CAN GUESSING INTENTION BE A USEFUL COMPONENT OF A PERSONALISED SYSTEM TO SUPPORT SOCIAL UNDERSTANDING?: A CASE STUDY INVOLVING THREE ADULTS WITH ASPERGER SYNDROME

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ABSTRACT

The 'social deficits' of people with Asperger syndrome (AS) are well evidenced both in personal accounts and in research. However, there is a lack of understanding of what adults with AS find useful to know in social situations. This study explored the information that three adults with Asperger syndrome found 'useful to know' in social situations, specifically whether they were able to guess the intentions of others and considered this useful. A case study approach involving semi structured interviews and diary accounts, revealed that participants focussed primarily on the self in social situations (e.g. 'will I be ok?') so found guessing the intention of others useful. Participants noticed the unusual in relation to people or situations as a cue to go 'on alert', then used their uncovered existing knowledge of the person or situation to guess their intention. Personalised systems to support social understanding were developed with each participant and used in a range of 'here and now' social situations, as well as in text messaging, past and future situations. Participants reported that using their 'systems' and specifically using their own knowledge, reduced their dependency on staff and increased their independent social understanding. The findings of this study provide a practical addition to current approaches to supporting social understanding and have implications regarding what may be useful for young people with autism to learn in order to prepare for the adult social world.

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CHAPTER 1

INTRODUCTION AND LITERATURE REVIEW

1.1.   The research context

Impaired communication and social interaction are central to the diagnosis of autism and Asperger syndrome, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV APA 1994) criteria. People with an autism spectrum condition (ASC) have profound social deficits, which persist over time (Bauminger 2007; Ponnet et al. 2007; Howlin 2008; Rao et al. 2008) and they may view themselves as lacking social competence and having difficulty forming relationships (Carrington and Graham 2001; Knott et al. 2006; Humphrey and Lewis 2008). Reported negative views of themselves (e.g. 'I'm like a freak') may at least in part be constructed through feedback they receive from others in social situations (Humphrey and Lewis 2008). Autobiographical accounts (e.g. Williams 1992; Grandin 1995; Jackson 2003) and reported comments by people with ASC (e.g. Beardon and Edmunds 2007; Jones et al. 2001), describe and confirm the complexities of the social world and the associated stress and fear from the perspective of a person with ASC. During my own clinical experience, I have witnessed the social vulnerability of people with ASC who have been the butt of jokes or victims of crime, often through apparently failing to read social cues.

Social deficits of people with ASC have understandably been an important area for research for over 20 years. During this time a deficit in 'Theory of Mind' (ToM) (Baron-Cohen et al.1985), has emerged as a key cognitive theory to explain social dysfunction in autism (Golan et al. 2006). This deficit is also referred to as a deficit in 'mentalising' (Frith 1989), and 'mindreading' (Wellman 1992). ToM is defined by Mitchell (1997; p. 37) as ''use of the processes of induction and deduction to make a supposition about the beliefs of another person'', while Howlin (2008; p 76) defines ToM as

> ''the ability to attribute mental states - intentions, beliefs, desires, pretence, knowledge, understanding etc. to oneself and others. It enables an individual to understand that mental states affect others behaviour and actions and can thus both explain and predict their behaviour. It also involves the ability to understand that other people's mental representations of the world do not necessarily reflect reality and can be different from one's own.''

Baron-Cohen et al. (1985) conducted the seminal study demonstrating the difficulties of children with ASC in false belief tasks (argued to be the 'litmus test' for ToM) compared to typically developing children. In this study, a doll 'Sally' put her marble in a basket and departed. 'Anne' then transferred the marble in to a box. Children were asked where Sally would look for her marble on her return. Most children with ASC (average age 12 years, mean verbal age 5 ½ years),

responded using their own knowledge, 'in the box', rather than on the basis of what may be in Sally's mind (in the basket). Typically developing children (average age 4 ½ years) responded correctly.   This study concluded that children with ASC have difficulty in acknowledging that someone else's belief (Sally's belief about the location of the marble) could be different from what they themselves knew. The difficulty of children with ASC in knowing what may be in another person's mind is a robust finding which has been repeatedly replicated (Leslie and Frith 1988; Perner et al.1989; see Howlin 2008 for a review). Studies suggest that a weakness in understanding that minds hold beliefs, means that children with ASC are at a serious disadvantage in predicting the behaviour of other people and thus seriously disadvantaged in social situations.

Difficulties in understanding and reasoning about mental states have been found to persist with older, and more able, people with ASC using a range of more complicated tasks (e.g. Bowler 1992; Happé 1994); thereby demonstrating the profundity of the impairment in ToM across age and ability levels. More sensitive and 'naturalistic' tests exploring the ability of higher-functioning people with ASC to read or infer emotions from static and dynamic pictures of the face and eyes (e.g. Baron Cohen et al. 2001; Back et al. 2007), from audio recordings of voices (Rutherford et al. 2002), from film clips (e.g. Heavey et al. 2000; Golan et al. 2006), and from animated movements of abstract shapes (e.g. Salter et al. 2008) have further confirmed persistent weaknesses in ToM in people with ASC compared to typically developing groups.

Although ToM has generated much interest and research (Howlin 2008), development and interpretation of other cognitive theories have contributed to the research of the social deficit in people with ASC (see Rajendran and Mitchell 2007 for a review of cognitive theories of autism). The Weak Central Coherence (WCC) theory of autism suggests that people with ASC have an increased focus on detail and process information in a detail focused way, rather than as an integrated coherent whole (Frith 1989). It is suggested that social functioning requires rapid processing of multi modal information, so an impairment of integration of information results in an impairment of social functioning (Frith 1989; Frith and Happé 1994). (See Happé and Frith 2006 for a review of WCC).

Some studies have indicated that no single theory accounts for the social deficit in ASC. For example, Golan et al. (2006) found that some adults with ASC who passed basic emotion recognition tasks, mislabelled emotions and mental states in film clips. They argued that their failure to integrate multimodal information (verbal content, prosody and facial expression) led to the errors, suggesting that both central coherence and ToM were needed for successful responses. However, Beaumont and Newcombe (2006) argued that people with ASC were able to integrate information when they consciously decided to do so, suggesting that processing style may be more of a preference than a deficit. In their study, adults with High Functioning Autism (HFA) and Asperger syndrome (AS) watched television commercials and were asked forced choice questions afterwards relating to ToM, central coherence and memory.

Significant ToM deficits were found which could not be accounted for by memory limitations, attention deficits or an inability to integrate information, but there was no difference in the number of central coherence questions correctly answered by the participants with ASC and the control group. Similarly considering processing of information, Loveland et al. (2001) suggested that people with ASC were able to detect relevant social information, but not understand the 'why' or apply the information to themselves to know how to respond, possibly therefore not processing the detected information in a useful way.

Some researchers have argued that the social deficit in autism may be explained by an executive dysfunction (e.g. Ozonoff et al.1991 p.1083), where executive dysfunction is defined as "the ability to maintain an appropriate problem solving set for a future goal", or that weaknesses in social problem solving may reflect both executive difficulties and impairment of ToM (Channon et al. 2001).

Studies have therefore repeatedly demonstrated the ToM deficits of people with ASC and it has been suggested that WCC, weak executive function and difficulty reasoning may all contribute to the social deficit of people with ASC. Whatever the root of the social deficit, the research remains clear that the social difficulties are real across the spectrum, regardless of age and IQ, and the need to develop effective interventions is of paramount importance (Howlin 2008).

1.2. Approaches to development of social understanding and social skills

The cognitive ability to understand others' minds has been recognised as a core deficit in ASC (Baron-Cohen et al. 1985), underpinning the recognised social deficit, so many interventions have focused on development of cognitive skills. Since it is not possible to review all the literature relating to remediation of the social deficit within the restrictions of this study, cognitive approaches to development of social understanding have been selected as the focus.

Some studies have investigated the specific teaching of ToM tasks to develop ToM in people with ASC, resulting in development of ToM, as measured by success on emotion and belief tasks (e.g. Ozonoff and Miller 1995; Hadwin et al. 1996 ; Hadwin et al.1997). However, generalisation of learning within these studies is reported as limited. Ozonoff and Miller (1995) found no significant reported differences in parent and teacher ratings of social behaviour, while Hadwin et al. (1996) found no generalisation of skills to a wider range of tasks and suggested that children had not gained understanding of the concepts underlying ToM, but had extracted rules to pass the tasks. Hadwin et al. (1997) found no corresponding advance in communication skills, measured in terms of the ability to expand on conversation and on increased mental state terms used.

A range of indirect approaches to development of ToM in people with ASC have also been used with mixed results, including development of conversation skills (Chin and Bernard Opitz 2001), where no impact on ToM is reported and use of a 'picture in the head' strategy (e.g. McGregor et al.1998; Wellman et al. 2002) where increased false belief understanding is reported. Fisher and Happé (2005) trained participants in either ToM or executive function and reported improvement in ToM task performance in both groups. Similarly, a social adjustment enhancement curriculum for boys with ASC was developed and used by Solomon et al. (2004) to target teaching of ToM and executive function. Improvements were reported in the target measures of emotional awareness (measured by facial expression recognition), and executive function (measured by problem solving skills), but the authors acknowledged that more research is necessary to ascertain whether skills taught in the group generalise to other contexts.

Further cognitive approaches to development of social cognition and social understanding include use of cognitive behavioural therapy as a structural framework for intervention to promote social cognition (Bauminger 2002), use of 'social thinking' (Winner 2000), teaching the 'why' behind the social skill (Crooke et al. 2008) and use of cognitive learning approaches alongside direct skill instruction (Cotugno 2009). These studies all report development of skills in the areas of intervention.

Cognitive strategies reflected in specific plans to support appropriate social behaviour in specific situations have also been used. For example, Bock (2007) taught students with AS to use 'SODA' scripts, ('Stop' 'Observe' 'Deliberate' 'Act'), where the first three stages were guided by self talk questions or statements such as 'where should I go to observe?', 'what is ... doing?', 'what would I like to do?' and the 'Act' section required participants to plan what they would do in that situation. It was suggested that 'SODA' could teach children and adolescents with AS the metacognitive process necessary to facilitate their social communication and social problem solving, if participants already had good understanding about the mental states of others. Similarly, Boutot (2009) used components of social stories (Gray 1994), social scripts (Kamps et al.1992), power card strategy (reviewed in Simpson 2005) and cognitive behavioural approaches to devise 'I will cards' for students. The cards served as reminders for self talk to plan 'what to do when', in identified potentially problematic social situations.

Cognitive approaches have been developed recognising the computer based interests of many people with ASC. Computer technology has been used to teach mentalising (Baron-Cohen 2003), while Parsons and Mitchell (2002) proposed that virtual reality technology is a tool that can accommodate the strengths of both behavioural and cognitive approaches to teaching social skills. Parsons et al. (2006) found that participants with ASC were able to improve judgement and explanation of 'where to sit' in a 'virtual' cafe, and a 'virtual' bus,

and further, that this knowledge transferred to videos of real cafes and buses (Mitchell et al. 2007).

The social deficit of people with ASC is well evidenced, and while primarily cognitive approaches discussed above have claimed some success in the development of social understanding by some people with ASC, in some situations, it is clear that there is no single successful approach to achieving and measuring changes in social behaviour in everyday social situations. Recent reviews of social skills intervention research for children with Asperger syndrome and high functioning ASC by Williams-White et al. (2007) and by Rao et al. (2008) confirm that research has shown that children are able to learn targeted social skills, but the improvement may be confined to those skills that are specifically taught. Rao et al. (2008; p358) argue that there are many limitations within published studies and that ''much work remains to be done in order to provide relevant efficacious interventions for children with Asperger syndrome and high functioning autism''.

In summary, the social difficulties of people with ASC are well evidenced and people with ASC themselves report the stresses and challenges experienced in social situations as a result of these deficits A range of approaches to develop social understanding and social skills of people with ASC have been developed, with mixed results. There is an identified need for further studies to continue to search for effective approaches to address the typical weaknesses in social understanding associated with ASC.

1.3. Weaknesses and gaps in the literature

My initial search of the literature looked for evidence of effective approaches to teaching social understanding to individual people with ASC, which are led by people with ASC and which are evaluated by people with ASC as useful to them in the real world. Such empirical evidence was not found. The real world value of reported cognitive approaches to development of social understanding and ToM was therefore considered within the reviewed literature. Weaknesses and gaps in the literature in relation to development of real world social understanding by the individual with ASC were revealed in the following areas:

1.3.1. Involvement of people with ASC in what is important to them to know in social situations

Although the importance of involving people with a disability and enabling them to have control over the research process and learning is recognised (Knox et al. 2000; Lewis and Porter 2004; Knott et al. 2006; Parsons et al. 2009) and a person centred approach is highlighted as important (Parsons et al. 2006), a review of the literature suggests that different researchers have different approaches to determining what is important for people with ASC to learn. 'Social skills training' may follow a programme or curriculum (e.g. Howlin and Yates 1999; Cotugno 2009; see Rao et al. 2008, for a review of social skills interventions) or the opinions of parents or teachers regarding what is important may be sought (e.g. Sanosti and Powell-Smith 2006; Parsons et al. 2006;

Mitchell et al. 2007) or other people with ASCs may be included in this decision

making (Parsons et al. 2006). Discrete skills may be taught (Parsons et al. 2006;

Mitchell et al. 2007; Bock 2007; Butot 2009; Cotugno 2009) while others aim to

teach the 'why' behind the skills (Crooke et al. 2008) or 'rules' relating to

identified deficits (Hadwin et al.1996; McGregor et al.1998). There are self

reports by people with ASC describing the importance of increasing social

awareness and reducing fear in social situations from the perspective of people

with ASC (Jones et al. 2001; Beardon and Edmunds 2007; Muller et al. 2008),

but the views of the person with ASC regarding specifically what may be useful to

them to learn, are rarely directly linked to approaches to intervention reported in

the literature.

