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How can autistic adults be enabled to contribute their own thoughts and knowledge to significant conversations?

by

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Abstract

There is a call from the autistic community as well as statutory obligations to hear the meaningful thoughts and opinions of autistic people, and to learn from them; yet there is little guidance about *how* a communication partner may best change their communication in order to support achievement of this. Further, there is a lack of use of autistic perspectives to inform approaches or learning that may be most useful to empower autistic people in conversation; and existing interventions to develop social abilities tend to focus on changes to be made by the autistic person rather than on the interactive setting and the communication partner.

This multiple-case study used a participatory approach to explore the conversation exchange in dyads of five autistic adults and seven adults without a diagnosis of autism, over a period of four to 12 months. The study was grounded in the perspectives of autistic people through a series of semi-structured interviews, observations, reflective conversations and diary records. Strategies used by communication partners without a diagnosis of autism were identified as both helpful and unhelpful to the autistic participants in optimising their engagement and supporting the autistic participant's thinking and their contribution of their thoughts and knowledge to conversation. All helpful strategies were informed by a strengths based understanding of the individual autistic person.

The study also explored autistic participants' knowledge that could be useful to them in conversation. Knowledge of the communication environment, and knowledge of the type and structure of talk was accessed and used by autistic participants. This reflected effective use of metacognitive abilities and enabled a greater perceived sense of empowerment and success in conversation, from the autistic person's perspective. Together, the findings provide evidence for the transformative potential of a collaborative approach to communication for participants with and without autism. The findings also provide insights as to how 'interactional expertise' (Milton 2014 p.795) may be developed and used to support the effective contribution of the voices of autistic people in everyday settings, in research, and during important assessments and other formal interactions that have direct implications on support and wellbeing.

Contents

List of tables

Appendix tables

List of figures

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Research Thesis: Declaration of Authorship

Print name:	Katharine Silver
Title of thesis:	How can autistic adults be enabled to contribute their own thoughts and knowledge to significant conversations?

I declare that this thesis and the work presented in it is my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;

2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

3. Where I have consulted the published work of others, this is always clearly attributed;

4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

5. I have acknowledged all main sources of help;

6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signature:		Date:	

Acknowledgements

Definition and abbreviations

AP	Autistic Participant
AS	Asperger Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
Block	Something that was said by the participant without a diagnosis of autism that generated no, little or irrelevant response to the topic from the autistic participant; i.e. something apparently unhelpful to the autistic participant
CBT	Cognitive Behaviour Therapy
Communication partner	The second person in the conversation
EF	Executive Functioning
Grease	Something that was said by the participant without a diagnosis of autism that generated further talk by the autistic participant, reflecting further thinking about the topic i.e. something apparently helpful to the autistic participant
HFA	High-Functioning Autism
Neurotypical	Without a diagnosis of autism
Non-autistic	Without a diagnosis of autism
Participant partners	The dyad of participant pairs one with and one without a diagnosis of autism
QoL	Quality of Life
Significant conversation	A conversation that potentially has a future impact on the autistic person and how they may plan or approach a situation, going forward
SLT	Speech and Language Therapist
Stock response	A response using a frequently used learned phrase, or an immediate, quick response which may not have been thought through
ToM	Theory of Mind
WCC	Weak Central Coherence theory

Chapter 1 **Introduction**

1.1 Use of terminology

I should like to preface my work with an explanation of my use of terminology relating to autism. There have been changes over time in the terms used to describe autism (see below) and in the way that people with a diagnosis of autism or Asperger Syndrome (AS) wish to be described (e.g. Kenny et al. 2016). In my own experience of working with people who have a diagnosis of autism, I find some people choose to be described and identify as 'autistic', but others dislike this term; so when talking with individual people I always use a vocabulary preferred by the person themselves. I do not wish to offend anyone.

I choose not to use the term 'autism spectrum disorder' when describing people on the autism spectrum, as I understand autism as a neurological difference rather than as a deficient or disordered way of being (Baron-Cohen 2002). Instead, I use 'autistic person' or 'people on the autism spectrum', 'person with autism' or 'people with an Autism Spectrum Condition (ASC)' to include all those who have a diagnosis of autism or any other Autism Spectrum Condition. These are all terms used by autistic people known to me. However, when quoting published work, I have used the terms used by the authors of the publication; so, for example, where participants are described as being participants 'with ASD', or having 'high-functioning autism', I use these same words when reporting the study.

Following my understanding of autism as a neurological 'difference', I use the term 'difference' when talking about the differences associated with autism. However, when writing about results or outcomes of other people's studies, or citing other people's opinions, I have used the term used by the author, which may include use of the word 'deficit'. To be clear, where I use the word 'deficit', this is neither my choice of word nor my own understanding.

I also refer to 'people without autism', 'non-autistic' and to 'neurotypical' people, meaning people without a diagnosis of autism, but I recognise the controversy in the use of this word; some members of the autistic community prefer the term 'neuro-

prevalent' to refer to people without neurological differences (Ortega 2009). I am also mindful of the concept of 'neuro-diversity' whereby being autistic is perceived as just one of the different neurological differences within the general population; so being neurotypical or neurodiverse are different ways of existing as humans (Jaarsma & Welin 2012).

Throughout my writing, I understand communication as existing between at least two partners, and use the term 'communication partner' to refer to people involved in the conversation.

1.2 An introduction to my study

This study focuses on conversation *exchange* in communication dyads between adults with and without autism, exploring what people without autism do in conversation that is helpful and unhelpful to the success of the conversation from the perspective of the autistic person. I also aim to explore what autistic participants know about conversation and about conversation partners that may be useful in conversation exchange; and how autistic people and their communication partners together can enable autistic participants to be able to best contribute their thoughts and knowledge to conversation.

I am a speech and language therapist, without a diagnosis of autism, and have worked with and learned from young people and adults with autism and their families for many years. During this time, I have witnessed people with autism who appear to talk well and to understand language spoken being misunderstood and having negative experiences of conversation. Unseen differences in autistic thinking and communication may impact on the autistic person's ability to process, understand and use language (described more fully within the thesis), but when this difference is not recognised or understood by the communication partner, misunderstanding may arise. These misunderstandings can have severe consequences for autistic people. For example, recently, a social worker visited a man with AS without letting him or the staff team supporting him know of her visit, meaning he was not prepared for the visit, nor supported within it. She spoke to him alone and afterwards reported that she asked about an incident several months ago, important from her perspective to 'close a

matter' on file. She said her chat had gone well. However, when she left, it became clear that the man had misunderstood the chat. He thought that he was being accused of something he had not done (he wasn't), he thought that staff had 'reported him' to her (staff hadn't) and he was unclear about what incident or time the social worker had been referring to in her 'chat'. It seems that his understanding of what had been said had not been checked. The man became very upset and an incident resulted where staff were physically and verbally threatened and he no longer believed what staff said to him, making it difficult for staff to support him. It has taken many months to repair this avoidable misunderstanding so that he can now work well again with staff. I have learned that when autistic people talk well, communication partners often do not see a need to 'check' to ensure that the autistic person has understood what has been said and felt able to contribute to the conversation in a way that they would like.

Autistic people I know often express frustration about important conversations, saying for example 'he didn't listen to me'; and also express anxiety about conversations and social situations, for example being reluctant to attend a social group or appearing unsure about a conversation with a doctor or work colleague. Autistic people often report learning social skills at school, but this learning does not appear to have been helpful in the real-world situations reported to me.

Autism is a brain-based neurodevelopmental condition (Lyall et al. 2017) that is lifelong (Masi et al. 2017). In developed countries, global population prevalence has been estimated at 1.5% (Baxter et al. 2015). The cause of autism is unknown, but genetic links have been recognised and environmental factors considered (Hallmayer et al. 2011; Lyall et al. 2017). The pattern of differences in presentation associated with autism were first recognised in profiles of young children by Kanner (1943, cited by Masi et al. 2017, p. 183) and by Asperger (1944, cited in Attwood 1998, p. 14), later described by Wing and Gould (1979) as the 'triad of impairments' associated with autism, including impairment of social interaction, imagination and verbal and nonverbal communication. Social communication remains core to the autism diagnosis, since persistent deficits in social communication and social interaction across multiple contexts are one of the main diagnostic criteria for autism in DSM-5 (American Psychiatric Association 2013). However, the concept of 'impairment' has now been revised to be considered as

'difference' by some writers (e.g. Brownlow 2010a); and there is a call for use of the social model of disability to understand people with autism (e.g. Wheeler 2011), whereby a 'disability' results from the failure of society to take account of, and provide supportive conditions for, the impairment (Shakespeare 2016). Because I am interested in the role of the communication partner (as described in the social worker example above), my study is grounded in a social model of understanding and this is discussed further in Chapter 2.

Over the years, cognitive theories have been developed to understand autism (described in Chapter 2, see Rajendran and Mitchell 2007 for an overview) including Theory of Mind (ToM) (Baron-Cohen et al. 1985), Weak Central Coherence (WCC) (Happé & Frith 2006) and weakness in executive function (EF) (Ozonoff et al. 1991). The theories focus on weaknesses or deficits observed in autistic people. Interventions have been developed to target these weaknesses, some of which are described in Chapter 3. However, more recently, there is developing understanding described within the thesis, that not all ToM is impaired (Ramachandran et al. 2009) and that a focus on this theory has meant that other areas of autism research have received insufficient attention (Hobson 2010). My reading about a changing understanding of ToM and of cognitive strengths in people with autism, particularly metacognition (see Chapter 2) mean that my study is informed by the concept of 'cognitive differences' (Kapp et al. 2013). I consider different aspects of each of the well-known cognitive theories, to inform my understanding of the communication exchange; however, I do not focus on one theory, or how the autistic participants' abilities fit with each theory, nor on deficit. Rather, I use a strengths-based understanding of the people with autism, developed through my clinical experiences, which have taught me that autistic people have many strengths and abilities but these are not always accessed and used. This thinking may be described as my 'personal theory' (Robson 2002, p. 62). I therefore aim to explore and use existing abilities and preferences of each autistic person, rather than focus on what they cannot do.

There is also now recognition of the heterogeneity of autism (e.g. Georgiades et al. 2013), acknowledging that no two people with autism have the same profile of

differences (see Chapter 3). This understanding fits with my clinical experience and underpins my thinking relating to this study.

I support the call for the voices of autistic people to be heard in development of policy and practice (Ridout 2017), for social barriers created by others to be removed (Milton & Moon 2012; Wheeler 2011) and for meaningful involvement of autistic people in developing understanding of autism (Milton & Bracher 2013). However, I am aware that meaningful consultation may not be straightforward, despite the existing body of knowledge of autism and interventions to support development of social and communication abilities described in Chapter 3. I am mindful of current legislation (Autism Act 2009) and statutory obligations (Autism Strategy – Fulfilling and Rewarding Lives 2010, Think Autism 2014; Care Act 2014) that require increased autism awareness and autism awareness training. However, I have known people who learn 'about autism' during staff or parent training, but then tell me that training has not equipped them to know *how* to change their own communication. The NICE (National Institute for Health and Care Clinical Excellence) Autism Quality Standard (2014) indicates that staff must be able to use appropriate communication skills when supporting a person with autism and understand how to make adjustments in their own behaviour and communication, so I hope that the findings from my study may contribute to *how* a person without autism can make such adjustments in order to best gain an understanding of an autistic person and recognise their knowledge and abilities.

The real-life example cited above illustrates my concern about how the conversation of people without autism can impact negatively on autistic people and yet the people without autism are unaware of this impact at the end of the conversation. Milton (2014 p.795) argue that people without autism should have 'interactional expertise', meaning expertise used to interact with autistic people, and suggest that learning interactional expertise is possible for non-autistic people, yet has been lacking in research. Working within the social model of disability I would like to know more about how interactional expertise can be learned in order that communication partners can best support the contributions of autistic people. In my study, avoiding a normalising approach (Milton & Moon 2012), I learn from the autistic participants and explore what the communication partner does in conversation that is helpful and unhelpful from the autistic perspective.

I hope that this learning may inform interventions and support, as desired by autistic adults (Pellicano et al. 2014).

I am also aware of the changing funding climate in the United Kingdom (Hedley & Fradd 2010) and the finance-driven assessments of needs for adults with AS. Ridout (2017) specifically comments on the use of the Personal Independence Payment assessments, which generally involve a standardised interview, even though autistic people have requested that these assessments use flexible methods adapted to their communication preferences (Ridout 2017). Indeed, one highly vulnerable man with ASC whom I know was perceived by a benefits assessor as very able, as he speaks so well. During the difficult interview he felt highly anxious, but he did not want to appear disabled or show weakness to an unfamiliar person, so did his best to hide how he really felt. Subsequently his benefits were reduced, leading to significant hardship for him. I hope my study will contribute to increased knowledge of both autistic people and communication partners about how to support their communication, thinking and contribution to assessments. Further, I wanted my study to contribute to improving the quality of life for people with autism (Lemmi et al. 2017) through addressing the challenges faced by autistic people in conversation (Ne'emen 2010), and I hope that learning more about the exchange of communication between people with and without autism will be useful to both people with and without autism in conversation.

My thesis begins with a discussion of reflexivity, since I consider this to be central to my study. I then move on to an introduction to relevant theories and known differences associated with autism and explore some of the social difficulties experienced by people with autism (Chapter 2), before reviewing the literature relating to some of the current interventions used with autistic people to enable development of social abilities (Chapter 3). The Methodology chapter follows in Chapter 4, before Data Analysis in Chapter 5, Findings in Chapter 6 and the Discussion of my findings in Chapter 7.

1.3 Reflexivity

As a practitioner-researcher, I am directly involved in the study. I have worked as an autism specialist speech and language therapist for many years and have conducted previous academic research relating to autism. I am also a senior leader within the

charity service provider organisation where the study took place. While I recognised the strength of reflection on my experience as a practitioner as a 'useful source of new knowledge and understanding' (Denzin & Lincoln 2011, p. 243), I also needed to consider the potential impact of my experience, clinical interests and status on my study, which may have shaped my personal views and expectations.

My study involved adults with autism who were being supported by the charity in their own homes, young adults being educated by the charity or volunteering in the school run by the charity, members of staff working for the charity in different roles and a family member of a person supported. I am aware that subjectivity cannot be neutralised where the researcher and the researched are both part of the social world under investigation (Conneeley 2002), so it was important to me to make subjectivity explicit through reflexivity and to consider thoroughly the potential areas of researcher bias at all stages of the project.

Berger (2015, p. 220) describes reflexivity as:

> Turning of the researcher lens back onto oneself to recognise and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation. As such, the idea of reflexivity challenges the view of knowledge production as independent of the researcher producing it and of knowledge as objective.

Following Berger's (2015) definition, reflexivity in research is therefore an active, ongoing process throughout every stage of the research and supports the ethical aspects of the research as well as the trustworthiness and rigour of it (Guillemin & Gillam 2004). Reflexivity must include awareness of the ways in which the researcher's social identity and background may impact on the research process (Robson 2002, p. 172), so that researchers understand the role of the self in the creation of knowledge and carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research (Berger 2015).

As a senior manager within the charity in which the study took place and an autism practice lead, I was aware of the power dynamics in my interactions with potential

participants, where they may know my job title and status, and how I managed these (Conneeley 2002). Prior to the study, I had not met two of the participants with ASC, (service users of the charity for whom I work) and I was introduced to them as a person who invited them to participate in a study in order that I could learn from and with them. This was my only role with them. They were not informed of my senior manager status prior to the study, as this was not considered essential information for the participants; they were informed that I worked at Head Office. In fact, whenever I work with people for the first time I am known as 'Kate from Head Office', so this explanation of who I was, is normal practice for me. It was important that, while conducting the research, situations for participants were kept within their ordinary experiences as far as possible. If any of the participants had asked me about my wider job role, I was ready to talk to them about my role and to let them know that while we were working together, my role was a researcher and to explain what this meant. Further, if there were other things that they wished to discuss outside of the research we could make a time to do this. In fact, nobody asked further about my role.

I knew the other participants with ASC, but they are not aware of my status within the charity; they simply know me as 'Kate', a person who talks with them from time to time. They know that in the past I have been helpful to them in supporting them to resolve difficulties. It is possible that respondents may be more willing to share their experiences with a researcher whom they see as sympathetic to their situation (De Tona 2006), so it may be that my previous experience with some of the participants meant that they were more open with me.

There were benefits to me having knowledge of differences associated with autism when beginning the research, since researchers seeking to undertake interviews with people on the autism spectrum need an understanding of the 'potential impact of autism-related impairments and the capacity to respond appropriately to these challenges' (Harrington et al. 2014, p. 159). I used my knowledge about interaction and communication with people with autism to enable me to ensure that participants with autism were able to understand their involvement in the research and to maximise their involvement in the interviews, which is discussed further in the methodology Chapter 4.

8

As noted above, I already had some knowledge of some of the participants through my clinical work, where I always aim to establish an equal power balance (Ferguson 2001; Martin 2015). For me, this means that the people I am talking to (staff, families and people with autism) are encouraged to freely question anything that I say, or to tell me if they do not follow what I am saying. I always aim for people with ASC to talk more than I do in an interaction; I avoid giving my opinions or ideas, and I always demonstrate active listening. Having this knowledge of how I usually work could have meant that participants were more open and able to explore ideas with me. Sterponi et al. (2015) suggests that the atypical situation of an unfamiliar interviewer asking questions will influence the participants' involvement in the exchange and their responses, and it is difficult for this influence to be taken into account in analysis, so having some knowledge of the participants may have better enabled me to hear their meaningful voice.

However, there could also be disadvantages to me having some knowledge of and familiarity with some of the participants. For example, I may have thought that I knew already what participants might say in response to questions or probes, and so may have been less objective in listening to their responses, or I may have led them to respond in a way that I expected from them (Cloke et al. 2000). To help to manage these kinds of influences, it was helpful for me to have a participant without autism observing my first interview with the autistic participants, and giving me written feedback. I asked for written, rather than face-to-face, feedback as I felt that this would be more likely to elicit more open responses. I was particularly interested in whether this observer felt that the responses given were reflective of the usual communication of the autistic person, as this would tell me whether the participants were relaxed and therefore best able to engage with me and provide me with meaningful information and knowledge.

I aim to be reflexive and reflective throughout my work and in fact, through this study, I wanted to further explore and understand the value of some of my own approaches to conversation with people with ASC. I consciously included myself as a participant worthy of particular scrutiny. I was very aware that it was my interactions with others that were at the heart of the methodology, so I needed to be aware of the tensions

between involvement and detachment in the research (Gemignani 2011). I am both an observer and an observed, through a reflexive lens, in this research.

I talked to all the participants without a diagnosis of ASC prior to the study and each of them knew my status within the organisation. However, I had previously worked with one of the participants without ASC, a teacher and briefly with two support workers and a family member in a clinical, not managerial role. This work was some time ago, when I had a different status, so they knew me as 'Kate' and were used to being involved in conversations where we shared ideas together in an informal atmosphere. Prior to the study, I spent time talking about my role as researcher with the University and about how I wanted to learn from and with them. I made it clear that this was different from my senior manager role within the organisation. Nevertheless, I was mindful that the participants without ASC were aware of my status and so tried to ensure that I adopted a very informal approach in both verbal and nonverbal communication when interacting with them, and during our conversations reminded them often of how we were learning together.

I regularly fed back my learning from participants with and without ASC, aiming to check with them that my interpretations were right and to reinforce their status and value in the study.

As a practitioner-researcher, I needed to be aware of feelings, emotions and tensions that can arise in a researcher when he/she attempts to keep to a marginal positioning on the boundary between the practitioner and researcher identities (Arber 2006). So, for example, there were times when a participant said something that excited me as a practitioner, as it was telling me more about something I may have learned with a previous participant, or related to something I knew outside of the study. At these times, I had to ensure that I retained my usual tone and type of response in order not to lead the participant by showing my feelings and to ensure that I kept our interview as the focus of this study. There were also times when I experienced frustration when the participants had not done what we had agreed that they would do (for example, retain diary records). I had to be sure that I accepted this and did not inadvertently use my organisational (managerial) status to make people feel that completion was mandatory.

I also had to be very clear that my role as a researcher was not to provide speech and language therapy during the data collections. I was careful to avoid moving in to giving advice at any time, remaining focused on finding out and using knowledge of all the participants, with and without ASC.

I was aware of my own clinical interest and my previous knowledge of the vulnerability of people with ASC in conversations. While this was useful to inform the study, I was also mindful that my bias may be to look for what I was particularly interested in and not to see or hear other things that the participants might be saying. My existing knowledge and background could be applied or interpreted as the lens for filtering the information given to me during the interview, and attaching meaning to it from my own expectations rather than the meanings that the research participants might prioritise (Kacen & Chaitin 2006). It was therefore important that I conducted member checking (Robson 2002) whereby, following our interviews, I checked with participants that I had fully understood what they had said to me and that I actively looked for contradictions to findings during the analysis stages to challenge any assumptions that I might have made.

When in conversation with participants with ASC I also aimed to engage as fully as possible with the lived experiences of participants (Milton & Bracher 2013), recognising that people with autism see, experience and process the world differently (Frith 2012). I was mindful that, while I might have some grounding in the culture of the autistic community, having been involved with people with autism and their families for many years and worked alongside people with a diagnosis of autism, there are limitations to my immersion in the culture and practices of autistic people (Milton 2014). I do not have a diagnosis of ASC. I take the position of 'insider-curious outsider', wishing to acknowledge the expert insider voice (Ridout 2017, p. 53), understanding that I could not experience their expertise in the same way (Martin 2015). I had to recognise the limitations of my perspectives and experiences as a neurotypical person in order to create research that is credible and useful to members of the community (Merten et al. 2011).

I used my knowledge of autistic communication gained over many years of learning from people with autism and their families as a speech and language therapist and as a researcher to strive to have interactive expertise; that is, to be 'more able to engage and interact with autistic language and communications' (Milton 2014, p. 796). I listened carefully and was cautious in my interpretations in order to minimise the outside-in approach described by Williams (1992), whereby interpretations about people with ASC are made by people without autism. I checked back with them my interpretations of what autistic participants had said. I also checked my interpretations of what participants without ASC had said to me. At times, all participants gave me further clarification or indicated that I had not got something quite right, which gave me confidence that the participants were not just agreeing with my interpretations or understanding but felt that they were being authentically heard and represented.

Chapter 2 **Literature Review: Differences associated with autism**

In order to set the context of my study, I will discuss the models and theories relevant to understanding conversation with autistic people. I will then explore further some of the known differences associated with autism that may have an impact on conversation ability and the different social experiences of autistic people.

2.1 Relevant models and theory

Wing and Gould (1979) described the 'triad of impairments' associated with autism, including impairments of social interaction, social imagination and verbal and nonverbal communication. I am aware that, although there may now be a developing understanding of the concepts in this model (specifically the concept of 'impairment' is being challenged, and the concept of sensory differences also being considered, see below), this model continues to inform some autism training and practice in the real world and the key concepts have informed some of my thinking about autism. I discuss differences associated with communication and associated social interaction identified in this model below, as well as my understanding of 'social imagination', as linked to cognitive differences. Following the model of the triad of impairments, cognitive theories to understand autism were developed (see Frith 2012 and Rajendran & Mitchell 2007 for an overview). I summarise these briefly here before examining some of the cognitive and communication differences associated with autism.

First, a deficit in Theory of Mind (ToM) (Baron-Cohen et al. 1985) emerged as a key cognitive theory to explain social and cognitive dysfunction in autism (Golan et al. 2006). A deficit in ToM is also referred to as a difficulty in 'mentalising' (Frith 1989) or mindreading (Wellman 1992). ToM is defined by Howlin (2008,.76) as:

> the ability to attribute mental states, intentions, beliefs, desire, 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.

A deficit in ToM in people with autism has been confirmed across a range of studies and ages including labelling emotions from pictures (e.g. Back et al. 2007; Baron-Cohen et al. 2001), from audio recordings of voices (Rutherford et al. 2002), from film clips (Heavey et al. 2000) and from movements of abstract shapes (Salter et al. 2008). Understanding mental states is described as central to ToM (Howlin 2008) and considered crucial to working out the motives of others and to predict behaviour (Parsons & Mitchell 2002). Success in ToM tasks and learning is usually measured by success on emotion and belief tasks (e.g. Hadwin et al. 1996, 1997; Ozonoff & Miller 1995), where the person is required to label an emotion from a stimulus.

However, to me, there are some weaknesses underpinning conclusions regarding impaired ToM. For example, in the literature I have read, when understanding and use of mentalising vocabulary is used as an assessment of ToM ability, it is often unclear whether the autistic person's understanding of the mental-state vocabulary within the assessment has been checked, so conclusions drawn may rely on assumptions of their understanding of that word. I have known people with autism who have learned to use a mentalising word in the right place (i.e. when others have taught them to do so), without having a full understanding of the meaning usually associated with the word.

More recently, some of the assumptions of ToM are also being challenged in the literature; some studies have found that recognition of emotion by people with autism is different, rather than globally impaired, as processing of social information may occur more slowly (Chevallier et al. 2013; Doody & Bull 2013; Uljarevic & Hamilton 2013) and it is argued that differences in the mechanisms related to reading the social cues of others are unlikely to account for all the variability in the real-world social difficulties in ASC (Lombardo & Baron-Cohen 2011). Further, the viewpoint of autistic people is not entirely egocentric (David et al. 2010), and ToM skills may be used when it really matters to the autistic person (Begeer et al. 2010). In addition, studies have shown that autistic people do have knowledge of others. For example, Heasman and Gillespie (2018) found that autistic adults had knowledge of the family members' thoughts and views about them; and also trait knowledge (knowledge of what people 'are like') by autistic children may be an intact aspect of ToM (Ramchandran et al. 2009).

There is also an emerging view that mindreading is not the principal form of typical social understanding (Froese et al. 2013), since conscious mindreading does not compensate for lack of immediate understanding. Froese et al. (2013) suggest that there should be a focus on the role of other processes, such as embodied social interaction, to support knowledge of social understanding. Indeed, Senju et al. (2009) have suggested that, where there is a difficulty in spontaneous mentalising (knowing what another person may be thinking or feeling), compensatory learning can take place to overcome this difficulty.

Further, it is argued that ToM differences may not be the only cause of social difficulties, since processing and sensory differences may cause what is described as atypical social behaviour in ASD (O'Connor & Kirk 2008), and also, competence in linguistic skills will impact on everyday social skills and social competence (e.g. Frank 2010; Hale & Tager-Flusberg 2005; Peterson et al. 2009). In my own view, it is important to understand the links between different cognitive abilities (including processing of information), and communication and social skills, that is, to understand how abilities in one area impact on other abilities. I discuss this further below.

Second, an alternative to ToM is the theory of Weak Central Coherence (Happé & Frith 2006), which suggests that autistic people process information in a detail-focused way, rather than as an integrated whole (Frith 1989). This means that social functioning, which requires rapid integration of information, will be impaired (Frith & Happé 1994). However, more recent studies are showing that autistic people can integrate social information. For example, Kuzmanovic et al. (2011) conducted a computer-based study with 15 adults with high-functioning autism and 15 matched control participants. Participants were asked to 'make an impression' of virtual people using verbal information (a sentence about the person) and nonverbal information (animation of the virtual person) in other words, to integrate social both verbal and nonverbal information. Results showed that although the high-functioning autism group relied more heavily on the verbal information than the control group and were less influenced by the nonverbal information, both groups used nonverbal and verbal information. Similarly, Beaumont and Newcombe (2006) found that in a naturalistic task, where adult participants with and without a diagnosis of autism watched television commercials and

were asked ToM, memory and central coherence questions, adults with autism were able to integrate information when they consciously decided to do so. In my opinion, it is therefore important to consider use of processing abilities when considering social situations.

The third main cognitive theory proposes difficulties in executive functioning as the core difficulty for people with autism. Executive functioning (EF) is defined as 'the ability to maintain appropriate problem-solving set for a future goal' (Ozonoff et al. 1991, p. 1083), and may impact on differences in memory (Boucher & Mayes 2012) (see below). Leung et al. (2016) argue that in the children and adolescents in their study there was a direct relation between the 'social symptoms' (p. 366) of the participants with ASD and abilities in metacognitive executive processes including initiation, working memory, planning, organisation and monitoring. However, they acknowledge that the link between social cognition and metacognitive executive functioning is a 'complicated and long-standing discussion' (p. 342). It seems that the link between executive functioning and social and language impairments in people with autism also remains unclear, as other studies, for example that by Landa and Goldberg (2005), do not find a direct link between executive functioning and language abilities.

There is, therefore, some inconsistency and debate about the exact nature of the cognitive differences and the social cognitive abilities typically seen in people with autism and how the cognitive theories inform understanding of these. Nonetheless, Frith (2012, p. 2087) argues that there is 'still reason to believe that a small number of cognitive mechanisms can explain a large number of phenomena', so it important that the different cognitive theories inform my understanding of social and communicative abilities in this study.

I intend to consider the all cognitive theories described, and be aware that cognitive abilities may change over time and may differ between autistic people, as shown by Pellicano (2010). She conducted a longitudinal study over three years to explore changes at two points in time in ToM, EF and WCC in children with ASD and found that, when compared to the matched typically developing children, children with ASD showed difficulties at both points in time in false-belief (ToM) understanding, problems

with higher order planning and cognitive flexibility and abilities in processing local information. However, not all children with ASD showed the same cognitive profile at both time points. While there were significant improvements in ToM and EF skills, children with ASD, in contrast to the control group, showed no improvements in local processing central coherence tasks, meaning that they continued to find it difficult to see the 'wholes', focusing instead on the detail. Pellicano (2010) concludes that cognitive differences in autistic people may change, but persist with time. This study also shows that cognitive abilities of children with autism are not all the same.

Indeed, the existing theories to describe autism emphasise core differences associated with autism, but do not further describe how these differences may be differently experienced by individuals, although the heterogeneity of autism is now very well recognised (e.g. Masi et al. 2017; Reinvall et al. 2013). Some writers refer to 'high-functioning' people with autism and may refer to 'verbal' or nonverbal' autistic people, but the categorisation remains broad. Within my study, drawing on my reading about the heterogeneity of autism in the literature and my own experiences of working with many different people with autism, I would like to look for common themes while respecting differences between the autistic participants.

Understanding of autism has long been informed by a medical model of disability, whereby approaches are developed to target the perceived deficits (Kapp et al. 2013). However, more recently there is a call for the use of the social model of disability to understand people with autism (e.g. Wheeler 2011), whereby a disability results from the failure of society to take account of, and provide supportive conditions for, the impairment (Brownlow 2010b).

The social model of disability thus challenges the long-held medical view that people with autism should change to fit in with society. As proposed by autistic self-advocates (Milton & Moon 2012), this model suggests that it is the communication partners and the environment that must change to acknowledge the differences associated with autism. Indeed, autistic people report difficulties in social situations because of the expectations of others. For example, Hull et al. (2017) asked 92 adults with ASC about their experiences of camouflaging, where their ASC characteristics are masked through

developing different personas during social situations. Respondents reported a social expectation from the general population that individuals with ASC need to change in order to be accepted by others and described the pressures caused by pretending to be 'normal enough' (p. 2523). The study emphasises that social outcomes for individuals with ASC do not solely rely on personal autistic characteristics but can be dependent on how other people respond to them. Similarly, Lai and Baron-Cohen (2015) emphasise the importance of changes to the physical and social environment to remove barriers to social life for autistic people; and Bellini (2006) suggests that teaching non-autistic peers about autism and how to interact with their peers with autism may be instrumental in reducing negative interactions with peers. Further, Sterponi et al. (2015) argue that if the features of autistic language are regarded as deficits by the communication partners, we are likely to try to encourage children to suppress or replace them rather than perceive these differences as competencies. These studies all show the importance of consideration of the impact of others in the social environment, within a social model of understanding of disability and this will inform my study.

I acknowledge the differences in connectivity in the autistic brain evidenced by magnetic resonance imaging brain differences (Frith & Frith 2006b) and the impact of these on the observable differences associated with autism (Frith 2012); I realise that recognition of biological differences may be linked with a medical model of understanding. However, my strengths-based understanding of autism and my experience of the impact of the communication partner on autistic people (described earlier) mean that my work remains grounded within a social model of understanding.

To help my reflection on how cognitive and communication abilities of autistic people may inform my interpretation of the cognitive theories discussed above, in the context of my study, I now explore the cognitive abilities of people with ASC then some of the communication differences associated with autism.

2.2 Cognitive differences

2.2a Differences in information processing

Relating to the cognitive theory of WCC, studies involving people with autism have repeatedly confirmed a preference for local processing over global processing (e.g. Booth & Happé 2018; Happé & Frith 2006; Koldewyn et al. 2013; Mitchell 2013; Mottron et al. 2006). It has been argued that attention to low-level perceptual information alongside decreased attention to global information may be the cause of atypical social behaviours in ASC (O'Connor & Kirk 2008); that is, because autistic people do not see the 'wholes' or the overview of a social situation, there may be misunderstandings.

However, it has been shown that autistic people can integrate information (see above) and also learn social processing. For example, in a study by Brim et al. (2009), four children with autism learned to seek and follow nonverbal information (for example a frown or a nod of the head) given by another person when they were uncertain in a task or situation. It is likely that the participants in this study learned how the information from another person could be useful to them and so were motivated to use their ability to look at others. Similarly, Rosset et al. (2011) found that children with ASD are able to process angry faces more rapidly and efficiently than happy faces, suggesting that the angry superiority effect is a spared critical social ability in children with ASD. Gaigg (2012), conducting a literature review, found evidence that children with autism could respond to faces indicating threat, but that difficulty occurs when there is ambiguity in the facial expression These studies suggest that some autistic people may be more able to process social information that is important to them, indicating that any support to learning in social situations should be informed by what is important to the person.

Further, it may be that reasoning bias should be considered alongside processing differences. Brosnan et al. (2014) assessed reasoning bias when making decisions in 20 adolescents with ASD and matched controls using computer-based task, concluding that the autistic participants had a circumspect reasoning style that is the opposite of 'jumping to conclusions'. Ne'emen (2010) argues that autistic people possess distinct strengths with respect to rational as opposed to intuitive decision-making and

systematic, categorisation-oriented thinking. So, it seems that autistic people reason differently, rather than have a deficit or absence of reasoning skill.

I am interested in how available social information may be processed and used by autistic people in the natural context (that is including all available social cues), and in the processing abilities (rather then difficulties) of autistic adults. Spek et al. (2011) found that, when asked to self-report, adults with high-functioning autism and AS have awareness of their preference for local information processing. They perceived themselves as being more detail-oriented and reported the use of more systematising strategies than the neurotypical group, demonstrating useful self-knowledge. It will be useful to know more about what autistic people know about their own abilities and about how these can be used in social situations, which is explored further below.

2.2b Differences in self-referential processing and knowledge of the self

Frith (2012) proposes that theory of <u>own</u> mind has been under-represented in research and that the self should be further explored, while Hobson (2010) argues that a focus in research on interpreting and judging the mental states of others by children with autism has marginalised considerations about other–self relations that may be important to understand social cognition. Moreover, Hobson (2010) proposes that self-experience is an important part of enabling a person to feel, to plan, to remember and to engage with people and that this may have an impact on social abilities. Mundy et al. (2010) also argue that there is a gap in research relating to the interplay between the self and other and cognition in social development; and that this interplay is important for the development of social competence. Similarly, Northoff et al. (2006) suggests that self-referential processing (concerning 'stimuli that are experienced as strongly related to one's own person' (p. 441)) is used for higher-order cognitive processing, important in social interaction and for mindreading of others. These studies suggest the importance of considering processing of information relating to the self in the social context. Further, Lombardo et al. (2007) explored self-referential cognition and empathy in adults with autism with 23 males and seven females aged 19 to 45 with high-functioning autism (4) or AS (26). Participants used a six-point scale to judge trait adjectives as descriptive of themselves, a best friend and Harry Potter, and other self-referential measures were then used. Results showed that Individuals with ASC showed better

responses in relation to Harry Potter than in relation to themselves, confirming that individuals with ASC have reduced self-focused attention and difficulties in the self-referential cognitive domain. Similarly, a study by Mitchell and O'Keefe (2008) showed that young adults with ASC have limited understanding of their own mental life. They involved eight young adults with autism and 16 with AS, matched with 24 typically developing participants to explore what young adults with ASC knew about themselves and what they thought others knew about them. The autistic participants thought about someone whom they knew well, (for example their mother) and judged how well that person knew things about them; then judged what they knew about themselves. The participants with autism did not think that they had more knowledge about themselves than their mother. The study concluded that people with autism have a limited understanding of their own mental life, interpreting this as a confirmation that theory of own mind may be impaired. However, there is some inconsistency in results of studies reporting on the ability of autistic people to know about themselves. Lombardo et al. (2007) found that autistic adults in their study could and did monitor their own inner states to some degree, confirming the findings of Berthoz and Hill (2005).

Nevertheless, Lombardo and Baron-Cohen (2011) note that much of the research on social difficulties in autism informed by ToM is one-sided, focusing mainly on autistic people reading social cues from others, rather than exploring knowledge of own mind, and call for a more balanced approach to investigating cognitive differences in autism.

Differences in self-referential processing therefore appear important to understanding differences associated with autism but, to date, much research has looked at how people with autism process or act on information from other people rather than exploring knowledge of the self. Following my previous research where I found that a focus on the self was important to the adult participants with AS (e.g. thinking 'will I be OK?') rather than reading the behaviour of others (Silver 2010; Silver & Parsons 2015), I would like to know more about what autistic people may know about themselves that may be useful in a conversation exchange. My study will explore autistic participants' thinking about the self in conversation and useful knowledge about themselves.

Extending thinking about the self, it is argued by Brown et al. (2012) that where children with autism lack awareness of their own reactions to personal experiences, this may be linked to differences in metacognition, described briefly below.

2.2c Differences in metacognition

Livingston (1997) describes metacognition as thinking about thinking, emphasising that metacognition includes *use* of knowledge, while Grainger et al. (2016 p. 65) describe metacognition as 'consisting of monitoring processes (the ability to accurately represent one's own mental states) and control processes (the ability to control one's cognitive processes effectively)'. It is proposed that there may be a link between metacognition and self-awareness and that a specific metacognitive process may be important to development of self-awareness (Frith 2012). Further, important to the social context of my study, it has been argued that the ability to represent one's own mental states (an aspect of metacognition) relies on the same mechanism as the ability to represent others' mental states (mindreading) (Grainger et al. 2014) and that metacognition may be more impaired than mindreading in people with ASC (Williams et al. 2009). In fact, Wilkinson et al. (2010) propose that a general deficit in metacognitive monitoring may underlie the differences typically associated with autism; and Fisher (1998) specifically highlights the importance of metacognition in the transferability of thinking skills.

Nevertheless, compared to the exploration of cognitive differences that dominated research in the later 1980s and throughout the 1990s, little is known about metacognition in autism and how individuals with autism think about their own mental states (Wilkinson et al. 2010). It seems that knowledge of own mind in people with autism is a relatively new and emerging area of research and metacognitive monitoring could be usefully explored further (Sawyer et al. 2014). If, as is suggested by Lombardo and Baron-Cohen (2011), the concept of self is fundamentally altered in autism, it will be important to a have a greater understanding of how people with autism may use knowledge about themselves in social situations. This is a key area of investigation for my own research.

2.2d Differences in memory

Memory is considered important to success in social situations, since the two hypothetical memory systems of semantic memory (memory for decontextualised factual information) and episodic memory (memory for personally experienced events) are used to inform thinking about one's future experiences (episodic future thinking) in social situations (Lind & Bowler 2010). For example, both memory systems may be used in conversation and social situations in self-report, to talk about things that have happened and to discuss and plan future action. Studies have reported episodic memory difficulties in people with ASC (e.g. Bowler et al. 2007; Crane & Goddard 2008). These may relate to the theory of weak EF, where there is weakness in accessing stored information, reduction in auto-noetic awareness (i.e. the conscious re-experiencing of a past event) and an increase in noetic awareness (an awareness of information in the absence of the recollection of the acquisition of that knowledge) (Boucher & Mayes 2012). Exploring memory with adults with autism, Crane et al. (2010) asked adults with autism to describe up to five memories linked to defining themselves as people and up to five everyday memories of something that was personally experienced but may be either important or unimportant. The findings confirmed that adults with autism are less likely than typical controls to retrieve specific autobiographical memories, focusing instead on more general events. This suggests that memories relating to their own experiences may be difficult to access and this may link to differences in self-referencing or metacognition in people with autism, as described above. This difference may be important, as Brown et al. (2012) suggest that autobiographical memory has an important role in establishing and maintaining relationships, an area reported to be difficult for many people with ASC (see below).

Autobiographical memory may impact specifically on social problem-solving (Goddard et al. 2007). Goddard et al. (2007) used a short-story test where a problem in a social situation is described, for example two people arguing and one leaving, and the required end point is then described, for example the two people being all right together in the end. The adult participants with AS and matched controls must then suggest steps to solve the problem and to reach the end goal. Goddard et al. (2007) found that adults with AS have reduced autobiographical memory and tended to

produce solutions to the hypothetical personal problems that were less effective, less detailed and less extended in time than a control group, and argued that these problem-solving impairments were linked to difficulties in retrieving specific memories. This study suggests that differences in memory, leading to being less effective in resolving social difficulties, could potentially contribute to some vulnerability in social situations described above. Indeed, in the example of my own experience given in the introduction, the autistic man could not access memory of the event described to him by the social worker and this caused difficulties. Further, in a study where 14 autistic adults were asked to report on events that had happened to them, Lind and Bowler (2010) found that individuals with ASC were more likely to take the observer perspective than the self-perspective when recalling past events, unlike people without ASC. This means that they were less likely to report an event through their own eyes and their own experience, but to report as though they were watching the event. This finding may link closely to differences in self-referential processing described above (e.g. Northoff et al. 2006).

Difficulty in accessing autobiographical memories to inform future planning may also impact on future thinking, as reported in children with autism by Terrett et al. (2013) and also in adults (Lind & Bowler 2010). This may have implications in social situations, where memory of previous experiences may not inform current action and is something that I will consider in my study. In addition, Jones et al. (2011) report impairment of everyday memory difficulties in 94 adolescents with autism compared to the control group, using the Rivermead Behavioural Memory Test. The authors argue that, because good everyday memory demands a number of abilities including EFs, social and communication skills and a motivation to remember, the memory system of people with autism may be more vulnerable, as they may have difficulties in all these areas. This possibly shows that, when I am exploring conversation with people with autism, I must consider how the reported differences and theories associated with autism may potentially impact on each other. Further, Jones et al. (2011) point out that memories may be constructed in favourable circumstances, and they call for greater consideration of the real-world application of memory rather than a focus on theoretical constructs. This is an important focus of my study.

Linked to ToM and WCC in the context of my study, it will be helpful to learn more about what may be helpful to people with autism to enable them to create or use memories that may be helpful in social situations and how these link to the known differences associated with autism. However, in the studies I have read, I have not seen reports of any assessment of whether the things that people were asked to remember were of any importance to participants, which I would expect to affect memory ability. Because it is recognised that people on the spectrum view the world differently (Frith 2012), there should be consideration of what is important from the autistic perspectives. Understanding the autistic perspectives is an important focus, for me.

Further, decision-making can cause difficulties for people with ASC (Luke et al. 2012), and this may also be relevant to recall and interpretations of social situations (Silver 2010; Silver & Parsons 2015). For example, a young autistic woman known to me was the victim of unpleasant comments made by male members of her social group. She disliked the comments but, using her recently acquired 'thinking about what I know' skills (her words), she was able to recall (or know) that the males made similar comments to many girls. She then used a recalled self-prompt, choice-making strategy to recognise that she had a choice either to ignore them and enjoy her evening or to let them ruin her evening (which, she recalled, made her feel bad). She chose to stay. She talked about how, prior to our work on 'thinking about what I know' and using her self-prompt strategy, she would not have done active 'thinking'. Instead, she would have left the group and possibly run into the road, as she 'would only have seen things one way' (her words). To flee and possibly to self-harm were her usual responses to a difficult situation.

The studies above demonstrate the importance of memory in social situations and the differences in memory in people on the autism spectrum. In real-world circumstances, people are often asked to recall events and so communication partners should be aware of differences in people with ASC in memory and future thinking. This theme is discussed further in the next chapter.

In summary, there is evidence from a range of studies that people with autism have different cognitive strengths, process information differently and think differently

(Vermeulen 2001) from people without autism; and that these differences in thinking are likely to influence social interactions and communication in important ways. This means that autistic people may experience the world differently (Frith 2012), leading to potentially different perspectives on situations; for example, what is judged to be important or useful to know in a social situation may be different from the perspectives of people with and without autism. In my study, I would like to learn more about the autistic perspectives of conversation.

The studies above also show the importance of understanding processing differences, as described in the theory of WCC, and also how processing differences may link to differences in ToM. I would like to know more about how perceived cognitive differences are linked and may be utilised as strengths (rather than perceived as deficits) in social situations; and also how cognitive differences may be linked to other areas of difference that may impact on conversation.

2.2e Differences in socio-cognitive abilities

In the context of my study, I would like to consider the cognitive abilities of autistic people within an everyday social context. Channon et al. (2014) tested adults with AS on a set of social cognition tasks based on awkward everyday scenarios, including understanding of sarcastic remarks, human actions and physical events and social problem resolution. Participants were 21 adults with AS and a comparison group of 21 matched adults without a diagnosis of AS. Compared to the control group, those with AS performed significantly less well for the social cognition measures where generating their own interpretations and problem solutions was required, and their interpretations of sarcastic remarks and actions were of lower quality. However, when asked to select from alternative interpretations they performed as well as the controls on the interpretation of human action. The AS group had greater difficulty in detecting the awkward elements of the problem situations, but not in generating practical (but not socially sensitive) solutions or in selecting the best solutions from alternatives. This study demonstrates that difficulties may lie in 'thinking up' solutions, reflecting differences with choice making (discussed above) and in considering the social context. This further confirms my view that cognitive differences and the context should be

considered when exploring the conversation abilities of autistic people and will be a part of my study.

Shulman et al. (2012) also explored social reasoning and judgment in social situations, comparing moral and social reasoning in 36 matched pre-adolescents and adolescents with and without autism. In an experimental task, participants were presented with 10 pictures of familiar occurrences in school, including representation of five moral transgressions (for example, one student hitting another) and five social conventional transgressions (for example, one student eating his snack on the floor while others ate at their tables). Participants were asked six questions about each picture: (1) What is happening in the picture?; (2) Is it OK to behave that way?; (3) If it's not OK, why is it wrong to behave in this manner?; (4) Would it be OK to behave in that way in any other situation, such as at home? Participants from both groups could accurately describe the interactions depicted and identify unacceptable behaviours as transgressions. However, when asked to provide explanations for their judgments, participants with ASD frequently included expected damage resulting from the transgressions and cited simple rules prohibiting and condemning the behaviour; this is in contrast to the typically developing participants, who gave abstract rules and rationales for their judgments. Shulman et al. (2012) argue that their findings reveal cognitive differences between the participants with and without ASD and suggest that individuals with ASD pay attention to surface features of interactions, so it becomes difficult for them to distinguish the most relevant features from the irrelevant ones. This aligns with the theory of WCC. This study was experimental, so real-world cues were lacking and participants' motivation to think and to complete the task is not reported. However, this finding suggests the importance of understanding social information in context in order to derive meaning and this will be a focus in my study.

My study focuses on autistic people in conversations, so important differences in communication associated with the diagnosis of autism will be considered next.

2.3 Differences in language and conversation

Some of the differences in use of communication associated with people with autism are described below. To inform my study, I will focus on differences in communication

of people with autism who are able to engage in conversation and consider differences in understanding and use of words, differences in comprehension and differences in use of language and conversation.

Most children with autism experience delayed acquisition of early language milestones (Jordan & Powell 1995), but also a different pattern of language development, with only those diagnosed with AS not showing any early language delay (Tager-Flusberg et al. 2005). Difficulties for young people with AS usually become apparent when there is a greater need to use language creatively, for example to negotiate or to explain (see below). In a review of longitudinal studies of adolescents with autism into adulthood, Magiati et al. (2014) found that although language, including knowledge of vocabulary and sentence construction, improved over time, individuals continued to experience significant language impairments in the functional and social aspects of communication in to adulthood. Difficult functional areas include negotiation (Hochhauser et al. 2015) or small talk (Trembath et al. 2012) and use of language appropriately in two-way social conversation (Happé 1994) or taking account of the information needed by the listener (Paul et al. 2009). Functional language difficulties have been recognised for some time. For example, Bishop (1989) explored the boundaries between autism, AS and semantic pragmatic language disorder and suggests (p. 20) that, 'the autistic child needs to learn not so much how to speak as how to use language socially to communicate'.

In my own experience, I have noticed that when autistic people appear to talk well, with appropriate sentence construction and vocabulary, people without a good understanding of communication and autism may fail to recognise their differences in the *use* of communication and misunderstandings may arise (as in examples in the introduction).

2.3a Understanding of spoken language

There are recognised difficulties in understanding language that are common to people with autism. These include difficulties in understanding metaphor, irony and jokes involving wordplay (Happé 1994); impairment of understanding of words to label mental states (such as angry, afraid) (Tager-Flusberg et al. 2005); impairment of processing of emotional language (Lartseva et al. 2015) and difficulty integrating

linguistic information, social cues and real word knowledge, meaning that the both the semantic (word meaning) and pragmatic (word use) aspects of language are impaired (Tager-Flusberg et al. 2005). There may be greater difficulty in processing both semantic and pragmatic inferences (Le Sourn-Bissaoui et al. 2009); that is, working out the intended meaning, so although an autistic person may be able to understand the individual words in a sentence, the person may not always use the sentence context to determine meaning (López & Leekam 2003). This may result in literal interpretation or a struggle to appreciate the broader social functions of irony or the speaker's intention to be funny (Pexman et al. 2011). In my experience, when autistic people talk well, their communication partner makes assumptions about their understanding and may not notice that the autistic person may be masking a difficulty in understanding when giving their response.

Comprehension of language in people with autism may be more impaired than expression, because an unusually high proportion of autistic expressive language is formulaic (Boucher 2003), meaning that well-formed phrases may be learned and used as learned chunks rather than always made of words put together creatively in new sentences. Saalasti et al. (2008) explored deficits in language performance in school-age children with AS and whether these difficulties contribute to their communication difficulties. The participants were 22 children with AS, mean age 8.9 years, and a control group of 23 children without a diagnosis of AS, mean age 9.0 years. Standardised measures were used to test language abilities, including naming, verbal fluency, sentence repetition, phonological processing, comprehension of instruction, and comprehension of syntax. Children with AS scored significantly lower than controls in the Comprehension of Instructions subtest, but no other significant differences were found on the language measures used. This suggests that children with AS can appear to have abilities in verbal expression comparable to children without AS but have more difficulties in following verbal instructions than typically developing children. Importantly, Saalasti et al. (2008) argue that problems in understanding language may have an effect on social behaviour and may contribute to the problems of communication of these children. They argue that language competence has to be considered when looking at social interaction difficulties in AS.

It is important to note that the study by Saalasti et al. (2008) was a test situation rather than a real-world situation, meaning that other cues that may be used to support understanding in the real world were not present, and that the participants in this study were children. Nevertheless, the findings are likely to be relevant to adults, given the literature reporting the lifelong communication difficulties of people with autism (as discussed earlier). The findings are important to my study as, without a good knowledge of language, most listeners will assume that a person with expressive language skills who sounds the same as typically developing people of the same age will have the same ability to understand language, and this assumption may cause difficulties for the autistic person.

Some autistic adults I know receive support from community services, including Alcoholics Anonymous, smoking cessation groups or work with psychologists on anger management. I notice that the autistic people attending these sessions are able to pick up and use the words and phrases used within the sessions, however, in deeper exploration, we often find that while these learned words are used in context, the words are not fully understood. Recently, following a conversation with staff over anxiety relating to use of e-cigarettes, one autistic person was explaining to me about things that were 'unlikely to happen' (her words) as a result of vaping (for example, 'pop lung'). After some time in the conversation, she said, 'what does "unlikely" mean?' Clearly, she had learned what she perceived to be the right thing to say (i.e. 'it's unlikely') without fully understanding what she was saying. It is recognised that good expressive language skills in people with AS can mask their difficulties with receptive communication (Saalasti et al. 2008) and, in my own experience, such masking can make autistic people vulnerable in conversation, as their understanding of spoken language is assumed by others.

Language processing differences may also impact on the ability of people with autism to use and understand communication (Spek et al. 2009). Kaland et al. (2011) explored response time and the impact of prompting with 13 young people with AS (mean age 16.4) and 13 matched control participants (mean age 15.6). Participants were presented with stories including day-to-day communication and a physical event then asked questions involving inferences about physical states. At the end of the story there was a

climax, and participants were asked questions involving mental-state inferences. Results showed that, compared to the control group, the participants with AS had impairments in understanding day-to-day communication, having particular difficulty with understanding intentions, irony and figures of speech. They also provided irrelevant and idiosyncratic responses on mental-state inferencing tasks, needing more prompts to respond, and performed significantly less well on both the physical-state inference tasks, needing longer response times both before and after the prompts had been given. Participants with AS are described by Kaland et al. (2011 p. 1135) as: 'hesitant and puzzled when trying to answer the test questions. They often articulated their answer slowly and seemed to proceed through laborious and cumbersome thought processes.' This study suggests that, in addition to specific recognised difficulties in understanding spoken language described above, slower speed of processing by the person with AS and the need for prompting from the communication partner may influence their success in conversation. This may link directly to the processing differences of autistic people described in the theory of WCC.

