

Essential Conditions for Research with Children with Autism: Issues Raised by Two Case Studies

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This article discusses conditions for research into the social experiences of children with autism in real-life contexts using material from case studies of two boys with autism and their friends in mainstream school settings. It is argued that essential conditions for research with children with autism in ordinary social contexts should include a participatory approach, take a wide perspective of group processes, and account for multiple influences on social behaviour. Socially focused, participatory research design allows the social competencies that children with autism do have to be seen and produces multiple perspectives on children's social activity. Children and adults thinking together and sharing their ideas about the nature of experience for a child with autism and their friends allows for shared interpretations and reduces the very real possibility of one researcher alone making wrong assumptions about the nature of the investigation. © 2013 The Author(s) Children & Society © 2013 National Children's Bureau and Blackwell Publishing Limited

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Introduction

The social basis of learning in human development is increasingly being seen as key to our understanding of and support for children with autism (Jarrold and Conn, 2011; White and others, 2007). There is growing indication that it is in social engagement — through shared attention, emotional engagement and social reciprocity — that cognitive development occurs and, despite the genetic basis of the condition, this is seen as having implications for our understanding of autism too (Humphrey and Parkinson, 2006). Children with autism are partly socially engaged and do develop; yet, little is known about how they share meaning and form friendships in real-life encounters with other children. Research approaches to studying the social engagement of children with autism tend to use quantitative methods, measuring amounts of engagement and identifying within-child capacities in experimental situations. Autism research and practice maintain a strongly dominant biomedical discourse, focusing on the individual with autism using measures against the 'norm' of development in children without autism and interventions that redress a 'deficit'. Nevertheless, in the literature on autism, the need is being highlighted for more to be known about the quality of social experiences for children with autism (Kasari and others, 2010), about how they engage in social processes, play and make friends.

Gaining knowledge of the social experiences of children with autism presents a challenge in terms of conceptualising a complex research frame, one that involves groups of children and their varied participation in naturally occurring social processes (Wang and others, 2011). Autism is a transactional difficulty, social in nature, where success or failure to make meaning involves at least two people. The social model of disability puts forward the idea that disability is at least partly socially derived, impairment not necessarily leading to

disability and perceived difference or difficulty constructed within social relations (Connors and Stalker, 2007). In settings such as a school, within-child capacity might be of far less significance than the environment of which the child is part, including other people, their understandings, behaviour, beliefs and feelings (Thomas and Loxley, 2007).

In the last two decades, a perspective on autism has put forward the idea of autism as a culture (Mesibov and Shea, 1998; Sinclair, 1993). Culture refers to people's shared patterns of thinking, behaving and communicating. Autism too affects these aspects of behaviour and many would argue that individuals with autism are not stuck at a developmental stage, but develop in qualitatively different ways to non-autistic individuals, processing information in novel ways and developing different cognitive and social styles within a form of naturally occurring neurodiversity (Langan, 2011). In relation to a study of autism, a focus on the experience of peer culture for a child with autism in a school setting gives rise to notions of cultural difference with questions arising about how mixed groups of children, with and without autism, share meanings and learn from each other, what misunderstandings occur and how they are resolved. The emphasis would be much less on what a child with autism cannot do in comparison with his non-autistic peers, but on what he is doing with them and compared with them and on their responses.

There does need to be caution, however, in applying too universal a notion of the social relations that exist in mixed groups of children with and without autism. People with autism describe a subjective experience that is highly individual in nature and varied in the way the sensory aspects of the condition are experienced. Firsthand descriptions of the experiences of an individual with autism emphasise a different kind of consciousness that does not automatically 'convert experience into abstractions and words' (Grandin and Johnson, 2005), but processes the world in different, primarily sensory ways. Donna Williams, a well-known writer with autism, points out that living in a sensory world means processing information according to individualistic perception and leads to the creation of a private 'language' that cannot easily be shared. She describes how she defined people and objects in terms of their emotional impact on her, which was derived from a set of rich and complex sensory data rather than from any social understanding (Williams, 1996). With autism, knowledge of the world is highly individualised and information stored idiosyncratically according to a set of criteria that focus more on the situation in which the person or object is perceived rather than any culturally recognised meaning. For someone with autism, his/her disposition to the world is not overwhelmingly social and his/her experience of disability must be viewed as the result of culture and structure, but also of a core physical impairment (Watson and others, 2000). What methods then can the researcher use to provide access to this autism-specific, partly social, highly individual type of experience?

