The social communication experience of children with autism in mainstream school

Julie Stephenson and Catherine Adams, UK

Editorial comment

Julie Stephenson is a speech and language therapist in Macclesfield and Catherine Adams is a lecturer from the School of Psychological Sciences at the University of Manchester. In this paper, the authors explored the experiences of children on the autism spectrum in mainstream school. They focused particularly on getting the point of view of the children and highlight the importance of doing this more often in future research, as well as in practice. The authors highlighted three themes which came up in their study: the potential to find a place in society; the impact of social communication difficulties at school; and school as a social context. This paper gives good guidance on including children in research, and provides some insight into the experiences of children on the autism spectrum in mainstream school.

Introduction

Effective communication in reciprocal social interactions remains an area of difficulty for children who have autism throughout the school years (Rubin and Lennon, 2004). The promotion of social inclusion in education (Chamberlain et al, 2007) has resulted in an increase in the number of children with autism in mainstream classrooms in the UK. However, as Sainsbury (2009 page 52) argues, if socialisation is seen as the main purpose of school inclusion, this will have implications if your primary disability is a social one. Relatively little is known about the impact of the social communication component of autism on children who are accessing mainstream education (Knott et al, 2006) and there are no studies that approach this from the perspective of the child with autism. A better understanding of the social communication experiences of the child may enable practitioners to improve support for socialisation and communication strategies in the school environment.

The study used a phenomenological approach, which involves trying to understand a phenomenon through interviews with subjects, in order to capture the ‘lived experience’ (Eatough and Smith, 2006). The social communication experience of children who have autism in UK mainstream schools was explored through interviews with children and their parents.

As a phenomenological study seeks to gain knowledge by representing an experience from the perspective of an individual, there is some concern that it may be incompatible with the cognitive processing style of individuals with autism (Scott, 2008; Newman et al, 2010). Furthermore as Knoll et al (2013) note, while some individuals on the autism spectrum are able to provide a self-report, this may not be appropriate for the entire population.
However, gaining the perspective of individuals with autism has the potential to highlight their needs, facilitate connection with specialists and enable more effective personalised support (DePape and Lindsay, 2016; Rosqvist, 2012). Some individuals with autism have given insider accounts but there are relatively few studies which focus on the views of children (Preece and Jordan, 2010). The principle of the United Nations Convention of the Rights on the Child (UNCRC) (United Nations General Assembly, 1989) that children should be empowered to express views, has led to an acceptance in research that children should be enabled to report valid experiences (Christensen and James, 2008). However, these rights are conditional on the developing abilities of the child (Alderson, 2007).

Newman et al (2010) suggest that the methods used by researchers need to take into account the impact of the cognitive processing style seen in autism. Some qualitative studies conducted with children have addressed aspects of this issue including methods of data collection, the format of the interview, preparing the child for the visit and differentiation of questions (Daniel and Billingsley, 2010; Humphrey and Symes, 2010; Preece and Jordan, 2010). As the use of language to express the interpretation of an experience may need to be supported and prompted (Newman et al, 2010; Losh and Capps, 2003; Goddard et al, 2014) some studies have advocated the use of visual methods. The use of photographs may enable ‘more to be said with fewer words’ (Oliffe and Bottorff, 2007 page 855), cue concrete memory (Newman et al, 2010) and provide an opportunity for a participant to show how they perceive the world (Checkoway and Richards-Schuster, 2005; Holme and Hanmore, 2001; Preece and Jordan, 2010).

**Aims**
The aims of this research were:

a) to gain an understanding of the social communication experiences of children with autism in mainstream school

b) to explore whether modified qualitative interviews can be effective in eliciting the views of children with autism to contribute to research

**Methods**

**Ethical permissions**
Ethical approval was obtained from The University of Manchester’s Committee on the Ethics of Research on Human Beings and followed all data security, informed consent/assent and confidentiality procedures with a distress policy developed for child participants.

**Participants**
A purposive sample of children who have autism was recruited in the north-west of England by members of the Local Education Authority Autism team. The referring practitioner confirmed autism diagnosis. A small sample was recruited to allow for the detailed analysis of each case and the development of a micro analysis across cases (Smith et al, 2003). Inclusion criteria were: a diagnosis of autism; spoken language as the child’s primary form of communication; attendance at a mainstream school; English as the first language of both the child and their parent. Five families returned the consent and assent forms and subsequently participated in the study, with data collected from the parents and the child participants giving a total of ten interviews.