Overall, these studies show that effective communication demands far more than an ability to construct sentences and to use words appropriately, and that the link between conversation ability and cognitive ability is potentially important.

2.3b Differences in understanding and use of specific words

Several studies have shown that children with ASC may use fewer emotional terms (such as angry, afraid) than typically developing children (e.g. Bang et al. 2013; Doody & Bull 2013; Losh & Capps 2006; Rieffe et al. 2007), and may use the terms differently, with less differentiation (Erbas et al. 2013). Similar differences in the use of emotion words have also been reported in autistic adults (Hill et al. 2004).

Bird and Cook (2013) conducted a review of studies reporting on the use of emotion words by autistic people (the ages are not reported), and found that there is a higher proportion of individuals with alexithymia (difficulty identifying and describing their own emotional state) among autistic people than in the population without autism. However, it not clear whether the difficulty lies in recognition of the experience of the emotional state or the labelling of it (e.g. Shalom et al. 2006). Nonetheless, it is possible

that such a gap could impact on conversations where a description of emotion is requested or expected.

Doody and Bull (2013) argue that the difficulties lie in labelling the emotion. They conducted a computer-based study with 40 male adolescents with AS and 20 matched controls without a diagnosis of AS. Participants were asked to match figures of people showing emotions though their body posture, then facial expression, and then to match the figure to an emotion label. The AS group made more mistakes than the controls in verbally labelling the emotion, but there was no significant difference on the matching tasks. The authors suggest that participants with AS may know that the stimuli represented a distinct mental state but were uncertain which mental state, or they experienced a specific problem in verbally identifying emotions. There was variation between participants, which may reflect the variability in skills of people with AS. Also, the task was computer-based rather than real world, so it is difficult to make generalisations about people with AS or their real-world abilities from this study. However, the study does show that the people with AS had some awareness of the differences in the representations of emotions, and the difficulty appeared to lie in applying a label to what they saw, which may be an important gap when in conversation with others. However, Balconi et al. (2012) report that some emotions may be more easily labelled than others. In a computer-based task, with 20 participants with AS aged between six and 15 years matched to 15 typically developing adolescents, participants were shown facial, pictorial and video representation of emotion and asked to label the emotion. Participants on the autism spectrum were able to recognise primary emotions on faces, including happiness, fear, anger and sadness, but found 'surprise' a more complex emotion, which requires more mentalising processes, more difficult.

In contrast, Brown et al. (2012) consider that the difference in use of emotion words may lie in awareness of the emotion. Brown et al. (2012) asked 30 children with Asperger's Disorder (AD) and 20 typically developing children aged six to 14 years to report their earliest memories and two emotional experiences (one positive and one negative). They found that children with AD were less likely to include emotional, perceptual and cognitive terms in their memory narratives, and suggested that this may be because children with AD lack awareness of their own reactions to personal

32

experiences (which may link to differences in self-referential processing discussed earlier). Hill et al. (2004) reported similar findings in their study of 27 high-functioning adults with ASD, 35 adult controls, and 49 relatives of individuals with ASD. Participants were asked to complete a self-report questionnaire investigating three aspects of emotion processing: difficulty identifying feelings; difficulty describing feelings; and externally oriented thinking. The findings were that 48.1% of adults with ASD were severely impaired in their emotional processing ability, while only one of the relatives and none of the controls were similarly impaired. The authors argue that a persistent failure of ToM may be the cause of the emotion processing difficulties, again showing that the cause of the difficulties in use of emotion words by autistic people remains unclear.

Going beyond cognitive theories, Silani et al. (2008) propose a difference in the brain as the cause of differences in processing emotion. They conducted a neuro-imaging study where 15 adult participants with ASD and 15 matched control participants were asked to rate the emotion evoked by affective pictures while MRI brain images were taken. Individuals with autism showed reduced activation in the self-reflection / mentalising regions of the brain (anterior insula), compared to controls, when required to introspect on their feelings. It was concluded that difficulties in emotional awareness are related to hypoactivity in the anterior insula.

It is also important to consider the autistic person's understanding of their emotion words used. This is illustrated in a study by Colle et al. (2008) where 12 adults (2 with a diagnosis of high-functioning autism and 10 with a diagnosis of AS) and a second group of 12 adults without autism were asked to look at the pictures in a book without words and to tell the story. All participants could understand and extract the plot of the story, but the AS group produced less cohesive stories and, when mental-state words were used, there was no further explanation of the cause or consequence of the mental state. This suggested that participants with AS had a limited understanding of the mental-state terms that they used. This finding is important to my study when considering misunderstanding in conversation, as it shows that people with AS may appear to use words in the same way as people without autism, and that it is only when there is further analysis of what is said that possible differences in understanding the

words used are revealed. If listeners take what is said at face value, without further exploration of understanding, it is possible that people with ASC may be misunderstood and this may contribute to some of the difficulties in social experiences that I have witnessed.

In summary, the studies reported above show that there are differences in the ability of people with autism to identify and label their own emotions, but the cause of this remains unclear. In practice, however, it means that we should explore the expression and understanding of emotion by autistic people if we are to understand it. Differences may lead to misunderstandings if it is assumed by people without autism that, because emotion words are used less frequently, the autistic speaker does not experience or understand emotions. I noticed that in the studies relying on self-report that there is no description of how the understanding of participants' word usage was checked or explored during the study.

Tager-Flusberg et al. (2005, p. 344) describe further differences in word use, suggesting that in young people with autism 'increased language use was associated with increased… peculiarities and perseveration'; and that neologisms [meaning 'odd phrases'] may be used. I worked with one young autistic man who expressed how he was feeling by talking about grids, and we came to understand that the description of the grid (including the colour and the depth below the grid) was linked to his current level of emotional arousal. Prior to working this out, it appeared to me that the young man was introducing irrelevant talk about grids into our conversation when, in fact, this was his way of making sense of his own emotional state.

In my own experience, I have often heard people with ASC using words without fully understanding them yet the listener has not picked this up. For example, one young man was upset because he said he was not achieving 'independence'. Staff had explained to him that he was gaining independence as he went out alone, had time without support and was learning cooking and other life skills, but he remained unhappy. Only when we explored his understanding of the word 'independence' did we find the difficulty. His definition of 'independence' was 'having sex, doing drugs and no staff'; it did not relate to gaining skills for daily living.

The examples above evidence the knowledge and understanding of autistic communication needed by the communication partner in order to avoid misunderstandings. The focus on the communication partner will be an important aspect of my study. This far in this literature review, I have considered the differences associated with autism individually, but in reality these are closely linked and cannot be seen in isolation. So, for example, use of memory to access knowledge, then decision-making to interpret the memory and to choose what to communicate use of language to know how to communicate, and processing of the words of the communication partner and the social situation must all be considered together in the real world. This integration of skills and knowledge should also be considered alongside further differences, including sensory differences. These may also impact on the social abilities of people on the autism spectrum, and are briefly discussed below.

2.4 Sensory differences

Differences in sensory perception, including hypo and hypersensitivity to different sensory stimuli, are well reported in the research literature (e.g. Bogdashina 2003), as well as in autobiographical accounts by autistic people (e.g. Grandin 1995). There is also a substantial body of research describing and studying the sensory differences (e.g. Donnellan et al. 2013; Pellicano 2013) and making recommendations for treatment. In the context of this study, it is important to be aware that sensory differences may have an impact on how an autistic person may experience a social situation and that this experience may affect the interaction. Importantly, different people with autism have different sensory differences, as expected in line with the heterogeneity of autism (Georgiades et al. 2013). Drawing on my own experiences, a ticking clock in a room was highly irritating to one autistic person, to the extent that he could not continue the interaction while it was there. By contrast, another person with autism had not noticed the clock in a room until it was pointed out as a possible difficulty. In my study, I will focus on understanding individual sensory differences relevant to social situations.

In summary, the differences associated with autism and their impact on social situations are well recognised. However, despite advances in knowledge about autism in recent years, major puzzles remain (Rutter 2011). Having given an introduction to the

differences associated with autism, I now briefly describe some of the experiences of real-world social situations for people with autism and consider how these may link to known differences associated with autism before reviewing some interventions to address the perceived social difficulties of autistic people.

2.5 Autistic people and social situations: Experiences and differences associated with autism

As described above, it appears that much is known about autism but, to inform my study, it is useful to now consider some of the real-world social experiences of some autistic people. This will enable an understanding of the real impact of some of the known differences associated with autism in everyday life for autistic people. Having explored some real-world experiences, in the following chapter I will then review interventions that may be used to support social difficulties with autistic people.

Difficulties in the social world are well described in autobiographical accounts by people with autism (e.g. Grandin 1995; Jackson 2003; Williams 1992). Specifically, experience of anxiety in social situations is described in studies with young autistic people (e.g. Carrington & Graham 2001; Humphrey & Lewis 2008; Jones et al. 2001; Knott et al. 2006) and autistic adults (Beardon & Edmonds 2007; Wittemeyer et al. 2015). Further, social anxiety is specifically reported as being at a higher level in people with autism than in comparison groups (Bejerot et al. 2014; Bellini 2004; Galanopoulos et al. 2014; Simonoff et al. 2008; Spain et al. 2016; White et al. 2006), when using a range of assessment measures. This matches my own experience of autistic people experiencing social anxiety, especially before important conversations or following conversations where they feel they 'did not do well' (as described in the introduction).

However, the causes of social anxiety remain unclear. White et al. (2006) reviewed 40 papers published between 1990 and 2008 reporting on anxiety and youth with ASD, and concluded that the presentation of anxiety is affected by age, level of cognitive functioning, ASD-specific difficulties (e.g. over-arousal) and degree of social impairment. Similarly, Spain et al. (2018) conducted a systematic review of 25 research papers published before 2017, reporting on relationships between core ASD symptoms and social anxiety in individuals with ASD aged from 10 years to adult, and found significant

statistical relationships between raised social anxiety and poorer social skills and competence, but it was unclear whether these impairments were related only to ASD. Trembath et al. (2012) explored self-reported anxiety in the everyday life of 11 young adults with ASD and 10 parents or professionals. They concluded that raised anxiety may arise from factors relating to others (interactions with and concern for others), fearful anticipation of an event or disappointment and the environment, which match the experiences of autistic people whom I know. By contrast, Bellini (2006) proposes a link between elevated physiological arousal and negative peer interactions, leading to further anxiety about a social situation.

Regardless of the cause of the anxiety, research shows raised levels of social anxiety in autistic people and the importance of a greater understanding of this (Bejerot et al. 2014). During my study, I would like to listen to reported experiences of anxiety during conversation and, thinking about the social model of understanding, I will consider whether the communication partner has impacted on this. I shall also consider the known cognitive and communication differences associated with autism.

It is further recognised that worry about social situations may cause a barrier to accessing social situations (Bellini 2006), leading to loneliness. Zeedyk et al. (2016) used parent and teacher reports of social competence and the Loneliness and Social Dissatisfaction Questionnaire (LSDQ: Cassidy & Asher 1992) with high-functioning children with ASD aged four to seven years. Nearly 40 per cent of the young autistic people experienced difficulty in making friends and a quarter reported feeling lonely. It may be expected that these early negative experiences will impact on expectations of social situations as the child grows up. Indeed, Mazurek (2014) used self-report measures to explore loneliness, friendship and emotional functioning in 108 adults with autism and found that loneliness was associated with increased depression, anxiety and reduced life satisfaction and self-esteem. He argues that loneliness may be a secondary consequence of social difficulties for individuals with ASD Similarly, Orsmond et al. (2013) proposed that impaired conversation ability and functional cognitive skills associated with ASD were associated with increased likelihood of social isolation, following their investigation of the social participation of young adults with ASD and intellectual disability (ID). They used longitudinal data for the people leaving their

education provision and found that almost 40 per cent of youth with ASD never socialised with friends, twice the rate for young adults with ID, and a third of people with ASD were completely socially isolated compared to 10 per cent of the group with ID.

Further, Levy and Perry (2011) conducted a critical review of empirical studies reporting on the outcomes for adults and adolescents with autism linked to diagnostic severity, cognitive functioning, language, academic performance and social outcomes. Outcomes were found to be highly variable and dependent on abilities and educational opportunities. However, in a finding similar to that of Mazurek (2014), only a minority of individuals (5–10%) reported developing lasting friendships and relationships. Similarly, Magiati et al. (2014) reviewed 25 longitudinal studies, published between 1985 and 2013, reporting outcomes for adults on the autism spectrum. Although some improvements over time in daily living skills were reported by participants, there was less reported improvement in socialisation skills, and continued impairment was reported.

Social anxiety, social isolation and loneliness are widely reported experiences for autistic people of different ages in the studies reported above. The studies do not report on the teaching relating to social situations and social skills received by participants, but it is likely that many autistic people will have received this teaching in school, yet the social anxiety remains. Therefore, a different approach to learning or teaching may be needed. Nor are there reports of the strategies or learning to reduce social anxiety and its consequences by the people who know the autistic individuals well. Autistic people known to me have talked about anxiety and fear of social situations, meaning for example that they are unable to go to work. I hope that learning more about conversation in my study will help me to gain an understanding of possible sources of anxiety in conversation for autistic people and the steps to be taken to reduce this anxiety.

Relationships are important to quality of life (Schalock 2004), so difficulty in making and sustaining relationships (in the context of what this means to each individual) may be expected to affect one's quality of life. Van Heijst and Geurts (2015) explored QoL

across the lifespan, using a meta-analysis including 10 studies (published 2004–2012) with a combined sample size of 486 people with autism and 17,776 controls. They found that QoL is lower for people with autism than without autism, with social functioning being the most affected domain of QoL across the lifespan for adults with autism, relative to controls. The number of studies included in their review is small and it is not clear how QoL was measured and reported but, in the context of my study, it is important to note that social functioning is again highlighted as an area of particular difficulty for autistic people. However, in contrast, an online survey of 55 adults on the autism spectrum conducted by Parsons (2015), regarding educational experiences and current life satisfaction, revealed that autistic adults had limited social networks yet were more satisfied with their friendships and living arrangements than with other aspects of their lives. This was a small sample conducted online rather than face-to-face, meaning that no exploration of the questions or any support for thinking or understanding were available and that responses could not be checked in any way. Importantly, Parsons (2015) cautions against making normative assumptions about outcomes, and notes that there was diversity in the responses received; that is, it is important to recognise that people with and without autism may value outcomes differently.

Self-report measures have been used in many of the studies cited above, but it is not clear whether the questions asked to elicit the self-report actually included areas important from the autistic perspectives rather than from a neurotypical perspective (see Chapter 3 for further discussion of use of the autistic perspectives) or what support the autistic person received in order to be able to give their opinion. Some QoL studies have aimed to recognise the differences associated with autism when assessing QoL. For example, Billstedt et al. (2011) assessed autism-friendly environments, including autism trained staff, use of structured education, individual training plans and everyday activities, yet it is not clear whether this description of 'autism-friendly' is from the perspective of people with or without autism. My study will be grounded in the perspectives of autistic people and aim to explore how autistic people can best contribute their knowledge and thoughts during self-report.

In fact, negative experiences of autistic people who feel that they must conform to the neurotypical world are increasingly reported in the literature. For example, autistic youth have suggested that pressure to conform to neurotypical expectations in social situations negatively influences their mental health (Crane et al. 2017). Young adults have reported anxiety as a result of having to change their communication style to talk to others without autism and of becoming anxious when they do not understand what is said in a conversation (Trembath et al. 2012, p. 218). Further, Hull et al. (2017) used an online questionnaire to explore 'camouflaging', which was described by the researchers as including:

> hiding behaviours associated with their ASC, using explicit techniques to appear socially competent, and finding ways to prevent others from seeing their social difficulties. (p. 2519)

Their questionnaire was developed 'by the researchers, in consultation with other experts in ASC' (p. 2522) (whether the questions were designed using an autistic perspective of social situations is not clear), and was accessed by 92 adults over the age of 16 years. The online link was to 'a study looking at experiences of coping behaviours in social situations' (p. 2523). This could mean that a person who had not had experience of using coping behaviours may consider the study to be irrelevant to them.

Despite these weaknesses, the study reveals that the majority of participants reported some camouflaging and frequently described this as being mentally, physically and emotionally draining. Respondents also reported significant pressure from themselves or others to camouflage successfully, and uncertainty of the success of the camouflaging could lead to experiences of extreme anxiety. This study suggests that, when considering anxiety of people with autism in social situations, it will be important to consider the specific social environment, including the impact of communication partners. Following a social model of understanding, I include the role and impact of the communication partners in my study.

It is of further concern that social difficulties may cause an autistic person to experience social vulnerability and victimisation (e.g. Jawaid et al. 2012; Mandell et al. 2005; Shtayermman 2007) and that this may be specifically linked to the misinterpretation of social situations (Van Roekel et al. 2010). There are also reports that rates of physical

and sexual victimisation are alarmingly high in individuals with ASC. For example, Brown-Lavoie et al. (2014) used online questionnaires to explore sexual knowledge and victimisation with 95 adults with high-functioning ASD and age matched 117 adults without ASD; 78 per cent of respondents with ASD reported at least one occurrence of sexual victimisation, compared to 47.4 per cent of the comparison group. Similarly, Fisher et al. (2013) explored social vulnerability through 103 caregiver questionnaires involving 103 parents or guardians of adolescents or adults with ASD (29), Williams Syndrome (38) and Down Syndrome (36). They found that 73 per cent of all individuals were victimised and that, specifically, the social vulnerability of individuals with ASD appeared related to their having less social protection from peers, as individuals with ASD had fewer friends and were less likely to be a part of a peer network. This finding relates to those reported above, showing that social isolation can have further consequences for autistic people. Fisher et al. (2013) requested that the questionnaire was completed by the caregivers rather than by the people directly involved in experiences of social vulnerability so, as indicated above, it is important to be cautious of interpreting social vulnerability from a neurotypical perspective. Nevertheless, the high numbers of people experiencing victimisation and the conclusions drawn in relation to the specific vulnerability of people with autism are consistent and striking, and they match my own experiences where I have known people to be vulnerable as they have failed to understand the intentions of others in conversation, resulting in, for example, a wallet or phone being stolen.

Difficult situations also arise for autistic people in school, when teachers may also be unaware of their invisible power (Ferguson 2001), meaning that autistic young people feel less able to contribute to conversations with teachers; further teachers may learn about autism yet fail to understand the needs of an autistic individual (Wheeler 2011); and, not realising the needs of the autistic person, as a conversational partner, a teacher may not provide interactional scaffolding, which might include re-asking and re-framing questions, limiting the scope of the questions, refraining from talking during inter-turn silences, requesting clarification or creating the interactional space for a child with AS to initiate a new topic (Rendle-Short 2014), to support the pragmatic challenges faced by people with ASC in interaction.

In summary, my own clinical experiences and the literature both evidence the reality of anxiety and of difficulty in social situations for people with autism compared to those without autism. However, any detail of the possible impact of the communication partner on the autistic person, from the perspective of the autistic person, is missing from most reported studies about the social experiences of people with autism. Instead, studies tend to focus on the experience or response of the autistic person, without taking the wider social context into account. In my study, in line with the social model of disability, the role of the communication partner will be an important aspect.

Autistic adults tell me about some of the interventions received at school to help with their social difficulties and others receive therapy, such as Cognitive Behaviour Therapy (CBT), to help with social anxiety and social difficulties. Some of the interventions used to support development of social abilities of autistic people are discussed in the next chapter.

Chapter 3 Interventions and Approaches Used to Support the Development of Social and Related Skills in People with Autism

3.1 Interventions and approaches to develop social abilities of autistic people

To date, many of the social interventions for people with autism have been informed by an understanding of the triad of impairments (Wing & Gould 1979) and ToM (Baron-Cohen et al. 1985), both of which focus on remediation of the deficit of the autistic person, following the medical model. Some interventions relevant to social interaction and conversation are discussed below. I begin with a brief review of social skills teaching and consider how this may fit with the social model and the cognitive theories of autism.

3.1a Social skills teaching

Given the wide reporting of ToM as an area of deficit for people with ASC (e.g. Baron-Cohen et al. 1985; see Howlin 2008 for a review), it is unsurprising that many of the studies and approaches to development of social abilities have been informed by ToM. Studies targeting teaching of deficits associated with ToM tend to report improvements in targeted abilities following learning, yet show little evidence of the long-term use or generalisation of ToM learning (Begeer et al. 2011; Hadwin et al. 1996; Ozonoff & Miller 1995; Solomon et al. 2004;). Failure to use or generalise learning from controlled ToM studies is therefore a well-replicated finding. The reasons for the lack of generalisation are not clear but, as much of the reported teaching is from the neurotypical perspective rather than the autistic perspective, it is possible that the teaching may lack meaning or value to autistic people in the real world.

As both social cognition and social skills are needed to be socially effective (Ferraioli & Harris 2011), social skills, often informed by an intention to remediate the perceived deficit of ToM, are widely taught in the schools that provide education to people with ASC (see Bishop-Fitzpatrick et al. 2014; Rao et al. 2008; Williams-White et al. 2007; also Parsons et al. 2009, for a review). However, there is currently no common, agreed upon approach to teaching social skills to children with an ASD (Flynn & Healy 2012). Recent reviews of research into social skills teaching have suggested that results should be interpreted with caution, as the studies use a wide range of methodologies and various

numbers, ages and abilities of participants. Follow-up data are often lacking as well, making it difficult to draw comparisons between studies or to judge the longer-term effectiveness (Gates et al. 2017; Reichow et al. 2013).

Some examples of studies relating to social skills teaching are briefly discussed below as a way of illustrating the typical approaches taken in the field. For example, McMahon et al. (2013) reviewed the current literature on group-based social skills interventions (GSSIs) for adolescents (10–20 years) with higher-functioning ASD. They found that group social skills teaching usually targets a specific subset of social skills, including: nonverbal communication (e.g. eye contact, facial expression, posture and gestures); verbal communication (e.g. tone of voice, humour and jokes, and nonliteral language such as metaphors, sarcasm and figures of speech); social interaction (e.g. friendship, or joining, maintaining or leaving a social interaction, or conversation, empathy); and/or social problem-solving (e.g. conflict in relationships, bullying and teasing, controlling negative emotions and good sportsmanship). These skills all appear to relate to differences in social interaction and communication recognised in the triad of impairments and link to ToM. It is reported that social skills were often taught through a didactic lesson and then modelled by a therapist or teacher. The participants would practise the skills and receive feedback. In other words, this teaching follows a medical deficit model; teaching is apparently informed by what neurotypical people may see as 'weak' in the autistic person. There is neither emphasis on change in the communication partner, nor exploration of what the autistic people already know or may find useful to know about social situations. Also, the social skills teaching largely took place in a contrived classroom teaching session rather than a real-world situation, so perhaps it is unsurprising that generalisation from such approaches is difficult to demonstrate.

Although parents and children in the studies consistently reported high personal satisfaction with GSSIs, McMahon et al. (2013) argue that this may not necessarily reflect improved social skills so much as the degree to which an intervention is liked by participants. In contrast, teacher-report questionnaires rarely showed significant improvements in social skills for the pupils involved, possibly because social skill improvements did not generalise to the classroom. However, clinicians or staff

conducting assessments of social skills frequently reported significant improvements in social skills. These mixed results highlight the difficulties in accurately measuring progress. Importantly, there is no reference in this study to the progress being measured in relation to what was important to an individual person to learn, which would make a difference to them personally, something that is important in my study. The authors point out that it is important to consider gains in both social knowledge (i.e. knowing a social skill cognitively) and social performance (i.e. applying that social skill appropriately) and this may be a gap in social skill teaching. Differences in knowledge and performance may link to the differences in metacognition described in Chapter 2, again showing the need to link the theories associated with autism when planning interventions. In my own experience, the difference between knowledge and performance is key. I have met people with autism who are able to clearly say what a person should and should not do in a social situation to keep safe, yet this knowledge does not impact on their own behaviour. For example, one autistic woman I know talks fluently about the risks of meeting men online and in person, and about how to keep herself safe. She has learned this through 'social skills teaching'. However, she often fails to use this knowledge when meeting men and has found herself in some very unsafe situations. Worryingly, because she can tell the social worker about the risks of meeting men, she is deemed to have capacity to make unwise decisions. The social worker does apparently not consider or explore her use of her knowledge in relation to herself. In other words, the cognitive differences relating to self-referential processing in autism are not considered.

Reichow and Volkmar (2010) also conducted a review of social skills interventions for individuals with autism. They concluded that the findings of social skills groups had inconsistent results and/or reported poor maintenance of skills, meaning that the effects of social skills groups in isolation remain largely unknown and the feasibility and social validity of social skills groups delivered in school settings need to be considered. These findings support those of Williams-White et al. (2007), who conducted a review of research into social skills interventions for children with ASD and concluded that relatively little is known about the effectiveness of psychosocial intervention approaches and specific treatment strategies. These studies with young people suggest

a possible gap in teaching and learning about social situations useful to the young people in the real world and as they grow up. This gap is possibly reflected in my own experience of autistic people known to me, who still report social difficulties despite reporting having 'done social skills' at school.

Some studies report a focus on development of social competence (Stichter et al. 2010) or social emotional understanding (Bauminger 2002); that is, the ability to use learned social skills correctly in response to the social setting rather than social skills alone; and these studies report learning in the young autistic people involved. However, the long-term effectiveness of these approaches is not reported and the researchers indicate that further research is needed, with larger samples and in naturalistic settings (Stichter et al. 2010), to gain a greater understanding of the contribution of different interventions to development of social emotional understanding (Bauminger 2002).

While it is clear that some positive outcomes of teaching social abilities are reported, Bottema-Beutel et al. (2018) suggest that social skills training curricula do not reflect what autistic people really need to know about social interaction. They argue that such curricula teach only the 'top-down norms' (p.964) of social interaction – that is, the frames of reference that allow interaction partners to attach social meaning to their interaction partner's utterances – and fail to include the nuances of social context and process. In other words, Bottema-Beutel et al. (2018) argue that there is insufficient attention given to the context in which the language and behaviour take place, or to how the behaviour may change within the duration of an interaction and how the communication partner can shape the interaction. It is proposed that, while it may be appropriate to teach some culturally expected rules ('top-down' norms), the bottom-up processes (the context) of social interaction should also be included.

Bottema-Beutel et al. (2018) propose a shift in social skills interventions to include an interactional domain, so that interaction is seen within the social context rather than just as an exchange of words and there can be a greater understanding of how social interactions are negotiated. This shift of focus is reflected in my own study, as my own view, shaped by my own experience and my previous research (Silver 2010; Silver & Parsons 2015), is that communication must be seen as an interaction between at least

two people and within a changing context in order for intention and meaning to be best shared and understood.

From the position of an autistic researcher, Milton (2014, p. 798) takes a similar view to that of Bottema-Beutel et al. (2018), indicating that confusion is caused as autistic people are taught social rules 'as if the rules are more fixed and static than they actually are in lived reality'. He argues that much social skills training relies on breaking down social skills into strings of information that must be learned, and that this does not help autistic people to adjust to the changing flux of negotiated socially constructed realities. Milton (2014) therefore suggests that social skills learned as isolated rules may be of little help to autistic people in real-world contexts. Further, this learning can become a cognitive demand on an autistic person, which can make a social situation even more difficult and could contribute to the raised levels of social anxiety reported above. Hull et al. (2017) agree with this, arguing that social skills teaching to people with ASC implies that there is a need to memorise and apply rules about the correct way to interact with others, and that this takes significant cognitive effort and could be counterproductive in developing social competence.

In my experience, it has been more useful for autistic people to learn and use their own strategies in social situations rather than learn other people's rules. Beginning with the autistic perspective, and what is useful to the autistic person, will be a focus of my research. Further, social skills are often taught in specific groups planned to facilitate social skills learning, and there is a call for the use of naturalistic (not contrived) settings to enable people with autism to learn about social information (Chevallier et al. 2013) and for a focus more on generalisation and maintenance of social skills and support from peers (Flynn & Healy 2012). Developing the concept of the importance of natural settings, Bishop-Fitzpatrick et al. (2014) propose that there must now be testing of success of intervention within the community and on more functional, practical learning. Indeed, Flood et al. (2011) recommend a focus on the processes involved in the interpretation of cues and behaviours and on enabling young people to develop strategies to respond to these, including an ability to withdraw from the situation. Flood et al. (2011) suggest that something beyond teaching ToM skills is required, that is teaching should be informed by a greater integrated understanding of what is needed.

These comments align with my own view that learning about social situations by autistic children should be owned by the young people and be useful in changing real-world situations as they grow up. This could enable autistic people to know how to reduce the risk of a sense of failure or anxiety in social situations.

Overall, while the literature reports on social skills teaching and teaching of social competence, it seems that there is little agreement on the long-term effectiveness of these approaches or on the best approaches to use. My own clinical experience supports this, since I regularly see adults who have attended specialist schools for people with autism and report having learned social skills at school yet who continue to experience anxiety and perceived failure in real-life social situations. This suggests that the ways in which social skills teaching may have been approached in those specialist schools did not always adequately equip these individuals to deal with real-life situations.

Self-prompt strategies have also been used to support social skills. For example, Bock (2007) taught such strategies to autistic students, including 'self-talk questions such as 'Where should I go to observe?, What is… doing?, What would I like to do?', then planning action. However, although Bock (2007) suggests that this teaching facilitates social problem-solving, it does not appear personalised to each autistic individual's perspective, needs or preferences. Similarly, Boutot (2009) developed the use of 'I will' cards for students, where reminders about what to do in potentially difficult situations are learned through rehearsal. For example, 'When people look at me funny, I will look away.' (p. 278). However, although success is reported, the use of the cards depends on memorising and remembering to use the 'I will' statement in the right situation and on planning 'I will' statements for various situations. This means that there may be limited opportunity for generalisation between situations or for these strategies to be used flexibly.

It appears that although the differences in the autistic brain are increasingly recognised and the impact of this on their perception of the world and the processing of it understood, but much of the teaching continues to target the perceived weakness in social competency from the neurotypical perspective relating to a list of skills to be

48

learned rather than seeking to understand and use the cognitive strengths and abilities of the autistic people, which is increasingly being recognised in research.

For me, this means that there is a compelling need to investigate strategies that may be more helpful in supporting social thinking and communication for adults with ASC using their own perspectives, and this is the focus of my research. Working in the context of the social model of disability, I am specifically interested in exploring what communication partners need to know to facilitate learning and communication with autistic people, as the detail of their role and approaches is rarely included in the reporting on social skills studies. There are some specific approaches to training of communication partners, which are often viewed separately to social skills training, and these are reviewed next.

3.1b Communication partner training

Communication partner training should be important, as communication is a two-way process, meaning social cognition involves understanding others, and understanding *with* others (De Jaegher et al. 2010); and it may hold benefits for the communication partner in reducing their own stress (Schultz et al. 2012). Therefore, it makes sense to think about training the person communicating with the autistic person, following a social model of understanding of disability (Shakespeare 2016), rather than the focus being on teaching to address the perceived social and cognitive weaknesses of the autistic person, following the medical model of disability (Kapp et al. 2013), which has been the focus, to date.

Existing training for communication partners

In contrast to the approaches to social skills teaching with school-age children (see above), parent training has been a focus of early support to families with autistic children, and parent training programmes are widely reported in the literature (see Matson et al. 2009; Patterson et al. 2012, for reviews). In alignment with my study, there is focus on interaction in context and how the communication partner may change (e.g. Kasari et al. 2010). In the main, these reviews report some improvements in the targeted areas (e.g. in verbal utterances or imitation), but reviewers call for more robust evidence-based parent training programmes. There are reports of

communication partner training for school-age children. For example Gantman et al. (2012) report on the effectiveness of the PEERS for Young Adults Program, a caregiver-assisted, manualised social skills intervention aimed at promoting the development of close relationships and improving the social and psychosocial functioning of young adults with ASD. Young adults and caregivers attended separate concurrent sessions. Results showed that the young adults with ASD showed increased cooperative behaviour and self-control, improved receptive and expressive communication and social skills knowledge, and reported significantly less loneliness. Caregivers reported significant improvements in young adults' overall social skills, social responsiveness, empathy and frequency of get-togethers. This study shows gains in the social areas targeted during the intervention programme, as well as outcomes that may improve QoL. This finding was matched in a similar study with adolescents with ASD and their caregivers by Laugeson et al. (2012); the studies show the possible value of training of care givers alongside the autistic participants.

However, compared to the focus on early years, there is relatively little evidence in the literature regarding effective communication partner training for people working with young people and adults (Parsons et al. 2009). In a review of social skills interventions for individuals with autism, Reichow and Volkmar (2010) found that no study had examined parent training for adults with autism. In my own literature search, I found reports of training the communication partner following stroke and a move towards individualising this training (e.g. Saldert et al. 2015; Wilkinson et al. 1998), the principles of which may be relevant to people with autism and their communication partners. However, I did not find literature specifically relating to training of caregivers or supporters of adults with ASC to develop the social abilities of individuals with autism, beyond implementation of specific programmes (e.g. SCERTS (Social Communication Emotional Regulation and Transactional Support); Prizant et al. 2003), which are discussed further below.

There is now a statutory requirement for staff providing support to autistic adults to receive autism training. Following the Autism Act (2009) and the Autism Strategy (2010) followed by Think Autism (2014), local authorities must make autism awareness training available. However, although NICE autism guidelines (NICE Quality Standard on Autism,

50

2014) have been developed, there is no standardisation of autism awareness training for staff working in the adult social care sector, so the content of this training is likely to be variable and may include training 'about autism' rather than informing the learners of their role as a communication partner and how they might adapt their own communication to best support the communication of individual people with autism.

Some programmes and training guidance for people working with autistic people have been developed. For example, the Autism Education Trust Competency Framework (Wittemeyer et al. 2015) is a structure against which staff can use self-reflection to evaluate their autism practice and see where further development is needed. While this may be helpful for staff to reflect on their practices, the framework lacks information about *how* to achieve competency from the perspective of the person with ASC. Paul et al. (2009) argue that guidance should enable the communication partner to know how a person with ASC can be enabled to use existing adaptive behaviours in interaction, while Geils and Knoetze (2008) emphasise the importance of understanding how an interaction is constructed, taking into account the perspective of the person with autism. I share these views and, in my study, I would like to learn more about *how* communication partners can best support autistic people to experience success in social situations.

The role of the communication partner is included in SCERTS (Prizant et al. 2003). SCERTS focuses on the development of functional communication within natural routines, and includes social partners as part of the solution. A case study reviewing the implementation of SCERTS, with four pupils on the autism spectrum within a primary school, is described by O'Neill et al. (2010). Improvements were reported in the pupils in the areas of joint attention, symbol use and mutual and self-regulation. Members of the multidisciplinary team in the school involved in the programme also reported a development in their understanding of emotion regulation and the importance of understanding their own roles in supporting the children when they were dysregulated. There was a greater understanding of the need for a sensory curriculum, and staff were able to identify ways in which they had changed their practice. Through using reflective practice, staff reported an increased understanding of their own role and changing their own approaches, and pupils appeared calmer and more focused. O'Neill et al. (2010)

report that use of the SCERTS model also allowed a focus on individual pupils and their strengths because, with training and reflection, staff were more able to understand the reasons for a child's presentation. This result is encouraging, but the time and resources taken to implement the SCERTS programme were reported as a difficulty. Busy staff require something that they can learn and implement easily to enable them to maximise interaction and communication with young autistic people. Moreover, funding restrictions within adult social care mean that the staff have less time allocated for training and recording than school staff. Although SCERTS is a framework for intervention that is designed and developed for use in schools, the role of the communication partner, as emphasised in SCERTS, has relevance across the lifespan and is a focus for my study.

In summary, although there has been some development of communication partner training, interventions following the social model of disability appear less detailed and less well developed. This has led to a call for an understanding of autism 'not merely as a problem in need of solution, but as a way of being in the world; a way that can teach about inter-subjectivity and our relations with others' (McGuire & Michalko 2011, p. 173). Training of the communication partner is very relevant to talk therapies, which may also be used to support development of social understanding and management of social anxiety with autistic people. Some of these are discussed below.

3.1c Talk therapies

Development of social cognition in people with ASC has been the target of Cognitive Behaviour Therapy (CBT) interventions. Specifically, CBT aims to promote retrievable memories of adaptive responses that can successfully suppress learned maladaptive responses, and is adaptable to multiple contexts (Wood et al. 2011). Although it is reported that there are very few well-designed studies of CBT and other talk therapies for people with autism (Wood et al. 2011 p. 198), several studies report success in the use of CBT with young people with autism (e.g. Bauminger 2002; Storch et al. 2013;) and youths with ASD (e.g. Ung et al. 2015). Weston et al. (2016) conducted a systematic appraisal of the literature investigating the effectiveness of CBT when used with individuals of all ages who have ASD for either affective disorders or the 'symptoms associated with ASD' (p. 51). This sounds as though the intention was to address a

perceived deficit. The self-report measures reported a small non-significant effect size, and informant-report measures resulted in a small effect size. Weston et al. (2016) do point out that very few researchers have developed interventions with a spirit of co-production with people with autism and their families, and these results suggest that is possible that outcomes were neither effectively planned nor measured from the perspective of the autistic person.

Kerns et al. (2016) use their own clinical experience and the literature to suggest potential modifications to CBT approaches in line with what is known about the differences of people with autism. However, their suggested modifications seem to be informed by a neurotypical perspective rather than by listening to autistic people and understanding what would be best for them. For example, Kerns et al. (2016) acknowledge that people with ASD may have 'limited emotional insight' (p. 333), but then go on to recommend the commonly used tools of personalised fear thermometers and mood-tracking charts without reference to *how* it would be certain that these are meaningful and useful to autistic individuals. It appears that the emphasis on the adaptation of the CBT is on making approaches concrete and visual (generally accepted as helpful to people with autism) (Jordan & Powell 1995). However, drawing on my own clinical experience and the cognitive differences associated with autism discussed earlier (e.g. Frith 2012), it would also be helpful to gain greater understanding of the cognitive abilities (including thinking and processing) and the perceptions of the autistic person receiving the CBT to address difficulties such as anxiety, to ensure the most effective engagement.

Hare et al. (2015) considered differences associated with autism when exploring differences in the experience of anxiety in real time between 20 adults with AS and 20 adults without autism. The AS group reported most thoughts as visual imagery and Hare et al. (2015, p. 549) reported that in the AS group:

> most anxious feelings are not associated with anxious thoughts, suggesting that cognitive approaches may first have to help people with AS recognise and articulate thoughts that are related to anxiety.

This finding possibly supports the reported differing abilities of autistic people to use a vocabulary relating to emotion (discussed in Chapter 2), but Hare et al. (2015) further

argue that this finding means that CBT for people on the autism spectrum should be cognitively informed. To me, this confirms my view that communication partners should understand cognitive differences and abilities and avoid neurotypical judgments on what an autistic person may be saying or thinking without a full understanding of how the autistic person perceives and expresses their own thoughts and feelings.

Lickel et al. (2012) report on assessment of prerequisite skills for CBT in children with autism, and suggest that limitations in emotional awareness, concrete thinking style and difficulty reflecting on own thoughts, intentions and beliefs should be considered within CBT for people with autism. They thus acknowledge that the communication partner should take autistic differences into account, but there is no description of *how* this may be best achieved with each person.

Eack et al. (2013) describe Cognitive Enhancement Therapy (CET) as another tool used for cognitive rehabilitation and suggest it has value in remediation of information-processing deficits of people with ASD. This approach is clearly informed by the medical model, alongside the theories of WCC or EF. Large and highly significant levels of improvement across all assessed cognitive and behavioural domains were reported at the end of the programme, and the authors claim that the findings provide evidence of the feasibility, acceptability and initial efficacy of long-term cognitive rehabilitation with CET for verbal adults with ASD. However, it is not clear whether what was learned was of value outside of the training situation and whether outcomes were measured in relation to knowledge (i.e. knowing what was taught) or to performance (using what was learned) in relation to skills and knowledge gained. Nevertheless, this is another example of the ability of adults with autism to develop and use cognitive skills, which could be of value to them in social situations.

Solution-focused brief therapy is another talk therapy used with people with autism, described by Bliss and Edmonds (2008, pp. 28–29) as being:

> different from traditional talk therapies… a lot of time is spent in what
> is called 'non-problem talk' which allows a person to talk about things
> they like and are good at while the solution-focused worker listens
> closely for evidence of the person's skills abilities and strengths.

Solution-focused therapy therefore has a focus on using existing skills and resources to achieve the desired outcome. However, while the value of drawing on people's own resources is clear, it is unclear exactly *how* the autistic person's existing knowledge would be meaningfully uncovered in a personalised way; that is, how the communication partner supports thinking so that the answers given are meaningful and useful rather than tokenistic. In my own clinical experience, I have met autistic people who are able to say the right thing in order to conclude an interaction rather than give a meaningful response, which may take longer to access and think through. This lack of detail in *how* to talk to autistic people to best find what they know appears to be a weakness in the talk therapies described above, and so this is an area that I will explore in my study.

In summary, talk therapies are widely used with people with AS and, in my experience, are often seen as the preferred solution for people experiencing social anxiety, for example. However, as reported above, outcomes are inconsistent. As I plan for my study to be based around conversation, it is helpful for me to be mindful of the possible reasons for these mixed results and to take these in to account where possible during my study. Within the review above I have already raised potential weaknesses in the reports of approaches used to enable autistic people to develop social abilities; I will now review further gaps and weaknesses in the literature I have read relating to social teaching, to inform my own study.

3.2 Weaknesses and gaps in approaches/interventions to develop social abilities

3.2a Heterogeneity of autism

It is important to consider the heterogeneity of autism when planning autism studies (Rajendran & Mitchell 2007) and interventions (Howlin 2008). However, such heterogeneity is not readily apparent in much of the social skills literature, which appears to report a 'one size fits all' approach. Some autistic writers report their frustrations with people without autism, using their general knowledge of autism to inform their understanding of an autistic person rather than understanding the autistic person as an individual (e.g. Loomes 2017; Wheeler 2011). In many of the studies reported above, the writers refer to the matching of control groups to the autistic group (for example by age and IQ), but I have seen few reports of assessment of abilities in the

autistic population (for example, assessment leading to more detailed matching of cognitive or communication abilities). Matching appears to be by diagnosis (for example, 'AS' or 'high-functioning autism'). In my study, I aim to understand the heterogeneity in autism, looking for common themes in my data, but understanding individual preferences and differences among the autistic participants, avoiding assumptions associated with diagnosis or the deficit models discussed above.

3.2b Hearing the autistic perspective

My understanding of the differences associated with autism is rooted in cognitive theories and differences associated with autism reported above, meaning that I recognise that autistic people may experience the world in a different way from those without autism. I remain committed to working within a social model of understanding, so it is important that my work is grounded in an understanding of autistic perspectives in order that, following the social model, I may respond to these perspectives.

Perspective taking is 'egocentrically anchored', meaning that it begins with an assumption that the other person has the same perspective as the self (Epley et al. 2004). I have noticed in some of the studies that I have read that the approaches considered helpful to support the involvement of autistic people appear to be determined by the researcher's perspective (using an egocentrically anchored perspective) rather the autistic person's perspective. As discussed previously, the things to be learned by an autistic person in social skills teaching appear to be led by a neotypical perspective (e.g. those discussed in the review by Williams-White et al. 2007), as does the support provided (e.g. the use of a picture to support understanding of emotion where understanding is not reported as checked (Harrington et al. 2014)), and do not include description of any exploration of what may be important to the autistic people involved to learn in social situations. Nor is there report of what is most helpful from the autistic perspective, nor of uncovering the existing skills and strategies that are already used. Further, where improvements in assessed abilities may be reported following teaching in artificial situations, it is often not clear whether success is measured beyond the taught situation, nor who measures success and whether what is learned is always useful in the real world, in the long term. That is, it is unclear

whether the learning helped with what the autistic person really wanted to know or needed to know in real-world social situations, from their perspective.

The requirement for learning by autistic people to follow the expectations of people without autism is described as a 'normalisation agenda' by Milton and Moon (2012), whereby the social perceptions of people without autism are considered normal, meaning that people with autism may internalise negative connotations of difference and, further, may deny essential aspects of autistic identity (Ne'emen 2010).

In other words, autistic advocates are calling for a different way of thinking so that support for and planning with people with autism is based primarily on the perspective of the autistic person. However, there is limited research that seeks to use the perspectives, strengths, knowledge and needs of people with autism as a starting point for intervention, something that is increasingly being recognised as an important gap in the field (e.g. Pellicano et al. 2014). Indeed, Parsons et al. (2009) argue for the importance of listening to the first-hand perspectives of people on the spectrum and their families in order to inform practice, while Milton et al. (2012, p. 2650) say, 'We believe that human dignity requires us to make every effort to access the views and perspectives of autistic people'. Wheeler (2011, p. 849) argues that teachers must move away from what they think is best for autistic people and to understand what is best for the individual, saying that the only way to do this is to consult autistic people. However, as reported earlier in this literature review, although differences in communication and cognition in people with autism are well documented and the social model of understanding autism is much called for, I have found very little detail about *how* the communication partner can best listen to and understand the perspective and knowledge of the autistic person. Nor have I found studies reporting the strategies that may be owned and used by an autistic person to enable them to best contribute to conversations and to let the communication partner know what would be most helpful to them.

I also will wish to consider the research reported by Hume et al. (2009), showing that many autistic individuals can acquire and demonstrate a wide range of skills, with the support of caregivers, but are often unable to use these skills once professional support

fades and their independent use of the skills is required. It will be important in my study to consider how the autistic person is able to take ownership of their own learning relating to conversation.

As described above, the communication partner is important in everyday situations but, crucially, if we are to learn from autistic people the autistic perspective must be meaningfully heard during research (Pellicano et al. 2014). Reflecting on the involvement of young people with ASD in research interviews, Harrington et al. (2014, p. 159) suggest that researchers must take into account 'an understanding of the potential impact of autism-related impairments and the capacity to respond appropriately to these challenges', further cautioning that:

> a narrow focus on the impairments associated with the diagnosis may lead researchers to underestimate the contribution young people with ASD can make to research.

Harrington et al. (2014) suggest that researchers should take the time to get to know each participant as an individual but, again, specific detail in what the researcher could consider or change about their own communication is lacking.

In order to learn from autistic people, self-report is often requested (as discussed when considering talk therapies and reported in studies earlier). However, self-report by autistic adolescents was found to be unreliable in a study by Mazefsky et al. (2011) looking at psychiatric self-report measures; and caution in use of self-report by people with AS is advocated by Hare et al. (2015). Hare et al. (2015) argue that people with AS may find a thought difficult to access and have difficulty appraising and expressing their own cognitions in relation to thoughts or feelings, and that poor autobiographical memory may influence their ability to recall and report situations. This fits my understanding that it is important to recognise the cognitive differences and metacognition in people with autism described previously, yet those studies that I have read do not detail how these differences have been assessed or how any difference is used and supported by the communication partner. This may mean that autistic people may be misunderstood. In my own study, I will try to be aware of differences in ability to recall and talk about past events and to express emotion, and use this knowledge gained when listening to and learning from the participants.

58

In summary, it seems that there is little detail about exactly *how* people without autism can learn about the perspective and knowledge of the autistic person; further, there appears to be a gap in considering the actual communication exchange between people with and without autism, outside of discourse analysis studies (e.g. Sterponi et al. 2015). Indeed, De Jaegher et al. (2010) argue that investigating interaction is central to understanding social cognition. Bottema-Beutel et al. (2018) argue that research methods that examine social interaction as a whole are particularly suited to exploring ASC. Moreover, Heasman and Gillespie (2018) point out that misunderstandings (when one party attributes an incorrect belief to another party) are experienced by both people with ASC and their relations, and argue that there is a lack of research methods systematically to compare the perspectives of each side within social relationships. A focus on exactly what the communication partner without autism says and does, and the impact of this on the communication exchange and the autistic person, is central to my study.

3.2c Artificial situations

Many of the studies and interventions reported above take place in artificial or contrived situations, lacking the additional contextual information that would usually be available in everyday encounters and situations. My previous study found that useful contextual information may include what has happened before the reported event, and knowledge about where the event is taking place and with whom (Silver 2010; Silver & Parsons 2015). Similarly, Uljarevic and Hamilton (2013) suggest that future research with autistic people should consider emotion in context. This reflects a move away from considering the theories of autism in isolation to inform intervention, and towards a call for a real-world view of the abilities of the person with autism in social contexts. In my own study, I will be interested to learn about contextual cues that are most useful to autistic individuals so that learning can take place in everyday situations.

3.2d Research with adults

During my literature search, I tried to exclude studies and reports that focused on very young children, aiming to include more studies relating to adults and to adolescents, but this was difficult. I found more studies relating to children than to older persons. Parsons et al. (2009, p. 108) suggest that 'there is a dearth of research on the adult

sector' and Edwards et al. (2012) confirm this in a review of the literature relating to interventions with people with autism. Edwards et al. (2012) found that only 1.7 per cent of the 295 reported participants in 146 studies were aged over 20, concluding that 'older people with autism are largely overlooked by intervention researchers' (p. 998). Pellicano et al. (2014) reported that participants in their online survey expressed frustration that most research focuses on children.

Although there is a significant gap in the number of studies focusing on adults, the autistic adult population is increasing (Bishop-Fitzpatrick et al. 2014; Edwards et al. 2012), and there is demand for a greater understanding of their needs and how these can be supported. Within my own work, I see the differing needs and vulnerabilities of autistic adults and so, during my study, I will focus on learning what may make a difference to autistic adults in conversations in real-world contexts.

3.2e Use of strengths

Much of the literature that I have found and reviewed so far continues to focus largely on remediation of the so-called deficit of autism, discussed earlier, rather than uncovering and using individuals' strengths. My view on intervention is in line with Milton (2014, p. 798) who proposes that people working with autistic people 'must appreciate the distinctive knowledge possessed by autistic people and build more constructive ways of relating to it'. I would like to know more about *how* communication partners can hear and understand the distinctive knowledge of autistic people, considering cognitive differences reported above.

The deficit-focused models previously used to inform education and intervention are now seen as problematic (Pellicano & Stears 2011). Parsons et al. (2009, p. 106) 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'. Stichter et al. (2010) also recognise that people with ASC have strong cognitive abilities alongside complex deficits and that there is a need to utilise strengths. It is increasingly recognised that autistic cognition is characterised by atypicalities yet also identifiable strengths (Pellicano & Stears 2011, p. 275). Support for learning should therefore begin with recognition of strengths.

Strengths may include the ability to use structure and cues, since rules and strategies are valuable in supporting social understanding of people with autism (Howlin 2008) and adults with AS refer to the need for rules and structure in order to function effectively (Hare et al. 2015). For example, structure in conversation has been shown to be useful to adolescents and young adults with ASC (Ponnet et al. 2008) and children with high-functioning autism were able to detect and interpret socially relevant cues when explicitly instructed to do so, that is, when the explicit instruction prompted or structured their thinking (Kuzmanovic et al. 2011). People with AS are able to engage in internal dialogue, which will be important in the use of any self-prompt strategy, and this may be used to structure thinking (Silver & Parsons 2015).

The tendency for research in the autism field to focus on deficits and what people with autism cannot do has often masked areas of social ability. Knowledge of traits and stereotypes is an emerging and important area of social ability in people with autism, as studies are now evidencing that at various ages they can demonstrate knowledge of other people. In an experimental study, White et al. (2006) asked adults with AS to judge pictures of people and stimuli in terms of certain social stereotypes and found they could make appropriate attributions of stereotypes, suggesting that this is an intact subcomponent of social cognition in the participants with AS. Similarly, Ramachandran et al. (2009) explored the ability of adults with AS to infer traits from descriptions of behaviour by asking participants to read sentences implying a behaviour trait and then to choose one of two words that best related to the trait described. For example, 'He ate all the scones without leaving any for his younger brother' (p.872) was used to describe 'greedy'. Results showed that, although participants with autism were slower than typically developing participants in making responses, there was evidence of spontaneous trait inference, suggesting that there was no absence of skill in this area. Ramachandran et al. (2009) concluded that trait inference in ASD 'may be a spared socio-cognitive function at least at the level relating to behaviour' (p. 877). This is an important strength that can be learned by people with AS that may be useful in reducing their vulnerability in conversation and social situations, as I found in my previous study (Silver & Parsons 2015). However, trait knowledge is not yet an area

much talked about in the autism training I have seen, nor explicitly in the social skills training I am familiar with.

Uncovering a further strength, Hamilton (2009) conducted a review of research and found evidence from a number of studies that children with ASD can infer the simple goals and intentions of other people, but that more research is needed to better understand this and to develop this potential strength. It would be useful to know more about the contexts in which the children were successful in order to understand the triggers to thinking and use of abilities and how understanding intention may be used in social situations. Further, Hirschfeld et al. (2007) used line drawings representing race and gender with eight-year-old autistic children and asked questions such as 'Who has four dolls?' They found that the autistic children who failed ToM tasks were able to know and use gender and race stereotypes, for example indicating that the female character, not the male, had the four dolls. It is argued that in autistic children there may be islets of social ability that are yet to be explored, and this finding may link with trait knowledge demonstrated by people on the autism spectrum.