The key challenge in research into the social engagement of children with autism is to find methods that balance 'listening to children', in line with current understandings about research methods suitable for use with children, with providing authentic accounts of a differential subjective experience. This article will use findings from two case studies of the social engagement of two boys with autism in their respective peer groups in the setting of their schools to explore methodological issues in relation to research with children with autism and their peers in ordinary social contexts.

Background to the case studies

The purpose of the studies reported here was to carry out a 'cognitive ethnography' (Daniels, 2008) into what goes on when a child with autism engages with other children in a natural setting. The aim was to gain detail about the social activity of children with autism with their peers and compared to that of their peers, exploring issues of sameness

and difference in a child's social participation and the ways in which others experienced it as appropriate and of interest, or as different and inappropriate. The project used the fact that most children with autism in a mainstream school setting have at least one or two children with whom they associate more regularly (Locke and others, 2010) to design research that looked at social engagement within three social contexts: the wider class group as a background point of comparison, the smaller peer group of which the child with autism was part, and finally, the individual participation of the child with autism compared to this small peer group. The idea was to take in a sweep of cultural activity within the same community each time, wide at first, but getting progressively more focused.

Material from two case studies is used here, each one based on research carried out in two mainstream primary schools. Both cases involve a child with autism within a Year 4 class (8-9 years old), the age by which children's peer groups are thought to be established (Corsaro, 1999). Both children had been in their respective schools from an early age (aged 4 years) and were described as being part of well-established peer groups. This consisted of a number of children in each case who themselves had some kind of special educational need. The studies used a qualitative research design, employing the Mosaic approach (Clark and Moss, 2001) for the collection and analysis of data. Research methods included semi-participant observations, conversations with children, practitioners and parents of the child with autism in each case, and a group interview with the focus peer group. The process of research was concerned with finding methods, which could yield partial ethnographic accounts of sociocultural activity within a group of children without imposing themselves on children's behaviour and obscuring natural forms of social engagement. Observations were carried out for the purpose of familiarisation and to understand the key themes in peer culture in that particular setting. Children were asked in simple terms about their favourite things to do with individual peers. Children's descriptions of their games were recorded and brief details of their conversation jotted down. All the material that was gathered from children and adults was put together in a child-friendly and visual form — using children's drawings, photos and conversation — and presented back for the purpose of discussion and a second stage of data collection.

Findings showed that both boys with autism participated appropriately with their peer group in a number of ways and that the social differences that were apparent — for example, needing to be the leader in play — were not necessarily viewed by peers as inappropriate or 'wrong'. Rather, children were observed and described by adults as enjoying the playful ways in which the two boys with autism engaged in peer culture. In particular, they appreciated the skills with which they reproduced ideas from media culture, one boy with autism being described as having a 'perfect recall' of the details of action-adventure films he watched, but which all his peers strongly valued. Findings from the research would support the affirmative model of disability that describes positive social identities for disabled people and perceives value in, in this instance, their cultural contribution (Swain and French, 2000). Material from the case studies will now be used to discuss essential conditions for research with children with autism. It will be argued that research into the social experiences of children with autism should be naturalistic and take a wide perspective of the multiple contexts of any behaviour. There should be a focus on the social competencies that children with autism do have and effort made to look at what is different and the same in children's behaviour compared to their peers. Finally, it will be argued that the differential subjectivity of autism necessitates an approach to research that allows for shared interpretations produced by research participants — including children and adults — thinking together with the researcher about the nature of children's experience.

The importance of a wide perspective in autism research

Bronfenbrenner (1979) argued that the interaction between the individual and their environment is not a straightforward one, individuals and environments helping to shape each other and reacting to change in each other. The individual and their unique personal resources, history and expectations interact with the distinctive patterns of activity in their immediate environment, which are in turn affected by those in the wider society around. Contemporary ideas about childhood put forward the notion that the more we understand the multiple contexts of any behaviour, the better we understand the behaviour and advocate a wide perspective that brings together, rather than separates out, the biological, social and cultural variables involved (Prout, 2005).