The first author conducted semi-structured interviews over a three-month period separately with the children at school and the parents (all mothers) at home. The school was the setting for the child interview as children with autism may not readily communicate about one context when they are in another (de Clercq and Petters, 2006). A social story was given to the parents to prepare the child for the visit by the researcher (Beresford et al, 2004). The child interview lasted 30 minutes with the first part based on an adapted topic guide; language was kept at a concrete level (Dennis et al, 2001), the questions were short and based around direct experiences (Newman et al, 2004) and explicit examples were used to support open ended questions (Wheelwright, 2006). A stop card was provided to support the children to indicate if they wished to move on to the next question (Humphrey and Lewis, 2008b). Photographs to illustrate ‘my school’, which school staff assisted the children to take prior to the interview and pre-published photographs of school social situations were used to support the second part of the child interview. The photographs
The process of developing themes was based on Interpretative Phenomenological Analysis (IPA) which requires the researcher to explore and make sense of how participants are making sense of their world (Smith et al., 2003). A reflective journal was used; the anticipated processing and communication difficulties of the children made it essential to acknowledge and reflect on the interpretive role of the researchers as part of the process of producing the data. Trustworthiness was enhanced by maintaining an audit trail consisting of the topic guides and detail on the analytical development (Spencer and Britain, 2003). The interview data from the parents served partly as a form of triangulation to corroborate the child data, with the detailed quotes used to illustrate the results supporting the soundness of the conclusions (Creswell, 2012).

The presentation of the interview was also adapted; children with autism may not understand the implicit meaning in more traditional prompts such as expressions of interest and may find maintaining eye contact uncomfortable.

Parent interviews lasted one hour and were supported by a topic guide designed to facilitate an exploration of themes.

**Analysis**

The transcript from each participant was examined to find patterns and ‘pare statements down to their core’ with cross case analysis then undertaken to explore similarities and difference between emergent themes (Smith, 2004). The photographs taken by the children were included as part of the data set with interpretation of the children's meanings interpreted by the researchers (Mason, 2002). The process of developing themes was based on Interpretative Phenomenological Analysis (IPA) which requires the researcher to explore and make sense of how participants are making sense of their world (Smith et al., 2003). A reflective journal was used; the anticipated processing and communication difficulties of the children made it essential to acknowledge and reflect on the interpretive role of the researchers as part of the process of producing the data. Trustworthiness was enhanced by maintaining an audit trail consisting of the topic guides and detail on the analytical development (Spencer and Britain, 2003). The interview data from the parents served partly as a form of triangulation to corroborate the child data, with the detailed quotes used to illustrate the results supporting the soundness of the conclusions (Creswell, 2012).

<table>
<thead>
<tr>
<th>Name</th>
<th>Age (years; months)</th>
<th>School placement</th>
<th>Level of support</th>
<th>Language and communication skills (described by parents)</th>
<th>Duration of child interview (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>7;03</td>
<td>Local mainstream school</td>
<td>1:1 support</td>
<td>Very verbal at home; uses limited speech at school</td>
<td>30</td>
</tr>
<tr>
<td>Marie</td>
<td>9;02</td>
<td>Resource base in mainstream school</td>
<td>Accesses mainstream school with support</td>
<td>Better expressive than receptive language skills</td>
<td>20</td>
</tr>
<tr>
<td>Gary</td>
<td>8;05</td>
<td>Local mainstream school</td>
<td>1:1 support</td>
<td>Receptive and expressive language delay</td>
<td>30</td>
</tr>
<tr>
<td>Andrew</td>
<td>10;01</td>
<td>Local mainstream school</td>
<td>1:1 support</td>
<td>Very talkative but listening skills and turn-taking are poor</td>
<td>45</td>
</tr>
<tr>
<td>Robert</td>
<td>10;02</td>
<td>Local mainstream school</td>
<td>1:1 support</td>
<td>Age appropriate receptive and expressive language skills</td>
<td>45</td>
</tr>
</tbody>
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Table 1: Study participant characteristics

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provided both a visual representation of the child's personal school environment and examples of social communication in the school setting.