Generally, these studies suggest the importance of a focus on uncovering the useful strengths and skills that autistic people do have and learning how these may be best used. Thus, not only is there a need to explore potential strengths further through systematic research, there is a need to translate what is learned by research into practice. This is another key objective for my own study.

3.3 My study

The discussion above shows how cognitive theory, particularly that of ToM, has been used to inform approaches to social intervention with autistic people. Such approaches operate within a medical model of teaching, often led by the perspective of the person without autism, in a contrived context such as a specific group or teaching session. Although much is reportedly now known about autism and interventions and teaching are used with the aim of developing social and conversation abilities, autistic people who may have received this teaching continue to report difficulties in social situations, particularly social anxiety in the real world.

More recently there has been a developing understanding of the cognitive models of autism. Some strengths of autistic people in mindreading (Ramachandran et al. 2009) and ability in processing (Spek et al. 2011) have been recognised and there has been acknowledgement of the potential importance of knowledge of 'own' mind (Lombardo & Baron-Cohen 2011) and metacognitive abilities (Sawyer et al. 2014). However I have not found this emerging knowledge reflected in reported social skills teaching to autistic people, to date.

Further, I have found little in the literature about *how* the strengths and cognitive abilities of autistic people can be meaningfully recognised and understood, in order to become the starting point for personalised strategies to support conversation abilities; and how teaching and learning relating to conversation can be informed by the autistic perspective.

There is now a call for the use of a social model of disability to understand autistic people (Wheeler 2011) for them to have more meaningful involvement in research (e.g. Gillespie-Lynch et al. 2017) and in consultation (Scott-Barrett et al. 2018); and there is now a statutory obligation for people working with autistic people to have autism awareness training (NICE 2014). However, relating to these calls, I have found little detail in the literature about the potential impact of the communication partner on the communication exchange with an autistic person or *how* a communication partner can best develop 'interactional expertise' (Milton 2014 p.795). Without this detail, the calls for greater involvement of autistic people may not result in the required and valued meaningful involvement.

It has been argued that teaching of social abilities to people with autism would be most valuable in interactive situations (De Jaegher et al. 2010) and in natural contexts (Bottema-Beutel et al. 2018). However, thinking of the real-world commitments of teaching and social care staff and families, I have not found practical everyday approaches describing how this may best be done. Therefore, my study will explore how communication partners without autism can best enable autistic people to contribute their thoughts and knowledge during important conversations, while avoiding any 'normalising agenda' (Milton & Moon 2012), whereby the 'outsider'

perspective (that is, neurotypical understanding and approaches) is used with autistic people. In planning the research, I was clear that I intended the learning from it to be of value to people with and without autism in everyday conversations and interactions. That is, I intended to focus on both sides of the interaction, both what the autistic person can do to feel more in control of the conversation and also how the non-autistic communication partner can modify their own communication to support best engagement of the autistic person. I wanted to focus on what both communication partners can *do* to help the interaction, rather than *what does the person with autism look like in this interaction*? The ultimate aim was to make a difference to families and autistic people through gaining effective 'interactional expertise' (Milton 2014 p.795).

Translating these aspirations into specific research questions, my research, therefore, sought to address the following three research questions:

- RQ1: How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?
- RQ2: What is useful for autistic adults to know about conversation?
- RQ3: In what ways can learning and knowledge about conversation be used in everyday conversation by autistic adults and their communication partners?

Chapter 4 **Methodology**

4.1 Introduction and overview

In my own clinical experience, I have seen autistic people involved in conversations that have not gone well, from their perspective, so I wanted to learn more about the communication exchange between autistic and non-autistic people. I therefore needed to look at communication as a two-way process (Ferguson 2001; Sterponi et al. 2015). The study involved twelve participants in dyads in two phases for four to 12 months.

In Phase 1 of the study, I explored the conversational exchange within dyads of communication partners who knew each other; one person had a diagnosis of ASC and the other person did not. I focused on the impact of what was said by the person without ASC on the contribution to the conversation by the person with ASC. I aimed to explore what might be said and done by both partners in the conversation in order to best enable the person with ASC to contribute both their thoughts and their own knowledge to the conversation. In Phase 2, I explored how the learning during Phase 1 by the partners with and without autism could be used in a conversational exchange to maximise the contribution of thoughts and knowledge of the autistic participant.

My methodology was informed by my philosophical position and by my knowledge of existing theory relating to autism and my personal theory. I describe these below, before describing the research design and procedure.

4.2 My philosophical position

My philosophical position is heavily informed by my professional experiences and how these relate to the big ideas on research philosophy discussed in the literature. I reject an objectivist ontology whereby 'there exists a reality out there driven by immutable natural laws' (Guba 1990, p. 20), which leads to an objectivist epistemology where 'the inquirer stands back, observing nature as she does her thing' (Guba 1990) as I do not share this view of reality. Instead, I understand that human beings construct meanings, and that such meanings do not exist independently of those human beings (Bryman 2008) and that social phenomena are produced through social interaction and are in a constant state of change (Scales 2013).

As a practitioner-researcher, I hold elements of a relativist ontological position, described by Guba (1990, p. 27) as perceiving that 'realities exist in the form of multiple mental constructions, socially and experimentally based, local and specific dependent for their form and content on the persons who hold them'. However my position may also be described as 'constructivist', since 'constructivists are relativists' (Guba 1990, p. 18). Charmaz (2014, p. 13) uses the term 'constructivist' to acknowledge researchers' involvement in the construction and interpretation of the data, meaning that research acts are not given but constructed. I aim to involve myself in the research, which means that, following Charmaz (2014, p. 13), I must be highly aware of my own actions and decisions through reflexivity at all stages of the study, as discussed in Chapter 1.

I understand epistemology as the 'relationship between the inquirer and the known' (Denzin & Lincoln 2011, p. 12). My involvement is another feature of the research that is important to me, as a practitioner-researcher, valuing the social context, the sharing of viewpoints of individuals and their experiences and developing understanding through being reflexive in the interpretation of what I hear and see. My subjective epistemological position may thus best described as constructivist.

I am working within an interpretivist paradigm (also referred to as constructivist: e.g. Lincoln et al. 2011; Mack 2010; Ormston et al. 2014; Robson 2002, p. 27), where I seek to 'gain understanding by interpreting the perceptions of those involved' (Lincoln et al. 2011, p. 102); in short, I seek to: 'understand reality through the interactions with, and perceptions of, others' (Scotland 2012, p. 14). However, a recognised limitation of the interpretivist paradigm is that it abandons the scientific procedures of verification and objectivity, such that the results cannot be generalised to other situations (Mack 2010, p. 8). However, my goal in my study is to seek theories that may be further explored in practice rather than to create generalisable research. I also aim to develop credibility through reflexivity and trustworthiness via a robust approach to data analysis (see Trustworthiness, below).

In planning the research, I took a pragmatic approach; I considered how to connect research questions to the data (Punch 2014) and began with consideration of the research questions that required answers, based on my professional curiosity as well as

the gaps identified in the literature in Chapter 3. I allowed the research questions to determine the method in the context of my philosophical position (Thomas 2015). My focus was choosing the right tools for the research task (Ormston et al. 2014), in contrast to a paradigm-driven approach whereby particular types of research questions and methods tend to arise from an articulated paradigm (Punch 2014).

My philosophical position led me to describe myself as a qualitative researcher, since qualitative researchers draw on their own experiences as a resource, think reflectively and seek strategies of enquiry that allow them to make connections with lived experiences in the here and now (Denzin & Lincoln 2011). This position influenced my methodology, described below.

4.3 Methodology

Methodology concerns 'what methods can be used for studying the reality?' (Punch 2014, p. 15), where the reality is informed by the ontological and epistemological assumptions of the inquirer and how one will go about studying any phenomenon (Silverman 2005). A qualitative approach uses methods that attempt to provide a holistic understanding of research participants' views and actions (Ormston et al. 2014), again matching my own intention to learn from the experiences and perspectives of those involved in my research. In planning my methodology, I was mindful of theory relevant to the phenomenon to be studied, that is, to the communication exchange between people with and without autism.

Theory can mean different things to different people (Robson 2002), but usually refers to a set of concepts to describe and explain some phenomenon (Silverman 2005) and is concerned with the development of systematic construction of knowledge of the social world (Cohen et al. 2007). I considered the cognitive theories relating to autism and the current developing understanding of these described in Chapter 2, and also my 'personal theory' (Robson 2002 p. 62), which is informed by my clinical practice and reading. My personal theory suggests that autistic people have abilities that are not always recognised by people without autism (as the abilities may differ from neurotypical expectations); autistic people may have knowledge relevant to a significant conversation (e.g. a planning or problem-solving conversation), but may not always be

able to access and contribute this knowledge during the conversation; and that both autistic adults and adults without a diagnosis of autism can learn and change. My personal theory is informed by the social model of understanding of disability. My methodology was chosen to enable me to explore these theories further.

Knowing that my research needed to be qualitative, I considered case study, action research and grounded theory as potential strategies. Action research starts from a specific problem or question; its purpose is to seek a solution, and its design is usually cyclical in nature and seeks a solution to a practical problem (Punch 2014, p. 136). By contrast, my research questions were exploratory: I wanted to know more about the 'how', rather than the 'what'. Consequently, an action research approach did not seem to fit my needs.

Grounded theory seeks to generate theory from data to explain a phenomenon (Punch 2014), meaning that theory will be grounded in the data. As theory is not predetermined, there is less emphasis on use of a literature review to generate issues for the research, and it is suggested that pre-reading may prematurely close-off or determine what is seen in the data (Cohen et al. 2002, p. 494). While I wanted to approach the study with an open mind, I also wanted to use knowledge of the literature and existing theory in the area of study so that I understood where the gaps might be, thus my study could be a valuable contribution to research knowledge (as well as professional practice). I wanted to explore successful and unsuccessful conversations between participants in depth and from different angles or perspectives, and gain insight and understanding (Thomas 2015). Therefore, I needed knowledge of the literature and autism before I began the work to inform my questions and approaches, so grounded theory as described by Cohen et al. (2002) did not meet my needs. However, the term 'constructivist grounded theory' is used by Charmaz (2014) to include a researcher's involvement and subjectivity, arguing that 'we are part of the world we study the data we collect and the analysis we produce….. we construct our grounded theories through past and present involvements and interactions with people, perspectives and research practices'(p. 16). Charmaz (2014) argues that this understanding of grounded theory is in contrast to Glaser and Strauss (1967, cited in Charmaz 2014), who described grounded theory methods leading to theory emerging

from the data, separate from the scientific observer. My own thinking appears to fit with this broader description of grounded theory and with some of the strategies used by grounded theorists described by Charmaz (2014). For example, in common with grounded theorists, I conducted data collection and analysis simultaneously on an iterative basis, I drew on narratives and descriptions within the data and I developed inductive abstract analytical categories through systematic data analysis. However, in contrast to the description of constructivist grounded theory given by Charmaz (2014), I did not wish to engage in theoretical sampling, as my work was informed by reading and theory. I wished to use both deductive and inductive codes for analysis, and not all my analytical codes would be actions and processes rather than themes. My study was therefore influenced by the perspective of grounded theorists, including grounded theory approaches using a constructivist lens, as described by Charmaz (2014), but I did not focus on theory generation from the start, as expected by grounded theorists.

I wanted to bring my own thinking to explore one thing; that is, the communication exchange between autistic and non-autistic participants, and understanding and interpreting what I found. Specifically, I wanted to explore what is useful to autistic people in conversation to enable them to best contribute to it and 'how' what people with autism already know can best be accessed and contributed to conversation. Case study has frequently been considered the major strategy in the advancement of knowledge about human beings (Valsiner 1986), and using one's own experiences and knowledge, staying 'real', is an important aspect of case study (Thomas 2015, p. 6), which as a research strategy aims to develop detailed intensive knowledge about a single case or of a small number of related cases (Robson 2002). It is about the particular, not the general, offering a rich picture with many kinds of insights coming from various angles (Thomas 2015). It is used where detail, richness, completeness and within-case variance is required and depth of knowledge is achieved (Flyvbjerg 2011, p. 314). Case study is described by Thomas (2015, p. 21) as 'like a torch beam of light, where the study focuses within the beam, thinking, "what happened here? Why did that happen?", Where there is an emphasis on singleness'. This seemed to fit my need for an in-depth focus on a small defined area of study. I adopted the definition of case study by Baxter and Jack (2008, p. 544):

> An approach to research that facilitates exploration of a phenomenon within its context using a variety of data sources. This ensures that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood.

It is not possible to generalise from case study (Thomas 2015; Yin 2003), but I was clear that my intention was to explore and get closer to the 'why' and the 'how' of what was happening in the communication exchange so that findings could be further explored in other situations. Case studies enabling detailed exploration of a case are useful for responding to 'how?' research questions (Yin 2003), taking into consideration how a phenomenon is influenced by the context in which it is situated (Baxter & Jack 2008). This description fits my needs. My focus on exploration rather than generalisation also fits my understanding of autism as a highly heterogeneous condition (Rajendran & Mitchell 2007), meaning that autistic people are different and use different strengths and abilities.

Case studies have been used successfully with people with ASC in exploring social situations (e.g. Carrington & Graham 2001; Ozedimir 2008) and are recommended by Rajendran and Mitchell (2007) and Howlin (2008) for investigating the social difficulties associated with ASC. Importantly, case study also enabled non-autistic participants with different experiences to contribute in a full and detailed way to the study, as their voice was important in enabling me to understand the conversation exchange and the useful learning about conversation taking place. I am seeking knowledge about people within specific contexts and from their own perspectives, and so the detail required for these explorations aligns with the broad aspirations of case study. I was clear that I required depth, not breadth, of knowledge to answer my research questions and decided that case study, as a research design frame, matched what I needed to answer in my research questions and my epistemological position.

Having chosen case study as the methodology, I considered the type of case study and case study design best suited to my needs. Yin (2003) places emphasis on planning a structured design of the case study at the start, suggesting that the study is informed by literature and theoretical assumptions and that each stage should be checked for construct validity, internal validity, external validity, and reliability to ensure rigour. By

contrast, Stake (1995) suggests a more flexible approach to case study design, arguing that the design will emerge and develop as areas being studied become clarified. My constructivist epistemology matches that of Stake (1995) rather than the more positivist epistemology of Yin (2003); I needed some flexibility within my design to respond to any changing needs or preferences of the participants (within the boundary of my study). However, in common with Yazan (2015), I felt that the lack of clarity in the style of design advocated by Stake (1995) could lead to uncertainty, for me. I therefore planned each stage of my design carefully, as suggested by Yin (2003), but acknowledged that my philosophical position meant that I wanted to very much learn from the people involved in the study, so some flexibility might be needed within the study, as suggested by Stake (1995), in order to maximise the participation and learning of the people involved.

Further, Yin (2003) and Stake (1995) use different terms to describe case studies. Yin uses the terms explanatory, exploratory and descriptive, and differentiates between single, holistic case studies and multiple-case studies, while Stake (1995) uses the terms intrinsic, instrumental and collective. I felt that my case study was best described as partly exploratory, whereby there is no clear single set of outcomes (Yin 2003), but also descriptive, as my study would describe a phenomenon in a real-life context (Yin 2003). However, my case study could also be described as 'intrinsic' (Stake 1995), meaning that the intention is to better understand the case because it is of intrinsic interest to the researcher. It was important to me that the type of case study matched my philosophical position, enabled me to learn what I needed to know and that I could demonstrate rigour and trustworthiness within this, rather than be tied to any specific case study category or definition described above.

I then needed to consider the number of cases to be included. A single case study focuses on just one person or case, while a set of individual case studies focuses on a small number of individuals with some features in common (Robson 2002, p. 181), but it is recognised that a large number of instances may not provide the insights that can be gained from a detailed case study approach (Denscombe 2003). According to Yin (2003), a single case study may be used when it represents a critical case in testing a well-formulated theory; when the case is an extreme or unique case, and so is worth

documenting or analysing; or when the case is representative or typical and the objective is to capture a commonplace situation; or when the case is revelatory (previously inaccessible), or longitudinal, looking at change over points in time. Although 'the force of example' of a single case can be important, informative and lead to further investigation (Flyvbjerg 2011, p. 305), and this could be a useful starting point for me, it was important for me to gain an in-depth understanding of unique individual cases and explore differences between them. This enabled me to gain a greater in-depth understanding of the communication exchange, not least since autism is such a heterogeneous condition (Rajendran & Mitchell 2007).

In choosing the number of cases for the study, I considered that Yin (2003, p. 52) suggests that having two cases may reduce potential criticisms of uniqueness, and the simplest multiple-case designs involve two or more cases. A multiple-case study (Yin 2003) or collective case study (Stake 1995) enables the researcher to explore differences within and between cases and to use a replication strategy (Robson 2002), comparable to multiple experiments, whereby a finding in a single experiment is then tested in further experiments (Yin 2003). Within the multiple-case study, I was able to uncover a significant finding in one case and then explore this in another case, enabling me to learn more about what may be useful (and not useful) to autistic participants.

Yin (2003) points out that cases should be carefully chosen so that the researcher can predict similar or contrasting results across cases. I sought participants using purposive sampling, where researchers 'handpick the cases to be included… on the basis of their judgment… of the particular characteristics being sought' (Cohen et al. 2007, pp. 114–115). I wished to include autistic adults who would be interested in the study, who had similar conversation abilities and experiences and who would be happy to be involved alongside their preferred communication partners. Considering my available time and the fact that each 'case' involved analysis of data from two participants, I chose to involve five cases in Phase 1 and three cases in Phase 2.

Having chosen the methodology, I considered the approach and methods to be used. In order to gain the participants' perspectives, I considered a participatory approach as described by Cargo and Mercer (2008, p. 326) as:

72

An umbrella term for a school of approaches that share a core philosophy of inclusivity and of recognising the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users, and stakeholders of the research.

This description appeared to fit my plan, as I value highly the contribution of the participants (my collaborators; Nicolaidis et al. 2011). I avoided viewing participants as 'subjects', whereby research is conducted 'on' people (Chappell 2000; Knox et al. 2000; Milton et al. 2012), and ensured that each participant's diverse experiences and skills were seen as critical to the outcome of the work (Brydon-Miller et al. 2011).

However, while participatory research was first understood as users being involved in the research to some extent, more recently it has come to be defined by some as user-controlled research (Ormston et al. 2014). In my study, participants were included not merely as sources of empirical material but as active participants in the production of knowledge on autism, as described by Milton and Bracher (2013). Participants, therefore, joined in the co-creation of knowledge about themselves, referred to as 'collaborative participatory research' by Nicolaidis et al. (2011), and the methodology was directly informed by the perspectives of people with ASC (Jones 2006). However, the research questions were written by me, and I used existing theory and knowledge in planning the study and I designed the study, so my methodology could be described as grounded in the principles of participatory research but not wholly user-led or user-controlled. Nevertheless, I aimed to give the participants as much power as possible in the research, avoiding taking an authoritative stance, as the researcher, by being very aware of reflexivity (described in the introduction). I aimed to be explicit about the level of involvement of people with ASC and on the evaluation of the partnership, allowing partners to provide the necessary expertise to aid the development and implementation of the overarching academic agenda (Jivraj et al. 2014).

4.4 Research design

My research questions ask about conversation, so the research was real-world based; that is, participants were involved in conversation in 'real-life' situations (Robson 2002, p. 3). I define these as situations where conversation already naturally and regularly occurs, rather than in a laboratory or an artificially contrived situation. Naturalistic

methods using everyday situations would enable me to focus on the voice of each participant and to explore the conversational exchanges between participants – the back and forth verbal exchange (Nadig et al. 2010). Further, using the real-world context is important to help autistic people to adjust to the changing flux of negotiated socially constructed realities (Milton & Moon 2012). Thus, in my study, exploring what was happening within natural conversations enabled me to understand how the natural environment (including the people in it) was helpful or unhelpful to each communication partner (Ferguson 2001).

My research questions could be described as loose and unfolding, rather than tight, focused and specified (Miles et al. 2014), and I learned during the study which aspects of the original loose questions were to be most important to the participants. Therefore, my study could be described as a flexible design (Robson 2002).

My area of study was thus small but detailed. I wanted to explore the detail of the communication exchange between communication partners in order to gain understanding from the autistic perspective, of what autistic participants and their communication partners can say and do, so that autistic participants may best contribute their existing knowledge and thoughts to the conversation. This means that 'the case' (the subject of study) (Thomas 2015) was the communication exchange between participant dyads with and without autism. The focus was on understanding the autistic perspective of what both participants within the dyad (with and without autism) could think, say or do to maximise the contribution of thoughts and knowledge of the autistic participant. The case becomes a case of something when the 'analytical frame' (the way that the case is viewed) (Thomas 2015, p. 15) is clear. My analytical frame was the analysis of how the conversational turns of the non-autistic participant impacted on the contribution to the conversation of the autistic participant's own knowledge. Also, the analysis concerned what the autistic participant already knew that was useful to them in the conversation, and how they could use this knowledge in order to feel more able to contribute own knowledge and thoughts (see Figure 4.1 below).

The case subject is the conversation exchange between participants
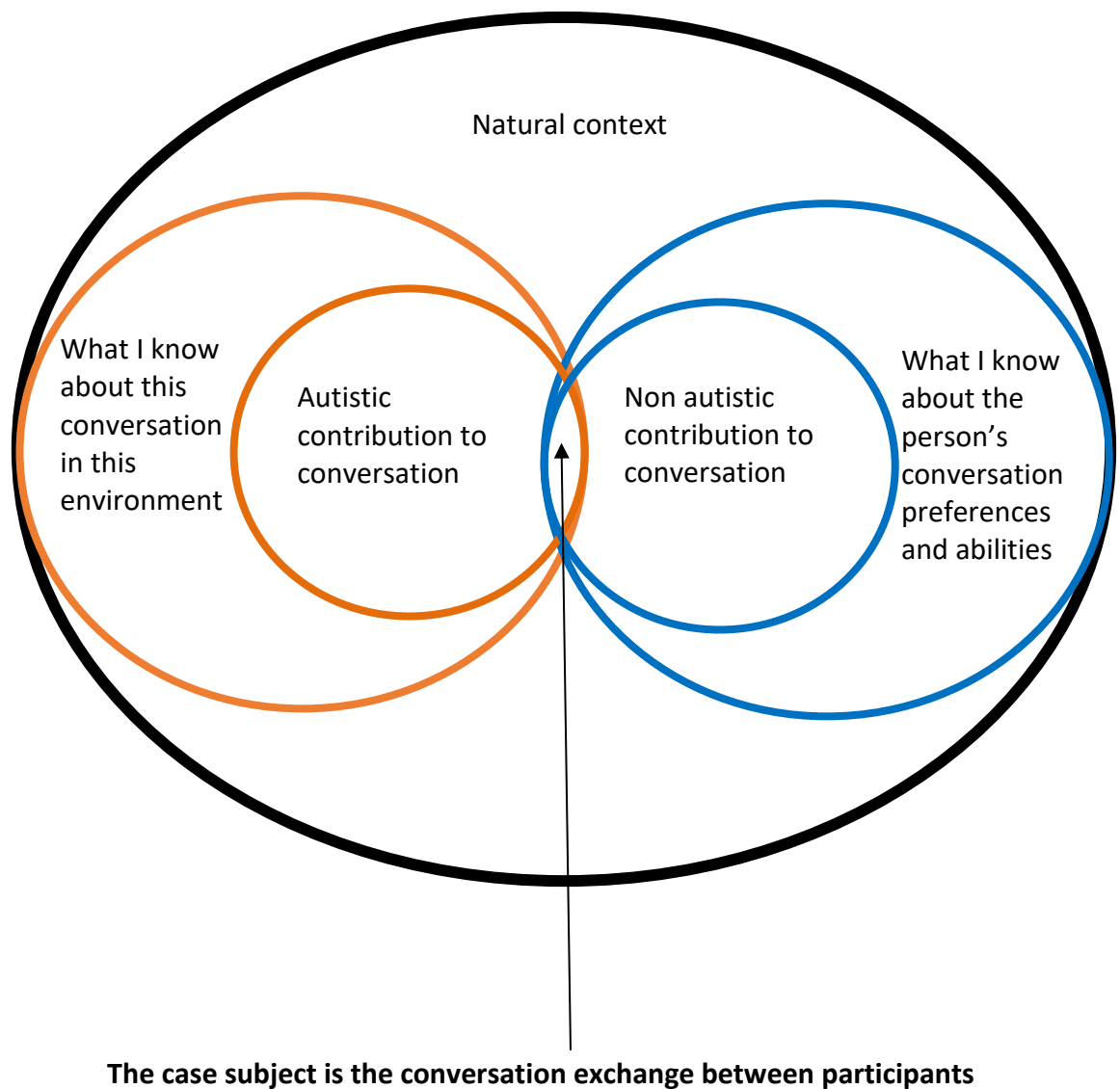
Figure 4.1 Case subject and analytical frame

Following Thomas (2015), I looked at the case from different angles using a range of data sources, summarised in Figure 4.2 below.

Involvement of the participants without autism

The perspective of the participant without autism

Observation of conversation between autistic participant and researcher.

Participants' reflection on their observations of researcher and of their own conversations with autistic participant partner.

Recording and reporting of change in their approaches to interaction with the autistic participant partner.

Talking informally and reflecting with autistic participant about shared learning about conversation.

Reflecting on learning with researcher.

Involvement of the autistic participant

The perspective of the autistic participant

Direct involvement with researcher in conversation.

Reporting on conversations with others to participant communication partner and researcher.

Written record of conversation with others in different places. Enabling shared reflection and learning.

Direct involvement in conversation with participant communication partner. Noticing/trying what has been learned.

Reporting to researcher and to participant communication partner, reflection of learning and changes made in interaction.

The Case Subject

The conversation exchange explored in the context of what the autistic participant knows about conversation that is useful to them; and what the non-autistic participant can do to support the contribution of the autistic participant's knowledge and thoughts to the conversation.

Figure 4.2 Detailed case study – Looking at the subject from different angles (Thomas 2016)

4.5 Methods

Case study is not a method in itself but an approach to study design that can be flexible with regards to the use of specific methods (Robson 2002). I chose my methods within these real and important boundaries.

4.5a Overview of enacted design
There were two phases to the study, each involving pairs of participants who knew each other well, one with and one without autism, and myself.

In Phase 1, I used semi-structured interviews, observation, reflective conversations and diary records with five communication dyads and myself to explore the autistic perspectives of conversations that had taken place (involving the autistic participants), reported by the autistic participants; specifically, what may have contributed to a positive or negative conversation experience from the autistic perspective. I also directly explored the communication exchange I heard between participants pairs; that is, whether the words of the non-autistic communication partner elicited a response that led to the contribution of the autistic participant's own useful knowledge (often knowledge not previously heard), that could be useful to the conversation.

I also learned about preferences and knowledge of the autistic participants useful to them in supporting their contribution to conversation. I was particularly interested in what participants with ASC knew and found useful to reduce their potential vulnerability to being misunderstood or not being able to contribute to conversation, and increase their success (from their perspective) in conversation.

During Phase 2, involving three communication dyads, I used semi-structured interviews in conjunction with informal 'keeping in touch' methods, including telephone and email and some face-to-face conversations, depending on the preferences and needs of participants. The 'keeping in touch' took place with participants individually and together as a participant pair. It enabled me to learn about how participants with and without autism were using what they had learned during Phase 1 with each other and in other real-world situations; that is, in their own everyday situations when I was not there. The final semi-structured interview with both autistic participants and

participants without a diagnosis of autism was to review the use and value of their learning about their conversation, and how this may be developed and used by them in future.

The phases of the study were linked for each participant and between participants. Specifically, when I had learned about something useful to one participant I explored its value with others. Where all participants had learned, or where autistic participants had accessed useful existing useful knowledge in Phase 1 of the study, this was built on and discussed further in the second phase.

An overview of the design and procedure is shown in Figure 4.3 below. Tables describing each stage of the study in more detail and the purpose of the inquiry at each stage are shown in Appendix 13, p. 248.

Figure 4.3 Procedure Overview

Involvement of participants with a diagnosis of autism

Semi-structured interview 1 Autistic participant and researcher

Completion of diary record

Reflective conversation with researcher to review the diary record

Being observed by the researcher when in conversation with the autistic partner

Phase 1:
What knowledge is useful to autistic participants in conversation? How can they be supported to access and use this knowledge by the participant without autism?

Involvement of participants without a diagnosis of autism

Completion of observation record of researcher and autistic participant during semi-structured interview 1

Reflective conversation with researcher to review the observation record

Joining reflective conversation with autistic participant and researcher to review the diary record

Being observed by researcher when in conversation with autistic participant

Reflective conversation where the researcher shared observation and learning

Phase 2: Learning by autistic and non-autistic participants

Semi -structured interview 2 With participant partners with and without autism and researcher

Participant pairs and researcher Keeping in touch conversations, face to face, phone and email

SSI 3 Participant partners and researcher

4.5b Participants

There was no intention to make a statistical generalisation from the study. It was important to me that participants wished to gain from participation in the study and that autistic people had similar communication abilities and were involved in similar conversations, so that I could use a replication logic (Robson 2002). I therefore used 'purposive sampling' (Robson 2002, p. 265), whereby I built the sample to meet the needs and aspirations of the project. I recruited adult autistic participants for the study by giving information about the purpose of the study, the potential benefits of involvement in the study and what involvement would 'look like' to senior managers and the head of the school and college at the specialist autism charity where the study took place.

When potential participants were suggested, I asked the speech and language therapist in the school to meet with the potential autistic participants in further education at school, thus avoiding any influence or bias on involvement related to my position. Senior managers within the charity approached autistic adults who they thought would be interested, again avoiding any influence from me at this stage. I then met with all potential autistic participants. I gave written information about the study to potential participants (see Appendix 1, p. 215 including a summary of involvement, Appendix 2, p. 220). Not all potential participants joined the study. When I had recruited the autistic participants, each autistic participant invited a person without autism, who was known to them, to join them as their partner in the study. All participants signed a consent form (see Appendix 3, p. 222 & Appendix 4, p. 224 (see Ethics, section 4.11, for further details).

The study began with five participant pairs and me, but, as described below, two more people without a diagnosis of autism were invited by the autistic participants to join the study at the end of Phase 1. Participants were therefore involved in the study as 'pairs' of one person with a diagnosis of ASC and one person (or two, in two cases) without a diagnosis of ASC. The pairs all had regular communication between themselves and all expressed a desire to be a better communicator. A brief pen portrait of each participant with ASC and their chosen conversation partner is given in Appendix 14, p. 251. As agreed with the participants, the names used are not the actual names of participants.

80

The autistic participants all had a diagnosis of autism based on the information provided at the time that they joined the Charity. Indeed, access to the services of the Charity is dependent on this being the case.

In summary, the participants (shown with the dyads) in addition to myself, were:

(Note: AP denotes 'Autistic Participant'. Where a name does not have (AP) following it, the participant does not have a diagnosis of autism.)

1.

Chloe AP	Female. Age: 42. Diagnosis: Asperger's Syndrome 1988
Wyn	Female. Support worker

2.

Carl AP	Male. Age: 34. Diagnosis: Autism Spectrum Disorder 1993
Mary	Female. Support worker

3.

Ruth AP	Female. Age: 21. Diagnosis: Autism Spectrum Disorder 1995
Lara	Female. Teacher

4.

Lee AP	Male. Age: 18. Diagnosis: Autism Spectrum Disorder 2012
Rachel	Female. Speech and language therapist
Oscar	Male. Teacher. Phase 2

5.

Cait AP	Female. Age: 40. Diagnosis: Asperger's Syndrome (date unknown)
Nina	Female. Support worker
Isla	Female. Mother of Cait. Phase 2

4.6 Methods and procedure

4.6a Phase 1

(i) First semi-structured interview

The first semi-structured interview between each autistic participant and me (observed by the non-autistic communication partner) explored conversations that the autistic participant had been involved in. We explored what the autistic participant felt worked well for them in conversation, enabling them to contribute to the conversation and feel that it was successful, and what they felt happened (e.g. what the communication partner said and did and the impact on them) when conversations did not go well, always aiming to understand their perspective. I wanted to avoid researcher bias by talking about conversations that I had not been a part of, thus avoiding my own interpretations of them.

I also explored the approaches that I was using during the interview. This was to find out what the autistic participant knew about different conversations and what I said and did that worked well and less well, to enable the autistic participant to think and to contribute their own existing knowledge.

Because the use of personalised vocabulary is important, it was not possible to specify beforehand the exact wording of the questions to be asked. I therefore used a topic guide rather than a list of interview questions (see Appendix 5, p. 226). I planned to ensure that I used 'friendly' questions such as 'How…' or 'Is there…?' (Yin 2003). I avoided 'why' questions, since these can cause defensiveness (Yin 2003). I used statements that prompted a response rather than closed questions that can limit responses (Lewis 2001), as well as prompts and probes (Gillham 2005) to elicit further discussion. I also reflected back what has been said to explore an element further (Gillham 2005). I was mindful that eliciting views rests on an assumption that the person has an opinion (Lewis & Porter 2004), so I always checked that participants were happy to talk about the interview topics and I was careful to avoid questions that assumed that the informant has or knows the required information (Cohen et al. 2007).

The autistic participants chose where and when the interviews were to take place so that they felt comfortable. For example, Lee works in the kitchens at school and did not

82

want me to talk to him immediately after his work, nor in the school environment; we therefore always met in the morning, in the college. We always checked that the room felt right to the autistic participants. For example, having chosen a room at the school, we found it had a clock that could be heard ticking. We therefore removed the clock. In order to maximise the involvement of the participants during the interview I included pauses (Lewis 2001), and watched for and responded to interviewee fatigue (Cohen et al. 2007). I aimed to listen more than to speak (Cohen et al. 2007; Robson 2002) and was mindful of how direct face-to-face contact or eye contact can be difficult for a person with ASC (Attwood 1998), so I monitored my body language carefully.

I was mindful of my vocabulary. I wished to gain an understanding of conversation from the perspective of the person with ASC, so I wanted to avoid imposition of my (or a non-autistic) way of talking about interaction, which might not be right for that person, or any assumption that differences in the use of language reflected deficits. I recognised differences in language or style as potential efforts to overcome difficulties (Sterponi et al. 2015) and, in probes or follow-up questions, I used participants' words rather than mine, where possible. For example, participants chose to use different words such as 'was not good for me' rather than 'unsuccessful'. The semi-structured interview included an exploration and agreement of the personalised vocabulary to be used to investigate conversation. I aimed to ensure that we had a shared understanding of the topic, and that any judgment on how the conversation had gone was from the autistic perspective, not mine.

When I heard a word used by me repeated by the autistic person, I explored their understanding of the word or the situation to check it and to ensure the reliability and trustworthiness (Lewis 2002) of information given. I was particularly mindful of my nonverbal communication, as I have learned from people with autism that non-specific hand gestures and movements can be distracting. Where I noticed any apparent interviewee disengagement or fatigue, I invited participants to take a break or finish the interview.

The interviews were recorded using a digital voice recorder. Each autistic participant was invited to take the recorder, so they could switch the recorder on and off or tell me

when to do this, in order to have control of the interview and the recording. Where autistic participants turned it off, or asked me to turn it off, while they told me something during the interview, this information was not included in the study. During the interview I wrote notes (referred to as jottings) to record my thoughts and observations relating to the nonverbal aspects of the interview, where relevant, including body language and the environment. Prior to taking notes, I checked with the autistic participants that they were happy for me to take notes during our discussion. This is normal practice in daily situations for them while in education and while being supported in the social care setting, so all readily agreed. The interviews were later transcribed on to a password-protected computer then thematically analysed.

The semi-structured interviews with each autistic participant were informed by the topic guide, but questions or requests for information were not always phrased in the same way or in the same order for all participants. This was so that I could change the phrasing of questions and probes to match the understanding of each autistic participant and ensure that the interview was conducted in the same form as a natural conversation, where one topic naturally leads to another.

I found that the first interview varied between autistic participants, depending on their recent experiences and current focus. It was conducted in two parts with three of the participants, as there was some loss of engagement. For example, during the interview with autistic participant Carl it was apparent that he had other things on his mind (including his lunch, when his flat mate unexpectedly invited him to join him for a burger) and he was enjoying talking about the past, rather than engaging in the current focus of the interview. I therefore listened to Carl talking about what was important to him at that time, exploring the interview topics when I could, and returned on a further date to complete the interview. Also, I knew that Cait (AP) has had many conversations that she has found difficult yet, when we first met, she could not recall any unsuccessful conversations. We therefore did not pursue this, but Cait (AP) and Nina agreed to consider it further, for us to discuss again at our next meeting. I was therefore careful to avoid researcher bias by appearing to require an immediate response to my topics or questions on the day of the interview if the participants did not have anything to say about my topic or were less interested in it that day.

84

The first semi-structured interviews with the autistic participants Ruth and Lee were more of a challenge for me, as I had not met them before. I sought feedback from their partners (the non-autistic participants Lara and Rachel) to know whether Ruth and Lee were engaging fully in the interviews or giving me 'stock answers' rather than considering a topic further and giving a more considered response. 'Stock answers' was a phrase used by Lara (non-autistic participant) to describe Ruth (AP) giving learned responses to situations and questions (and is a phrase I will use later in this thesis).

The interviews were linked between participants, in that I explored valuable knowledge uncovered with one participant with the other participants. For example, Chloe (AP) talked about knowing about 'type of conversations' as a useful concept, so I explored the understanding and value of knowing about 'types of conversations' with others.

On completion of the first semi-structured interview, the autistic participant and I had learned about conversations that went well, from their perspective, and about what appeared to be important or useful to them in conversations. We then talked about how a diary could be used to record successful and unsuccessful conversations and whether the things that are important to the participants had been present in those conversations (see section 4.9c below).

(ii) Observation 1: Observation by the non-autistic participant of me (the researcher) and the autistic participant during the first semi-structured interview
I invited the participant partner without autism to observe the first semi-structured interview between me, as the researcher, and the autistic participant and to complete an observation record. There can be a danger that an observer affects a situation (Robson 2002), but in this case the participant without ASC was someone chosen by the participant with ASC. Consequently, talking with this person in the room was a very natural and ordinary situation for them, so it is unlikely that the observer participant significantly changed the behaviour of the participant with ASC. I asked the participant without autism whether the conversation and behaviour of the autistic participant was usual or had changed during the semi-structured interview with me. Each time I was informed that, although at the beginning of the conversation the autistic participant had appeared more hesitant than usual, all autistic participants became involved in the

conversation in a way that was usual for them. However, I recognise that it is never possible to be entirely certain of this.

I was aware that the recording of observations might be a challenge (Punch 2014) if I was to gain useful and accurate data. I wanted the observation to be formal (Robson 2002, p. 313) yet 'unstructured' (Mulhall 2003), as is usual in qualitative approaches. In this sense, 'unstructured' does not mean unsystematic but rather includes some idea of what the observer will focus on (Mulhall 2003). I listed the aspects of the conversation for the observer to pay attention to (i.e. aspects of the conversation important to my research questions), including space for their own thoughts, and prepared an observation record to be used by the non-autistic participants during observation (see Appendix 6, p. 230).

Prior to the observation, I checked the non-autistic participant's understanding of each area of interest and their understanding that they should include anything else of particular interest to them, as I might not have considered aspects of the interaction important to others. This contributed to reduction of researcher bias, as I explicitly asked for the ideas of the other non-autistic participants rather than just asking them to respond to my ideas. I indicated that participants might prefer to write in the form of a 'narrative' or 'minutes' or 'headings'. It was important that the recording was manageable for them and made sense for the person and their skills/knowledge.

I was happy for the non-autistic participant observer to become a participant in the interview situation (Mulhall 2003; Robson 2002) where this added to the naturalness of the situation, but wished to minimise observer effects where an observer may change the thing being observed (Robson 2002). I therefore talked to the non-autistic participants prior to the observation about minimising their interaction during my conversation with the participant with ASC and responding only minimally to any conversation directed towards them in order not to disrupt the flow or topic of conversation.

In practice, only one non-autistic participant used the observation record during the observation (Lara), but she supplemented this with further comments. Others (Rachel and Nina) wrote their own notes and then sent their version of the observation record
86

to me later. Wyn preferred to talk to me immediately after the observation rather than write notes, as she did not feel comfortable in her ability to make an accurate record. Finally, Mary took observation notes during the interview and talked to me about what she noticed in relation to the areas I was interested in, but she did not send me a written record as promised. I was therefore flexible around the preferences of the participants (and their perceived strengths) and how they liked to be involved, so that they were able to contribute as fully as possible. Imposing completion of the observation record, as I had initially suggested, may have resulted in less rich data, as the participants clearly did not find that format as helpful as I had hoped.

(iii) Reflective conversation to review the observation record

I used a short, informal, reflective conversation with the participants without autism to review the observation records made following the observation. I wanted to ensure that I understood what had been recorded and to check for researcher bias or selective attention (Robson 2002, p. 324), where only part of the observation may have been recorded. I also aimed to understand what each participant without autism had found most interesting or most different about my interaction during the interview, compared to their informal observation of others in conversation with the autistic participant or themselves. Their comments contributed to the triangulation of data.

(iv) Diary record

Following the first semi-structured interview, I invited autistic participants to maintain a diary record of some of their conversations, so that I could know more about the conversations that they were involved in (that did not involve me). I was interested in whether these were successful or unsuccessful, from their perspective, and whether the conversations included approaches or learning that we had identified as useful to them during our first semi-structured interview. We agreed how long they would like to keep the diary record for and the date when I would next see them to discuss it. We also agreed how the diary record would be completed, whether they would receive support to do this; and how the diary would be recorded. Each autistic person agreed to handwrite the record except Carl (AP), who wished to complete it electronically.

All autistic participants agreed to keep the diary record for one week except Chloe and Ruth, who agreed that they would keep it for two weeks. I did not stipulate how many conversations should be recorded. We agreed that participants would record a conversation when they felt they had something specific to report about the conversation (for example, they noted that it was particularly successful or unsuccessful or they used something they had learned during the study).

Following my epistemological position, it was most important that the diary records were personalised, recording what was important to the participant and owned by them. It was also important that they received personalised support to complete diary records if needed. This meant that the diary records looked different from each other and were completed in different ways (see examples of diary records: Appendices 7, p. 234; 8, p. 237; & 9, p. 239). For example, Ruth (AP) worked with Lara to devise her own typed diary record sheet, which she photocopied and completed by hand. Chloe (AP) wrote under headings that I had noted down (at her request) when we met, while Rachel met with Lee (AP) on a regular basis and provided a summary of conversations rather than individual records. Cait (AP) noted information important to her about conversations in a notebook. Carl (AP) prepared his own typed diary record.

I hoped that the diary records could support reflection of the autistic and non-autistic participants, and that autistic participants would be able to report on a wider range of conversations, thus broadening the scope of the study. However, only Ruth and Chloe (APs) completed the diary record in the way that we had originally planned, making regular records of conversations and reflecting on their conversations. This may reflect their level of interest in the study and the purpose they saw in it: they possibly recognised involvement in the study as a learning opportunity for themselves. Interestingly, Cait (AP) found the request for a diary record initially quite difficult, and we agreed that she would complete it with her support worker. However, as the study progressed, she appeared to gain in confidence and knowledge about conversation and independently made records of conversations that she had had, which she thought I would be interested in, usually where she felt that she had been successful, and she liked to explore the reasons for this. Lee (AP) also completed the record with the non-autistic participant partner (Rachel). All autistic participants except Carl recorded a

88

minimum of three conversations. Carl did not complete any diary records. Although Carl was initially enthusiastic and felt that he would learn from reflecting on his conversations, at the time of the study he appeared to have other priorities, as did the participant partner working alongside him.

(v) Reflective conversation to review the diary record

I met the autistic participants to review the diary records. I probed further where needed to ensure that I had a good understanding of what was written and to check that what was written was important to the autistic person. I reflected with the participants on what worked well for them in conversation, both from their own perspective – what they knew and what they could do to help themselves – and also what approaches or actions from the conversation partner were helpful to them. The semi-structured interview to explore the diary record was structured around what was written, so this interview may be more accurately described as a reflective conversation; the focus followed whatever the participants found important and wanted to talk about. I later fully reviewed the diary records as part of the thematic data analysis.

(vi) Observation 2: My observation of the autistic and non-autistic participant pairs in conversation

In order to learn directly from what the non-autistic participants do in conversation, I planned to observe a typical conversation between the participant pairs with and without ASC, talking about topics usual for them. I explained that, during the conversation, I would join the conversation if requested, to maintain a situation as close as possible to real-world natural situations, but that I would try to make my input minimal so that the conversation was between the two participants and not influenced by me, thus avoiding researcher bias. I also checked that I could take notes during the conversation, recording in relation to the planned areas of observation used by the participants without autism (Appendix 6, p. 230). The observation was planned at the end of the reflective conversation relating to the diary record and, to support engagement in the study, we aimed for this to take place within the following two weeks.

Prior to my planned observation of conversations between the participants with and without ASC, I may have thought we had already established 'habituation' (Robson 2002, p. 328) to reduce the observer effect; that is, the participants had become used to me being a part of the conversation in their previous interactions. However, in talking to each pair of participants about the observation, I found that one of the pairs of participants felt uncertain about being observed and so recorded themselves talking when I was not present. Prior to the recording, I asked them to ensure that the participant with ASC felt comfortable and in control of the interview situation (as described above in section 4.9a). The other participant pairs chose to talk between themselves with me present as observer, and also as participant joining the conversation where it was natural to do so. Their conversation was recorded, and I made observation notes during the exchange in relation to the areas of conversation and interaction that I was interested in. Typically, the conversations that formed the basis of this part of the methodology lasted approximately forty minutes.

There was variation in the data received at this stage. Ruth (AP) and Lara were very happy to be observed by me, but also suggested that they make a recording of themselves without me present, which they did. Wyn and Chloe (AP) said they were happy to be observed in conversation, but in fact their conversation appeared very unnatural until I joined in. Usually, when Chloe, Wyn and I are together we all talk together and it appeared difficult for them to move away from this more typical type of conversation. The data from the conversation between Chloe and Wyn therefore included more of my input than I would have wanted. I learned that it would have been helpful if I had agreed beforehand the topics of conversation to be discussed between Chloe and Wyn, as this would have made particularly Wyn more confident and natural in the conversation. I had refrained from doing this in order to try to minimise researcher bias. I also learned that, although having previous knowledge of some of the participants was useful, it was possibly also a disadvantage when I was asking the participants to do something that was outside of what we 'usually' do.

Lee (AP) was reluctant to be observed by me in conversation, so he and Rachel suggested that they would make a recording of a conversation between themselves, which they did. By this stage of the project, Lee's teacher (Oscar) had become

90

interested in our learning through the study and, during conversation with me, Lee had indicated that he wished that some conversations with Oscar were better. Oscar suggested that he become directly involved so that he could learn more about Lee and himself in conversation that would be of benefit to them both. Lee agreed. Oscar read the information for participants with me and signed a consent form, then agreed with Lee that he would record a conversation between them in a personal tutorial, which they did.

Carl (AP) and Mary agreed to have a conversation between themselves, with me observing, but I found that I joined in the conversation more than I had planned in order that the conversation became less of a narrative about past events and more about problem-solving. However, within the conversation, there were some useful and interesting exchanges between Carl and Mary, which I was able to thematically analyse.

When I talked to Cait (AP) and Nina about me observing a conversation, they said they were happy about this. However, before we had planned the observation date, Cait asked whether her mother (Isla) could be involved. Cait's mother is an important part of Cait's life and they have many important conversations together. Cait and Nina told me that they had talked to Cait's mother about what they were learning during the study and that both Cait and her mother felt it would be useful for Cait's mother to learn directly herself, as a participant. I thought that the fact that Cait had asked for her mother to be involved showed that she was really taking ownership of both her involvement and learning in the study and how it could be useful to her and her life. Ownership and meaningful involvement of the participants and contributing to the direction of the study were important aspects of the study to me, as discussed earlier.

Cait's mother (Isla) read the information for participants with me and signed the consent form. I then observed and recorded two conversations between Cait and Isla where, as noted above, I found myself joining in perhaps more than I had planned in order to maintain the natural quality of the conversation when Isla asked a question of me. I observed and recorded two conversations, as I felt that that I had been too involved in the first conversation and Cait and Isla were very happy to meet me and talk again. Nina, the participant without ASC, who had been involved in the study from the

start also made small contributions to the conversation between Cait and Isla when invited to do so.

(vii) Reflective conversation: What works?

The second reflective conversation with the participant without ASC was planned following my observation of the conversation described above, and it was important to me that the planning and timing were convenient for the participants, rather than my diary. This means that the conversations took place within one and three weeks later. It was a personalised, open discussion lasting approximately forty minutes, where I shared what I had learned so far about the approaches used in conversation that appeared to scaffold further thinking and conversation of the participant with ASC, and approaches that appeared to cause a 'block', meaning reduced thinking and contribution to the conversation by the participant with ASC. Following this discussion, the participants without ASC each agreed what they would try to do differently when in conversation with the participant with ASC, going forward.

As with other stages of the study, the interview did not take place exactly as planned with all participants. I met individually with Lara (the non-autistic communication partner of Ruth), and individually with Rachel and Oscar (non-autistic partners of Lee); but met Isla and Nina (non-autistic partners) alongside Cait (AP), and met Wyn alongside Chloe (AP). Both Cait and Chloe (APs), were able to comment on what I said I had learned, which was useful to me and, with hindsight, talking with Isla alongside Cait (AP) contributed to increasing Cait's confidence in talking to Isla about how she could be more helpful to her in conversation. Unfortunately, the conversation with Wyn alongside Chloe (AP) included less reflection about her learning and I felt unable to probe further with Chloe (AP) present, as I did not want to appear at all critical about Wyn in front of Chloe. The conversation was therefore more about our general learning about what is helpful to Chloe (AP) rather than specific learning of Wyn.

By this stage, it appeared difficult for Carl (AP) and Mary to prioritise meeting with me so, although we noted as we went along 'what appeared to work well' to enable conversations to be successful from Carl's (autistic) perspective, I did not conduct a second semi-structured interview with them as planned. I considered returning at a

future date to do this, but decided that Carl had other things happening in his life. Additionally, he and Mary said they had already learned from the study, which was important to me ethically, as they were not being used by me as objects of study. I was also working within a timeframe and had gained other rich data that I had not anticipated from involvement of others, and so I did not pursue the second interview.

By the end of Phase 1, each participant with and without autism had learned something useful about him or herself in conversation to help conversations to be more successful from the autistic perspective, and they agreed to try to use this learning in other conversations.

4.6b Phase 2

Bearing in mind the necessary constraints on the size of the study and my own time, I planned to reduce the number of participant pairs taking part in Phase 2. I had planned to continue to involve the participants who appeared most engaged in the study and seemed to be gaining the most from their involvement in it. Ruth (AP) and Lara, Cait (AP) and Nina and also Isla, and Lee (AP) and Oscar and Rachel were all very involved. Carl (AP) had been enthusiastic when invited to take part in the study, but unfortunately other priorities arose in his life, meaning that he could not focus on conversations and the study. Chloe (AP) remained enthusiastic about the study, but at this stage staffing difficulties meant that it was difficult for her participant partner without autism to be available to meet with us, so as a participant pair any continued involvement would have been difficult. To maintain integrity, I have continued to see Chloe (AP) outside of the study, and have been able to support her to use what she has learned while involved in it.

In summary, Phase 2 involved the following people:

Table 4.1 Participants involved in Phase 2

Autistic participant	Participant partner without a diagnosis of autism
Ruth	Lara
Lee	Oscar and Rachel
Cait	Isla and Nina

(i) Semi-structured interview with the participant pairs

In Phase 2 of the study was planned to begin as soon as was convenient for the participants (between two weeks and a month). I used a semi-structured interview to explore what we had learned during Phase 1 about was most important to the participants with and without autism, and what strategies they used in everyday situations, so that conversations were more successful from their perspectives. (See topic guide in Appendix 10, p. 241).

These interviews lasted around an hour. For example, we talked more about awareness of 'feelings in the body' to know where a conversation was not going well, with Lee (AP), about 'what I know about a person' with Ruth (AP) and when a communication partner 'did not listen' with Cait (AP). The interview therefore began as a semi-structured interview with some specific questions/areas of interest in mind, but became more open as I elicited areas of interest and explored autistic participants' knowledge used by them in conversation. At the end of this semi-structured interview, we agreed the areas of conversation that would be a focus for continued reflection, learning and change for each participant with and without autism.

(ii) Keeping in touch

During this next phase of the study, the participants with and without ASC worked together to use what they had learned in conversations with each other and with others. I wanted to leave a period of time (more than 10 weeks) to enable me to know whether the participants continued to want to use what had been learned during Phase 1 of the study or whether learning was forgotten, or used only when reminded. I thought that this would help me to understand the value of the learning to each

participant. However, during this time I also wanted to keep in touch so that I could answer any questions that participants might have or explore building on learning if this was requested. If the learning had not been useful, I would have wanted to explore the reasons for this and possibly to revisit the data from Phase 1, in order to further explore what may be more useful.

