Engaging young people with Autism Spectrum Disorder in research interviews

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Accessible summary
- Listening to young people with autism spectrum disorder is important.
- Researchers can help support young people to have their say.
- Each young person is different. The supports used need to match their needs.

Summary
This study draws on the first author’s doctoral research on the mainstream schooling experiences of young people with autism spectrum disorder (ASD) and their parents in Queensland, Australia. The aims are to share some of the practical strategies that were adapted and developed to engage the young people in the research and to critically reflect on what this means for future inclusive methodological approaches in this area. The key message is that diagnostic-related assumptions about impairments can lead researchers to develop strategies which exclude or restrict rather than maximise participation of disabled people in research. To enable young people with ASD to provide rich and meaningful insights researchers need to acknowledge and plan creatively and flexibly for the interactive dynamic that is unique to each individual as well as for needs which might be shared.

Keywords Asperger Syndrome, autism, interviews, methodology, qualitative, young people

Introduction
Since the United Nations Convention on the Rights of the Child (1989), there has been increased recognition of the need to include the views of children and young people, including those with a disability in research concerning their lives (Lewis 2009). Corresponding to this a new sociology of childhood has emerged in which children are viewed as social actors who actively shape and respond to their social world (James et al. 1998). Whilst the importance of including the voices of children and young people is no longer contested, debate continues as to the best method for eliciting their views and the extent to which they can participate during the research process (Lewis & Porter 2004). A number of authors have highlighted some common methodological issues arising from the use of interviews with children and young people, including those with complex and profound learning needs and those with speech, language and communication needs (Beresford 1997; Kelly 2007; Lewis & Lindsay 2000; Lewis & Porter 2004; Morris 2003; Whitehurst 2007). These include issues with gaining...
permission from gatekeepers to interview young people; barriers to obtaining informed consent; communication difficulties arising from the language and questioning techniques used by the interviewer; and the need to develop a range of approaches and resources to address individual communication needs (Beresford 1997; Kelly 2007; Lewis & Lindsay 2000; Lewis & Porter 2004; Morris 2003; Whitehurst 2007). To tackle these issues, a number of authors have developed methods and practical guides for researchers who seek to capture the voices of children and young people (See Beresford 1997; Bishton & Lindsay 2011; Dockrell & Lindsay 2011; Lewis & Lindsay 2000; Morris 2002).

There is little documented about the distinct methodological issues faced by researchers undertaking interviews with young people with ASD (Preece 2002). Thus, knowledge about the approaches that maximise their participation is limited. In part, this can be explained by the limited body of qualitative research which specifically captures the views of young people with ASD (Preece & Jordan 2010). It is possible that there has been a reluctance to involve young people with ASD due to the communication challenges associated with the condition (Beresford et al. 2004; Lewis 2009). Assumptions about their perceived vulnerability to exploitation if included as participants may also have led to their voices being omitted from research (Lewis 2009). It is also possible that diagnostic-related assumptions impact negatively on decisions about including young people diagnosed with ASD in research but also lead to generalised assumptions about participation. Within a medical discourse, ASD is defined as a lifelong developmental disorder characterised by a qualitative impairment in reciprocal social interaction, communication, and the presence of restricted, repetitive and stereotyped patterns of behaviour, interests, and activities (American Psychiatric Association 2000).

A number of authors claim that diagnostic labelling under the medical model overlooks the role society plays in constructing difference and is pathologising as it reduces individuals to a set of deficits and ignores their unique personalities and characteristics (Allred 2009; Baron-cohen 2002; Connor 2011; Molloy & Vassil 2002; Wheeler 2011). In a research context, diagnostic-related assumptions about impairments can lead researchers to develop generic strategies which ignore each young person’s needs, interests and abilities. However, the medical discourse is contested, particularly in relation to the diagnosis of Asperger Syndrome (Allred 2009; Baron-cohen 2002; Connor 2011; Molloy & Vassil 2002; Wheeler 2011). Some authors contend that Asperger Syndrome is socially constructed and suggest an alternative interpretation is to reframe Asperger Syndrome as being a neurological difference (Allred 2009; Baron-cohen 2002; Connor 2011; Molloy & Vassil 2002; Wheeler 2011). In a research context, there needs to some way of identifying differences to cater for each participant’s needs. Norwich (1996) proposed an approach to consider a balance between different types of need: individual needs which arise from characteristics unique to the individual; common needs which are shared by all and exceptional needs, which arise from characteristics shared by some.

