learning Disabilities*, *35*(1), 55–61. https://doi.org/10.1111/j.1468-3156.2006.00405.x

Table 1   *Search syntax*

Search term	Syntax
Method	AB (Method* OR tool* OR technique* OR approach* OR framework*) OR TI (Method* OR tool* OR technique* OR approach* OR framework*
Voice	AB (voice* OR view* OR perspective* OR communicat* OR participat* OR consult*) OR TI (voice* OR view* OR perspective* OR communicat* OR participat* OR consult*)
Child	TI (child* OR "young pe*" OR pupil* OR student* OR "young adult*" OR teen* OR adolescen* OR infant* OR youth* OR preschooler*)
Complex needs	TI ("complex need*" OR "non-verbal*" OR "no words" OR "pre-verbal" OR "communication need*" OR "communication impairment*" OR "communication difficult*" OR "learning difficult*" OR "special educational need*" OR "multiple need*" OR disab* OR autis* OR ASC OR ASD)
Experience	AB (experience* OR preferenc* OR decision* OR choice* OR evaluation* OR perception*) OR TI (experience* OR preferenc* OR decision* OR choice* OR evaluation* OR perception*)
Elicit	AB (elicit* OR explor* OR promot* OR gather* OR express* OR listen* OR share OR access* OR ascertain OR collect) OR TI (elicit* OR explor* OR promot* OR gather* OR express* OR listen* OR share OR access* OR ascertain OR collect)

| Education | AB (educat* OR school* OR nurser* OR college* OR provision* OR setting* OR service*) OR TI (educat* OR school* OR nurser* OR college* OR provision* OR setting* OR service*) |

Table 2 *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
Children and young people must be aged between 0 and 25 years*.	Children and young people are over 25 years old.
The study explores the development and use of a data collection method(s).	Inclusion within the study is contingent on the child or young person's ability to verbally engage or cognitive ability.
The focus of the research is on facilitating the voice of children who have complex needs/limited verbal communication.	The views of adults (e.g., parents or teachers) have been used as a proxy for children's views.
The study has been carried out in an education setting (e.g., preschool, primary school, residential special school etc.) and focuses on understanding the views, preferences and perspectives of children and young people.	Research is focused on eliciting the views of adults and / or children's views have been elicited as part of a wider study involving others (e.g., parents or teachers) and their views cannot be separated from the view of adults in the data.
Qualitative, peer reviewed research.	The study has been carried out in a non-education context (e.g., hospital, community centre)
Written in English.	Research published pre-1989, i.e., prior to the publication of the UNCRC, which marked a shift in research emphasising the importance of eliciting children's views.
	Research published in books, doctoral and master's theses or dissertations.

* The World Health Organisation includes young people up to age 24 in their definition; the Special Educational Needs and Disability legislation in England (Department for Education / Department of Health, 2015) puts the upper age range at 25 years.

Table3 Quality assessment of included studies [*Note.* Asterix indicates additional criteria]

Study	Hart (2021)	Rouvali & Riga (2021)	Bloom et al. (2020b)	O' Leary & Moloney (2020)	Parsons, Ivil et al (2020)	Richards & Crane (2020)	Bradley & Male (2017)	Hill et al. (2016)	Simmons & Watson (2015)	Loyd (2013)	Ajodhia-Andrews & ...	Gray & Winter (2011)	Whitehurst (2007)	Fitzgerald et al. (2003)
1. Clear statement of aims	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Appropriate qualitative methodology	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Appropriate design	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Appropriate and clearly stated qualitative paradigm*	Yes	Somewhat	Yes	Yes	Yes	No	No	Can't Tell	Yes	Yes	Yes	Yes	No	No
5. Appropriate recruitment strategy	Somewhat	Can't tell	Yes	Yes	Yes	Yes	Can't tell	Can't tell	No	Yes	Can't tell	Can't tell	Can't tell	Can't tell
6. Appropriate data collection	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes
7. Considered researcher-participant relationship	Yes	Yes	Somewhat	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Can't tell	Somewhat	Somewhat
8. Ethical consideration	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell
9. Rigorous data analysis	No	No	Yes	Can't tell	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Can't Tell	No	Can't tell	Can't tell
10. Clear statement of findings	Can't tell	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	No	No	No	Yes
11. Valuable	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 4 *Descriptive summaries of studies included in the review (ordered from most recently published)*