I had initially planned a further diary record for this phase of the study. However, learning from the inconsistencies in the use of a diary record in the first phase and the importance of participants remaining engaged if I was to be able to collect data to build on the findings in Phase 1, I chose to personalise how I reviewed the use of the learning and further learning. When keeping in touch, participants reported their success to me but also reported frustrations or identified areas that appeared of less value than originally thought. For example, during Phase 1, Lee (AP) became aware of his leg moving up and down involuntarily when he was less relaxed and had thought this would be useful in sending a message to himself to 'think'. However, he reported in Phase 2 that noticing the leg was 'annoying now' and we needed to think again about how he could use the moving leg as a helpful signal.

Keeping in touch was different with different people, following preference and need. I made two further visits to meet with Ruth and Lara and three visits with Cait and Isla, but used email and telephone with Oscar and had conversations with Lee and Rachel.

During this contact, I was able to learn what was emerging as most important to all the participants and I also learned who had found the learning most useful, enabling me to think about who this type of learning may be most useful for.

(iii) Final semi-structured interview with each pair of participants
In the final semi-structured interview with each pair of participants, I explored what each had found most useful during the study and how they would use this learning in future (see Appendix 11, Topic Guide, p. 244). This interview took place between six and 11 months after the start of Phase 1. I found that engagement in this interview, its content and the depth of learning revealed reflected what was most important to each person in the study. I conducted the final interviews in the way that was most useful to each pair of participants so that they felt most able to share and reflect on their

learning. I talked to Ruth (AP) and Lara together and to Lara alone. Lara later followed this up with a written record of her learning. I talked to Oscar and to Rachel individually and alone, and to Lee (AP) alone. Oscar gave me a written record of what he felt he had learned and used. My conversation with Lee was very short, as he was able to briefly summarise what he had learned, indicate that he was pleased in the change in conversation of some people working with him and suggested that we do some staff training together. He then felt that he had nothing else to add. I talked to Cait (AP), Isla and Nina together about what was most important to them; this was the change in Isla's communication approaches following her involvement in the study.

At the end of the study, I visited each participant pair and talked about what I had learned from them and from other participants, and thanked them again for their involvement. Lara was keen to use her learning in her work with other autistic people and I agreed to support her with this outside the study and to include Oscar and Rachel. Cait (AP) and Isla wanted to keep learning and wanted Cait's father to learn too, so I agreed to keep in touch so that they can continue to learn together. Cait (AP) reviewed with me the words I had used for the themes and helped me to change these to help other people to understand the meaning of the theme. Lee asked if we could use our learning in staff training: one session has been delivered and another planned.

Throughout the study, I learned that I needed to be flexible in how I collected data if, following my philosophical position, I was to gather rich data and if the participants were to gain from participation as I had hoped they would. However, my flexibility remained within the boundaries of the study (see below). It was important to me that throughout my study I was aware of the importance of trustworthiness and ethical considerations. These are discussed below.

4.7 Trustworthiness

In order for my study to have value to the participants and to future readers of the study, it needed to be a trustworthy study, where trustworthiness was assessed in the context of the purpose of the study. The purpose of my qualitative study was not to generalise to other people or places but to explore in depth a specific phenomenon (the communication exchange) and to build further knowledge that is sensitive to the

research participants. From the literature, I found that writers have different concepts and approaches to assess trustworthiness, with concepts of mainstream social science such as rigour reliability, validity and generalizability being frequently used (Morse 2015). I needed to use the concepts that were right for my study.

Guba (1981) proposed a model for assessing the trustworthiness of qualitative research, rejecting the often-used terms 'reliability' and 'validity', preferring instead credibility, transferability, dependability and confirmability. Although authors may use various terms to label how qualitative research may be assessed in terms of quality, all agree on the use of strategies to minimise any threats to the quality of the research. My approach to the assessment of trustworthiness was informed by that described by Krefting (1991), an occupational therapist and healthcare provider-researcher (similar to myself). She interpreted and used Guba's model (Guba 1981) to assess trustworthiness during several qualitative research projects and, like Robson (2002) suggests strategies that may be employed to increase the trustworthiness of qualitative work. These strategies used to support trustworthiness are described below.

First, credibility requires adequate submersion in the research setting to enable recurrent patterns to be identified and verified (Krefting 1991). I sought credibility through 'prolonged involvement' (Conneeley 2002; Robson 2002, p. 172), as I was involved with the participants for up to a year in interviews, reflective conversations and 'keeping in touch' phone calls, emails and conversations. Therefore, I had prolonged and varied field experience that could develop rapport, with the participants volunteering more information and knowledge than at the beginning of the project (Krefting 1991). However, I also needed to be mindful of researcher bias through the prolonged contact (Robson 2002) and be aware that the closeness of the relationship between me and the participants could be a threat to the truth value of the study (Krefting 1991). It was important that I was aware of the need to avoid subjectivity and a possible bias towards verification (Flyvbjerg 2006), but the fact that I was sensitised to this enabled me to monitor my own thinking while being aware that I was a part of the world I was studying (Charmaz 2014). As suggested by Flyvbjerg (2006), my views were tested as they unfolded when I talked to the participant pairs, individually and together.

To further strengthen credibility, I used member checking (Krefting 1991; Morse 2015; Robson 2002), where I shared interpretations that I had made with the participants and explored these interpretations with them to check whether my understanding was correct or incorrect. Importantly, when analysing the data, Krefting (1991, p. 218) argues that:

> A qualitative study is considered credible when it presents an accurate
> description or interpretation of human experience that people who
> also share the same experience would immediately recognise.

In line with this aspiration of credibility, I wanted to be sure that the participants recognised my interpretations as accurate and relevant to their perceptions and understanding of knowledge of the conversation. Finally, to enhance credibility, I looked for contradictions or 'negative case analysis' (Morse 2015; Robson 2002), described further in the data analysis section. I also kept a robust audit trail of what I had done.

I also used triangulation in order to increase the trustworthiness of my study. Triangulation is the use of multiple sources to enhance the rigour of the research (Robson 2002, p. 174), by enabling cross-checking of data from different sources. I used data triangulation as I employed more than one method of data collection: semi-structured interviews; observations; and diary records. I used observer triangulation in that I observed conversation between the participant with autism and the non-autistic participant. The non-autistic participant also observed me in conversation with the same autistic participant. I included multiple perspectives as I looked at the conversation exchange from the perspective of both participants and, in addition, my own reflective and reflexive perspective when I analysed the conversation data. For example, I was able to check whether the information given to me in the diary records matched the information given to me in the semi-structured interviews and to explore any discrepancies. Furthermore, I used triangulation of data sources in that I worked with the various participants, exploring the same thing, over a period of time.

I was aware of some tensions during the study, which could potentially have affected its trustworthiness. I was aware that the participants did not become involved in the diary record in the way that I had planned and that some interviews took place over several sessions. However, I returned to the literature regarding the binding of the case by

98

definition and context (Miles et al. 2014) and felt that these changes were within the boundary of the case study (Baxter & Jack 2008). My concentration thus remained on the focus of the case (Nije & Asimiran 2014) and the scope of the study did not change. Further, these small changes fitted with my epistemological position, whereby I wanted to be flexible in learning form the participants and with my grounded approach, where I responded to the emerging data with the participants. A further possible tension is that of insider/outsider, as I do not have a diagnosis of autism and could have been making assumptions from an outsider neurotypical perspective about what the autistic participants were saying, or about their perspective of being involved in the study (Gillespie-Lynch et al. 2017; Milton & Bracher 2013). However, the whole focus of the study was on understanding more about the communication exchange and how misunderstandings can be avoided, from the autistic perspective. I was therefore highly sensitised to any possible assumptions that I might be making. Using my grounded approach, I learned from the autistic and non-autistic participants during this study about how communication by a non-autistic person could be more helpful to the autistic participant and I used this learning in subsequent interviews. In addition, member checking, described above, reduced the risk of incorrect assumptions.

4.8 Critical evaluation of methods used

4.8a Use of interview

Interviews are at the heart of qualitative research (Nind 2008) and, in order to find out what people with ASC know about conversation (Research Question 2) and how what they know can be used to support their contribution to conversation (Research Question 3), it would seem sensible to ask, but I wanted to be very careful about asking. This project was interested in the circumstances and practices that may contribute to the vulnerability of autistic people in conversation, through being misunderstood; in my clinical experience, I have heard people with ASC become vulnerable in interviews or conversations where they respond to questions without fully understanding the question, or without seeking and using existing knowledge. For example, when asked why a person did something, I have heard the autistic person give an answer that they have heard or used before, such as 'because there was too much noise' or 'because I was stressed' rather than thinking further about the situation now. It was therefore

important that I considered the use of interview using my existing clinical knowledge about communication. Following the principles described by Lewis (2002), I ensured that views are fair and representative, checked that views or interpretations are correct, and checked reliability or trustworthiness concerning whether the responses are typical of what the person believes. To do this, I used member checking described above, but also watched carefully for nonverbal signals of a person appearing to change in any way (e.g. become more hesitant or less responsive). If I saw any change, I would stop and check whether the person had any difficulty or change my topic or style of question. Thinking of the non-autistic participants, I was conscious of whether they may say what they may have thought I wanted to hear, so always made sure that I explored what they said to check that it was their own substantiated opinion.

Robson (2002, p. 270) describes three main types of interviews: (1) fully structured, where questions are predetermined, with fixed wording in a preset order; (2) semi-structured, where the questions are predetermined, but the order and wording can change through the interview; and (3) unstructured, where the interviewer has an area of interest in mind but lets the conversation develop in this area. I felt that semi-structured interviews would be appropriate for my study. Semi-structured interviews enable participants to provide new and unanticipated information (Denscombe 2003), occupying the role of informant rather than respondent (Yin 2003) and have previously been used to investigate the views and experiences of people with ASC (e.g. Carrington & Graham 2001; Humphrey and Lewis 2008). It was important to my epistemological position that the interview situation felt as natural as possible for both participants with and without autism, in order that they would feel most comfortable ini contributing to it.

(i) Limitations of interviews

I needed to be aware of the limitations of using interviews. An interview situation can be potentially difficult for an autistic person, as it can demand swift processing of spoken language, planning and expressing what to say and managing the sensory environment, and recalling personal memories and events, all of which are known to be potentially problematic for people with autism, as highlighted in Chapter 2. In addition, using spoken language to communicate may not be the participant with ASC's preferred

100

method of communication when thinking and planning what to say (Bagatell 2010). I am also aware that people with autism may find it difficult to contribute knowledge or information in just one interview rather than allowing information to be gathered over time (Ridout 2017). I was careful to allow the autistic person time to think about and plan what they wanted to say and to return to topics, if needed, and I checked that I had understood what had been said.

I also needed to be mindful of some of the known disadvantages of using semi-structured interviews. These include: interviewee fatigue (Cohen et al. 2007); involuntary use of nonverbal communication by the interviewer, which may influence the response of the interviewee; lack of interview standardisation; and the fact that interviews and their transcription are time consuming (Robson 2002, p. 273). Considering these disadvantages, I paid attention to the interviewee and how he/she was responding to the interview (see procedure section 4.9 below). I checked that I covered the planned topics (see Appendices 5, p. 226; 10, p. 241; & 11, p. 244) and I remained reflective and reflexive in relation to myself (see Chapter 1) to aim to limit any influence that I might have had on the interviewee. I was able to plan time for the interviews and the transcriptions.

In summary, I felt that the benefits of being able to use the semi-structured interview as a flexible way of finding things out (Robson 2002, p. 272) and being able to adapt interviews to the communication needs of each person (Bagatell 2010) enabled me to gather rich data to respond to my research questions, in keeping with my philosophical position. I used semi-structured interviews during both phases of my study with all participants.

4.8b Use of observation
My first research question asks about how autistic people may be supported by a communication partner without autism to access and contribute their own knowledge to conversation. A transcribed and analysed interview conducted by me with the person with ASC enabled me to explore how I might do this from my perspective only. In order to increase the trustworthiness of my study, I wished to include data from multiple sources (Robson 2002) and triangulation of data involving the perspectives of others. I

considered filming natural interactions when I was not present, but this was considered impractical in the setting and potentially intrusive. A third-person observation of a semi-structured interview appeared to enable me to gain another perspective on the communication exchange between participants with and without autism. Robson (2002) suggests that observation can usefully complement information gained by any other technique and is appropriate for the real world and real life, while Cohen et al. (2007) further suggest that observation has the potential to yield more valid or authentic data than is the case with mediated methods. Observation can be of facts, behaviours and events (Cohen et al. 2007), so I was able to match the observation to the questions of my study.

In order to answer my research questions, I required qualitative data describing what was happening in the situation within the predetermined areas of exploration, rather than quantitative data, which may result from a highly structured coding scheme where occurrences of behaviour are counted (Robson 2002, p. 325). I therefore asked the non-autistic participant to record what they noticed as helpful to the conversation and the approaches (use of language/words/silences/body language) that they saw as possibly different from the conversations that they usually hear. This enabled me to consider their perspective of the interview as well as my own. Importantly for me, I intended the observations to reduce researcher bias, as I was listening to the views of others rather than relying solely on my own interpretations. They enabled others to comment on what I was doing within the interaction from their own perspective. This would not be possible alone.

I also needed to be aware of the disadvantages of observation. It is well recognised that an observer may affect the situation under observation (Robson 2002), and that if a participant is very aware that they are a part of a study their behaviour may change; this is known as the Hawthorne effect (Adair 1984). I therefore considered how to minimise this impact in the planning of the observations (see above). I used observations during Phase 1 when I invited a participant without autism to observe the semi-structured interview between myself and the autistic participant, and again when I observed a conversation between the participants with and without autism.

4.8c Use of diary record

A diary record can be defined as a document created by an individual who maintains a regular, personal and contemporaneous record, although the form of the diary may vary (Alaszewski 2006). In effect, diary records can be seen as self-administered questionnaires (Robson 2002), but should be planned with the same care and preparation as a more traditional questionnaire (Hinds 2000). They are considered to be less intrusive than interviews and so have been applied in research with people with autism (Humphrey & Lewis 2008). Diaries may be particularly useful in recording sensitive issues (which may be the case in my study, if a participant experiences a sense of failure in a situation) and may take the form of audio or audio-visual diaries as well as written diaries (Bates 2013).

Although the use of diary appeared to fit with my emphasis on individualised approaches, enabling me to hear the uninterrupted voice of the participant, I needed to be aware of the disadvantages of use of diary. A diary places much responsibility on the respondent, which could be difficult for participants with ASC without planning and support, which in itself may cause reporting bias. There are also dangers of mis-reporting, possibly to please the enquirer, or changing the behaviour being reported (Robson 2002). Consequently, the use of diaries alone would be unwise, and they are best used as part of a multiple methods approach (Silverman 2005), which is the approach I took.

4.9 Ethics

Thought must be given to ethical aspects in the early stages of preparation to carry out an enquiry (Robson 2002, p. 65), and there may be particular ethical problems associated with working with vulnerable groups (Robson 2002, p. 70). The main ethical issues can be summarised as harm, consent, deception, privacy and confidentiality of data (Punch 1994, cited in Punch 2014, p. 43). I considered each of these areas in the planning and ethics submission prior to beginning the fieldwork.

I considered the risk of harm (i.e. the issue of non-maleficence; Punch 2014), particularly the risk of psychological or emotional harm, by ensuring that all participants felt as far as possible in control of any interview or meeting with me and that they had

ownership of their involvement in the study. I did this by ensuring that their routine, or what was important to them, was not disrupted when I was planning to meet with them, and that the environment for our meeting was chosen by the participants rather than by me. Where participants did not feel like being involved in the interview at the planned time (for example, Lee was feeling tired one day when I arrived to meet him), I postponed the interview. From the start, I made it clear that participants could choose to cancel or rearrange appointments or stop the interviews if they did not feel engaged in, or motivated by, the process.

Where participants did not wish to engage in aspects of the study or not to engage in the way that I had suggested (for example, the completion of the diary records), I talked about how we could make the task more manageable for the participant. Alternatively, the participant could choose not to complete that aspect of the study. Where participants found involvement in the study difficult due to other demands, they withdrew from the study. I ensured that any changes made did not change the focus of the study (see above).

Where I could see that the participant without autism was possibly causing 'blocks' to the contribution of the autistic person or the conversation could have been 'better' because the autistic person was contributing little to the conversation, I was able to feed this back during reflective conversation so that there was learning from it by both the participants with and without autism.

I summarised what was expected from involvement in the study in an 'information for participants' document that I shared with all participants prior to the study (see Appendices 1, p. 215 & 2, p. 220). I checked the understanding of the purpose of our meeting with all participants prior to the start of each semi-structured interview or reflective conversation to reduce the possibility of misunderstanding and anxiety associated with this and checked understanding during the conversations (ensuring understanding of the autistic person was actually a focus of the study itself).

Informed consent must include explicit recognition of the rights of the individual to agree or disagree to their involvement in the study (Lewis & Porter 2004). In my prepared information sheet about the study given to all participants, I detailed why I
104

was doing the study, how the person could be involved, how the person could opt out and how the information that I gained during the study might be useful to the participant and to others. I gave all participants the prepared information about the study document, then talked through it with each person to ensure their understanding of it, giving further information or rephrasing the information to ensure understanding. I then checked their understanding by asking them to confirm what the study was about and what they thought they would be doing within it.

Participants without ASC were able to give fully informed consent. All participants with ASC who had been invited to be involved had a level of understanding and use of communication that enabled them to give informed consent and to participate meaningfully in the study. As a speech and language therapist, I was also able to check thoroughly their understanding of the information that I presented to them to ensure their informed consent. All participants were asked to sign a consent form prior to the study commencing, and a copy of this can be found in Appendix 3 (p. 222) and 4 (p. 224).

The transparency of the information about the study and the consent form enabled me to guard against any deception. Throughout the study, I checked with participants what they felt that they had learned, what we were doing next and how our learning was to be used within the next steps of the study. This also enabled me to check ongoing consent, and the process further maintained transparency during the study. At the end of the study, I talked to each person about what had been learned and asked for their ideas about how we can make best use of our learning in the future. Two people have since chosen to be involved in staff training based on our findings.

When seeking consent from participants for involvement in the study, I was mindful that I work in senior management for the national charity where the participants with ASC are supported and where other participants work (in roles with a lower status than mine). I was conscious of my perceived 'power', as already noted in the reflexivity section in Chapter 1. However, I have known four of the people involved in the study for some time when I have been working in other roles; and others were approached to be involved in the study by their speech and language therapist rather than directly by me

initially, so that it was easier for them to decline to be involved. When working together in clinical-type work, we always aim for as equal a power balance as possible. I spent some time with participants without ASC prior to the study so that they could see me as a researcher rather than as a senior manager.

I maintained privacy and confidentiality by storing data on a password-protected laptop and never recording the full names of participants or any other personal details. I stored hard copy data in my private house and never left material in my car or in a place where others could see it. Before sharing anything that I had learned from one participant with another, I asked their permission to do so. Importantly, this actually increased motivation for continued involvement in the study, as participants were explicitly aware of how they were helping others. I noted only the first name or initial when audio recording conversations. When writing up the study, I used an initial for each participant to maintain confidentiality. I completed all the necessary paperwork for an ethical review of my research at the University of Southampton, and received approval from the Faculty of Social, Human, and Mathematical Sciences Research Ethics Committee (Ethics ID: 17940). All relevant documents relating to ethics approval, including the risk assessment, may be found in Appendix 12 (p. 246) and 15 (p. 258). The following chapter shows my data analysis process and provides an overview of the main themes that emerged.

Chapter 5 **Data Analysis**

5.1 Introduction

The qualitative data was collated through semi-structured interviews (subsequently transcribed), observations, conversations and diary records collected in natural settings. The data was rich, being the words of various people describing their experiences of everyday situations, over time and from their own perspective. However, the apparent simplicity of the data must not mask their complexity (Miles et al. 2014). I was aware that the everyday words used must be explored, understood and analysed, so a rigorous approach to analysis was needed. The method had to be systematic, disciplined and seen and described (Punch 2014). An audit trail was needed, demonstrating continuous and rigorous analysis.

During the planning of the data collation, I considered the analytic method to be used. I was analysing talk between people, so conversational analysis, described as a 'method for investigating the structure and process of interaction between humans' (Peräkylä & Ruusuvuori 2011, p. 534) appeared relevant. However, Robson's (2002, p. 365) description of conversational analysis as calling for 'a very detailed analysis of small fragments of discourse', and Miles et al.'s (2014, p. 8) description of conversation analysis as 'paying meticulous attention to the nuances… of literally every word in a data corpus' did not appear to fit with the aims of my study.

I was concerned that, since I was inexperienced in conversational analysis, while focusing on detail in pattern and form, I might miss some of the meaning in the conversation exchange. Indeed, Peräkylä and Ruusuvuori (2011) acknowledge that the technical exactness of conversation analysis studies may mean that that the meaning of talk is neglected at the expense of the form of talk. Further, Marshall (1994, cited in Robson 2002, p. 366) points out that within conversational analysis the interview becomes less about exploring the views of the participant and more about the language or discursive practices used, which does not appear to match the purpose of my study.

Peräkylä and Ruusuvuori (2011) describe how conversational analysis includes 'inter-subjective understanding'; that is, 'understanding of the preceding turn displayed by

the current speaker' (Peräkylä & Ruusuvuori 2011, p. 535) and, while I wanted to look at conversation exchange, I wished to explore this exchange holistically, beyond the actual words used and over several conversational turns. This was important when considering the processing differences associated with autism (see Chapter 1) and the impact of the conversation on the autistic person.

I was aware of the value of the analytic techniques using a thematic approach described by Miles et al. (1994), having used these successfully in a previous qualitative case study (Silver 2010; Silver & Parsons 2015). Moreover, Robson (2002) considers thematic methods of analysis to be particularly suited to case study. I considered that a thematic approach would be relevant to this study, and I discuss this further below.

5.2 The analytic method used

The analytic method was informed by my epistemological position, which may be conceived as constructivist (Charmaz 2014) in that I am interested in exploring the experiences and the reality of participants' day-to-day experiences, and in the 'exchange' of meaning between participants in order to answer the research questions. I could not use analytic methods that are based on a single particular theoretical position, described by Braun and Clarke (2006, p. 78) as 'one-recipe guides analysis', because I wanted to be able to respond to what I found in the data in relation to my research questions rather than impose a predetermined structure on it or test particular theories.

5.2a Thematic analysis

Braun and Clarke (2006) describe thematic analysis as providing 'theoretical freedom' (p. 78), fitting with my own use of different cognitive theories relating to autism and my own personal theory (see Chapter 1); and providing a method for identifying, analysing and reporting patterns (themes) within data. During thematic analysis, matching my constructivist position, the researcher has an active role, selecting and reporting patterns/themes of interest rather than waiting for themes to 'emerge' from the data. This is important to me, since themes must be more than direct reporting or description of what is there in the data, and must be informed by an in-depth understanding of the data, for example looking for the meaning behind the words spoken rather than taking

108

them at face value. I also want to be able to take a holistic view of the data, finding any commonalities between participants and patterns within a participants and thematic analysis allows me to do this.

In planning the use of thematic analysis, I was aware that an advantage for me is the flexibility of the approach, but this could become a disadvantage if I were not to follow a very clear process and evidence carefully the processes that I had followed. I needed to ensure that I was clear on the process that I was to use and to avoid an 'anything goes' approach to analysis that would be criticised (Braun & Clarke 2006, p. 78). However, I would also need to be careful that, in trying to be systematic, I did not lose the flexibility to capture the emergent nature of the findings arising from the range of interactions supported through this research.

Miles et al. (1994) described a framework for analysis that I used in my previous research (Silver 2010; Silver & Parsons 2015). This has further evolved (Miles et al. 2014) and is described as 'including some techniques from grounded theory' (pp. 9–10), thus matching with my study being informed by grounded theory approaches; I wished to use a part inductive approach and part deductive approach to data analysis. This thematic approach selectively collates data to create inductive inference, searches for patterns and clusters, then draws inferences based on the links between the data segments. The principles of this method fit with the approach described by Braun and Clarke (2006) because both seek and report patterns in the data as themes, enabling interpretation of the data. For clarity for me, I chose to approach the data analysis using the very clear step-by-step guide to thematic analysis described by Braun and Clarke (2006), maintaining a check of these steps against the moves described by Miles et al. (2014), ensuring that the method was systematic and transparent. The steps used are described next.

5.3 The data analysis process

5.3a Familiarising myself with the data
I collected a range of data, including audio recordings of two or more semi-structured interviews with each autistic participant and myself (including handwritten notes made during the interviews), two recordings of each autistic participant and their partner

without a diagnosis of autism, talking together, diary records by the autistic participant, observation records by the participants without autism, records of conversations between myself and participants where notes were made during the conversation (unrecorded) and 'keeping in touch' emails that reported progress. The audio recordings were transcribed word for word and notes made where silence was used, or an interruption was heard (for example, a phone ringing in a bag in the room). Where an utterance was inaudible in the recording, 'inaudible' was noted.

Prior to data analysis, if I did not know the autistic participant, I had to learn more about their understanding and use of communication from people who knew them well. This ensured that I explored the intended meaning of words used, where necessary, so that the words and meanings could be correctly coded. I also checked that what participants had said and done during the interview was quite usual for them, and therefore the interaction to be analysed was reflective of usual everyday communication. I was aware that if the autistic participant did not know me there was a risk that they might respond during the interview at a superficial level or give stock responses. If I were to code this data, it would lack the depth and richness that I sought within the study. Despite this attention to detail on my part, my professional knowledge tells me that many factors, both internal (how the people in the interaction are both feeling) and external (events that have just happened or are about to happen or the physical surroundings) can influence the type and success of a conversation or interview.

I organised all the data (including jottings and my early thoughts on patterns and conclusions) chronologically and by participant in sections in folders. In doing so, I read and re-read the data and revisited my early thoughts. This process enabled me to become very familiar with the data, effectively immersing myself in it, as is important in qualitative research (Robson 2002).

In order to define the data set (data to be used in the analysis) from the data corpus, I reviewed the data in the context of the research questions and my knowledge of autism. My knowledge of communication in autism was important to the data analysis, as it enabled me to avoid neurotypical assumptions about the words used and to consider different interpretations of what I heard. For example, I was able to consider

that when I noticed a topic switch, it may be the result of a misunderstanding rather than a desire to talk about a new topic, and to consider that a person might be using words with different meanings attached. This knowledge supported the robustness of the coding.

I discarded data that did not answer the research questions. This included long monologues about past events, irrelevant to the topic under discussion, and asides, for example wanting to check if the kettle was switched off. When discarding chunks of data from further detailed analysis, I checked for any relevance at all to the research questions.

While reading and re-reading the data, I thought actively about what participants without autism had said and its impact on the contribution to the conversation of the autistic participant. I looked for types of sentence and meaning and length of conversational turn by the participant without autism; I looked at what was appearing important to the autistic participants in conversation and at how and when their contributions to the conversation varied. In doing this, I looked for commonalities and differences between the participant dyads. This enabled me to begin to see patterns that would become early inductive codes and to check that my thoughts on deductive codes would be relevant. For example, I noticed early on that 'type of conversation' appeared important to more than one autistic participant, so this became an inductive code.

5.3b Generating initial codes

The coding was an important part of the data analysis. It enabled me to retrieve and categorise similar data chunks so that I could cluster the data segments in relation to the research questions (Miles et al. 2014), to notice new and emerging codes and also specifically seek data segments that responded to my research questions.

A code can be described as 'a word or short phrase that symbolically assigns a summative, salient, essence capturing attribute for a portion of language-based data' (Saldaña 2013, p. 3). Some codes were theory driven, 'top down' and deductive, and provided a 'start list' (Miles et al. 2014, p. 81).

My study was informed by the social model of understanding of disability, so deductive codes in relation to Research Question 1 included the identification in the data of things said or done by the participant without autism that had a positive or negative impact on the contribution of the autistic participant, and whether what was said appeared to facilitate 'uncovering' the knowledge of the autistic participant.

Deductive codes in relation to Research Question 2 were informed by the developing understanding of cognitive theory and cognitive differences relating to autism (see Chapter 1), and my personal theory (based on experience) that autistic people have knowledge but that this is not always readily accessed or contributed to conversation. Deductive codes therefore identified segments where the autistic participant's knowledge about conversation or interaction was heard and used in the conversation (I referred to this as 'uncovered' knowledge); and in response to my practice knowledge and reading, linked to my research question, I looked for vulnerability in the conversation and a 'physical response' during the conversation.

I described operational definitions (Punch 2014) of the deductive codes to be used (see the list of deductive codes in Table 5.1 below).

How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?

Table 5.1 Initial deductive codes in relation to Research Question 1

Code	Definition	Excerpt
Block B	Something that was said by the participant without a diagnosis of autism that generated no, little or irrelevant response to the topic from the autistic participant; i.e. something apparently unhelpful to the autistic participant	Kate: can you think of any conversation at any time that has not gone well? Have you ever had a conversation that has not gone well? Ruth (AP): erm…. I don't think so
Grease	Something that was said by the participant without a diagnosis of autism that generated further talk, reflecting further thinking about the topic by the autistic participant i.e. something apparently helpful to the autistic participant	Chloe (AP): depends on what someone is saying as to… Kate: so it depends on what someone is saying to you Chloe (AP): depends on exactly what it is, if it is… (Chloe then carries on with a clear explanation of when her jaw 'stresses out')
Uncover U	The code U was used for 'uncover', showing when the AP contributed new or unheard knowledge or ideas, in response to something said by the participant without autism	Kate: I can't remember what you said, was it the beating heart? Carl (AP): Or sinking (exploring the sensation in Carl's body)
Power balance PB	Where the autistic participant is fully engaged and having a long (but meaningful), conversation turn in relation to the established topic, where a 'finish' is reached and the other participant has a shorter or broken conversational turn so that the person is not 'overloaded'. *See below, that where the power balance is not equal, the person disengages*	A chunk of conversation where Kate and Chloe used 14 equal conversation turns, to explore the reasons for Chloe describing a conversation with a visitor as 'not a relaxing atmosphere'. Both were engaged in the conversation, where Chloe was thinking and adding ideas and worked out that a the visitor used 'different words to what you Wyn and Linda would say' and that the visitor was 'just blurting'… 'it was too fast'

Research Question 2:

What is useful for autistic adults to know about conversation?

NB The note regarding the autism context in the table below is a reminder that the code is important in relation to theory and knowledge about autism.

Table 5.2 Deductive codes derived from Research Question 2

Code	Definition	Excerpt (taken from autistic participant)
Existing knowledge of unsuccessful interaction (EKU) **Autism context –** difference in social understanding and difficulty in social interaction evidenced	Comment on involvement in bad/unsuccessful conversations or interactions	Carl: When someone is talking negatively, I would see that as a bad conversation Lee: too many interruptions, it's not going well
Existing knowledge of good/successful interaction (EKG) **Autism context –** difference in social understanding and difficulty in social interaction evidenced	Comment on experiences of good and successful conversation. Comment on experiences of good and successful conversations. Code as EKG when the conversation described was clearly good from the perspective of the autistic participant	Cait: she was helpful. We got it solved Ruth: I understood what she was saying, it was very clear
Existing knowledge of response to an interaction (EKR) Code quickly became renamed as: **Existing knowledge of their response to an unsuccessful interaction,** as response was only described in relation to situations described as	Comment where the autistic person talks about something that they thought, did or felt in response to something said or done to them in the conversation or interaction	Lee: I wanted to hit him in the face Ruth: there's a little voice in my head that said you don't have to be in this

114

'bad' (or a word carrying a similar meaning) and coded as unsuccessful (EKUR)		
A physical response EKPh

I looked for this based on my practice knowledge, so have categorised it 'deductive' | Comment on something happening within the body when the conversation or interaction is not 'right'.

The definition began as a 'physical response' but was expanded to include 'sensation' when sensation became a pattern in the data set | Chloe: my jaw started to stress out

Ruth: the sensation I got in my body was quite tensed, I was kind of stuck against the wall |
| Vulnerability

Categorised as 'deductive' because I looked for it in relation to RQ1

Autism context – vulnerability is well reported | Comment on vulnerability in interaction, whether it vulnerability is experienced, and what vulnerability means to the person | Lee: they tried to twist the questions

Ruth: Vulnerable, erm erm, I know how to describe it… erm it's really hard… possibly when you're in classes you're vulnerable there cos you don't know what to say and you're struggling to find the words like I am at the moment |

However, I also approached the data with an open mind, looking for patterns and information of unexpected particular interest in relation to the research questions. These codes were therefore data driven, 'bottom up' and so inductive; that is, data segments were not fitted into an existing coding frame, as the codes were developed in response to the data (Braun & Clarke 2006). So, when I found repeated patterns in the data, I began to define a code, and to code the data according to the definition of the code (see inductive codes examples below in Table 5.4 and Appendices 14 & 15, pp.

251–261). I considered the reliability of coding, and I aimed to define a code so that another researcher would be able to analyse the same data through coding in the same way. I tested this informally by asking a peer research student to read my code description and look to apply the code to my data. I refined the description of some codes following this process.

5.3c Approach to the deductive and inductive coding

Braun and Clarke (2006, p. 87) suggest that 'immersion usually involves "repeated reading of the data in an active way, searching for meanings, patterns and so on"'. In order to answer the research questions, I needed to consider the knowledge of the autistic participant, the approaches of the participant without autism, and the impact of these on the autistic participant and the exchange between the two communication partners, so I reviewed the data in three ways, ensuring that I was immersed in each perspective, while coding, to ensure accuracy:

1. I read the data taking the perspective of the person with ASC, in relation to Research Question 2, coding the things that autistic people actually said that they knew about conversation and found helpful; but also coding in relation to my understanding of chunks of conversation when taking their perspective. For example, Carl (AP) was asked by Mary, 'How does rage feel?' and replied, 'Not very good'. I coded this for possible difficulty with mentalising vocabulary, as it was not clear from Carl's response whether, from his perspective, he understood the words 'rage' or 'feel', and this was not further explored at that point. Using inductive coding, I gained knowledge about any areas of conversation that appeared difficult for the autistic participant. I later further explored the impact of the conversation partner on this possible area of difficulty.

2. I then re-read the data from the perspective of the participant without a diagnosis of ASC in relation to research question 1. I coded the things said by the participant without autism that enabled the autistic participant to access and use their knowledge in the conversation (within the study I referred to this process as 'how the knowledge was uncovered').

3. When focusing on the conversation exchange, I noticed 'blocks' (that is, the communication partner saying something that appeared to 'block' the thinking and contribution of the autistic participant) and 'grease' (that is, the communication partner saying something that appeared to support the thinking and contribution of the autistic participant). In the example above, where Carl (AP) replied 'Not very good', the question asked possibly served as a 'block', as Carl provided only a short response and immediately changed topic. 'Blocks' and 'grease' were deductive codes, but were then expanded upon using inductive codes, as I learned about the possible causes and types of 'blocks' and 'grease'.

4. I then re-read the data, looking specifically at my own involvement as a participant in relation to research question 1, to help me to explore *how* the autistic participant's knowledge can be uncovered and contributed to the conversation.

    I coded what I was saying in the conversation exchange in relation to deductive and inductive codes. I did this separately to ensure reflexivity when reviewing my own words. I also coded what participants without a diagnosis of autism said directly about my interaction and how this was different. I re-read all the data, noting the exchange between participants with and without autism, noting 'blocks' and 'grease' and checking that I had not missed anything that I could have coded.

5. I then read and coded the diary records using the same approach to coding.

6. I read and coded the observation records using the same approach to coding.

7. Finally, I re-read all the data and my fieldnotes to ensure that I had not missed any important aspects of the data and checked for any possible misinterpretations.

The codes used were either a descriptive code, summarising the basic topic of a segment of data, or a process code summarising the content or intention of an utterance (Miles et al. 2014). Descriptive codes and process codes labelled action in the data. (See examples of codes below in Table 5.3.)

Table 5.3 Examples of descriptive and process codes used

Utterance	Code – process or descriptive
Example 1	
Chloe (AP) 'that did not go well with that JD gym situation'	**E**xisting **k**nowledge of **u**nsuccessful conversation –
	Coded as EKU. Descriptive code
Example 2	
Kate repeating previous utterance of Chloe)) 'it did not go well'	**S**upporting **e**ngagement
	Coded as SE. Process code
Chloe 'that is when my jaw started to stress out'	

Coding was performed manually, following the framework described by Braun and Clarke (2006). I was aware that computer software is widely used in the analysis of qualitative data and that its users report benefits. For example, time is saved and reliability and validity can be considered to be greater (Seale 2005), and coding takes place in more depth and that invaluable reports can be produced (Basit 2003). However, Yin (2003) suggests that computer software packages are of most value where a verbatim record is to be analysed, or the study is aiming to derive meaning from the word usage and frequency patterns found in the text. My data analysis required more than the analysis of patterns; and Basit (2003) points out that there must be considerable investment of time in learning to use a computer-based approach, worthwhile for very large numbers of interviews, but that the software does not eliminate the need to think about codes, to reject and replace them. Basit (2003) concludes that whether to code manually or by computer software depends on the size of the project, the time available and the inclination and expertise of the researcher.

I am conducting this research on a part-time basis, have limited computer knowledge and have previously successfully used manual coding to analyse case studies, so I decided that a manual approach to coding would be most suited to my needs.

I coded words within sentences (e.g. mentalising words), whole sentences (e.g. questions) and chunks of data (e.g. power balance), so the data set was segmented in different yet meaningful ways within the context of the dialogue. Codes consisted of letters to represent the name of the code. For example, 'Existing knowledge of people differences' was coded EKPD. Different-coloured pens were used to make it easier to see the various code names. When coding, I wrote codes referring to the perspective of the person with ASC beside data segments on the hard copy of the transcriptions of the interviews on the left-hand side of the page. I wrote codes on the right-hand side of the page when coding the exchange or the utterances of the person without ASC (see examples in Appendices 21 (p. 288) and 22 (p. 289)). I coded the hard copies of jottings and emails, where relevant to the research questions.

As I reviewed and coded the data in relation to the research questions, I set up a codes log, adding inductive codes and their definitions as I found new patterns in the data, expanding codes that appeared too broad and abandoning codes that appeared irrelevant. The names of some codes were changed to better reflect what they represented. I recorded key examples of each code to support the reliability of my coding. I also added a column to show how the code had changed during the course of the data analysis, whether expanded, redefined or abandoned. (See Appendix 16, p. 262 for full code log in relation to RQ1 and Appendix 17, p. 274, for full code log in relation to RQ2.)

Table 5.4 is an example of the coding log for inductive codes in relation to Research Question 1.

Table 5.4 Example of the coding log for inductive codes in relation to Research Question 1

Inductive codes: Codes that arose from identification of repeated patterns in the things that I heard people report or say about their knowledge of conversation

Code	Definition	Example (all spoken by autistic participants)	Where the code came from/whether relevant to all autistic participants	What happened to the code
Use of an existing strategy in response to a conversation or interaction EKS	Comment on what was 'in the head'/what was thought about to inform behaviour in the situation, or comment on use of what may be described as a self-prompt strategy	Ruth: I concentrate on getting myself out of stuck mode Cait: When they asked if I had any questions, my mind just went blank, since then if I think of anything I just write it down Carl: When they talk negatively I walk off	Developed after coding of exploration of response to interaction when it became clear that autistic participants were using different strategies Examples from all autistic participants	Expanded to: Self-talk strategy Other strategy
General awareness GA	Any comment that suggested an awareness (or knowledge) of the autistic participant self or of someone else at the time of the interaction	Carl: There are lots of situations that I can't cope with Lee: When I'm in a meltdown I say things that I don't tend to mean Cait: You can't really think when you're stressing out Chloe: It was more B telling me things Ruth: There is outdoor and indoor language. My outdoor language goes indoors	Developed after a pattern of people commenting on awareness of knowledge or self became clear across the data set Examples from all autistic participants	Expanded to: EKPD Existing knowledge of people differences (see below) and merged with: Existing knowledge of strategy use Existing knowledge of physical response (see below). The GA code was then abandoned, as it was too broad

cont/

120

Code	Definition	Example (all spoken by autistic participants)	Where the code came from/whether relevant to all autistic participants	What happened to the code
Topic of conversation Topic Recognition that the topic of conversation can have a good and bad effect on the conversation (on EKU and EKG)	Any comment on the topic of conversation as having an impact on how the conversation 'went' (good or bad), from the perspective of the autistic participant	Carl: Certain subjects are to be avoided, they get me agitated Ruth: It depends what we are talking about Lee: I hate things being brought up again Chloe: A subject I didn't want to talk about, they kept asking me 'why'	Developed after a pattern became clear of the topic of conversation having an impact on whether the conversation was successful and unsuccessful Examples from all autistic participants	Topic links closely with type of conversation, but has been maintained as a stand-alone code. Topic, while personal, is clearly important to people. I was aware of the importance of 'topic' when coding non-autistic participant data in relation to 'cueing in'

5.3d Further development of codes

The need for further expansions of the codes became clear when I saw patterns within the extracted data segments collated under a single code title. For example, reviewing the data segments coded EKPh (existing knowledge of physical response), I recognised that data segments included both an actual physical response and a described physical sensation, so expanded the code to include both physical response (e.g. the jaw moving – Chloe (AP)) and physical sensation (e.g. the stomach swinging – Carl(AP)). A further example is given in Table 5.5 below.

Table 5.5 Example of expansion of 'existing knowledge of people differences' code

Code	Definition	Key example
'Existing knowledge of people differences' code (EKPD) Expanded when I saw patterns in what autistic people knew about people. The expanded codes were:	Initially, EKPD was defined as: any comment on knowing things about people. This may be personality, traits, face, behaviour, body language	Initially, all examples in this column were under a single 'EKPD' code
a) Knowledge of personal traits/ attributes	Knowledge of what other people 'are like' or knowledge of what other people 'know'	Lee (AP) 'They didn't know what I was like' Ruth 'Dad has a work mode. He has a bossy work voice. He's not bad bossy' Cait (AP) 'I know she has a sense of humour. I was surprised when she was taking it seriously, I said "don't take it seriously, she's only kidding".' Carl (AP): 'K's quite softly softly, quite understanding, like not a very direct person'
b) Knowledge of professional traits	Knowledge of what to expect from other people because of their profession or role	Cait (AP): 'You can't go any more relaxed than with your doctor, cos they know what is good for putting in your body' Lee (AP) talks about teachers telling him what to do, 'because that's what teachers do' Ruth (AP): 'I know it's OK now for her to be blunt with me, she's the manager, it's her job' Chloe (AP) talks about how support workers should listen to him 'because that's their job' In talking about her dad, Ruth is clear that she expects him to be 'bossy because he is dad'.

When coding, I became aware of some codes that appeared to become increasingly significant, as there were examples of the code from all participants, or they occurred frequently within the data from one participant. I noticed that these were the codes that were usually expanded. Other codes appeared to be bringing little illumination and understanding to the data, as there were few examples or the initial code developed appeared to have little meaning to the remaining data set.

Having completed the coding process on hard copies of the transcripts, diary records, observation records and notes, I extracted the coded data segments from the hard copies by rewriting data segments, or by using photocopied or retyped data segments (when I cut the paper to extract the section I required), clustering the data segments by code heading (Braun & Clarke 2006). Where necessary, I also kept a little of the surrounding data or made a note of the context. In this way, I avoided misinterpretation through decontextualisation, since a common criticism of coding is that context is lost (Bryman 2001).

Some emerging clustering of the data segments was abandoned when I found that the way in which I had begun to collate it was not sufficiently detailed. For example, I began to create a 'question' table to collate the data segments coded as 'question', but ceased to do this and created further codes when it became clear that the code of 'question' should be further divided. I began to notice that some data segments fell under two codes, for example an utterance might be a 'question' (inductive code) that caused a 'block' (deductive code) and consisted of vague vocabulary (inductive code). Some data segments were therefore included under more than one code.

Throughout the coding process, where I realised something was of particular interest in one data item I searched for it in other data items in other cases, enabling cross-case synthesis (Yin 2003). For example, when Ruth (AP) talked a great deal about the face of her communication partner, I looked for reference to the face of the communication partner in the transcription of Chloe (AP). She had mentioned it, but only once, so initially I had not coded it as potentially important.

5.3e Final review of the data

Having reviewed and coded the data and developed the coding logs, I then revisited the data to check for any significant uncoded data and to review the data in the context of my emerging early findings and what participants had said was important to them in the early stages of the study. This ensured that important knowledge from the perspective of the participants had not been overlooked in the detail of the analysis.

This review supported the credibility of the analysis. For example, during this final review I noticed that I had coded 'stressed' as 'use of mentalising vocabulary', but realised that I had missed the concept of stress from the autistic perspective and how the participant without autism possibly contributed to it. I had missed some data segments that should have been coded under two codes. For example, I had coded a description by Ruth (AP) of a person being 'judgmental' (her word), which she described as 'there is no way of changing that person's mind, 'cos they have got their mind set', under 'mentalising vocabulary', but not under 'EKPD' (existing knowledge of people differences). Also, where additional codes had been developed from the first-level coding process, these were added to the transcription. For instance, SE (supporting engagement) became 'Conf' (confirmation), where relevant.

In reviewing the data, I looked at the codes used to seek things that the communication partner did and said that were apparently unhelpful to the autistic participant, as well the coding relating to the direct reports from the autistic participants about what was helpful and unhelpful to them.

Also at this stage, thinking actively about the research questions, I recognised that I had abandoned 'vulnerability' as a code (although exploration of vulnerability in conversation was explicit when planning my project), since direct questions about vulnerability had not provided useful information and it was hard for participants to define the word. However, I realised that I should have included descriptions that could be interpreted as a person being vulnerable in a conversation, and so included such references under the code 'vulnerability'.

Throughout the coding process, I was aware of some necessary judgments made during the coding and the reliability of these, so was always looking for contradictions. I

125

checked my assumptions and my emerging interpretations made through the coding with the participants, to check that what I was finding made sense to the participants; that is, the codes appeared relevant to real conversation in the real world.

At the end of the iterative coding process, the data corpus had been given full and equal attention (Braun & Clarke 2006) and either discarded from the data set or coded in the context of answering my main research questions.

5.4 Searching for themes

A theme captures something important in relation to the research question and represents some level of patterned meaning or response within the data set (Braun & Clarke 2006). The themes show a progression from organisation and description of the data (codes) to interpretation of the data through identification of themes. Miles et al. (2014) describe this as 'second-cycle pattern coding', where pattern codes are explanatory or inferential and identify an emergent theme.

After completion of coding, I reviewed the list of codes for each research question in turn and actively explored which codes linked together and may be clustered under an 'overarching theme' (Braun & Clarke 2006, pp. 89). I did this by writing the codes on pieces of paper and physically grouping them together, developing an overarching label to describe and interpret each group of clustered codes as a 'theme'. I searched for both semantic themes, which were identified from the explicit or surface meaning of the data, and latent themes, which arose from ideas and meanings underpinning the actual words spoken, so some interpretation was involved (Braun & Clarke 2006) (important to my constructionist approach). I found that some initial code labels became themes or sub-themes, while some theme labels arose from the clustering of the codes (see codes clustered by theme, Appendix 18, p. 280).

I then considered the relationship between the emerging themes and wrote the themes as a first thematic map, showing the themes and the links between them. I began to note which themes appeared to be main overarching themes and which may be sub-themes falling under main themes (Braun & Clarke 2006). In some cases, the theme label was the name of an original code, for example 'atmosphere', while in others it was

a new label to describe the interpreted meaning of the group of codes, for example 'knowledge of own self and response'.

5.5 Reviewing the themes

Following Braun and Clarke (2006), I then the reviewed the themes, and as suggested by Miles et al. (2005), this enabled me to qualify rather than discount themes (or 'pattern codes'; Miles et al. 2005). The links between themes on the thematic map were reviewed and some theme labels were redefined several times before they appeared to accurately reflect and interpret the coded data. This ensured that I did not become locked into naming a pattern too quickly (Miles et al. 2014), avoiding premature theory construction (Silverman 2005) that would weaken the robustness of the analysis.

5.6 Finalising the themes

Having developed the themes, I revisited the codes and the coded data clustered within each theme. I checked that the codes and data did in fact form a pattern described or interpreted by the theme label (Miles et al. 2014). I read all the data segments that were coded under the theme and considered the validity of the theme (Braun & Clarke 2006); I checked that there was sufficient data across the data set within the theme and that the codes clustered as a theme pattern. I also checked that all working codes had been allocated or meaningfully merged or discarded (Braun & Clarke 2006). Not all code labels appear in the thematic maps, as they were discarded or renamed.

5.7 Defining and naming themes

To demonstrate that my analysis had answered my research questions, I defined each theme, capturing its essence (Braun & Clarke 2006, p. 92) in relation to each research question in turn (see Appendix 19, p. 282). I created thematic maps showing themes and links between them for Research Questions 1 and 2. These are included as Figures 5.1 and 5.2, below.

RQ1. How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?
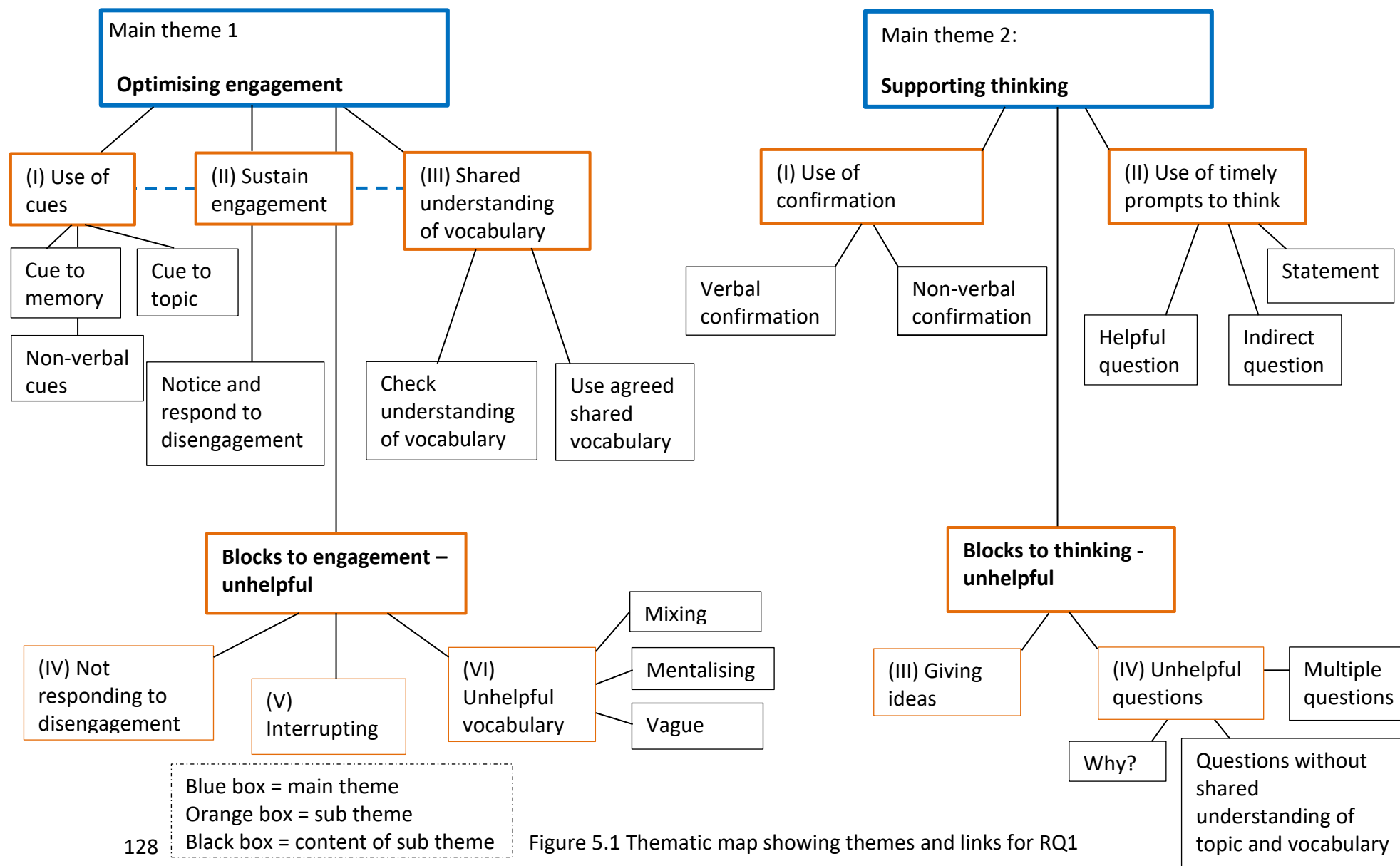
Figure 5.1 Thematic map showing themes and links for RQ1
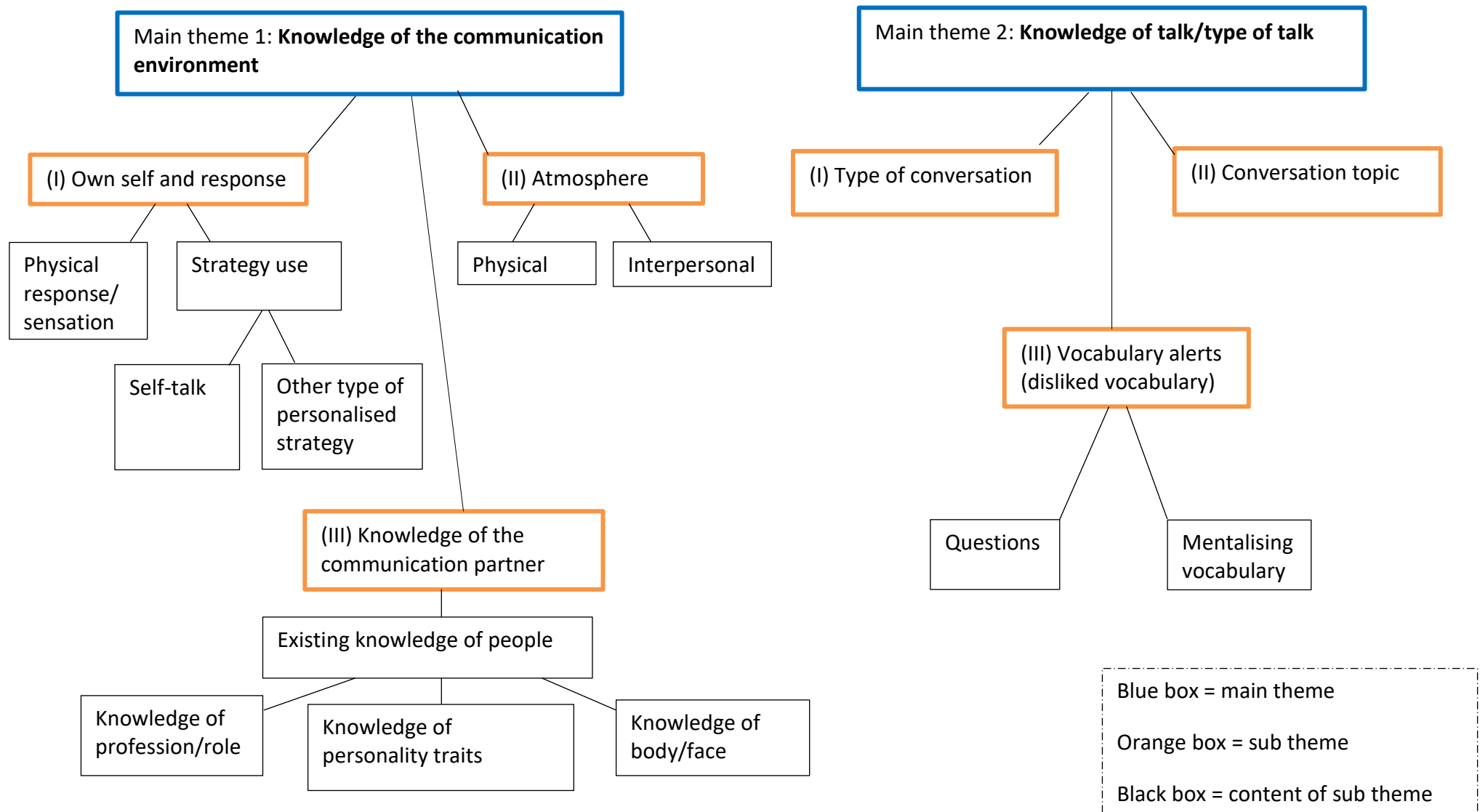
128

RQ2: What is useful for autistic adults to know about conversation?