Researchers have encountered the ‘exceptional’ needs of young people with ASD during research with them. Studies by Preece (2002) and Preece & Jordan (2010) revealed that the ability of children with ASD to participate in interviews about their experiences was constrained by the central characteristics of their condition such as impairments in social interaction and communication. Children exhibited distress whilst communicating, and had difficulty remembering past events, discussing their preferences and emotions and answering open-ended questions. They tended to use limited language that was often idiosyncratic (Preece 2002; Preece & Jordan 2010). Several authors have developed strategies to address ‘exceptional’ needs. Lewis (2009) interviewed children with ASD about their views concerning spirituality and proposed a number of strategies for modifying interview techniques when communicating with them such as use of statements rather than questions, using closed questions and repeating questions. Beresford et al. (2004) interviewed children and young people with ASD about their views concerning outcomes of social care and support and developed a methodological approach which incorporated Social Stories™ (Gray 1994), a familiar craft-making activity and photographs.

There is not a single, prescriptive formula for conducting research interviews with young people with ASD, as approaches need to be adapted to cater to individual, common and exceptional needs (Norwich 1996). Moreover, qualitative research with young people with ASD is a recently emerging field and little is known about the approaches that maximise their participation. Those studies that have captured the views of young people with ASD have generally focused on reporting research results rather than sharing the strategies used to elicit their views. Thus, the area warrants further attention. Specifically, there is a need for more researchers to report on the process they used to develop their methods and the strategies that were used successfully during their fieldwork (Beresford et al. 2004). This study addresses these issues. In this study, the authors’ share some of the practical strategies that were adapted and developed to engage the young people in the research. Then, they critically reflect on the unconscious diagnostic-related assumptions that were made about the young people during the research process and how this impacted their participation. Finally, the implications for future inclusive methodological approaches in this area are discussed.
The research project

This study draws on the first author’s doctoral research on the mainstream schooling experiences of young people with ASD and their parents in Queensland, Australia. From the perspective of the young people and their parents, the research aimed to develop an understanding of their experiences of participation in mainstream education in Queensland across primary and secondary school, and the barriers and facilitators to their participation.

Parents with a child with ASD were recruited for the research. The sample of nine families comprised eleven parents – two couples (father and mother) and seven mothers. The sample also included eight young people with ASD aged 12–15 (seven males and one female). One young person withdrew from the research after indicating an unwillingness to participate. They were all diagnosed by paediatricians: three had been diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); and five had been diagnosed with Asperger Syndrome. The young people were all able to communicate verbally. Seven communicated using complex sentence structures; however, one young person had noticeably less expressive communication than the others.

In-depth, semi-structured interviews were chosen to elicit the views of the parents and the young people. Each parent was interviewed on two occasions for 1.5–3.5 h per interview. The purpose of the first interview was to document the mainstream schooling experiences of their child chronologically, identifying the key events and barriers and facilitators to participation along this timeline, whilst the second was used to clarify and explore the barriers and facilitators to their child’s participation in mainstream school more extensively.

One interview with each young person was undertaken following their parents’ interviews, with the aim of exploring their own perspectives, experiences and responses to participation in mainstream school. For example, they were asked what they did and did not get to do at school, what they liked and did not like about school, and whether they felt they fitted in at school and why. These interviews lasted between 30 and 70 min.

In this study, the authors focus specifically on the strategies that were used during interviews with the young people to enhance their engagement in the research. Analysis of the interview data is currently being completed; therefore, the findings of the research will be reported on elsewhere at a later date. The study discusses issues in relation to gaining informed consent, the methodological approach and the preparation and conduct of interviews. Communication strategies that were used to address the issues and engage the young people are highlighted and quotes from the young people are used to demonstrate the efficacy of the strategies. Pseudonyms are used to maintain the confidentiality of the young people. Finally, key lessons learnt during the research process are discussed.