Study and country	Setting	Participant information			Data collection methods		
		Characteristics	Diagnosis(es)*	Verbal communication skills	What method has been developed/used to elicit voice?	How is 'voice' represented?	For what purpose?
Hart (2021) New Zealand	Two urban special schools	N: 3 Age: 21 years Gender: male	Autism (n = 2) Autism, severe and multiple learning difficulties, visual impairment (n = 1)	Non-verbal (n = 1) Limited verbal communication (n = 1) Verbal (n = 1)	Observation - fieldnotes and photographs and videos. Adapted interviews cocreated with the young adults.	Visual methods, including objects, photographs, and videos.	To express the young adults' capabilities, perspectives, and transition preferences.
Rouvali & Riga (2021) Greece	Mainstream Early Years setting	N: 1 Age: 6 years Gender: female	Autism and Global Developmental delay	Non-verbal	Multiple methods including observation, photographs, Talking Mats, adapted questionnaire. Mosaic approach used to triangulate and assist interpretation.	Vignettes written by the researcher. Visual methods including photographs, symbol and photo-based sorting activities to indicate preferences.	To explore an autistic child's wishes, needs, emotions and experiences, to develop her new Individual Learning Plan (ILP).
Parsons, Ivil et al. (2021) England	Nursery school	N: 5 Age: 4 years Gender: male	Autism (n = 5)	Pre-verbal (n = 5)	'I am…' Digital Stories created in collaboration with adults who know the child well. Video clips of children representing their actions and behaviours were recorded on video cameras and	Unique insights and children's perspectives are represented within the Digital Stories. Wearcam footage showed children's choices,	To explore the experiences, perspectives, and interactions of children to support

							transition to primary school.
					small Wearcams, worn by each child, which provided insight into children's interactions and choices from their perspective.	interactions, and preferences from the child's point of view.	
Bloom et al. (2020b) England	Six mainstream and special schools	N: 7 Age: 4-18 years Gender: 3 males, 4 females	Verbal dyspraxia (n = 1) Down syndrome, hearing impairment, SLD (n = 1) Autism (n = 3) Autism and ADHD (n = 1) FAS (n = 1)	Verbal dyspraxia (n = 1) Verbal (n = 4) Non-verbal (n = 1)	'Your Voice, Your Choice' toolkit (multiple methods), comprising of semi-structured interview, questionnaires, observations, reports, and the interviewers' reflections	Photographs or illustrations of children's experiences and emotion cue cards, used to indicate preferences.	To explore children's feelings about their school learning and support experiences.
O'Leary & Moloney (2020) Ireland	Preschool and primary school	N: 9 Age: 3-6 years Gender: N/A	Autism (n = 9)	Verbal (n = 4) Non-verbal (n = 5)	Visual elicitation methods - visual storytelling to create child-centred stories. Narrative interview method with parents.	Visual methods, including photo-elicitation and use of artifacts. Parent narratives.	To understand the early years education experiences of young children transitioning to primary school.
Richards & Crane (2020) England	Residential special school	N: 10 Age: 15-26 years Gender: 6 male, 5 female	Autism and cooccurring conditions including: Epilepsy (n = 4) ADHD (n = 2) Tourette's syndrome (n = 2) Additional	Limited verbal communication (n = 10)	Multimodal 'Talking Wall' – adapted graffiti wall created by combining several elements from previously trialled methods in the literature, including: Photovoice, Talking Mats, School Preference Cards,	Young people's collective voice was showcased on "interactive collection points" i.e., the walls contained text, artefacts, images photographs and	To capture the experiences and preferences of autistic young people within a residential special school.