Figure 5.2 Thematic map showing themes and links for RQ2

Main theme 1: **Knowledge of the communication environment**

(I) Own self and response

Physical response/ sensation

Strategy use

Self-talk

Other type of personalised strategy

(II) Atmosphere

Physical

Interpersonal

(III) Knowledge of the communication partner

Existing knowledge of people

Knowledge of profession/role

Knowledge of personality traits

Knowledge of body/face

Main theme 2: **Knowledge of talk/type of talk**

(I) Type of conversation

(II) Conversation topic

(III) Vocabulary alerts (disliked vocabulary)

Questions

Mentalising vocabulary

Blue box = main theme

Orange box = sub theme

Black box = content of sub theme

> *In what ways can learning and knowledge about conversation be used in*
>
> *everyday conversation by autistic adults and their communication part*ners?

In the final semi-structured interviews, I talked with autistic participants and participants without autism about their learning during the study and about how they had used their learning. At this stage, I also reviewed the 'keeping in touch' emails and conversations with the participants without autism to ensure that I had understood their reporting to me correctly and to probe where I was unclear or wished to know more about what had been reported. During the interviews, I made jottings where I noticed that autistic participants were using new knowledge or learning. I analysed the final semi-structured interview and the 'keeping in touch' conversations and emails after I had completed all analysis relating to Research Questions 1 and 2, described above. I specifically looked for comments linked to the themes identified within Research Questions 1 and 2 when reviewing the data for each participant relating to Research Question 3. However, I also kept an open mind and looked for any other common themes. This enabled me to use the final semi-structured interview as a check on whether the themes on my thematic maps accurately represented what appeared to be important to the participants in the real world, as well as listen for new themes. The common themes are summarised in Table 5.6 below.

Table 5.6 How knowledge is used by autistic participants: common themes between participants

Knowledge used	Comment regarding link to an existing theme and meaning
Autistic participants	
Greater awareness of what is important during conversation and increased confidence in letting others know this	This became a new overarching interpretative theme, 'knowing what is important to me in conversation'. Comments made by the participants revealed a greater confidence in their knowledge of what is important to them in conversation and felt able to let others know this
Use of knowledge about people: knowing what people are 'like' helped to know what people	Links to the theme 'knowledge of communication partner'.

might do/how they might act	All participants spoke of the value of 'knowing' things about people to predict what people may and to feel more in control of the conversation
Use of recognising the 'type of conversation'	Links to the theme 'type of conversation' All participants spoke of the value of recognising the different types of conversation, even though they had different personalised labels for the types of conversation, for example, 'conclusion solving' conversation, banter, getting instructions conversation
Conscious awareness of the physical response or physical sensation as a cue to knowing something is not right and to 'think' or problem-solve sensation	This is within the 'physical response/ sensation' sub-theme. All participants talked about using their experience of a physical response or sensation as an indicator that they may need to think or do something different in a situation

Participants without a diagnosis of autism

More aware of the need to maintain a balance in conversation	Within the theme of 'notice and respond to disengagement' and the sub-theme of 'meaningful power balance'
Greater awareness of own vocabulary and language use, especially questions	Within the 'blocks to engagement' and the sub-theme of vocabulary and also within the theme of 'blocks to thinking' and the sub-theme of 'questions' and 'use of timely prompts to think' and the sub-theme 'helpful questions'
Greater awareness of the importance of allowing time for thinking and development of solutions	Within the theme of 'use of timely prompts to think'
Use of the themes found useful to the autistic participants in this study, with other autistic people	Participants without a diagnosis of autism who work with other autistic people, all talked about how they had used the learning above with other autistic people

(see Appendix 20, p. 286, for common themes of learning and examples from

participants)

5.8 Variations within the participants' data

During the data analysis process described above, I searched across the data for themes common to all participants, and these are described in Table 5.6 above. However, I am mindful that, as the heterogeneity of autism is well documented (e.g. Masi et al. 2017), it was important for me to recognise that aspects of the learning identified in the themes above would be useful to a greater or lesser extent to the participants, depending on what was important to them and their own current knowledge and abilities in conversation. Also, I was aware that the learning may be used by the participants in different ways (for example to plan conversations, during conversation or to review conversations after they had taken place). I therefore revisited the data to look at the journeys of the 'participant pairs' (i.e. each participant without a diagnosis of autism working with the autistic participant) to uncover the themes that each participant pair identified as most important and useful to them during our review of learning. These are presented and discussed in Chapter 6.

Chapter 6 **Findings**

6.1 My approach to reporting the findings

I wanted to keep in mind the individuality of each participant, as well as recognise some commonalities across all participants, where findings may be relevant to the wider participant group. I also wanted to maintain focus on the 'exchange' in conversation and on the autistic perspectives, as these concepts are central to this study. I begin by exploring the identified themes relating to Research Questions 1 and 2 in relation to the wider participant group during the conversation exchange. I then report on findings in relation to Research Question 3, including the learning by each participant dyad and how this was used in everyday situations outside the study, as well as my own learning as a participant in the study. The themes are summarised and defined in Appendices 18 (p. 280), 19 (p. 282) and 20 (p. 286), and the links between the themes are shown on thematic maps in Figures 5.1 and 5.2.

6.2 Research Question 1 (see Figure 5.1, Thematic map)

> *How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?*

This question asks about the communication behaviour of the communication partner without autism, that is, what the non-autistic participant said and did that enabled the autistic participant to contribute more to the conversation and especially to contribute new or previously unheard knowledge.

In responding to this research question, the concepts of 'grease' (helpful communication by the communication partner) and 'blocks' (unhelpful communication by the communication partner) were important. I thought of what had been said by the non-autistic communication partner as 'grease', or helpful, when it had the impact of enabling further meaningful contribution to the conversation by the non-autistic participant. By contrast, I considered the non-autistic communication partner to have possibly caused a 'block' or been unhelpful to the autistic participant's thinking and contribution to the conversation when the autistic participant apparently became disengaged and contributed little to the conversation.

In relation to each main theme, I was able to consider sub-themes together reflecting helpful communication behaviours by the non-autistic communication partner and consider sub-themes together that reflected unhelpful communication behaviour. The themes and sub-themes are listed below and shown in Figure 5.1.

Main theme 1: Optimising engagement

Sub-themes:

(i)   Use of cues
(ii) Sustaining engagement
(iii) Shared understanding of vocabulary used

The above are all helpful to optimising engagement of the autistic participant ('grease').

(iv) Not responding to disengagement
(v) Interrupting
(vi) Use of unhelpful vocabulary

The above are all unhelpful in optimising engagement of the autistic participant ('blocks').

Main theme 2: Supporting thinking

Sub-themes:

(i) Use of confirmation
(ii) Use of timely prompts to think

The above are helpful to support the thinking of the autistic participant ('grease').

(Iii) Giving ideas
(iv) Unhelpful questions

The above are unhelpful to supporting thinking of the autistic participant ('blocks').

6.2a Main theme 1: Optimising engagement
I learned that good engagement by the autistic participant was reflected in a series of conversational turns on a topic, where the autistic participants contributed their own

thoughts and knowledge to the conversation. There was prolonged and at least equal contribution to the conversation.

Sub-themes (i) to (iii) reflect communication behaviour of the non-autistic participant that is helpful to optimise engagement of the autistic participant.

(i) Use of cues

Analysis showed that use of cues by the communication partner relating to topic, conversation type (e.g. problem-solving) and memory were helpful. These cues supported the engagement of, and contributions from, the autistic participant. An effective cue was often not just a single conversational turn, but a series of turns supporting the contribution of the autistic participant, focusing their memory and attention on the topic and type of conversation. The following example shows how I used cues to enable Chloe (AP) to recall a conversation from the previous week (memory) and to make clear what the conversation now was to be about (topic):

> Kate: What day did I come here? (*cue to memory)*
>
> Chloe (AP): you came on Friday wasn't it?
>
> Kate: You're right, it was Friday
>
> Chloe: when Barb was here (*memory of Friday confirmed*)
>
> Kate: When Barb was here… How about the Barb conversation to talk about? (*cue to topic*)
>
> Chloe: That did not go well with the JD gym situation with Barb (*confirmation of the topic and the memory of the conversation*)

Without such 'cueing in', I found responses given were more likely to be stock responses or single words, such that the autistic participant's new or existing knowledge was not heard within the conversation.

(ii) Sustaining engagement

Where the participant without autism saw a stock response or irrelevant response as possible disengagement, they were able to use cues to guide the autistic person back to the initial topic, and this enabled the re-engagement of the autistic person. This re-engagement enabled further thinking and conversation contributions, as well as

exploration of knowledge or ideas. The data showed that where the autistic participant appeared to switch topic, it was important to acknowledge what they had said and then create a 'bridge' back to the topic. For example, Oscar (communication partner without autism) said, 'I lose him, but then go to what he was talking about and then walk back to my topic'.

A meaningful power balance was important for engagement to be sustained and optimised. Where the non-autistic participant took long conversational turns, the response of the autistic participant was usually short and rarely revealed new or previously unheard knowledge or opinion. However, interestingly, it was also important for the non-autistic communication partner to notice when the autistic participant was taking long conversational turns, sometimes moving between topics and not revealing new knowledge relevant to the original topic. For example, during the first two semi-structured interviews Carl (AP) took long conversational turns, describing past events, and it was difficult for me to find a way for the conversation to feel more equal, whereby Carl and I had a consistently shared understanding of the topic, and Carl contributed to it. Being aware of the power balance and ensuring that this enabled meaningful contribution of the autistic participant was therefore important to sustaining engagement.

(iii) Shared understanding of vocabulary used
Further engagement and contribution to conversation and the development of ideas were supported when the conversation partner checked the understanding of the vocabulary used and invited the autistic participant to provide their own words for a concept, which were then used by both conversation partners. Words chosen by the autistic participants were often 'novel' words; that is, words or concepts that may not be generally used, understood or applied to talk about that specific situation. For example, 'conclusion solving' was used by Chloe (AP) to describe a particular type of conversation, as she understood it.

It appeared that discussion relating to the vocabulary to be used supported greater engagement and understanding by the autistic participant. In the example below, Ruth (AP) talked with me about the 'tension' that she experienced. Exploration of the word

'tension' and the choice of word preferred by Ruth (AP) revealed more about her experience of 'tension' and how she could talk about it:

> Kate: where do you feel the tension most?
>
> Ruth: in my legs
>
> Kate: in your legs
>
> Ruth: Sometimes when I am in that situation I get the feeling like I am stuck in mud
>
> Kate: I like those words, shall we use those words?
>
> Ruth: Yeah, 'cos I can't get out of that situation like I'm stuck in the mud really
>
> Kate: And when you have the sensation of stuck in the mud, what do you do?
>
> Ruth: I tend not to listen, really

The next sub-themes, (iv) to (vi), relate to unhelpful communication behaviour by the non-autistic participant, potentially causing 'blocks' to engagement of the autistic participant)

(iv) Not responding to disengagement

Where the communication partner without autism did not notice possible disengagement of the autistic participant (seen, for example, in reduced contribution to the conversation, reduced apparent thinking or topic switch), the conversation appeared to become stuck (or 'blocked') and further contribution by the autistic participant did not take place.

(v) Interrupting

Where the conversation partner interrupted or finished a sentence of the autistic participant, or summed up what had been said too soon, the autistic participant often appeared to lose their train of thought and their contribution to the conversation was reduced. For example, below, Mary and Carl (AP) talked about physical sensation:

> Carl (AP): I think I mentioned it before…. I feel a deep pit in my stomach and my heart flutters but the main one is the deep pit in my stomach…
>
> Mary: Does that make you feel sick? (*interrupt*)

Carl: It can do, yeah (*short response*)

Mary: What else?

Carl: I dunno (*appears that train of thought has gone*)

My comments are in italics.

In the example above, Mary's questions were intended to help Carl (AP) to think further about the sensation and give further description, yet it appears that they had the opposite effect, as Carl's responses gave no further information. Recognition of interruption by the communication partner without autism was also important as, where knowledge of the autistic participant was heard, thinking was supported often over a number of conversational turns (see sub-theme (i) above, relating to use of cues), enabling the autistic participant to focus on the topic.

(vi) Unhelpful vocabulary

Disengagement and reduced contribution to the conversation occurred where the participant without a diagnosis of autism used vocabulary that was possibly unclear to the autistic participant. When mixed vocabulary was used, as in the example below, disengagement occurred.

Lee (AP): I like *men* and women but I dunno, it's towards the men because I'm always with the men more than the women

Rachel: Ok….. you like men more than women

Lee (AP): Yeah, but I also like girls and lads as well (*vocabulary changed but not explored*)

Rachel : OK, so you say you like *boys* more because you know more boys (*vocabulary for male changed again but not clarified*)

Lee: Yeah (*disengagement*)

Where vague vocabulary was used, it was difficult to know whether the autistic participant actually understood what was being asked, especially when a minimal response by them was given, for example:

Oscar: In terms of the strategies, what is your feeling on *those*? (*words in italics are vague and it is not clear that there is shared understanding of these words*)

Lee (AP): I've used *them* a few times, sometimes I forget *they* are there (*what is being talked about is not clear*)

Oscar: Do you think they help? (*what is being talked about is still not clear*)

Lee: Yeah (*disengagement*)

Oscar: So are you happy with *the strategies*

Lee: Yeah (*disengagement*)

The autistic participant did not always indicate that they did not understand the words or were confused by them. This could lead to misunderstanding if the communication partner without autism does not notice this, and shared understanding is assumed.

Where mentalising vocabulary was used, the conversation could appear to become stuck unless a shared understanding of the mentalising words was established, as in the following two examples:

Mary: You were very upset, so when you became very upset, how did you feel inside?

Carl (AP): Totally agitated

Mary: What does totally agitated feel like? (*it is difficult to know how relevant this is*)

Carl (AP): Upset, wrath (*these appear to be words learned as they do not further describe any personal feeling and repeat 'upset' from above*)

Silence followed (*no further contribution, so no further understanding gained of the situation being described*)

Ruth (AP): I used to feel stressed as well

Kate: Is there a difference between stressed and anxious?

Ruth: Erm there can be

Kate: There can be?

Ruth: Yeah, sometimes it can be a bit of both, a mixture of the two, sometimes I find them hard to understand

During the extended conversation, Ruth was using both 'stressed' and 'anxious', but above it became apparent that her understanding of the words was unclear.

During the analysis, I learned that Cait (AP) did not use a mentalising vocabulary and I asked her and her mother about this. They confirmed that Cait uses only 'panic attack' to describe negative mental states and avoids using other mental-state words. It is therefore important for the communication partner to be aware of gaps in vocabulary as well as the vocabulary that is used by the autistic person, in order to uncover the way in which the autistic participant talks about experiences.

6.2b Main theme 2: Supporting thinking

I learned that 'supporting thinking' appeared to take place when the communication partner without autism said or did something that resulted in the autistic participant appearing to be able to consider and develop an idea, or to consider and access existing knowledge; and then to contribute what they know to the conversation.

Sub-themes (i) and (ii) relate to communication behaviour that is helpful to support the thinking of the autistic participant.

(i) Use of confirmation

Autistic participants often contributed existing knowledge or new thoughts to the conversation when the participant without autism confirmed that what they had said had been heard and/or understood. It seemed that the confirmation enabled participants to have the time and space to think. In the example below, I am talking with Chloe (AP) about an earlier conversation:

> Chloe: it was more stressful, more frictional, it wasn't a relaxing atmosphere like it is today
>
> Kate: you're right, it wasn't a relaxing atmosphere (*confirmation*), I wonder what it was that made it not relaxing?
>
> Chloe: mmmmm
>
> Kate: it's hard to say (*confirmation and allowing time*)
>
> Chloe: hard to pinpoint exactly
>
> Kate: mmm I don't know (*confirmation* and *allowing time*)

Silence (*allowing time but showing listening*)

Chloe: Oh, I know what it was, it's just clicked in. You talk slower, it's like the speed she was talking. People can talk very fast. You know we said earlier that me putting my point across was stressing me more because I wanted this gym, and the wording that Barb was saying was different to the wording that you and Wyn would say.

In the example above, I allowed Chloe the thinking time and space by not adding anything to the conversation, but watching and listening to Chloe's responses to ensure that she remained engaged and appeared to be thinking on the topic. Allowing her this time to think enabled Chloe to recognise two things that she had found difficult about the earlier conversation (the pace of speech and the vocabulary used).

It was also important for the participant without autism to use the perspective of the autistic participant when giving confirmation, avoiding giving an unchecked interpretation of their words. For example, when Lee (AP) commented that he 'liked lads', Rachel responded 'so you are more in favour – you like men more than women'. This appeared to be an interpretation of what Lee said rather than a confirmation, as he had not actually suggested a preference of 'lads' over 'women'. When reflecting on use of these words, Rachel said her words were intended as a confirmation and to help Lee's thinking. She agreed that her words functioned as an interpretation rather than as intended confirmation.

(ii) Use of timely prompts to think

Autistic participants responded to some direct and indirect questions and statements as prompts to think, and then gave an idea or knowledge not previously heard during the conversation. A range of question types enabled thinking and ideas to be shared. Helpful questions were usually grammatically simple. Indirect questions (for example, use of rising intonation to infer a question) and statements used as prompts to think worked in the same way as the helpful questions.

However, the timing and content (i.e. following the train of thought of the autistic person, rather than introducing a new idea) of the questions or prompts to think were most important. Questions were only successful as prompts to think when asked at the right time.

Themes (iii) and (iv) reflect behaviours by the participant without autism that appeared to inhibit or fail to support the thinking and contribution of thoughts and ideas to the conversation by the autistic participant.

(iii) Giving ideas

When the communication partner without autism gave an idea to the autistic participant that was quickly accepted and not commented on further it appeared that, having heard the idea presented, the autistic participant ceased to think further for themselves. For example, Carl (AP) had been talking about an incident with a peer who had called to see him at his flat:

> Mary: after it happened, you and I had a talk and you said you didn't know how to tell Dan that you wanted time alone (*idea given regarding what happened*)
>
> Carl (AP): that is true (*brief response, immediate agreement*)
>
> Mary: so it was easier for you to threaten him and for him to leave than actually to say 'no' to him? (*idea given, which is not checked*)
>
> Carl: that is true, yes (*brief response, immediate agreement*)
>
> Mary: so is that more about you worrying about upsetting him, so it was easier to shout and get the staff to do it? (*idea given*)
>
> Carl: yeah, that's what I meant (*brief response, immediate agreement, then topic change*)

In the next example, Cait (AP) was talking about a situation where she had been asked to go for a drink by her friend, but she did not want a drink, and she found the conversation difficult:

> Isla: You could have just gone for coffee. *(Giving idea)* How would you have felt if you had just gone for coffee?
>
> Cait (AP): I would have felt all right (*immediate response*)
>
> Isla: Yes, so you could have just said that then (*confirming own idea*)
>
> Cait: that's what I should have said (*no apparent ownership or engagement in what Cait felt she could have done in that situation, but agreeing with Isla, then silence*)

Here, Isla gives an idea to Cait (AP) about what she could have done in a difficult situation rather than uncovers Cait's own thinking about it and her own solutions. Giving the idea appears to function as a 'block', as Cait does not engage or discuss the idea but immediately accepts it.

(iv) Unhelpful questions

'Why' questions: All autistic participants reported a dislike of 'why' questions, and the impact of some of these could be seen in the data. In the following example, Ruth (AP) was describing a difficult situation with a peer to Lara:

> Lara: Why do you think you had a problem with her?
>
> Ruth (AP): I don't know, I really don't

The conversation then moved in a different direction. It seemed that the use of the direct 'why' question did not support any thinking or understanding of the situation by Ruth, nor the uncovering of any knowledge about the person. Similarly, in the example below, Carl (AP) was talking about feeling vulnerable in the workplace:

> Mary: you said you are vulnerable from other co-workers. Why is that?
>
> Carl (AP): I said on the website that I had Asperger's. You know the programme, the Office…? (*Carl then continues to talk about the Office*)

In the example above, Carl does not respond to the 'why' question. He appears to change topic to talk about a TV programme, and his understanding of knowledge of feeling vulnerable in the workplace was not explored further.

In both the examples above, use of the 'why' question appears to have failed to support thinking by the autistic participant and so failed to uncover knowledge or understanding about the people and the social situation that could have been useful to the autistic person.

Multiple questions: Several questions asked one after the other during a series of conversational turns appeared to result in a 'block', where the response from the autistic participant was a single word or other response, suggesting lack of engagement. In the next example, Lee (AP) was talking with Oscar about staff:

> Oscar: Do you like working with Mike?
>
> Lee (AP): Yes
>
> Oscar: Can you tell me why you like working with Mike in particular?
>
> Lee (AP): Because he's male (*immediate response, no evidence of the thinking leading to this response*)
>
> Oscar: So that links to other things we have discussed, doesn't it?
>
> Lee (AP): Social development stuff, that's what it is (*immediate response, which is not further explored, so no evidence of what Lee may mean or understand by 'social development stuff'*)
>
> Oscar: So would you value more male input at college?
>
> Lee (AP): Yeah (*immediate short response, possible lack of engagement and thinking*)
>
> Oscar: Ok right. How are things at home?

Here, Lee (AP) gives immediate responses, and the knowledge and understanding relating to his responses are not explored. Having given a prompt to think, it was important that the participant without autism allowed time for the autistic participant to think in order to avoid causing a 'block' to thinking.

6.2c Research Question 1: Findings summary

In summary, the above themes showed that knowledge was best contributed by the autistic participant when the participant without autism enabled them autistic to become engaged with the topic, using cues and shared vocabulary so they remained engaged in the conversation; then supported thinking, enabling the autistic participant to contribute more to the conversation, possibly sharing knowledge or ideas previously unheard.

By contrast, contribution tended to become stuck or 'blocked' if a request to think (such as a question, statement or indirect question) was made prior to the autistic participant

being focused on the topic and both participants having shared understanding of the topic and vocabulary relating to it. In this case, the request to think was unhelpful. Further, an intention by the non-autistic participant to be helpful to the autistic participant, including giving ideas or suggestions and asking questions to try to understand the reason for something, for example 'why', often seemed to function as a 'block'.

My clinical work is always on focused on what works well in order to build on this rather than focus on what is not working, but it became apparent that I also needed to focus on what was not working and what was 'unhelpful'; that is, what was causing 'blocks' in thinking and contribution to conversation. The failure by the communication partner to recognise the 'blocks' to thinking and to accept responses that are not thought through may cause vulnerability through misunderstanding for the autistic person.

I noticed that with the exception of the theme of 'failing to notice and respond to disengagement', the 'blocks' involved the communication partner *actually saying* something that functioned as a 'block' rather than *failing to do something* to create 'grease'. That is, 'blocks' were often based on the presence of particular communication styles or words rather than the absence of cues or ways of supporting engagement. In reporting the findings, I therefore paid as much attention to the 'blocks' created during the interaction by the communication partner without a diagnosis of autism as to what the communication partner said and did to support the thinking of, and contribution to, the conversation by the autistic participant.

Also of particular interest to me was my learning about use of questions by the participant without autism. The potential impact of these on the autistic participant's response was more complex than I had first thought. When I began the data analysis, I saw a number of instances when a question had clearly been unhelpful and had led to a 'block'. This led me to a (premature) assumption that questions served as 'blocks' to thinking. It was only through finding contradictions during further analysis, where I saw that questions could also elicit knowledge, that I learned that the timing of the question and the way in which a question is asked are of particular importance. It appeared that cueing to the topic and ensuring that the autistic person had time to think and develop

their thinking were as important as the question type itself. I noticed that questions of similar complexity in relation to grammar and vocabulary could function as either a 'block' or a prompt to think, depending on when they were asked in the conversation. I also noticed that some very simple questions could serve as a useful cue to memory, for instance 'What day did I come here?'

I looked at contradictions in relation to the findings for Research Question 1. I then recognised that the impact of the communication partner saying or doing something unhelpful and apparently causing a 'block' to thinking and contribution was important to the autistic participants in various conversations to varying extents. This was not something that I had explicitly considered or tried to define beforehand. I realised that the impact of the communication partner was most important when the topic of conversation appeared more important to the autistic participant (as in my examples in the introduction with the social worker and the benefits assessment). For the purpose of this study, I call these 'significant conversations' and my working definition of this developed as 'a conversation that potentially has a future impact on the autistic person and how they may plan, feel or approach a situation, going forward'. This contrasts with other kinds of conversations, which appear to have little significance to the people involved, where there is no evidence of raised or reported raised levels of emotional arousal or that the conversation had potential future impact on the autistic person. Within the data set, examples of significant conversations included:

- Exploration of difficult subjects. For example, discussion regarding Lee's sexuality (Lee and Rachel).
- Problem-solving in relation to a situation that appeared to be causing a raised level of emotional arousal (this term is used as it can be difficult to be sure of the emotion aroused) or anxiety to the autistic participants. For example, Chloe choosing a gym, Cait needing trousers to be shortened, Carl experiencing conflict with co-tenant and Lee finding peers noisy.
- Conversations where the autistic person appeared to experience potential vulnerability. For example, Ruth having a difficult conversation with tutor and with a peer, Chloe and Lee both experiencing vulnerability to the suggestions of others and Cait having difficulty in interaction with work colleagues.

146

Reflecting more generally on the overall findings relating to Research Question 1, I suggest that a high degree of reflection and reflexivity on the part of the participant without autism is required in order to recognise what has been said or done to either promote or 'block' contribution to the conversation by the autistic participant.

6.3 Research Question 2 (see Figure 5.2, Thematic map)

What is useful for autistic adults to know about conversation?

Research Question 2 asks about what autistic participants know and find useful in conversation. The overarching finding was that the autistic participants did have knowledge about what was important to them personally in conversations with others. Different participants found different aspects or knowledge relating to conversation most important to them (see RQ3 findings, section 6.4), but all reported that recognising what is personally important to them to know was helpful. The findings are reported in relation to the following themes:

Main theme 1: Knowledge of the communication environment

Sub-themes:

(i) Own self and response

(ii) Atmosphere

(iii) Knowledge of the communication partner

Main theme 2: Knowledge of type of talk

Sub-themes:

(i) Type of conversation

(ii) Conversation topic

(iii) Vocabulary alerts

6.3a Main theme 1. Knowledge of the communication environment

Knowing what to think about in the communication environment (including both the physical environment and the people within it) was helpful to autistic participants. The sub-themes follow.

(i) Own self and response

Autistic participants talked about awareness of a physical response or sensation within their own body when a conversation or interaction was not going well. They were able to use this awareness as a trigger to use their thinking to use self-prompt strategies in order to plan how to make the situation better, for example:

> Chloe (AP): it did not go well
>
> Kate: it did not go well
>
> Chloe: that was when my jaw started to stress out, … which does happen in every stressful situation

Chloe recognised that clenching her jaw (which she refers to as her jaw 'stressing out' or 'going') happens when she is in an uncomfortable situation. When Chloe notices her jaw, she knows that something is not right for her and she uses this as a prompt to begin problem-solving. She gave the following example:

> I was in the car on the way to the gym with Wyn, I could feel it going. We planned the meeting then it was sort of reducing…. problem-solving was the outcome.

Ruth (AP) described a 'sensation like I am stuck in the mud' when things are difficult, which she shortened to 'stuck mode'. She later described how she was able to use this feeling as a self-prompt, saying, 'there's a little voice in my head that says you don't have to be in this situation, you need to get yourself out of it'. Ruth went on to describe how, having recognised that she needed to get out of a situation, she sometimes thought 'reverse back out of it' or 'take a back seat on this now, see what it's like then try again'.

Autistic participants reported that recognising and using a physical response or sensation helped them to feel more in control or more confident in a social situation, but described the physical sensations without attaching any mentalising words to describe an emotion being experienced by themselves at the time. This finding links with the finding in relation to RQ1 that use of mentalising vocabulary by the non-autistic participant caused a 'block' to thinking and contribution to conversation, at times. Recognition of physical responses or sensations may have value in place of an

emotion word to describe how something feels. Communication partners were able to talk about the leg (Lee – AP) or the jaw (Chloe – AP) in place of asking how the autistic person was feeling.

(ii) Atmosphere

Autistic participants reported that some environments were easier to talk in than others and discussed disliked aspects of a physical environment. For example, an environment with interruptions, unpredictable behaviour by others or noise was disliked by Lee. When asked to reflect on the first semi-structured interview, Lee said: 'it wasn't going well with all those interruptions', yet he had not specifically commented on this when the interruptions were happening (a phone ringing in a bag and a person entering unexpectedly).

Lee (AP) disliked the ticking clock in a room but, when we asked Ruth (AP) about this, she reported that the ticking clock did not concern her. Cait (AP), however, also disliked busy and unpredictable environments. Ruth says that she now asks her friend to 'turn her voice down a bit' when she finds it too loud.

It is clear that all participants had preferences in relation to the physical environment and knew what these were, even though they had not always previously talked about these. It is also of note that the different autistic participants had different preferences, meaning that assumptions about the preferences of people with autism as a homogenous group should be avoided. Autistic participants reported that being more aware of disliked and preferred environments enabled them to indicate their dislikes to others and, where possible, to make changes to the environment.

The interpersonal environment was also important. All autistic participants reported that some people were easier to talk to than others. For example, Chloe identified that a person who talks too fast is not helpful to her, and Cait and Lee both disliked environments where many people were talking. Autistic participants identified that feeling listened to, or 'having my say' (Ruth), was important. This crucially linked to 'power balance'; that is, a feeling of being 'equal' in the conversation and being able to have a say.

(iii) Knowledge of the communication partner

The data analysis showed that autistic participants used knowledge of people's professions, personalities and usual face and body postures to support their understanding of people in conversations. For example, talking about her manager in the first semi-structured interview, Ruth (AP) described how she sounded bossy and had a stern face. She later reflected that the manager had to be like this because she was in charge and needed people to do things, so her sounding bossy no longer bothered Ruth. In other words, Ruth recognised the traits associated with the role of manager and ceased to be concerned about how the manager spoke to her. Talking about his teacher, Lee (AP) said, 'I don't like being told what to do', but then, using knowledge of people linked to profession, he recognised that 'telling is the teacher's job'. He had knowledge about the role of a teacher and could use this to inform his expectations of that conversation.

Autistic participants also demonstrated knowledge of others' personality, which was useful to them. Showing knowledge of her father's personality, Ruth said,

> Sometimes he does not switch off from his work mode, he has his work mode at home as well, so he will say 'right Ruth, you do that, you do that'…. It doesn't bother me, I know my Dad and he has done it for years.

Cait (AP) talked about the differences between two GPs at her surgery:

> The younger one… really listens, really switched on….the regular doctor has been with the company quite a while… you feel like you are getting pushed out of the surgery.

This knowledge enabled Cait to know what to expect from each GP when she attended an appointment and so reduced her anxiety about the appointment.

Cait (AP) also talks about joking with one of the managers at work, 'because he likes to joke', but would not joke with the other manager. She said that this knowledge is useful to her and enables her to feel more confident in her interactions at work. Cait commented that she would not joke with her dad 'because Dad doesn't do joking'. Cait likes to joke, so having this knowledge about other people and their response to joking

enabled her to avoid joking with people who do not like this and so avoid an unsuccessful interaction.

Autistic participants also had knowledge of body language. For example, Lee commented that he knows not to approach his teacher when she puts her hands on her hair because it means 'she is stressed and won't listen'. He says that once he learned this, the number of bad conversations with his teacher reduced.

Showing knowledge of Lara's 'body language', Ruth (AP) said,

> She has her normal face, but I know when she is busy or when she is flustered, she grabs her hair like this. (*Ruth then demonstrated how Lara runs her hands through her hair*)

Ruth is able to use this knowledge of people to understand what she hears and sees and therefore to inform her own response to this; that is, she is not concerned about her father's work mode and knows to stop talking when Lara looks flustered. Interestingly, Ruth said that she can 'pick up different people's vibes', which appeared to refer to having some knowledge about people, but was unable to describe this concept further.

Using existing knowledge about people's individual traits was useful to all autistic participants. It enabled them to know what people may do, thus increasing the predictability of other people to them. It also enabled them to know when something done or said was 'unusual' for someone and to begin to think what may be causing the person to be 'unusual' and whether it would affect them personally and/or what they should do.

6.3b Main theme 2: Knowledge of talk/type of talk
The sub-themes for the second main theme of knowledge and type of talk follow.

(i) Type of conversation
Autistic participants reported that knowing the type of conversation enabled them to know what was expected of them (e.g. thinking is expected in a problem-solving conversation) and know what the conversation partner may say or do, meaning that they felt more able to contribute to it. Autistic participants labelled different types of conversation, including, for example: 'bollocking' conversation (Lee); conclusion-solving

(Chloe); and agreeing (Ruth). Lee talked about how knowing the type of conversation enabled him to know 'when to switch the brain on', while Ruth talked about knowing when she needed to think 'super hard'. This finding links to the finding relating to RQ1 that cues given by the communication partner were important to support engagement of the autistic person in the conversation.

(ii) Conversation topic

From their point of view, autistic participants reported that they liked to be clear about the conversation topic. For example, during her involvement in the study Chloe (AP) recognised how important it is for her to know the topic of the conversation and so, prior to having a conversation important to her, Chloe will now list exactly what she wants to talk about (for example, the gym, the cost and the trainer). Chloe and the conversation partner then both know which topic they are talking about. This finding relates directly to the finding above that cues to topic by the non-autistic communication partner support the engagement of the autistic participant.

(iii) Vocabulary alerts

All autistic participants reported a dislike of some vocabulary (for example, talking about feelings) and types of sentence (too long and complicated or questions). For example, Cait, Ruth, Chloe and Lee all commented that they disliked 'why' questions or too many questions. Talking about 'why?' questions, Chloe said 'it pressures you to get the answer' and 'if no one's asking me a question, I can explain it without someone asking me why'. Ruth commented, 'I didn't really want her to ask all the "why" questions'. This finding reflected an internal reliability between my observations and interpretations of where 'blocks' to thinking occurred and the autistic participants' own perspectives. Autistic participants reported that it was helpful for them to become more aware of words that they disliked in order to be able to let the communication partner know this. For example, Chloe now says, 'You know I don't like "why" questions', while Lee now lets Oscar know that he needs time when presented with words that he does not like.

This finding relates directly to the finding that when the non-autistic communication partner checked that there was shared understanding of vocabulary used and avoided

152

unhelpful vocabulary, the contribution to the conversation of the autistic participant was greater.

6.3c Research Question 2: Findings summary

In summary, the above themes suggest that autistic participants liked to 'know' things about the conversation and the people in it. This knowledge meant that the participants were more able to predict what may happen in the conversation, meaning that they felt better prepared for it. Awareness of physical responses in their body meant that they and were more able to use a self-prompt strategy (e.g. 'I need to get out of here') when they recognised that the conversation was not going as anticipated.

Moreover, 'knowing' things about their own likes and dislikes in a partner's communication enabled them to make requests of the communication partner (e.g. 'don't ask too many questions'). This resulted in conversations that were more successful, from their perspective.

The findings above also reflect the heterogeneity of autism as, although common themes were found and could be labelled (as described above), there was personalisation within each theme about what was important to each person. During the initial analysis, I had to be very clear about what was a contradiction and what was part of a broad them, so that I understood individual differences between participants. For example, Carl was clear that he had no physical response in his body when things were not going well, in contrast to reports by three of the other participants (Chloe, Cait and Lee) who reported an experience of a physical response when an interaction was not going well. However, during analysis of further interviews, I noticed that Carl talked about physical sensations that were obviously unique to him (for example his 'stomach swinging'). Therefore, all participants reported some physical experience when things were not going well, but the exact nature and awareness of this differed between them.

6.4 Findings for Research Question 3:

In what ways can learning and knowledge about conversation be used in everyday conversation by autistic adults and their communication partners?

The participants with and without autism all used the knowledge gained during the study to support their conversations in different ways and I was able to identify themes describing the knowledge most commonly used by all participants (see Table 5.6 in Data analysis chapter). The themes described in Table 5.6 all had some relevance to each participant pair, but some themes were important to different participants to varying extents.

Participants demonstrated various levels of ownership of learning in the final stage. Cait (AP) could see a difference in Isla's interaction with her and wanted her father now to learn what her mother had learned. When Cait talked about other successful conversations, she reported on her own knowledge that she used to help her to feel all right in the conversation. When talking about Cait's conversations with Isla, and Nina and Cait's reporting on conversations, both Nina and Isla reported that Cait appeared more confident; but this is difficult to demonstrate through data analysis. With hindsight, my exploration in the final semi-structured interview with the autistic participant could have focused more on the incidental outcomes of the learning, such as increased confidence. Isla was very clear about what she had learned and has begun to ask Cait and Nina to let her know what she is doing 'wrong' when they see her forgetting what she has learned, so that she can be a better communication partner for Cait.

Although Lee (AP) was able to talk about what he had learned about himself, the changes in the people around him were most important and he wanted all staff to benefit from our learning. Oscar was able to say what he had learned and what he would do differently now.

Both Ruth (AP) and Lara were able to talk about their learning. Ruth described how her learning had made a difference at work, and Lara talked about how she used what she had learned with others when apart from Ruth.

As this study focused on the conversation within the dyads, it was important to me to consider the findings in the context of the dyads and what was learned by each communication partner that made the most difference to the conversation in each pair, as well as to understand what learning had been most important to each participant
154

individually. The learning reported as most important by each of the pairs is summarised below, meaning there is no comment on all themes for each dyad, only on those most important to the dyad.

I have reported learning in the dyads of Lee (AP) and Oscar rather than Rachel, and Cait (AP) and Isla rather than Nina. This is because although Rachel and Nina reported learning alongside Lee and Cait respectively (included in some examples above), at the close of the study the primary communication partner was Oscar for Lee and Isla for Cait. This reflected the fact that more time was spent in these communication dyads, and the autistic participants felt that learning with Oscar and Isla respectively was most important to them.

6.4c Ruth (AP) and Lara
(i) Type of conversation
Both Ruth (AP) and Lara talked enthusiastically about the value of noticing the different types of conversation, but for different reasons. Ruth identified general chit chat, help and advice, banter/winding up and 'working out' conversations and said that recognising a 'working out' conversation was most important for her. She commented that knowing when she was going to have to work something out meant, 'Knowing when to switch on the brain and when to tune out; I hadn't thought about this previously'. Ruth (AP) recognised that in a 'working out' conversation 'my brain has to work super hard'. Lara said that she had not thought about the different types of conversations previously, but that, 'knowing the different types of conversation and recognising that we all have them' had made a difference in her work with Ruth and also with others. Lara said that she now always labelled the type of conversation and felt that this enables Ruth and others to contribute more effectively.

Referring to 'type of conversation' also enabled Lara and Ruth (AP) to structure their conversations between themselves, indicating for example when the chit chat was finished and it was time for the 'working out'. Ruth reports that this clarity helps her to 'tune in'. Lara was able to support Ruth to plan for successful conversations in her workplace, considering the type of conversations that Ruth was expecting to have there. This knowledge about types of conversation was also used by Ruth away from

Lara, for example when supporting her mother at the GP and on an independent visit to the optician, where she anticipated the type of conversation to be had as 'help and advice', and knew she must 'really listen' (her words). Although other participants found knowing the 'type of conversation' useful, knowing when to 'switch on the brain' for a particular conversation, was more useful to Ruth (AP) than to some other participants and this became common language between Ruth and Lara.

Lara also said she had new 'awareness of zooming in and out of a conversation', that is, 'when to listen'. She related this both to herself and to Ruth, having increased awareness of when it was particularly important to tune in so as to support engagement and meaningful contributions from Ruth.

(ii) Knowledge of the communication partner

Ruth (AP) talked in the first interviews about how 'not knowing' things caused her anxiety. During the study, Ruth found that thinking about what she knows about a person and about a person's profession helped her to prepare for and manage situations. For example, using what she knows about her father, she knew what to expect when he came home from work; using what she knows about consultants, she knew what to expect when seeing her consultant. Specifically relating to Lara, Ruth commented that she knows when Lara is not feeling right because she puts her hands through her hair more often than usual. Ruth said that she then knows that she may have been talking too much or that it is not a good time for a long talk.

Thinking about the communication exchange and the impact of her communication on Ruth (AP), Lara then recognised that it is important for her to be predicable to Ruth; in other words, to do the things that she usually does in interaction, which are familiar to Ruth, in order for Ruth to be most comfortable and to have the most successful conversations with her. However, Ruth learned that it is also 'OK' to question Lara when she sees or hears her doing something different. Now that Lara knows that 'knowledge of communication partner' has been helpful to Ruth, Lara has been able to elicit this from Ruth when reviewing reported difficult interactions and when planning for what she may do in the same situation next time.

156

(iii) Sustaining engagement: use of cues

Lara recognised the importance of cueing Ruth (AP) into a topic or conversation in order that she could best contribute to it. Lara said she became aware of the different cues that she uses. Lara commented on the importance of not interrupting the flow of conversation and allowing time for processing and thinking. This links to 'power balance' from Ruth's perspective as, when Lara does not interrupt, Ruth feels that (important to her) she can 'have my say'.

(iv) Timely prompts to think

Lara also recognised through the study that if she listens to Ruth (AP) and gives prompts to thinking, Ruth will usually feel listened to and have her own solutions to situations, using her own thinking and knowledge (as above) and does not need 'advice' given from Lara's perspective. Lara is therefore aware of avoiding the 'blocks to thinking', which also link to 'power balance' from Ruth's perspective. Lara reported that she has now supported Ruth to think about what she knows about people and about situations in order to plan for or understand a social situation, rather than 'telling her' about a situation and what to expect.

In order to do this, Lara reported specifically avoiding any question or other request to think until she was sure that Ruth (AP) was engaged in the conversation, usually after several conversational turns, which usually involved Lara using confirmation and summarising of what Ruth (AP) had said. Lara was very aware that her prompt to think must be timely and she talked about how she now saw that 'why' questions often served as a 'block' to Ruth as they shift the power balance, when Ruth experiences a feeling of 'having' to give an answer. Ruth said that she liked being able to tell Lara that she did not like 'why' questions and to be able to tell her when she was asking too many questions.

Lara talks about how she is much more aware of her own use of language in conversation, both the vocabulary (what she says) and the amount she says. She says she tries 'not to put my own words and ideas' to Ruth (AP).

(v) Use of confirmation

Lara found use of confirmation rather than questions very useful and she also learned from Ruth (AP) about the importance of her own presentation (an open body language and 'smiley face' are liked by Ruth). This was not emphasised by other participants, but was very important to Ruth and appeared to function as 'confirmation' to Ruth that everything was all right, giving her confidence to continue to contribute to the conversation.

(vi) Feeling listened to, power balance

In the early stages of the study, Ruth (AP) talked much about the importance of 'having her say'. Ruth is now aware of how important this is to her and says she is more confident in managing the conversations. For example, she says, 'I am more aware of conversations and I do not get into people talking at me; I can walk away or I can relay back to them what they are saying'. In other words, Ruth has become aware of what is important to her and developed use of her own strategies to achieve what she needs within conversations. However, she has not needed to use these strategies in her conversations with Lara since their participation in the study.

In summary, the themes most important to Ruth (AP) and Lara link directly, suggesting they learned together through their participation in the study. When I spoke to them together, I could hear them explicitly using the things they had learned during the study, for example talking about the type of conversation, using what they knew about people and Ruth overtly commenting when Lara was playing with her hair to check whether Lara had a problem. Knowing whether or not Lara had a problem enabled Ruth to have more confidence in the interaction. By contrast, I noticed that other participants appeared to learn in a more parallel manner; that is, both learning and using what had been learned but independently rather than together (see below).

In the early interviews, Ruth (AP) vividly described the physical sensations and symptoms experienced when an interaction was not feeling right, yet at the end of the study she did not report using this awareness in her everyday interactions. This may be because (as she reported) she had fewer difficult interactions or it could be that this awareness was of less value to her than first anticipated. Ruth competed her final

interview saying, 'Doing this has helped me a lot. I know more about what I know about myself'. This comment appeared to reflect an overarching increased awareness of what she knows about others (trait knowledge), as well as what she knows that she needs in conversation. Use of the word 'know' is interesting to me, as it is in contrast to how Ruth talked at the beginning of the study when she appeared very uncertain of her own knowledge of what she knew and what was useful in relation to social situations. Finally, Ruth and Lara reported that they had been able to apply some of their learning during the study to situations retrospectively, for example to think about what Ruth (AP) knows about a person to gain an understanding of the possible reasons for the person behaving in a certain way.

6.4b Lee (AP) and Oscar (working together in college)
(i) Type of conversation

Lee (AP) identified chatting, agreeing (meaning agreeing solutions to problems), praising and 'bollocking' as different types of conversation. During the study, we learned that Lee had an expectation that certain conversations would be 'bollocking conversations'. We recognised that this expectation of the conversation impacted on Lee's engagement in the conversation, when this expectation of the conversation was not shared by the conversation partner (for example in personal tutorials). Oscar learned to make clear what type of conversation he intended to have and recognised that this helped to optimise Lee's engagement. Oscar reported that he makes use of Lee's enjoyment of banter/chatting to establish the conversation (and engagement), then lets Lee (AP) know that they are moving to an 'agreeing' conversation, which functions as a cue to Lee (AP), so Oscar now uses his new knowledge about 'type of conversation' to structure his interaction with Lee.

Establishing the type of conversation prior to the conversation has enabled Lee and Oscar to have shared expectations of the conversations and better outcomes, especially during personal tutorials.

Iii) Atmosphere – Feeling listened to

Lee (AP) talked about the importance of feeling listened to and 'getting a good response' (his words) from conversation partners, but continued to find it difficult to

159

describe or control this. He reported that, during the study, he was more aware of where he did and did not get a 'good response', and commented that the conversations with Oscar had been better since the time we had spent reflecting on conversations.

Directly linked to Lee's learning above, Oscar became very aware of the power balance in conversations, trying to say less and ask fewer 'why' questions. He now asks Lee (AP) for definitions of words to ensure that both he and Lee have a shared understanding of vocabulary used. Oscar commented that, through involvement in the study, he has 'moved away from 'showing I am listening' to always exploring what Lee (AP) says and ensuring shared understanding of what is said'. Oscar says that he is less directive and more aware of his suggestions. Oscar has learned to be cautious in his use of mentalising vocabulary, as he now recognises that Lee (AP) may use this with a different meaning attached. In considering his comments above these themes are clearly important to Oscar: **Shared vocabulary; power balance; use of timely prompts to thinking; helpful questions;** and **avoiding 'blocks' to thinking.**

Oscar reports that he is now more aware of Lee's vulnerability in interaction, especially when Lee's understanding of vocabulary used by Lee (AP) is not explored and is overestimated. Oscar reports that difficulty with the conversation is not always recognised as the root of lack of engagement. Oscar understands that lack of real exploration and checking of what Lee (AP) is saying may contribute to Lee (AP) not feeling listened to and not getting a 'good response'. This may reflect the fact that Lee (AP) wants or expects a certain response yet does not let his communication partner know this. Oscar says that he realises that he needs to think 'how' to find out what Lee (AP) knows, if he is to best enable Lee (AP) to solve his problems. Lee says that he now does feel listened to by Oscar and gets a 'good response'.

(iii) Knowledge of the communication partner
During the study, Lee (AP) learned that he knows a good deal about people familiar to him, including how they may act and what to expect from them. Prior to the study, he had not realised that he had this useful knowledge. He is now able to use this knowledge, for example he knows one teacher is 'stressed' when she touches her hair and knows that this is not a good time to talk to her. He did not comment on knowledge

160

of Oscar, beyond at the beginning of the study that he expects a 'bollocking' conversation when talking to him. As already noted, during the study he learned to expect an 'agreeing' conversation with Oscar instead.

Oscar has elicited Lee's knowledge of people when reviewing situations with Lee (AP). This has been useful to Lee, increasing his understanding of the possible reasons for a person doing or saying something and agreeing what he would do in that situation in future through considering what he knows about the person. Oscar is able to elicit Lee's knowledge of people when supporting his thinking to be able to guess what others may do or how they may respond, and this has been useful to both Oscar and Lee (AP). Developing awareness of his knowledge of his communication partner has been useful to Lee (AP). He no longer tries to persist with a conversation that is not working for him when he recognises that the communication partner is not listening. However, knowledge of the communication partner was not used in relation to Oscar.

(iv) Awareness of self and physical responses
Lee (AP) became aware of his leg moving up and down as an indicator that something was not right for him. In his sessions with another member of staff, he reported using this as a 'leg to mouth message', whereby 'the leg tells me I need to stop and think'. However, he did not report using this strategy with Oscar and, later in the study, said to me that he was 'fed up with the leg'. Oscar did not make any reference to the physical response used by Lee (AP). It thus appears that this new knowledge about the meaning of Lee's leg moving was used by other communication partners, not in the communication partnership between Oscar and Lee (AP). It seems that different aspects of learning are useful with different people and in different situations.

Overall, during the study, Lee (AP) developed knowledge or became aware of knowledge he had, but did not always use this knowledge with Oscar. However, reports from other members of staff suggest that he uses his knowledge (for example, relating to his leg and the type of conversation) in other situations. In the final interview, Lee (AP) spoke positively about the changes in his conversations with Oscar. However, he either lacked confidence or ability to describe the new knowledge specifically and how this was used, or perhaps was not yet taking ownership of it and using it effectively to

manage situations (as Ruth (AP) describes she did, above). It would be useful to explore this further with him.

Oscar was very aware of several changes in his own communication with Lee (AP) and how these made a difference to Lee (AP), and Oscar also reported a number of situations where he had used his learning effectively with other pupils, as well. Importantly, Oscar commented that he felt that he had overestimated Lee's understanding and ability, which could contribute to misunderstanding Lee (AP).

Although the focus of this study is on the communication exchange in the dyad of the participants, it appears that the learning by Oscar and Lee (AP) was actually used by both outside their own dyad as much as (if not more so than) within it. However, exploring this further was beyond the scope of the present study.

6.4c Cait (AP) and Isla
(i) Atmosphere, feeling listened to
During the study, Cait (AP) became more confident in requesting to be listened to, for example saying to Isla 'you're not listening'. Isla recognised that she talked too much and gave too many of her own opinions. She has begun to remain silent for longer and to confirm or acknowledge what Cait (AP) says, rather than 'jumping in' (Isla's words) with her opinion. Isla talked about how her intention has been to be helpful, but she now realises that Cait (AP) has many of her own solutions, which are right from Cait's perspective.

