



**The Development and Evaluation of the Cognitive Behavioural Social
Competence Therapeutic Intervention for Adults with Autism Spectrum
Disorder without an Intellectual Disability (CBSCTI-ASD)**

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Abbreviations

ABA	Applied Behaviour Analysis
ADOS	Autism Diagnostic Observation Schedule
ASD	Autism Spectrum Disorder
BOLD	Blood Oxygen-level Dependent
CBSCTI-ASD	Cognitive Behavioural Social Competence Therapeutic Intervention for Autism Spectrum Disorder
CBT	Cognitive Behavioural Therapy
DLPFC	Dorsolateral Prefrontal Cortex
DSM	Diagnostic and Statistical Manual
EEG	Electroencephalogram
FFA	Fusiform Face Area
fMRI	Functional Magnetic Resonance Imaging
fNIRS	Functional Near-Infrared Spectroscopy
MGSSI	Manualised Group Social Skills Intervention
ID	Intellectual Disability
MANOVA	Multivariate Analysis of Variance
MGSSI	Manualised Group Social Skills Intervention
MPFC	Medial Prefrontal Cortex
Oxy-Hb	Oxygenated Haemoglobin
PEERS	Program for the Education and Enrichment of Relational Skills
MPFC	Medial Prefrontal Cortex
RCT	Randomised Controlled Trial
ROI	Regions of Interest
RRBs	Restrictive Repetitive Behaviours Activities and Interests
SCIT	Social Cognition and Integration Training
STG/STS	Superior Temporal Gyrus/Sulcus
TPJ	Temporo-Parietal Junction

Abstract

Many young people with autism spectrum disorder (ASD) can have an average or above average IQ yet still struggle with the social competencies needed to successfully navigate into adulthood. Despite many individuals with ASD experiencing significant challenges during their transition into adulthood, evidence-based social skills interventions to support individuals with ASD during this transition are rather limited. There is growing evidence to suggest that social competencies in adults with ASD without an intellectual disability (ID) can be enhanced through both individual Cognitive Behavioural Therapy (CBT) and group CBT. However, little is known about the benefit of combining these modalities for individuals with ASD transitioning into adulthood. Moreover, there are no studies which have investigated the neural plasticity of a multimodal CBT intervention for adults with ASD without ID. The first stage of this PhD project involved developing and writing the Cognitive Behavioural Social Competence Therapeutic Intervention (CBSCTI-ASD) manual for Adults with ASD without ID. This PhD project includes a total of three studies: Study 1 Evaluation of CBSCTI-ASD; Study 2 Neuroplasticity of the Social Brain Following CBSCTI-ASD and Study 3 Exploring the Experiences of Parents' with an Adult Child with Autism Spectrum Disorder. For Study 1, CBSCTI-ASD was developed and delivered to five young adults with ASD without ID. The aims of the first study were to evaluate intervention feasibility and efficacy by triangulating data findings. Feasibility was supported and CBSCTI-ASD received high user satisfaction ratings. Adherence to the intervention were high, recorded at ~90% and fidelity to treatment were also high ranging from ~86% to ~100%. Quantitative findings from study 1 indicates that over an eight-week time period the intervention group experienced significant improvements with regard to their social motivation, non-verbal conversation, emotional empathy, assertiveness, interpersonal relationships and self-control.

Qualitative findings provide further anecdotal support towards intervention feasibility and efficacy. After the completion of CBSCTI-ASD, four participants who received CBSCTI-ASD and two of their parents completed semi-structured interviews. Thematic Analysis (TA) revealed four main themes: satisfaction with CBSCTI-ASD, important components of CBSCTI-ASD, challenges and critiques and recommendations. Two qualified cognitive behavioural therapists helped with the delivery of CBSCTI-ASD. Their opinions and experiences of CBSCTI-ASD delivery were explored during a focus group. Findings from TA revealed three themes: training and delivery, successes and challenges, and therapist recommendations. The qualitative findings from study 1 also highlight factors which those involved in delivering and receiving CBSCTI-ASD believed could be effective in guiding the further development of the intervention. Study 2 involved applying functional near infrared spectroscopy (fNIRS) to explore neurological function and changes in neural activity in cortical regions of the Prefrontal Cortex (PFC), an area associated with the social brain. The aim of study 2 was to assess functional regions of the social brain and evaluate the possible neurological effects of CBSCTI-ASD. While applying fNIRS to measure neural functioning, the five participants from the CBSCTI-ASD intervention group from study 1 and a closely matched typically developed control group completed a pre/post-test conversation task. Findings from study 2 show that both the intervention group and the typically developed control group significantly increased neural activity in the Medial PFC (MPFC) during the conversation task, thus confirming a target region of interest for measuring change in neural function. However, no significant differences in brain activity over time between the intervention group and the typically developed control group were identified. Post hoc analysis did shows that the intervention group significantly increased neural activation in the left MPFC from pre-test to post-test. Finally, study 3 aimed to explore the experiences of

seven parents with an adult child with ASD without ID. TA was conducted on semi-structured interviews and six main themes emerged: receiving a diagnosis, challenges, parents coping strategies, support and treatment, recommendations for intervention and positive parenting. The findings from study 3 highlight important and complex issues which should be considered when providing support to adults with ASD and their families. The findings from study 1 and 2 indicate that CBSCTI-ASD appears to be a feasible intervention and efficacy is supported at improving social competencies in young adults with ASD without ID. Qualitative findings from study 3 elucidates the intricacies of living with ASD and provides a promising starting point to further the development of CBSCTI-ASD. While these initial findings are promising, additional research is needed to further develop CBSCTI-ASD and provide an assessment of the efficacy of the intervention using larger randomised controlled trials.

Keywords: Autism Spectrum Disorder; social impairment; social cognition; social competence; neuroimaging; group social skills interventions.

Chapter 1: General Introduction

1. Introduction

A multidisciplinary approach which draws on research from developmental psychology, clinical psychology, and cognitive neuroscience were adopted during this PhD project. A causal model of autism spectrum disorder (ASD) was also adopted as it offers a clinical framework to provide a visual representation of ASD as a neurodevelopmental disorder (see Morton, 2008). The causal model approach has three vital components which relate to three levels of scientific discussion: biological, behavioural, and cognitive. A significant benefit of the causal model for ASD in intervention research is that the role of the environment is also taken into account across all three components.

The PhD project objectives were threefold:

1. To develop and evaluate the efficacy and feasibility of the Cognitive Behavioural Social Competence Therapeutic Intervention (CBSCTI-ASD) for young adults with ASD without an intellectual disability (ID).
2. To explore the neuroplasticity of the social brain in participants who received CBSCTI-ASD.
3. To explore the experiences of parents with adult children diagnosed with ASD without ID.

