



‘It’s about sharing a moment’’: Parents’ views and experiences of home reading with their autistic children with moderate-to-severe intellectual disabilities

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ABSTRACT

Background: The home literacy environment plays a critical role in the development of children’s literacy and language development. Little is known, however, about the home literacy environment of autistic children, especially those with moderate-to-severe intellectual disabilities.

Aims: The current study used a sequential mixed-methods design to understand how parents attempt to engage their autistic children in reading activities and support them in learning to read.

Methods and procedure: First, 63 parents (53 mothers) whose autistic children attended an autism-specific special school completed a bespoke questionnaire about the home literacy environments for their children (n = 69, age range = 3–11 years, 61 boys, 8 girls). Second, a subsample of parents (n = 19, 15 mothers) participated in focus groups to understand in-depth their views and experiences of home reading with their children (n = 20, age range = 3–11 years, 19 boys, 1 girl). We used reflexive thematic analysis to analyse the focus group data.

Outcomes and results: Across questionnaire and focus group methods, parents were united in considering reading to be an important life skill, a sentiment that was reflected both by their often literacy-rich homes and the ingenuity in their efforts to engage their children in shared home-reading activities – even when such engagement could be challenging. They also emphasised, however, the importance of valuing these activities as an opportunity to “catch a moment” with their child.

Conclusions and implications: Parents and teachers should work together to identify ways to enhance autistic children’s engagement in shared home-reading activities, listening to and learning from each other’s experiences and expertise, and to show what is possible within each learning context.

What this paper adds?

This paper contributes to the limited literature on the home literacy environments of autistic children with intellectual disability

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and often-limited spoken communication – a group that is under-represented in current autism research. Parents of autistic children reported finding it difficult to engage their children in shared home reading activities. Nevertheless, they spoke of using creative ways to engage their children, including harnessing their children's interests and strengths to make shared reading more appealing to, and enjoyable for, their children. They also saw home reading activities as an opportunity to spend quality time with their child. These positive experiences are encouraging and have rarely been reported on this topic, especially for autistic children with high support needs. Schools should work together in partnership with parents to support further their children's literacy and language development, including assisting with ways of presenting tasks, using resources and setting up the reading environment. Listening to and learning from each other's experiences and expertise in this way should serve both to shape these children's early reading experiences and also to deepen parent-child relationships.

1. Introduction

The teaching of reading is a core part of the primary school curriculum in mainstream and special schools alike, providing children with a fundamental skill and paving the way for better academic achievement in later childhood (Shahaeian et al., 2018) and employment-related outcomes in adulthood (Crawford & Cribb, 2015). Learning to read, however, is not solely a classroom pursuit. The home literacy environment and parental involvement in the teaching of reading skills are also key factors in children's reading development (Lucas & Norbury, 2018; Westerveld, 2017). There is, however, a paucity of studies focusing on home reading with autistic¹ children specifically, and even fewer on autistic children with limited-to-no spoken language and/or moderate-to-severe intellectual disabilities, who are overlooked in current autism research (Russell et al., 2019). This lack of knowledge makes it difficult to understand how best to promote their reading development and success. The current study sought to address this gap. It was conducted within a broader program of work designed to develop a home-school partnership program for facilitating the literacy skills of autistic students in one autism-specific special school in Outer London. To inform this program, we sought first to understand the home literacy environment of the children attending the school, as well as to examine in depth parents' views and experiences of reading with their children at home. Here, we report on the results addressing this initial aim. Before we describe the study in detail, however, we begin by presenting a brief literature review to outline what is known and what is not yet known about the home literacy environments of autistic children.

Autistic children are at particular risk of developing reading disabilities (Ricketts, 2011; Ricketts et al., 2013). Several studies have compared the ways that autistic and neurotypical children acquire emergent literacy skills, including alphabet knowledge, phonological awareness, listening comprehension – which, overall, are significantly different to that of their neurotypical counterparts (see Fleury & Whalon, 2021, for review). On the one hand, autistic children tend to have relative strengths in discrete decoding skills such as word or letter recognition (Lanter, Freeman et al., 2012), with some demonstrating exceptional skills in this domain, or hyperlexia (Nation, 1999; Silberberg & Silberberg, 1967). On the other hand, autistic children can find it difficult to understand the function of print, that is, that text conveys meaning (Lanter & Watson et al., 2012). Also, many can find it difficult to understand what they read (Davidson & Weismer, 2014; Ricketts et al., 2013). The reading profiles of autistic children also vary widely and have been shown to be linked to variation in their language skills, intellectual ability, and autistic features (Dydia et al., 2019; Westerveld, 2017).

Variation in autistic children's literacy skills can also be attributed to their exposure to, and engagement in, informal literacy-based activities in the home. It is now well established that parents' attitudes to and beliefs about reading, the number of printed reading materials in the home, and the frequency with which parents and children engage in shared reading activities – which together reflects the 'home literacy environment' – have an impact on children's literacy and language development (Roberts et al., 2005; Swanson et al., 2011). Typical children's engagement in shared home-reading activities in particular have been shown to promote their reading attainment (Hewison & Tizard, 1980), reading rate (Kelly-Vance & Schreck, 2002) and comprehension (e.g., Scarborough et al., 1991). Such activities have benefits beyond the development of children's literacy skills. Parent-child home-reading activities are highly social in nature (Flewitt et al., 2009; Street, 1998), and include opportunities for children to ask questions about the book in which they are engaging, to respond to parents' questions and to make comments on what they notice. It is perhaps not surprising, then, that regular engagement in home-reading activities has been shown to improve the quality of parent-child interaction (Swain & Cara, 2018), encourage the development of children's joint attention and social skills, and enhance expressive and receptive language development (Wasik & Bond, 2001), including in children with mild-to-moderate intellectual disabilities (Davie & Kemp, 2002).

There are, however, several reasons why autistic children might find it difficult to engage in, and benefit from, shared reading activities at home. Difficulties in social communication, especially joint attention (Mundy, 2016), as well as with spoken language skills (Kjelgaard & Tager-Flusberg, 2001), can make such activities challenging for autistic children, and may impact on their motivation to engage. They can also struggle to generalise their learning from one setting to another (Cowan & Allen, 2007; Gulsrud et al., 2007), which can make it difficult to apply the literacy skills they acquire in formal school settings to the home environment. The few studies examining the home literacy environment of autistic children have demonstrated that, although they generally enjoy participating in shared reading activities with their parents, they nevertheless tend to show less interest in these activities (Dydia et al., 2014; Lanter, Freeman et al., 2012) and read for less time (Lucas & Norbury, 2018) than non-autistic children. The quality of these interactions can also be limited, with autistic children responding less frequently than non-autistic children to questions posed by adults (Fleury, Ford et al., 2021) and struggling more with their concentration and behaviour (Bean et al., 2020; Dydia et al., 2014;

¹ In the autistic community, identity-first language, e.g., "autistic person", is often preferred to, and considered less stigmatising than, person-first language, e.g., "person with autism" (Gernsbacher, 2017; Kenny et al., 2016; Sinclair, 1999).