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Table 2: Steps in the process of analysis

<table>
<thead>
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<th>Step</th>
<th>Researcher activities</th>
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<tbody>
<tr>
<td>Transcription</td>
<td>Verbatim transcription of the parent and child interviews</td>
</tr>
<tr>
<td>Reading and rereading transcripts</td>
<td>Transcribed interviews read several times while the recording was listened to with initial noting</td>
</tr>
<tr>
<td>Close line by line analysis</td>
<td>Development of a table for each participant, with significant points and interpretations of the data highlighted</td>
</tr>
<tr>
<td>Examination of the photos taken by the children</td>
<td>Reflection on the meaning of the photographs for the child</td>
</tr>
<tr>
<td>Developing emergent themes</td>
<td>Emergent themes were noted</td>
</tr>
<tr>
<td>Searching for connections across emergent themes</td>
<td>Themes were developed across the data set</td>
</tr>
<tr>
<td>Looking for patterns across cases</td>
<td>Themes were ordered at a more theoretical level</td>
</tr>
</tbody>
</table>

Results
Analysis of the data revealed three higher-order themes derived from subthemes:

- the potential to find a place in society
- the impact of social communication difficulties at school
- school as a social context

The potential to find a place in society
As Sally’s mother stated, many parents felt that mainstream school offered the children a chance to be ‘more or less like everybody else’. Edward’s mother discussed this as not putting children ‘in a bubble’.

Andrew’s use of ‘we’ in relation to school projects indicated that he does indeed feel a connection to school life:

“Okay, this is the sandstone path that supposed to lead to the stone path but the stone path not be created yet. We just have loads of plans.”

All the parents emphasised the importance of the happiness of their child but they frequently perceived them as vulnerable. Marie’s mother explained:

“‘In a mainstream school if they didn’t understand autism and they didn’t deal with it correctly, then there’d be alarm bells going.”

Andrew’s and Marie’s own comments convey a sense of the happiness that their parents aspire to for them:

“This is Mrs Mills office; the reason it says ‘everyday matters’ is that what the schools about” (Andrew).

Interviewer: “Tell me the best thing about school.” Marie: “Lots of fun…. I love Emma, and a sensory room with me in and Emma so that’s a bit funny.”

Part of this happiness however seemed dependent on self-esteem as expressed by both Robert and his mother.

“His big passion is cycling… it is great if he achieves because it affirms him as a person and boosts his self-confidence” (Robert’s mother).

“I’m the best cyclist in school, I’m glad I’m the best at something” (Robert).

The parental dilemma is captured by the mother of Marie; the desire to support the child to achieve their potential while fearful of negative consequences.
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The impact of social communication difficulties at school
Parents often discussed how the child's social communication difficulties impacted at school both academically and socially:

“Mrs Smith said numbers 1-10 which one is the biggest; she said well they’re all the same size… it’s that kind of rigidity and lack of flexibility” (Sally’s mother).

“He struggles sometimes with parties at school… the minute it becomes unstructured…he’s not really knowing what he’s expected to do” (Edward’s mother).

Through their responses the children provided examples of their social communication difficulties at school, as shown in Andrew’s confusion over the term ‘front door’. While some of the children, like Edward, demonstrated insight into their own difficulties.

(A photo of the school entrance) “This one’s making me confused, people say it’s the front door but we don’t normally go through that door, we normally have doors that go to our classes” (Andrew).

Interviewer: “Is anything about talking difficult?” Edward: “Maybe if they’re talking about something I don’t know about I go sorry, I don’t know what that means”.

Parents noted that their children use language largely for functional purposes, did not ‘chat’ and as Andrew’s mother observed, there was lack of two way communication.

“If he finds someone who will listen to him he will talk really fast about something like Spiderman… he’d just carry on till he’d said what he wanted to say.”

These difficulties could be seen first, in the way the children coped with the social process of the interview as shown in the following extract from Marie and second, in their responses to social scenarios with Gary’s limited descriptions of lunchtime conversation.

(To the interviewer) “What did you have for breakfast? What’s your favourite programme on TV? Your turn to ask me – ask me!” (Marie)

(A photo of a school dinner hall) Interviewer: “What are they saying?” Gary: “That’s my dinner.”