Quasi-experimental methods were used to establish the impact of CBSCTI-ASD on social competencies and cortical level neural functioning associated with the social brain.

Qualitative investigations aim to provide anecdotal data on the feasibility, efficacy and future development of CBSCTI-ASD.

2. Background

As classified in The Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5, American Psychiatric Association; APA, 2013), ASD falls under the category of neurodevelopmental disorders and is characterised by impairments in social communication and social interaction, and restricted repetitive behaviours, interests, and activities (RRBs). ASD is a complex and pervasive condition which is often associated with mental health and behavioural challenges which continue into adulthood (Howlin & Moss, 2012; Rattaz, Michelon, Munir, & Baghdadli, 2018). Individuals with ASD can differ

greatly in their clinical and functional presentation, resulting in potentially substantial differences in the type and cost of treatment, care, and support (Elsabbagh et al., 2012). ASD comes at a high financial cost to both families and society alike and the presence of ID in individuals with ASD can greatly increase the economic costs over an individual's lifespan (Ganz, 2006; Knapp, Romeo, & Beecham, 2009).

A comprehensive report by Buescher, Cidav, Knapp, & Mandell (2014) estimates the cost of supporting a person with an ASD and a comorbid ID during an individual's life to be approximately \$2.4 million in the United States (US) and £1.5 million (US \$2.2 million) in the United Kingdom (UK). Although some individuals with ASD without a comorbid ID go on to live independently, many still need continued support in adulthood (Taylor & Seltzer, 2011). Although costs are estimated to be lower for supporting an individual with ASD without ID, the fiscal impact on the economy of the US and the UK are estimated to be \$1.4 million and £0.92 million (US \$1.4 million) respectively. However, the estimates of US calculations of productivity loss may have been underestimated in the review by Buescher et al., (2014). A very recent review calculated productivity loss but also factored in average US salaries, along with the salaries of individuals in supported employment, and estimates of lifetime support for individuals with ASD were approximately \$3.6 million (Cakir, Frye, & Walker, 2020).

The most expensive costs for children and adolescents with ASD have been shown to be special education services, therapeutic costs and the loss of productivity from caretakers (Buescher et al., 2014; Rogge, & Janssen, 2019). During adulthood, costs have been found to be most considerable in terms of residential care, supportive living accommodations, individual productivity loss and medical care expenses (Buescher et al., 2014; Rogge, & Janssen, 2019). While financial estimates may vary, costs of lifetime care are considerable and as prevalence and demand for support increases, economic costs will likely continue to rise in years to come (Buescher et al., 2014; Cakir et al., 2020).

2.1 Prevalence and Aetiology of ASD

Over the years there has been a steady increase reported in the prevalence of ASD, most notably in individuals with average or above average cognitive abilities (Reichow et al., 2012). In the 1960s and 1970s prevalence estimates were approximately 5 per 10,000, whereas since the late 1990s and early 2000s rates were fairly consistent ranging from approximately 72 per 10,000 and 100 per 10,000 (Howlin & Moss, 2012; Newschaffer et al., 2007). Similar rates have been estimated at a global level with worldwide prevalence of

ASD being reported at approximately 62 per 10,000 (Elsabbagh et al., 2012). The most recent CDC survey estimates suggest that the prevalence of children in the US being affected with ASD has risen from 1 in every 100 children in 2007 to 1 in 54 in 2016 (Baio et al., 2018). Traditionally ID has also been associated with ASD and some epidemiological studies suggest that the prevalence rates of a comorbid ID ranges between 30% and 60% (Baron-Cohen et al., 2009; Bruhga et al 2016; Chakrabarti & Fombonne, 2001; Emerson & Baines, 2010; Fombonne, 2003; Yeargin-Allsopp, 2003).

While prevalence rates have been predominantly based on the reports of children diagnosed with ASD, Bruhga and colleagues (2011; 2016) utilised the UK Adult Psychiatric Morbidity Survey to report data on the presence of ASD in adults. Their findings suggest that the ASD prevalence rates for adults are in-line with past epidemiological studies based on children (e.g. Baird et al., 2006; Baron-Cohen et al., 2009). The authors reported adult ASD prevalence rates of approximately 1% in the UK general population, with prevalence rates in males being higher at 1.8 % compared to just 0.2% in females. Although, male gender was only found to be a strong predictor of ASD in individuals without ID or mild ID (Bruhga et al., 2016).

ASD is a disorder which likely results from both genetic and non-genetic risk factors and their interactions. Research has shown that genetic causes play a significant role as atypical genes and chromosomes have been found in approximately 10% to 20% of individuals diagnosed with an ASD (Miles, 2011). A large population-based longitudinal study which included more than two million families evaluated the familial risk of ASD and reported heritability estimates to be 50%, suggesting that genetic factors may account for half the risk of ASD (Sandin et al., 2014). Twin studies have also demonstrated high risk of heritability with reports of concordance rates ranging from 76% to 92% in monozygotic twins (Tick, Bolton, Happe, Rutter, & Rijdsdijk, 2015). While past research findings do suggest a significant level of heritability, ASD is most likely the result of complex interactions between both genetic and environmental risk factors (Kim & Leventhal, 2015).

Environmental factors that may contribute to the development of ASD have been identified from clinical and epidemiological studies that relate neurodevelopmental disorders with specific environmental exposures. Various environmental causative elements including pre-natal, peri-natal, and post-natal factors, have been implicated as contributing to ASD (Chien et al 2019; Kolevzon et al., 2007). Prenatal and Peri-natal factors related to ASD include exposure to teratogens, maternal anticonvulsants, viral infections, preeclampsia, polyhydramnios, oligoamnios, placenta previa, umbilical cord knot, and

gestational diabetes (Chien et al 2019; Kolevzon et al., 2007). ASD develops in juxtaposition with other atypical developments caused by congenital rubella syndrome such as: eye impairments, deafness, intellectual disability and cardiac abnormalities. Other perinatal factors are low birth weight, abnormally short gestation length, and birth asphyxia (Kolevzon et al., 2007). Postnatal risk include factors such as advanced parental age, premature conception, low birth weight, hyperbilirubinemia, pregnancy complications, autoimmune diseases, viral infections, hypoxia, mercury toxicity and even social factors such as maternal immigrant status (Ng, Montigny, Ofner, & Do, 2017). When considering the complex nature of ASD, it is likely that a combination of genetic and environmental factors together, play a role in the pathology of ASD.