Fleury & Hugh, 2018).

The challenges experienced by parents of autistic children in trying to engage their children in shared reading activities at home are also likely to affect how parents approach reading with their children. Parents of children with intellectual disabilities, who, like autistic children, often have additional speech and/or language difficulties, report having lower expectations of their children's literacy development than parents of children without disabilities (van der Schuit et al., 2009). That said, parents of autistic children recognise that reading is an important skill (Lucas & Norbury, 2018), reflected in the frequency of their shared reading activities and the quality of their book reading, both of which are on par with parents of non-autistic children (Dyonia et al., 2014; Fleury & Hugh, 2018; Lanter, Freeman et al., 2012; Lucas & Norbury, 2018). They are also sensitive to their children's particular needs. Lucas and Norbury (2018) found that autistic children aged 7 – 13 years with concomitant language difficulties, who may need extra support for their language and literacy development, were engaged in shared reading significantly *more* frequently (albeit for shorter durations) than non-autistic children of a similar age.

1.1. The current study

Previous studies on this topic have almost exclusively focused on samples of autistic children without intellectual disability and with at least some spoken language skills (see Mucchetti, 2013, for an exception), not unlike autism research more broadly (Russell et al., 2019). The current study therefore sought to investigate the home literacy environment in autistic children with moderate-to-severe intellectual disabilities and limited-to-no spoken communication, all of whom attended a government funded, local special school in Outer London. One of the school's priorities was to develop deeper relationships with the parents of the children attending the school and, ultimately, to develop a home-school partnership program of the effective teaching of reading with these particular pupils. Yet, staff in the school had identified that they had little awareness of the home literacy environment of their pupils, nor about whether parents engaged in shared reading interactions with their children.

To understand these issues in greater depth and to inform the design of a partnership program, we sought to understand the home literacy environment of the school's students. To address this aim, we used a sequential mixed-methods design, consisting of two distinct phases (Creswell et al., 2003). In the first phase, we conducted an initial, brief (quantitative) questionnaire with parents whose autistic children attended the school to gain an overall sense of the characteristics of the students' home literacy environments and parents' home-reading practices. In the second phase, we invited a subsample of parents to participate in (qualitative) focus groups, the

Table 1
Child characteristics, as reported by parents participating in the questionnaire.

	Autistic children (n = 69)
Year at school	
Nursery (3–4 years)	n = 3 (4 %), 3 boys
Reception (4–5 years)	n = 6 (9 %), 6 boys
Year 1 (5–6 years)	n = 11 (16 %), 10 boys, 1 girl
Year 2 (6–7 years)	n = 6 (9 %), 5 boys, 1 girl
Year 3 (7–8 years)	n = 13 (19 %), 13 boys, 0 girls
Year 4 (8–9 years)	n = 11 (16 %), 8 boys, 3 girls
Year 5 (9–10 years)	n = 9 (13 %), 8 boys, 1 girl
Year 6 (10–11 years)	n = 10 (14 %), 8 boys, 2 girls
Home languages	
English only	n = 43 (62 %)
Lingala	n = 7 (10 %)
Turkish	n = 5 (7 %)
Somali	n = 3 (4 %)
French	n = 3 (4 %)
Twi	n = 2 (3 %)
Farsi	n = 2 (3 %)
Bengali	n = 1 (1.5 %)
Polish	n = 1 (1.5 %)
Tamil	n = 1 (1.5 %)
Urdu	n = 1 (1.5 %)
Communication at home^a	
Verbal sounds and approximation of words	n = 40 (58 %)
Verbal language (single words and short phrases)	n = 38 (55 %)
Verbal language (long phrases and sentences)	n = 19 (28 %)
PECS ^b : single symbol level	n = 30 (44 %)
PECS: sentence level	n = 18 (26 %)
Makaton ^c signs	n = 21 (30 %)
Gesture and physical interaction	n = 56 (81 %)

^aNumber of children reported to use these types of communication either 'a lot' or 'a bit'; ^bThe Picture Exchange Communication System (PECS) Bondy and Frost (2001) is a form of augmentative and alternative communication which enables those with spoken language difficulties to communicate using symbolic picture cards; ^cMakaton (www.makaton.org) is a language programme using signs and symbols to support spoken language.

nature of which was informed by the initial questionnaire. We asked these parents to examine in-depth the results arising from the initial questionnaire, specifically about their experiences of shared reading activities with their autistic child(ren), the perceived benefits and challenges of reading in the home-learning environment, as well as their particular support needs.

2. Method

2.1. Participants

Participants were recruited from one state-funded special school for 3- to 11-year-old pupils on the autism spectrum. At the time of study, there were 95 pupils in the school, including nine girls (9 %) and 86 boys (91 %). All pupils had received an independent clinical diagnosis of an autism spectrum condition and had co-occurring moderate ($n = 16$; 17 %) or severe ($n = 79$; 83 %) intellectual disabilities. Most pupils (approx. 80 %) were considered by the school to be non-verbal, pre-verbal or minimally verbal, using > 10 words in spontaneous, functional communication, and a high proportion of pupils presented with high support needs, including behaviour that challenges. All pupils were in receipt of an Education, Health and Care Plan (UK Department for Education, 2014), a legal document that details the child's needs and services that the local educational authority has a statutory duty to provide.

The borough in which the school is located is ethnically and socio-economically diverse. Approximately one third of the borough's population is overseas born. The largest ethnic groups are White British (40.5 %), Other White (largely Greek and Turkish) (18.2 %), and Black (17.2 %). On average, just over half (51 %) of pupils' home language is English, while other frequently spoken languages include Turkish, Somali, Polish, Albanian/Shqip and Bengali. Poverty rates are high, with almost half (42.6 %) of borough households having less than the average household income for England (~£30,000 per annum). This ethnic, linguistic and socio-economic diversity is reflected in the backgrounds of the pupils attending the school.

2.1.1. Questionnaire

Sixty-three of parents (66 %) returned the questionnaire, including from 53 mothers or female caregivers, nine fathers or male caregivers and one extended family member (aunt), who completed the questionnaire on behalf of the child's parents, who were not fluent in English. More than half of respondents ($n = 39$; 62 %) reported that they had either completed high school ($n = 18$, 46 %) or gone on to further education ($n = 21$, 54 %), while the remaining 24 (38 %) reported either some high school qualifications ($n = 16$, 67 %) or no qualifications ($n = 8$; 33 %). Most respondents ($n = 50$, 79 %) were not in employment, either because they were unemployed ($n = 28$, 56 %) or economically inactive ($n = 22$, 44 %) through, for example, not seeking employment because of childcare or other commitments.