The Department for Education and Skills Autism Research Group (2006)

specifically recommends that research and methodology should be informed by

the perspectives of individuals with ASC. This will enable researchers to

understand what is important for them to learn in relation to their recognised

social deficit. McGeer (2009) emphasises the importance of self narratives of

people with ASC, suggesting that these give the best means of accessing what

the minds of people with autism can be like and give an insight in to their

idiosyncratic linguistic and psychological development. This suggestion

acknowledges the importance of avoiding neurotypical assumptions about what

may be important to a person with ASC.

Williams-White et al. (2007) suggest that social skills intervention trials should identify primary outcome measures, but these may be of limited value unless they relate to what may be useful to each individual to learn. Evaluation of learning is often made by the teachers or family (e.g. Bauminger 2002; Cotugno 2009). Parsons et al. (2006) seek feedback directly from the participant regarding generalisation of the taught skill, but this is rare in the literature. There is a need for evaluation of intervention to listen to the views of the people with ASC as well as those important to them.

The heterogeneity of autism is recognised (Rajendran and Mitchell 2007; Howlin 2008; Parsons et al. 2009) and Howlin (2008) argues that the wide variation in characteristics and in responsiveness to treatment may demand a far more individualised approach to intervention, but reported individual approaches to intervention based on individual strengths and needs were not found in the literature. Parsons et al. (2009; p107) further suggest that

> "the achievements and first hand perspectives of adults with ASC should be regarded as priorities for future research in order to develop greater understanding of the diversity and potential that exists within the autism spectrum."

There is clearly a need to listen to people with ASC and to use their experiences, to design individual approaches to intervention, which enable people to learn and use social information achievable and useful to them.

1.3.2. The use of existing strengths of people with ASC

The literature revealed some approaches to development of social understanding which appeared to be specific to the needs of people with ASC; for example, the use of rules and strategies is recognised as valuable in supporting social understanding of people with ASC (Howlin 2008) and is reported in some studies (e.g. Fisher and Happé 2005; Wellman et al. 2002; Bock 2007; Crooke et al. 2008). Use of rules and strategies can lead to some generalisation of learning (e.g. Parsons et al. 2006). Ponnet (2008) notes that people with ASC prefer activities and situations that are more structured and the use of strategies may support this structure. Rules and strategies may work with the strengths but this is not specifically reported. Wellman et al. (2002) viewed the use of thought bubbles as an artificial prosthetic device that can be used to compensate for the lack of a larger mechanism for understanding in some ways and in some situations. This compensatory strategy to support thinking about another person's mind, perhaps uses visual strengths of people with ASC, but is not reported as based on strengths.

Although rules, strategies and compensatory mechanisms are recognised as useful to people with ASC, the literature search did not reveal studies explicitly recording use of strengths of people with ASC as a basis for intervention, or studies further exploring existing strengths and the potential to use these in social situations. Instead, the social deficits of people with ASC are repeatedly evidenced in the research literature.

Although many people with ASC enjoy a range of social situations and may demonstrate skills to 'fit in' in these situations, approaches reported in much of the literature continue to focus on 'targeting the deficit' from the viewpoint of people without autism. Approaches frequently begin with 'the problem' and teaching what research has shown people with ASC find difficult (such as reading facial expression, body language, mental states), rather than recognising skills people with ASC do use in social situations and beginning with these. Parsons et al. (2009; p106) argue, ''there is a strong imperative to move away from the deficit model of disability and promote the successes and potential of learners with ASD''. The exploration of a 'different approach' which uses existing strengths and successes of people with ASC to develop compensatory strategies would be a useful addition to the literature relating to development of social understanding.

1.3.3. The learning and understanding by people with ASC following teaching to address their social deficit.

The literature revealed some possible limitations in interpretation and understanding of what people with ASC have learned following teaching to address their social deficit and whether what they have learned is useful to them in the real world (discussed below). What people with ASC actually learn during mental state teaching and the value of this in the real world could be questioned.

1.3.3. a. Evaluation of learning

Where evaluation of learning is linked to tasks relating to the teaching, rather than real world use of learning, information regarding what has been learned is limited. A forced choice procedure has been used in evaluation to assess performance on specific tasks relating directly to the teaching of false belief, labelling of emotion (e.g. Bauminger 2002) and labelling of facial expression (e.g. Solomon et al. 2004) or prompts have been given (e.g. Parsons et al. 2006), which do not exist in the real world. Where multiple choices or prompts are given, not only is the situation detached from the real world, but the cognitive demand to think of responses may be reduced, thus increasing task performance. Channon et al. (2001) argue that the tasks alone may act as a 'structured cue' to focus attention on what has been taught, which does not exist in the real world and since Beaumont and Newcombe (2006) found that people with ASC were able to integrate information when they consciously decided to do so, performance on the task may be increased by this 'cue'. Evaluation in tasks linked to learning may therefore demonstrate that a person has learned, but does not necessarily demonstrate whether the learning may be used by a person with ASC without prompts intrinsic in the 'testing'. Evaluation in real world settings would provide a better indicator of the value of the teaching.

1.3.3. b. Generalisation of learning

Parsons et al. (2006) point out the importance of teaching being relevant to real life experiences of participants. Teaching and learning reported in the literature

often takes place in experimental, 'naturalistic' or 'classroom' type situations and reported generalisations of learning are limited. Indeed, Peterson et al. (2008) argue that success in the laboratory is not enough to guarantee social-conversational interaction skills for a child with autism and raise the question of whether ToM understanding as indexed by laboratory false belief tests, has real world relevance. Ramachandran et al. (2009) suggest that there is a separation between performance on some ToM tasks and social competency, so although a person has knowledge, it may not be useful to them, which may explain why more able individuals with ASC perform well on simple tests of ToM but still have significant difficulties in real world interactions. Where 'teaching' does relate to real world situations, it may relate to the planned use of the taught strategy or plan in a specific situation (e.g. Bock 2007) and the use or potential generalisation of the skill or strategy to new situations, important to the person with ASC is not reported. If learning is to be effective to the individual, greater consideration could be given to learning in real world situations important to the person and/or generalisation of learning to other situations. The challenge for researchers is to translate approaches that work in the laboratory in to strategies that are truly effective in real life (Howlin 2008).

1.3.3. c. The understanding of the focus of the teaching, by the individual with ASC.

'Mental states' are considered central to ToM; Howlin (2008; p.74) describes ToM as ''the ability to attribute mental states - beliefs, intentions, desires, pretence

knowledge, understanding etc. - to oneself and others'' and Parsons and Mitchell (2002; p.433) suggest ''consideration of mental states of others is considered crucial when trying to work out their motives and predict behaviour''. Not surprisingly then, the literature revealed a continued focus over many years on teaching of 'mental states'. However, correct labelling (not understanding) of mental states is often reported as a measure of development of ToM (e.g. Ozonoff and Miller 1995; Hadwin et al.1996) and alternative interpretations of understanding linked to appropriate labelling or mislabelling may not be considered. For example, Salter et al. (2008) found that children with high functioning autism used mentalising labels as often as the control group to provide descriptions of animated movements of abstract shapes, but the terms were less appropriately used. They suggested that this reflected a difficulty in interpretation of the social sequence, and apparently did not consider a different understanding of the words used as an alternative interpretation of their findings, since understanding of words was not reported. There appears to be an assumption in the literature that knowledge relating to 'intentions, motives, predicting behaviour and desires' is reflected within use of a mental state label. Where meaning attached to labels used is not checked, assumptions that labels are used with a neorotypical meaning attached appear to be made. This approach may lead to assumptions regarding understanding of mental states by people with ASC.

Oberman and Ramachandran (2007; p.316) suggest that individuals with autism "may be taught rules regarding how a person may think or feel in a situation, but will still have difficulty really knowing the other person's mental state", perhaps suggesting a weakness in understanding the implications of a thought or feeling. The importance of 'understanding' rather than labelling emotions is raised by Cole et al. (2004) who propose that understanding emotions allows anticipation and comprehension of other people's behaviour. Begeer et al. (2007) confirmed the importance of such 'understanding', reporting that the influence of mood on behaviour may be acknowledged by children with HFA, but their responses suggest rote learning rather than causal understanding of the role of mood on behaviour. My literature search did not reveal further studies specifically investigating understanding of the link between mental state labels and recognition of intention or predicted behaviour of others by people with ASC. However, recognising intention (a single aspect of a 'mental state'), may be useful to people with ASC to reduce their real world vulnerability, frequently witnessed within my clinical experience. Exploration of the knowledge or understanding regarding other people and/or their 'mental states' that makes a difference to the person with ASC in their real social world would be useful.

Specifically, it has been suggested that a lack of ability in reading mental states from facial expression could be central to the social difficulties experienced by people with ASC (Back et al. 2007) and several studies report a focus on teaching of labelling of facial expression (e.g. Solomon et al. 2004). Although it is

well recognised by people without autism that a person's face may not always reveal their true mental state or emotion, this does not appear to be considered within the reviewed literature, nor do studies report checking of the participants' understanding of the mental state labels they use in relation to a certain facial expression. For example, does a mentalising label used by a person with ASC refer only to 'a certain position of the face or body' or does it tell a person with ASC how a person may act and react and tell the person with ASC what to do? Anecdotally, in my clinical experience I have found that people with ASC are often interested in changes in the face and comment on changes such as 'going red' and 'water in the eyes', but may not link these observations with learning regarding emotional states or potential behaviour. Knowledge regarding the information people with ASC may derive from facial expression would be useful, in order to explore their understanding of facial expression of real people in the real world.

1.3.4. Involvement of adults with ASC

Adults with ASC have been involved in studies investigating social differences in people with ASC (e.g. Baron-Cohen et al. 2001; Beaumont and Newcombe 2006; Golan et al. 2006), but studies focussing on teaching to support social deficits focus primarily on children and adolescents. Parsons et al. (2009; p.108) suggest ''there is a dearth of research on the adult sector and as the diagnosed population continues to increase, an evidence base for the support needs of this group is urgently needed''. In my experience there is an increased need for social

competency beyond the school environment, since community living may bring increased risks to adults with ASC.

1.4. The present study

The review of the literature revealed well documented social deficits of people with ASC and associated cognitive teaching approaches (usually involving children) devised by people without ASC to target these deficits. Mixed results following teaching are often reported. The findings in the literature converge with my own clinical experience, where I have met people with ASC who find typical teaching relating to social understanding difficult to understand and use. I have also witnessed people who may remain vulnerable in the real world, despite having received teaching relating to mental states and social skills.

This study will acknowledge the fact that there are well evidenced differences between the social cognitive skills of people with ASC and people without ASC. It will seek an approach which may support people with ASC to learn and know what is achievable and useful to them, as an alternative to approaches which ask them to learn what people without autism think they should know, in a way that people without autism learn. The study will listen to what may be useful for a person with ASC to know in a social situation, with a focus on the value of guessing intention (defined as what a person may do next) and on uncovering the knowledge that a person already uses to support social understanding in a

social situation. 'Using' knowledge rather than 'having' knowledge will be important. The value of the development and use of a strategy/prompt system in real world situations, to further support social understanding will be investigated. Any compensatory system developed will be based on existing knowledge, strengths and what is important to an individual to know. The study will focus on adults with ASC. It will seek to address the following research questions:

1. What do people with AS (Asperger syndrome) find useful to know about other people in a social situation?

2. To what extent is being able to guess another person's intention in a social situation useful to a person with AS?

3. Can an explicit self prompt system/approach/strategy utilising intention cues be used in social situations to support social understanding of people with AS?

CHAPTER 2

METHOD

2.1. Rationale for Case Study Design

The importance of learning from people with disabilities who have previously been viewed as 'subjects' is highlighted (Knox et al. 2000; Chappell 2000), while the Department for Education and Skills Autism Research Group (2006) recommended that research and methodology should be informed by the perspectives of people with ASC. My epistemological position is that in order to learn about people with ASC, researchers must listen to people with ASC. The richness and authenticity of the data collected therefore depends on detailed attention to each participant's individual communication needs, so that participants can fully understand questions and themes to be explored and be supported to express their views. A case study design, defined by Robson (2002; p.89) as ''development of a detailed intensive knowledge about a single 'case' or a small number of related cases'' is a participatory methodology which facilitated this important attention to detail.

This study searched for new insights to development of social understanding. Denscombe (2003) argues that insights gained from the detailed case study approach may not come to light from a larger number of instances, while Valsiner (1986) suggests that the study of individual cases has always been the major

strategy in the advancement of knowledge about human beings, suggesting that

case study design is appropriate to this project. A review of the literature

revealed that case study design has previously been used successfully to

investigate the effectiveness of innovative approaches with people with autism,

(e.g. Vismara and Rogers 2008; Ozdemir 2008; Parsons et al. 2006). Further, the

heterogeneity of the population with ASC and the relevance of single case

studies as a useful research design methodology to investigate the social deficits

associated with ASC is recognised by Rajendran and Mitchell (2007) and Howlin

(2008). Yin (2003) suggests that even a 'two case' study, is more likely to

produce a good study than a single case design, since the 'analytical benefits' of

two or more cases are substantial. I began with one 'case' and in order to

maximise the 'analytical benefits' within the time restrictions of this study, I

involved two further cases, building on initial findings. I recognised that the

multiple case study is akin to multiple experiments (Yin 2003) so there was no

intention to make generalisations from the three case studies.

2.2. The participants

Following the recommendations of Yin (2003), the participants were all known to

me and accessible to me. All were able to discuss ideas and opinions and

wished to develop their social understanding, important to this study. Previously,

I had worked with each participant to support their communication in relation to

problem solving and during our general discussions, each had expressed desire

for the voice of the person with Asperger syndrome to be heard within academic research. Each had also expressed a desire to 'give something back' for the support that they had received from me, wishing to shift from the role of 'recipient' of support' to informant or 'expert'. Each participant recognised that their knowledge would be valuable to the project and potentially to others with Asperger syndrome and all were motivated to take part. All participants had a diagnosis of Asperger syndrome (AS). C is female aged 34, P is male aged 35 and J is female, aged 33. The participants all receive support from a care provider and were invited to choose to involve a support worker known to them, to support their participation in the study. The type and amount of the support provided was directed by each participant.