2.2 Clinical Features of ASD

The clinical and functional presentation of ASD is heterogeneous in terms of the symptoms and their severity (see Table 1). For instance, at one end of the autism spectrum an individual may feel they want to stay close to others and while they may have a strong motivation to interact, they often lack the social skills to navigate social interactions proficiently. On the other end of the spectrum, individuals may be aware of their social difficulties and strongly lack any motivation to socially engage with others and as such avoid superfluous social interactions whenever possible (Reichow, Steiner, & Volkmar, 2013).

There have been many debates over the diagnoses of ASD, the ASD sub-types, and the definitions of the diagnostic thresholds (Maenner et al., 2014; Volkmar & Reichow, 2013; Weitlauf, Gotham, Vehorn, & Warren, 2014). The most marked change to the DSM-5 was the removal of ASD subsets (e.g., autistic disorder, Asperger Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified) previously found in the diagnostic classifications of the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV-TR; APA, 2000). Although modifications to the diagnostic criteria reflected the growing concern over the validity of some ASD subtypes (Volkmar & Reichow, 2013), changes have also led to concerns over current criteria being too restrictive, particularly for individuals without a co-morbid ID diagnosis (Maenner et al., 2014; Matilla et al., 2011; McPartland et al., 2012). Despite the concerns about the DSM-5 criteria being more restrictive (Maenner et al., 2014; Matilla et al., 2011; McPartland et al., 2012), since its release a reduction in the rate of ASD diagnosis has not yet been reported. Survey estimates from the Centre for Disease Control (CDC; 2017) suggest that there has been a slight increase in ASD prevalence rather than a reduction. It is likely that clinicians have become

highly cognizant of the DSM-5 criteria and as a result have developed a tendency to document symptoms that received more emphasis in the DSM-5.

Table 1 *DSM-5 diagnostic criteria for ASD*

Severity levels & specifiers	Social communication and interaction	RRBs
Level 1: Requiring support	Persistent deficits in social communication and social interaction across multiple contexts, current or historical	Manifested by at least two of the following criteria:
Level 2: Requiring substantial support	(1) Deficits in social-emotional reciprocity, ranging from abnormal social approach and failure of normal back-and-forth conversation, to reduced sharing of interests, emotions, or affect, to failure to initiate or respond to social interactions	(1) Stereotyped or repetitive motor movements, use of objects, or speech.
Level 3: Requiring very substantial support	(2) Deficits in nonverbal communicative behaviours used for social interaction, ranging from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language or deficits in understanding and use of gestures, to a total lack of facial expressions and nonverbal communication	(2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour
Specifiers:	(3) Deficits in developing, maintaining, and understanding relationships, ranging from difficulties adjusting behaviour to suit various social contexts, to difficulties in sharing imaginative play or in making friends, to absence of interest in peers	(3) Highly restricted, fixated interests that are abnormal in intensity or focus
-With or without accompanying intellectual impairment		(4) Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment
-With or without accompanying language impairment		
-Associated with a known medical or genetic condition or environmental factor		
-Associated with another neurodevelopmental, mental, or behavioural disorder		
-With catatonia		

There also seems to be a certain amount of stability and overlap between the DSM-5 and the DSM-IV-TR criteria (Mazefsky, McPartland, Gastgeb, & Minshew, 2013) which is important when comparing and interpreting past and present ASD research. Mazefsky and colleagues (2013) found that individuals with ASD deemed eligible for research using standardised diagnostic instruments based on the diagnostic algorithms of DSM-IV-TR, also meet most of the DSM-5 criteria. Based on the combined data of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview – Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) in a sample of 498 individuals with ASD without ID, 93% demonstrated evidence of symptoms in all DSM-5 domains required for diagnosis. It seems unlikely that changes to the DSM-5 criteria have had a significant impact on research participants eligibility as there appears to be some level of continuity between the DSM-IV-TR and the DSM-5. However, it should be noted that the ADOS only accounted for 33% of all the DSM-5 requirements found which varied significantly when compared to the ADI-R at 83% (Mazefsky et al., 2013). This discrepancy between screening instruments may suggest that the methodology of assessment may have had more impact than the actual diagnostic criteria (e.g., observation versus interview).

2.3 Empathy and ASD

Empathy and ASD have been the focus of a number of studies over the years (e.g., Baron Cohen & Wheeler 2004; Blacher et al., 2003; Gillberg 1992). The nature of empathy requires an individual to understand another's mental state and to respond with an appropriate emotion or action. Within the ASD literature two types of empathy are often discussed: cognitive empathy and affective empathy (Harmsen, 2019). Cognitive empathy refers to the ability of a person to understand another person's perspective (often equated to ToM), whereas affective (or emotional) empathy refers to a person's emotional responses to the mental state of others (Cox et al. 2012; Rogers et al. 2007).

While impairments in affective empathy have not been linked to ASD, in recent years cognitive empathy impairments have often been reported (Jones, Happé, Gilbert, Burnett, & Viding, 2010; Rueda, Fernández-Berrocal, & BaronCohen, 2015; Senland & Higgins-D'Alessandro, 2016). It has long been suggested within the medical model that knowledge of empathy in ASD is important and effective treatments should derive from critically examining empathy in the context of clinical characteristics and the mechanisms that cause empathic impairments (Harmsen, 2019). However, recently it has been argued that empathy in ASD has a more complex nature which goes beyond medical model social

deficits. Some have argued that in order to truly understand the nature of empathy in ASD, a social developmental approach is needed (Mitchell, Shepard & Cassidy, 2021).

Researchers have started to approach ASD as a developmental disability which can be positioned within a social context (Mitchell, et al., 2021). In contrast to the medical model assumption about empathy, the social developmental approach to ASD suggests that an individual's development is formed by the types of responses and reactions experienced when interacting with others (Sasson et al., 2017). The social development approach sees the importance in understanding how ASD related behaviours are viewed and understood by others and how these social experiences can impact on social development (Lopez, 2015). Milton (2012) describes how there can often be a breakdown in mutual understanding during social interactions and these breakdowns can contribute to the social difficulties experienced by individuals with ASD. There is a growing body of research suggesting that social communication problems are attributed by a mutual incomprehension during social interactions between individuals with ASD and typically developed peers (Sheppard, Pillai, Wong, Ropar, & Mitchel, 2016; Sasson et al., 2017).

Milton (2012) uses the term "the double empathy problem" to describe a theory that moves away from medical models which are theorised within the fields of cognitive neuroscience and psychology. Rather than deficits in cognitive empathy, the double empathy theory postulates that social interactions between individuals with ASD and typically developed peers are often hindered by misunderstandings due to differing perspectives. According to Milton (2012), individuals with ASD not only find it difficult fitting into society due to misinterpreting others, but they are also often misunderstood themselves. The double empathy problem views empathy as a two-way process which presents differently for individuals with and without ASD. These differences in empathic processing can lead to communication breakdowns and increase unfavourable social experiences for both ASD and typically developed individuals.