Together, these 63 parents and caregivers reported on 69 children in total (73 % of the school population), including 61 boys and 8 girls ranging in age from 3 to 11 years (nursery to Year 6; M age = 7.50, $SD = 2.15$) (see Table 1). Five respondents had two or more autistic children who attended the school and completed a separate questionnaire for each child. Ten autistic children (14 %) were reported to be sole children, while the remaining 59 had either autistic ($n = 13$; 22 %) or non-autistic ($n = 46$; 78 %) siblings. Most children ($n = 54$, 78 %) lived in homes where English was the main language spoken and parents reported that children used a range of

Table 2

Background characteristics of participating focus group parents ($n = 19$) and their children ($n = 20$).

	Parents of 'pre-readers'	Parents of 'emerging readers'
Parent participants	10 (8 mothers, 2 fathers)	9 (7 mothers, 2 fathers)
Education level of parents	No qualifications: $n = 1$ GCSEs A-C ^a : $n = 1$ A levels ^b or equivalent: $n = 1$ Diploma of HE ^c /Foundation Degree: $n = 1$ Bachelor's Degree: $n = 4$ Missing: $n = 2$	GCSEs A-C: $n = 2$ GCSEs D and below: $n = 1$ A levels or equivalent: $n = 2$ Diploma of HE/Foundation Degree: $n = 1$ Bachelor's Degree: $n = 1$ Missing: $n = 2$
Employment status of parents	Employed: $n = 0$ Unemployed: $n = 3$ Economically inactive: $n = 5$ Missing: $n = 2$	Employed: $n = 0$ Unemployed: $n = 2$ Economically inactive: $n = 5$ Missing: $n = 2$
Child gender	11 boys	8 boys; 1 girl
Child year group	Nursery/reception (3–4 years): $n = 2$ Year 1 (5–6 years): $n = 2$ Year 3 (7–8 years): $n = 2$ Year 4 (8–9 years): $n = 3$ Year 6 (10–11 years): $n = 2$	Nursery/reception (3–4 years): $n = 0$ Year 1 (5–6 years): $n = 5$ Year 4 (8–9 years): $n = 2$ Year 5 (9–10 years): $n = 1$ Year 6 (10–11 years): $n = 1$
Home language (used with child/ren)	English: $n = 5$ Farsi and English: $n = 1$ French and English: $n = 3$ Turkish and English: $n = 1$ Bengali and English: $n = 1$	English: $n = 6$ Turkish: $n = 1$ Somali: $n = 1$ Farsi and English: $n = 1$

Notes: ^aGCSE: General Certificate of Secondary Education (GCSE), a UK academic qualifications that students take when they are 15 or 16 years old, at the end of Year 11; ^bA-Levels (Advanced Level qualifications) are a UK subject-based qualification for students aged 16 and above; ^cHE = Higher Education.

ways to communicate with them, including forms of augmentative and alternative communication (Table 1). One third of the children ($n = 26, 38\%$) were reported either to never or hardly ever use verbal sounds or words at home.

2.1.2. Focus groups

Following completion of the questionnaire, all participating parents were invited to take part in a focus group. Nineteen of these parents agreed to participate (see Table 2 and Section 2.2.2 below).

2.2. Materials and procedure

The study procedures were approved by the UCL Institute of Education Research Ethics Committee. All parents gave written, informed consent to take part prior to participation.

2.2.1. Questionnaire

We developed a short bespoke questionnaire for parents containing 16 items organised into three sections (see Supplementary Materials for full details), as detailed below. Parents and caregivers of all pupils ($n = 95$) were invited to complete the initial questionnaire, which was sent home in pupils' schoolbags. Only complete questionnaires were considered in analyses below.

Section 1 (7 items) – *Information about you and your family*. Participants were asked closed questions regarding their relationship to the autistic child about which they were responding, other children in the household, main language spoken at home, employment status and highest educational qualification. Participants were also asked to report the frequency with which their autistic child used a range of communication at home, on a scale ranging from 'a lot', 'a bit', 'hardly ever' or 'never' (Table 1).

Section 2 (5 items) – *Reading experiences in your home*. Participants were asked about their reading habits and attitudes (following Fletcher et al., 2010). They were also asked to report which family member usually reads with the autistic child, how often reading activities usually take place, and how long reading activities between the main reader and autistic child usually lasted.

Section 3 (4 items) – *Your autistic child's reading (or pre-reading) ability*. In this section, participants were first asked to report the frequency of a range of reading behaviours for their autistic child (see Supplementary Materials), followed by questions about how well they felt their autistic child performed a variety of reading tasks. Participants were then asked to rate their confidence in supporting their autistic child to learn to read and to report their agreement about whether they would like to learn more about supporting their autistic child with reading.

2.2.2. Focus groups

Interested parents were invited to attend one of two focus groups at the school, one for 'pre-readers' (those children who were felt to be at the earliest stages of learning and beginning to explore symbols, words and books but not yet able to read) and one for 'emerging readers' (those children who were felt to be able to read some words, phrases and sentences but may struggle with unfamiliar words). These groups were formed based on discussions with school staff and the possibility of tailoring the nature of the discussion to children's specific characteristics. Parents could choose which focus group they attended based on the level they felt best matched their child's engagement at home. There were four focus groups, including 10 parents in one of two pre-reader focus groups ($n = 5$ in each), who reported on 11 children (all boys, M age = 7.18, $SD = 2.48$) and the remaining nine in one of two emerging reader focus groups ($n = 4$ in one, $n = 5$ in the second), who reported on nine children (8 boys, 1 girl, M age = 7.22, $SD = 2.33$) (Table 2).

In all focus groups, parents were asked primary questions regarding (a) parents' views and beliefs about reading with their children and (b) their experiences of supporting their children to read. Parents were encouraged to share specific examples of successful and not-so-successful experiences of reading at home with their child.

The length of focus groups was kept short for the convenience of parents (ranging in duration from 18 to 21 mins). All focus groups were audio-recorded with participants' prior consent and transcribed verbatim. The resulting transcripts were analysed using reflexive thematic analysis (Braun & Clarke, 2019). We adopted an inductive approach (bottom-up) approach (i.e., without integrating the themes within any pre-existing coding schemes or preconceptions of the researchers) to identify patterned meanings within the dataset. We provided descriptive overviews of the key features of the semantic content of data within an essentialist framework. Our analytic approach was informed by our training in education (RW, JS and EP) and psychology (EP). Two authors (RW and EP) independently familiarised themselves with the data, discussed preliminary themes and generated a list of provisional codes. The authors met several times to review the results, consider researcher biases, resolve discrepancies, and revise and refine on the final themes and subthemes. Analysis was therefore iterative and reflexive, moving backward and forward between data and analysis.