Since Isla has worked on sustaining engagement and meaningful power balance, Cait (AP) now reports feeling listened to. Cait (AP) said that Isla 'has changed'. Cait (AP) describes this as 'listens more'. Isla reports that she is communicating more effectively with Cait (AP) and that she is trying to give Cait choices and help her to find her own solutions.

(ii) Knowledge of communication partner
Cait (AP) became more confident in knowing what she knows about communication partners and using this knowledge to feel more confident in a conversation; that is, knowing what someone would be 'like'. She described interactions with colleagues at

162

work that would previously have caused her difficulty. For example, she reported that she now knew 'what Jean was like', and so her abrupt tone did not bother her any more. Isla acknowledged that Cait (AP) is now using her knowledge of communication partners, but this was not used in interaction with her. Nevertheless, Isla has noticed that since Cait (AP) began to recognise that she knows about communication partners, Cait (AP) has been less anxious about conversations (for example, in the workplace) and has been more confident in telling Isla and her father what she needs in a conversation when she knows they talk too much (for example, saying 'Just listen, Dad'). In summary, both Cait (AP) and Isla reported a significant change in their communication as a result of their participation in the study: Isla changed her own communication style, which enabled Cait (AP) to feel listened to and also gave her time for thinking, to draw on her own knowledge and to think up her own solutions.

(iii) Awareness of self and physical responses

At the beginning of the study, Cait (AP) had been aware of her 'cold arm' as a physical indicator of things not being right for her, but this was not raised again. When I asked about it in the final semi-structured interview, Cait (AP) and Isla both commented that it had not happened recently and that this probably reflected the fact that Cait (AP) felt more confident in social situations. It therefore appeared that this sub-theme was less important to Cait (AP), but it may be more reflective of her learning about interactions and growing in confidence during the study. As with Lee (AP), it seems that an area of learning that at first appeared important did not appear to be of as much value as first thought as the study progressed. As with Lee (AP) and Oscar, it seems that much change was made by the participant without autism (Isla), which made a difference to the quality of the conversations, but the main change for Cait (AP) was increased confidence in conversation with Isla.

6.4d Research Question 3: Summary of learning

Different aspects of knowledge were more or less important to different autistic and non-autistic participants, as would be expected in any group of individuals. However, taken together, the data from the autistic participants indicate that they felt more confident in interactions as a result of their participation in the study, because they gained and used greater knowledge of the conversation, both the people in it and the

conversation type and structure. This knowledge may have made the interaction more predictable for them, therefore less anxiety-provoking. Autistic participants also reported that they had gained greater confidence in knowing what was important to them in conversations and being able to manage these more effectively; for example, knowing when the conversation is not going well and the use of strategies to manage this, or requesting that disliked vocabulary is not used by a conversation partner.

Similarly, different aspects of how the knowledge and ideas of the autistic person may be 'uncovered' (i.e. what the non-autistic participants could say to enable the autistic participant to access and contribute their own knowledge) were important to different participants without autism to a varying extent, possibly depending on their knowledge of communication and typical communication style. However, overall, the participants without autism reported that they had become much more aware of what they are doing and saying during conversations, recognising a need to support the thinking of the autistic person (and knowing how to do this) rather than to question, interrupt or give advice. For example, Lara commented, 'I was aware when I may have put something in her mind, so stopped and checked'. Indeed, all participants without autism talked about how their participation in this study had helped them to recognise that the autistic person often had their own solutions if their thinking was appropriately supported. They all focused on talking less, especially reducing the frequency of giving opinions and ideas.

Interestingly, different participants used their own simple summary statements, reflecting the themes described during the data analysis. For example, Oscar wrote to me, 'this work is enabling both staff and people with ASC to THINK'. Participants without autism began to use their own words for the themes. For example, rather than 'optimising engagement', Oscar talked about how he now understands the importance of supporting Lee (AP) to be 'in the right frame of mind' during conversation, while Lara talked about 'supporting Ruth (AP) to be in the right place' to enable thinking. Oscar commented that, previously, when he may have thought that Lee (AP) was 'not in the mood' for discussion, he now recognised what he could do differently to support Lee's engagement and thinking.

164

All participants without autism commented on the value of becoming much more aware of themselves and the 'blocks' that they created during conversation with the autistic partner. They acknowledged that previously their focus was on eliciting information from the person with autism without thinking about how it could be best elicited, or wondering about whether what was said was actually the autistic person's own ideas or opinion. They also talked about how it was helpful to know what was important to the autistic person during conversation, for example knowing the type of conversation and using their own words for this.

In addition, participants without autism talked about how they had used what they had learned with other autistic people. Rachel commented that her learning from the study had been 'integrated onto everything' which she said was more useful than a 'programme' of implementation of learning for autistic people or staff. Oscar commented: 'I have found myself considering the language I use a lot more carefully in a lot of situations.'

6.5 Reflection on my own learning as a participant and researcher in relation to Research Question 3:

> *In what ways can learning and knowledge about conversation be used in everyday conversation by autistic people and their communication partners?*

The process of the data analysis brought further learning for me in relation to developing my understanding of the use of questions in my own and others' communication and the complexity of this, as well as the importance of reflexivity and self-reflection within the conversational exchange. During the data analysis, I noticed that in the conversations I was involved in, I stopped to check vocabulary because I knew through my knowledge of communication and autism that particular vocabulary may be difficult for the person (such as mentalising vocabulary). This was in contrast to other participants without autism in the study, who did not always check their shared understanding of vocabulary with the autistic person at points when I would have done so. I also noticed the absence of vocabulary used; for example, I noticed that Cait (AP) did not use any mentalising vocabulary beyond 'panic attack' and explored this with her and Isla. I may have noticed this absence by using my professional knowledge rather

than necessarily through the analysis (though, certainly, the latter confirmed the importance of this aspect). Regardless of the source of this noticing of absence of vocabulary, it does have implications for training and is something that I return to in the Discussion chapter.

I also noticed that I tended to stop and explore what was meant by some responses from the autistic participants that were immediate responses (or stock answers), which I felt had possibly not been thought through, or where I wanted to be sure that I understood the meaning of a word used. In this way, the response of the autistic participant became more meaningful to me. For example, I explored Ruth's use of the word 'anxiety'. Ruth (AP) was hesitant to describe it, yet 'anxiety' is a word that she had used frequently:

> Ruth (AP): I used to have a lot of anxiety
>
> Kate: How would you describe anxiety?
>
> Ruth: Scary
>
> Kate: Scary
>
> Ruth: Yeah very scary
>
> Kate: Wow, so scary
>
> Ruth: it almost feels like…. It almost feels like some big monster's come and hugged you...you know, given you a massive bear hug

I was asked by other participants without autism how I knew when to explore the words that were used. Subsequent reflection has made me think that I knew when to do this because of my focus on the exchange as much as on the words said. Therefore, if an answer appeared to be very 'quick' in the exchange, I then explored the thinking and evidence behind it with the autistic person.

Also in relation to vocabulary, I was interested to learn how the autistic participants often had their own words for concepts, such as 'type of conversation' or physical sensation. Consequently, it was most helpful for me to understand and use their own words rather than to expect them to use vocabulary that may be more typically used in the situation. I noticed that I explored and accepted vocabulary used by the autistic

166

participant where other communication partners without autism tended not to do this and instead moved on. Towards the end of the study, Lara, in particular, frequently explored the vocabulary used and has found this to be a very helpful conversational strategy. I have subsequently been able to use this learning in my own interactions about how and when to explore the meaning of vocabulary, and how to enable autistic people to use their 'own' vocabulary in other situations.

During data collation and analysis, and when considering the findings, I was continually interested in the concept of conversational 'blocks', which was new to me. I learned that spotting when and how these occur made a big difference to the communication of the participant without autism. This is in contrast to the usual focus by staff on 'what is working' during assessment and during their own learning. I was also surprised to see how often a participant without autism suggested an idea or gave an opinion, apparently with the intention of being helpful, and how this 'blocked' the thinking of the autistic person. In sharp contrast, I could see in the data analysis that, where engagement had been supported through cues, autistic participants were very able to contribute their own ideas.

In summary, I found that all participants experienced learning during the study, which had some continued impact on their conversations. However, not all learning was used and different aspects of learning were important to different people and in different situations. I reflect further on my findings during the following discussion, in Chapter 7.

Chapter 7 **Discussion**

7.1 Aims of the research and overview of the key findings

The focus of the study was on the 'communication exchange' between autistic adults and their communication partners without autism, within a communication dyad. Specifically, the study aimed to learn about the impact of the communication partner without autism on the thinking and contribution to a conversation of the autistic participant; and what the non-autistic communication partner could do, so that autistic participants were best able to contribute their knowledge and thoughts to conversations. The study also aimed to find out what was useful to autistic participants to know and do during conversations, so that they felt most able to contribute.

The motivation for pursuing this aim came from my work with autistic adults and autistic young people within social care and education, where I see autistic people being misunderstood in communication or unable to meaningfully contribute to conversations. I also see people without autism, intending to be helpful, teach or give advice from their own perspective rather than first understand what an autistic person may already know about a topic being discussed and make this the starting point. In my clinical work, staff often ask 'what do I need to do to be better at talking to… (autistic person)?' and people with autism express frustration about interactions and conversations experienced that have left them feeling unclear or not listened to. I used a case study approach to explore communication exchanges between five dyads of participants in Phase 1, and three dyads in Phase 2 (each dyad including one person with a diagnosis of autism and one person without a diagnosis of autism) and myself. Participants were involved in the study for between four and 12 months.

The learning from this study is most relevant to what I have called 'significant conversations'; that is, conversations where the outcome will have an impact on future planning or action for the autistic person. In these conversations it is vital that the meaningful thoughts of the autistic participant are heard and that their risk of vulnerability through being misunderstood is reduced. Significant conversations may include exploring current difficulties, and problem-solving and decision-making in relation to these, but also conversations relating to statutory processes such as

assessment for the social benefits of Personal Independent Payments and Mental Capacity Assessments (Mental Capacity Act 2005). I return to this context when discussing the implications for practice below.

Findings showed that the non-autistic communication partner had an impact on the contribution to conversation of the autistic participant. During reflective conversation and data analysis, I learned that use of unhelpful vocabulary, interrupting, unhelpful questions and giving ideas by the non-autistic communication partner led to a reduced contribution to the conversation by the autistic participant, meaning that their thinking and communication abilities appeared 'blocked'. When thinking appeared 'blocked', I recognised that the contribution by the autistic participant may not reflect their optimised thinking and communication abilities. However, strategies including use of cues, checking that understanding of vocabulary was shared, sustaining engagement, and use of confirmation and timely prompts to think appeared helpful and appeared to facilitate (or provide 'grease' to) the thinking and communication abilities of the autistic participant, resulting in the meaningful contributions and thoughts being expressed and enabling a greater understanding of the autistic perspective.

In summary, an important finding was a change in focus by the communication partners without autism to 'enabling thinking' of the autistic participant and knowing how to do this. This is in contrast to 'giving advice' when there was a reported difficulty, or asking questions from the neurotypical perspective, when seeking the thoughts of the autistic participant. This change enabled contribution to the conversation of the autistic participant. The strategies used by the non-autistic participant to support engagement and thinking appeared to be linked to supporting differences associated with autism in the areas of flexibility of thinking, metacognition, processing and language discussed in Chapter 2. This is discussed more fully below.

From their own perspective, autistic participants felt more able to contribute to a conversation when they had a feeling of control and knowledge of the conversation. They found it helpful to know about the communication partner and the communication environment, including the type of conversation (for example 'conclusion solving' or 'banter') and the topic of conversation (for example, 'a

conversation had last week', or 'sexuality'). Knowledge about themselves and their response in the conversation was also helpful. During the study, autistic participants were able to learn how to access and use their knowledge, and reported greater confidence in conversations. Their learning appeared to be closely linked to the development of abilities relating to metacognition (that is, cognition about cognition, encompassing both knowledge of cognitive processes and the ability to monitor and control one's own cognitions: Grainger et al. 2014). Consideration of metacognition and theory of own mind (Williams 2010) extends thinking about the cognitive theories of autism and intact aspects of ToM (Ramachandran et al. 2009), and this is also discussed further below.

The learning by the autistic participants and participants without autism about what was helpful during conversation was used within their own communication dyads, and also in other situations outside the study. Although generalisation of learning was not the focus of this study, this suggests that that the learning was owned by the participants.

My findings support the social model of understanding, where change is expected to be made by the person perceived to be without a disability (Shakespeare 2016), rather than a medical model of understanding autism (e.g. Kapp et al. 2013), where learning and the focus of change is on the autistic person (perceived as having the deficit). However, because learning took place by both partners and together, the findings from my study show the benefits of thinking about learning and change informed by a non-binary model (not 'us' and 'them', (Runswick-Cole 2014 p.1117)) of understanding, rather than a wholly social model where one side of the dyad is expected to change. I return to these models to discuss them more fully below.

I will now consider the learning of the participant without autism in the context of interaction with the autistic participant, and how the learning may be understood in the context of widely reported theory and models relevant to understanding people with autism.

7.2 Learning by participants without autism informed by the autistic lens

All participants without autism taking part in the second phase of the study learned about the impact of what they said and did on the autistic participants, saying that they had not always previously recognised this. They learned how they could change their communication to best support engagement and thinking of the autistic person. They reported that this awareness resulted in changes in the way that they participated in conversations and in noticeable changes in the contributions by the autistic participant. The finding that non-autistic participants had been unaware of their impact on their autistic partner confirms the 'double empathy problem' proposed by Milton (2012a). He argues that non-autistic people lack insight into the minds and culture of autistic people as much as autistic people lack insight into non-autistic perceptions and culture. In a similar finding, Sheppard et al. (2018) found that people without autism were ineffective in interpreting the mental states of adults with ASD. In my study, an example of lack of insight or understanding may lie in the incorrect interpretation of the autistic person's actions. For example when Lee (AP) did not engage in conversation, Oscar had usually thought that Lee was 'not in the mood' to talk rather than recognising that Lee was experiencing some difficulties and that he (Oscar) could change his own communication to support these; or Isla now understanding that Cait (AP) may appear to change the subject possibly because of differences in processing of information rather than because she was 'ignoring' Isla, as she had previously thought. In these situations, Isla and Oscar acknowledged that that they may have lacked insight into the minds of the autistic participants and made incorrect assumptions about what was helpful to the autistic people.

The finding that non-autistic communication partners can make changes to their communication, useful to the autistic participants, fits with a social model of understanding of autism, where a person may be disabled because society does not accommodate the person's differences (Brownlow 2010b). The finding also contributes to the recent call for a greater understanding of how interpersonal interaction can contribute to the challenges experienced by autistic people (e.g. Milton 2012a; De Jaegher 2013).

In my study I found that the changes made by the communication partner were linked to (that is, supported) the known cognitive differences associated with autism (see further below). It is recognised that cognitive differences are underpinned by neural differences (Frith 2012). Consequently, as argued by Anastasiou and Kauffman (2013), denying the biological and mental realities relating to disabilities can have severe consequences for the person with the differences, and so both the biological and social dimensions of disability should be considered. My findings may thus support an understanding of autism informed by understanding cognitive differences, where understanding of cognitive differences is applied within an understanding of the social model of disability. Consideration of biological (brain), psychological (cognitive) and social elements together may be described as a 'bio-psychosocial' model of disability (Engel 1997), meaning that biological, psychological and social factors should all be taken into account when looking at a person's difficulties. However, there is currently little agreement about this model or how the areas relate to produce a disability (Milton 2012(b)), so it is difficult to consider my findings fully in the context of this model. I would argue that the findings from my study therefore contribute to a social model of understanding of autism, where individual differences in neurology and sociality are recognised (not perceived as a 'deficit'), as advocated by autistic writers and advocates (e.g. Ne'eman, 2010; Wheeler 2011; Milton 2012a); and the role of the communication partner is considered in the context of the cognitive differences of people with autism (De Jaegher 2013) in the sense that they need to have an understanding of these in order to be able to more effectively communicate with the autistic person.

I learned that the conversation of the person without autism can impact on the ability of the autistic participant to use their thinking and communication within the social interaction, these being the three areas described as 'impaired' for a person with autism within the triad of impairments (Wing & Gould 1979). My findings therefore share some areas of interest with Wing and Gould (1979). However, in contrast to Wing and Gould (1979), who focused on impairments of the autistic person, my findings showed that when the communication partner supported optimised engagement and thinking of the autistic participant there was evidence of flexibility of thinking (e.g.in solving problems) and use of communication abilities (in meaningful contributions to

the conversation) used by the autistic participant. Also, assumptions made by the non-autistic communication partner regarding 'impairment' in social interaction were shown to be incorrect, as I saw conversations perceived as successful by both partners within the dyad. My findings therefore do not agree with a model of thinking about autism informed by 'impairments' of the autistic person alone.

It has been argued that the key universal core weakness found in autistic people is an impaired ToM (Baron-Cohen et al. 1985; Baron-Cohen 1997). This means that that there is a weakness in reading the minds of others, including empathising and imagining their thoughts and feelings, in order to understand comprehend and predict the behaviour of others, and that this weakness impacts on the social and communication abilities of the autistic person (Baron-Cohen 1997). Because my findings demonstrate the impact of the communication partner on the conversation ability of the autistic person, they extend thinking about ToM in naturalistic contexts involving others. In other words, the conversation partner has an impact on the ToM abilities of the autistic person in conversation. WCC (Happé & Frith 2006) is another long-standing cognitive theory, proposing that autistic people may use a piecemeal approach to processing information (in this study, this would be conversation within interaction), rather than seeing the words and conversation in the context of a whole social interaction. However, I found that, where processing was supported by the use of cues and timely prompts to think, there was no evidence of a piecemeal understanding of the conversation or the interaction, as may be expected by WCC. My findings therefore contribute to the understanding of the existing cognitive theories within a real-world social interactive context. The findings give some detail of what a non-autistic communication partner may do, in order that the autistic people could best engage in the conversation and communicate their thinking, often showing abilities in processing social information and in ToM. My findings therefore support De Jaegher (2013, p. 3) who argues:

> None of the mainstream theories provides an account of the role that interaction processes as such play in how autism manifests, develops, and affects the people on the spectrum as well as those around them.

Using participant Oscar's words, I may summarise the change in approach of the communication partners without autism as 'enabling thinking' of the autistic participant

(different from previously 'giving advice' or 'listening'). This was an important finding and contributes to an understanding of effective listening. Oscar had learned during teacher training how to use active listening (Conte 2009), whereby a listener shows that they are attending to what is being said, for example by nodding the head and using accurate summarisation (Conte 2009). However, the findings of my study suggest that active listening used to elicit thoughts and ideas of the autistic participants should be informed by an understanding of the potential cognitive differences in the areas of processing, flexible thinking and memory; and an understanding the impact of these differences on what is said by the autistic person. This finding therefore adds to thinking about how best to meaningfully listen to autistic people and reinforces the importance of use of a social model whereby the communication partner must know how to change their communication in response to the cognitive abilities of the autistic person.

However, if the focus is on supporting thinking, it follows that the non-autistic communication partner must specifically have a good understanding of the cognitive differences of the autistic person, how these impact on thinking relevant to conversation and what they may do to help to maximise these. This finding fits with Cashin et al. (2012), who propose an understanding of autism informed by a cognitive processing triad, arguing that (p. 143) 'while behaviour varies relative to context, what remains constant is the underlying information processing and thinking styles of people with autism'.

Although my findings would disagree with the concept of 'impairment' of cognitive processing proposed by Cashin et al. (2012, p. 146), they do support a need for an understanding of the different cognitive processes resulting in a different way of seeing and experiencing the world (Frith 2012), argued to arise as a result of differences in the brains of people with and without autism (e.g. Hyde et al. 2010).

The success of the communication partner making changes to their own communication, thereby enabling thinking of the autistic participant, also depends on the non-autistic communication partners using an understanding informed by an expectation of abilities of autistic people; rather than using a restricted understanding of autism, focusing on individual deficits. A deficit understanding could cause an

assumption by the communication partners that the autistic person needs advice, assuming that they may be unable to 'think up' and contribute their own knowledge and solutions. The value of taking an enabling thinking approach supports recent literature that has highlighted the need to move away from assumptions about autism relating to deficits, which can have a negative impact on autistic people. For example, Gillespie-Lynch et al. (2017) report on the stigma associated with autism, caused by lack of understanding and misconception by people without autism, and suggest that autism training should be informed by less stigmatising conceptions of autism. Similarly, Fletcher-Watson et al. (2018) report on a series of seminars involving autistic and non-autistic delegates and highlight the need for assumptions about deficits relating to autism to be challenged. Furthermore, Heasman and Gillespie (2018) found that relatives of autistic adolescents overestimated their social limitations, reflecting an expectation of deficit. Underestimation of the abilities of autistic people by people without autism was confirmed by the findings in my study. During my study, the communication partners reported that they gained belief in the abilities of the autistic participant and a commitment to better understand their perspective, and how they might best elicit their knowledge and thoughts. In effect, they challenged some of their previous beliefs about the abilities of the autistic person within their dyad.

 Further, my findings relating to exactly *how* a communication partner may usefully change their thinking about an autistic person and their communication in order to gain their thoughts and ideas may contribute to the identified gap in knowledge of people without autism about autistic communication. Milton (2014) considers the expertise that is needed by non-autistic people to be able to interact with autistic people and suggests that learning this is possible yet has been lacking in most research to date. The findings from my study have given some insight into how people without autism can gain such 'interactional expertise' (Milton 2014 p.795); that is, *how* they may change their communication in order that it fits better with the cognitive abilities of the autistic participant rather than expecting the autistic person to fit in with non-autistic expectations for communication. Indeed, Atherton et al. (2018) argue that engaging autistic individuals in ways that they can express themselves and understanding of the

autistic ToM, as explored in my study, means that the double empathy problem (Milton 2012a) can be addressed.

Thus far, the finding of the importance of 'enabling thinking' has been considered in an interactive context informed by a strengths-based understanding of autism, both of which are reported gaps in the literature. For the purpose of planning and conducting the study, the research questions were separated in to the two sides of the communication dyad, with Research Question 1 asking about the communication of the non-autistic communication partner (discussed thus far) and Research Question 2 asking about what was useful to the autistic participant in conversation, before asking how the learning in the study was used by the participants both within their dyads and independently in Research Question 3. In discussing the findings now, I will consider the contributions of both the autistic participant and the non-autistic participant in the communication exchange and some of the known differences associated with autism that appear to relate directly to my findings. These are differences in the areas of flexibility of thinking (Pellicano 2010), information processing (Happé and Frith 2006), memory (Bowler et al. 2007) and language (e.g. Magiati et al. 2014), and metacognition (Grainger et al. 2014) and trait knowledge (Ramachandran et al. 2009), all of which are discussed more fully below.

7.3 Participant learning in the context of known differences associated with autism

7.3a Flexibility in thinking

I found that engagement of the autistic participant was optimised by the communication partner's use of cues to topic and memory, avoiding interruption and avoiding vague language (e.g. Oscar talking to Lee (AP) said, 'what did you think of *that*?' where the reference for 'that' was unclear, hence vague). I can speculate that the value of use of these specific cues by the communication partner may lie in the reduction of the need for the autistic participant to use cognitive flexibility to work out what the conversation was about, or what words meant, and to keep their own train of thought. When an interruption or an idea is given, the autistic participant may have to stop his or her own line of thought in order to flexibly 'jump to' what has just been said. Inflexibility in thinking has been recognised in autistic people (e.g. Pellicano 2010; Vermeulen 2001) (see Chapter 2) and the ToM hypothesis of autism (Baron-Cohen et al.

177

1985), as well as the triad of impairments (Wing & Gould 1979) propose an inflexibility in thinking as an impairment of the autistic person. The findings from my study show that specific cues by the communication partner could reduce the need for flexible thinking and hence reduce the impact of any inflexibility of thought.

From the autistic perspective, knowing the 'type of conversation' (for example 'joking' or 'help and advice') and the topic of conversation (for example, about the 'trousers that needed repair') (Cait AP) or 'the conversation with B last week' (Chloe AP)), was useful to all autistic participants. This is not something that I, nor anyone else involved in the study, had explicitly considered prior to the study but rather it was something that emerged as important during discussions and reflections with the autistic participants. Having this knowledge appeared to make the conversation more predictable so that, for example, autistic participants could know 'when to switch on the brain' (Ruth (AP)'s words). In other words, to know when thinking was needed, and to prepare for the conversation. This finding fits with a focus on thinking about thinking (metacognition) (Grainger et al. 2014) discussed further below, but also with support to flexibility of thinking where a need to work out the type or topic of conversation was removed.

I could speculate that knowing the type and topic of conversation may also have helped the autistic participants to use existing knowledge of the conversation type to anticipate the structure of the conversation, thus reducing the need for cognitive flexibility to work out what was required of them within the conversation. It is recognised that people with autism often prefer structure (Ponnet et al. 2008), and this structure may be used to teach conversation skills (e.g. Doggett et al. 2013) and that certain types of conversation that may lack structure can be particularly difficult for autistic people, for example small talk (Trembath et al. 2012) and negotiation (Hochhauser et al. 2015). My findings add to the literature by suggesting that it may be useful to explore further how knowing the type and topic of conversation can contribute to use of structure in conversation.

178

7.3b Information-processing differences

The value of use of confirmation (which may allow thinking time) and awareness of the importance of timely prompts to think (that is, giving time for thinking and processing and only inviting thinking after the autistic person's cognitive flexibility has been supported as described above, and he/she is engaged in the topic) may contribute to an understanding of the well-documented differences in speed of information processing in autism (e.g. Chevallier et al. 2013; Booth & Happé 2018). My findings show that the autistic participants were able to process spoken information, but benefited from time to do this. Where this time was not given (for example where multiple questions were asked), resulting in an apparent 'block' of the autistic participant's thinking, it is likely that the autistic participant had not been able to process the questions in the time allowed by the communication partner.

My findings support the importance of understanding the processing differences of autistic people, as described in the WCC theory (Happé & Frith 2006), but I would argue that these should be understood in the context of the communication exchange as described above rather than as a deficit in the autistic person. This finding supports Ridout (2017), who argues that recognising the different time required by each to process information is critical to the way in which autistic, neurodivergent and non-autistic individuals communicate with each other.

7.3c Differences in memory

I found specifically that cues to memory were important to the autistic participants. When these were given at the beginning of a conversation, they enabled the autistic participant to remember information relevant to the topic to be discussed and then to focus on it. For example when Chloe (AP) and I were going to talk about a conversation that we had had the previous week, we talked first about the day of the week on which I visited, who was present and who was in the conversation, which all served as useful cues to recall the conversation. Difficulties of autistic people in episodic memory (memory for personal experiences) are reported by Bowler et al. (2007), Crane et al. (2010) and Crane and Goddard (2008) (see Chapter 2), but the findings from my study show that memories may be accessed when useful cues to memory are given by the communication partner. This finding again potentially contributes to *how* 'interactional

expertise' (Milton 2014 p.795) may be developed to support the autistic person to access their personal memory and use this within conversations.

7.3d Differences in language and conversation

I found that ensuring a shared understanding of the vocabulary used by the participants was important, particularly in relation to mentalising words and idiosyncratic words or phrases. The findings showed that the autistic participants used some mentalising words without being clear of their typically expected meaning. For example, Lee (AP) used the word 'meltdown' to describe his mental state in a difficult situation but, when asked to describe this, said that it was his GP's word, not his. Indeed, my study found that there were times when the autistic participants were asked about their own mental states and a 'block' or communication breakdown followed. However, my findings also showed that the autistic participants were able to describe their mental states in ways unique to them, for example Ruth used the words 'stuck in the mud' and Cait used 'panic attack' to describe what appeared to be an overwhelming feeling that she could only describe in physical symptom terms, but did not use other mentalising words.

Over the last two decades, there have been a number of studies exploring the link between alexithymia, defined as difficulty in identifying and describing own feelings (Nemiah 1977), and autism (see Lartseva et al. 2015 for a review). It is suggested that approximately half of the autistic population experience alexithymia (Poquérusse et al. 2018) but, as yet, the precise relationship between alexithymia and ASD is little understood (Poquérusse et al. 2018). My findings perhaps contribute to this discussion, suggesting that the autistic participants had some knowledge of their feelings but used a unique vocabulary to describe these, so it was important to avoid neurotypical expectations of understanding and use of mentalising words.

Further, autistic participants used idiosyncratic words or phrases, such as 'conclusion solving' and, in line with a social model of understanding, it was helpful to the autistic participants that the meaning of words used by both partners in the conversation was checked to avoid misunderstanding. When the words of the autistic participant were then used by the communication partner with a shared meaning attached, engagement

of the autistic participant appeared supported. There are recognised differences in understanding and use of communication associated with autism (see Chapter 2), but differences in understanding and using language are typically reported as being the 'difficulty' of the autistic person. This is in contrast to the findings of my study, where words used by the autistic participants could be explored and usefully used, rather than perceived as a 'deficit', because expected or typical vocabulary was not used.

Further, the use of cues to the topic of conversation, which were found useful by autistic participants and described above in the context of cognitive flexibility, may have supported the people with autism in adhering to a conversation topic, which is reported as a difficulty for some people with autism (Paul et al. 2009; see Ying Sng et al. 2018 for a review). However, I have not been able to find literature that includes comment on whether or not the topic of conversation, and the expectations in relation to the type of conversation were made clear prior to the conversation. So, the findings of my study may contribute to the literature relating to how conversation can best be supported by the person without autism and what is useful for the autistic person to know prior to the conversation, thereby enabling them to experience greater control of the conversation and greater involvement in it.

Autistic participants in my study all commented on a dislike of some questions, particularly multiple questions (i.e. several questions asked one after the other in a single conversational turn), and 'why' questions, but they were able to contribute thoughts and ideas in response to other questions (I have identified this as an area of future research below). However, I have found little helpful comment by other autistic people about being asked questions. Although one participant in a study by Robertson et al. (2018 p.16) suggested that he preferred 'direct questions', there is no further definition of the meaning or context of 'direct questions'. My finding regarding the dislike of some questions by the autistic participants may therefore begin to contribute to a gap in thinking about how questions can be both helpful and unhelpful to people with autism and how questions can be best used with an autistic person to support thinking and contribution to a conversation.

The findings regarding the importance of attention to the language used by both the communication partner and the autistic person described above may further contribute to the call for understanding the autistic culture and 'interactional expertise' (Milton 2014 p.795) rather than assume or impose a neurotypical understanding and use of words on the autistic person without ensuring shared understanding of the vocabulary.

7.3e Metacognition – Thinking about what I know about people and the current environment

Autistic participants reported that having knowledge about the communication environment and people in it, and the type of talk, removed uncertainty. For example, Cait (AP) commented she felt more confident now she knows that she knows what the people she talks to 'are like', and knows more about conversation types. However, at the beginning of the study, the participants did not appear to be aware that they had knowledge of people and conversation available to use. This knowledge was not immediately revealed or used in responses during the first semi-structured interview; it was uncovered through supporting the thinking of the autistic participant during the study. Summarising learning at the end of the study, Ruth (AP) commented: 'Doing this has helped me a lot. I know more about what I know myself'. When participants began to talk about what they 'knew' during the study, we described this as 'knowing what I know' and 'thinking about what I know', which appears to link with definitions of metacognition.

Livingston (1997) describes metacognition as 'thinking about thinking', emphasising that metacognition involves use of own knowledge. Koriat (2000) adds that knowing about knowing implies not only knowing something but knowing that it is known. The findings of my study, whereby development of metacognition was found useful by the autistic participants, may contribute to research that recognises the importance of knowing more about autistic metacognition within social situations. For example, Wilkinson et al. (2010) propose that a general deficit in metacognitive monitoring (knowing about own self and thinking) may underlie the social differences typically associated with autism; and Mitchell and O'Keefe (2008) found that autistic participants suggested their mother knew as much about them as they did themselves, reflecting a lack of awareness of knowledge of themselves. Further, my own previous, small-scale research (Silver 2010;

Silver & Parsons, 2015) showed that adults with AS may have knowledge that can be used to increase understanding of social situations, but that they needed structured self-prompt strategies to help them access and use this knowledge effectively. My current findings also confirm that it may be helpful for autistic people to know what they know, also to know how their knowledge can be accessed and used in social situations. Further, my findings suggest that it would be useful for communication partners to have a greater understanding of the metacognitive abilities of autistic people and to know how they can enable an autistic person to access and use what they know in social situations.

The apparent lack of conscious awareness of their own knowledge by the autistic participants may also link to known differences in self-referential processing in people with autism (see Chapter 2), whereby there may be a difference in processing of information relating to the self. In my study, I found that autistic participants were able to notice changes in themselves, (for example a sensation in the tummy) (Ruth) or the jaw moving up and down (Chloe)), and were able to use self-prompt strategies (for example, 'I just need to get out of here') when they noticed these changes. This shows an ability to be aware of changes in the self in relation to what is happening within the environment, but not all participants used this ability. Frith (2012) argues that a specific metacognitive process may be important to the development of self-awareness in autism, and the findings from my study suggest that the autistic participants had the ability to use a metacognitive process that enabled self-awareness yet had not previously used this. My findings relating to the ability to use self-awareness and metacognition in relation to what is happening in the environment also support the call for further exploration of self-referential processing (Lombardo & Baron-Cohen 2011).

The findings from my study relating to metacognition therefore extends current thinking about the cognitive differences associated with autism by showing that autistic participants were able to access what they knew about people and situations to inform their understanding and contribution to a conversation. My study may also contribute to thinking about metacognition in a social context (using a social model of understanding), since the findings give some indication of how the communication partner could help the autistic participants to access and use their own knowledge.

However, metacognition and autistic people is a relatively new and emerging area of research and so, compared to the exploration of cognitive differences (particularly ToM) that dominated research in the later 1980s and throughout the 1990s, there is much less known about what people with autism know about their own thinking (Williams 2010) and how this knowledge could be helpfully used in social situations could be explored further (Sawyer et al. 2014).

7.3f Trait knowledge

All autistic participants reported that accessing and using knowledge of their communication partner was useful, saying how it enabled them to predict what the communication partner may do or say, hence making the communication partner more predictable to them (possibly reducing the need for cognitive flexibility during a conversation). My findings showed that autistic participants had some trait knowledge; that is, knowledge of personality traits (what people known to them 'are like') as well as traits relating to professions (e.g. 'what teachers do'). This aligns with the findings of Ramachandran et al. (2009), who investigated the ability of adults with ASD to infer traits from descriptions of behaviour and reported trait inference to be a spared socio-cognitive function.

Frith and Frith (2006) propose that the ability to predict what another person is like and what another person is likely to do next are two major aspects of social cognition. A number of studies have looked at the ability of people with autism to predict or to guess intention, with mixed results. For example, Carpenter et al. (2001) found that young children with autism were able to understand the intentions of others almost as well as matched controls, and Russell and Hill (2001) found that young children with autism were able to report the intentions of other agents in an experimental task. However, in an experimental study with children, Williams and Happé (2010) found that autistic children had less awareness of the intention of others than the matched comparison group, as well as reduced ability to recognise their own behaviour as either intentional or unintentional. Going further, Sinha et al. (2014) argue that many of the salient traits in autism in the areas of ToM, sensory hypersensitivity, preference for sameness and abilities in rule-based tasks, may have roots in an underlying impairment in predictive abilities. I speculate that my finding that the autistic participants could use

knowledge of what a person 'is like' to guess what the person may do may confirm the value of use of prediction to autistic participants. However, in contrast to the studies reported above, which focus only on the difference in the autistic person, my findings suggest that when the communication partner enables thinking, predictive abilities are present and may be accessed by the autistic participant. My findings may therefore contribute to the discussion in the literature regarding the ability of autistic people to guess intention and the value of this to them.

Furthermore, in relation to metacognition, all autistic participants reported that they were previously unaware that they had this trait knowledge, and how these showed in what people said and did. In other words, they did not know they knew about people in this way and so did not use this knowledge. Further, their familiar communication partners within the dyad did not know that the autistic participants had this knowledge of people, possibly reflecting negative assumptions of autism (Fletcher-Watson et al. 2018) or lack of awareness of metacognition as an area to explore (Sawyer et al. 2014).

My findings regarding trait knowledge also support the development in thinking about what ToM means in practice (Atherton et al. 2018); that is, in a real world context. The autistic participants in my study demonstrated an ability to know what a familiar person may be feeling in a social context (e.g. Lee and Cait both described known people as 'stressed'), and an ability to use this knowledge to guess intention (what would happen next) and to change their own behaviour or conversation in response. This finding supports the call by Atherton et al. (2018) to explore autistic social processing strengths and ToM differences, rather than deficits, using more naturalistic approaches involving others, and for both autistic and non-autistic people to gain a greater understanding of autistic people's ToM abilities.

A further important finding was that the autistic participants became more aware of what was helpful to them in conversation (which may relate to an increasing knowledge or awareness of own self as discussed above) and were able to request what was important to them within the dyads in the study (for example, no 'why' questions), and this is discussed below.

7.4 Autistic participants' perception of what is helpful in conversation

Autistic participants learned to know and say what was helpful to them in a conversation, for example Lee (AP) began to ask for the conversation type and topic prior to the conversation and Chloe (AP) has begun to say, 'You know I don't like "why" questions' when asked a 'why' question. This ability may have given them a sense of greater control of their experience of the conversation. This finding may relate to a shift in power balance, whereby the reflective learning by the non-autistic communication partners had enabled a willingness to understand and listen to the needs of the autistic participant from the autistic perspective and communicated this to the autistic participants more effectively through the strategies described in the findings chapter. This finding of a possible shift in power balance aligns with those of Wood and Milton (2018), who argue that, although there is a willingness to include autistic people as equals in projects, there are often unconscious limits by people without autism to shift the power to autistic individuals; that is, they are unaware of the way in which they maintain the power in a situation. Participants without autism became more aware of power balance during my study.

Further, I may speculate that my finding that changes made by both participants with autism and without autism are helpful to the autistic participant, may contribute to the current discussion in the literature relating to camouflaging (Hull et al. 2017). Where there is greater shared understanding of the strengths and the needs of the autistic person, and the autistic person is able to say what is important to them in conversation; and there is a helpful response to these needs by the non-autistic person, the need for a pretence to be normal (Willey 2014) and the associated anxiety may be reduced.

I was interested to identify communication behaviours used by the communication partners that were perceived to be helpful or unhelpful to the autistic participants (as analysis showed they resulted in 'blocks' or 'grease' to the autistic participant's thinking and contribution to the conversation). However, not all identified helpful and unhelpful communication behaviours were recognised as such by the autistic participants, prior to me exploring my findings with them. This finding therefore supports the importance of recognising that autistic participants may benefit from specific approaches (some of

which may be within the findings of this study) to enable them to explore their own thinking or to know what they know, meaning that it would be unwise to 'just ask' when seeking their meaningful perspectives.

7.5 Learning by the participants during the study

All participants in the second phase of the study reported learning useful to them during their involvement. Learning took place through active engagement in self-reflective discussion and was used by the participants with and without autism within their dyad, but also in other situations. Given the heterogeneity of autism (e.g. Masi et al. 2017) and differing abilities and opportunities for learning of the participants without autism, it is not surprising that there were differences in the detail of what the autistic participants found most useful to know and in what was most helpful from their conversation partner; and also differences in the learning the participants without autism found most useful to themselves and to the autistic participant. Further, different aspects of learning were important to different dyads to a greater or lesser extent and used in different ways.

However, in summary, the autistic participants found that recognising and using what they knew about the communication environment (including knowledge about themselves and the communication partner) and making sure that they knew the conversation type and topic, helped them to know what might happen in a conversation. They reported that this knowledge helped them to feel more confident within the conversation or social situation. Participants without autism all became far more aware of their own communication and how it impacted on the autistic person, especially when something said or done caused cause a 'block' or breakdown in the communication and thinking of the autistic person. In other words, the participants without autism thought more about the 'exchange' in the conversation rather than just about the autistic person's contribution to the conversation, as they had done previously. The overriding learning by the non-autistic participant could be summarised in Isla's words as 'saying less and listening more' in order to find out what the autistic participant already knows about a topic and making this the starting point for further discussion.

Participants without autism also learned to better understand the autistic perspective through reflective discussion and understanding the cognitive differences associated with autism; and this enabled them to know how to change or what to do to maximise the autistic participant's contribution of thoughts to the conversation.

They also used an understanding of 'listening' that encompassed both understanding what was said and enabling thinking of the autistic person, rather than hearing and responding to words spoken. The participants without autism therefore used a positive perspective of autism, whereby they believed that the autistic participants would have knowledge to contribute and would have 'the answer' (as said by Isla, Cait (AP)'s mother). This finding supports the value of the call for changing assumptions about autism (e.g. Fletcher-Watson et al. 2018).

The finding that learning together was helpful may reflect the fact that a social situation is 'actively constructed by social agents' (Milton 2012a, p. 884) meaning that that social interaction will differ as a result of the contributions of the different people involved and the purpose of it. This again confirms the importance of considering the social and conversation abilities of autistic people within a naturalistic interactive context (Atherton et al. 2018) rather than in an artificial and one-dimensional assessment context. This finding also confirms the value of a social model of thinking to understand what may be most helpful to individuals with and without autism in a conversation, while at the same time avoiding binary assumptions about autistic people or non-autistic people as homogenous groups (Runswick-Cole 2014). Put simply, learning took place together and by participants with and without autism in the dyad, rather than by each person separately, and learning was in relation to individual learning needs of autistic and non-autistic participants.

It is argued that the concept of 'neurodiversity' can help autistic and non-autistic people to focus on the diversity of people's needs, their strengths and interests as well as their challenges (e.g. Brownlow 2010b; Milton & Sims 2016). Neurodiversity posits that differences in the brains of people result in differing beliefs, desires and emotions (Ortega 2009), in contrast to the medical model way of thinking about autism as a disorder to be cured. Proponents of neurodiversity argue that the autistic differences in

socialising, communicating and sensing are to be respected rather than rehabilitated (Jaarsma & Welin 2012). My findings may support a concept of neurodiversity, whereby it is recognised that autistic people and non-autistic people have recognised brain differences that may impact on cognitive differences and communication differences (Frith 2012), and thus on conversation between people. A non-binary understanding of a conversation exchange, informed by this concept of neurodiversity, may lead to an improved experience of the conversation for both autistic and non-autistic conversation partners.

I found that non-autistic participants could learn to understand the autistic perspective and learn what they could do that was helpful to the autistic participants in conversation. This finding may contribute to a response to the reported frustration of autistic people that a lack of understanding by others causes difficulty to them (e.g. Milton & Sims 2016, Robertson et al. 2018). The findings about *how* the non-autistic communication partner may change may also contribute to the call for 'interactional expertise' by Milton (2014 p.795); that is, the expertise that is needed by non-autistic people to be able to interact with autistic people. Further, my finding that autistic participants could give some indication of what they wanted from their communication partner may respond to Milton's question about how we may know when interactional expertise in autistic culture has been acquired by non-autistic people. The autistic participants have a role to play in this by becoming more aware of their own communication needs and preferences and being able to give direct feedback on this to their partner in the dyad.

7.6 Variation in participant learning

The use of self-reflection was important to support learning during the study. Although the members of staff in the study were trained in reflective practice, this study enabled them to reflect specifically about the exchange in the communication rather than just on what the autistic person said, so they were able to gain a better understanding of the autistic perspective. This finding further exemplifies the kind of knowledge that is helpful for underpinning a social model approach to understanding autism, whereby

reflection on own approaches could be usefully informed by knowledge of the cognitive differences associated with autism.

Reflecting on learning by the non-autistic participants, I found that the more experienced practitioners (including Cait (AP)'s mother, Isla) appeared to gain more from involvement in this study than newer practitioners. This was an unexpected finding and perhaps indicates a level of willingness to self-reflect or motivation to learn. Motivation may come from greater experience of vulnerability of people with autism in conversation, or possibly greater awareness of stock responses and masking by autistic people (Hull et al. 2017), and the potential consequences of these (for example, masking relating to abilities has led to reduction in benefits payments, for one person). Wyn and Mary showed little motivation to change, but reported that they already felt successful in the conversations that they were having with the autistic participants, possibly revealing a different level of self-reflection to that of some of the other participants without autism.

Autistic participants also gained differently from their involvement in the study. Ruth, Chloe and Cait all readily reported on their learning during the study and have since reported further impact on their conversations in their workplaces and with others. This generalization of learning beyond the dyads in the study suggests that they themselves have owned and used changes to thinking and communication, independent of their specific communication partner. This provides some anecdotal evidence that the changes they reported were not just because of learning and alterations by their communication partner in the study, and that there seemed to be a wider effect of the learning. By contrast, although Carl (AP) was initially very enthusiastic, he did not appear to learn much about conversations from his participation in this study. This may be because he had other things happening in his life that were more important to him and he was not motivated to focus on learning more about conversations because of other priorities. He did not readily report current examples of difficulties in conversations at the start of the study (although he and staff members know that he does have such difficulties). It therefore seems that some current recognition of difficulties could affect motivation to engage in thinking and learning in a process such as this.

190

Lee (AP) was able to describe some difficult conversations at the beginning of the study. He also reported positive changes that he had noticed in his communication partner that had been helpful to him at the end of the study. However, he was less able to describe how he could take responsibility for making changes to the conversation and communication environment to reduce the risks of an unsuccessful conversation. At the beginning of the study, Lee had been known to his staff for only a few weeks and had had many difficult previous experiences. It could be that his awareness of his own thinking and confidence in his own ability to be able to take control and to change required further support, beyond the timeframe and scope of this study. However, from this I learned that perhaps having a level of awareness of own thinking and own ability to be able to take control are important to be able to use this learning most effectively. It may be that, as Carruthers (2009) argues, metacognition is needed before mind reading and that knowledge of the relational self could be important in social situations (Andersen & Chen 2002). It would be useful to explore these concepts further in future research.

My findings also contribute to the research relating to adults and to verbally able people on the autism spectrum**.** In searching the literature, I found relatively few studies looking at the communication and conversation abilities of verbally able people and how these can be supported and developed. Ying Sng et al. (2018) argue that, although there is research on the conversation skills of people with autism, the research is fragmented and that further research is needed before conclusions may be drawn. My findings may contribute to learning about conversation in verbally able people with autism and also to the call for research with autistic adults (Damiano et al. 2014).

In summary, my findings relating to optimising the thinking and contribution of the autistic participants in conversation do not appear to be underpinned by a single theory relating to autism (for example, ToM or WCC), nor a single model of understanding (for example, the social model or medical model), nor just the recognised differences associated with autism in isolation. Instead, my findings suggest that it is helpful to consider a more integrated understanding of the differences of the autistic person, recognising unseen cognitive differences within the social interactive context, so that both sides of the communication dyad are recognised as important. The integrated

understanding appears to be best informed by a strengths-based understanding from both autistic and non-autistic perspectives.

7.7 Implications for practice

When planning this study, it was important to me that its outcomes could make a difference to the participants and that its learning could be applied in the real world. I work with autistic people and staff within both adult social care and education. I see verbally able autistic adults who have received teaching to develop their social and communication abilities yet remain vulnerable in social communication situations; and I see the social skills teaching and the staff training delivered. It seems to me that to reduce the vulnerability and misunderstandings of autistic adults in conversation something more or different to enable the conversation abilities of autistic people would be useful.

7.7a Staff training

I am aware of constraints on time available for staff training, but have learned that understanding how best to talk to verbally able people with autism is important if we are to hear their ideas and meaningful contributions to conversations. This is particularly important in social care, where staff may be working alone, have limited experience and limited time for training and yet may be involved in significant conversations with people supported on a very regular basis. I consider the implications for practice from my study in relation to contribution to staff training, how staff can best support autistic people to gain and usefully use knowledge in conversation, and what may be useful for autistic people to learn (both in schools and as adults).

The findings from my study show that it is helpful for the cognitive differences of autistic people to be taken into account and supported during conversation. Participants without autism learned that their contributions to the conversation could cause a 'block' to the thinking and contribution of ideas by the autistic person and that, where this happened, it was often because cognitive flexibility had not been supported (for example, the autistic person was not engaged by the topic or type of conversation), or vocabulary had been used without checking that it had a shared understanding.

Training could therefore usefully include the potential impact of cognitive flexibility associated with autism on conversation, and on *how* cognitive flexibility is supported at the beginning of, and during, the conversation (based on the key themes in this study, see Tables 5.1 and 5.2). In the literature that I have reviewed, I have not seen 'how to' descriptions that would enable communication partners to apply practical knowledge of cognitive differences in people with autism.

The positionality of my study is different from much of the literature I have read, as the starting point was exploring what the autistic participant knew already in relation to conversation. Staff training would usefully enable staff to understand how they may support communication and thinking in order that they can hear the autistic perspective, and use this as a starting point, rather than their teaching being from the perspective of the participant without autism.

It may be useful to re-evaluate some of the staff training delivered in relation to vocabulary understanding and use. Autism training that I know of typically includes some reference to difficulties of the autistic person in understanding and using language and often to difficulties in pragmatic aspects of conversation. My findings suggest that it could be helpful to move away from this deficit-focused view to strengths-based teaching. In such an approach, learners would recognise that autistic people may have their own words, which can be learned and used by others, and that words are not always used with the same meaning attached as that of the communication partner. Moreover, it is important to raise awareness of assumptions that autistic people should be expected to acquire and use a mentalising vocabulary to match the expectations of a person without autism. How to know when to explore vocabulary and when compensatory strategies may be developed for gaps in vocabulary is discussed in future research below.

I was surprised that the communication partners without autism all reported that noticing when they caused a 'block' in thinking or contribution to the conversation was valuable to them. Interestingly, use of the word 'block' appeared to have a greater impact in practice than the more typically used word 'unhelpful'. Usually, when talking to staff and families about what may be useful to autistic people, I focus on what goes

well and from this work out what to do, rather than what not to do. Through this study I learned that training for communication partners could usefully include development of awareness of causing a 'block' (in other words when they have done something 'wrong') and then understanding the potential causes of this, as described above. It is helpful for communication partners without autism to recognise that their role is to listen and elicit further thinking and development of ideas by the autistic person in order to gain a shared understanding, rather than to tell and give information or ideas.

Increased self-awareness requires self-reflection (Mann et al. 2009), and reflective practice is a term widely used in practice settings. Indeed, self-reflection is now often an essential part of formal reporting (for example post-incidents, during performance management and supervision sessions). Mann et al. (2009) synthesized the findings of 29 studies of reflective practice in the health professions and conclude that reflection emphasises 'purposeful critical analysis of knowledge and experience, in order to achieve deeper meaning and understanding' (p. 597). However, Mann et al. (2009) found little evidence beyond self-report to support the proposal that reflective practice improves self-understanding, while Jayatilleke and Mackie (2013) argue that evidence to suggest that a learner's self-reflection skills can be improved by training is still lacking. Further, D'Cruz et al. (2007) argue that 'reflexivity', 'reflectivity' and 'critical reflection' are used by different authors to mean very different things (sometimes interchangeably) and that there is general lack of clarity relating to 'reflection'.

It may be that a lack of detail on how to reflect, or what to reflect on, may be contributing to poor reported outcomes following self-reflection. I have not found literature giving insights into specifically what may be most useful to think about, or reflect on, during and after a significant conversation with a verbally able autistic person. My findings suggest that it could be useful for training given to communication partners to explore how there may be *shared reflection* on the conversation between the autistic person and the communication partner without autism. This would enable people without autism to be critically analytical and to learn, and also to consider knowledge about themselves during reflexivity (see below). Self-reflection may be different for different communication partners and people with autism, and should

focus on the conversation exchange in the context of the cognitive abilities of the autistic person rather than individual utterances or words spoken. It may include:

What do I know about this person?

What do I know about cognitive differences associated with autism?

What do I need to *do* to enable the thinking and talking of the autistic person?

How will I *do* this?

What vocabulary am I using?

What is happening in the exchange?

Is there 'grease' or 'blocks' in what I am saying? How do I know this?

Am I understanding correctly? What is s/he meaning?

Do I need to *do* anything differently now?

My findings showed that directed thinking during self-reflection could usefully be accompanied by an increased awareness of own assumptions and preferences (as described as a part of reflexivity by Robson (2002)). Reflection informed only by a neurotypical way of understanding the world could be less relevant to reflection on a situation involving a person with autistic thinking. Training could aim to ensure that people recognise where they may be likely to make assumptions and contribute their own ideas (even though the ideas are intended to be helpful), as well as to use certain styles of language (for example, multiple questions or particular facial expressions) and know how to reflect on whether this is helpful to the autistic person.

Reflexivity is recognised as important in the context of research (Berger 2015), where it is important to guard against hearing what we expect to hear, or finding what is in line with own views (Kazdin 2014, cited in Sigstad & Garrels 2018). In practice settings, reflexivity also applies: counsellors should know themselves well and be able to metaphorically step outside themselves and look back at their own feeling and responses, including physical responses such as eye movements (Conte 2009). However,

I have not found literature describing how people without autism should learn about their own propensity to make assumptions that are based on neurotypical thinking, which may in turn be unhelpful to autistic people in conversations. Consequently, this practical implication from my research represents a valuable contribution to knowledge.