Within autism research, there has been a recognition that more needs to be known about how people with autism respond to actual social interactions (White and others, 2007), but the approach to research has remained a reductionist one, complex social processes simplified and reduced to single variables for the purpose of study. Researchers have sought to investigate ordinary social—emotional situations under experimental conditions, asking children and their parents to participate in situations that mirror real-life ones, for example, where a child is asked to carry out a task and is then praised (Kasari and others, 1993) or put in a situation where they are made to feel jealous (Bauminger, 2004). One major issue implicit in this approach, of course, is the ethical one of asking children to participate in research that may cause them distress. However, further challenge exists in the notion of how far it is possible to recreate ‘real life’, replicating experimentally the richness and unfolding nature of real life contexts. Research shows that children with autism do respond differentially to different social situations (El-Ghoroury and Romanczyk, 1999) and this makes the notion of research as a cultural practice and interpersonal experience a consideration for research into autism too (Woodhead and Faulkner, 2008).

My concern in carrying out the studies reported here was with groups of children in the natural setting of a school, essentially a much more complex field than an experimental situation. The approach used distinctively defined social contexts as culture and sought to locate social interaction in the light of the cultural exchange of which it was part, the experiences of the individual child with autism being examined in relation to a wider and historically unfolding culture. The research process was seen as an augmentative one and had the aim of identifying layers of cultural influence within the community of children being investigated and describing the ways in which culture was being reproduced by all individuals within it, including the child with autism in each case. I wanted to use the idea that children are not simply passive recipients of socialising influences provided by parents and teachers, but are themselves ‘social actors’ who try to make sense of social relations and help to create their own social experiences (James and others, 1998). What I was seeking was information about the nature of individual participation within a group and how that is perceived and responded to. I did not want ‘micro-level’ details about individual behaviour, but wider ‘macro-level’ information about the flow of interaction, including peer and adult perceptions of children’s participation and the perceived appropriateness of all children’s activity within the group.

What was interesting in the data was that both boys with autism participated in peer group processes in a number of ways that were perceived by others as appropriate and of interest and that, although some social difficulties were evident, they reflected features of the environment. One boy with autism, Richie, aged 8, had certain fears about the sun falling out of the sky and dinosaur bones reconstituting themselves and coming back to life. These fears were thought to originate in films and other cultural sources and were described by the

adults who knew him as 'extreme'. They gave his parents considerable concern as Richie refused to go outside the home by himself. During the research process, where children were asked to talk about their social experiences of school, it emerged that irrational fears were present in Richie's peer group and wider class group and that these were particularly related to areas of the school where adult presence was minimal, for example, the children's toilets. Several children mentioned that they frightened themselves and each other by talking about scary topics and describing imaginary things as if they were real. Richie's parents and school staff practitioners had little knowledge of this aspect of children's culture, although on questioning it was apparent that Richie had had access to it. The wide perspective of the research design revealed that Richie had a more extreme experience of this aspect of culture, perhaps being less able to seek emotional reassurance or social explanation about frightening things because of his autism, but that his fears were not out of the realm of other children's experience in this setting.

The need to focus on competencies

Research indicates that children with autism are partly socially engaged and this makes a strength-based model of research possible (Dolan and others, 2006). In the two case studies reported here, the two children with autism displayed a number of competencies in relation to their individual settings, both boys being part of an established group of peers that had existed for some time, that shared play interests, played regularly and expressed an enjoyment of being together. One child, Kyle, aged 9 years, despite having expressive language difficulty and some echolalia in his conversations with adults, nevertheless showed competency in terms of the patterns of discourse that were present within his group. In sociological approaches to researching children's social worlds, discourse around friendship has been seen as particularly important to children's construction of acceptable social identities (James and others, 1998). Kyle was able to use the same language as his peers to describe the particular nature of friendship within his group. These boys enjoyed playing imaginative role play games based on the films and TV programmes they watched. The games involved a large amount of play fighting that regularly became real fighting, with individuals often getting into trouble with school staff. The boys in the group made the distinction between a 'friend', a 'friend's friend' and someone who was part of a 'team'. This understanding was something that was shared within the group and closely conformed to the content of the children's play, where they 'teamed up' against each other to play their fighting games. The distinction was made by several children between someone you felt close to and who was a 'friend', and others with whom you played regularly, but with whom you sometimes fell out and so described in less intimate terms, as a 'friend's friend' or part of a 'team'. In his interview where he was asked to describe the peers with whom he regularly played, Kyle, the child with autism, also made this distinction:

CC: Who's this? [*Looking at photo of peer*]

Kyle: Joshua, he's my pal.

CC: What do you like about him?

Kyle: Sometimes clever he is.