In recent years the evidence to support the double empathy hypothesis has started to emerge. For instance, a recent study by Edey and colleagues (2016) investigated how well typically developed individuals could recognise the mental states of individuals with ASD. Researchers created a variation of the task developed by Heider and Simmel (1944) where geometric shapes were used to act out a specific social interaction. Typically developed and ASD participants were video recorded while using the movable shapes to demonstrate four target mental states e.g., coaxing, mocking, seducing and surprising. Recordings were shown to participants, six ASD and six typical animations of each of the

four mental state words were presented. Participants were then asked to make inferences about the mental state being demonstrated. Typically developed and ASD participants had greater accuracy in their inferences when the target was a typical animation. However, individuals with ASD showed no significant differences in assigning the intended mental states to autistic animations or typical animations. Finding partially support the double empathy hypothesis showing that it can also be difficult for typically developed individuals to interpret the actions of individuals with ASD.

It appears that some typically developed individuals may also have problems effectively interpreting real life emotionally expressive behaviours of an individual with ASD. Sheppard et al., (2016) replicated procedures from past research but in a more natural setting with the aim of increasing ecological validity (see Pillai et al., 2012; 2014). In this study, a mixture of typically developed and ASD participants were greeted with a range of behavioural expressions provided by the researcher during their initial meeting e.g., the researcher greeted with either a compliment, a joke, a story relating to the researcher's difficult day, or they were neglected while the researcher was on a personal telephone call. Participants who were greeted were blind to the fact they were being video recorded during this social interaction. Similarly, typically developed participants who were asked to view the videos did not know if they were watching a typically developed or ASD individual being greeted in the videos. Finding show that typically developed individuals had greater accuracy when making an inference about a greeting scenario which included other typically developed individuals. However, in more than one scenario the individuals with ASD were found to be equally expressive when compare to typically developed counterparts, even though they were found to be more difficult to read.

Social biases may also have an impact on the quality of social interactions experienced by individuals with ASD. In a recent study, Sasson et al., (2017) video recorded typically developed and ASD participants separately during a short social interaction. These videos were then later viewed by typically developed observers. Videos were rated on a series of scales relating to social favourability and once again the observers viewing the videos were blind to whether they were watching a typical interaction or and ASD interaction. The researchers found that typically developed observers not only found it harder to read individuals with ASD, but they also reacted with more negative first impressions when viewing videos which included an ASD interaction. Negative first impressions are likely to be noticed by individuals with ASD and this may explain why their experience of social interactions are more challenging.

There also appears to be a further link between the double empathy problem and how typically developed individuals view their ASD counterparts (Alkhalidi, Sheppard, & Mitchell, 2019). To investigate the link between social misunderstandings and unfavourable perception, Alkhalidi and colleagues (2019) used the same video procedure from Sheppard et al., (2016), combined with an adapted version of the social favourability scale used by Sasson et al., (2017). Findings from this study once again show that individuals with ASD are often viewed as less socially favourable when compared to typically developed individuals. Participants with ASD who were seen to be more difficult to interpret were more likely to be rated less socially favourable. Greater awareness and new conceptions of the interactions experienced between typically developed and ASD individuals may provide ways to reduce the mutual misunderstandings that often hinder meaningful social interactions. The double empathy theory suggests that for effective communication, individuals who have similar ways of interacting will better understand each other. It will be important to increase awareness and understanding of ASD within society in order to change the unfavourable impressions which often hinder meaningful social interactions between typically developed and ASD individuals.

While the social development model of ASD provides an alternative viewpoint, more research is greatly needed to identify and understand specific communication mechanisms which foster positive social interactions between typically developed and ASD individuals. Additionally, while the research on double empathy is positioned within a social development model, there is limited evidence to support the double empathy problem in children with ASD or those with comorbid intellectual disability. It is possible that increased awareness in schools over the past decade has led to a greater understanding of ASD and attitudes towards children with ASD maybe more positive than adolescents or adults. Future research in this area may provide more evidence that negative behaviours towards individuals with ASD is learned through experience and not driven by innate differences.

2.4 Comorbid Psychiatric Disorders in Individuals with ASD

Individuals with ASD often experience comorbid psychiatric disorders. Epidemiological studies have suggested that around 25% to 30% of individuals with ASD may experience a psychiatric disorder, with the most common and often in combination, being obsessive compulsive disorder (OCD) and mood disorders, including depressive disorders and anxiety disorders (Howlin & Moss, 2012). A comparative study of psychiatrically referred adults with and without ASD were evaluated on measures assessing psychiatric comorbidity and psychosocial functioning (Joshi et al., 2013). Findings suggest

that adults with ASD have higher levels of psychiatric comorbidity and dysfunction when compared to a clinically referred population of adults without ASD.

Psychiatric comorbidity in adults with ASD is highly recurrent and there is a wide overlap between some psychiatric symptoms and the characteristics of ASD (e.g., Cath et al. 2008). Psychiatric symptoms that share similar features with ASD can complicate accurately detecting comorbid psychiatric disorders (Bakken et al., 2010), or may even obscure ASD symptoms (Dossetor, 2008) which could be a factor when measuring responses to interventions. For example, such overlaps have been reported in studies which compared individuals with ASD and individuals with schizophrenia. Researchers found overlaps in the presentation of symptoms such as motor control, cognitive ability, social communication and social interaction impairments (Each et al., 2013; Konstantareas & Hewitt, 2001; Sheitman, Kraus, Bodfish, & Carmel, 2004 Vannucchi, et al., 2014). Similarly, in a 30-year follow-up study (childhood through adulthood) researchers reported high rates (35%) of comorbid diagnosis of schizophrenic spectrum disorders in patients diagnosed with ASD (Mouridsen, Rich, & Isager, 2008). When considering that individuals with ASD can frequently express auditory hallucinations, delusions, and paranoid ideation, some ASD features may be misconstrued (Dossetor, 2007) and may lead to misdiagnosis.

The rate of anxiety disorders and mood disorders in adults with ASD without ID has been reported to be significantly higher than rates in their typically developed counterparts (Joshi et al., 2013; Lecavalier, 2006). The prevalence rates of anxiety disorders in an ASD without ID population has been estimated to be between 50% and 56% (Lugnegard et al., 2011) and for mood disorders rates have been reported between 53% and 70% (Hofvander et al., 2009). In comparison, anxiety and mood disorders in the general population have much lower rates of between 3% to 12% and 5% to 17%, respectively (Bijl et al., 1998; Jacobi et al., 2004). In a study of adults with ASD without ID, 56% of participants were found to be affected by at least one anxiety disorder and approximately 20% of participants presented with two or more anxiety disorders (Lugnegard et al., 2011). Social anxiety and general anxiety disorders were the most common accounting for 22%, and agoraphobia, panic disorders and OCD represented 15%, 13% and 7%, respectively.