2.3. Ethical considerations and consent

When undertaking research, the interest of participants should be protected, researchers should avoid deception, and participants should give informed consent to take part (Denscombe 2003). Further, when working with vulnerable groups, considering whether people can knowingly and freely give informed consent is important (Robson 2007). Lewis and Porter (2004) suggest explicit recognition of the rights of the individual to agree or disagree to their involvement in research must be evidenced.

To address these issues, each participant was given written information about the research project (see appendix 1), prepared following the advice of a person

with AS in the pilot study (see below for an overview of the pilot study). Participants discussed this information first with a support worker, then with me and were encouraged to ask questions, to ensure their understanding of the purpose of the project and their role within it. Participants who agreed to take part were asked to sign a prepared consent form before proceeding (see appendix 2). Participants' understanding of the consent form and reasons for it, were checked prior to signing.

2.4. Procedure: overview

There were five phases to the study (described in detail in section 2.6 below). During phase 1 of the project, participants recalled and discussed social contexts important to them. In phase 2 participants watched and discussed selected scenes from a contemporary feature film, (a research method previously used successfully by Golan et al. (2006) to investigate emotional state recognition in adults with and without ASC). Selected film clips included a range of situations, people and emotions familiar to participants, which I would be unable to share with participants in the real world. During phase 3, participants were invited to choose a location in the community important to them, which we visited together. We discussed the social context in real time. This shared situation grounded the research in the 'real world', important to my research questions. It avoided inaccuracies in recall possible in phase 1 and added a naturalistic setting to the contrived contexts of phase 2. A self prompt 'system' was then designed to

support participants' social understanding in social situations, based on information uncovered in phases 1-3. During phase 4 this 'system' was used in real world social contexts chosen by the participant and participants were invited to record use of their 'system' on a diary sheet (see 2.5.2. below). Finally, the use of the system by each participant, its' value and participants' associated learning was discussed in phase 5.

The phases of the study were linked for each participant and between participants, since existing knowledge and 'useful to know' information relating to a social context uncovered at each phase, was used to inform both the semi-structured interview at the next phase and discussion with other participants.

The procedures described above were informed by a 'pilot study' with a 40 year old male with Asperger syndrome, known to me. He provided helpful recommendations regarding, prepared 'information for participants', the consent form and the diary sheet. We piloted the semi structured interviews and he gave useful feedback regarding the design and presentation of the interviews and making best use of the film clips and the community situations. I recognised that a different person may have provided different feedback, but useful amendments were made following his comments.

At the conclusion of the study, the findings of it were discussed with the three participants and with the person involved in the 'pilot study'.

2.5. Methods of data collection

The research tools used within the study were designed with the participants in this study and were specific to them. They were not designed for generalisation to other people or situations. Semi-structured interviews and diary sheets were used to collect data. These are described below.

2.5.1. Semi structured interviews

2.5.1. a. Design of the semi-structured interviews

Semi-structured interviews (previously used successfully to investigate the views and experiences of people with AS e.g. Humphrey and Lewis 2008; Carrington and Graham 2001) were used during phases 1, 2, 3, and 5 (phases described below in section 2.6). A semi-structured interview has some predetermined questions, but the order in which the questions are asked remains flexible and discussion is developed around the issues raised, meaning participants may explore topics underpinning the question and provide new and unanticipated information (Robson 2007; Denscombe 2003). This enables the participant to occupy the role of 'informant', rather than 'respondent' (Yin 2003; Robson 2007), important to my epistemological position.

The semi-structured interviews included 'friendly' questions (Yin 2003), including 'how?' or 'is there…' questions. 'Why' questions were avoided where possible, since 'why?' questions can cause the interviewee to experience defensiveness

(Yin 2003) and furthermore, may be difficult for a person with AS to understand and respond to. Statements that prompt a response were used (Lewis 2001), as well as prompts and probes (Gillham 2005) to elicit views and further discussion. 'Reflecting' (Gillham 2005), whereby the substance of what the participant says is offered back to focus the participant on an element of the interview or to explore an element further was also used. Attention was also given to choice of vocabulary and avoidance of prejudicial language, ambiguity, questions that make assumptions and the assumption that the informant has the required information, following Cohen et al. (2007). A 'scaled' response' (Cohen et al. 2007) was used to investigate some beliefs, since people with AS may find it difficult to use language relating to feelings (Attwood 1998) or to evaluate their skills or abilities, but may relate to the concreteness of a scale. Finally, interviewer bias can be difficult to avoid (Robson 2002) and my awareness of potentially leading questions or statements was important (Lewis 2001).

2.5.1. b. Delivery of the semi structured interviews in phases 1- 3 and 5: overview.

Lewis and Porter (2004) suggest that eliciting people's views rests on the assumption that the subject is one on which they have an opinion. Similarly, the participant in the 'pilot study' pointed out that he was able to give me useful information because he had an interest in our topics of discussion. So, at the beginning of each semi-structured interview for each phase, I checked that the participant was happy to talk about the discussion topic. All participants learned

and understood that 'I don't know' was an acceptable response to a comment or question.

In order that information given reflected true views (as far as possible), the delivery of the semi-structured interview was designed to be similar to usual discussions between me and each participant. Pause was included in the interview to accommodate processing time often needed by people with AS, highlighted as important by Lewis (2001), which also acknowledged potential interviewee fatigue (Cohen et al. 2007). I monitored my body language, avoiding direct face to face contact and eye contact at times, as these may cause anxiety to a person with AS (Attwood 1998) and since careful listening is the central skill in interviewing (Gillham 2005), I listened more than I spoke (Robson 2002; Cohen et al. 2007). Participants chose for interviews in phases1, 2, and 5 to take place in their own home.

The interviews were recorded using a digital voice recorder and control of the interview was given to the participant through this tool. Each participant switched on the voice recorder to begin the interview and switched off to pause or finish, so participants understood that the interview could be stopped at any time.

Cohen et al. (2007) caution against data loss and distortion when transcribing the interview, so I wrote notes during the interview and used these alongside the transcription to document my thoughts regarding the non-verbal aspects of the interview.

2.5.2. Design of the diary sheets

Diary sheets were used in phase 4, to record participants' use of their 'system' (see section 2.6.2 below and see appendix 6). Diaries may be seen as self-administered questionnaires (Robson 2002) and must be planned with the same care and preparation as a questionnaire (Hinds 2000). The diary sheets were planned, prepared, then presented to the participants, but following feedback in the pilot study, participants were encouraged to 'personalise' the diary sheets choosing their own words to use to prompt themselves to record the required information. The words chosen reflected 'personalised' systems (see below). Humphrey and Lewis (2008) argue that diaries may be useful for people with AS, as they are less intrusive than interviews. In this project diary sheets facilitated participants' ownership of the 'system' and reduced dependence on staff.

2. 6. The Data Collection Process

2.6.1. Phase 1 The initial semi structured interview

Participants were invited to recall a range of social situations they had been involved in recently. Through discussion, two of these social situations were chosen as the focus of the initial interview, to be discussed in turn, one where the participant had been relaxed and one which the participant had disliked.

Questions in the initial semi structured interview (see appendix 3) were closely linked to the main themes in research questions 1 and 2 (what is useful to know

about other people in social situations, whether guessing intention may be useful to the participant). 'Where?', 'when?' and 'who was there?' questions helped participants to focus attention and recall the situation accurately, then participants were asked specifically about the people in the situation (e.g. how well they 'knew' the people, whether they knew what the people may do next and whether they considered what the people may be thinking or feeling). Questions explored the information that participants found useful to know about people and were designed to uncover their existing knowledge about the people and the situations (e.g. where participants recalled knowing what may happen next, they were asked 'how did you know that?). Participants' level of ease in the situations was accessed through use of a rating scale graded 1-7. Participants attached their own words to the scale, but generally, point 1 implied 'feeling very bad/uncomfortable' and 7 implied 'feeling relaxed'. The reasons for the ratings given to the situations were explored. Where the participant disliked the situation being discussed, additional questions were asked where participants were asked to consider what may 'go wrong' in the situation.

2.6.2. Phase 2 Film clip semi - structured interview

Prior to the interview, I gave an overview of the film and participants confirmed the film was not familiar to them and they were happy to watch clips from it. Participants set up the DVD and pressed play to begin the film. I paused the film in the same selected places for each participant. I asked questions linked to themes within research questions 1 and 2 (useful to know information in the

social situation and whether guessing intention was potentially useful). (See appendix 4 for interview themes). For example, participants were asked how they would 'notice' or 'become aware' of a person in a situation as well as what would be important for them to know in that situation. They were asked to guess the intention of characters and to discuss how they guessed intention correctly. Importantly, where participants had demonstrated use of existing knowledge in phase 1, this was investigated further in phase 2; where knowledge of a person's traits or of typical expectations of the situation was used in phase 1, there was exploration of whether this knowledge existed and could be used in situations within the film clips.

2.6.3. Phase 3 'In the community' semi structured interview

Invited to choose a preferred place in their local community, where we could go together and watch and discuss the people present and their actions, all participants chose their local pub. The walk to and from the pub provided a further social context for discussion and data collection. In the pub, participants chose where to sit, ensuring that we could see people, the bar and the door.

Following phases 1 and 2, discussion focused on uncovering what the participant found useful to know about people in the community situation, who the participant would pay attention to and why, and on the information that each participant used to guess intention (Research questions 1 and 2. See appendix 5 for semi structured interview themes). We discussed whether there were differences

between used and useful knowledge in the community situation and situations discussed previously. Specifically, where participants had mentioned use of a strategy within phases 1 or 2 (e.g. 'thinking about what I know', or 'noticing the unexpected'), the potential value of such a strategy was also discussed in the community situation. References were made to successes in demonstrating knowledge of people and intention within the film clips and whether this success could be repeated in the community setting. At the end of phase 3, the development of a self prompt 'system' to guess intention, using uncovered existing skills, was discussed.

2.6.4. Phase 4 Development of 'the system' to support social understanding

Participants were invited to review their knowledge and understanding uncovered in phases 1-3 with me, in order to create a self prompt 'system' (research question 3) to support knowledge of when and how to guess intention in situations important to each participant (see Chapter 3 for detail of the 'systems'). Participants were invited to 'personalise' the system by changing, adding or deleting words and phrases.

When the 'systems' were agreed by each participant, I designed personalised 'diary sheets'. These sheets included a set of questions to enable participants to record where and how they used their 'system'. Each participant's agreed systems and prompt words were also recorded on the sheet (see appendix 6).

The diary sheets used the words of each participant's 'system' so the diary sheet was meaningful to them.

I met with each participant two weeks after establishing the 'system' and diary sheets, to discuss their experiences of the 'system' and their recording and to discuss any required amendments to either the 'system' or the diary sheets. I then maintained regular telephone contact to participants and/or support staff to check that they were happy to continue to use the system and to be a part of the project.

2.6.5. Phase 5 The final semi structured interview

The self prompt 'systems' were used for an average of 10 weeks by the participants. I then met each participant for the final semi structured interview relating to research question 3 (see appendix 7). Discussion in the final interview revisited the theme of 'useful to know' information in a social situation and exploration of changes in perception of what may be 'useful to know' during the study. Participants' experiences of how and when they guess intention and the value of this to them was discussed. We concluded by discussing whether participants would use what was learned during the study in the future or whether, in their opinion, what they had learned would be of value to other people with ASC.

Staff involved in the research project were also invited to give written feedback in relation to what they had learned, their opinion of the value of the 'system' to the participant and the perceived impact of the involvement in the project on the participant. (See appendix 8)

2.7. A note on reflexivity

Reflexivity is considered critical practice for social researchers (Adkins 2002) and was important during my project. I have worked as a practitioner within my field for many years, the participants in my study were known to me and I conducted the interviews myself, so I needed to be aware of my existing knowledge and role within the interaction throughout the project. Prior to participants signing the consent forms, I asked the support workers to talk to participants to ensure that they were involved in the study because they chose to be, rather than because they felt any obligation to me. Prior to each semi structured interview, I checked each participant's understanding of the session to ensure that our discussions in the session related to the research questions of this study and so were different to previous discussions that I may have had with the participants. During the interviews I actively kept an open mind to information given to me, which was important to facilitate uncovering of new information. I used my knowledge and experience as a valuable component of the research rather than treat it as a 'bias' to be controlled for (Robson 2002). It contributed to the 'rapport' between myself and the participants (Cohen et al. 2007; Knox et al. 2000) and enabled me

to communicate effectively with the participants and to elicit valuable insights. The investigation depended on the participants' commitment to think about some potentially difficult concepts and to explain their views to me. Therefore, the rapport we already had through my professional role was important to being able to carry out this research.

Furthermore, my knowledge meant that I was able to interpret comments sensitively and check participants' intended meaning, not just record them, as through listening, I aimed to have a firm grasp of the issues important to each participant (Robson 2002). I accepted that it is impossible to remove personal influences from such an in depth study and was aware of the need to examine the assumptions and values that I brought to the study, that may have led to misinterpretation of information given. I remained open to contrary findings. (Robson 2002).

The data collated was stored separately for each participant on a password protected computer. The following chapter explains how the data across the five phases was coded and analysed, before moving on to a presentation of the main findings.

CHAPTER 3

DATA ANALYSIS AND MAIN FINDINGS

3.1. Data Analysis

The process of data analysis was not a self contained phase of the research but was ongoing (Basit 2003). There were two main approaches to data analysis, a 'top down' approach, using coding categories developed directly from the research questions and a 'grounded' approach, described below, responsive to themes emerging from the data. Prompt analysis of the transcriptions of the semi structured interviews and noting of emerging themes enabled important themes to be addressed more thoroughly in subsequent phases of the project.