All the parents perceived emotional understanding to be a key area and expressed the view that their child was not unemotional but the difficulty lay in understanding and expressing their emotions. The parent and child comments in conjunction provided insight into the individual child’s experience of emotions in school. In these extracts looking at photographs of school scenes Gary misreads the emotional content, while Robert is able to suggest appropriate emotions and the perspective of others.

(A photo of two angry boys fighting, with one’s mouth turning up in rage) “That one looks like he’s happy and that one looks like he’s angry” (Gary).

(A photo of two girls looking at a teddy) “She looks a bit sad ‘cos she took her teddy, trying to be nice to teddy but she doesn’t appreciate it” (Robert).

However, in spite of Robert’s relative strength in this area, the following extract by his mother supports the observation by Hanbury (2005) that emotional impact encompasses the effect of the autism itself, the resulting behaviour and the consequent attitudes of others.

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However, in spite of Robert’s relative strength in this area, the following extract by his mother supports the observation by Hanbury (2005) that emotional impact encompasses the effect of the autism itself, the resulting behaviour and the consequent attitudes of others.

“Even if he’s perceived as being charming there will always be an element of him that won’t quite work it out. As long as he can cope with that and other people can cope with that he will be alright.”

For individuals with autism social and emotional information requires cognitive processing capacity rather than being processed ‘intuitively through dedicated systems’ (Jordan, 2005 page 58). Through Andrew’s description it appears he has some awareness of the
strategies that help him to cope with these demands.

“Loads of my class mates is talking over the teacher, its giving me a headache. Sometimes I go like this (hands over ears). Teacher tells them off, gets so annoying sometimes I go aghh…just try to ignore them.”

A key supportive strategy identified by three parents was structure and clarity within the day. This was indicated in the comments of some of the children; Andrew showed that the school routines support his understanding of social communication expectations, while the importance of structure and predictability was apparent for Marie when she gave the opinion that the class rules should be in a more prominent position.

(A photo of assembly) Interviewer: “What are the children doing?” Andrew: “They don’t talk at lesson time… it’s assembly – like stuff that the teachers say… listening.”

(A photo of the class rules) Interviewer: “What’s this?” Marie: “A picture of the rules. We should pick that up and put it down a bit. Rules – so don’t break any.”

Mesibov et al (2001) suggest that ways should be found to link the special interests of children with autism to other functional skills. Both the comments of the parents and the children illustrated that social communication can be facilitated through a shared interest because, as Robert’s mother described, there is then “communication for a purpose rather than for the sake of it”. Together the comments of Andrew and his mother illustrate how his interests scaffold his social communication with peers who share them.

“If he’s doing Lego he will talk more and do a conversation…almost a vehicle for communication…he’s not just dealing with – what shall we talk about?” (Andrew’s mother).

“Lots of times me and John play Spiderman… like John normally picks me to be the black one – yay!” (Andrew).

Parents also expressed that their own ‘lived experience’ included a need to be vigilant for problems at school which the children may not able to communicate about.

“I regret not seeing the signs at the time, I just thought it was her and she was nervous about going to school…she just couldn’t communicate, she couldn’t say what was the matter.” (Marie’s mother)

Furthermore Marie’s mother noted:

“I need her version of events… I always have this one sided version of a story and she cops it.”

It is often observed that children with autism have difficulty in taking the perspective of others. Part of their lived experience at school may be that their social communication difficulties mean that their perspective is not readily expressed or recognised by others, with a potentially negative outcome for the child.

School as a social context
All the parents aspired for their child to develop social communication through contact with mainstream peers. However, perhaps indicative of their understanding of their own child, these aspirations ranged from exposure, to witnessing, to learning from them. Parents often talked about the level of engagement their child wanted with peers. Marie’s mother identified a limited interest and a need for her to learn acceptable strategies to manage social situations. Marie’s responses during the interview were interpreted as supporting her mother’s comments.

Interviewer: “Who do you sit next to?” Marie: “I don’t know, I don’t want to tell you.” Interviewer: “Who are your friends?” Marie: “I don’t know, I don’t want to tell you.”

Gary was described by his mother as eager to make friends but to not understand how to achieve this. This was borne out in Gary’s reference to friends who he was then unable to name.