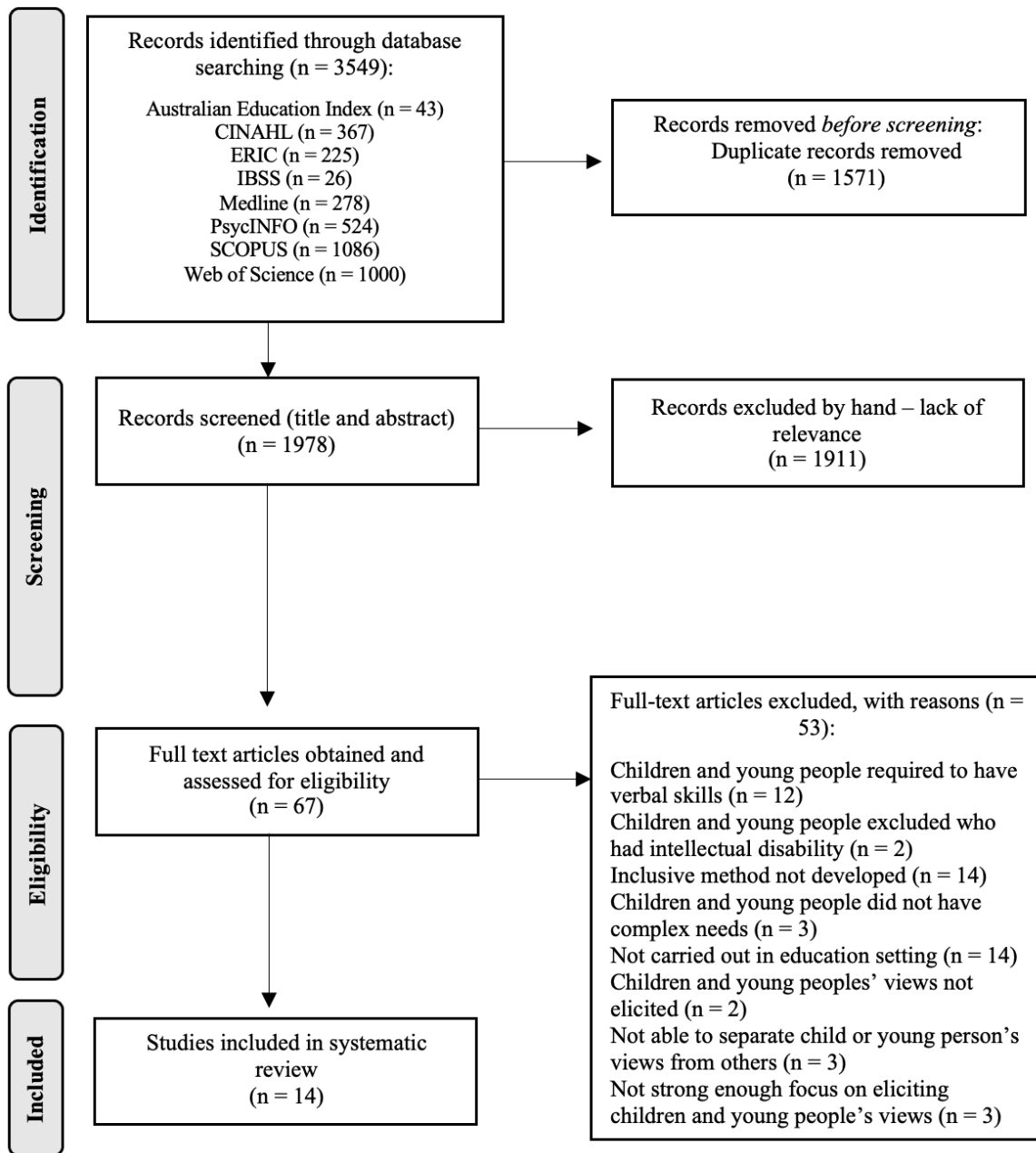|							
			medical needs (n = 1)		Graffiti Wall and the Mosaic Approach.	audio-based evidence (p. 4269).	
Bradley & Male (2017) England	Special school (forest school provision)	N: 4 Age: 6 -8 years Gender: male	Autism and Severe Learning Disability (n = 4)	Not specified	Multiple methods including, video footage of children's experience in school which formed a 'Forest School Movie', one was created for each child and adapted interviews which were carried out with each child to capture their verbal and non-verbal responses to their video.	The Forest School Movie captured the children's preferences, explorations, and interactions. Children were supported through creative expression (e.g., drawings) to express their views.	To explore what children liked and did not like about Forest School, and how Forest School made them feel.
Hill et al. (2016) England	Residential special school	N: 83 Age: 8 -19 years Gender: 50 male, 33 female	ADHD (n = 2) ASD (n = 44) BESD (n = 3) SLD (n = 1) Epilepsy (n = 3) HI (n = 11) MLD (n = 3) PMLD (n = 2) SLCN (n = 13) VI (n = 1) Note: Many children were reported to have cooccurring needs.	Not specified	Diamond ranking activity and graffiti wall used for children with verbal ability. Two methods developed specifically for children with PMLD (n = 15) and limited verbal communication including, School preference cards, comprising photographs of the child's environment, which involved a card sorting activity, and an Ethnographic approach using SCERTS communication checklist, an approach which used	Photographs and symbols were used to represent the child's environment. These were sorted into preference categories by the children. Photos of these boards were taken to capture their preferences. A first-person narrative (known as an 'ethnographic narrative') about the child's life at school was written by the researcher.	To elicit children's school preferences, and to understand the motivations underlying their responses. To capture and describe the nature of interactions between children and support staff.