3.2. Coding

A broad coding category 'start list' (Miles and Huberman 1994) was created to collate information to answer the research questions. Broad codes were refined and further codes added in response to common or unexpected emerging themes between participants. For example, 'useful to know information' became 'information about people' and 'information about the situation'. Some codes merged, for example, 'emotion words' and 'existing skills' as the two became clearly linked. The transcripts were continually revisited to collate illuminative quotations (Basit 2003) for each code.

Use of codes reduced the volume of transcription data, organised the data for analysis and facilitated comparison of data between participants. Recording of quotations in a chronological order within each coding category for each participant provided evidence of participants' individual journeys during the research project. The data was coded manually using pens and a colour coding system; direct involvement with the data facilitated increased knowledge and deeper understanding as analysis progressed.

In foregrounding the voices of people with AS, data analysis and presentation included verbatim quotations from the data, rather then paraphrases. Any interpretations of the meaning of words spoken were 'checked' with the participant. Quotations included below are selected from a large body of data, each representing a repeated theme used by the participant.

A familiar support worker chosen by the participant was present throughout the data collection for two participants (P and C) and for phases 1-3 for the third participant (J). Following each semi-structured interview, the support worker and I discussed the interview and emerging themes. This helped me to avoid researcher bias in the coding and analysis of data.

3.3. Main findings

Key themes emerging from coding categories are reported below in four sections which relate directly to the research questions. The research questions, methods of data collection and reporting of findings are summarised in table 1.

Table 1 Research questions, method of data collection used and key emerging themes: summary

Research question	Method of data collection	Key emerging themes (and corresponding findings section number)
1. What do people find useful to know about other people in a social situation?	Semi structured interviews focusing on 'what may be useful to know about people' Phase 1: Recall of recent involvement in social situations. Phase 2: Film clips. Phase 3: The community.	3.3.1. Participants' reporting of useful to know information about **people** in social situation, prior to development of a system
2. To what extent is being able to guess another person's intention in a social situation useful to a person with AS?	Semi structured interviews exploring knowledge and value of guessing intention. Phase 1: recent situations. Phase 2: Film clips. Phase 3: The community.	3.3.2. Participants' knowledge and use of guessing **people's intention** in social situations, prior to the development of a system.
3. Can an explicit system/approach/strategy utilising intention cues in social situations support social understanding of people with AS in social situations?	Phase 4: Development of the personalised system using uncovered knowledge. Use of the system Phase 5: semi structured interview discussing the value of the system and the participant's journey during the project.	3.3.3. Personalising the developed **system** 3.3.4. The **impact** on each participant of use of the system

Key themes emerging from coding categories are discussed in relation to each research question below.

Research question 1.

3.3.1. Participants' reporting of useful to know information in social situations, prior to the development of the 'system'

Participants liked to know different information about different people in different situations. This different information could be grouped in to three broad categories, described in the following sub sections:

3.3.1. a. Differences in 'useful to know' information between people and situations

'Useful to know' information varied according to the situation and to how important the people in the situation were to the participant. Participants did not wish to know information about people perceived as unimportant to them, but wanted to know that people important to them were 'ok'. For example, P said he always wanted to know his brother was 'ok', but talking about a man shouting in a film clip, he said he would want to know 'when he is going to leave so he is not affecting number one' (referring to himself). J said that she would want to know that people 'close' to her were ok, while C, talking about a film clip involving a man shouting at a wedding, said that she would ask 'what's wrong?' if she knew him, but would walk away if she did not know him.

Participants were uncertain about what was useful to know in unfamiliar situations. However, all participants said they usually had no need to know anything about people in very familiar situations, when everything was as expected, or in situations where interaction with other people was unlikely. They felt more relaxed in such situations. For example, P said 'when everything is chilled, I just don't think very much'. He reported being more relaxed in a friend's house with a few familiar people than in a large group in a pub. Similarly, J said that she is most relaxed 'when people are doing their own thing and there is no need for me to interact'. C described feeling relaxed in the gym she visits regularly, saying it is 'sort of like safe' and 'I've adapted to the environment and that'.

3.3.1. b. The potential impact of people on the participant

All participants wanted to know about the potential impact of other people on them personally. For example, C said information to 'avoid a sticky situation where you'd be in trouble' would be important. P suggested he needed to 'think about number one' and to 'make sure I am ok', while J wanted to know 'where I stand' and 'whether I am being lied to'.

All participants reported that information regarding other peoples' thoughts or feelings was often not helpful, since it was often perceived as irrelevant to them. For example, talking about people in the gym, C said 'whatever they're feeling would be personal at home or with their families'. P described himself as 'not

really that bothered' about what other people were feeling. J said 'I only need to know what someone is feeling if it affects me'. Discussion highlighted the complexity of recognising both others' mental state and the potential impact of this.

3.3.1. c. Meaning of facial expression

In phase 1, two participants described using facial expression to guess intention of a familiar person, where the meaning of the person's particular expression had been learned. In other words, their understanding of the expression was based on learning the use of specific expressions by specific people, rather than use of recognition of a mental state per se. (see further 3.3.2.b below). For example, C's support worker began, 'sometimes C talks out loud to herself at the gym ..', C interrupted, 'I don't need to be told, I only need to get some eyes showing from the other side of the gym. Their look says ''C you are talking out loud in front of everybody'' '. C had learned the meaning of that facial expression in that situation. She then described how she uses her existing knowledge of 'usual' facial expressions to guess others' intended meaning:

> 'I check whether people are looking at me more or looking at me
> differently. Check whether staff have a different expression. If things are
> going smoothly, staff look at me briefly then look around at something
> else. I think they look at me the longest when I should be finishing off the

machines. It's not a constant stare. It's a longer look than what it would

normally be'.

Similarly, P said he knows when it is time to leave a friend's flat, because of the

'evil stares'. He uses the 'different' facial expressions to know what he should do.

Research question 2

3.3.2. Participants' awareness of people's intention in social situations

prior to the development of the 'system'

Participants had not considered guessing people's intention prior to the project,

and were surprised that they had this skill. Participants' views on intention could

be grouped in to broad categories described in the sub sections below:

3.3.2. a. Existing knowledge of the concept of guessing people's intention

'Guessing intention' was a new concept for all the participants, but all

demonstrated the ability to do this and showed surprise at their discovered ability.

For example, when asked whether she was surprised at her ability to guess

intention during the film clips, C replied, 'I am actually, very'. P doubted whether

he would have this skill in real life situations, saying 'I don't do people', and

suggesting his success in phase 2 was 'because it was a movie'. When J was

asked whether she knew that she had the skill to predict what people would do,

she replied, 'No. I don't really think about it'.

Discussion in phase 3 revealed that participants had concerns regarding 'wrong' interpretations of intention in real life situations and the potential consequences of these. For example, C was reluctant to guess what people may do next in the pub, saying 'I'm not so equipped as with the video', but happily guessed what people could do next in the gym, 'because it is low risk'. P said he was more relaxed in making interpretations about what people may do in a movie, 'because there is no fall back' (meaning 'come back').

3.3.2. b. Awareness of how intention is guessed correctly

Each time participants guessed intention successfully, they were asked how they guessed correctly. Initially all suggested they used 'body language' or 'facial expression'. However, discussion in phases 1-3 revealed that all participants used their existing knowledge of what is usual in relation to people and situations to guess intention. For example, predicting what a character in a film clip may do, C rightly guessed, 'he is going to explode', suggesting she knew this 'because of the facial expression'. It was pointed out that the face was not visible; she was invited to think again, she then said hesitantly

> C: 'How do I know he is not happy about it, erm let me think …let me think'.
>
> Researcher: 'Is it by looking at his face?'
>
> C: '….I noticed a sigh and the way he put his knife down … actions first'.

C thus became aware that she was using existing knowledge regarding how people 'usually' put knives down to know that this scene differed from the 'norm'

and there was something 'wrong'. In the same film clip, P suggested he guessed

intention correctly, 'by looking at his face'. When it was pointed out that the face

was not visible, he said, 'Don't know really, just guessing'. Further discussion

revealed 'I guessed from a few bits about the characters', reflecting development

of awareness of knowledge of the man's (explosive) character.

3.3.2. c. Use of existing knowledge to guess intention

Participants' use of existing knowledge to guess intention, uncovered during

phase 2, (the film clips), was developed through prompting in phase 3, (the pub).

For example, C rightly guessed that having ordered at the bar and returned the

menu, a man was going to a table:

> Researcher: 'How did you know that he was going to a table?'

> C: 'I knew by where he was standing, I was looking at where he had his

> head, where he was looking'.

> Researcher: 'I wonder if you knew using a really easy way'.

> C: (after some thought) 'He was giving the menu back, then he had to go

> and find a table'

Further discussion revealed that C used existing knowledge of what people

usually do having ordered food at the bar.

In phases 3 and 4 participants began to use existing knowledge with reduced

prompting. For example, P's support worker walked away in the pub and P

guessed where she may be, using his knowledge of her to guess that she would

not have left the pub without him. P also discussed a 'friend' who caused him anxiety through talking about herself, apparently showing little interest in him. With a reminder to think about what he knew about the friend, P was able to successfully guess that she would do this next time they met. This reduced his frustration in this situation.

J described how she thought a support worker 'nosey', who phoned to enquire what she was doing. This made J uneasy. Through discussion regarding what J knew about the support worker, J deduced that her intention had been to check on J's well being, not to be 'nosey'.

C discussed feeling uneasy about a shop assistant who regularly appeared unpleasant, so she was reluctant to use that local shop. Discussion uncovered what C knew about this assistant. C then guessed that next time she went in the store, the assistant would 'bang down' the cigarettes, because she always does. C then felt confident entering that situation.

Participants were able to use existing generic knowledge of people to guess intention. For example, in the phase 2 film clip, where much ketchup has been put on the food, the researcher stopped the film:

Researcher: 'Dad speaks next, have a guess what he may say'.

C: 'Erm, erm',

Researcher: 'think about what you know about situations like this. What do

Dads say?'

C: 'Dad says 'don't do that, it's too much ketchup'.

C's guess was correct, based on her knowledge of fathers in those situations.

In the same film clip, P said the father would 'tell his son off'. He knew this

'because he was putting too much ketchup on his food', reflecting his knowledge

of what fathers do.

Participants also used knowledge of people in situations. For example, in phase

3, the pub, C demonstrated increased confidence in using her knowledge of what

is usual to guess intention, saying, 'I know what those two are going to do next…

the one with the menu is going to order it… let's see, I will kick myself if I am

wrong'. C was right. When asked 'How did you know that?' C replied: 'It's what

people usually do there'.

3.3.2. d. Use of existing choice making skills to guess intention

During phases 1 and 2, participants described either 'knowing' what would

happen whereby they expected a single outcome or 'not knowing' what would

happen, rather than considering alternative or most likely intentions. However,

when prompted during phases 2 and 3, participants began to use existing choice

making skills to make a 'best guess' regarding intention. For example, C

discussed her anxiety regarding children running up to her in the gym and what

may happen. She suggested only that they would disrupt her routine, but with

further prompting, she was able to list several potential outcomes. Similarly, when the support worker left in the pub, P was able to make several suggestions about where she may be, when prompted. J was also able to give different explanations relating to what people had said and done at a party, when prompted to think about alternatives. Previously, she had only perceived a single interpretation of events.

3.3.2. e. Noticing the unexpected as a trigger for guessing intention

Participants' knowledge of what is 'usual' enabled them to notice something unusual or unexpected. For example, in the familiar pub, on a quiet afternoon, P said 'there is nothing here to pay attention to, this is calm', reflecting use of his knowledge of what is usual in the pub. The unusual became a trigger to 'go on alert' and to guess a person's intention. For example, P said, 'if I see something unusual, I just watch'. He described a man who pushed in to his trolley in the supermarket; being 'on alert', P watched and avoided the man during his shopping. Similarly, J said she 'tunes in' to people in the pub if something unusual happens such as someone coming close to her table or raised voices. She also described a phone call from a support worker at an unexpected time as a reason to be 'on alert', thinking there must be a problem. C used her knowledge of what is usual in her street, in phase 2, when approaching a group of boys wearing 'hoodies'. She said groups often congregate there and there was no reason to be 'on alert'. However, when C noticed an unusual bottle being passed around, she recognised this as 'different', became 'on alert' and crossed

the road. Not having C's knowledge of the situation, I was 'on alert' much sooner, indicating the importance of knowledge of the situation to support interpretation and to plan action.

Noticing the unusual in relation to the self and the potential impact of the person or situation on the self was most important to participants. For example, C did not consider a stranger tapping my arm in the pub as a reason for her to be 'on alert' as the impact was not on her.

Crucially for these participants with AS, this recognition of when to go 'on alert' avoids the need to think about the behaviours and intentions of people all the time, which the pilot study participant had indicated 'would make me paranoid'.

3.3.2. f. The value of guessing intention

All participants found guessing what people would do or say next useful and were more relaxed in situations where they 'knew what to expect'. J described many situations where not knowing what to expect caused anxiety. For example, J recalled when she wanted to go out with her sister and thought her sister should agree to this when she asked her. However, she was unsure what her sister may say and describes how annoying it is for her when people do not behave in the way she expects. She is more relaxed when she knows what people are going to do. Similarly, C said she is more relaxed in situations where she knows what to expect and that this knowledge was useful 'because you need to know to, you

know, expect it and be equipped'. C suggested that not knowing what may happen may cause anxiety, which was evident when discussing a film scene in phase 2, where a man was shouting:

> Researcher: 'I wonder what you would be like if you were with that man?'
>
> C: 'I would be a bit edgy'
>
> Researcher: 'you would be a bit edgy because.. '
>
> C: 'you don't know what is going to happen next'

P said knowing what was likely to happen was important to 'look after number one' and to 'feel ok'. P compared his experience in the pub (which he disliked), with a situation in a flat, where he was relaxed with familiar people:

> Researcher: 'It sounds like you knew what was going on in the flat?'
>
> P: 'I did, in the other one (*the pub*), I never'
>
> Researcher: 'Did you know what the people were going to be doing and talking about in the pub?'
>
> P 'No, but I did in the flat'.