Ethical statement

Ethical approval was granted for this research by the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland.

Developing the methodological approach

A wide range of sources were consulted in developing the research methodology. Beresford et al. (2004) support consultation with the field as a way of gaining valuable insights into practice approaches, which can be used to maximise the participation of young people with ASD in a research context. As a social worker who was formerly employed in this field, the first author drew on her professional networks to learn from other practitioners such as speech therapists, occupational therapists and teachers about their approaches for communicating with young people with ASD. This generated a number of approaches that could be used in the research such as Social Stories™ (Gray 1994) and visual supports which will be discussed in the next section.

Potential methodological challenges were also identified through review of the empirical literature on ASD. For instance, several research papers highlight that some children with ASD have difficulty recalling and narrating personally experienced events (Brown et al. 2012; Bruck et al. 2007; Millward et al. 2000). This supported the need to focus interview questions predominantly on present experiences. Research also indicates that some children with ASD may provide limited information in response to open-ended questions (Bruck et al. 2007) and thus simple, closed questions may be more appropriate (Preece 2002). The interview protocol was designed to include many closed, yes/no questions and fewer open-ended questions. Furthermore, research suggests that whilst children with ASD can express basic emotions, some may have difficulty identifying and discussing complex emotions and processes involving the self (Losh & Capps 2006). Therefore, questions requiring reflection on basic emotions such as sad and happy were included in the protocol. People with ASD may have difficulty understanding nonverbal communication and initiating and sustaining conversation (Smith Myles et al. 2005). Some may interpret language in a literal manner, metaphors and figures speech can cause confusion (Martin & McDonald 2004; Mitchell et al. 1997). Some individuals with ASD display advanced expressive communication skills, which mask difficulties with receptive communication (Saalasti et al. 2008). To gain a better understanding of each young person in the research, parents were consulted prior to the interview about their child’s particular social and communication needs and how best to address these.
Gaining informed consent

Obtaining informed consent from young people with ASD warrants particular consideration. Whilst people with ASD may have the intellectual capacity to give informed consent; some may not understand the full implications of their participation in research (Jordan 1999). As the young people were all under 18 years of age, their parents were required to provide consent. However, assent from the young people was also obtained. A number of strategies were used to fully inform participants about the research and the implications of participation. A key consideration was ensuring information was adapted to accommodate the individual needs of the participants. For example, consent forms were developed in two different formats to maximise understanding. One version utilised a written format with clear, concrete language to explain the purpose of the research, the potential risks, data collection procedures and the expectations of participants. The other version incorporated a combination of pictures and basic words. All of the young people were given the opportunity to ask questions about the research.

In conducting research interviews with young people with ASD, there is the potential for acquiescence (Preece & Jordan 2010). Some young people may feel obliged to say yes, either due to the power imbalance with the adult researcher or because their parents have already given consent for their participation (Beresford 1997). Therefore, there is a need to look beyond initial agreement for further indicators of consent (Beresford et al. 2004; Preece & Jordan 2010). Preece & Jordan (2010) suggest a secondary indicator of consent is the perceived level of engagement that the young person displays towards the researcher during their initial meeting. In the first meeting with the young people to discuss the research, most appeared relaxed and interested in participating. Parents also commented on their children’s eagerness to share their schooling experiences with the researcher. One young person conveyed unwillingness to participate despite her parent’s consent by refusing to speak to the interviewer and hiding under her bed during her scheduled interview time. As this behaviour was interpreted as a lack of assent the interview was cancelled and she was not included in the research.

Negotiating consent involves ‘a continuous and interactive process’ (Ramcharan 2006, p. 183). In the current research, the young people were informed about their rights to decline to comment or answer particular questions during their interviews and to withdraw from the research at any time. Some young people with ASD may not feel confident to withdraw their consent verbally, and therefore, it may be necessary to look for nonverbal signals (Beresford et al. 2004). The young people were offered a ‘stop card’ that they could hand to the author if they wished to terminate their interview and were not able to explain this verbally. However, all of the young people completed their interviews with none electing to use the ‘stop card’.