3. Results

3.1. Questionnaire

3.1.1. Reading practices at home

Of the 63 parents, 58 (92%) responded to questions about their own reading behaviours, with the majority reporting spending more than 1 h per week (1–5 h: $n = 28, 48\%$; >6 h: $n = 23, 40\%$) reading for themselves at home, including books (factual, fiction or both), newspapers, magazines and electronic texts; only seven (12%) reported reading for less than one hour per week (six of whom reported English as a second/additional language). Of these 58 parents, most agreed or strongly agreed that they liked to spend their spare time reading, when given the chance ($n = 44, 76\%$) and that reading was an important activity in their home ($n = 49, 84\%$).

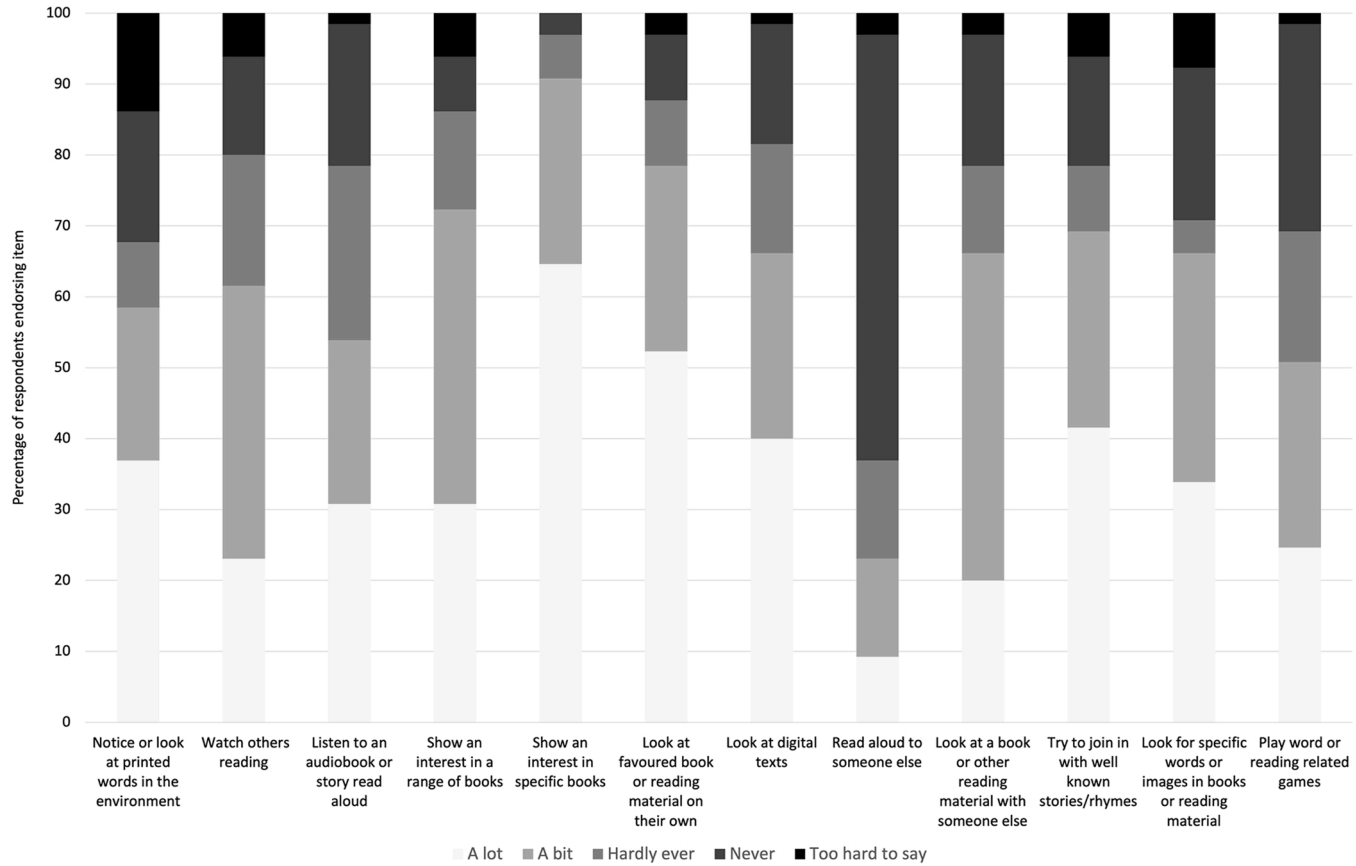


Fig. 1. Parents' reports of how frequently their children engaged in a range of reading activities.