There are also some symptomatologic features of OCD and ASD which seem to overlap considerably. Family history of OCD has been shown to predict higher prevalence and severity of RRBs in individuals with ASD (Hollander, King, Delaney, Smith & Silverman 2003; Abramson et al., 2005). Research suggests that up to 20% of adults experiencing symptoms of OCD also appear to exhibit features of ASD (Bejerot, Nylander

& Lindstrom, 2001; Kushki et al., 2019). It has also been suggested that OCD with comorbid ASD should be recognised as a valid OCD subtype, analogous to OCD with comorbid tics (Bejerot, 2007). In order to provide accurate diagnosis and effective interventions, a greater understanding of comorbid symptomology and their impact on treatment outcomes are essential for tailoring interventions for a broad range of clinical issues (Brookman-Frazer et al., 2018).

2.5 Gender Differences in ASD

It has previously been reported that males are at greater risk of developing ASD than females with male-to-female ratios being reported at a rate of approximate 4-to-1 (Fombonne, 2005) and 3-to-1 respectively (Loomes, Hull, & Mandy, 2017). Research findings suggest that females present with somewhat differing phenotypes than males, although they seem to have the same underlying social communication disorders that are typical in a male ASD population (Kopp, Kelly, & Gillberg, 2010). It has been strongly argued that the current diagnostic criteria may not be sensitive enough to capture the variability in the presentation of symptoms (Gould & Ashton-Smith, 2011), the normative distribution of ASD traits (Constantino & Charman, 2012; Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013) and developmental differences between male and female ASD populations (Lai et al., 2011, Kreiser & White, 2014).

It is important to highlight here that many of the clinical characteristics of ASD have been identified in samples which are mostly male and there may be differences in the way behavioural characteristics are expressed between genders (Dean, 2014). There have been some differences reported in the clinical and behavioural expression of ASD between genders in adulthood. In an investigation of behavioural characteristics in male and female adults with ASD without ID, researchers found that female participants showed more lifetime sensory symptoms, fewer socio-communication difficulties and more self-reported ASD traits than male participants with ASD without ID (Lai et al., 2011). However, males and females did not differ significantly in self-reported empathy, systemising, anxiety, depression, and obsessive-compulsive traits or mentalising performance. Nor did they find differences in the severity of childhood core ASD symptoms which suggests that changes may occur as a result of maturation (Lai et al., 2011). How these characteristic differences may impact on general social functioning and issues such as dealing with psychiatric disorders (e.g., depression) are relatively unclear and are worthy of further investigation.

Under the current DSM-5 criteria, those individuals that do not meet criteria for RRBs are provided with an alternative diagnosis of social communication disorder (APA, 2013). This may be problematic for females acquiring a diagnosis of ASD as there appears to be somewhat of a consensus that one potential rationale for the prevalence discrepancy found between genders is that males typically display more overt or eccentric RRBs than females (Hartley & Sikora, 2009; Van Wijngaarden-Cremers, Van Eeten, Groen, Van Deurzen, Oosterling, & Van der Gaag, 2014; Zwaigenbaum et al., 2012; Mandy, Chilvers, Chowdhury, Salter, Seigal, & Skuse, 2012; Koenig & Tsatsanis, 2005; Kreiser & White, 2014; Rivet & Matson, 2011). While many females with ASD may display RRBs, these may differ from the stereotypical RRBs typically exhibited in a male ASD population (Hull, Mandy, & Petrides, 2017). It has been argued that the current diagnostic criteria for RRBs does not represent the full spectrum of RRB types, and this may result in females not fulfilling the criteria for an ASD diagnosis (Hull et al., 2017; Mandy et al., 2012). The presentation of RRBs in females may be more likely to be viewed as socially acceptable, resulting in the identification and recognition of atypical behaviour more difficult (Kopp & Gillberg, 1992; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Therefore, when considering the gender differences in the presentation of ASD, providing an accurate diagnosis may be more clinically challenging in a female population.

It has been suggested that a more accurate male-to-female ratio is likely to be significantly lower and closer to ratios which have been reported for other neurodevelopmental disorders (Fennell, Eriksson, & Gillberg 2013). Although there is a greater prevalence of males in the adult ASD population, this may simply reflect a greater willingness and ability for females to conform to social norms, while males tend to adopt more eccentric behaviours (Tantum, 2014).

Mattila and colleagues (2007) have proposed that females with ASD may adopt surface level social skills which may help to mask (i.e. hide) their social impairments. This behaviour is also known as the “camouflage” hypothesis which has been defined as the discrepancy between social and interpersonal external behaviours and the individuals actual internal state (Allely, 2019; Lai et al., 2017). Many females with ASD have been shown to have a greater ability to imitate socially acceptable behaviours such as remaining within close proximity during peer interactions (Dean, Harwood, & Kasari, 2017; Ehlers & Gillberg, 1993; Gillberg, 1993; Goldman, 2013; Mattila et al., 2007; Haney, 2016). While such overt behaviours may lead to difficulties in recognising ASD symptoms in females, it does not eliminate the difficulties expressed in their social interactions. For instance,

research has shown that staying close to others (waiting and hovering) is an effective strategy for peer group entry but this does not always relate to social success (Dodge, 2014; Dolgin, 1986), whereas more complex social skills such as knowing when to make positive comments, attempting to create positive reactions and positively reacting to other, have been shown to lead to more cooperative positive social interaction, greater self-control, and greater levels of assertiveness skills (Şenol, & Metin, 2021).

2.6 Age Related Change in ASD

Previous studies which investigated age-related change suggest that the expression of ASD symptoms typically stay stable or become less severe over time (Seltzer et al., 2004; Shattuck et al., 2007; Whitehouse, Coon, Miller, Salisbury & Bishop, 2010; Woodman, Smith, Greenberg, & Marsha, 2015). Over the years several studies have reported significant age-related declines in repetitive behaviours and interests (Chowdhury et al., 2010; EsKensen, Seltzer, Lam, & Bodfish, 2009) and verbal communication impairments (Woodman et al., 2015). In a large longitudinal study (N=242), researchers investigated changes in the ASD symptoms of adolescents and adults with ASD (age range from 10-52 years) and found that on average ASD symptomatology improved over time (Taylor & Seltzer, 2010).