Preparation and conduct of interviews

A number of strategies were used to prepare the young people for their interviews. Most of the young people had no prior experience of participation in research interviews. Thus, it was anticipated that some of them may feel anxiety about the unknown interview situation. To build rapport and enhance comfort with the interview, the first author spent time with each young person at their home engaging in activities that they enjoyed and getting to know them. For example, time was spent getting to know one young person by playing with him and his dog.

Carol Gray (1994) developed Social Stories™ as a way to share social information with clients with autism to improve their understanding of events and their associated social expectations. Social Stories™ (Gray 1994) have been successfully transferred to research settings and are used to prepare people with ASD for a researchers visit. A Social Story™ used by Beresford et al. (2004) in their research with children with ASD was adapted for the current research (Fig. 1). It provided information about what would happen during their interview such as who the researcher was, what the young person would be asked about and how long the interview would last.

When it came to conducting the interviews with the young people, it was important to choose a setting where they would feel comfortable and relaxed. The interviews occurred in the young people’s homes. Seven of the eight declined the offer of having a parent present. The presence of a parent yields strengths and limitations. The parent was able to assist their child to respond to questions by providing memory prompts; however, the parent interrupted and corrected their child if they felt their response was inaccurate. Preece & Jordan (2010) encountered similar challenges when parents were present during their interviews with children with ASD. In seeking to address the parental influence during the interview, questions were deliberately redirected back to the young person and to gain his perspective and to check whether he agreed or disagreed when his parent answered a question on his behalf. For example, when the young person was discussing teachers yelling in the classroom:

Interviewer do you know why it was bad?

Jake the reason is it just puts pressure on me. I don’t know, like getting yelled at and stuff.

Parent voices have to be kept at a level with Jake or he thinks he’s in trouble. So having a teacher that may have a
more forceful voice so to speak, that would make him retreat back because it’s uncomfortable, intimidating, it sounds like someone’s yelling at him and they may not actually be doing that, but that’s how it sounds. Does that make sense?

Interviewer does that sound about right Jake?

Jake yeah.

This strategy had some success, however sensitivity was required to recognise how often it could be used as the interviewer wanted to ensure that the parent did not feel their perspective was unimportant.

Communicating with the young people

Linguistic factors may influence a young person’s capacity to engage in an interview (Dockrell & Lindsay 2011). In seeking to elicit the views of the young people, it was necessary to understand each of their communication capabilities and to use strategies to facilitate communication. There was considerable variation in how the young people communicated. When asked about what he disliked about school one young person responded with one to three word phrases:

Interviewer what are the worst parts about school?
Zane the bullies.

Interviewer yeah? Are there other things besides the bullies that you don’t like about school?
Zane (shakes head)

Whereas another young person was articulate and expressive and able to provide a detailed account:

Interviewer what don’t you like about school?
Declan the whole set up.

Interviewer what about the set up?
Declan it needs to cater to individual learning and what they want to do with their life, not what the school wants them to do with their life and what the school curriculum is set up for. For instance, there are no things at school for fixing computers so I was getting in trouble all the time for fixing computers and looking at them and whatnot.

The verbal communication style of the interviewer was adjusted to accommodate each young person’s communicative abilities. During the interviews, the interviewer attempted to use simple language and avoid ambiguous language and figures of speech, gave concrete examples, rephrased questions and asked clarifying questions to check the accuracy of interpretations. The interviewer also used the vocabulary of each young person as it was acknowledged that this would be more personally relevant and meaningful to them (Owen et al. 2004).

Use of visual supports

Visuals are often used effectively with people with ASD to supplement written information and improve processing (Arthur-Kelly et al. 2009; Dettmer et al. 2000; Quill 1997). A number of researchers have incorporated visual supports into their research interviews with children with ASD as a way of increasing their engagement (Ashburner et al. 2012; Beresford et al. 2004; Preece 2002; Preece & Jordan 2010). In the current research, a written schedule which incorporated pictures was developed for the interviews to indicate the sequence of events in the interview (Fig. 2). The young people all seemed to respond well to the schedule as they knew which topics had been covered, and which were yet to be discussed. This appeared to help maintain their concentration during the interview. Prior to commencing their interview, it was explained that: ‘this is the plan for your interview: there are three topics we are going to talk about. I am going to tick each one off once we are finished. When we finish the interview you can have free time’. The schedule was then used as a prompt throughout the interviews: ‘we
have finished the section talking about what happens during school so I can tick that off, now we are going to discuss what you do after school.’