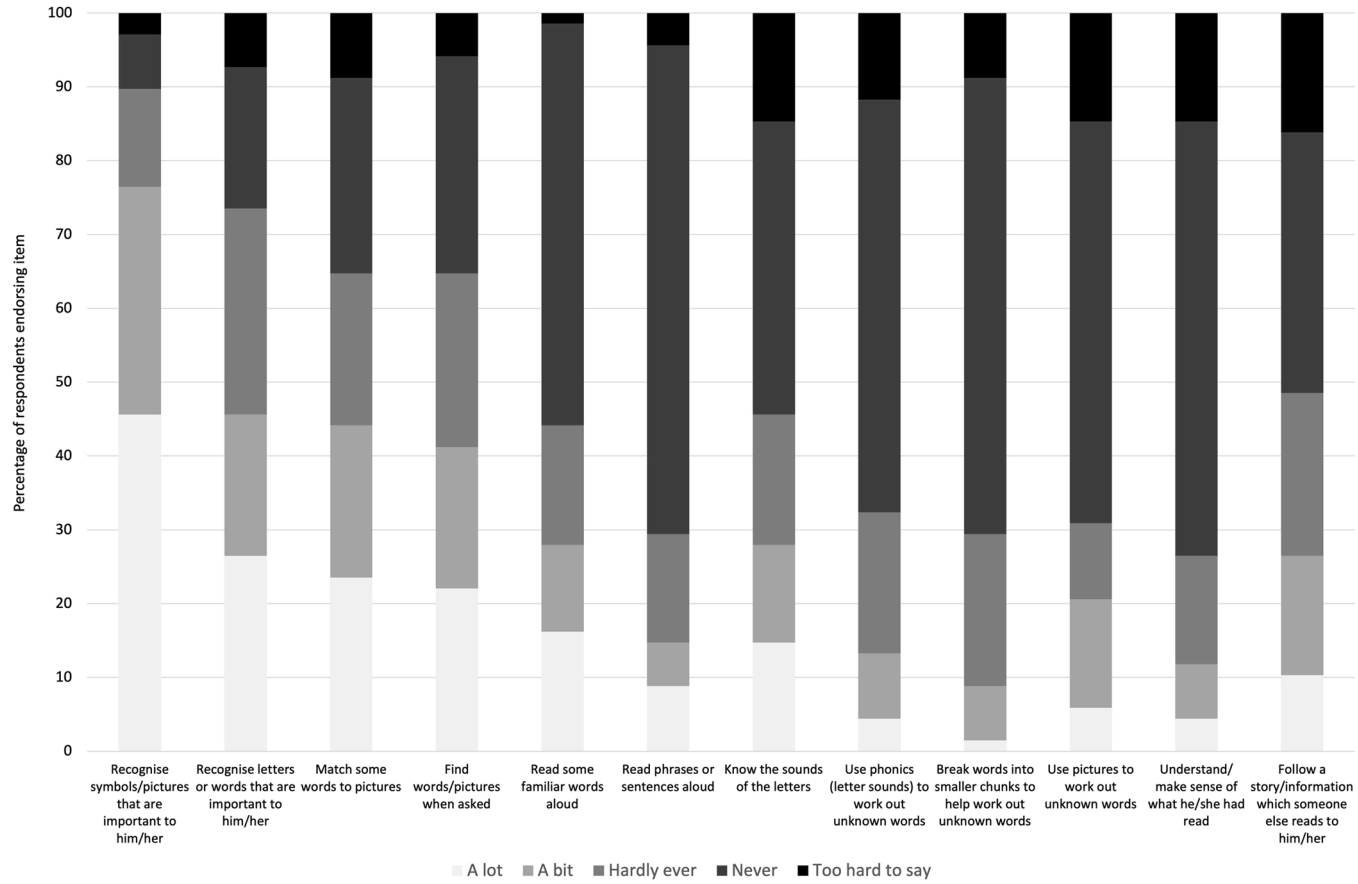


Fig. 2. Parents' perceptions of their autistic children's (pre-)reading skills.

In almost all cases, the person who completed the questionnaire for each child was the person who usually read with them at home, including mothers/female caregivers (n = 47, 75 %), fathers/male caregivers (n = 9, 14 %), both parents regularly (n = 2, 3 %) and siblings (n = 6, 10 %). All parents reported that reading happened with the child at least once or twice a week, with 37 (54 %) reporting that reading took place with their child every day or almost every day. Two thirds (n = 46, 67 %) reported that these reading activities lasted for more than five minutes.

3.1.2. Parents' perceptions of their autistic child(ren)'s (pre)reading behaviours

Parents' responses about how frequently their children engaged in a range of reading activities are shown in Fig. 1. Overall, most children were reported to show most of these behaviours either 'a bit' or 'a lot', especially showing an interest in a range of books (n = 50, 72 %) or in specific books (n = 63, 91 %), and in looking at a book or other reading material on their own (n = 54, 78 %) or with someone else (n = 46, 66 %), although parents reported that the latter was more likely to happen a bit rather than a lot. The one exception to this pattern was that only one quarter (n = 16, 23 %) of children were reported to read aloud at home a bit or a lot; 48 children (74 %) never or hardly ever read aloud.

3.1.3. Parents' perceptions of their autistic child(ren)'s reading ability

Parents reported that most of their children were able to recognise symbols/pictures that they found important to them (n = 52 of 69 children, 75 %) (see Fig. 2). Parents also often observed their children handling books and reading materials conventionally with 47 children (68 %) holding books and reading devices the right way up and 48 (70 %) turning pages correctly. Children were reportedly less capable with their decoding skills: 51 children (74 %) did not use phonics and 56 (81 %) did not break words into smaller chunks to help them read. Their comprehension skills were also perceived to be limited. According to parents, 50 of their children (72 %) understood what they had read either 'not well' or 'not at all'. Notably, a significant minority of parents found it 'too hard to say' whether their children had particular skills, including whether they could use pictures to work out words (n = 10, 14 %), know the sounds of letters (n = 10, 14 %), make sense of what they had read (n = 10, 14 %), or follow a story or information read to them (n = 11, 16 %), and may have found it difficult to interpret their children's behaviours or responses.

Parents ranged in how confident they felt supporting their autistic children to read at home, with almost one third (n = 19, 30 %) reportedly feeling very or extremely confident, another third (n = 20, 32 %) feeling quite confident and the remaining 24 (38 %) feeling only a little confident or not confident at all. When asked about whose responsibility they felt it was to teach their children to read, the majority (n = 48, 76 %) strongly *disagreed* with the statement, "Teaching my autistic child to read should be done entirely by the school". Instead, almost all felt that such teaching should be shared between teachers and parents (n = 60, 96 %) and, encouragingly, wanted to learn more about supporting their autistic child(ren)'s reading through school (n = 62, 98 %).

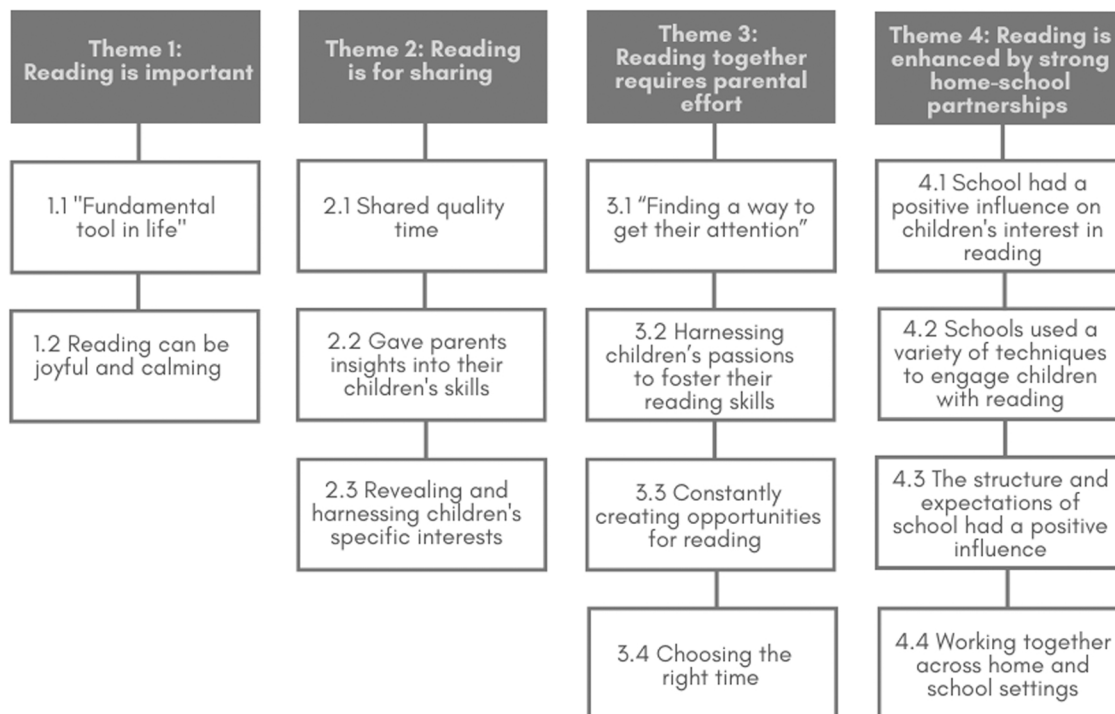


Fig. 3. Parents' views and experiences of supporting their autistic children to read: themes and subthemes.