However, most improvements tend to slow down significantly after exiting school (Taylor & Seltzer, 2010). Even though the current research suggests that most individuals with ASD do demonstrate improvements as they age (Seltzer et al., 2004; Shattuck et al., 2007; Whitehouse et al., 2010; Woodman et al., 2015), this is not the case for everyone (Chowdhury et al., 2010; Fecteau et al., 2003; Woodman et al., 2015). Some individuals with ASD have been shown to have persistent or worsening symptoms, in particular, repetitive behaviours and stereotyped interests (Chowdhury et al., 2010; Fecteau et al., 2003) and social reciprocity (Shattuck et al., 2007; Woodman et al., 2015) have been documented to worsen. It is this subset of individuals who are likely to be the most affected by the social demands of adulthood.

2.7 Adulthood Transitions for Individuals with ASD

Impaired social functioning is persistent and pervasive throughout life for many individuals with ASD and is arguably the most defining challenge to overcome during adulthood (Laushey & Heflin, 2000; Tobin, Drager, & Richardson, 2014). There is currently

no 'cure' for ASD and maturation alone does not always improve the social difficulties which affect the outcome of individuals with ASD (Hendrick & Wehman, 2009; Shattuck et al., 2007; Woodman et al., 2015). Social difficulties can continue to persistently impact negatively on important aspects of life and transitioning into adulthood can be a specifically challenging developmental stage (Wehman et al., 2014). As social contexts become more complex and social expectations grow, individuals with ASD may become more vulnerable.

Studies have shown that adolescents and adults with ASD frequently have adaptive functioning skills (the important skills which enable safe and socially responsible living) which are below what would be predicted by their cognitive ability, and the incongruity between adaptive functioning and cognitive function can increase during adulthood (Bolte & Poustka, 2002; Kanne et al., 2011; Klin et al., 2007; Palmen et al., 2012). Impaired social skills have been shown to negatively impact on a number of specific life functions such as maintaining friendships, entering romantic relationships and completing basic daily living activities (Barnhill, 2007; Hendrick & Wehman, 2009; Howlin, 2000; Nordin & Gillberg, 1998).

Building meaningful long-term relationships can often be hampered by characteristics such as expressing a lack of interest towards others, scarce emotional reciprocity or empathy, aversion to physical closeness and excessive self-confidence (Roy, Dillo, Emrich, & Ohlmeier, 2009). Other challenging characteristics found in adults with ASD can include, dull intonation, discussing topics repetitively with difficulties in shifting attention, impaired visual emotional awareness, and difficulties in two-way conversations (Vannucchi, et al., 2014). Adults with ASD without ID are often viewed as eccentric or odd to others as they tend to be overly focused on a particular topic of conversation and frequently demonstrate behaviours which are guided by strict and repetitive routines (Vannucchi et al., 2014).

It has been well established that many individuals with ASD without ID find social interaction and engagement exceptionally difficult (Schall & McDonough, 2010) and it seems that without any form of intervention, specific and non-specific symptoms of ASD may even worsen over time (Kanne et al., 2011; Palmen et al., 2012; Schall & McDonough, 2010). In a longitudinal investigation, researchers found that difficulties with social communication continued to persist well into adulthood (Schall & McDonough, 2010) and core ASD symptoms contribute to more negative outcomes in later life (Shattuck et al., 2012; Tantum, 2014).

Many young adults with ASD without ID find transitioning into adulthood especially difficult as social impairments can often interfere with building interpersonal relationships, vocational and occupational functioning and connecting with others in the community (Hendrick & Wehman, 2009). Research has shown that adults with ASD are more likely to not be married or in a romantic relationship, have a poor education and be economically deprived when compared to the general population (Brugha et al., 2011). Similar findings were reported in a review by Howlin and Moss (2012) which found that many adults with ASD, including those with an average or above average IQ, were significantly disadvantaged in terms of employment, social relationships, physical and mental health, and quality of life.

Individuals with ASD have also been shown to be more vulnerable to bullying and victimisation during childhood and adolescents (Cappadocia, Bebko, Pepler, & Weiss, 2014; Schroeder et al., 2014) and these susceptibilities can continue into adulthood (Tantum, 2014). Rates of bullying and victimisation in youths have been shown to be approximately four times higher for individuals with ASD compared to their typically developing peers (Carter, 2009). A report from the National Autistic Society (2016) in the UK found that nearly half of their survey respondents with workplace experience reported bullying or harassment (48%) or discrimination or unfair treatment (51%) related to their ASD symptoms. Research has shown that exposure to abusive behaviour can increase the risk of suffering from a comorbid mental health disorder and accentuate the effects of ASD symptoms (Schroeder, Cappadocia, et al., 2014; Strang et al., 2012) which likely increases social isolation (Mazurek, 2014).

Loneliness and limited access to social interaction and social experiences are a common problem for adults with ASD (Hickey, Crabtree, & Stott, 2018; Howlin & Moss, 2012; Mazurek, 2014; Taylor & Seltzer, 2011). Muller, Schuler and Yates (2008) found that during adulthood individuals with ASD may start to become more aware of, and hurt by, feelings of social isolation. The authors also reported that for some individuals, as they become older, a heightened awareness of their differences leads to feelings of anxiety and/or depression. A number of the participants in their study reported having only shallow acquaintanceships as opposed to having deep and meaningful friendships. Participants commonly reported that communication difficulties had a major impact on their ability to competently participate in unstructured activities and understanding abstract language such as implied communications, inferences or nonverbal communication. Similar findings were reported in an investigation into employment and post-secondary educational activities for

adults with ASD. Researchers found that participants with ASD without an ID were highly likely to have no daytime activities, suffer social isolation and report poor mental health when compared to individuals with ASD and a comorbid ID (Taylor & Seltzer, 2011). The authors also reported that employment rates of their participants were extremely low, ranging between 4.1% and 11.8% irrespective of whether there was a comorbid ID.

Even when an individual with ASD has a graduate level education they can still face significant employment challenges such as limited employment or no employment at all (Barnhill, 2007; Hendricks & Wehman, 2009; Henninger & Taylor, 2012; Hurlbutt & Chalmers, 2004; Schall et al., 2015; Shattuck et al., 2012). In addition, individuals with ASD who are transitioning into adulthood have lower rates of participation in vocational education and postsecondary education (Shattuck et al., 2012). The outcome research on adults with ASD paints a rather bleak picture and it appears that there is a pronounced need to provide continued support over their lifespan. Many adults with ASD may feel unable to cope with the challenges of adulthood so it is important to provide continued support and develop effective interventions which improve their future outcomes.