Research question 3

3.3.3. The development of a system to support social understanding

A personalised system to support recognition of when and how to guess intention was developed and used by each participant (see appendix 6). The following two sections describe how participants personalised the systems and then used their systems in their everyday lives.

3.3.3. a. Personalising the developed system

The system devised in phase 4 used existing knowledge uncovered during phases 1-3, to help participants to know information recognised as useful to them in social situations. All participants chose for me to set the framework of the 'system', which they then 'personalised'.

The 'system' framework consisted of 3 broad stages:

1. **Recognising the unusual**. All participants used existing knowledge of what is usual regarding people or situations, to notice the 'unusual'. The unusual became a trigger to go 'on alert'. 'On alert' was initially labelled '**stop**'.

2. **Using existing knowledge**. Participants used existing knowledge about the people and/or the situation to inform guesses regarding what may happen next. This stage was labelled '**think**'.

3. **Choice of action**. Participants considered available choices and chose what to do to achieve the best outcome for themselves. This stage was labelled '**do**'.

All participants personalised the system. **Stage 1 'stop'** was named 'go on red' by P, while J added 'something is bothering me'. **Stage 2 'think'** was called 'go to amber' ('think what to do') by P. J added 'think about alternatives, what do I know?' while C added 'check', meaning 'what are the choices about what may be going on, what do I know?' **Stage 3 'do'** was re named 'green' ('go and do it')

by P, and renamed 'action' by J, while C added 'will it affect me?' and 'what shall I do?'

3.3.3. b. Use of the 'system'

Participants used the systems and became familiar with them. Diary sheets used to record use of the system were abandoned by two participants, who perceived them to be a 'reminder' that was no longer required because they 'knew' their system.

The participants used their systems in a wide range of situations important to them. They were used in situations with **people participants knew well**. For example, when P was upset by a close family member on the telephone (this being very unusual), he 'stopped'. He thought about what he knew about the family member and realised that it was unlikely that the family member was being 'malicious' as he had first thought. He chose what he should do and resolved the situation successfully. In another situation, he was concerned by something said by a 'friend', then 'stopped', used his knowledge of that person to know she often made 'threats', recognised another probable 'threat', then planned what to do, focusing on looking after himself.

C used her system when a familiar gym instructor 'sounded critical' of C, (unusual for him), causing her to 'stop'. She considered what she knew about him, realised that his intention was to be helpful and responded positively to his

comment. She said that prior to this project, she would have walked away. During the first three phases of the project, J spoke frequently of frustrations with her boyfriend. She was often uncertain of his intentions. For example, prior to 'the system', J had presumed that if he said he loved her, he would move in with her and she became frustrated when this did not happen. J said that on several occasions, her system reminded her to use her knowledge of what he 'is like' and what he 'usually does' to guess his intentions. She then chose her own responses to him and felt more in control.

The systems were also used by participants **within the community in less familiar situations with less familiar people.** For example, P noticed a man sitting on the pavement as unusual, 'stopped', then chose to cross the road. C unexpectedly used her system when she became anxious about funeral cars outside her house. She used her knowledge of her own situation and funerals, to recognise the cars would not impact on her. She was pleased that using the system enabled her to think this through for herself without seeking 'reassurance' from staff.

Although the systems were developed to support 'here and now' face-to-face interactions, participants used their systems **in non face to face interaction, to plan action in future situations and to provide a 'self debrief' system for past situations.** For example, J used her system when reading text messages from a friend. She 'stopped' because (unusually) she did not understand the text.

She used her knowledge of the friend to make the best interpretation of his intended meaning, then felt confident in responding.

Two participants used the systems retrospectively to make sense of past social situations, which had continued to cause them anxiety. C recalled how she was asked to leave a pub when a fight broke out, but refused. She had remained upset about the situation, but now using her system, suggested that in that situation now, she would see the fight begin, recognise it as unusual and choose to leave without being asked. C said she wished she had had her system 'a long time ago'.

In summary, although a common framework was used, each system was personalised by each participant, so they had understanding and ownership of it. Participants used the systems when and where they chose to use them, rather than when they had been 'told' to use it. This approach uncovered some unexpected use of the systems, such as the retrospective analysis of situations noted above. The systems focused on the participant themselves and their knowledge, rather than on other people in the situation. This focus on the self was important and will be returned to in the discussion.

The importance of involvement of a familiar support worker in the project was considered. P and C worked closely with a chosen support worker initially and said they found this helpful. The support worker chosen by J became absent

soon after the project started. J said that she did not think that this had made

any difference to her development and use of the system. The importance of the

involvement of a support worker may vary with individuals.

3.3.4. Personal impact of the development and use of the system

During the project, all participants talked about their enjoyment of learning. For

example, during one session, C commented 'We're having an educational

afternoon! I like this!' Each participant and people who knew the participants well

noticed their learning. Different aspects if the system were most important to

each participant.

3.3.4. a. Significant learning

All participants said they had learned and would continue to use aspects of their

system. The choice making aspects of the system were important to J. She said

she used to think about people in 'pure black and white' but now did 'things

differently' and perceived alternative interpretations of words and intentions

rather than consider only one. She said the system was useful because it 'stops

having to wrap people in cotton wool if they can think about what someone

means and what to do'.

The most useful aspect of the system for P was recognition of 'what I already

know' and use of this knowledge to interpret people's intentions within 'here and

now' situations. However, he also used 'the system' to plan future social situations.

C said that thinking 'what do I know about this?' and focusing on choices to guess intention and to plan her own actions were equally important. She is pleased that she no longer asks staff to make choices for her when she is in a 'sticky situation' as she can think, guess what may happen and make a choice about what to do next.

3.3.4. b. Participants' individual journeys

The researcher and the support staff recognised the individual journeys of the participants during the research and these are summarised briefly below:

P: In phase 1, P demonstrated limited awareness of his knowledge of people and social situations, saying he was 'oblivious' in many social situations. He described feeling 'out of control' and not knowing what may happen in social situations. He liked discovering his ability to think about what may happen during phases 2 and 3 and currently enjoys practicing this when watching films with his support worker. Using the system in phase 4, P learned to apply existing knowledge about people and situations and said he has been surprised at what he knows. In the final interview, the support worker commented to P 'your radar is a lot more efficient'. She said he notices what is happening in social situations but most importantly, he now 'knows what he knows'. She was surprised at the

level and content of P's uncovered existing knowledge. She commented that the system 'had structured the guesswork'.

C: In phase 1, C's belief that Asperger syndrome meant that she could not 'do' body language and so could not 'do' people was apparent. She described feeling fearful and vulnerable in some social situations. In phases 2 and 3 she was genuinely surprised at her own ability to predict what people may do and at how useful this could be to her. Using the system in phase 4, she enjoyed thinking about what she knew and considering alternative interpretations and alternative plans of action. People who know C well, including her family who she sees infrequently, commented that they have noticed a real difference in C during the project. It was said that C is 'thinking more' through use of her system. Staff noticed that C's new ability to use existing knowledge has reduced her dependence on 'checking' with staff what something or someone may mean and about what she should do. Staff report that she has confidence in her ability to think through social situations.

J: Discussion in phases 1-3 revealed that J had well developed strategies to understand and manage many social situations. However, she frequently expressed frustration about social interactions with familiar people. Her frustration appeared to have roots in her singular expectation of what somebody 'should' do or say, described by J as 'thinking in black and white'. Using the system during phase 4, J reported learning to consider different interpretations of

a person's words and actions, based on what she already knows about a person, then guessing what they may do so she can choose what to do. She said that this thinking has reduced her frustration in social situations.

In the next chapter, the key conclusions drawn from the main findings are discussed in relation to the research questions.   Implications for teaching and supporting social understanding are also explored.

CHAPTER 4

DISCUSSION AND CONCLUSION

This study investigated what information may be useful for an adult with ASC to know in a social situation, focusing firstly on the value of guessing intention and uncovering useful existing knowledge; then whether this information could be used to develop a self prompt 'system', based on existing knowledge, which may compensate for weaknesses in social understanding in real life situations. Identified gaps in the literature were addressed through listening to what may be important and useful to an adult with ASC in real world social situations and involving them directly in the development and evaluation of a compensatory system or strategy. To avoid well documented difficulties with generalisation of understanding between contexts, real life situations were the focus of the study.

The findings indicated that the potential personal impact on the participants of other people in social situations was most important, so guessing intention was useful. The recognition of something unusual about a person or a situation served as a cue/trigger to guess intention and the likely impact of the person or situation on the participant personally. Existing knowledge of what is 'usual' for both people and situations and existing choice making skills were used to guess intention. A compensatory personalised 'system' was developed, which supported the recognition of the unusual, guessing what may happen and planning of own actions. It was based on existing knowledge and was developed

and used by each participant in real situations important to them. The 'system' was particularly useful in reminding participants to use existing knowledge and to 'think differently', in order to assess the potential impact of the people in the situation on them personally and to choose what to do in the situation. The conclusions from the main findings are discussed below in relation to each research question.

4.1. Research question 1: What is useful to know about other people in a social situation?

The reviewed literature revealed an emphasis on teaching 'mentalising' or recognising what other people may be feeling to people with ASC, in order to target the evidenced social deficit associated with ToM. Participants in this study were clear that other people's minds were not their focus in real world social situations (see below).

4.1.1. Knowing the potential personal impact of other people was most important to all participants

Participants reported that it was most important for them to know that they were 'ok' in social situations, so wanted to know the potential impact of other people in the situation on them personally. They suggested that knowing others' mental states was only useful if it provided this information. This unexpected finding, whereby participants focused primarily on themselves, rather than on the mental

states of others in social situations, supports the robust ToM deficit theory of autism, whereby people with ASC have a weakness in knowing what is in another person's mind. People are perhaps unlikely to focus on something that is difficult or unachievable. Indeed, a lack of focus on others by children with ASC has been confirmed by previous studies; Brim et al. (2009) found that children with ASC rarely, if ever, observed social discriminative stimuli during ambiguous situations by looking towards familiar others, nor did they respond as a result of the affective display of the others. Similarly Hobson et al. (2009), found children with ASC showed little anticipatory concern towards the expected feelings of someone else. Loveland et al. (2001) argued it is likely that both the ability to reason about others mental states (which require a focus on others) and to use this and other information to regulate one's own behaviour, are impaired in autism. So, beginning with the self for example, 'what might happen to me?' 'What do **I** need to know in this situation?' and 'what do **I** need to do?' could be more meaningful and achievable for people with ASC than focussing on interpretation of mental states of others in social situations.

Specifically, many approaches to teaching of 'social understanding' reported in the literature instruct people with ASC to use another person's facial expression or body language to label a mental state, with some reported successes. Investigation of knowledge of the potential impact of a person as a result of a recognised facial expression or mental state in the real world, was not found in the reviewed literature, but participants in this study reported facial expression to

be useful when it helped them to know what a person was going to do or say next. The findings from this study suggest that learning to 'read' facial expression or learning mental state labels, may not be useful to a person with ASC where the facial expression or label does not reveal the potential impact of the person on them personally.

4.2. Research question 2: To what extent is being able to guess another person's intention useful in a social situation to a person with AS?

The findings from this study indicate that guessing intention (defined as guessing what a person may do next) was a useful uncovered existing skill for the participants. However, teaching of 'guessing intention' was not revealed in the literature review.

4.2.1. Participants found guessing intention useful in some situations

During this study, participants became aware that they could guess intention and could use this to assess the potential impact on them personally of the people in the situation. They were able to guess intention not through deduction of another person's mental state but by use of uncovered existing knowledge about the person or situation (see below). Although Gallese (2006) proposed that the social deficits associated with ASC may be ascribed to a deficit of 'intentional attunement' caused by a dysfunction of the mirror neuron system in the brain, findings from my study suggest that the ability to guess intention may be intact

and may be useful to support the 'social deficit' despite these brain 'deficits'. Frith and Frith (2006), reviewing studies relating to how we predict what other people are going to do, conclude that the human brain is particularly well equipped to predict social behaviour. Supporting Frith and Frith (2006), this study revealed that the participants were able to predict behaviour. However, findings also suggested that it may be necessary to 'uncover' this ability in people with ASC.

4.2.2. Uncovering and using existing knowledge to guess intention was important.

Participants used different aspects of uncovered existing knowledge, discussed below, to support guessing intention. The initial literature review had not revealed information relating to use of the uncovered existing knowledge in social situations.

4.2.2. a. Use of existing knowledge relating to facial expression

During the study, all participants initially suggested that they were using facial expression and complex cues relating to body language, such as 'where she had her head' to guess intention, but subsequent discussion showed these cues were in fact not used. Research has demonstrated that people with ASC have difficulty in reading mental states from non verbal cues including eyes (Baron-Cohen et al. 2001), voice (Rutherford et al. 2002) and facial expression (Wallace et al. 2008). Discussion revealed that participants had clearly learned that they must appear to 'read' non verbal cues, in order to gain social information, even though, as

suggested by the reviewed research, they lacked the knowledge or understanding to do this. Their assumption that they must use non verbal cues to derive social information may result from teaching by people without autism, to whom these cues are useful.