3.2. Focus groups

We identified four themes from participants' focus group discussions (Fig. 3). Throughout, quotes are attributed via participant IDs (PR: pre-reader; ER: emerging reader).

3.2.1. Theme 1: reading is important

Parents spoke of reading as a “*fundamental tool in life*” (PR_005) (subtheme 1.1) – a life skill that would help to give them a better future. They described that their autistic children's lives were “difficult enough as it is” and that “if they can learn to read, their life will improve a lot” (ER_004). They therefore felt that it was important for their autistic children to learn to read “just like every other child” (ER_007).

Parents also described how *reading can be joyful and calming* for their children (subtheme 1.2). They spoke of how their children love reading and would show enjoyment of familiar stories by choosing and reading them repeatedly. For some children, reading was felt to be a way to enjoy their passions, such as showing a preference for a dinosaur encyclopaedia (ER_007), a book on chocolate (PR_005) or books featuring favoured characters such as *Maisy Mouse* (ER_010), *Thomas the Tank Engine* (ER_007), or Disney characters (ER_009). Reading could also have a calming effect for their children. One mother described her son using reading as one way to self-calm:

If he's in a terrible mood, sometimes, books are the only things that calm him down, but that's the one time he doesn't want anyone with him, he has to read on his own, then. You can hear him, because he'll sit reading out loud, so he knows that you know he's around, but he won't let you go near him. (ER_006)

Another mother noted that face-to-face interaction could cause her daughter's mood and behaviour to deteriorate if she was already feeling unsettled. This mother felt that sharing a book together was helpful as a calming strategy because they could both focus on the book rather than “have a face-to-face”. She also noted that reading together helped her to be calmer with her child as it is a way to interact that is “less confrontational and your voice becomes calmer” (ER_001).

3.2.2. Theme 2: reading is for sharing

Parents spoke repeatedly about how much they valued reading with their children. This *shared quality time* (subtheme 2.1) was often perceived to be more important than the reading itself, as one parent described:

For me, it's about engaging with them, it's not necessarily about reading, but it's a moment of sharing a moment, you know? There are so many times you want to catch the children, to share moments, while they're playing, you're trying to get into their little world. What are they thinking? And how they engage with you. And, I think, reading, for me, is very much to catch a moment, sometimes the reading doesn't happen, it's just that we've been sitting together, close enough and sharing one thing, you know? (PR_001)

This sentiment was echoed by another mother, who said:

I find more than anything, that it is important because it's time I get to spend with my kids, and they actually want to sit and listen for a change, and especially if they get to pick the book, you know they're going to interact, then, and they really enjoy it. It's more important to me than anything, if they don't never read that book again, they've sat with me for 10 min, and it's really... It's nice. (ER_009)

This same parent further noted that if her child chose books or asked to read with her, she would make time for it immediately and “everything else goes out the window” (ER_009). One mother summed up this feeling: “[My son] loves reading, and I love enjoying it with him” (PR_003).

This shared time reading together also *gave parents insight into their children's skills* (subtheme 2.2), about which parents were often surprised: “I didn't actually realise until the other day, but he can actually read! And it's not just memorising the words, he actually read, cover to cover, two *Maisy* books” (ER_010). She went on to explain that her child “was non-verbal for a long time” and so she had not been aware of the knowledge and skills that he was gaining until he could speak, but that she had been reading to him “since he was a baby... he's actually been taking all the words in, all the stories in” (ER_010). One father spoke of a similar scenario with his son who is “not very verbal and only just speaking a few words”. He explained that he had been looking for simple books with three-word sentences because they had assumed their son's language was at that level. However, they soon found “he could actually read more than that” (ER_003). This sense of disbelief was also echoed by parents whose children were more talkative and able to ask questions, and who felt more aware of their children's learning. Some reported that they were surprised at how quickly and easily their children seemed to memorise new words: “He actually asks me, he's like, ‘What's this, Mummy? What's this?’ So, I'll read it to him, and then after that, he almost stores it somewhere, and he's like, oh, I've seen that word before, it's this one. So, he's getting that quite well” (ER_007).

Shared reading activities were often important in *revealing children's interests* (subtheme 2.3). For example, one parent (ER_009) reported how her son chose specific Disney books and read phrases from them carefully mimicking voices he had heard on the TV. Parents also spoke of how their children's special interests or passions were important in motivating them to develop reading skills and that, once children engaged with books of significant interest, their skills became more apparent. One parent (ER_007) described how her son loved dinosaurs and the words he would ask her to read for him would be complex dinosaur names, which he would then

recognise and read independently once she had vocalised them for him. For other children, who enjoyed reading activities at a more sensory level, parents reported them being motivated to learn to turn pages so that they could feel textures or press the buttons of ‘touchy-feely’ books. Another parent explained how her son was particularly motivated by the iPad and could use this to learn and demonstrate his skills: “He’s very independent on the iPad. So, he learns from the iPad, and he reads from the iPad, and types out... He can type out things that I can’t even spell, he’s good at typing out words, and knowing what they are” (ER_009).

For some parents, however, discovering that their child was interested in very specific type of books sometimes caused mixed feelings. For example, one couple described themselves as “tired parents” of two autistic children and that although they tried to offer a variety of books, their son had “specific interests” and would only accept books about trains (PR_001). They felt that they had to “give in” to their son’s topic preference so that he would read and share books with them, but they were concerned that this was “very narrowing” and not conducive to broader learning.

3.2.3. Theme 3: Reading together requires parental effort

Parents often spoke about how much effort home reading activities could take, especially with focusing their children’s attention with the (reading) task at hand. One mother described how her son, “wanders off, so... you’ll call out to him when you’re reading, sometimes he’ll respond, sometimes he’ll continue, he’ll find a distraction somewhere, but we go through the whole story, anyway” (PR_010). Other mothers also expressed their frustration having bought books and made the time to spend with their children, only to have them “jumping around” (PR_007) and “flying all over the place” (ER_003). Often, they felt like it was a waste of their time, “he’s not listening... doing all these other things” (PR_008).

“Finding a way to get their attention” (PR_005) (subtheme 3.1), including by removing distractions, was often key. Parents spoke of using aspects of books to try and engage their children, for example, the colour of the book (PR_005), the action of the pages turning, or the touch and feel of the books (PR_004). Some would point out aspects of the illustrations and comment on the characters to try to draw their child in: “I show the picture to him, and I just say, oh, there’s a Mr. Man, there’s a Mr. Impossible, jumping over the house. I try to make him interested” (PR_006). Electronic devices were often cited as a distraction, which they sometimes had to remove: “They like sitting on the computer, playing games on the computer and the iPad. So, if I want to read a book with them, I have to take the iPad away, and then help them to read the story” (PR_009). Nevertheless, despite their efforts, parents lamented that “attention span is always an issue, and it can be very difficult to make them sit down quietly and then learn how to read” (PR_008).