Chapter 2: A Systematic PRISMA Review of Manualised Group Social Skills Interventions for Adults with Autism Spectrum Disorder without an Intellectual Disability

1. Introduction

This chapter reviewed the available literature on manualised group social skills interventions (MGSSI) for adults with autism spectrum disorder (ASD) without an intellectual disability (ID). MGSSI are often used for training of social competence skills among individuals with ASD (Gates et al., 2017, Spain & Blainey, 2015). These interventions can be characterised as the group participation of individuals in a therapy session led by one to three therapists, although definitions for optimal treatment intensity and duration have not been established (Reichow, Steiner, & Volkmar, 2012). Intervention trials aim to provide evidence to support the efficacy or effectiveness of intervention in terms of delivery and outcome. Efficacy trials determine whether an intervention produces the expected result under ideal controlled circumstances. Efficacy trials then progress on to trials of effectiveness which measure the degree of beneficial effect under “real world” clinical settings (Godwin et al., 2003; Singal, Higgins, & Waljee, 2014).

Ten studies published in peer-reviewed journals were identified for meeting the inclusion criteria. Amongst the studies reviewed, the majority of participants were young adult males. Each of the interventions reviewed utilised a group format, although there were significant variations in terms of the structure, duration and topics covered. There was also significant heterogeneity amongst the applied procedures and methods of assessment. The findings for this review suggest that there is some evidence to support efficacy of MGSSI for adults with ASD without ID. In addition to a summary of the existing literature, clinical implication and recommendations for future research are discussed.

2. Rationale

Many adults with ASD have a strong motivation to socially interact, but their social impairments can often lead to negative experiences (Howlin & Moss, 2012). Individuals with ASD have an increased risk of severe emotional distress which can have a profound effect on an individual’s quality of life (Kaltiala-Heino, 2010; Kim & Leventhal 2008; Renty, & Roeyers, 2006). Combined, mental health and social impairments often result in social isolation (Hendrick & Wehman, 2009; Tantum, 2014; Howlin & Moss, 2012; Taylor & Seltzer, 2011) and may even lead to suicidal behaviours (Raja, Azzoni, & Frustac 2011; Shtayermman, 2007). Suicidal risk in ASD is a growing concern as research has shown that

adults with ASD attending psychiatric services have a high risk of suicidal behaviour and serious social failures and social isolation are likely contributing factors (Raja et al., 2011).

Even though there is no cure for ASD, interventions have been shown to play an important role in improving social skills in children and adolescents (Reichow et al., 2012; Olsson et al., 2017). A large number of individuals with ASD without ID are often severely affected by rapidly changing social demands as they transition into adulthood. Social impairments often lead to specific negative life issues and it seems that without intervention social challenges are unlikely to diminish (Palmen, Didden, & Lang, 2012; Schall & McDonough, 2010). Due to the broadening of the diagnostic criteria and a greater awareness of ASD, global prevalence rates are increasing and in-turn, the demand for accessible and effective interventions continue to rise (Elsabbagh et al., 2012).

There is some, albeit limited, research to suggest that several of the intervention strategies used for adolescents can extend their utility to adults with ASD (e.g., Gantman et al., 2012; Laugeson et al., 2015). In the only review on group social skills interventions for adults with ASD, five studies were included, and all were considered to be pilot studies (Spain & Blainey, 2015). The review reported a narrative analysis which identified didactic teaching, small and larger group discussions and providing practical tasks as the most promising strategies for teaching social skills to adults with ASD. In addition, analysis indicated that group social skills interventions for adults with ASD may support efficacy for the enhancing of social knowledge and understanding, improving social functioning, reducing loneliness and potentially alleviating co-morbid psychiatric symptoms.

Interventions which aim to improve social impairments usually fall under the category of either a focused intervention or a comprehensive treatment model (Bishop-Fitzpatrick, Minshew & Eack, 2014). Typically, focused interventions are individually driven and target a specific behaviour, skill or goal, whereas comprehensive treatment models are usually developed from a conceptual framework which aims to achieve more extensive improvements on core ASD symptoms (Bishop-Fitzpatrick et al., 2014). Comprehensive group treatment modalities are gaining in popularity and have been employed with some promise in a select few social skills group intervention studies for adults with ASD without ID (Spain & Blainey, 2015).

The benefit of a manualised group social skills intervention is that treatment delivery is not heavily reliant on a specialist doctorate-level clinical psychologist or psychiatrist (LeMay & Wilson, 2007). Health care professionals with less than a doctoral level degree,

or relatively little experience of working with ASD can be proficiently trained to successfully implement manualised interventions (see McVay et al 2016; White et al., 2015). Due to the high financial costs of treatments and the increasing demand on health care services (Buescher et al., 2014), it is increasingly likely that more interventions will need to be facilitated in the community by a range of specialist and non-specialist professionals. These professionals in particular would benefit from the specific guidance offered by evidence based manualised social skills interventions.

Group social skills intervention for individuals with ASD have been the focus of a number of systematic reviews but the results suggesting effectiveness have been somewhat mixed (Cappadocia & Weiss, 2011; Rao, Beidel, & Murray 2008; Spain & Blainey, 2015; White, Keonig, & Scahill, 2007). A comparison of studies can be difficult as interventions tend to focus on a wide range of targeted social skills and studies often significantly differ in terms of design, structure, remit and assessment (Miller et al., 2014; Spain & Blainey, 2015). The potential benefits of MGSSI are to some degree unknown in adults with ASD and further investigation is greatly needed to strengthen the evidence-base to support efficacy. However, due to the limited amount of intervention research conducted on adult with ASD, there is a lack of standardised measure for this population. The development of sensitive measures to demonstrate changes in core ASD symptoms in an adult population is crucial (Herbrecht, Lazari, Notter, Schmeck, & Spiegel, 2019). The assessment of ASD-specific interventions for adults presents a rather large problem for testing the efficacy of a given social skills intervention. Many of the standardised measures that are used for measuring ASD symptoms were not designed for use with adults, demonstrate differences in interpretation of DSM-5 criteria and were not developed to be sensitive to change (Brugha, Doos, Tempier, Einfield, & Howlin, 2015, Evers et al., 2020).

Numerous assessment tools used to measure the responses to interventions often rely on the participants' perception (e.g., self-report questionnaires) of symptoms change. As social communication difficulties are at the core of ASD and emotional recognition and understanding is often impaired, the reliance on questionnaire measures alone may not provide an accurate representation of improvements. Some studies which assess children and adolescents with ASD have controlled for such limitations by using standardised informant-based assessments of ASD symptoms (e.g., The Autism Diagnostic Interview-Revised; Rutter et al., 2003). These assessments are based on parental information, however some adults, in particular those living alone, may find it difficult to include a family member or friend knowledgeable enough to provide reliable responses. Due to the lack of

standardised assessment measures for an adult ASD population, current recommendations for regular clinical practise need to be considered with caution (Brugha et al., 2015).