However, facial expressions of familiar people provided useful information to the participants regarding potential intention when they 'knew' the particular expression and its meaning, or because they were able to notice something 'different', which indicated something 'different' may happen next. They thus perceived salient information in a face, but their perception of what is 'most salient' may differ from that of people without autism. Klin et al. (2002) investigating visual fixation patterns during viewing of naturalistic social situations, found that individuals with autism focused two times more than people without autism on the mouth region, two times less on the eye region, two times more on the body region and two times more on the object region relative to age and verbal IQ matched controls. Their findings confirm that people with ASC view people and faces 'differently' to people without ASC, so potentially may need to use different cues or knowledge to support interpretation of peoples' intentions. Further, Begeer et al. (2006) suggested that children with autism only took emotional expressions in to account in their study when this was triggered by asking them to focus on behavioural outcomes. My study perhaps supports this finding as participants could derive information from familiar faces when there was a reason for them to do so (the reason being 'knowing' expressions

associated with particular outcomes). The value of continuing to teach people

with ASC to label generalised mental states through reading facial expression,

using approaches used by people without autism, must be questioned.

Uncovering use of existing knowledge of people with ASC regarding 'reading'

facial expression could be a more useful approach.

4.2.2. b. Use of existing knowledge of 'what is usual'

Participants also used existing knowledge of what is 'usual' (in relation to both

people and situations) to inform guessing what may happen next. Knowledge of

stereotypes (for example, 'what dads do') as well as knowledge of particular

people was revealed. At the beginning of the study, participants had limited

awareness of this existing knowledge; it was revealed through successive 'how

do you know?' questions and probes. I did not find studies reporting investigation

of use of knowledge of 'what is usual' to support social understanding in my initial

literature review. This finding had therefore not been anticipated but raises two

areas for consideration. Firstly, the role of 'knowing what I know' in supporting

interpretation of social situations and people's intentions, and secondly the

potential value of the knowledge of traits and 'what is usual' to compensate for

deficits in ToM in social situations. These are discussed below.

4.2.2. c. 'Knowing what I know'

Metacognition consists of two components: 'monitoring' ('knowing about

knowing'), being the subjective assessment of one's own knowledge, and

'control', being use of the results of monitoring to regulate cognitive processes and behaviour. 'Knowing about knowing' implies not only that 'I know something', but 'I know that I know it' (Koriat 2000). Participants in this study could guess intention but initially lacked conscious knowledge about how they did this (they did not know what they knew). Questioning during the study appeared to make knowledge relating to what is 'usual' conscious. During implementation of 'the system', the cue 'what do I know?' may have facilitated 'monitoring' of knowledge, making existing knowledge conscious.

The relationship between mindreading and metacognition has been explored. Carruthers (2009) argues that mindreading is developed prior to metacognition, which would suggest that people with ASC with a mindreading deficit, would have impaired metacognition, while Frith and Happé (1999) suggest that individuals with autism may know as little of their own minds as those of other people as they are unable to reflect on their own mental states (thoughts and feelings), lacking introspective awareness. Williams et al. (2009) also suggest that metacognition may be more impaired than mindreading in people with ASC, where their definition of metacognition refers to knowledge of own mental states rather than 'knowing what I know'. So, although research suggests that introspection may be impaired, findings from this study indicate that one aspect of metacognition, (defined as 'knowing what I know'), may be developed through consistent use of a cue and may potentially compensate for a possible deficit in mindreading in social situations. Furthermore, anecdotally, I have often heard

people with ASC discussing a difficult situation say, 'I didn't think' and it may be that the cue 'what do I know?' also served as a prompt to 'think' and to bring salient knowledge to mind, rather than stop at 'I don't know'.

Further, Deak et al. (2004) suggested that a verbal metacognitive reminder discouraged 'impulsive responding' when investigating the rule switching flexibility in young children using a sorting task. Deak et al. (2004 p.386) define 'cognitive flexibility' as ''the ability to select task appropriate responses and to shift responses when task demands or task context changes''. In my study, participants were able to notice a change in the context (something unusual) and trigger knowledge and plan action through the cue 'what do I know?' This inhibited a potentially 'impulsive' response based on a single perception of a person or a situation. The 'what do I know?' may therefore support 'cognitive flexibility', but may also support the weakness in 'reasoning' about other's cognition proposed by Loveland et al. (2001), since it focuses the person's thinking and may enable people with AS to integrate information when they 'consciously decided to do so' (Beaumont and Newcombe 2006).

Participants described not 'knowing' they had knowledge, rather than 'not remembering' they had knowledge. Goddard et al. (2007) found specific deficits in autobiographical memory functioning and social problem solving in young adults with Asperger syndrome and argued that social deficits are due to a more general inability to see the relevance of knowledge to particular problems, rather

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than a result of incompetence. Their finding is perhaps supported by this study, where the 'what do I know?' cue may have reminded participants to seek and use relevant knowledge. Whatever the root of the lack of awareness of existing knowledge, participants found use of a cue to access and use existing knowledge useful.

4.2.2. d. Knowledge of traits and 'what is usual' are intact

Participants used noticing 'the unusual' in relation to people and situations as a trigger to use the 'what do I know?' cue, before guessing intention. Although participants reported that 'what is usual' in relation to familiar people and situations had not been specifically discussed or taught, this knowledge appeared to be intact. Ramachandran et al. (2009) investigated the ability of adults with ASC to infer traits from descriptions of behaviour and also found trait inference to be a spared socio cognitive function, suggesting that people with ASC inferred the traits implied in a described behaviour 'effortlessly and spontaneously'. Wellman (1992) suggested that traits and mental states are interrelated in being part of ToM, which underlines the need to avoid assumptions regarding total ToM deficits and to uncover individuals' existing skills relevant to social situations when teaching social understanding.

Use of both knowledge of what a person usually does in a situation and existing choice making skills facilitated an informed 'guess' about what was likely to happen, without 'reading the person's mind' to increase their understanding of

the social situation. Knowledge of traits and 'what is usual' may have compensated for participants' possible difficulty in reading someone's mind.

Noticing the 'unusual' as a cue to guess intention enabled participants to avoid 'thinking about people all the time', which participants reported to be unachievable. The studies included in the literature review did not teach people with ASC 'when' it is important to focus on another person and this may be an important missing component.

4.3. Research question 3: Can an explicit system/approach/strategy be used in social situations to support social understanding of people with AS?

The literature review revealed the value of rules and strategies to support social understanding and behaviour, a finding supported by the findings of this study; all participants successfully developed and used a rule based strategy to support social understanding.

4.3.1. Development of a personalised 'system'

Each participant developed and used a personalised system to support social understanding and reported a personal journey of learning during the project. The structure provided by 'the system' may have supported the preferences of these people with ASC for structure and strategies, as argued by Ponnet (2008).

Unexpectedly, the developed systems were not based on recognition of physical 'intention cues', such as type and speed of body movement or facial expression and eye pointing. This finding was unexpected as anecdotally, such physical cues are often considered by people without ASC to provide clues about what a person may do next; and teaching mentalising labels associated with such cues is widely reported in the reviewed literature as an intervention with some success. Instead the systems were based on existing cognitive skills: recognising the unusual, drawing on existing knowledge and choice making skills to make best sense of the situation and using choice making skills to plan what to do.

Although the principles of the 'system' were the same for each participant, personalised development of the systems meant they were tailored to individual preferences and needs. Different aspects of the 'system' (i.e. recognising the choices of interpretation or thinking 'what do I know?') were most salient to each participant. This finding supports the concept of autism as a heterogenic condition (Rajendran and Mitchell 2007) and the need for personalised approaches to intervention (Rajendran and Mitchell 2007; Howlin 2008).

4.3.2. Use of the system

Unexpectedly, participants in this study used the 'system' in text messaging, to make sense of past situations and to plan for future situations where they were uncertain about what may happen, as well as in the expected 'here and now'

situations. The system developed was different to other self talk strategies, which plan or 'remind' a person with ASC what to do in a particular social situation, such as SODA (Bock 2007), 'I will' cards (Boutot 2009) and social stories (Gray 1994). Situation specific strategies do not allow for spontaneity of use of the system and because they are based on following a plan, they do not support development of thinking. In the current study, support workers and family members noticed participants' increased independent thinking in a range of situations, as they learned and used their systems, suggesting that the personalised system facilitated some generalised incidental learning and thinking.

Broad and personalised use of the systems may also result from listening to the participants to understand their needs and strengths and perceiving the participants as 'the experts' (Knox et al. 2000). This ensured that the system was grounded in existing skills and knowledge and could be used and evaluated in situations important to each participant.   In my own clinical experience, I have found that some people with ASC do not adopt taught information unless they understand exactly how it is useful to them. Personalised discussion facilitated participants' understanding of how and why the system could be useful to them. This approach is different to those where people with ASC 'learn' a 'social skill' or strategy, where the teaching may be based on how people without autism think in social situations and their perceptions of what people with ASC need to learn and where evaluation is not in real world situations important to the participants (see

Rao et el. 2008 for a review). Such approaches to teaching do not acknowledge the heterogeneity of autism (Rajendran and Mitchell 2007).

Each participant's 'personalised system' utilised the skills of the individual to enable them to know information useful to them in a social situation, so served as a useful, easy to learn compensatory strategy, which may also have contributed to the successful use of the systems. Similarly, Wellman et al (2002), proposed that their compensatory 'thought bubbles strategy' does not target a normal developmental concept, that children with autism fail to develop, but compensates for a lack of other mechanisms. A compensatory approach to supporting social understanding rather than a 'targeting the deficit' approach reported in much of the literature, may be more effective for some people with ASC.

4.4. Limitations

This was a very small study over a relatively short period of time. Case studies are recommended to increase knowledge of social skills interventions in ASC (Rao et al. 2008), but the findings of this study relate only to the cases involved and generalisations to the wider population of people with ASC must be made with caution (Yin 2003). Involvement of more people with ASC including a wider age range and broader spectrum of existing social competence would have provided richer data, from which to make further recommendations. Further

follow up data would have been useful to investigate whether the participants continued to use the systems without the 'prompts' intrinsic in participation in this study.

Time constraints meant there was no formal assessment of abilities relating to social understanding prior to the study, which some researchers consider to be an indicator of learning and social success. For example, Happé (1995) argued that an average verbal mental age of 9 years is required in order to pass ToM tasks, while Crooke et al. (2008) report that success in their study depended on whether a child has a level of language and cognition that will allow understanding of the 'why' behind the social behaviours. Similarly, Bock (2007) suggests that the people who used the SODA strategy to facilitate social communication and problem solving, had already learned to understand the mental states of others. while Travis et al. (2001) proposed that 'intuitive aspects' of social understanding are closely linked to peer interaction and pro social behaviour in a sample of people with high functioning autism.

Assessment of abilities linked to social understanding prior to involvement in my study would have enabled consideration of whether success was clearly linked to an existing skill level. An existing ability to think about what may be important in a social situation and why may have been particularly important in this study. However, as it was intended that the resulting compensatory system would be

person centred and personalised, such data may or may not have been relevant and may actually have deflected from the personalised approach.

Nor did the study investigate the reasons for the participants' learning and successful use of the systems. Such information would have provided further insights. Koegel et al. (2001) suggested that success may be linked to motivation. In this study participants all accessed the community unsupported, enjoyed social contact with familiar people and had a desire to increase their social competence, so it is likely that each person's motivation to develop social competence was an important contributor to their success. Desire to learn and motivation (as defined by the individual participants) may have been important factors which were not directly investigated. Further, the participants were well known to me and it is possible that our previous working relationship, whereby they have learned skills relating to communication with me previously, may have influenced their learning and successful use of the systems in this study. This was not investigated.

The importance of the support worker as facilitator and the support worker's existing knowledge and experience were not taken in to account in this study. The support workers involved had both worked with me previously and both were committed to supporting development of participants' social competence, which may have supported the participants' motivation. Parsons et al. (2006) suggest that in their study, the facilitator was an essential part of the learning process and

should always be adequately planned and provided for as an integral design feature. I did not plan or collate information regarding exactly what each support worker said and did to support the participant in the study. It is likely that this differed for each participant, but this information would have been useful. The reasons for success would have to be investigated before further generalisations could be made.

This study involved two females and one male. Although all participants said they had learned through participation in the study, the effect of gender was not considered, yet differences in abilities relating to social understanding according to gender have been previously demonstrated (e.g. Lawson et al. 2004). It may be that the desire to develop social skills may be more important than gender, but research investigating differences in acquisition of social understanding between males and females with ASC would be relevant in order to make further recommendations.

The limitations of the data collection process must be acknowledged. The elicitation of information in the first semi structured interview relied on episodic memory (which depends on encoding events as part of a personal dimension), which is known to be weaker than semantic memory (information based on facts) in people with ASC (Jordan and Powell 1995), so the reliability of the information must be considered. Acknowledging potential weaknesses in imagination, a defining characteristic of ASC (Attwood 1998), discussion focused only on

situations familiar to the individual, within the experience of the interviewer. This also limited the richness of data. It would have been useful to specifically gather information about what may be useful to know in novel situations.

During the film clips, all information was taken from one film. This was beneficial in that information regarding the characters could be accumulated during the clips, however, the social situations assessed were limited to the context of the film. Other researchers have used a variety of film clips (Golan et al. 2006), but accumulating information about characters is then compromised. In order to collect more comprehensive data, successive clips from more than one film could have been used, showing a greater variety of social situations, actions and associated emotions and consequences.

Useful data collection in the community relied on the people and events in the situation at the time of the semi structured interview. The situations and events that could be assessed were therefore different for each participant. Although the natural context was important to my epistemological position, this actually limited the situations available for data collection. It may have been useful to collect data from a situation where a person was vulnerable to deception or to abuse, but this would probably have to be 'staged' within the natural context and was not possible for this project as it would raise significant ethical concerns. As the system devised was dependent on the data collected, it may be that with

further data collection, the system could be further personalised and so more effective for each person.

I focused specifically on the value of guessing the intention of others to people with ASC. This focus may have limited the information given to me. There may be other aspects which are useful to know in social situations, but the limitations of this project means that these were not fully elicited or included. It should be recognised that 'guessing what may happen next' is only one aspect of social understanding. The motivation for this investigation lay in a search for a strategy that would reduce both vulnerability and frustration for people with ASC in social situations. Although the 'system' as described in this project may have some value in these areas, it could perhaps best be used alongside other social skills learning, not in place of other teaching.