Interviewer: “Who do you sit next to?” Gary: “All my friends.” Interviewer: “Can you tell me their names?” Gary: “Seven names…and don’t know.”

In contrast Robert’s mother remarked that he strived to ‘fit in’ but that this required work on his part.

“He couldn’t cope with football at all because of the need to work with others but he’s worked very hard at it, he wants to fit in.”
Parents often described that, while their child might talk about friends, as Andrew's mother noted, in reality they had a limited concept of friendship.

"He likes people around him who make him feel safe, so I think he'll refer to friends as kind of people around. I don't think he really knows what a friend is."

Andrew was unable to give any description of friendship. In response to the question ‘what is a friend?’ he held up the stop card and his own rationale for friendship was pragmatic.

Andrew: “Melissa and Cara are in the same class.”
Interviewer: “Is that why they are friends?” Andrew: “Yes.”

However it was striking that some of the children, like Gary and Marie, gave a detailed positive definition of friendship in spite of the fact that this did not appear to reflect their own experiences.

“‘They help you do stuff when you’re stuck on something … They always say yes when you say can I play” (Gary).

“Like your bestest friend…Person that you love…A person who looks after you.” (Marie)

Parents often noted that the development of an acceptable role within their peer group was based on a level of understanding and accommodation by other children.

“He uses the fact that he’s different and a bit odd and makes people laugh and he’s accepted.” (Robert’s mother)

Children with autism may have a high risk of being bullied (Humphrey and Lewis, 2008a). When shown a photograph depicting mild bullying all the child participants indicated awareness of the concept, but with different levels of understanding of the incident.

Marie: “She’s sleeping.”

Gary: “Look at those people shouting her- ha ha you hit the wall.”

Robert: “She’s being mean to that girl. Very sad…. every time someone says that to me I say don’t care.”

This may point to the children’s personal lived experience of this type of behaviour in school being influenced by their interpretation of the behaviour of others as well as by the behaviour itself.

Parents often expressed fear that their child would be alone at playtimes. When the parents and children were asked about playtime preferences their responses pointed to their experiences. Sally showed limited awareness of the playtime possibilities with a description of playground equipment rather than social play.

“We only have trials and one class can go on each day. We don’t have any swings or slides in our playground.”

In contrast Andrew was able to describe taking part in a peer based game, contrasting with his mother’s perception of him as someone who preferred to be alone.

“We have wakened the mummy, and we have to run away from the mummy.”

However, Gary’s mother explained that he did attempt to play interactively but this was usually unsuccessful.

“There was a few boys kicking a football about and Gary went in and stood there “can you pass me the ball please” …they totally ignored him and he come out in tears absolutely breaking his heart”

Part of successful social communication is dependent on an interest in being social. However as discussed by Rowley et al (2012) this illustrates that increased social attempts may also increase the risk of rejection.
Discussion
This study employed a modified phenomenological approach to gain an understanding of the social communication experience of children with autism in mainstream school.

The first identified theme was the potential to find a place in society. Parents believed that inclusion not only developed the child’s own abilities but, by increasing knowledge of both autism and the child, it had the potential to lead to acceptance and a greater connection with society (Leyser and Kirk, 2004). However, importantly, this study showed that all parental participants expressed the need to balance the benefits of inclusion with issues of happiness, vulnerability and self-esteem. As the qualitative data from the child participants allowed access to a perspective which may not always be considered (Roulstone and Lindsay, 2012; Marshall and Goldbart, 2008) it was possible to reflect on the extent to which the children indeed had a sense of acceptance and happiness. The findings suggest that, if the issues that children with autism face as they live their lives are to be taken seriously, (Morrow and Richards, 1996) there needs to be greater recognition by practitioners of these broader concerns and that ways should be found to explore them with the child.

The second identified theme, of which both the parents and to some extent the children were aware, was the numerous ways in which social communication difficulties could impact at school. However, while research has indicated that inappropriate social communication may be due to reduced awareness of the impact of behaviour on another person (Rubin and Lennon, 2004) the children in the study had varying degrees of this awareness. The insight gained from the parents and children therefore illuminated the individual nature of the priorities for each child.