Parents reported being acutely aware of how important their children’s passions and interests were (“If it’s something he’s not interested in, he’s not listening”; PR_007) and sought to *harness children’s passions to foster their reading skills* (subtheme 3.2), including trying to read “words on a board or a numberplate, or whatever you can” (PR_005). One bilingual mother described using her child’s interest in football to try to teach him to read:

He’s interested in all things football... he’s reading all football teams in Turkish and English. Then I tried to help him by writing four to five football teams, and then writing one different word: bird, or dog, or something. And then tried to help him, with reading not only football teams, but some [other] words. (ER_009)

One father, whose child liked travelling on buses, would encourage his son to read the print associated with the bus routes and destinations:

It was difficult to try to open a book and read, but [I would say], ‘What’s on the bus? Where is it going? Can you see? He would say ‘... 307 to XX Hospital’, then, when you see the words XX Hospital again, you say, ‘What’s that word?’ Then he will recognise it... he connected it to XX Hospital, from the bus, then he is interested. (ER_004)

Parents spoke about needing *constantly to create opportunities for reading* (subtheme 3.3) – both outside and inside of the home. They did so within the home by placing “books everywhere... on the staircase, in the toilet, everywhere (PR_001) so that parents had a chance of “catching the moment when they [children] are receptive, and it’s on their terms” (PR_004). One parent (PR_006) described creating an atmosphere with a familiar story to help her children “really enjoy it”, by switching off the television and computer, putting on the “soft lights”, and putting on the audio associated with a favoured book such as *We’re Going on a Bear Hunt* or *The Gruffalo*, and softly joining in with the voices and phrases.

Choosing the right time (subtheme 3.4) for reading activities was also critical. They described reading at bedtime, as part of a regular routine, which they considered to be a time during which children were more likely to be relaxed and more easily settled. Parents spoke of spending a significant amount of time looking at books at this time, with one child spending “40 min, an hour, going through all his books” (PR_002) while others would share up to four books with their children at bedtime.

3.2.4. Theme 4: Reading is enhanced by partnerships between home and school

Parents reported feeling that children’s reading experiences at school had a *positive influence on their interest in reading* and willingness to engage with books at home (subtheme 4.1): “since he’s come to school, he has more understanding” (ER_003). One parent (ER_001) described that reading certain stories with her son at home had not been very successful until “the school’s done the same book, and the penny just drops, it’s that connection”. Others reported similar effects, having been “doing *Dear Zoo* at home for ages, [he was] more into it, having done it at school” (PR_002). Parents explained that, prior to starting school, they had “tried to do stories at bedtime, still, he wasn’t having it” (PR_007). Since having started school, however, it had awakened their interest in listening to stories: “now, yes, he wants me to read a story every night (PR_007)”.

There was an awareness among parents of the variability in their children's reading ("If there are 90 kids, there are 90 techniques"; ER_001) and that *schools used a variety of techniques to engage children with reading* (subtheme 4.2). Parents discussed how each child would need a slightly different approach and parents of autistic siblings reported trying different things with each of their children, some of which proved more successful with one sibling than the other. Such uncertainties were a little daunting to some parents: "90 % of how they should be taught, is in a school. Then they give me tools to do at home, and then I'll feel confident that I can teach him to do something" (ER_003). Parents described how they had picked up ideas through working with school and had tried to apply them at home, such as using symbols and labels on items to teach nouns:

You know that the symbols are used, and things are used, so you have an idea. You don't know precisely, the techniques, as I was saying, but you know that there is a different way to communicate with them, and for them to communicate... I am no expert, I'm no professional. I'm not talking about [Child A], because he's not [at that level], but the way I teach [Child B], I've been doing that since the summer. So, on her peg, I've written peg, and I've stamped it, and on her door, I've written door, and on her bed, you know? I've filled her room with words. (ER_005)

Parents further felt that *the structure and expectations of school had a positive influence* (subtheme 4.3) on their children's lives and reading skills: "They're more structured and everybody's doing the same thing" (ER_003). They gave examples such as getting children to wear their own rucksacks rather than dropping them on the floor for mum to pick up or sitting at the dinner table rather than wandering around eating. Parents reported being hopeful that things they struggled to achieve with their children could be made possible through working with the school, including learning to read: "it's a really long process and, I think to me, the school is more geared to do that initially and then I can push it a lot more when he gets home" (ER_008). Parents felt it was important to work together with the school to find solutions. For example, one parent (ER_007) explained that the teacher had introduced a library rule for her son. He was allowed to take home a dinosaur book each week, but he also had to choose a different one too. The parent was then encouraged to use a 'first and then' system with him at home, whereby he would be expected to read the other book first before having access to the dinosaur book. Gradually, he came to accept this approach and would get out the non-preferred book first when reading at home. Another parent (ER_010) reported not knowing how well her son could read for some time because he was very quiet and had not previously demonstrated his skills at home. The class teacher had seen a very different side to this child in lessons and taught the mother to say, "Use your loud voice" when she sits with her son to read at home, "so that's what I do and now I know he can actually read!" (ER_010).

Consequently, parents emphasised how important it was to *work together across home and school settings* (subtheme 4.4), providing more opportunities for learning and skill development through the week. They felt that reading experiences in the home and in school complemented each other and supported progress: "It's helping him to further himself a bit more" (PR_010). They stressed that this home-school working was necessary for all children, regardless of their learning needs:

I think that, maybe, some people think because they're special needs, you don't do certain things with them, like you do with a regular child. And then, maybe, leave it and think, oh, once they go to school, that's it. No, you have to do the same at home as what they do in the school. (PR_007)

4. Discussion

We sought to understand the home literacy environment of primary-aged autistic children with moderate-to-severe intellectual disabilities and limited-to-no spoken communication, and parents' views of supporting their children in shared reading activities at home. Parents considered reading to be an important life skill, a sentiment that was reflected both by their often literacy-rich homes and their willingness to engage their children in shared home reading activities. Parents wanted their autistic children to learn to read (or at least recognise print) regardless of their language and general cognitive levels and reported adopting a wide range of strategies to support this endeavour. Nevertheless, parents emphasised that engaging their children in home literacy activities was not a straightforward task and felt that working together with teachers, through sharing techniques and insights and a greater breadth of topics and contexts, could help to overcome some of the challenges. These issues were highlighted by the results from the initial, quantitative phase, and further corroborated by the second, qualitative phase, which sought to understand these issues in greater depth.