This project relied on elicitation of relevant information from the participants. As an experienced practitioner having an existing rapport with the participants, I was able to use questions and probes understood by the participants to elicit the required information, but I am aware that the data collated may have been very different had it been elicited by a stranger or by a person with limited understanding of communication and ASC. It would be important for future studies to recognise the required skills and understanding of the 'interviewer' in finding out what is important to a person with ASC.

This study relied on information provided by people with ASC. While 'listening to the experts' is perceived as important (Knox et al. 2000), there may also be limitations to this approach. McGeer (2004) questions how seriously and literally we should take the contents of first person reports of people with ASC. She questions the accuracy of episodic memory and suggests that cognitive theorists interpret these reports with presuppositions and react to them to build cognitive theory. Participants in this study reported that they enjoyed being listened to and felt useful in contributing to a research project that may help other people with ASC. They felt supported in giving feedback and opinions. The support provided during 'consultation' will undoubtedly affect the information collated. Despite these limitations, the findings may usefully provide pointers to practice and to future investigation and research (see below).

4.5. Implications for practice

Despite the limitations of this study, the reports of participants mean that some tentative implications for practice may be drawn. Firstly, development of a system based on what was useful for participants to know in social situations, rather than what people without autism find useful to know, may have contributed to the success of the systems. Future development of social understanding could usefully begin with establishing a shared understanding of what may be useful and important to an individual with ASC in a situation and why, recognising that

this may be different to that which is important to people without autism and that this may vary with people and with time.

Participants may have used the system because full involvement in the development of the system and personalisation of it meant they had ownership of it; this confirms the value of an 'individualised approach' recommended by Howlin et al. (2009). It may therefore be helpful for teaching of skills relating to social understanding to be personalised. Learning in naturalistic situations important to each person and involving learners in evaluation of their learning may also be important.

Although research repeatedly demonstrates the differences between the social understanding of people with and without ASC, many interventions continue to 'target the weakness' using the viewpoint of the person without autism, rather than uncover and use the differences and strengths of each individual with ASC. Participants in this study reported enjoyment of discovering and using previously unconscious or unrecognised skills and knowledge. Interventions that focus on use of strengths to support social understanding may be effective for people with ASC. The impact of learning to recognise existing knowledge appeared empowering, while anecdotally, I have observed a focus on 'deficits' or 'disorder' appear to contribute to feelings of helplessness and low self esteem. It may be important to train staff working with people with ASC to think differently about

what is useful to people with ASC, aiming to use the perspective and strengths of the person with ASC.

'Guessing intention' was useful to the participants in this project in different situations important to each person and may be useful to other people with ASC, when the benefits to them of guessing intention are understood. Where emotions or mental states are taught, specific teaching regarding the potential impact on the individual of the perceived mental state may be useful. When teaching facial expression, each person's existing knowledge could be uncovered and used. In this study, participants had apparently unconsciously 'learned' facial expressions of familiar people and could notice 'the unusual' in facial expressions of people important to them as a cue to be 'on alert'.

Participants in this study were able to guess what may happen next and did this by using existing knowledge about people and situations. Their approach to guessing intention may therefore be different to that used by people without autism. Knowing what is 'usual' and what to expect in a situation or expect from a person (from both individuals and stereotypes) may be particularly important to a person with ASC. This knowledge may enable a person to plan his own actions, thus lowering anxiety (as reported by one of the participants). Importantly, it also enables a person to recognise the unexpected and to use this as a cue to seek existing knowledge to understand the situation and to regulate behaviour. This could impact on reduction of vulnerability. Teaching what to

expect in situations and recognition of 'the unusual' could be useful to people with ASC.

Recognising choices in interpretation of situations was important to all participants. Cognitive flexibility and reasoning, important to deduce what may be happening in a situation and choosing what to do (Loveland et al. 2001) appear to be important skills. Guessing can be uncomfortable for people with ASC and difficulties with choice making are recognised. An everyday focus on making choices of interpretation of what is seen, heard or reported in books and films and in natural contexts and guessing what may happen next, may support development of cognitive flexibility. It may be useful to support people with ASC to 'know what they know' to inform choice making and guessing, since all participants commented that they were unaware of their ability to access and use existing knowledge at the beginning of the project, but found this useful. Macleod and Johnston (2007) suggest that the reflections of adults with ASC can and should provide invaluable information about the needs of children and young people on the autistic spectrum. All participants in this project suggested that noticing the unusual, thinking about what may happen next and planning what to do, would be a useful teaching focus for children with ASC in school.

All adult participants in this project reported useful learning, indicating that teaching of strategies to support social understanding is useful to adults as well as children. Indeed, it may be more important to adults who may be accessing

the community unsupported more frequently and have a greater need to anticipate what people may do in order to reduce vulnerability. In practice, specific learning opportunities relating to their strengths and weaknesses associated with ASC, should continue to be available to adults.

Support workers who worked with me on this project spontaneously began to use informal compensatory systems relating to guessing intention and planning action, with other people they support. They reported success with several other people with ASC in learning 'what to expect' and to 'know what I know', to support understanding of social situations and to reduce vulnerability. This compensatory system was described by one of the support workers to a group of students studying ASC, including parents of children with ASC. Several parents indicated that the system 'made much more sense' than the focus on learning social skills and facial expression taught to their children in school and suggested that they would begin to use it immediately with their own children. Moreover, it appears that the principles of the 'system' appear to be simple to learn and transferable. During this participatory research, all participants commented without prompting, that they enjoyed feeling involved and 'useful'. In practice, there should perhaps be a greater focus on enabling people with ASC to recognise their own needs and to develop their own compensatory strategies as well as share their experiences and knowledge with others.

4.6. Future research

Further investigation regarding who is able to learn and benefit from such a compensatory strategy would be useful. Participatory research including greater numbers of people with ASC of different ages and different social communicative abilities would provide further insights. A longer follow up study would reveal any long term benefits of this approach. The heterogeneity of autism means that further case studies may be valuable.

Future research may separate the 'system' in to its component parts, (knowing what is usual, recognising the unusual, awareness of 'what I know', choice making skills in interpretation of the situation and in planning own actions and learning and using a 'system'), then investigate knowledge, existing skills and teaching necessary for each component separately. In relation to 'what I know', investigation of knowledge of traits may be important, since Ramachandran et al. (2009) suggest that people with ASC may be 'trait behaviourists' rather than 'trait mentalists', a proposition apparently supported by the findings of this study, where actions not thoughts of others were important. Investigation of how people with ASC may derive meaning from facial expression also be useful as may general awareness and use of own knowledge. There is a need for exploration of further simple personalised, compensatory systems, based on strengths.

Use of the system was generalised by all participants to situations important to them, including texting, past and future situations. Further investigation regarding the reasons for the ready generalisation of the system may inform future teaching and learning.

There is a need to develop effective approaches to staff training where staff learn to understand and support the differences of a person with autism, as in this study, rather than to identify 'weaknesses'. Investigation of staff skills and knowledge necessary to support successful uncovering of existing knowledge and use of a 'system' would also be useful, while information from the participants regarding how the 'system' was learned and remembered would be helpful to inform future teaching.

This research uncovered the value of one small aspect of social understanding. Given that autism is a lifelong condition and government initiatives expect funding to be attached to community living and participation within the community, there is a need for further research to provide greater understanding of what is useful to an adult with ASC in social situations. Waltz (2005) argues that the best known case studies relating to people with ASC are written from a position of power, in which the words and views of those described are rarely heard. Research that learns from the experiences of adults with ASC, which acknowledges that adults can continue to learn and which listens to what is important to people with ASC would be enlightening. However, increased recognition of the skills needed to

support people with ASC to think and to communicate their experiences and ideas is also needed.

ToM is a well evidenced key cognitive theory to explain social deficits in people with ASC. However, 'intention' is defined as one aspect of ToM, which this study suggests may be intact. It may be useful to investigate further component parts of ToM and whether they may be similarly supported, rather than view deficit of ToM as a unitary weakness.

4.7. Conclusion

The findings from this study indicate that in social situations all participants were most motivated to know the potential impact of other people's behaviour on them personally. This finding was unexpected, but is understandable in the context of much research evidencing the ToM deficit and in the light of my clinical experience, where I have seen people with AS become victims of crime and deception, often through not anticipating the impact of another person on them. Guessing intention was therefore considered valuable by all participants as it enabled anticipation of what may a person may do and the potential impact of this on them personally, but all participants were surprised at their ability to guess intention. Cognitive strengths were uncovered during the study, which were unexpected by me and previously unrecognised by the participants. Perhaps most important of these was the ability to access existing knowledge through

becoming aware of 'knowing what I know' about people and situations. This

knowledge appeared more important to participants than physical 'intention cues'

to enable them to guess intention. The participants developed personalised

systems, grounded in use of existing knowledge to guess intention, which

supported social understanding in a range of situations important to each

participant. Different aspects of the systems were most important to each

participant, underlining the need for a personalised approach to developed

strategies. This study enabled us to uncover existing strengths of participants

and to create an innovative but simple approach to supporting social

understanding, which potentially reduces both vulnerability and dependence on

staff or others, so increasing social independence of the participants with AS.

Appendix 1 Information for participants

Dear

<u>Learning about what is helpful to know about people in social situations</u>

I have worked with people with Autism and Asperger Syndrome for a long time. Lots of people have told me that often social situations are difficult for them because they do not know what to do. They may feel like a spare part and feel as though they do the wrong thing sometimes. People have noticed that sometimes other people get cross or upset with them and they do not know why.
Some people have told me about how they have been tricked. For example, people have been told things that are not true. People have had things stolen from them by others pretending that they were looking at them or borrowing them. People say they may end up feeling silly or stupid.

I am doing a project. Birmingham University is helping me to do this project. I would like to find ways that may help people with Asperger Syndrome to know more about people in situations where they feel this is important.

I think that the best way to find out what may be helpful to people with Asperger Syndrome is to talk to people with Asperger Syndrome to listen to what they have to say. I think that people with Aspergers are the experts on Aspergers and on themselves.

I know that often people with Asperger Syndrome have lots of things that they do well around other people. I hope that by talking to people with Asperger Syndrome, together we can work out what people already know and already do well and then we can find new ways to help people to feel more confident in social situations. I think it may be most important to help people to know when they may be being tricked or lied to or when they may be about to get in to some trouble.

I would like it if you would work with me on this project.

What you would have to do

1. Chat with me. I would ask you about people and places where you feel relaxed. I would ask you about people and places where you may feel

uncomfortable perhaps because you are worried, unhappy or scared. I would ask you about whether you have been tricked or lied to. This chat would take about an hour. We could invite a member of staff to join us in our chat. The member of staff could help you in the project. I would write down what you say …. Just like I always do! But if it is ok with you, I may have a tape recorder and tape what we say.

2. Chat with me again. This time I would show you a video. We would chat about the people in the video. We would talk about what they were doing and we would talk about what they may be thinking. We would work out how we may guess what people may be thinking or what people may do next, if we think this is helpful. I hope that it would be fun doing this. It will not be a 'test'.

3. Go out with me and the member of staff. We may go to a pub or a café or a shop. You can choose. While we are out, we will look at other people and see if we can guess what they may be thinking or guess what they may do next. We will work out what you are already good at knowing about other people. We will work out what may be helpful for you to know around people. If it is ok with you, I may record what we say. I will write down what we say …. as usual!

4. We will see if we can work out a way to help you to feel more confident around people in social situations or to guess what people may do next, if this would be helpful to you.

5. If we think of any way to help you to feel more confident around people, you can try it out. The member of staff may help you if you like.

6. Chat with me again! You can tell me about anything that you have changed or done differently in social situations that has been helpful to you.

After this chat I will write down everything that we have talked about. I will talk to you about what I am writing. I hope that together we can find ways of helping people with Asperger Syndrome to feel better around people. I am hoping that our project will be helpful to other people with Asperger Syndrome. I will be really grateful for your help in helping other people.

If you want to be in the project

If you would like to be part of the project, I will ask you to sign a piece of paper to say that you know what the project is about and that you are happy to be part of the project. I have to do this so that the people at the university know that I have

asked you to be part of the project. They need to know that I have not forced you to be in the project or tricked you in to it.

If you don't want to be part of the project

If you start the project and then don't want to be in it, that is ok. You can withdraw. That means you can say 'I don't want to do this any more'.

Before you make up your mind about the project I can chat to you. You can ask me any questions and I tell you anything else you may want to know.

Thank you for reading this

Best wishes

Kate Silver

Appendix 2 Consent form

The Project to help people with Asperger Syndrome to know more about people

This is a project that Kate has started with Birmingham University to learn about how to help people with Asperger syndrome to know more about people.

Kate would like to learn from people with Asperger Syndrome. Kate would like to work with people with Asperger Syndrome in the project. She has asked me to be a part of the project.

Kate has told me about the project. I have read about the project. I know how I would help Kate. I know that by being part of the project I may be helping other people with Asperger Syndrome.

I have decided that I would like to be a part of the project

I know that if I don't want to be part of the project I can say, 'I don't want to do this any more'.

Signed …………………………………………….

Date …………………………………………….

Appendix 3

Initial semi - structured interview

Questions to be adapted to individual communication needs.
Questions begin after two situations for discussion have been selected.

Situation
Who is in this situation?
Why you like/dislike the situation? *Aim of this is to explore what the participant focuses on in a situation environment, self, people etc..) and to help the participant to focus in order to facilitate further discussion.*
Score On scale of 1-7, what score would you give to how you are in that situation? *Ask for words to attach to the score. If feeling words are used, ask for definitions of these and attach them to the scale to personalise the scale If giving the score is difficult, then provide ' where 1= rather not be there and 7=perfectly ok and relaxed' until the participant has given the score, then my words),*
Is it possible that something that you are not expecting/not nice/a problem may happen ….. like what? *This question is to assess degree of importance people may attach to thinking about different situations. Because I need to be aware of the fact that people with AS may become anxious if they feel they must be always thinking about people in all situations, this question provides opportunity to reinforce the fact that it can be very unlikely that there will be a problem in certain situations and that you do not really need to focus on the possibility of bad things happening all the time.* *The next question focuses more specifically on people, but may not be necessary if people are included in this response.*

What do you know about the people in this situation… eg do you know what they may do, do you know when there is going to be a problem with any of the people?