The potential for the child’s special interests to have a positive impact on social interactions is consistent with previous research (Daniel and Billingsley, 2010; Carrington et al, 2003; Saggers et al, 2011) as it was shown to effectively function as a familiar script and reduced the impact of the child’s social communication difficulties.

A prevalent theme in the parent interviews was the importance of the child being able to communicate any issues to other people. Sally’s mother reported that, when asked what it was like to have a child with autism she would say “it’s like having a very anxious child”. Some parents identified that these high levels of anxiety, combined with a restricted ability to communicate, could impact both on the child’s behaviour and then on the behaviour of others if they applied the ‘normal template for understanding other people’ (Jordan and Jones, 2012 page 65). The children showed some ability to reflect on the value of coping strategies they used themselves or which had been introduced. The findings point to the importance of practitioners recognising that children with autism need to be supported to reflect on and convey any school issues and to identify and evaluate coping strategies at school.

The third identified theme was school as a social context. Humphrey and Lewis (2008a) note that the relationships of children with autism with their peers can be both a barrier and an enabler to successful inclusion in school. A recurrent theme identified in the current study was the need to consider the level of interaction with peers that might facilitate social communication.

The data showed that all the children in the study had some understanding of peer relationships but there was variation in the level of their understanding (Attwood, 2000; Bauminger and Kasari, 2003). There is debate as to whether children with autism want or have friends (Bauminger and Kasari, 2003; Chamberlain et al, 2007; Ochs et al, 2002; Rowley et al, 2012; Whitehouse et al, 2009) and while some of the children talked about having friends, the actuality varied. However, the findings support the view of Chamberlain et al (2007) that a central consideration is a child’s social satisfaction. This may be one explanation as to why, as noted by Baxendale et al (2013), those who know a child with autism may have different perspectives about the impact of their impaired social communication. The child’s school placement is the context for their social communication and practitioners need to be aware not only of the child’s social communication competence but also their functioning and aspirations in that social world.
Although more children with autism are attending mainstream schools, there is still inadequate understanding of this experience from their perspective (Müller et al, 2008). Furthermore it is not possible to address all aspects of social communication through direct intervention (Adams et al, 2012), with some needs specific to all children with autism and others unique to the individual (Norwich, 2007). Researchers and practitioners therefore need to listen to the experiences of children with autism (McLeod, 2011) in order to understand their everyday social communication reality in mainstream schools; their sense of connection, the impact on different aspects of their functioning and their satisfaction with their relationships with others. Gaining the perspective of the child may support the development of a knowledge base from which to plan interventions which have greater value and purpose because they are based on outcomes informed by the child (Humphrey and Lewis, 2008a; Lindsay et al, 2012; Haertl et al, 2013).

The dilemma is that these very social communication difficulties often impact on the ability of the child with autism to share their experiences. There needs to be first an acceptance that they can provide insight into their own situation (Dillon et al, 2014; Rosqvist, 2012; Haertl et al, 2013; Rossetti et al, 2008). Second, the challenges inherent in eliciting the perspective of a child with autism need to be recognised and responded to by being as responsive as possible (Miskelly and Roulstone, 2011; Preece, 2002; Larkin et al, 2006). The onus is on both researchers and practitioners to find sensitive and imaginative ways to access an understanding of the child’s experiences including consideration of modifications to questions, adaptation of questioning style and the use of additional scaffolding techniques in order to understand the child’s everyday reality and individual priorities.

Concluding comments
It is difficult to respond to the needs of a person without understanding their individual experience (Falkmer et al, 2012; Carrington and Graham, 2001; Lloyd et al, 2006; Griffith et al, 2012). There is therefore a need for both researchers and practitioners to consider the perspective of children with autism in order to develop an understanding of their experiences and highlight their individual priorities.

While acknowledging the implications of the children’s social communication difficulties and processing style for the research process, adapting the methods in the study allowed meaningful data to be collected (Beresford et al, 2004; Carrington and Graham, 2001; Lloyd et al, 2006). The challenges inherent in striving to gain the first person perspectives of children with autism need to be acknowledged and reflected on both at a research and practitioner level. However, the study revealed the potential to gain insight through the use of appropriately adapted elicitation methods.

By embedding social communication outcomes in an understanding of a child’s lived experience in mainstream school, interventions may be developed which are more effective because they have significance for their daily lives.

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