Previous studies have shown that the home literacy environments of children with disabilities can be limited (Dahlgren Sandberg, 1998), including for children with intellectual disabilities (van der Schuit et al., 2009), who often have fewer experiences with books and writing materials in the home. One might expect this environment to be particularly limited for children who are non-speaking or who have limited spoken communication, and who therefore might interact less with their parents during shared book reading. It is striking, then, that all of our questionnaire respondents reported that they read at least one or twice a week to their autistic child, with almost two thirds reporting that shared parent-child reading occurred almost every day. These findings echo those from the Lucas and Norbury (2018) study, which showed that shared reading practices occurred more frequently for those autistic children who were not proficient readers and required the most support and, together, emphasise parents' commitment to fostering their children's language and literacy development.

The qualitative focus groups revealed *why* our parents regarded shared reading activities as opportunities to spend quality time with their child: they felt such activities to be revelatory, providing insight into their children's interests, passions and ways of

thinking, as well as their language and literacy skills. Indeed, our questionnaire respondents indicated that their children tended to show stronger skills in, and preferences for, whole-word recognition (particularly with words of importance to the child) combined with weaker decoding and comprehension – a profile of reading skills that is characteristic of autistic children (Johnels et al., 2019; Lanter & Watson et al., 2012). It is noteworthy that our focus group participants almost never mentioned helping their autistic children to read unknown words. Parents of neurotypical children commonly focus on supporting their children to decode the text accurately during shared home reading activities (Goddard-Tame, 1986; McNaughton et al., 2010) and the same has been found for autistic children (Arciuli et al., 2013). This discrepancy could be potentially explained by differences in sampling characteristics, with the children of our participants being at a much earlier stage of language and literacy development than those in Arciuli et al.'s study.

Instead, our participants' focus was primarily centred on promoting their children's engagement and enjoyment during shared home reading activities. Their qualitative accounts clearly illustrated that they viewed these literacy activities as shared, social practices (Flewitt et al., 2009; Street, 1998), "a chance of catching a moment" with their child. Parents attempts to secure their children's engagement went beyond the shared storybook setting, however. They further enriched their children's literacy experiences by capitalising on literacy moments in everyday contexts, for example, by reading bus routes and destinations while travelling, and adopted multiples modes of communication to promote their children's knowledge of single words, for example, by filling their child's bedroom with symbols and labels. In so doing, parents showed that they were highly sensitive to their children's specific needs, interests and preferences and used a range of strategies to encourage their children's interaction during these activities.

Nevertheless, parents also made it abundantly clear that shared home reading activities were not without their challenges – as attested by the findings across each phase of data collection. Consistent with previous studies (e.g., Lanter, Freeman et al., 2012), parents across questionnaire and focus group discussions indicated that many of their children enjoyed looking at books on their own but only a minority showed engagement for shared book reading. Our focus group findings further illustrated why this might be the case – because their autistic children could often be distracted during reading activities (see also Bean et al., 2020; Dynia et al., 2014; Fleury & Hugh, 2018) and their engagement depended heavily on parents' attentiveness to their children's mood and their ability to gauge the 'right time'. That said, they showed much persistence and creativity in engaging their children in shared home literacy activities, adopting innovative strategies such as encouraging recognition of environmental print, labelling items round the house and repeatedly returning to texts featuring their child's favourite themes or characters. Fleury and Hugh (2018) found that autistic children showed the greatest engagement when they read familiar books with their caregivers, which is an important practice for any child because it provides repeated opportunities for adults to scaffold children's language (McGee & Schickedanz, 2007). Our parents reported greater engagement with their children when they revisited favoured books and used the same books that their child(ren) was studying at school.

Almost all parents who completed the questionnaire endorsed the statement that teaching autistic children to read should be shared between teachers and parents. Our focus group parents agreed and provided some explanations for this view. They were conscious that consistency across home and school settings is particularly important for autistic children, who often have challenges generalising their learning from one setting to another (Cowan & Allen, 2007; Gulsrud et al., 2007). They were also keen to connect their own, distinctive approaches to reading at home with approaches taken at school, and were keen to draw on the school's advice and guidance. Successful parent-school partnerships - considered best practice in autism education (Charman et al., 2011) - in which parents and teachers work together to ensure both that school staff can utilise parents' knowledge of their children (Lilley, 2011) and that parents can help their children make sense of their learning across school and home settings (see Lilley, 2019). Such partnerships, however, require strong, trusting relationships between parents and teachers, which can be challenging to establish and sustain (Azad & Mandell, 2016). In this study – across both quantitative and qualitative phases – it was clear that parents reported both high levels of enthusiasm and motivation for helping their autistic children learn to read, and a great desire to work in partnership with schools to support their children's literacy and language development.

4.1. Limitations

There are several potential limitations of this study. First, we did not include a comparison group, so we cannot be sure whether the home literacy environment for the particular children sampled herein is similar or different to autistic children without intellectual and/or language disabilities, or to children who are not disabled. Second, we did not measure the (pre)reading abilities of the children themselves so we cannot comment on, for example, whether children whose parents reported greater engagement in shared home reading activities also had better reading skills (see Lucas & Norbury, 2018), or whether reading skills were related to parents' socioeconomic status. Understanding precisely which aspects of the home literacy environment might predict later language and literacy development of autistic children with moderate-to-severe intellectual disabilities is an important avenue for future research. Such research should seek both to design and validate a measure of home literacy environment with parents of autistic children and also formally to observe the extent and nature of the shared home reading activities between autistic children and their caregivers (as per Arciuli et al., 2013). Finally, although the school population from which we recruited is socially and economically diverse in nature, we cannot be sure that the views and experiences of our (self-selecting) participants are representative of all parents whose children attend this school, or of parents of autistic children more broadly; indeed, we might expect those who are most enthusiastic about reading and have the time to participate were most likely to have responded to our invitation. Relatedly, we note that the children on which our participating parents reported were predominantly boys, a pattern consistent with the gender ratio of the school population from which this sample was drawn. Although we know of no theoretical or empirical reasons to expect gender differences in the home literacy environment of autistic children with moderate-to-severe intellectual disabilities, future research should make efforts to understand the views of parents of a diverse group of autistic children.

5. Conclusion

Parents of autistic children with moderate-to-severe intellectual disabilities and often limited spoken communication wholeheartedly agreed that learning to read is a fundamental skill for their children that will, ultimately, enhance their quality of life. They also emphasised, however, the importance of shared home reading activities as an opportunity to deepen their own relationship with their child. Engaging their children in these activities was not easy but parents appeared instinctively to use a wealth of multimodal strategies to harness their children's interests and strengths to make shared reading more appealing to, and enjoyable for, their children. The strength of these relationships between parents, children and school, and parents' ability to be creatively engaged with the specific requirements of their children appear to be of great importance in shaping these early reading experiences.

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CRedit authorship contribution statement

RW, JS, and EP conceived of and designed the study. JS and EP supervised data collection and analysis. RW collected the data. RW and EP led the analysis and interpretation of the data. RW and EP verified the underlying data and wrote the original draft of the manuscript. All authors contributed to reviewing the analysis and editing the manuscript prior to submission.

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Appendix A. Supporting information

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