					ethnographic methods and structured observations.		
Simmons & Watson (2015) England	Special school and mainstream primary school	N: 1 Age: 9 years Gender: male	PMLD (cerebral palsy and visual and auditory impairments)	Pre-verbal	Participatory observations as a method to 'get to know' the child and a way of 'being with'. Non-participatory observations led to the creation of vignettes describing the child's interactions, behaviours and experiences. 'Behaviour state ethogram' provided a lens to interpret the child's behaviour.	Through vignettes (first person narratives) produced from 'sensitive observation' and 'co-constructed interpretation of [the child's] behaviour and interactions' (p. 63)	To understand the child's actions and behaviours and to explore how their social engagement across both mainstream and special school settings impacts their development and learning.
Loyd (2013) England	Autism unit at an FE college	N: 10 Age: 16 -18 years Gender: 6 female, 4 male	Autism (n = 10)	Verbal (n = 4) Limited/no verbal communication (n = 6)	Observation in drama and other lessons for 34 weeks. Multimodal interview approach (4-part process) using Talking Mats, visual support, photographs and videos of the young people in drama.	Expression of their preferences and engagement through symbols, video footage and photographs. Pupils who communicated nonverbally used familiar Widgit symbols to communicate their preferences.	To explore young people's social communication and interaction skills when participating in drama education and to understand young people's experience within drama sessions.
Gray & Winter (2011)	Pre-school	N: 18 Age: 3-4 years	Autism (n = 8) Autism and ADD (n = 4)	Not specified	Multi-method approach was used, informed by the Mosaic Approach. A toolbox of	The children used tape recorders, attached thumbs up and thumbs	To elicit the views and preferences of disabled and non-