While I have focused the writing above on staff training, it is also relevant to parent training and it would be helpful to incorporate many of the principles above in to any parent training programme or session. Indeed, a parent involved in my study reported significant learning during the study and changes in the way that she and her daughter were able to communicate. Thus, my findings potentially have implications for practice for anyone who supports an autistic person.

7.7b A rethink about what may be useful for people with autism to learn about conversations

The findings from my study showed that autistic participants had knowledge about what was useful to them in conversations yet had not always previously realised or discussed this. It may be useful to enable autistic people to develop knowledge of what is important to them in the communication environment (this was found to be knowledge of the self, communication partner, atmosphere and type and topic of conversation, in my study). Knowing what is important and useful to an autistic person in a conversation may be learned through a conversation with a communication partner who is able to uncover and develop existing knowledge, rather than to teach from the neurotypical perspective.

Specific learning could usefully include a greater focus on development of metacognition, so that people with autism may become more aware of what they know and more able to use this knowledge (as found in my study). It would also be useful for people with autism to gain a conscious awareness of what may be unhelpful to them in conversation and be able to communicate this to others. During the study, the autistic participants gained an ability and a confidence to let the familiar communication partner know when they said or did something that was not liked (e.g. use of 'why' questions or too many questions). Developing awareness and skills to be able to do this could, therefore, be an important component of guidance or training relating to effective strategies for communication.

7.7c A possible contribution to understanding of social anxiety

The literature search revealed a large number of current articles relating to anxiety and autism; the statistics for raised anxiety in people with autism are high (Kerns & Kendall 2012), and anxiety is very real but insufficiently understood (Halim et al. 2018). Although I did not ask participants in my study specifically about anxiety, at the end of the study autistic participants talked about feeling better in social situations through use of greater knowledge about the situations and having greater control of the conversation. Robertson et al. (2018) conducted a study with autistic adults to explore their experience and impact of anxiety. Factors contributing to anxiety were identified as uncertainty and change, miscommunication and being accepted. Concerns about unpredictability are reported within the theme of uncertainty and change contributing to anxiety, including a communication partner of an autistic person, who said (p. 12):

> Anything in a conversation that he doesn't expect [is problematic], so if you change the subject then he says 'Why are you changing the subject?' or if I bring up something that he doesn't expect or doesn't want, he goes in a complete fury.

This supports my argument that knowing the type of conversation and the topic of conversation potentially reduced the unpredictability for autistic people, which they find difficult, meaning that they were more likely to be able to contribute to the conversations (possibly because anxiety levels were lower and thinking was more effective).

Consequently, my findings relating to the predictability of conversation types could help in this regard, too. Indeed, since the study, I am aware that two of the participants have continued to gain in social confidence and have both reported fewer social difficulties in the workplace. This finding may be linked to what others may refer to as reduction of anxiety yet would require more systematic follow-up and exploration.

7.7d Supporting autistic people to gain and use knowledge in social situations

The findings of this study bring together the different areas of counselling, communication, understanding thinking, reflection and knowledge of self in a way that may be more accessible to busy staff and families, who may have little time for in-depth study or assessment and recording. The learning from this study enables better

understanding of how to think about the autistic perspective and the impact of self on the communication exchange, which can have an impact in many everyday situations. It enables communication partners to immediately think about how they may change their communication, focusing on the exchange and how autistic people may use existing knowledge. This is immediately applicable to real-world situations and is generalisable between situations. It is very different to the use of (often lengthy) programmes to teach social skills (see Chapter 3) or full counselling training, or acquiring the in-depth language and communication knowledge of a qualified speech and language therapist. In effect, where participants without autism in my study became more aware of the impact of themselves on the communication exchange and used knowledge of cognitive differences associated with autism and knowledge of the individual, there was a change in the contribution of the autistic person to the conversation. The practicalities that follow from the findings from my research could therefore have wide relevance and universal application, regardless of which practice setting a person may be working in.

7.8 Other potential applications of learning during this study

The learning from this study is potentially useful in any significant conversation between an autistic person and a person without autism; that is, a conversation where the outcomes are likely to have an impact on future understanding or planning. I provide a non-exhaustive set of examples below to show how and where the approaches developed in this study could be useful.

7.8a Personal tutorials

During the study, the learning was used effectively by both Lee (AP) and Oscar to enhance the outcomes of a personal tutorial (a talking session planned to explore and resolve any current difficulties (Christie et al. 2008)). Oscar and Lee (AP) were able to agree the type of conversation prior to the start of the tutorial and the topics to be covered. This enabled Lee to engage more fully, as he felt more confident in what was expected of him and what the outcome of the personal tutorial would be. Unpredictability was therefore removed and Lee felt an equal partner in seeking a solution to the problem, rather than expecting a 'bollocking', as he reported previously.

7.8b Assessments of physical and mental health by medical practitioners

Much assessment depends on talking to the person to understand where any difficulties may lie. The outcome of this conversation may result in for example medication changes and can have a significant impact on quality of life. I have witnessed situations where a verbally able autistic person has given a stock response in a medical appointment (a response that has been learned for use in that situation, rather than a meaningful, thought-through response), but the medical practitioner has not recognised this, so their decisions regarding mental health status and requirement for medication and support may be based on inaccurate information. Such misunderstanding and vulnerability could be avoided if the medical practitioner had had training that enabled them to optimise engagement, support thinking and understand the cognitive and language differences associated with autism that may lead to such stock responses.

7.8c Assessment of mental capacity

The Mental Capacity Act (2005) means that capacity for decision-making must be assumed and that, where there is doubt, it must be assessed in relation to a single decision. Assessment includes the ability to understand and retain the choices, weigh up the choices and communicate the decision. Guidance is clear that all steps must be taken to support understanding, yet there is little emphasis on checking understanding or masking in people who are verbally able. I have experienced situations where people who talk well are assessed as having capacity in relation to a decision, because the assessor has failed to explore understanding and just taken the first response as evidence of understanding. Equally, I have seen verbally able people who have been assumed not to have capacity because they were not engaged in the conversation. The outcome of the capacity assessment can have a significant impact on life choices for the person involved. Therefore, as above, training of the assessor to enable them to optimise engagement and support thinking and to understand the cognitive and language differences associated with autism could contribute to the robustness and validity of mental capacity assessment.

7.8d Social care benefit assessment

There is a changing funding climate in the United Kingdom (Hedley & Fradd 2010), meaning that there is greater assessment of support needs and benefits such as Personal Independent Payments, which may appear to be finance driven. These assessments are often conducted on a single occasion by a person who may have limited training in the differences associated with autism. Assessors may tend to conduct the assessment on their terms on a single occasion, rather than on the terms of a person with autism and over a period of time, as advocated by Ridout (2017). I know people who have had their benefits and support hours reduced because they have given responses that mask their real difficulties but were not noticed or explored by the interviewer. The outcome of these interviews has a huge impact on the lives of people. Improved knowledge of the autistic perspective and the assessor's awareness of their own impact on the autistic person would potentially make a difference to the contribution of the autistic person and the outcome of the interview or assessment.

7.8e Cognitive Behaviour Therapy (CBT) and counselling

Hare et al. (2015) talk about the importance of 'cognitively informed' CBT for autistic people and Robertson et al. (2018) report that the autistic participants in their study also identified practical barriers to CBT. Robertson et al. (2018) question the 'appropriateness' of the CBT treatment (e.g. one person described how her rigid thinking in autism meant that her gains from CBT were limited), and whether the therapist had appropriate levels of autism understanding and awareness. Cooper et al. (2018) report on a survey of CBT therapists regarding how they adapt their CBT for autistic clients. Therapists reported challenges including the rigidity in thinking of autistic people and how to pace the sessions, and felt less confident in using their knowledge to help autistic clients. The findings from my study may give some indication of how the communication partner or therapist may be sure that their approach takes into account the cognitive differences of the autistic person, not least through recognising that they have significant responsibility for helping to shape the communication in a positive way.

Although the findings of my study may have close links with some of the principles of listening and responding used in counselling, there are also differences. For example,

the importance of 'building rapport' and 'focusing the client' (Conte 2009, p. 32) are important during counselling, but optimising engagement described in my findings above require an understanding of the autistic perspective and the specific cognitive differences associated with autism in order that both communication partners with and without autism can be sure that they are ready to talk about the same thing. Further, Conte (2009) suggests that counsellors cannot be effective if they focus on every word said rather than the totality of what the client is saying. This is similar to my finding whereby there must be a focus on the communication exchange rather than individual utterances taken in isolation. However Conte (2009) then proposes (p. 32), that 'focusing involves cutting clients off, confronting and facilitating clients staying on the topic'. This is in contrast to my findings whereby interruption caused a 'block' to the autistic participant's thinking. In order to be helpful, it was important to establish the topic and type of conversation prior to the conversation so that, having planned the conversation, the autistic person felt more able to keep to that type of conversation and topic. This is quite a different strategy than that proposed in counselling approaches to communication, and so the use of strategies found helpful to support engagement and thinking of autistic participants in my study could usefully be employed by counsellors with autistic people. This, too, would ensure a positionality within the counselling session to ensure that understanding the autistic perspective is a starting point for supporting effective communication.

Ridout (2017, p. 61) summarises the importance of communication environments being considered from the autistic perspective, arguing:

> In order to facilitate meaningful processes of engagement, autism-friendly environments need to be established, which includes addressing communication preferences, attention to sensory and social processing differences and shifting the location of power by placing the autistic voice as the expert insider voice.

In this context, my research contributes new knowledge about how such an autism-friendly environment can be enabled through raising awareness of, and paying attention to, specific communication features, especially within significant conversations.

7.8f Interviews within participatory research

There is a call for autistic people to be equal partners in research (Fletcher-Watson et al. 2018; Gillespie-Lynch et al. 2017; Milton 2014), as this has been lacking to date. Further, listening to young people with autism and ensuring that their voices are meaningfully heard can be difficult for some researchers, who report difficulties in the areas of power balance, building rapport, communication and meaningful outputs (Fayette & Bond 2018; Scott-Barrett et al. 2018). There is also a reported weakness in studies with young autistic people in data collection (Fayette & Bond 2018). There is some guidance relating to following good autism practice in research interviews (e.g. Harrington et al. 2014), and Ridout (2017) suggests that knowing what works best for the autistic person and having a familiar person who understands them can facilitate the participatory process. However, this guidance appears somewhat vague and not specific to the differences associated with autism, unlike the findings of my research relating to what is helpful to autistic participants for them to be able to best contribute to the conversation. In my searches of the literature I have found little specific guidance or detail on the *how*, or exactly what may people without ASC need to change about their communication. I have not found any emphasis on how to ensure that the generation of meaningful ideas and contribution of the autistic person is supported, nor how to ensure that the control of the interview does not lie with the interviewer. Indeed, Sigstad and Garrels (2018) argue that less attention has been paid in the research literature to 'how appropriate communication techniques may enhance interviewer's communicative competence and how this may strengthen the conversation more directly' (p. 694). My findings may contribute to this recognised gap.

7.8g In 'consultation'

Decision-making is known to be difficult for adults with ASC (Luke et al. 2012), but being able to make and communicate decisions is of huge importance in relation to people 'having their say' as advocated in statutory guidance (e.g. Valuing People Now, Department of Health 2009) and by regulators (e.g. Care Quality Commission, Ofsted). My finding relating to use of supporting engagement and supporting thinking is significant in consultation in the real world, where decision-makers are asked to ensure that people supported are able to make choices about their lives, for example choosing

where to live, whether to receive support and what support would be used for or whether to undergo a medical treatment. However, in my experience, where an autistic person appears to talk well, an inexperienced communicator may 'just ask' a significant question without ensuring engagement in the topic and supporting the thinking of the autistic person. For example, I have known a social worker who wished to know whether a person wishes to move house to 'just ask', without first enabling the person to focus on the topic of moving and what he knows about moving and what the choices and consequences may be. This, as above, risks a stock response.

Further, there is a call to learn more from young autistic adults and their families. For example, a recent study by Sosnowy et al. (2018) suggests that perspectives of young autistic adults on desired outcomes in life are more complex than current conceptions suggest, meaning that it is of great importance to listen and understand these, rather than making assumptions. The learning from my study will enable people who listen to and consult with verbally able people with autism to begin to know how to change their communication, in order to better listen to the meaningful voice of the autistic person, including their thoughts and perspective, rather than responding first to what is said.

7.9 Future research

This study raised many questions for me, which could be usefully explored in further studies. These are summarised first in relation to the communication partner without autism, then in relation to the autistic perspective and, finally, from a more general perspective.

7.9a When to stop and explore an understanding of vocabulary or phrase used

Sigstad and Garrels (2018) emphasise the importance of validity in qualitative interviews to be confident about the interpretations and conclusions. The same principles must apply in a 'significant conversation' to avoid potentially misunderstanding the autistic person. The findings from my study showed the importance of recognising and exploring possible stock responses. Using stock responses may also contribute to successful camouflage or masking (Hull et al. 2017), which, in turn, may contribute to raised levels of cognitive demands and stress for the autistic person. However, exploring answers to ensure an understanding does take

more time and, if done unnecessarily, may inhibit the flow and goal of the conversation. It is therefore important that we learn more about how to notice answers that may need further exploration.

Although communication partners without autism felt that they became better at spotting words and phrases that may be used without their full meaning by an autistic person, it is not yet clear to me how this was done. At this stage, I can only say that the communication partners became better at listening out for words and phrases that may be used repeatedly or which may not be understood by the autistic person. It is most likely that the communication partners had become more aware of the cognitive processes of the autistic person and tuned in – in a different way – to the things that they were saying. However, without knowing how the phrases were spotted, it is not possible to transfer this learning to situations in which the communication partner may be less familiar with the autistic person.

7.9b What does 'timely' really mean when planning prompts to think?

It was clear that the timing of prompts to think was important. If an autistic person was asked to think about a response before their attention was engaged on the topic and before there was a shared understanding of vocabulary, the prompt to think resulted in a 'block' to thinking or a stock response. The participants without autism in the study appeared to learn when to ask a person to think, but it would be useful to know more about exactly how we know when either to ask or not ask a person to think, in order to inform future staff training.

7.9c When do questions cause a 'block' to thinking?

There are times when questions cause a 'block' to thinking and times when they do not; some questions are more difficult than others. Why?

When I started data analysis, I had a very naïve understanding of the questions that people ask in conversations, assuming that certain question types would be helpful and certain types unhelpful, but this was not the case. Although greater awareness of questions was an important area of learning for all participants, including me, my study showed that questions could be both helpful and unhelpful to the autistic participants' thinking. Sometimes they caused a 'block' to thinking and contribution and sometimes

204

they supported thinking. It appears that the timing of the question was important (a finding in common with Capps et al. 1998), and I noticed that timing in relation to engagement, memory and topic focus was a crucial aspect. However, I feel that I have insufficient knowledge about what constitutes good timing of the question. Additionally, the type of question, the number of questions asked and the grammatical structure of the question all appeared to have an impact on the thinking of the autistic person. 'Why' questions were disliked by autistic participants Chloe, Ruth and Cait, but it would be useful to know more about whether or how 'why' questions can be useful and how we may find different ways of eliciting possible reasons or explanation without asking a direct 'why' question.

My study found that unhelpful questions (that is, 'why' questions, multiple questions and vague questions) very clearly caused a 'block' in the autistic participants' thinking and contribution of thoughts and ideas, but it was difficult to always anticipate what would be an unhelpful question. I found that questions that were grammatically simple and linked to the current topic provided little difficulty, matching the finding of Hewitt (1998), who looked at communicative breakdown between young adults with autism and a communication partner. Nevertheless, I was surprised that some questions, which I had considered simple (for example, short questions) remained difficult to answer. Other studies have also suggested that questions may cause difficulties for people with autism (Tager-Flusberg et al. 2005) and that this may be linked to difficulties in perspective taking (Curcio & Paccia 1987) and taking the context into account (Frith 1989). My study showed that setting the context for the question was most important, but the syntax and need for inference could have been further specifically explored.

When thinking further about questions with people with autism, I would argue that neurotypical assumptions should be avoided. For example, Sigstad and Garrels (2018) give examples of interviews with people with intellectual disability and suggest that it may be necessary to rephrase or expand a question during a research interview. However, the examples given within their study (p. 697) suggest to me that there are times when the question is being rephrased yet the understanding of the vocabulary in the question is not checked. Similarly, Antaki (2013) propose that using an interrogative question followed by a hint or elaboration can be useful in gaining a greater response to

a question with people with intellectual impairment. However, some autistic people have suggested to me that rephrasing what has been said while they are still processing what has been said actually adds to the cognitive load and causes further confusion. I would also be mindful that, when talking with people with autism, it is important that the hint did not become giving an idea. My findings showed that giving an idea frequently resulted in a 'block' to thinking.

I suggest that better understanding of the impact of questions on an autistic person would be an important area for staff training; and also for autistic people to learn to know when they may have not understood fully and to indicate this, as well as to know which questions are personally disliked by them.

7.9d Exploration of the autistic perspective of conversation specifically linked to social anxiety

As noted previously, there is much in the literature reporting the experience of social anxiety of autistic people. During my study, the autistic participants reported feeling more confident and reported fewer difficulties in conversations (especially Ruth and Cait) compared to some occasions that they recalled. Cait has described her 'panic attacks' whereby her arm goes cold prior to a sense of overwhelming feelings (although the word anxiety is not used by Cait) and, during and after the study, reported fewer of these. It is therefore likely that levels of social anxiety may have been reduced, but I did not specifically explore this. It may be useful in further studies to link learning relating to conversation more directly to the experienced levels of social anxiety and to better understand which learning has the most impact on the reduction of anxiety levels, from the autistic perspective. Spain et al. (2018) conducted a systematic review of studies looking at relationships between core ASD symptoms and social anxiety in individuals with ASD and similarly conclude that further studies are needed to enhance identification of causes of social anxiety, and the maintaining and protective factors. Autistic people frequently reported the use of reassurance from others to manage anxiety (Robertson et al. 2018), which in itself is of concern, as this suggests that the autistic people lacked the resources to take some control and to know how to manage the anxiety themselves. It would be useful if learning from this study could contribute to

enabling autistic people to know what is important to them to reduce anxiety levels and to know how to make this happen.

7.9e Alternatives to teaching emotion

Considering the differences in metacognition and reported prevalence of alexithymia, could we consider an alternative to teaching autistic people a vocabulary of emotion typically used by people without autism?

Alexithymia is well reported (see above), but I have not found literature exploring compensatory strategies for this known area of difference in autistic people. During the study I was surprised that all autistic participants described some physical response or physical sensation when a conversation was not going well, from their perspective. The participants had not previously thought to use this as a trigger to begin problem-solving to take control of the environment or their situation in order that they could feel better. Physiological arousal associated with anxiety is discussed by Bellini (2006) and by Trembath et al. (2012). It would be useful to explore further how the awareness of physical responses may be developed and used by autistic people to recognise and manage an emotional response without a dependence on a vocabulary of emotions that may not make sense to themselves or, indeed, to others.

7.9f Further knowledge of use of trait knowledge by autistic people

Although trait knowledge is reported as a spared socio-cognitive function in autism (Ramachandran et al. 2009) and participants in my study were able to access and use this knowledge to work out what a familiar person may do or say next, I have found little in the literature describing how this strength could be usefully developed further. Therefore, a future line of enquiry for research could be to explore how trait knowledge could potentially be developed as a useful compensatory strategy with autistic people.

7.9g A better understanding of vulnerability of the verbally able autistic person in conversation

I began to ask about vulnerability at the start of the study, but ceased to do this when I realised that participants found the word 'vulnerability' difficult to know about or describe. However, it was clear that stock responses given could contribute to vulnerability through misunderstanding, if these were taken at face value (for example,

the comments made by Lee (AP) in relation to his sexuality). Masking or camouflaging may also contribute to vulnerability. It would be useful to have more detailed knowledge of where vulnerability lies and exactly how learning from this study from both the autistic and non-autistic perspectives can reduce this for the autistic person.

7.9h Who benefits?

There is now an awareness that autism in females is often less well recognised than in males (Loomes et al. 2017) and that females can be more adept at masking and camouflaging their differences associated with autism (e.g. Dean et al. 2017; Lai et al. 2017) than males. There is now a call to place sex and gender differences in autism and their impact in a social context (Mandy & Lai 2017). However, during this study, I did not consider any balance of females or males when recruiting participants and was not specifically looking for gender differences as an influence on the findings. To contribute to the growing body of literature on the differences between male and females with autism, I could have paid greater attention to gender differences and the social environment that may be influencing the presentation of participants.

7.9i How to best talk about this work to staff, families and autistic people

I have learned from previous research, as well as from staff and family training, that learners are only interested in information if they see a purpose in it, and only make changes to their behaviour if they see a reason to do so. To me, a strength of the outcomes of my study is that they can appear very simple (and participants reported how they enjoyed learning some things that were so obvious that they had not previously considered them). However, the downside of this is that people may recognise neither its complexity, nor the thinking behind this learning.

I would like to know more about who would benefit from learning the strategies described in my findings (from both the autistic and non-autistic perspectives). The different responses of all the participants within in the study showed me that a certain amount of insight (and possibly confidence in self) is needed in order to be able to question the self and to recognise that the self could take some responsibility to make things better, and that the difficulties experienced are not because of the other person. I want to be able to present this work in such a way that learners do not think, 'he's OK

with me' or 'I do that already', but learn to question themselves. There are many areas of learning from this study, including the abilities and needs of the autistic person, the communication of the person without autism and the impact of this on the exchange in communication and the thinking and contribution of the autistic person. I have already talked about this research in several forums to staff and find I need to focus on one aspect of it and to be sure to place this clearly in context, explaining the 'blocks' and how things go wrong as much as the 'what to do' or the 'grease'. I would like to learn more about how I can best personalise and present this work to make a practical difference to people in the real world, so systematically evaluating training that uses this approach would be an insightful aspect of developing the evidence base for the approaches developed within this thesis.

7.10 Limitations

7.10a I am not autistic myself
I am listening to autistic people, but I am not autistic myself. The purpose of the study was to know what people without autism can do to ensure that the communication of autistic people is best listened to and understood, and I learned this primarily through listening to autistic people. It may be argued that I do not have the lived experience of an autistic person and therefore cannot speak for autistic people (e.g. Gillespie-Lynch et al. 2017) yet, throughout my reporting of my findings, I do not intend to speak for the autistic participants but rather reflect what I have learned from them. Throughout the study, I used reflective practice and reflexivity alongside listening, which I tried to personalise to each person, and did my best to avoid my own assumptions regarding the experiences of autistic people.

7.10b The choice of communication partners
The autistic participants chose their communication partners and I then checked that the communication partners both understood their proposed involvement in the study and were happy with this. I wanted my study to be centred on the preferences of the autistic participants and to be of value to them, so wished for the autistic participants to choose who they would like to work with during the study. However, with hindsight, I could have further explored the communication partners' knowledge and understanding of the communication process and their role in it, and their desire and

feeling of need to develop and to change prior to the study start. This may have given me more information about who will benefit from this work and possibly the prerequisites, pre-training or pre-knowledge to benefit from it.

7.10c Limited use of *learning*

In using a case study design, I am aware that there are limitations to the generalisation of learning from this study. However, I have found that participants have themselves generalised their learning to other situations and to other communication partners. I am wary when talking about the learning of the study and repeatedly point out the heterogeneity of autism and the risks of assumptions and generalisation to other people. I am also aware that the presentation of autism can change with time (Hobson 2014) and that much of the literature used to inform the study was based on young people, as there is relatively little relating to adults. Nevertheless, this is also an area where my own work contributes to the literature by focusing on the communication of adults rather than children.

7.10d Limitations of self-report

I am aware that although I was able to see and hear communication exchange during the semi-structured interviews and I analysed this, much of the reported learning during study was also based on self-report and there are limitations to this, as already acknowledged and documented in the literature review (Chapter 2). However, it was essential to my epistemological position to hear the self-reports of autistic people and I approached this with care to ensure that I avoided its known limitations. I am also aware that caution that must be taken in drawing interpretations and conclusions from qualitative interviews (Sigstad & Garrels 2018) and took care with my interpretations and conclusions, regularly checking these with participants to ensure authenticity and trustworthiness.

7.10e Attention to reported detail in the semi-structured interviews and observation records

During the semi-structured interviews, nonverbal signals were used (for example, facial expression or gesture), as well as silences. I recorded these when I observed them in the interview, but did not specifically analyse these aspects of the recording. With hindsight, I could have paid greater attention to specific recording of the nonverbal

aspects of the conversation and the analysis of these, however this may have required video recording. When planning the study, I decided that use of video was too intrusive and might affect the naturalness of the conversation, which was important to my study. When planning the observation record for participants, I did not ask for 'blocks' to be recorded. I now realise that learning about the 'blocks' to thinking and contributions to the conversation by the autistic participant were important, and it should have been helpful to have more information about these. However, the importance of the 'blocks' only became clear during the analysis and so this is something that could be included in future research rather than something I should have done differently in this study.

7.10f Limited length of involvement

The timeframe of the study meant that the length of involvement with each dyad was limited. I know that three of the participants are continuing to use their learning after the close of the study, but a follow-up study, in time, to explore how this learning has been further sustained and developed (or not) should have been useful. Lack of follow-up data in studies has been identified as a weakness in the study of social abilities (e.g. Gates et al. 2017) and so this is something that could usefully strengthen future research in this area.

Chapter 8 **Conclusion**

As a practitioner I have witnessed the vulnerability of autistic adults in conversation, where they are misunderstood and report that they do not feel listened to.   Further, staff and families have talked to me about wishing to know more about what they can helpfully do when talking with autistic people, so that autistic people may contribute their meaningful knowledge and own thoughts to the conversation. This reflects the double empathy problem (Milton 2012a), whereby people without autism may lack understanding of autistic people. While there is a call for the voices of autistic people to meaningfully inform support and services provided to them, as well as research and policy that impacts on them, there is little specific guidance about how a communication partner may change their communication to support the conversation contributions of the autistic person.

This multiple-case study used a participatory approach to explore the conversation exchange in dyads of five autistic adults and seven adults, looking specifically at how autistic adults can be supported to by a communication partner to contribute what they know to conversation, and what is useful for autistic adults to know in conversation. The findings from this collaborative study, grounded in the individual perspectives of autistic people, provide insights as to how communication partners without a diagnosis of autism may usefully focus on the conversation exchange and their potential impact on the conversation contribution of the autistic participant. Learning from and with the autistic participants, the non-autistic participants were able to change their own communication specifically to support the engagement and thinking of the autistic participants, thus supporting their meaningful contribution to the conversation. The changes made by the non-autistic communication partners took account of the heterogeneity of autism (Georgiades et al. 2013) in focusing on the use of strategies identified as most helpful to individual autistic participants. Additionally, all strategies were informed by a strengths based understanding of cognitive differences associated with autism, and used within a naturalistic interactive context.

Importantly, this study shows how changes made to the communication between the participants enabled the uncovering of individual autistic participants' strengths and

knowledge relevant to conversation, and so provides insights into how normative assumptions (Parsons 2015) and a normalisation agenda (Milton and Moon 2012) that may underestimate abilities of the autistic participants, could be avoided. The study also contributes to an understanding of 'interactional expertise' (Milton 2014 p.795), leading to improved communication between autistic and non-autistic participants.

The findings also show that autistic participants could successfully access and use their knowledge of the conversation environment (including knowledge of self and others in the environment) and the type of talk taking place within naturalistic settings, giving a greater sense of empowerment within the conversation. Use of this knowledge reflects metacognitive abilities that were previously unrecognised by both the autistic participants and their non-autistic communication partners. This finding contributes to the strengths based understanding of the cognitive abilities of autistic participants and the call to explore metacognitive abilities of autistic people further (Sawyer et al. 2014), and also contribute to more recent thinking about ToM, whereby ToM is considered within an interactive context and it is recognised that not all ToM is impaired (Atherton et al. 2018). The ability to think about what they know, relevant to the conversation, the environment and the people, and then to use this knowledge was an approach that became owned by the autistic participant. This meant the process of uncovering and using own knowledge was transferable outside of the participant dyad and led to self-reported reduced anxiety in conversation and increased confidence in conversation in other everyday settings.

The potentially transformative changes in the thinking and communication of both partners in the conversation dyad show the value of taking a non-binary approach to enabling the contributions to conversation of the autistic participants within a naturalistic interactive context. Where autistic and non-autistic people learned together, conversation was more successful from both perspectives within the dyads.

From my own perspective as a practitioner, the findings have had a significant impact on my own reflective practice. I am now usefully aware of where to focus my attention on my own communication during a conversation, in order to support engagement and thinking of the autistic person; and I am able to use this learning to reflect on the

success of my conversations. During the study I was surprised at the changing thinking and communication of people without autism who have spent a lot of time with autistic people, as well as the changed thinking and contribution to conversation of the autistic participants. I had not expected that adults would learn and change so readily and I suggest that the focus on the conversation exchange during the study was helpful to participants with and without autism. A focus on the conversation exchange and learning together is now a focus of my own clinical practice.

The findings from this study have valuable implications for staff training, for working with families and for learning by autistic adults. The findings could be applied in any significant conversation with autistic adults, in wider consultation forums and in participatory research with people with autism. The learning from this research for autistic people and non-autistic communication partners could be usefully further explored with younger autistic people as well as with autistic people of different verbal abilities. Overall, the findings have the potential to make a difference in the lives of autistic people through empowering them to use their existing knowledge and strengths in conversation, and supporting non-autistic people to develop more attuned interactional expertise that respects autistic perspectives.

Appendices

Appendix 1: Information Sheet for

Participants

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Southampton

Kate is doing some research and a PhD degree at Southampton University. Her research is about interaction between people with and without ASC (Autism Spectrum Condition). She is thinking about:

What we can do to make interaction between people with ASC with people without ASC most successful.

The full title of Kate's study is: How can existing skills and knowledge of people with Autism Spectrum Condition be uncovered and used, to support successful social interaction and to reduce social vulnerability?

Information for people who may like to work with Kate in her study

About the study

Lots of people with autism and Asperger Syndrome have talked to Kate about getting on with other people. People say that sometimes being with people goes well, but sometimes getting on with people can be difficult.

As part of the research, Kate would like to learn more about:

- what people with ASC think about when talking to other people
- what people with ASC know already about the people and the situation when they are talking
- what makes an interaction go well
- what people without ASC can do to enable people with ASC to feel more confident about social situations and about getting on with people
- what people without ASC can do to make the interaction most successful

About the people who may be involved

Kate would like to talk to people with ASC who are interested in social interaction and interested in learning more about what they do now and what else they could do, to feel more confident in social situations. Kate thinks that people with ASC know best about what is helpful to them. Kate would like to learn from people with ASC.

Kate would also like to work with staff who work with the people with ASC. Kate will ask the people with ASC involved in the study to invite a member of staff to be involved too.

The member of staff can choose whether to be to be involved in the study or not. If they choose not to be involved in the study, the person with ASC can invite someone else to be involved.

About taking part in the study

Part 1

For the first part of the study, people with ASC taking part will talk to Kate about social situations and talking to people. People will talk about their successes in social interactions and about where they would like to be better. They will also talk about what they already know about social situations and about what they do well in social interactions. The conversation will last about one hour.

The member of staff taking part in the study will listen to the conversation. Kate will ask the member of staff to take some notes. We can look at the notes to check what has been written about the conversation.

The staff member will be invited to talk to Kate about their notes and what they noticed when the person with ASC and Kate were talking

People with ASC can choose where they would like the conversation to take place.

Kate will ask each person involved if it is OK to record what he or she says, on a digital recorder.

After talking, Kate will ask people with ASC involved to do some writing about their experiences in social situations (if people do not like writing, people may choose to use a recording or a video instead or may ask someone else to do the writing). The member of staff involved may support this recording

After the writing or recording about the social situations, the person with ASC can pass the writing or recording to Kate, or talk about the writing or recording to Kate. This will help Kate to learn more about social interaction. Kate would like to use what we have learned to learn some more. Kate would like to do some more talking and some thinking with people with ASC. Kate would like to think about what may be helpful in social situations.

Part 2

Some people may choose to carry on working with Kate, but other people may choose not to be involved any more. It is OK to say, 'I don't want to work with Kate on the study', it is OK to choose to carry on working with Kate on the study.

Some people with ASC and their members of staff without ASC will be invited to take part in the second stage of the study, part 2.

Part 2 will involve talking to Kate again about conversation and about interaction and thinking a bit more about the things we learned about interaction in part 1. It will involve Kate listening to a conversation between the member of staff and the person with ASC and it will involve keeping a record of conversations and interactions again.

About any risks involved

People involved in the study will just do the things that they are used to doing, in places that are familiar. There will be nothing new or unusual involved.

For people with ASC, talking with Kate and talking with the member of staff will be the same as talking with Kate and the member of staff at any time, but we will be talking about the study. Kate will be talking to the member of staff only about the interaction and the study.

Kate and people involved will be thinking about new ideas to try to make interaction better. If the talking or thinking is too hard or if people do not like the talking and thinking, people involved can just tell Kate that they would like to stop, and this is OK.

At the end of Part 1 and Part 2

At the end of the first parts of study, Kate will talk to people who helped her. Kate will talk about what we found out about what is helpful in social situations. Kate hopes that what we work out may help other people with ASC to feel better in social situations.

Kate will write about what we find out. Kate will write about people who worked with her, but people can choose how Kate refers to them in the writing. For example, people can choose to be referred to by an initial or by a false name instead of their own name.

The good things about being involved

Taking part in the study may help the people involved to learn new things about themselves and to learn more about getting on with other people.

The things we find out during the study will help other people with ASC and people working with them

Kate would like to invite you to work with her. Kate can talk to you to tell you more about the work if this would be helpful

Remember

You do not have to agree to work with Kate. If you do choose to work with Kate, you can choose to say, 'I do not want to do the work with Kate any more' at any time. Choosing to stop working with Kate will be OK.

If you are not happy about anything in the study at any time, you can talk to your staff, or to the manager of your service or the head of the school, or your Area Manager to let them know, or you can talk to Kate.

If you still have a concern or a complaint about the study or a concern or a complaint about Kate, please contact the Head of Research Governance at the University of Southampton. Telephone: *02380 595058;* Email rgoinfo@soton.ac.uk

Where can I get more information?

If you would like further information about the study, please contact Kate.

You can contact Kate by email: <u>kms1g11@soton.ac.uk</u> or you can contact Kate at Head Office 0151 330 9500.

You can also contact Sarah Parsons, who supervises Kate's research at the University: Telephone: 023 8059 2977; Email: <u>s.j.parsons@soton.ac.uk</u>

20 November 2015

Appendix 2: Summary of Involvement

The tables below give a summary of what people involved in Kate's study would do.

The table below is a summary of what taking part in the first part of the study would involve:

Participants with ASC	Participants without ASC
Talk to Kate for about one hour about social interaction and conversations that you have had recently.	Observation of interaction between the person with ASC and Kate. Make some notes of what you notice during the interaction.
Keep a record of some interactions or conversations for 3 days.	Talk to Kate for about half an hour about what you noticed in the interaction. Support the person with ASC to keep the record of conversations if this support is requested. Let Kate know if there are any difficulties with or concerns about the record keeping.
Talk to Kate about the interactions or conversations you have been having with other people.	

Part 2

Participants with ASC	Participants without ASC
Talk to Kate for one hour in an environment chosen by the person with ASC, about the things that people with ASC told Kate in part 1. We will talk about what people know and notice about social interaction	
Have a conversation with the member of staff for 30–45 minutes. Kate will listen	Have a conversation with the person with ASC for 30–45 minutes. Kate will listen
Talk with Kate and the member of staff about how the conversation went	Talk with Kate and the person with ASC about the conversation went
	Talk to Kate about what can be helpful and unhelpful in conversation with people with ASC
Keep a record of conversations and interactions for 2 weeks	
Talk to Kate about the record of conversations and interactions and about what we could do to help to make conversation and interaction more successful	

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Appendix 3: Consent Form (participants with ASC)

Consent Form (participants with ASC)

Study title: How can existing skills and knowledge of people with Autism Spectrum Condition (ASC) be uncovered and used to support successful social interaction and to reduce social vulnerability?

Researcher name: Kate Silver

Ethics reference: Submission ID: 17940

Agreeing to be involved in Kate Silver's study.

The study is about finding out what we can we do to make interaction between people with ASC with people without ASC more successful.

This form is to make sure you know what you will do if you take part in the study.

Please put your initials in the boxes below if you agree with what is written.

	I agree
I have read the information sheet about Kate Silver's study. The sheet I read was dated 20 November 2015.	
I have talked about the study and asked questions where I did not understand, or where I wanted more information.	
I understand what the study is about. I understand what I will be invited to do, if I take part.	
Working with Kate means that I will spend some time talking to Kate about my experiences when I am with other people.	
A member of staff who I know well, will also work with me and Kate.	

224

I may also write down or record some information to give to Kate. I may choose whether I write this information down or record the information some other way.	
It is OK for Kate to write down or to record what I say as part of this study. I understand that Kate will keep any information given by me on a computer protected by a password. The information will only be used for this study.	
I understand that I do not have to choose to work with Kate.	
If I do choose to work with Kate, I can choose to stop working with Kate at any time. It will be ok to tell Kate, 'I do not want to do this anymore'.	
I know who to talk to if I am not happy about anything during the study.	
When Kate writes about the study, I can choose for Kate to use my name or I can choose to be anonymous. That means that Kate will not use my real name. I can choose a different name or choose for Kate to use an initial or another letter.	

I have decided that I would like to do the work with Kate in the study.

Participant signature:

Date:

Researcher signature:

Date:

Appendix 4: Consent Form (participants without ASC)

Consent Form (participants without ASC)

Study title: How can existing skills and knowledge of people with Autism Spectrum Condition (ASC) be uncovered and used to support successful social interaction and to reduce social vulnerability?

Researcher name: Kate Silver

Ethics reference: Submission ID: 17940

Agreeing to be involved in Kate Silver's study.

The study is about finding out what we can we do to make interaction between people with ASC and people without ASC more successful.

This form is to make sure you know what you will do if you take part in the study.

Please put your initials in the boxes below if you agree with each statement.

	I agree
I have read the information sheet about Kate Silver's study. The sheet I read was dated 20 November 2015.	
I have talked about the study and asked questions where I did not understand, or where I wanted more information.	
I understand what the study is about. I understand what I will be invited to do, if I take part.	
Working with Kate means that I will work with Kate and a person with ASC. I will make observations of interaction between Kate and the person with ASC and Kate. I will talk to Kate and the person with ASC about the	

interaction. Kate will observe me talking to a person with ASC and we will talk about this. I may support the person with ASC to keep a record of their interactions to discuss with Kate.	
It is OK for Kate to write down or to record what I say as part of this study. I understand that Kate will keep any information given by me on a computer protected by a password. The information will only be used for this study.	
I understand that I do not have to choose to work with Kate.	
If I do choose to work with Kate, I can choose to stop working with Kate at any time.	
I know who to talk to or contact if I am not happy about anything during the study.	
When Kate writes about the study, I can choose for Kate to use my name or I can choose to be anonymous. That means that Kate will not use my real name. I can choose a different name or choose for Kate to use an initial or another letter.	

Participant signature:

Date:

Researcher signature:

Date:

Appendix 5: Semi-structured Interview 1 Topic Guide

Semi-structured interview 1: Researcher and autistic participant

Topic Guide

All semi-structured interviews must be personalised.

The topics planned for inclusion are listed below, but the order in which the topics will be explored and how information is elicited will be responsive to what is said by the participant.

1. Think about experiences of different types of interaction or conversation e.g. with the social worker, with the family, discussing 'issues' with staff.

    Prompts given such as:

Think about conversations you have had recently…

Have you been talking to anyone today? Can you remember what the conversation was about?

- Is there a difference between conversations you have?

Prompts given such as:

Thinking about the conversations you have had, do some go well and some less well? Would you say some conversations are successful or unsuccessful (the words to be used must be right for each person) Words may include go well/don't go well, good conversation/bad conversation.

We then choose a conversation to talk about further to explore, with the aim of exploring both a 'successful' and 'unsuccessful' conversation.

2. When exploring a 'successful' conversation we explore the following:
- Who was in the conversation
- Where the conversation took place

- The conversation was successful/went well because… Explore through probes anything that the participant says helped the conversation to go well from their perspective.

Probes may include e.g. 'I wonder what was different about…' 'That sounds really interesting, can you tell me a bit more about…?', 'I wonder if you did (or said) anything yourself to help the conversation go so well…', 'Can you think what the person you were talking to did or said that helped the conversation to go well?'

- What the participant noticed or knew about people in the conversation.

Prompts may include asking about the person in the conversation and how well the participant knew the person then probing what they knew about the person.

3. When exploring an unsuccessful conversation, we explore:
   As above i.e.:
- Who was in the conversation
- Where the conversation took place
- The conversation was unsuccessful/went not so well because… Explore through probes anything that the participant says that meant that the conversation did not go well from their perspective.

Prompts will enable exploration of what other people in the conversation did, and what the participant with ASC did.

Prompts may include:

E.g. 'I wonder what was difficult for you in that (naming/giving detail of what we are talking about) interaction then'. 'I wonder what was different about…', 'Can you tell me a bit more about…'

'Can you think what the person you were talking to did or said that meant the conversation did not go well?', 'I wonder if you did (or said) anything yourself that you wish you had not said or done…'

- When and how the participant became aware that the conversation was not going well.

Prompts may include:

E.g. it sounds as though that was not going well (when this has been described)… how did you know that the conversation was not going well? Probe further if needed.

What the participant 'felt' when the conversation was not going well (the word 'feel' may be used or not used, depending on the participant's preferred use of vocabulary, the prompt may include talking about changes in feeling in the head or the body rather than requesting use of emotion words).

Probe to understand any 'feeling' described to ensure shared understanding of the words/vocabulary used.

- What the participant did when aware that the conversation was not going well.
    4. When discussing all conversations, include:
- Specific exploration of the participants perception of **who is in control** of the interaction
- Explore vulnerability in the conversation

Explore understanding of the word vulnerable to ensure shared understanding of the word

Request examples of when the participant may have felt vulnerable and the reasons for this.

    5. Throughout the semi-structured interview:
- Listen for how mentalising concepts/feelings/emotions discussed or expressed and explore meaning attached to these and how useful these concepts are to the participant.

Probes may include e.g. I noticed you used the word 'stressed, I am wondering what that word means or I am wondering where you learned that word…' or, mentalising

words may be specifically to explore, e.g. 'I am wondering whether anybody talks to you about emotions. Let's think of some emotion words…'

- Agree a shared vocabulary to talk about conversations that go well and those that do not go so well.
- Explore what participants find helpful/unhelpful about the person they are talking to (their conversation partner) in both successful and unsuccessful conversations.

I also included exploration of new uncovered knowledge learned from one participant with other participants.

Appendix 6: Observation Record

Observation Record

Used by participant without a diagnosis of autism while observing autistic participant and researcher in conversation.

Observation focus	Comment	Response of person with ASC **Comment here on whether the person with ASC became more engaged or more disengaged**
Use of questions including type, whether it was repeated or rephrased		
Use of silence		

How understanding is checked		
When it is checked		
Phrases used		
What keeps the conversation going?		

What helps the person to 'think' and to 'remember'?		
Any differences between this interaction and interaction the person with ASC has with other people Positive and negative observations		

Engagement throughout		
Power balance between the communicators		

Conversation record (Developed by Ruth (AP) and Lara)

Who?	What?	When?
How do you rate the conversation? (1–5) 1 2 3 4 5		
Did the conversation make sense?	Yes	No
Why?		
Did you have your say?	Yes	No

Who did more of the talking?	Other person	Rosie	Same

Was it a **good** conversation or a **bad** conversation?	Good	Bad

Why?
For bad conversations:

How did you feel in your body when the conversation started to go wrong?		
What helped you to get out of the situation?		
Were emotion words mentioned?	Yes	No
What was the word?		
Was it the right emotion word or the wrong emotion word used?	Right	Wrong
Why? Did you think something different?		

How did the person act? (Body language/face) *Describe:*

Appendix 8: Diary Record Carl

Carl (AP)**'s Conversation Record** (*typed by Carl)*

Date of conversation:

People involved in the conversation:

The conversation was about:

The beginning, middle and end of the conversation:

Notes about the conversation:

About the topic:

Type of conversation: was it small talk, problem-solving, philosophising or something else?

Who did most of the talking?

Was the other person listening? Yes or No?

Was there a feeling of something not being right?

Were there any feelings in the body – heart or stomach or anywhere?

Appendix 9: Diary Record Chloe

Chloe's Diary Record – (headings typed by Chloe (AP))

Who was in the conversation?

Speed of talking

About the atmosphere.

Face of the person.

Were words used that you don't like?

Was it a conclusion solving conversation?

Did your jaw start clicking?

What happened before the conversation?

What happened after the conversation?

Appendix 10: Semi-structured Interview 2, Topic Guide

Researcher and participant with a diagnosis of autism and without a diagnosis of autism.

Purpose:

To review participation in the study to date.

To share our learning about the things that appear to be helpful during conversation.

To agree what participants will continue to try to be aware of during conversation or try to change about themselves.

Each interview must be personalised to each person's learning.

Autistic participants: Topics

- Invite autistic participant to talk about conversations they have had recently

Prompt: reminder of conversations I know they have had.

- Listen for the things I know that individual participants have been thinking about since planning the diary records and also things that I have recognised as potentially important during the further analysis of the first interviews and diary records

Where I hear something possibly useful in a conversation that we have previously discussed, (e.g. a comment on 'conversation type', a comment on what someone is 'like'), confirm use of this knowledge, ('I noticed that you commented on …') then:

- Explore participant's awareness of this knowledge (depending on their response to my comment, a direct question may be needed, e.g. did you know you were using 'what your mum is like..?')

- Explore whether the knowledge is helpful (e.g. I wonder whether it helpful for you to know…')

- Confirm the knowledge that is apparently useful in conversation or interaction and being used now (I have noticed you are using… does… work well for you?)

Remind of the things that we have done and learned in the study to date (previous conversations, discussions with communication partners).

- Check whether the participant is happy to continue in the study

- Check whether the participant is happy to continue to try and use the things we have agreed appear useful to them

- Check what the participant will do now

Participant without autism: Topics

Sharing my learning from the data analysis about what appears to help a conversation to move along and what 'blocks' a conversation with the autistic participant. Give examples from conversations.

- Explore 'grease'

E.g. I noticed that when you… it was really helpful and… (describe how the autistic participant continued to be engaged in the conversation and to develop ideas or uncover knowledge)

Invite comment and discussion e.g. 'Have you noticed that too?'

- Explore 'blocks'

E.g. I noticed that when you ….., X (the participant) appeared stuck… (describe 'stuck' e.g. gave only singe word answers…)

Invite comment and discussion e.g. 'Have you noticed that too?'

Where this semi-structured interview takes place alongside the autistic participant, invite comment from the autistic participant too.

- e.g. When x (person) does y (example of what the person does e.g. shows they are listening by…), does that make a difference to you? (use the participant's language as needed e.g. does it make you feel better/good or no different)

Review discussion above then agree what the participant without autism will try to do to make the conversation 'better' for the autistic participant.

Agree what the participant without a diagnosis autism will do now.

Appendix 11: Final Semi-structured Interview 3, Topic Guide

Researcher with participants with and without a diagnosis of autism.

Purpose:

Reflect on learning during the study

Explore whether or how learning will continue to be used

Thank participants for involvement

Each interview must be personalised to each person's learning.

Topics

- Recall what we have done during the study

Prompts: remind participants of how the study started and what we have done during the study,

Encourage participants to 'join in' the recollection, recalling for themselves what we talked about at different stages

Provide further prompts to memory as needed

- Recall what has been learned

Prompts e.g. so I remember that you agreed to think about some things/try some things out during conversation/interaction….

Further prompt: can you remember what those things were?

- Explore whether any of the learning has been used and whether it has made a difference

Prompts: e.g. so you are more aware of… (something important to the person e.g. types of conversation) and that has been helpful. In what way/how/ has it been helpful/what difference it has made to you?

Further probes: ask for examples of conversation where the learning has been helpful or unhelpful to further understand exactly how it helped or did not help.

Aim to explore several conversations/situations and whether any learning was used.

Probe in relation to conversations/situations that had been described as 'difficult' (use the words of the participant) at the start of the study.

Also probe to elicit discussion about situations or people that we have not talked about previously.

If relevant, probe for any 'incidental outcomes' i.e. anything (good or bad) that has happened as a result of using the learning.

- Where participants are interviewed together, encourage each to give feedback to the other about whether each can notice the changes in the other

E.g., where a person without autism had agreed to try to do something different to make the conversation better for the autistic person, has this happened?

Where the autistic participant had agreed to e.g. 'say' when something is not right for them, has this happened?

Explore reasons for the changes taking place or not taking place.

- How will any useful learning continue to be used now?

Thank you for participation

Appendix 12: Ethics Approval

Sent: Tuesday, December 22, 2015 9:00 AM

To: Silver K.M.

Subject: Your Ethics Submission (Ethics ID: 17940) has been reviewed and approved

Submission Number: 17940

Submission Name: How can existing skills and knowledge of people with Autism
Spectrum Condition be uncovered and used to support successful social interaction and
to reduce social vulnerability?

This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety
approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments

1. I have found your participant information sheet quite long and possibly complicated,
especially for people with ASC, but you have covered in your ethics form how this
information will be communicated effectively to all participants so I am happy to
approve this application. Good luck with your study.

2. Very thorough, thank you. Good luck with the research.

Click here to view your submission

ERGO : Ethics and Research Governance Online

http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

From: ERGO [ergo@soton.ac.uk]

Sent: Friday, October 21, 2016 8:19 AM

To: Silver K.M.

Subject: New note/attachment to your ethics submission (Ethics ID:17940)

Submission Name : How can existing skills and knowledge of people with Autism Spectrum Condition be uncovered and used to support successful social interaction and to reduce social vulnerability?

Submission ID : 17940

A note has been added to your ethics submission Comments : Extension approved providing there are no other changes arising from the extension, such as changes to the protocol, sample size or researcher.

To view this note in full and view any attachments please use the link below and click the HISTORY tab Click here to view comments in full<http://www.ergo.soton.ac.uk/submission_info.php?submissionID=17940

Appendix 13: Overview of Procedure

A brief overview of the procedure during both Phase 1 and 2 is shown in Tables 9.1 and 9.2 below.

Table 9.1 Phase 1: Research Questions 1 and 2

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Research Question 1:
How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?

Research Question 2:
What is useful for autistic adults to know about conversation?

Participants: Five pairs of participants, each pair being people who know each other well, one with a diagnosis of autism, one without a diagnosis of autism, and the researcher.
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Method of inquiry
</td><td>

Purpose of the inquiry. How learning was used
</td></tr>
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Semi-structured interview 1 between researcher and the participant with ASC,

Observation of the interview by the participant partner without autism
</td><td>

To understand what the participant without autism says and does that appears helpful to the autistic person, enabling them to contribute their own knowledge to the conversation. This learning can be further explored and used in the next stages.

To explore what the autistic participant knows about conversation and the people and the environment of the conversation

To inform semi-structured interviews (SSIs) with other participants with ASC, enabling me to explore areas of emerging interest with other participants (e.g. I learned about 'types of conversation' as being important in the first SSI 1 and explored this in other SSIs).

To understand what is important to each participant with ASC in conversation and to plan the diary record using what is important to the autistic person.
</td></tr>
<tr><td>

Reflective conversation regarding the observation

Between the researcher and participant without autism
</td><td>

To inform how I requested subsequent observation records.

To check shared understanding between researcher and participant without autism of the completed observation record.

To understand what is working well in approaches to conversation so that these can be further explored in subsequent interviews and observations.
</td></tr>
</table>

Diary record to be maintained by the autistic participant with support from the participant without autism, where requested	To learn more about the conversations that autistic participants are involved in in their everyday lives and their perception of the success of these; with a focus on what is important to them in conversation (uncovered during the semi-structured interview).
Reflective conversation regarding the diary record (**keeping in touch**) between the researcher and participant with autism, the participant without autism may be involved, depending on preference	To ensure I understood what was written in the diary record To understand difficulties in development and completion of the diary records and to inform how I made requests for subsequent diary records. To provide further support to completion if requested.
Observation of conversation, or review of recorded conversation between the pairs of participants with and without autism Conversation with the participants without autism	Following observation, feedback was given by the researcher to participants without autism, about things they did that worked well and less well in supporting the contribution of knowledge of the autistic participant. They could begin to reflect and to make changes to their own communication approaches to better support uncovering and contribution of the autistic participants' own knowledge.
Reflective conversation between the researcher and each participant without autism. The autistic participant may be involved, depending on preference	To review learning to date and to agree what the participant without autism would do differently in conversation and interaction with the autistic participant.

Table 9.2 Phase 2: Using learning

Research Question 3:	
In what ways can learning and knowledge about conversation be used in everyday conversation by autistic adults and their communication partners? **Participants:** Three pairs of participants, each pair being people who know each other well, one with a diagnosis of autism, one without a diagnosis of autism, and the researcher.	