CC: What's your favourite thing to do with Joshua?

Kyle: I play with him all the time.

CC: What about Liam? [*Shows photo*]

Kyle: It's Sam Collins' best friend. And he sometimes teams up with me.

CC: So what's your favourite thing to do with Liam?

Kyle: He plays Terminator as well. He's mostly friendly, but sometimes he's not.

CC: When is he not friendly?

Kyle: When he gets into trouble and ends up in the 'Own Goal' book. I won't get caught up with that.

By focusing on children's actual lived experience, it is more likely that the parameters and constraints of the investigation can be seen and that quality in research can be achieved. Sociometric measures of children's friendship groups, where children are asked to list who they play with and nominate 'best friends', are typically used in autism research, but problematic when one considers the sensitivity of the topic of friendship for children and the variation that exists in patterns of children's friendships. In the two case studies reported here, what came across most strongly in talking to children about their friendships was the sensitivity of the subject and how closely it was tied to issues of personal identity. Many children, including both boys with autism, were concerned with showing that they were someone who had friends, eagerly naming names of children with whom they played. However, the number of children who had a best friend — who regularly spent time together, had sustained their friendship for a period of time and mutually declared that they were 'best friends' — was relatively small in each setting and the idea of 'a best friend' came across in much of children's talk as an ideal that had not been experienced personally.

Progressive focusing and researcher effect

Friendship is not the only area of social activity where it is possible for adults to make wrong assumptions about the form and quality of social experience in children's cultural worlds. Autism research has typically looked at the parity of participation that exists in social engagement, for example, by measuring the number of social initiations and amount of turn-taking in interaction, but social research into children's worlds indicates that differing patterns of social organisation exist which are determined by the nature of social activity and may not involve turn-taking or equal participation (Blatchford and others, 2002). Findings from these case studies suggest that it is often play activity that determines the form of social relations, physical activity play with PE equipment giving rise to a good deal of parallel play, where children played alongside each other, but with little social engagement, and imaginative games involving a situation of leader and followers and more in the way of talk. In one setting, where the peer group had a preference for imaginative role play games, the group was always organised into a situation of leader and followers, with Kyle, the child with autism, taking the role of leader and narrating the story of the play. There was little conflict about this within the group, Kyle's ability to remember in great detail the films that they acted out together used to advantage in his leadership role. Blatchford *et al.* (2002) point out that leadership in play is a natural and frequently occurring form of social organisation for children. The implication for autism research is that pre-conceived categories for use in observation or questioning may miss critical aspects of children's actual cultural experience and concerns, and that 'progressive focusing' (Siraj-Blatchford, 2010), where categories of study are allowed to emerge from the data, is a more suitable approach to research.

Humphrey and Symes' (2011) study into peer interaction patterns of adolescents with autism in a school setting shows that the researcher effect must be considered too. They were interested in positive, co-operative interactions as well as negative and aggressive ones, but found that pupils did not always go along with being observed, sometimes hiding from the researchers and sometimes changing their usual patterns of behaviour. It is well documented

in the literature that children are sensitive to the presence of a researcher and will stop what they are engaged in when watched by an adult (Tudge and Hogan, 2005). In one of the case studies reported here, I found that children, including the child with autism, were concerned with not being witnessed doing something they knew would get them into trouble with school staff. I took a semi-participant role in making the observations for this study, standing on the fringes of what children were doing and including the background presence of other groups of children in my observation of one group. Nevertheless, I found that children were aware of me particularly when they were engaged in an activity which they knew overstepped the mark:

Adam was a zombie who had been knocked to the ground. Kyle stood over him and said, 'It's OK, I got him covered'. Joshua said, 'Bang, bang', pretend shooting Adam who was still on the ground. When Adam would not lie still, the children kicked him for real, all of them looking over at me afterwards to see my reaction.

Shared interpretation within a participatory design

An interpretive approach using qualitative methodologies is most frequently used in research with children (Christensen, 2004; James, 2001), but this also presents challenge in terms of research with children with autism. Qualitative research methods are often pinned on the making of a good social connection with the child. Corsaro (1992) has produced very rich accounts of young children's activity and advocates the method of moving in, sitting down and letting the children react to him. He argues that it is the researcher and the participants together who must collectively work out the research process, gradually defining the role of the researcher through repeated social encounters. How different this is to the situation I found myself in as a researcher collecting data for one study. Richie was well integrated with his peers, but showed much less interest in the adults around him:

When one child went off to play, a girl at the table invited me to sit beside her. I hesitated for a moment as this meant that I would block Richie from the rest of the group. I did move however because to refuse seemed rude. Richie carried on eating his sandwiches, apparently not noticing my move beside him. He did not talk to me, glance in my direction or shift in his seat. He did not seem to 'see' me at all.