Northern Ireland		Gender: 9 male and 9 females Note: each of the 18 children with disabilities was paired with a non-disabled child so 36 participants in total	VI (n = 3) Down's syndrome (n = 2) Cerebral palsy (n = 1)		methods was developed to represent the children's views. The toolbox included: a rag doll (used as a stimulus), stickers, smiley faces, drawings, cameras, and tape recorders.	down signs to most and least liked objects, took pictures using the disposable cameras and created paintings.	disabled children on their daily experiences in their preschool setting.
Ajodhia-Andrews & Berman (2009) Canada	Elementary school	N: 1 Age 10 years Gender: male	Not specified	Non-verbal	Modified Talking Mat – 62 picture symbols uniquely designed for the child using their interests. Story Board Game – storyboard reflecting a typical day at school. The board contained picture symbols and blank spaces for the child to complete with his responses. Digital pictures and observational field notes – the child's responses within each activity were document via digital photographs. Observational field notes were taken by the researcher.	The child's responses in the Talking Mat and the Story Board Game were documented via digital photographs.	To provide a safe and respectful space to understand a child's perspectives of school life.

Whitehurst (2007) England	Residential special school	N: 6 Age: 7 -19 years Gender: n/a	Profound autism ADHD Down's Syndrome Severe Learning Disabilities Worster Drought Syndrome (a form of Cerebral Palsy) Note: Many were reported to have cooccurring needs.	Non-verbal (n = 1) Limited verbal skills (n = 2) Verbal skills which varied in ability (n = 3)	Young people were supported to engage in an adapted interview using a range of visual methods, a combination of photograph elicitation methods, Makaton and Talking Mats.	Description by the author using illustrative quotes as well as descriptions of non-verbal preferences made by the children.	To capture the views of students with profound and complex learning difficulties to understand their views and experiences during a two-year inclusive drama production.
Fitzgerald et al. (2003) England	Special school	N: 8 Age: 14-18 years Gender: n/a	Severe Learning Difficulties (not formally diagnosed)	Not fully specified. Sign language-Makaton (n = 3)	Task-based approach. The researcher identified the preferred communication methods of the children and shaped the activities and tasks accordingly, utilising multiple methods and approaches to elicit the students' views.	Through their preferred communication method: symbol and picture exchange, Makaton sign language, gestures and use of objects. Young people also produced a poster which they were able to display in the school to illustrate their work during the project.	To gain an insight into the P.E and free-time experiences of students with severe learning disabilities.

*Terminology key: ADD = Attention Deficit Disorder; ADHD = Attention Deficit Hyperactivity Disorder; ASD = Autism Spectrum Disorder; BESD = Behavioural, Emotional and Social Difficulties; FAS = Foetal Alcohol Syndrome; HI = Hearing Impairment; MLD = Moderate Learning Disability; PMLD = Profound and Multiple Learning Disability; SLCN = Speech, Language and Communication Needs; SLD = Severe Learning Disability; VI = Visual Impairment

Identification

Records identified through database searching (n = 3549):

Australian Education Index (n = 43)
CINAHL (n = 367)
ERIC (n = 225)
IBSS (n = 26)
Medline (n = 278)
PsycINFO (n = 524)
SCOPUS (n = 1086)
Web of Science (n = 1000)

Records removed *before screening*:
Duplicate records removed
(n = 1571)

Screening

Records screened (title and abstract)
(n = 1978)

Records excluded by hand – lack of relevance
(n = 1911)

Eligibility

Full text articles obtained and assessed for eligibility
(n = 67)

Full-text articles excluded, with reasons (n = 53):

Children and young people required to have verbal skills (n = 12)
Children and young people excluded who had intellectual disability (n = 2)
Inclusive method not developed (n = 14)
Children and young people did not have complex needs (n = 3)
Not carried out in education setting (n = 14)
Children and young peoples' views not elicited (n = 2)
Not able to separate child or young person's views from others (n = 3)
Not strong enough focus on eliciting children and young people's views (n = 3)

Included

Studies included in systematic review
(n = 14)

1

Figure 1: *Preferred Reporting Items for Systematic Review and Meta Analyses (PRISMA) diagram (Moher et al., 2009) to show paper identification and selection*