Method of inquiry	Purpose of the inquiry. How learning was used
Semi-structured interview 3 with the participant with autism, alongside the participant partner without autism	To confirm what knowledge of the autistic participant was useful to them during conversation To confirm what the communication partner without autism could say and do that was useful in conversation from the perspective of the autistic participant. To reflect on knowledge and learning by the autistic participant about (in the diary record and the first semi-structured interview) and to agree what the autistic participant would try and do differently in conversation. To reflect on learning and changes made during conversation and interaction by the participant without autism and agree what the participant without autism would try and do differently in conversation, in response to what had been identified as helpful and unhelpful to the autistic participant.
Keeping in touch – informal conversation, email, phone calls	To maintain engagement in the study. To check that what we had agreed was important remained important and useful in conversation and to make changes if it was felt not to be of value. For me to learn was what emerging as most useful to participants with and without autism.
Semi-structured interview 3 with each pair of participants with and without ASC	To learn how involvement in the study had been useful to all participants. To learn how participants were going to maintain/ build on knowledge gained.

Appendix 14: Participants Involved in the Study

Table 9.3 Participant pair 1

Participant with ASC: Chloe
Female Age: 42 Diagnosis: Asperger's Syndrome 1988 Chloe has been supported in residential settings since 1993. She lives in a shared supported living setting and receives support from a care provider. Chloe was a participant in a previous study and requested that, should I ever do any further study, she would be involved again, as involvement had been of real benefit to her. I have known Chloe for 8 years and see her intermittently (not at all in some years, 3 or 4 times a year in other years), when she asks to talk to me. Chloe accesses community activities and appointments both independently and with support, and would like to further develop strategies to increase her confidence in social interaction. Chloe talked freely about conversations that she found difficult and those she enjoyed and found easy, and enjoyed reflecting on and learning what was useful to her in conversation. She was motivated to keep the diary record herself and to talk about this. Chloe did not join Phase 2 of the study. Since being involved in the study, it has been reported to me in informal feedback that she has continued to use what she learned.
Participant without ASC: Wyn
Female. Wyn has supported Chloe in the residential setting for 10 years, so feels that she knows Chloe well and communicates successfully with her. Chloe invited Wyn to be a part of the study. Wyn is aware that there are times when communication with Chloe is not as successful as it could be, particularly when staff are not familiar with Chloe, and she wished to better understand what would make conversation with Chloe more successful. I had met Wyn but not worked with her in this way prior to this study. She brought a knowledge and understanding of Chloe that I do not have, and also the perspective of being a support worker. Wyn was interested in the study and talked to Chloe about her diary records. She was interested in what Chloe was learning and how she could use this learning, and was able to support Chloe to use what she had learned. However, during the study Wyn had a significant amount of time off work and it was more difficult to maintain continuity in reflecting on learning. Wyn did not join the second stage of the study. Chloe and Wyn were involved in Phase 1 of the study for 5 months in total.

Table 9.4 Participant pair 2

Participant with ASC: Lee
Male Age: 18 Diagnosis: Autism Spectrum Disorder 2012 Lee lives with his family Lee has been educated in several schools, and was placed at the college in the Charity where I conducted the study 4 months prior to involvement in the study. He was therefore not very well known to the school staff team and I had not met Lee prior to this study. Lee was invited to take part in the study by Rachel, the speech and language therapist working with him. Lee reported many experiences of unsuccessful interaction and communication, and was keen to learn more about himself and about communication and interaction through involvement in the study. Lee was very happy to talk about his experiences of conversation and enjoyed working out what he knew that could be helpful to him in conversation, especially with staff at school. He enjoyed exploring what people talking to him could do to be more helpful to him; he was keen to be involved in staff training to share learning about approaches that were helpful to him. However, Lee did not enjoy tasks that perhaps he perceived as less meaningful or important to him. He required help to complete the diary record and appeared to have some difficulty in reflecting on the impact of his increased knowledge of conversation and conversation partners. I now know that Lee does not like to feel 'tested' and does not like to get things 'wrong', so I could have perhaps been more aware of this and considered other ways of enabling Lee to provide meaningful reflection. Lee took part in both phases of the study.
Participant without ASC: Rachel, female
Rachel is a recently qualified speech and language therapist (SLT). Prior to beginning the SLT training, she worked as a support worker with people with autism for 4.5 years. I had not met Rachel prior to the study, but the head teacher of the school where the study was conducted told me that Rachel had a strong desire to maximise her effectiveness as a SLT and so the head teacher invited her to contact me to find out more about the study. Rachel recognised that the training she received has not fully equipped her with all the skills and knowledge that she feels that she needs in the real world to support development of conversation and successful interaction. Her professional knowledge and her perspective was an important contribution to the study, reducing the risk of researcher bias, as Rachel readily asked further questions of

my interpretations of my findings and contributed her own professional knowledge.

At the time of the study, Rachel was working closely with Lee.

Rachel shared Lee's learning about what useful to him to support successful conversation and our learning about what the communication partner can do to be more helpful to Lee with other members of staff working with Lee. As a result of this, Oscar a teacher who conducts personal tutorials with Lee, joined the study to learn about himself and about Lee (see below).

Rachel was able to reflect on her useful learning during the study and has found this learning useful with other young people and in training staff.

Additional participant without ASC: Oscar Male

Oscar is a teacher. He did not take part in the observation of me or the diary record phase of the first part of the study, which were completed by Rachel. He talked with me about the study and our learning and made a recording of himself and Lee conducting a personal tutorial (following the protocol for making a recording described to ensure that Lee felt in control), which I then analysed, as the equivalent of me observing Lee and Oscar. Following this, I was able to provide Oscar with feedback on what he said that appeared to scaffold Lee's thinking and further communication and what appeared less useful to Lee. In follow-up conversations and keeping in touch, Oscar let me know how he had tried to change his way of talking to Lee and the outcomes of this. He enjoyed learning during the study and has used this learning with other young people.

Lee and Rachel were involved in both phases of the study over 12 months.

Oscar was involved in Phase 2 of the study for 6 months.

Table 9.5 Participant pair 3

Participant with ASC: Ruth

Female

Age: 21

Diagnosis: Autism Spectrum Disorder 1995

Ruth lives at home with her family. She had a number of school placements prior to attending the autism specialist school where the study was conducted from the age of 14 until 19, and at the time of the study attended a mainstream college while doing voluntary work within the school that she attended. Ruth also delivers autism awareness training.

Ruth accesses community activities and college without support.

Ruth was invited to be involved in the study by Lara who worked with her while she was at school and who supervised her volunteering position. I had not met Ruth prior to involvement in this study. Ruth has had some difficult social interactions and continued to have these at college; she was highly motivated to learn more about herself and how she can best manage interactions. Ruth was also keen to contribute to our learning, in order to inform what we should be enabling young people with autism to learn and how we should be best training staff to communicate with people who appear to talk well, so that that other young people may avoid some of the many difficulties that she experienced at school.

Ruth talked freely and enjoyed reflecting on conversations both in the semi-structured interviews and in the diary records. She was motivated to complete the diary records independently and to use what she had learned. Ruth took part in both phases of the study.

Participant with ASC: Lara, female

Lara is a teacher and has worked in the autism specialist school for 20 years. She worked with Ruth within her class group when she was in school, and at the time of the study supervised Ruth's voluntary placement and worked alongside Ruth to deliver autism awareness training.

I worked with Lara as a peer in my early work as a SLT within the educational provision and knew that Lara was always interested in communication and in learning, but I have not worked with Lara for 10 years.

Lara brought useful autism knowledge and experience to the study, and her feedback and comments helped to avoid researcher bias because she was confident in giving feedback to me when she did not fully understand some interpretations that I had made. She reported useful learning during the study and has continued to use this learning with other young people in school.

Ruth and Lara were involved in both phases of the study for 12 months.

Table 9.6 Participant pair 4

Participant with ASC: Carl
Male Age: 34 Diagnosis: Autism Spectrum Disorder 1993 Carl has been supported within a residential setting since 2009. He accesses the community with and without support. I have known Carl for 5 years and have met with him intermittently, usually to enable me to provide support to his staff team when difficulties have arisen. Carl attended several different educational settings and, while he feels that his ability to interact successfully has improved, he feels that he has difficulty in successful social interaction. He had heard about my previous research and asked if he could be involved in any future study, as he wanted to be helpful and wanted to learn. Carl likes to 'philosophise' (his words) and enjoyed reflecting on what may be useful and not useful to him in conversation. However, during the study Carl experienced some personal difficulties and so it was not as easy as had been hoped for Carl and his support worker to focus on involvement in the study. Carl did not take part in Phase 2 of the study.
Participant without autism: M Female
Mary is a service manager of Carl's service, but regularly provides direct support to Carl. She began to work with Carl a year prior to the study, having worked for some time with people with learning disability. Mary was keen to learn more about his and her own communication so that the team can better support Carl. Mary invited Carl to be involved in the study and Carl suggested that she be involved too, when asked to choose his communication partner. I had met but not worked with Mary in this way prior to the study. Mary helped to ensure that the project and the language and concepts used and developed within it would be accessible to support workers. Mary readily gave feedback on whether our learning was useful. When Carl developed the personal difficulties, Mary's focus was to support these. She did not join Phase 2 of the study. Carl and Mary were involved in Phase 1 of the study for 4 months.

Table 9.7 Participant pair 5

Participant with autism: Cait
Female Age: 40 Diagnosis: Asperger's Syndrome (date unknown) Cait lives alone, close to her parents, and receives 10 hours community support from a support worker each week. Cait works part time in a local supermarket. Cait attended mainstream school but has always been aware of her difficulties, which have impacted on her confidence. I had met Cait previously when her mother contacted me and asked for some advice. Nina (support worker, see below) invited Cait to be a part of the study. Cait was keen to take part in the study in order to feel valued in contributing to development of new knowledge. She was keen to learn more about herself. Although Nina was aware of many conversations that Cait had found difficult, it was initially not easy for Cait to talk about these, as she wanted to focus on what had gone well. Cait was clear about what she was learning and asked that her mother could join the study, as she wanted her mother to learn too, so that conversations between them could be improved. Cait's mother is a very important part of her life. Cait took part in Phase 1 and Phase 2 of the study.
Participant without autism: Nina Female
Nina is a support worker employed by the charity where the study took place. She supports Cait in Cait's own home three times a week. She has been working with Cait since 2015 and has a good knowledge of Cait. She was invited to take part in the study by Cait. I had not met Nina prior to the study. Nina felt that she had a good rapport with Cait and communicated well with her, but she was aware that Cait had some difficulties in social situations and that she was not always able to resolve these with Cait, so she hoped that involvement in the study would help her to learn what may be most useful to Cait. Cait was interested in the observation of me and reflection on this, but then when Cait's mother became involved Nina took less of a direct role, but joined in conversations and interviews when this was natural. Nina reinforced Cait's learning with her. This supported Cait's engagement in the study. Nina was very aware of what Cait and her mother had learned during the study, but was possibly less aware of her own learning.

Additional participant without ASC: Isla

Isla is the mother of Cait. Isla and Cait talk at least once every day and see each other several times a week. I had met Isla on two occasions prior to the study. Isla had said to me previously that she finds it difficult to understand Cait and wished that she could do more to help her.

When Cait invited her to be a part of the study, she was pleased to join and to learn. I recorded two conversations between Cait and Isla, and we then agreed what Isla could do to be more helpful to Cait in conversation. Isla took an active part in the study, taking ownership of her own learning. She took notes when we met and shared these with her husband. She began to self-monitor what she was saying to Cait, so would say 'I shouldn't have said that', for example. Isla felt that she gained knowledge about how best to communicate with Cait through involvement in the study.

Cait and Nina were involved in the study for 6 months.

Isla was involved in Phase 2 of the study for 5 months.

Appendix 15: Risk Assessment

January 2012

Risk Assessment Form

UNIVERSITY OF
Southampton

Researcher's name:

Katharine Silver

Part 1 – Dissertation/project activities
What do you intend to do? (Please provide a brief description of your project and details of your proposed methods.) I will explore how existing skills and knowledge of people with (Autism Spectrum Condition) ASC can be uncovered and used to support successful social interaction and to reduce social vulnerability. In order to do this, I will use a case study design, working with 6 adults and young adults with ASC who are currently supported by national care provider charity and 6–12 members of staff (additional staff may be needed to cover unexpected staff absence). The study will involve semi-structured interviews in a familiar place chosen by the participants. It may also invite the participants to independently make some records of their experiences.
Will this involve collection of information from other people? (In the case of projects involving fieldwork, please provide a description of your proposed sample/case study site.) The study will involve collection of information from people with ASC and from staff members who know them well. The semi-structured interviews will be conducted in a place chosen by the participant. This is likely to be their home or their school. Participants may choose a familiar place in the community that is already known to them and frequently visited by them e.g. the local gym. The study will not include a place that is unfamiliar or has not been previously frequently visited by the participants.
If relevant, what location/s is/are involved? The home and college of the participants. Possibly a familiar community location chosen by them.
Will you be working alone or with others? I will be working directly with the participants. I will be conducting some semi-structured interviews with the person with ASC, some with the member of staff. Participants will be asked if they would prefer for a third person to join and observe the interview. I will conduct an interview with the person with ASC and the member of staff together. When in the participant's home and school, there will be other staff in the building.

Part 2 – Potential safety issues / risk assessment
Potential safety issues arising from proposed activity? No expected hazards likely to cause significant harm or injury
Person/s likely to be affected?
Likelihood of risk? Low

Part 3 – Precautions / risk reduction
Existing precautions: Existing documentation and processes will be followed: Environmental risk assessments will already be in place for the school and the person's home. Health and safety checks are carried out in these buildings on a monthly basis. Positive intervention support plans and personal risk assessments are in place for each person supported by the National Charity. Participants supported by the National Charity will have been assessed for a Personal Emergency Evacuation Plan (PEEP) and will have a PEEP in place if this is needed. When in the community, usual reasonable precautions will be taken to look out for any potential unexpected hazards or danger. The fire exits will be noted in any public place.
Proposed risk reduction strategies if existing precautions are not adequate:

CONTINUED BELOW …

Part 4 – International Travel
If you intend to travel overseas to carry out fieldwork then you must carry out a risk assessment for each trip you make and attach a copy of the International Travel form to this document

Download the Risk Assessment for International Travel Form

Guidelines on risk assessment for international travel at can be located at:

www.southampton.ac.uk/socscinet/safety ("risk assessment" section).

Before undertaking international travel and overseas visits all students must:

- Ensure a risk assessment has been undertaken for all journeys including to conferences and visits to other Universities and organisations. This is University policy and is not optional.
- Consult the University Finance/Insurance website for information on travel and insurance. Ensure that you take a copy of the University travel insurance information with you and know what to do if you should need medical assistance.
- Obtain from Occupational Health Service advice on any medical requirements for travel to areas to be visited.
- Ensure next of kin are aware of itinerary, contact person and telephone number at the University.
- Where possible arrange to be met by your host on arrival.

If you are unsure if you are covered by the University insurance scheme for the trip you are undertaking and for the country/countries you intend visiting, then you should contact the University's Insurance Office at insure@soton.ac.uk and check the Foreign and Commonwealth Office website. |
| Risk Assessment Form for   / NO   (Delete as applicable)

International Travel attached |

Appendix 16: Research Question 1, Coding Log

1. RQ 1: How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?

Initial deductive codes

Deductive codes were taken from the research question and from theory and practice where I was actively looking for something based on the research question and my knowledge, rather than finding it arising from the data.

Code	Definition	Whether the code is relevant to all participants	What happened to the code
Block B	Something that was said by the participant without a diagnosis of autism that generated no, little or irrelevant response to the topic from the autistic participant i.e. something apparently unhelpful to the autistic participant	All participants	Where conversation 'blocks' occurred, patterns were sought and inductive codes developed relating to 'block', see below
Grease	Something that was said by the participant without a diagnosis of autism that generated further talk, reflecting further thinking about the topic by the autistic participant. i.e. something apparently helpful to the autistic participant	All participants	Where conversation 'grease' occurred, patterns were sought and inductive codes developed relating to 'grease', see below
Uncover U	The code U was used for 'uncover' when new relevant knowledge or ideas were given by the autistic participant in response to something said by the participant without a diagnosis	All participants	This was abandoned as it was recognised as duplication. Uncovered knowledge of the autistic participant was coded in relation to RQ2
Power balance PB	Where the autistic participant is fully engaged and having a long (but meaningful), conversation turn in relation to the established topic, where a 'finish' is reached and the other participant has a shorter or broken conversational turn so that the person is not 'overloaded' . i.e. there is a feeling of 'equal' in the conversation See below that where the power balance is not equal, the person disengages	All participants	This code was used after differences in 'power balance' were looked for, following analysis of the semi-structured interview with the autistic participant

Inductive codes

'Grease' – helpful to the autistic participant in the conversation

Code	Definition *The definitions require some judgment of the utterance. Judgment is informed by the context of the utterance in the context of the full analysis of interview.*	Examples	Where the code came from	What happened to the code/comment on use of code
Sustained engagement expanded to: Sustaining engagement **Nonverbal** e.g. silence, rising intonation, facial expression,	Where a note has been made of nonverbal actions that supported sustained engagement	Use of silence left for thinking time Use of slow pace of talk Smile, nod. Chloe – 'It's always a smile with it'	When reviewing the transcripts, the importance of nonverbal cues to sustain engagement was recognised	
Sustained engagement expanded to: **Use of confirmation** i.e. repeating back/summarising what has been said acknowledging	Where the participant without a diagnosis of autism made a comment or statement to confirm understanding of and/or agreement with what the autistic participant had said and this enables the autistic participant to say more	Chloe – BB was blurting, can I say that? Kate – Blurting, that's a great word (confirmation) Chloe it was different words, but also the speed of voice, the speed of talk, it was both Kate -so we have worked out that the speed was very fast (confirmation)	Confirmation is the most frequently used cue throughout the transcripts	This sustained engagement confirmation often leads to better definition/shared understanding too. Need to link these e.g. 'so there are the words in your head again' (awareness of strategy use)

when knowledge is emerging (but different to interrupting)		Chloe – yes and it was more straight to the point Lee – I just felt like I was getting pushed out Kate - you felt as though you were getting pushed out Lee – yeah, like I was trying to push myself out. Ruth describing a difficult conversation Kate – so that was obviously not a good conversation was it (confirmation) Ruth – no, I wanted to hit him in the face, I know violence isn't everything..'		
Sustained engagement expanded to: Noticing and responding to disengagement	Note where disengagement has been noticed and re-engagement supported so that more information relating to the topic is uncovered. Noticing disengagement (disengagement may show in eg lots of single word answers, flippant response), and reengaging on topic to elicit fuller response Avoiding getting stuck in the conversation or diversion to a different topic by the autistic participant	Kate – can we just go back to…'. Lee – well I just tell them I've got autism… (L not engaged in thinking about the topic of conversation) Kate – let's think about some of the teachers in your other school (specific cue to think and topic to think about) Lee – When I was in High school none of the teachers knew what I was like. (then goes on to talk about teachers and interactions in school)	I was able to see examples of noticing and responding to disengagement (or not) with all participants at some stage	The noticing engagement and disengagement is the important thing, probably most significant as a 'block' when disengagement is not recognised. The re-engagement usually consists of one of the other cues, e.g. cue to memory, cue to topic, confirmation, etc.

266

Sustained engagement expanded to: Positive feedback	Note where positive feedback has been given which appears to enable the autistic participant to provide further knowledge/information	Your brain is working well You have a good memory I like your words I like the way you say that	I use this with all participants, but for different reasons, usually to give confidence for continued involvement	This links with nonverbal feedback of smiling and nodding i.e. positive responses Also with cues to think possibly

Inductive codes expanded

Code	Definition *The definitions require some judgment of the utterance. Judgment is informed by the context of the utterance in the context of the full analysis of interview.*	Examples	Where the code came from	What happened to the code/comment on use of code
Sustained engagement expanded to: Sustaining engagement Nonverbal e.g. silence, rising intonation, facial expression	Where a note has been made of nonverbal actions that supported sustained engagement	Use of silence left for thinking time Use of slow pace of talk Smile, nod. Chloe – 'It's always a smile with it'	When reviewing the transcripts, the importance of nonverbal cues to sustain engagement was recognised	
Sustained engagement expanded to: Use of confirmation i.e. repeating back/summarisin	Where the participant without a diagnosis of autism made a comment or statement to confirm understanding of and/or agreement with what the autistic participant had said and this enables the autistic participant to say more	Chloe – BB was blurting, can I say that? Kate – Blurting, that's a great word (confirmation) Chloe it was different words, but also the speed of voice, the speed of talk, it was both Kate – so we have worked out	Confirmation is the most frequently used cue throughout the transcripts	This sustained engagement confirmation often leads to better definition/shared understanding too. Need to link these e.g. 'so there are the words in your head again' (awareness of strategy use)

g what has been said acknowledging when knowledge is emerging (but different to interrupting)		that the speed was very fast (confirmation) Chloe – yes and it was more straight to the point Lee – I just felt like I was getting pushed out Kate – you felt as though you were getting pushed out Lee – yeah, like I was trying to push myself out. Ruth describing a difficult conversation Kate – so that was obviously not a good conversation was it (confirmation) Ruth – no, I wanted to hit him in the face, I know violence isn't everything, ..'		
Sustained engagement expanded to: Noticing and responding to disengagement	Note where disengagement has been noticed and re-engagement supported so that more information relating to the topic is uncovered. Noticing disengagement (disengagement may show in eg lots of single word answers, flippant response), and reengaging on topic to elicit fuller response Avoiding getting stuck in the conversation or diversion to a different topic by the autistic participant	Kate – can we just go back to…'. Lee – well I just tell them I've got autism… (Lee not engaged in thinking about the topic of conversation) Kate – let's think about some of the teachers in your other school (specific cue to think and topic to think about) Lee – When I was in high school none of the teachers knew what I was like. (then goes on to talk about teachers and interactions in school)	I was able to see examples of noticing and responding to disengagement (or not) with all participants at some stage	The noticing engagement and disengagement is the important thing, probably most significant as a 'block' when disengagement is not recognised. The re-engagement usually consists of one of the other cues, e.g. cue to memory, cue to topic, confirmation, etc.

Sustained engagement expanded to: Positive feedback	Note where positive feedback has been given which appears to enable the autistic participant to provide further knowledge/information	Your brain is working well You have a good memory I like your words I like the way you say that	I use this with all participants, but for different reasons, usually to give confidence for continued involvement	This links with nonverbal feedback of smiling and nodding i.e. positive responses Also with cues to think possibly
Checking comprehension of vocabulary expanded to: *Using* **the words used** by the participant in the conversation, having checked understanding'	Note where a word or phrase was used by the participant e.g. 'stuck mode', meaning was explored and then the participant without a diagnosis of autism used the word in conversation, which supported engagement and understanding	Kate – I see it was difficult… so when the conversation was …. What word shall we use? Ruth – wrong Kate – yes when the conversation was wrong…. Chloe – it **pressures** people to get the answer on why Kate – it pressures you Chloe – pressuring you to get an answer ..and I think that's the wrong way ... (talk re another conversation) Kate – so was there any **pressure**? Chloe – no, none at all, that's the difference	I used words used by all the participants	
	Where the participant without autism has made the need to think explicit, with the effect of supporting someone to continue to think and uncover knowledge	I know this is a hard question' That's a tough one	(I realised this was important, as both Ruth and Cait talk about the need to 'switch on' to thinking)	Does this explicit cue support the metacognitive difference?
		It's hard to work out what it means		

'Blocks' – unhelpful to the autistic participant in the conversation

Where 'grease' (aspects of conversation/interaction that help a conversation move along) are not in place, 'blocks' may occur

Developed Inductive codes

Code	Definition *The definitions require some judgment of the utterance. Judgment is informed by the context of the utterance in the context of the full analysis of interview.*	Example	Where the code came from/whether relevant to all participants	What happened to the code/comment
Giving ideas GI	Where an idea is given by the communication partner and the autistic person agrees and does not add to or question the idea e.g. responds 'yeah', 'mmm'	Rachel 'you might want to have friendship, like your brother' Lara: I was aware that I may have put something on to her so I stopped	It became clear that giving ideas frequently served as a 'block' This was marked in all participants	This could come under the sub-theme of 'blocks to thinking' as giving ideas appeared to result in agreement and no further thinking
Questions Q Clarified as 'unhelpful questions' Links with shared understanding Vague vocabulary	Where use of a question leads to a response irrelevant to the topic, or to a minimal response, or to no response	Lara: I feel stressed out, can you give me a cigarette? 'Do you really think a cigarette would help?' Lara: well it does you' Well I don't think it does and it costs a lot Lara: well quit then End of conversation	This code was used after it became clear that questions could be helpful and serve as a 'block'. I was looking for the importance of 'questions' emerged as theme in analysis of the data of the autistic person All participants	Further expanded Multiple questions, several questions in one utterance or further questions asked after a short/minimal response to the first question Why? Where the response appears irrelevant, there is no response or the response appears very quick/not considered. Irrelevant questions, questions that do not follow previous utterance, i.e.

				used without cueing to the topic (merged below)
				Questions asked without establishing shared understanding of the topic
				(this became a code alone but then merged with supporting thinking)
				Direct questions
				(this to be merged with cue in to topic/establish shared understanding of the topic)
				Vocab – Questions are unhelpful where the vocabulary within the question is not helpful e.g. 'in terms of the strategies, what are your feelings on those?'
				the unhelpful questions are all be under a theme of 'blocks to thinking', as these questions elicit no response, an irrelevant response or a response without apparent meaning
Power balance PB	Where the autistic participant is not engaged in relation to the established topic and may give an irrelevant response or no response and where the participant without a diagnosis of autism has a long conversational turn in contrast to the short response		This code was used after differences in 'power balance' were looked for, following analysis of the autistic participant The impact of the shift in power balance where one participant said a lot and the other very little is clear across participants	Expanded. The following contributors to power balance were noted: Long conversational turn Too many questions/multiple questions Interrupting Vague questions move to vocabulary Telling v. uncovering Nonverbal cues (facial expression, speed of speech)

Vocabulary used without checking comprehension V	Note where a question or comment elicits a response that does not further the interaction and in the context of ASC and possible weaknesses in comprehension, there may have been some weakness in understanding vocabulary used	Ruth – 'I didn't like her loud mouth' Lara (communication partner) then talked about people who say things they shouldn't Ruth – it's a sort of 'outdoor voice' (i.e. referring to voice volume, so there was a misunderstanding of 'loud mouth')	This code was used when it became clear that non-comprehension of words used or not checking shared understanding of words used, functioned as a 'block'	Expanded to: Use of mentalising vocabulary and requests for use of mentalising vocabulary e.g. 'how did you feel?' Mixing vocabulary, different words used for the same thing Vague vocabulary 'that' 'everything' 'anything happening?'
Not responding to lack of engagement or thinking	Where disengagement appears to have taken place resulting in response which appear flippant	Rachel – 'right' Lee – 'left', or dismissive Oscar – 'shall we talk about yesterday?' Lee – 'noooo' Oscar then talks about yesterday or silent	This code was used when it became clear across the data set, that not responding to lack of engagement or thinking functioned as a 'block'	
Negative response without supporting the thinking behind/reason for the negative response 'head on negative response'	Where a response is given that does not support thinking and contributes to disengagement	Lee – 'I want to go to the shop' Oscar – '-no it's lesson time'	Two of the participants without a diagnosis of autism responded in this way	This links to establishing the topic and shared understanding so will be **merged with Cueing** below
Cueing – Not cueing in to topic to establish shared understanding	Questions asked or a response is given without establishing shared understanding of the topic Topic and focus not established	Lee – I feel stressed out can you give me a cigarette Oscar – Do you really think a	Failing to establish shared understanding of the topic was a 'block' for all participants	This links to establishing the topic and shared understanding so will be merged

272

| before a question is asked or a response is given (this was developed from the questions code)

Carl | as shared. No evidence of supporting thinking on the topic | cigarette would help?

Lee – Well it helps you

Oscar – No it doesn't, it costs a lot

Lee – well quit then

Disengagement occurred

(no development of shared understanding of the cause of stress, the benefits or risks associated with cigarettes, other stress management)

We think you are obsessed with books, why? | | |

Further expansion of inductive codes

Questions further expanded to: Multiple questions	Several questions in one utterance or further questions asked after a short/minimal response to the first question	What about other conversations that haven't gone so well? What about in your work?	All participants without autism asked a second question without waiting for an answer to a first	
Questions further expanded to: Why?	Where the response to the 'why' question appears irrelevant, there is no response or the response appears very quick/not considered	Oscar – 'Can you tell me why you like working with Mike?' Lee – 'nope' Oscar – 'Can you tell me again why you weren't in college?' Lee – 'noooo'	'Why' was commented on as being difficult by three autistic participants	
Questions further expanded to: Apparently irrelevant questions,	Questions which appeared to have no relevance to the autistic person	Mary – 'what were you feeling as the bus was coming?' Cait – 'erm ….'	2 participants (M and R) asked these questions frequently, usually relating to feelings	
Questions further expanded to: Questions asked without establishing shared understanding of the topic Direct questions	Questions that do not follow previous utterance, i.e. used without cueing to the topic (merged below)	Oscar – 'in terms of the strategies what are your feelings on those?' Lee – 'OK'		This is linked to supporting thinking)
Questions further expanded to: Vocabulary – Questions are unhelpful where the vocabulary within the question is not helpful	The vocabulary used is not clear	Isla – 'What do you think of *that*?' Cait – No response	All participants without autism used 'that' where the meaning was not clear	Merged with vague vocabulary
Use of mentalising vocabulary	Where the autistic participant is	Mary – 'how do you feel	Used frequently by M and at	

274

and requests for use of mentalising vocabulary	asked about an emotion or thinking process	when he says those things?' Carl – 'it depends'	times by others	
Mixing vocabulary,	Different words used for the same thing	Discussing sexuality, males were referred to interchangeably by Rachel as man, boy, lad, which appeared to confuse Lee	Examples of communication partners using different words for the same thing	
Vague vocabulary 'that' 'everything' 'anything happening?'		Rachel – 'how was that in the end?' Lee pause …. 'alright…'	See above	

RQ2: What is useful for autistic adults to know about conversation?

'A' in the table below indicates a link with the known differences associated with autism

Initial deductive codes

Deductive codes were taken from the research question and form theory and practice where I was actively looking for something based on the research question and my knowledge, rather than finding it arising from the data

Code	Definition	Whether relevant to all autistic participants	What happened to the code/comment
Existing knowledge of unsuccessful interaction EKU **A** – difference in social understanding and difficulty in social interaction evidenced	Comment on involvement in bad/unsuccessful conversations	All autistic participants	This code was expanded to include coding for what people DID know (see below) This code was abandoned as it was too broad
Existing knowledge of good/ successful interaction EKG **A** – difference in social understanding and difficulty in social interaction evidenced	Comment on experiences of good and successful conversation	All autistic participants	This code was expanded to include coding for what people DID know (see below) This code was abandoned as it was too broad
Existing knowledge of response to an interaction EKR	Comment reporting what the participant said or did in response to	All autistic participants	This code was quickly expanded to include

	something said to them		• Use of an existing strategy
			And merged with
			• Physical response (see below)
			The code EKR was abandoned as too broad
Existing knowledge of their response to an unsuccessful interaction EKUR	Comment on what the participant did when the conversation was bad/unsuccessful	All autistic participants	This code merged with the codes above The code EKUR was abandoned as too broad
A physical response (or sensation) EKPh I looked for this based on my practice knowledge, so have categorised it 'deductive'.	Comment on something happening within the body when the conversation or interaction is not 'right'	All autistic participants	The code was expanded • Physical response • Physical Sensation
Vulnerability Categorised 'deductive' because I looked for it A	Comment on vulnerability in interaction, whether it is experienced, what it means to the person	2 people did not appear to have the understanding of vulnerability attached to the word when they talked about vulnerability and it was difficult to establish a shared understanding of the worked within the interview 1 person said she had not experienced it (but people who know her well reported differently)	Code abandoned. It was not possible to gain meaningful information about vulnerability in the context of this study, i.e. without focusing on it at the risk of losing the interaction needed within the SSI, but there are implications for future work

Inductive codes

These codes arose from patterns across the data set i.e. where I saw the same things/types of things being said by autistic participants or I noticed about the conversation of autistic participants .

Codes that arose from things that autistic participants said:

Code	Definition	Examples	Where the code came from/whether relevant to all autistic participants	What happened to the code/comment
Use of an existing strategy in response to a conversation or interaction EKS	Comment on what was in the head /what was thought about to inform behaviour in the situation, or comment on use of what may be described as a self-prompt strategy	Ruth 'I think I said to myself if she's talking at me its OK ….' Lee: 'I thought I'll run away instead'	Developed after coding of exploration of response to interaction when it became clear that autistic participants were using different strategies Examples from all autistic participants	Expand to • self-talk strategy • other strategy
General awareness GA	Any comment that suggested an awareness (or knowledge) of self or someone else at the time of the interaction	Chloe:' I can pull the wool over most people by talking about my favourite subjects' Lee: 'I get on very well with my social worker' Chloe: 'if people talk very fast, it stresses me out more'	Developed after a pattern of people commenting on awareness of knowledge or self became clear across the data set Examples from all autistic participants	Expanded to: • EKPD existing knowledge of people differences (see below) • Existing knowledge of self (see below). This code was then abandoned, as it was too broad
Topic of conversation Topic Recognition that the topic of conversation can have a good	Any comment on the topic of conversation as having an impact on how the conversation 'went' (good or bad), from the perspective of the autistic participant	Chloe: 'when someone is talking negatively I see that as a bad conversation' Lee: 'in court I had to give evidence… and they try and twist it and stuff… that gets	Developed after a pattern became clear of the topic of conversation having an impact on whether the conversation was successful and unsuccessful	Topic is still a separate code but linked to type of conversation (below)

and bad effect on the conversation (on EKU and EKG)		me angry and stuff'	Examples from all autistic participants	I was aware of the importance of 'topic' when coding non-autistic participant data in relation to 'cueing in'
Recognition of different types of conversation TC	Comments on the function or outcome of any conversation, good or bad	Chloe; 'a conclusion solving conversation' Cait: 'that was the outcome' Ruth: 'it was general chit chat'	Developed when exploration of successful and unsuccessful conversation showed a pattern of the conversation type influencing the interaction Examples from all autistic participants	Need to subdivide in to types recognised across the data set and possibly recode
Existing knowledge of differences between people EKPD **A –** Theory of mind deficit evidenced, but trait knowledge is preserved	Any comment on knowing things about people. This may be personality, traits, face, behaviour, body language	Carl: 'Bob had a lack of ability to understand what I was about' Cait:' she really listens, really switched on' Cait: 'he funny… I put up with his jokes' Chloe 'I can tell in their face if they are listening'	This code arose from a clearer definition and division of the 'awareness' code (see above). Examples from all autistic participants	This was further expanded to • Face and body language (including knowing when listening) • Personality/ attributes/traits • What others know and like
Power balance PB	Where people comment on control /having my say, or on who did most talking within the conversation	Chloe: 'it was more B telling me things, rather than getting the two together from B's half and my half' Cait: 'he had the actual patience, not just telling me how to do it' Carl: 'it's a much more equal conversation, you don't ask me the same question over and over'	Examples from all autistic participants	Shared understanding and feeling listened to were added to this code definition I used this code in the analysis of the communication partner without a diagnosis of autism too having recognised the importance of it in this analysis

Vocabulary disliked (Disliked words) Vocab **A –** weaknesses in comprehension of spoken language	Any comment on word, phrase, type of sentence, something spoken to the person, which the participant said was disliked	Cait: 'she asked why and my mind just went blank' Chloe 'why is like pressuring you to get the answer'	Examples from all	Expanded to • disliked words/vocab (this was later refined to disliked mentalising vocabulary – see below) • disliked questions I was then aware of the importance of questions and disliked words when coding data collated form the participant without a diagnosis of autism
Shared understanding through feeling listened to/feeling understood	Note where people comment on whether or not they feel listened to and whether or not they 'feel understood'. (These were words used frequently)	Lee: 'Mr F understood… the rest of them teachers, they just didn't know' Cait: 'she really listens, she knew more what I was talking about'	All participants I recognised this as important to Lee and then looked in others	This has moved to merge with power balance and/or knowledge of people differences and shared vocabulary
Atmosphere **A –** sensory differences	Any comment on the general feeling at the time of the conversation either about the physical environment, the interpersonal environment or the personal environment	Chloe 'it was not a relaxing atmosphere' Ruth: 'I asked her to turn her voice down a bit' Lee: 'it's not going well this far' (indicating the ringing phone and the door where there had been previous interruptions)	Examples from all participants I recognised this this in Chloe and then looked in others	Expanded as below: • Internal atmosphere, how feel in self and ability to think, knowledge of self • Physical atmosphere eg interruptions • Behaviour/response of communication partner, loud voice, speed of delivery

Codes that arose from things that were learned /worked out by researcher and participants

Code	Definition	Examples	Where the code came from/whether relevant to all autistic participants	What happened to the code
Mentalising vocabulary was noticed as an area of interest, as use and understanding of mentalising words may be mixed by participants. Participants comment on this. MV **A –** weakness in comprehension of spoken word	Any mentalising word used to describe a response in a situation. The use may be further annotated Note any mentalising vocab used. Extend to whether it was used with the usual meaning attached or differently	Chloe: my anxiety was coming past' Lee: 'bad means stressful' Ruth: 'I was stressed and anxious in school' Chloe: I don't like stressed, can I put anxious?'	Examples from all participants except CB who finds it difficult to give a mentalising response	This has been expanded to • Hesitant use of MV • Use of MV in a different way to usual/expected use Further analysis needed I was then aware of the importance of mentalising vocab when coding data collated from the participant without a diagnosis of autism

Appendix 18: Themes and clustered codes

Research Question 1

Main theme 1: Optimising engagement

Theme	Clustered codes
Use of cues	Topic, memory, thinking,
Sustain engagement	Sustaining engagement. Confirmation, nonverbal confirmation, respond to disengagement , positive feedback
Shared understanding of vocabulary used	Checking comprehension of vocabulary Using words of autistic participant
Not responding to disengagement	Not noticing/responding to disengagement
Interrupting	Interrupting
Unhelpful vocabulary	Mentalising vocabulary, mixing, vague,

Main theme 2: Supporting thinking

Theme	Clustered codes
Use of confirmation	Confirmation, nonverbal confirmation,
Use of timely prompts to think	Question, statement, indirect question
Giving ideas	Giving ideas
Unhelpful questions	Multiple questions, why?, irrelevant, 'direct', (abandoned), vocabulary not shared (merged with vocabulary above)

Power balance 'grease' and 'blocks' throughout

Research Question 2

Main theme 1: Knowledge of the communication environment

Theme	Clustered codes
Own self and response	Physical response, physical sensation, self-talk strategy, other strategy,
Atmosphere	Internal atmosphere (became knowledge of self above), physical atmosphere (interruptions was then separated above), comment on communication partner response
Knowledge of the communication partner	General awareness, existing knowledge of people differences , existing knowledge of self,

Main theme 2: Knowledge of talk/type of talk

Theme	Clustered codes
Type of conversation	Type of conversation
Conversation topic	Topic
Vocabulary alerts	Disliked words, disliked questions,

Within RQ2, existing knowledge of successful and unsuccessful interaction of autistic participant noted throughout, also power balance.

Appendix 19: Definition of Themes Used in Response to RQ1 and RQ2

Research Question 1: How can autistic adults be supported by a communication partner to access and contribute what they know to conversation?

Table 9.8 Definitions of main theme 1 and sub-themes (RQ1)

Sub-theme	Definition	Sub-themes
Main theme 1: Optimising engagement	Definition: The person is actively involved in the two-way conversation	
Use of cues	Use of language that enables the communication partner to 'tune in' (think about and anticipate the topic of conversation) to the conversation topic	**Cue to topic:** where direct information about the topic is given e.g. 'we are going to talk about'.. or the 'scene' of the topic is set **Cue to memory:** where the person is supported through cues to think back and 'remember' an event that will be the topic of conversation before the conversation begins
Shared understanding of vocabulary used	Both conversation partners having the same understanding of words used	Checking understanding of vocabulary used. The communication partner explore and checks understanding of vocabulary used **Shared use of agreed vocabulary.** The communication partner uses the vocabulary of the autistic person e.g. conclusion solving, 'lad', rather than the vocabulary they may usually use
Sustaining engagement	Maintaining involvement in the conversation, enabling the autistic participant to contribute more, through use of comment, refocus, nonverbal cues	**Meaningful power balance:** ensuring that both conversation partners have a feeling of being equal, and have shared involvement in the conversation i.e. no one person is dominating or overpowering **Nonverbal cues**: sounds e.g. mm, interested facial expression used to sustain power balance **Notice and respond to disengagement:** noticing where the communication partner is providing perhaps only one-word answers or irrelevant responses or appears otherwise occupied and doing something about this that is right for the person and the conversation to support re-engagement

Main theme 1: 'Blocks' to engagement		Definition: Something that stopped the conversation or contributed to disengagement of the person with ASC or minimal responses
Not responding to disengagement	Not noticing when the person is no longer contributing to the conversation, appears distracted or contributing only minimal responses Beginning to talk before the person has finished and moving the subject on rather than confirming or affirming	
Interrupting	**Mixing vocabulary:** using different words for the same meaning e.g. man, lad boy **Mentalising vocabulary**: use of vocabulary relating to emotions or cognitive processes without checking shared understanding of these words	
Unhelpful Vocabulary	**Vague vocabulary:** e.g. 'that' it', 'them' without checking understanding	

Main theme 2: Supporting thinking		Definition: Something said or done that enables the person with ASC to THINK and to provide a response that has been considered
Acknowledgement/ confirmation	Something said or done that shows the person with ASC that they have been understood	**Verbal:** spoken confirmation of understanding of what has been said **Nonverbal.** e.g. nodding of the head, 'I see' facial expression, 'mmm'
Use of timely prompts to think	Something said or done at a time that is effective in enabling the autistic person to think of their own ideas or responses	Helpful questions A question asked when the person is focused on the subject, grammatically constructed so that the person can understand Indirect questions: e.g. 'I wonder …' **Statement** e.g. I am thinking that that may sound a bit like .., Explicit cue to think. 'We need some good thinking',

Main theme 2: 'Blocks' to thinking		Definition: Something said or done that results in minimal responses or 'stock' answers, for example responses that may have been learned and repeated rather than owned and understood
Giving ideas	Suggesting what the autistic person should or could do, providing own explanation/ideas relating to something raised, rather than eliciting understanding from the autistic person	**Why:** use of a 'why' question before the person has had time to think and where it appears that an answer/reason is expected
Unhelpful questions	Questions asked that are difficult for the person to understand or respond to	**Multiple:** asking more than one question, one after the other, without waiting for a response to the first question
		Without shared understanding of topic or vocabulary: question asked without checking that the person understands the vocabulary or concepts within the question

Research Question 2: What is useful for autistic adults to know about conversation?

Table 9.9 Definitions of main theme 2 and sub-themes (RQ2)

Sub-theme	Definition		Sub-themes
Main theme 1: Knowledge of the communication environment		Definition: What autistic participants know about the physical environment and about the people in it	
Knowledge of own self and response	Noticing something different within the body Using own way of managing something (i.e. a strategy)		**Physical:** noticing a physical response e.g. shaking leg **response/sensation:** noticing a 'feeling' e.g. stomach swinging **Strategy use:** e.g. self-talk. 'I said to myself'…or own strategy e.g. 'I just need to get away'
Knowledge of Atmosphere	Noticing changes in the physical environment e.g. noise, temperature Noticing the 'feeling' between people in the environment e.g. busy, difficult		Physical atmosphere Background noises, physical interruptions, light, where to sit Interpersonal atmosphere Number of people in the environment, what the people are doing, how they are interacting

		Both the above contribute to the person feeling listened to
Knowledge of communication partner	Knowing things about people (traits) e.g. what people are 'like', what people may do or say. Knowing who is saying the most or who appeaser to 'control' the interaction	Existing knowledge of people differences **Knowledge of profession or role** e.g. that's what teachers are like **Knowledge of personality traits** e.g. knowing that someone jokes a lot, talks a lot, usually has a serious face. **Knowledge of body/face changes:** knowing when something changes in a person and knowing what that means e.g. when she touches her hair he is stressed. **Power balance:** Knowing whether/how the conversation can feel equal so the autistic person 'has their say'

Main theme 2: Knowledge of the structure of talk/type of talk	Definition: Knowing the type of conversation e.g. problem-solving, banter, 'bollocking' and knowing what to expect from a conversation topic e.g. from goal setting conversation	
Type of conversation	The purpose of the conversation e.g. solving a problem or just small talk to fill time	
Conversation topic	What the conversation is about and whether it is interesting or whether the topic may mean the conversation may be difficult e.g. going back over something that the person feels they did 'wrong'	**Vocabulary alerts:** knowledge of words that are disliked e.g. why questions or some emotion words Knowledge of topics that are disliked and would rather avoid or prepare for **Questions:** knowledge of disliked questions e.g. 'why' or complicated questions **Mentalising vocabulary:** Knowledge of disliked emotion words or concepts

Appendix 20: Research Question 3: Common Themes and Participant Examples

Research Question 3: In what ways can learning and knowledge about conversation be used in everyday conversation by autistic adults and their communication partners?

Common themes and participant examples
Autistic participant

Uncovered knowledge used	Cait	Ruth	Lee
Greater awareness of what is important during conversation and increased confidence in letting others know this	'Will you just listen Dad' 'You know I don't like 'why' questions' 'What are you on about?'	'I have noticed I am more confident in asking them to explain again if I don't understand' 'I have got better at asking people to write it down'	Agreement with his personal tutor that he will say 'hang on' when needing time to think or when the balance in conversation does not feel right
Use of knowledge about people to know what people are 'like' and what they may do/how they may act	(Talking about Claire 'fussing over' the dogs rather than talking to her): 'it's to be expected. I know Claire' 'I know what Shirley's like now. I used to be bothered by her, but not now.' 'you know Mark, he's the one who winds me up'	'I just know myself that it's OK for her to be blunt. I was not really used to the bluntness at first. She was very blunt, very to the point and serious at the same time'. 'She frowns a lot, she doesn't really smile, but she's not horrible. ' 'You work me really hard' 'I didn't really know the woman, so I had to focus on her'	'Something changed in R's face, it sprung to me .. she didn't agree' 'I know when S is not listening, so I give up' 'she touches her hair when she is stressed'
Use of recognition of 'type of conversation'	'which conversation is this?'	'Depending on the type of conversation, my brain has to really switch on' Describing a 'help and advice', followed by 'general chat' within one conversation with the tutor 'Working with the children I don't have to think a lot, in the debrief with the staff I zone in' 'I know if my brain really needs to think'	'I usually have bollocking and praise conversations with Oscar' 'I have chatting and agreeing conversations with J' It has been reported to be helpful when Lee has been told that a conversation about to take place is not a 'bollocking conversation'
Conscious awareness of the physical sensation	'I felt it the other day, but I was just cold'	'I felt it, but it wasn't strong'	'I need a leg to mouth message'

Participant without a diagnosis of autism

Uncovered knowledge used	Isla	Lara	Oscar
More aware of the need to give time to think and to maintain a balance in conversation	'I listen before I put my opinion' 'I keep my big gob shut' 'Dad is making an effort to say less too'	I now: Try not to interrupt the flow of a conversation Allow time for thinking Be aware of the signs of someone not understanding Awareness of the person with ASC feeling in control of the conversation	'I am more conscious of avoiding 'telling' and the need to 'explore together'. 'I have moved from showing I'm listening to something else, …gaining a shared understanding'
Greater awareness of own vocabulary and language use, especially questions	'Why' is like an interrogation' Isla was heard self-correcting during conversation – 'what do you think about *that*?' (unclear) was immediately corrected to 'where do you think we should draw the line, say no?'	'I didn't phrase that very well' 'I'm finding it hard to explain without putting words in people's mouths 'I try not to ask 'why', I am more explicit than open ended when asking, I am more aware of how to cue people in to a conversation' the importance of open body language and a smile	'I am less directive, I am moving away from questions, especially 'why' 'I am conscious of the need for open questions, but its more than that' 'Considered use of language is needed'
Greater awareness of the importance of allowing time for thinking and development of solutions	'we listen, Carl needs to find the solutions, we let her talk'	'I know that the autistic person may have their own answers'	'I am very aware of any of my suggestions' 'I see the importance of equipping people with ASC and staff to think' 'You can't rely on "It will be OK to have a conversation", you have to really think *how* to uncover if you really want to find out and make a difference'
Use of the themes found useful to the participants in this study with other autistic people	NA	Use of type of conversation, trait knowledge, supporting people to 'know what they know' and cueing have been useful	Use of types of conversation and own changed approaches with other students

Excerpt from Semi Structured Interview 1

L 16 March 2016

K: So back on thinking about your body and last time we met, you talked about your leg. *(cue)* *(Q)*
When you were in that conversation there, can you remember feeling anything in your
body?

(MV) L: Yeah, I could feel my anger building up, like I just wanted to explode, trash the place or go
and punch someone. After it had finished, I just broke down in tears
K: Such a difficult situation *(confirmation)*
L: Yeah it was yeah
K: And so I like the way you talk about the anger building up and going to explode. When *(confirmation)*
you get that any time, can you tell me what's going on in your body? *(Q)*
Silence. *(block:)*
L: No. It's hard to describe
Silence
L: No I cant describe it
K: And that was a long time ago ,so you didn't like that conversation because everything was *(conf-misword)*
twisted., that conversation with the police and the conversation in the court, really horrible
K: Have there been any other horrible conversations? *(not engaged?)* *(Q)* *(block?)*
L: No its been alright for me so far, just that court thing
K: Who do you like *(emphasis)* talking to ? *(Q)*
L: I talk to my mum, my granddad, talk to people at school , O, he's the teacher here, J who's
the counselor, talk to my friends
K: Mmm there's quite a lot of people you like talking to. *(confirmation)*
L: Erm, one placement which was P, Mr F understood how I was always feeling and always *(grease)*
helped me out. He understood and a couple of other teachers but the rest of them just
(EXPV) didn't know
K: You said something really interesting there, you said he understood and that's obviously *(confirmation)*
really important isn't it. *(giving ideas)* *(block?)*
L: Yes *(single word)* *(block)*
K: I wonder how we can work out who understands and who doesn't That's a tough one. *(cue)*
How did you know he understood? *(Q)*
(listened to) L: Cos he was always there, if I had a problem I could always turn to him and he was always
(EKG) there, he even said to me, if you have a problem come and see me and I knew straight way
(topic) that he was the one I could turn to if I had a problem. *(? conclusion)*
K: So that's something about time isn't it? You can come anytime *(giving ideas)* *(block:)*
Is that right ? *(Q)*
L: Yeah *(single word)*
K: So what about the rest of them. You said there were about 3 that understood and the *(Q)*
rest just didn't *(confirmation)* *(cue)*
L: At P we were split in to blocks so we had our own area and we had to walk back to the
(EKPD) school, so I spent most of the time in the block so most of the teachers did not get to know
me.
K: Oh yeah *(confirmation)*
(EKPD) L: They didn't know what I was like so didn't know what my triggers were
K: Right, so they didn't know what you were like, didn't know what your triggers were *(confirmation)*

K: Yeah
Silence
K: So you obviously know different things about people. You know who knows you and you
know who doesn't. *(confirmation)*
Background noise here
K: Some teachers at P were not easy. I think you talked about your GP *(cue)* *(grease)*
(EXPV) L: Oh yeah, my GP is good I can talk to him. He understands about what I've been going
(EKG) though and how I feel
Phone ringing.

290

Excerpt from Semi Structured Interview 1

R 3 March 2016

R: So this woman said 'why are you ignoring me you stupid cow' erm and then I just turned round and looked her, I didn't say a word 'cos what the point, I just carried on then my tutor went and said this thing, and erm that was it and after this part of the presentation then me and this woman went outside in the corridor

K: What happened in your conversation when you were outside in the corridor?

R: Erm I was just talked at, I just stood there and not said a word

K: Right so just talked at

R: Yes and this woman was just talking at me saying yes I know you have autism, but so do I, you have to respect me cos I am older than you. Erm

K: And did that make any sense to you?

R: Not really, none of it, she just really spoke out to me well it felt to me

K: Yes, that's a really good way of putting it

R: Yeah, cos I'd rather be talked TO, than talked down to

K: Oh did it feel talked down to?

R: It felt as though she was talking at me and talking down to me

K: How would you describe talking down to?

R: Cos I am younger than her, she thought I was disrespecting her cos she's been brought up with the same so she treated me as I've been treating her really but I have not got that bad bone in my body but she thought I was disrespecting her so she thought she would talk down to me

K: That's all really complicated isn't it

R: Very

K: I see why it is difficult, So when the conversation was …. I don't know, what word shall we use…?

R: Wrong

K: wrong, yes that's a good one, lets say when the conversation was going wrong, did you get any sensation anywhere in your body…. This is quite hard, think back to the room… just think

R: Yeah, the sensation I got was my body was quite tensed

R: I can definitely feel that I was kind of stuck against the wall

K: That's a nice way of putting it

R: Cos I was kind of that tensed up, I was not feeling anxious in myself cos I knew what was going on but because she was talking down to me, just tense, just looked like I was listening but really I wasn't,

K: Yeah

R: Cos after the first sentence had come out, that was it, gobbledogook really, it wasn't making sense at all

K: That is what it was like, cos when you were trying to repeat it back to me, I agree, it wasn't making sense to me

R: Yeah,

K: So it's just gobbledegook

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