As noted earlier in the study, research suggests some children with ASD may have difficulty identifying and discussing complex emotions (Losh & Capps 2006). Picture Communication Symbols™ (PCS) were developed by Mayer-Johnson as communication aids and are commonly used in clinical contexts to facilitate communication and have been successfully used in research (Preece 2002). The young people were presented with PCS™ representing different emotions if it appeared they required assistance identifying and communicating their feelings. One young person had limited verbal communication, with one to three words on average and difficulty verbalising feelings when asked about the bullying he experienced at school. The PCS™ enabled him to express how he felt – sad, lonely and angry. The young people were also provided with a pictorial ‘break card’, which could be used if they wanted to have a break; however, none of them chose to use it. They also had a pictorial ‘stop card’ that they could use if they wished to terminate the interview. Whilst none of the young people chose to use the ‘stop card’, in some cases, their nonverbal cues gave the interviewer an indication that the young person was restless and that their attention may be waning. Hence, the interviews were concluded soon after so as to not cause them discomfort or further fatigue.

**Processing interview questions**

Some people with ASD may have trouble processing information at the usual conversational rate (Jordan 2005). Two of the young people displayed delays in processing language and took substantial time before they responded to the interview questions. For example, one young person took up to 11 s before responding to each question. To address this, extra time was given to allow him to process the question before proceeding to the next question. This appeared effective as responses were forthcoming when adequate time was provided. The validity of long pauses to encourage a response from young people with communication needs is supported by other research (Lewis 2001).

As mentioned earlier, literature suggested that some children with ASD have difficulty responding to open-ended questions (Preece 2002). However, the young people in this study did not have as much difficulty as previous research indicated. For instance, they were able to answer open questions for the most part, particularly when an open-ended question followed on from a closed question. For example, here is a response from one young person when asked about his help seeking behaviour in the classroom:

*Interviewer so you can ask for help?

Luke mmm. I have, there’s usually a support teacher as well, so I can generally go to her, support teacher for help.

Interviewer and are they able to help you?


Interviewer what do they do that helps you learn?

Luke they can just guide me, not give me the answer, but guide me through it.*

One possible explanation is that this sample of young people with ASD had less communication difficulties than those discussed in the previous research. This highlights the need for researchers to get to know the communication capabilities of each of their participants to cater for their unique needs.

**Remembering past events**

There is evidence that some children with ASD have an impaired ability to recall personally experienced events in detail (Brown *et al.* 2012; Millward *et al.* 2000), including recent and distant memories (Bruck *et al.* 2007). Impaired memory was evident during interviews with only some of the young people. When asked to recall particular events that had happened at school they sometimes responded ‘I can’t remember’. However, most of the young people were able to recall the majority of their previous experiences.

**Keeping on topic**

Young people with ASD often have special interests, which may consume much of their attention (Smith Myles 2005). It was anticipated that it may be difficult to keep the young people on topic and that they may digress and talk unremittingly about their special interests during their interviews. However, this only occurred with one of the eight participants. This young male participant’s special interest was movies. Numerous times throughout his

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**Table 1**: Zane’s interview schedule.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Tick for finished</th>
</tr>
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<tbody>
<tr>
<td>1 Talk about <em>during</em> school</td>
<td></td>
</tr>
<tr>
<td>2 Talk about <em>after</em> school</td>
<td></td>
</tr>
<tr>
<td>3 Talk about school <em>in general</em></td>
<td></td>
</tr>
</tbody>
</table>

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engaging young people with ASD in research

Interview, he steered the discussion onto this topic. This was addressed by allowing time to talk briefly about his interest, without further encouragement through questions and then redirecting his attention back to the next interview question. For example:

**Interviewer any particular films?**

**Brad** just like history of movies. Like I found out that you know those... you know Dr. Jekyll and Mr. Hyde? There was a 1931 version and a 1941 version, well the 1941 version was played by Spencer Tracey and I forget who played the 1931 version. It turns out later on in the 50s they were actually in the same movie called ‘Inherit the Wind’ which is kind of interesting.