Interpretive methods that focus on children's own meaning making are socially rooted at the stage of both data collection and data analysis. There is an assumption that data about individual experience, if carefully managed, will yield meaning at a cultural level that can be shared. Many methods used in research with children rely on making 'authentic' person-to-person contact with children where communication is open, questions are direct and understanding is collective (Mayall, 2008). Writing about interviewing children, Westcott and Littleton (2005) argue that researchers need to understand the moment-to-moment co-constructive processes through which meaning is negotiated in the interview, paying careful attention to children's activity and continually asking the question 'What is the child making of this?'

The differential sociocultural experience of autism raises questions about how far meaning-making can be directly accessed by the researcher, whatever their level of reflexivity. Individuals with autism point out that for them social orientation does not come naturally and often has to be intellectually compensated for (Sainsbury, 2000). In this study, I noticed during initial observations that Richie seemed to jump ahead of people in social interaction, as if he had anticipated what they were going to say and had worked out his reply beforehand. In a jokey question and answer session with the teacher, Richie laughed along with the others, but always gave his answer very quickly, almost before the teacher had asked him.

However, if intersubjective access to individual experience may be problematic, neither is it the case that using sensory methods will provide access. Although subjectivity in autism is clearly strongly rooted in sensory experience, sensory research methods do not provide direct access to this (Mason and Davies, 2009). Visual research methods such as drawing, for example, use symbols and are culturally based. Many children with autism find it hard to express themselves through drawing, although some are accomplished artists. Drawings are open to interpretation with meaning typically located in children's expression of their social and emotional world. In this study, Richie was an excellent artist and gained status amongst his group of boys with his sophisticated drawings of fast cars, but it was apparent from conversations with staff and his parents that Richie's interest and expertise in drawing cars was not necessarily open to culturally based interpretations. His intense passion about cars seemed to reflect more an engagement with the car itself, specifically the sensory experience of speed and movement along lines on a road and was not an experience that was socioculturally based and available for cultural sharing.

Research into the social experiences of children with autism requires the careful use of a range of research tools and forms of communication that overcome the difficulties inherent in one language- or symbol-based method alone (Morrow and Richards, 1996). Information that is gathered in different ways and from different sources, including children and adults, can be reflected on together and used to create a shared interpretation of the nature of individual experience. Differing views can be seen to add to the richness of the data and reflect the nature of individual experiences. Such an approach allows for multiple perspectives to contribute to an overall picture of a child's activity and how it is received by others within a setting. An approach that uses a participatory design, with only partial reliance on ethnographic accounts, also allows for a more transparent and socially less crucial role for the researcher, with the aim of the research clearly explained at the outset (O'Kane, 2008).

Conclusion

The approach taken in these case studies, of focusing on group processes and individual participation in these rather than on the individual child with autism, provides a wide view of social engagement and gives additional information about the contexts of individual behaviour. Social processes are complex and findings from these case studies indicate that multiple variables operate in social situations, with time and the constantly changing nature of sociocultural experience a feature of this. Discourse should be viewed as central, specifically how individuals make sense of, construct and share meaning around key concerns. The data suggest that individual difficulty in producing culture cannot be assumed in children with autism. An important consideration in this is the way in which the individual child's social participation is received and experienced by other children and by adults, and this is also something about which it would be hard to make assumptions or generalisations.

Recognising the existence of competencies and weaknesses in all children's sociocultural participation and that social difficulty bears a relation to the particular features of the social context perhaps helps us to understand why autism research has presented such complicated, sometimes contradictory, findings in relation to the social capacities of children with autism (Chamberlain and others, 2007). A research process that takes a consultative approach, which focuses on real-life events and gives serious consideration to the experiences and views of children, teachers and parents, is naturally oriented to practice and more available for use. Education research indicates that practitioners make decisions and plan actions based on this kind of context-dependent knowledge, using actual cases and particular contexts. It is argued here that autism research would benefit from this kind of context-thinking too, where

assumptions are not made about children's social worlds and where individual experience is carefully reconstructed with children themselves.

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