Try to explore whether the people are familiar, whether they do not interact, whether the other people are effectively redundant in the situation and have no influence on the participant. Elicit what they do know about the people and how they know it. It may be that 'the system' will only be necessary when the people in the situations are less well known and therefore less predictable. Aim in this question is to draw out their knowledge of different levels of knowledge of people.

Would it be useful to know how somebody is feeling? …. Why/why not? (*use their words*)

Aim here is to listen to words that people attach to the word 'feeling'. Definitions will be explored and written down. Also to draw out the fact that knowing how someone is feeling may enable a neuro typical person to inform their own behaviour but is this the case for people with AS? How does it help them? Question is moving towards what they really need to know in social situations.

Would it help to know what someone is thinking? …. Why/why not?

How do you know what someone else is thinking or feeling in this situation?

If words to describe emotion are used or the term 'body language is used, which have not been previously used, ask what the words mean and ask how emotion or body language is useful to them.

Would it be useful to know what someone may do next? …. Why/why not? (*Phrase according to individual)*

What would make you **think about** what someone may do next in this situation?

The aim of this question is to explore when/how people may begin to think about what people may do next. They may not be aware that they do this.
If the participant says that they would never think about this, explore as to why this is and what the benefits of thinking what someone would do next would be.

How do you **know/ how do you guess** what somebody may do next?

Use discussion to support thinking. Ask if there is anything particular that they look at/listen to/know. Focus on what people can do.

On a scale of 1-7, how good do you think you are at working out what is useful to you about people in this situation? (what people are feeling/thinking/ may do next, depending on responses above)

Is there anything else that you wish you knew about the people in this situation?

Additional questions for situations disliked by participants

What bothers you most in this situation? What is it that makes you feel uncomfortable? *(but use their word previously used, rather than uncomfortable if possible)*
What might go wrong? *Aim is to understand what may be important …. Prompts may be necessary. Discuss whether it may be helpful to know in advance that something could possibly go wrong.*
Have people laughed at you? *Explore when, what happened, how did the participant know they were being laughed at.*
Have people shouted at you? *Explore their understanding of why this may have happened and what their response was to this. Ask whether it would have been helpful to guess that someone may shout at the participant.*
Have you been tricked or lied to? *Explore their awareness of whether this could happen. Explore how they knew this was happening and whether it would have helped to anticipate that it may happen*
How would you know if someone was tricking you or lying to you? *Aim is to uncover any strategies that the participant may already use.*
Have you ever felt vulnerable? (define what this means)
Have you ever made a good decision/choice about what to do in this situation, which helped you to feel better?
Have you ever made a bad decision in this situation which made things worse for you?

Further questions.

If the information required in these questions has already been discussed, these questions will not be used.

- Name some feelings/emotions
- If someone is feeling ….. (one they have named) what does that mean?
- Do people always show their feelings or do they hide them.
- What does body language mean?
- How do you know what someone is feeling/thinking/do next? Do you always know or always not know what someone may be feeling/thinking/do next? (as relevant)
- People use the word 'trust'. What do you think that means?
- Do you think it is useful to think about trust or not?
- Have you ever touched someone or kissed someone and then been surprised at what happened next?

Appendix 4

Semi structured interview 2: The film clips

The film will be stopped at the same 10 places for each participant.

At each point the following will be explored. Questions and language used to be adapted to match with individual communication needs:

Main themes:
What is useful to know about other people?
Is being able to guess intention useful? … does this vary with people or circumstances?
How are you guessing intention when you guess successfully?

- Who are you looking at here? ..   why? *where there are several people in the situation in order to understand who attention is paid to and why*

- Is there anything that would make you feel uncomfortable *(use each person's equivalent word)* in this situation?

- If you were in this situation would you notice this person/these people? *Prompting may be necessary to support imagination of 'being there'*

- Would you think anything more about them? ….*prompt eg they are ok, there is no problem, they are of no interest to me. Follow up on ideas from interview 1 re who is important to the person and why*

- Would you zone in or zone out on them? …*words previously used by 1 participant but amend words as necessary*

- I wonder whether it is possible to know things about people in these situations

- Can we guess what the person is thinking?

- What about what he is feeling?

- Do we know what he may do next?

- If you were in that situation (*support thinking by giving a specific place where the participant would be)* what would be useful for you to know? *Prompt… thinking, feeling do next if necessary and ask for other ideas*

- I wonder why ..(*whatever was said above*) is most useful.. or … may be useful because ….

- I wonder why … *list the others said to be less useful…*is not so helpful.

- *If guessing what someone may do next is said to be useful…*How can we guess what the person may do next? *Explore detail re facial expression, body language, 'knowing' as mentioned in interview 1, elicit any other cues used.*

- *At points where people, are beginning to argue or fight..* would you be uncomfortable in that situation? *Question response …*why? *or use equivalent word.*

- I wonder how the person is feeling? *question meaning attached to emotion words used.*

- I wonder what the person may do next? …*explore choices of interpretation*

- What would you do?

- Whenever emotion words are used by the participants, explore how labelling the emotion is actually useful

- If looking after 'number one' (or equivalent) is mentioned again, explore what 'number one' needs to know to look after number one. Explore what can go wrong for number one.

- *Immediately prior to resuming the play of the film, recap,* so what do you think will happen next?

- *The film may then be stopped for discussion of incorrect or correct guesses of intention and the reasons for these.*

Appendix 5

Semi structured interview 3: In the community

In a social situation agreed with participant

Questions to be adapted to individual communication needs

- *Ask the participant to choose a person* …… How/why did you choose that person? ….*was attention drawn to a person… checking for an 'alert' system previously apparent*

- Observe …. I wonder what the person is doing… *checking for existing knowledge/understanding of the person/situation*

- What do we know about the person? *(feel, are thinking etc..) … remind participants about what they knew about people in the film if necessary.*

- What is easy to know about the person? *exploring further existing knowledge and the 'mystery' of knowing things about people… following up previous statements eg 'I don't do people' and questioning these in the real world. Also follow up ideas from previous interviews where participants have been confident in knowing things about people (that he seems ok, that he is about to…, .that he probably wont move for a while etc..)*

- How do you know that? …. *reinforcing ideas raised in previous interviews relating to existing knowledge. If required, use reminders of success in previous interviews, to prompt to use same systems to know information.*

- What is interesting or useful to know about that person? … *revisiting discussion from previous interviews, checking whether the focus for useful to know changes in a real world situation, ask about thinking and feeling and 'do next'.*

- What may the person may do next? *….Prompt*..think… look for clues *(to potentially elicit new ways of knowing information), prompt to use existing knowledge as used previously if necessary .. using words previously used*

- What are the choices about what he may do? ….*encourage thinking of more than one interpretation of what the person may do/what may happen next.*

- Do you know what he may do or not know or 'maybe' know?

- Make a guess. *Discuss how confident the participant is in their guess and why (revisiting existing knowledge, no prompting to check ownership/understanding of information, will show whether knowledge is owned)*

- *Watch. Evaluate. Discuss success and reasons or reasons for 'wrong' guess*

- I wonder whether it is useful to know what that person would do next … when may guessing what someone may do next be useful here?…. *check if responses are the same as in previous interviews. If not, remind of previous responses and discuss differences.*

If the situation has little going on or the participant says there is nothing to pay attention to…
- How do you mean there is nothing to watch/pay attention to? *(use their words)* …. Why don't you need to pay attention?

- What would make you pay attention? *Give scenarios of unexpected events to prompt if necessary eg a man approaches this table, a man starts shouting, a lady falls on the floor etc..*

- I wonder why you would pay attention then…

- What would you want to know if … (*use the example discussed above*)

- Thinking about what you would you do… what choices would you have about what to do?

Appendix 6: The Diary Sheets

6a. P's Diary sheet

Date

Getting my mind working … working out a system to feel better around people

Situation … where was I … who was there?

EITHER

Everything is as I would expect, everything was ok… what was happening?
How did I know that everything was ok?

…………………… Didn't need to pay attention

OR

There was something unusual or I was unsure….. what was happening?
How did I know there was something unusual or what was making me feel unsure?
What did I want to know?

……. I needed to pay attention

Something unusual

STOP RED … what made me stop
THINK AMBER … what was going on. What did I **know** about this situation or this person **CHECK…** Guess what might be happening **…** what are the choices about what might be happening .. have I made the best guess
DO GREEN … what should I do to look after number one?

Appendix 6b

J's diary sheet

J

Knowing where I stand. Thinking about 'will this person affect me?'. Working out what may happen. Thinking about the best thing to do

SBAKA
Stop …. There's something unexpected
Bothering me… what is it?
Alternatives … what else could be meant or what else could be going on?
Know …… what do I know about this person and this situation
Action ……… what shall I do?

Date	
Situation. **Where was I? Who was there?**	
Would the person or people in the situation affect me?	
Yes **Tune in and think….** **Listen and watch for things you are** **not expecting or things that are** **unusual**	**No** **Why not?**

Yes:

1. Stop, there's something unexpected
2. What's bothering me? Why did I tune in?
3. Think. Alternatives. What might happen?

4. What do I know about the person or the situation   **What is most likely?**
What did I need to do? Action?

SBAKA: Stop, what's **bothering** me, **alternatives?** What do I **know? Action**

Appendix 6c

C's diary sheet

C

Date

Being aware of what's around you. Being equipped. Avoiding sticky situations.
A system to feel better around people

Situation … where was I … who was there?

EITHER

Everything is as I would expect, everything was ok… what was happening?
How did I know that everything was ok?

……………………PEOPLE WERE IRRELEVANT

OR

There was something unusual or I was unsure….. what was happening?
How did I know there was something unusual or what was making me feel unsure?

What did I want to know then?

SO ……………..PAY ATTENTION TO PEOPLE

Something unusual

STOPALERT … what made me stop?

THINK … what was going on?

Would it affect me? …. What might happen?

CHECK… Guess what might be happening…. what are the choices about what might be happening .. have I made the best guess?

DO … what did I do to avoid a sticky situation?

Appendix 7

Final semi structured interview

Introduction reminding the participant of the beginning of the research project and thanking them for taking part. Remind the participant of the different stages and what we did together and what they have done alone. Discuss some of the examples of use of their system reported in the diary sheets or verbally.

Explain that I would like to ask some last questions about the system and their use of it and whether the system could be of any further use. Questions below to be adapted to individual communication needs

- What do you find useful to know about people in a social situation? *Comment on any differences between answers in initial interview and this one*

- *If intention is mentioned* ..What information do you use to guess what a person may do next or may be about to say?

- How useful do you find guessing what people are going to do? *Use rating scale 1-7 if this helps* When is it useful?

- How good are you now at guessing what people may do? *compare to previous responses/comments made*

- What do you think that you have learned during our chats?

- What do you do differently now?

- What has surprised you?

- Give an example where your system has been most useful

- How did you remember to use the 'system' that we talked about?

- Comments on use of the diary sheet

- Will you continue to use the system now?

- What do you think you would like to be better at now?

- Thinking about what you have learned, what do you think other people with autism should learn… maybe in school?

Elicit comments on any differences that you think this work has made, either here

Appendix 8: Final feedback from staff

This information was used to seek written feedback from 1 staff member and as a basis for spoken feedback from another.

Dear *staff*

Thank you very much for agreeing to write some thoughts for me. I have reminded you of the purpose of the research below, then written a few questions for you to comment on, but please do not feel restricted by my questions. I would like you to be able to write about what you have seen as important. Thank you.

This piece of research has focussed on:
Exploring what people find useful to know about other people.
My aim here was to listen to opinions regarding the usefulness of facial expression and 'emotion'. I felt that deriving meaning from facial expression and emotion may be very difficult, as repeatedly proven in the research. I wanted to explore whether focussing on expression or emotion may be confusing rather than helpful to many of the people that we support and to look for other things that maybe useful to know.

Discover whether guessing intention or knowing what people may do next is helpful
I wanted to explore whether what a person may do/say next and what we should do, is more useful to people than recognising the emotion alone. I wanted to explore whether people with AS may well have skills that enable them to guess what a person may be about to do or say, even though they cannot label an emotion correctly and further, that they have skills that would enable them to know what to do next.

Discover whether people with AS are able to work out a system that supports their understanding and helps them to decide what to do in social situations.
I wondered whether people would be able to learn and to develop their skills in this area. Different people had slightly different systems and it was important to them to use the system in different ways. However, all participants mentioned the 'stop' there is something unusual here, all participants were able to use what they 'knew' about a person or a situation, but all seemed unaware of these skills in the early stages of the work. All participants were able to use choices to work out what may be going on and what they should do.

I would be very grateful for any comments on the following (examples will be really helpful if you have them):

- What does *participant* do now in social situations that he did not do before taking part in this research? What has been the most significant change?
- What has *participant* learned about his existing skills during this research?
- Did you notice developments in *participant*'s thinking during social situations during the research period?
- *Participant* appears to use the 'system' in situations that I had not anticipated. When have you noticed that it is most helpful to him?

- Has taking part in this research been of benefit to *participant* in any way not directly related to the aims of the research (eg feeling listened to/valued etc..)

Please can you also comment on your own experiences of taking part in the research. Perhaps include
- what surprised you during the research
- how you think the 'systems/approaches/thinking' we have discussed could be of benefit to *particpant* in the future and
- How could the 'systems/approaches/thinking' be of benefit to other people that we support.

Please can you also add any other comments that you may have in relation to my original objectives, *participant*'s experiences or your own thoughts.

I really have appreciated your help throughout this process

Thank you

Kate

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