**Interviewer so you said you go to the library before class and then lunches as well?**

**Brad** yeah and morning teas.

This strategy was successful as it enabled him to get back on topic; however, it needed to be repeated each time he steered the discussion to his special interest. Owen et al. (2004) used a similar strategy in their research with children with communication difficulties. They reported that allowing the children to briefly discuss their interest seemed to result in a longer period of active participation for them.

**Discussion**

Engaging the young people with ASD in interviews was challenging. However, the successful use of creative and flexible strategies enabled the young people to express their views. This demonstrated that if given the opportunity they can provide rich and valuable insights into their own experiences. Similar studies in the field of inclusive education such as Humphrey & Lewis (2008) have captured rich data by interviewing young people with ASD which has shed light on their perspectives on their schooling experiences and how their participation in school could be improved. In this research, each young person participated in an interview lasting 30-70 min and was able to discuss what they did and did not get to do at school, what they liked and did not like about school, and whether they felt they fitted in at school and why. The length of their interview transcripts ranged from 16 to 34 pages. Analysis of interview data is currently being completed; however, the authors feel the data will provide meaningful insights into the young people’s perceptions and experiences of participation in mainstream school in Queensland.

Doing research that captures and does justice to the views of young people with ASD requires extensive preparation. This may include consulting with practitioners working in the field with young people such as speech therapists and occupational therapists to gain insights into practical approaches which can be used in a research context to maximise the participation of the young people (Beresford et al. 2004). Piloting the interviews and establishing a reference group comprising young people with ASD could be used to obtain their feedback on the information to be collected, the best methods for gathering it and could assist with designing the interview schedule (Morris 2003). Developing a range of strategies that can be adapted to each young person’s needs, interests and abilities during the interviews is also necessary (Beresford et al. 2004; Morris 2003). Additionally, conducting multiple interviews with each young person may allow them the space in which to feel comfortable to express their views and would allow the researcher the opportunity to explore their experiences in greater depth.

Researchers seeking to undertake interviews with young people with ASD undoubtedly need an understanding of the potential impact of autism-related impairments and the capacity to respond appropriately to these challenges. Although they share a diagnosis, people with ASD are a highly heterogeneous group with diverse individual qualities, interests and capabilities. Whilst it is important to ensure that autism-specific challenges are considered and accommodated where required, these accommodations should not limit opportunities for young people to fully express their views. A narrow focus on the impairments associated with the diagnosis may lead researchers to underestimate the contribution young people with ASD can make to research. As mentioned earlier, the literature on ASD suggested that some children have difficulty recalling past events (Brown et al. 2012), discussing their feelings (Losh & Capps 2006) and responding to open-ended questions (Preece 2002). The interview guide for this research was grounded in this literature. However, the young people did not have as much difficulty as previous research suggested. For instance, whilst it was evident that some of the young people had some difficulty with recall of certain events, it is important to note that they were all able to recall many of their previous experiences. Similarly, in their research on autobiographical memory Bruck et al. (2007) found that although the children with autism recalled less detail, their recall was no less accurate than their typically developing peers, and they were able to recall some information about past events. Hence, questions pertaining to the past experiences of young people with ASD should be included in interviews. In this case, it is possible that the interview guide at times restricted rather than maximised the participation of young people. The onus is on researchers to develop appropriate strategies, which capture to the views of children and young people (Dockrell & Lindsay 2011). It is therefore crucial that future researchers keep an open mind throughout the research process, challenge preconceptions about impairment and take the
time to get to know each participant as an individual so that the approach used matches their unique needs and capabilities as well as the exceptional needs shared by young people with ASD.

Conclusion

This study has discussed some strategies that can be used to increase the engagement of young people with ASD in research interviews, including communication strategies and visual supports. Whilst this study focuses on the personal reflections of the authors, it is hoped that by sharing these experiences, other researchers may benefit from these insights and strategies utilised to assist young people with ASD to more fully participate in research. The capacity to capture the voices of young people with ASD is critical to an in-depth understanding of their experience.

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