Currently, there is a growing demand on health care services to provide accessible, financially viable, effective treatments to those with ASD struggling to transition and function in adulthood. A systematic review following PRISMA guidelines (PRISMA; Preferred Reporting Items for Systematic Reviews and Meta-analysis, Moher, Liberati, Tetzlaff, & Altman, 2008) was undertaken to qualitatively summarise and synthesise the available information from the research literature on manualised group social skills interventions for adults with ASD without ID.

2.1 Research Aims and Objectives

The objective of this review was to examine and evaluate the studies which utilised a MGSSI for adults with ASD without ID. There was a further aim to elucidate the specific components of MGSSI which could be adapted for use within the CBSCTI-ASD manual.

2.2 Variables Examined

- Population size and participant characteristics in each of the intervention studies.
- Identify study design.
- Outcome measures
- Characteristics of each manualised group social skills interventions
- The reported results of each outcome measure.

3. Method

3.1 Screening process

A single reviewer independently screened all samples of records. The reviewer attempted to retrieve the full text of all records which met the inclusion criteria at the title and abstract stage. Any articles which were unclear whether they met criteria went to further review by two project supervisors who reviewed full-text articles. Differences were resolved by discussion until a consensus was reached.

3.2 Eligibility Criteria

Peer review journal articles that utilise a MGSSI in ASD without ID population.

Participants were adults over the age of 17 years. Articles which report quantitative outcome data from baseline to endpoint. The intervention includes an intervention group which consists of more than three participants.

3.3 Information Sources

The following databases were initially searched on July 9th 2018: Journals@Ovid Full Text July 9th 2018 , PsycArticles Full Text, AMED (Allied and Complementary Medicine) 1985 to July 2018, HMIC Health Management Information Consortium 1979 to July 2018, PsycINFO 1806 to July Week 1 2018, Ovid MEDLINE(R) 1946 to Present and Epub Ahead of Print, In- Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily.

An updated search was run on September 22nd 2020, however exact replication of the original search could not be carried out due to the removal of Allied and Complementary Medicine and Health Management Information Consortium databases within the Ovid search options. Since the search could not be replicated to accurately update the original search, a new full literature search was run on the following available databases: Journals@Ovid Full Text, APA PsycExtra 1908 to September 22, 2020, APA PsycInfo 1806 to September Week 4 2020, Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to October 01, 2020. All articles returned from the search run on September 22nd 2020 were screened. Book chapters, reference lists, previous reviews and meta- analysis were also examined, and only original articles were used. Journal articles that were published or translated in English were exclusively included in this review.

3.4 Search Terms

Numerous permutations of the search terms on GoogleScholar and an electronic database search strategy were carried out based on article titles and abstracts using the following search terms:

["autis* spectrum condition*" or "autis* spectrum disorder*" or "autis*" or "asperger*" or "pervasive development disorder*" or "high-functioning autis*" or "ASD" or "hfASD"] AND ["social" or "social skill*" or "social skill* development" or "social behavio*" or "social interaction*" or "social skill*" or "social interact*" or "social-communicative" or "social cogniti*" or "social and commun*" or "social and commun* development" or "social adjustment" or "social-emotional understanding"

or "social problem solving" or "social competence" or "social conversation"] AND
 ["therapy" or "intervention*" or "training" or "treatment*"] AND ["adult*"]

3.5 Records Through Other Sources

There were a total of four records identified by a hand search of past reviews and reference sections.

3.6 Study Selection

Article titles were examined in the first stage of screening. Articles were excluded that were noticeably:

- Not published or translated in English.
- Not a social skills intervention for ASD.
- Not a peer reviewed journal article.

In the subsequent stage, titles and abstracts of articles were thoroughly screened. Articles were excluded at this stage that were not:

- A social skills intervention study which adhered to a manual.
- An adult ASD without ID population (subject age ≥ 17).
- A group modality.
- A research design which measured improvements in social competencies.

In addition, at this stage review papers and book chapters were excluded.

3.7 Data Collection Process

The Data Collection Form, Intervention review – RCTs and non-RCTs (Cochrane Collaboration; Effective Practice and Organization of Care, 2013) was adapted and refined according to the needs of this review.

Data Items:

Each of the following items were assessed:

- Study design

- Participants demographics
- Characteristics of group facilitators
- Characteristics of each intervention
- Outcome measures used to assess change for each group
- Reported results
- Follow-up data

3.8 Risk of Bias

The Cochrane risk of bias tool (Higgins et al., 2011) was used for assessing the quality of research. Initially two reviewers independently completed the risk of bias report. Results were compared and any differences were discussed until a consensus agreement was reached. The Cochrane risk of bias tool covers the following five domains: selection bias, performance bias, detection bias, attrition bias, and reporting bias.

3.8.1 Random Sequence Generation

Selection bias was assessed by examining group allocation randomisation. A judgement of: 'low risk' was provided if the participants were allocated to a group using randomisation sequencing; 'unclear' was provided if the randomisation methods were not clearly specified; 'high risk' was given when randomisation was not carried out due to the study design.

3.8.2 Allocation Concealment

Allocation sequence concealment secures strict implementation of the allocation sequence without the knowledge of group assignments. A judgement of 'low risk' was given when participants and researchers were unaware of participants allocation in each condition until after decisions about eligibility were made and informed consent was obtained; Judgement of 'unclear' was provided when allocation concealment was not clearly stated or unknown; 'high risk' when allocation was not concealed from either participants before informed consent or from researchers before decisions about inclusion were made or allocation concealment was not used.

3.8.3 Incomplete Outcome Data

Incomplete data was assessed based on the inclusiveness of the authors reporting of reasons for any missing data. A judgement of: 'low risk' was given when all participants completed the group condition in all participant groups and where data was missing, justification was clearly given; 'unclear' was given when information about which participants completed the study was not clearly stated; 'high risk' when there is clear evidence that there was attrition or exclusion from analysis in at least one participant group without justification.

3.8.4 Blinding of Outcome Assessment

Performance bias was assessed by investigating if participants and outcome assessors were blind to group and condition during assessments. A judgement of: 'low risk' was given when participants performance on outcomes were measured prior to the intervention and assessors were reported to be blind to the group and assessment condition. A judgment of 'unclear' was given when no baseline outcome measure was reported or blinding of conditions/time were not clearly reported; 'high risk' was given when significant differences exist at baseline and no blinding of assessor or participants were reported.

3.8.5 Selective Reporting Bias

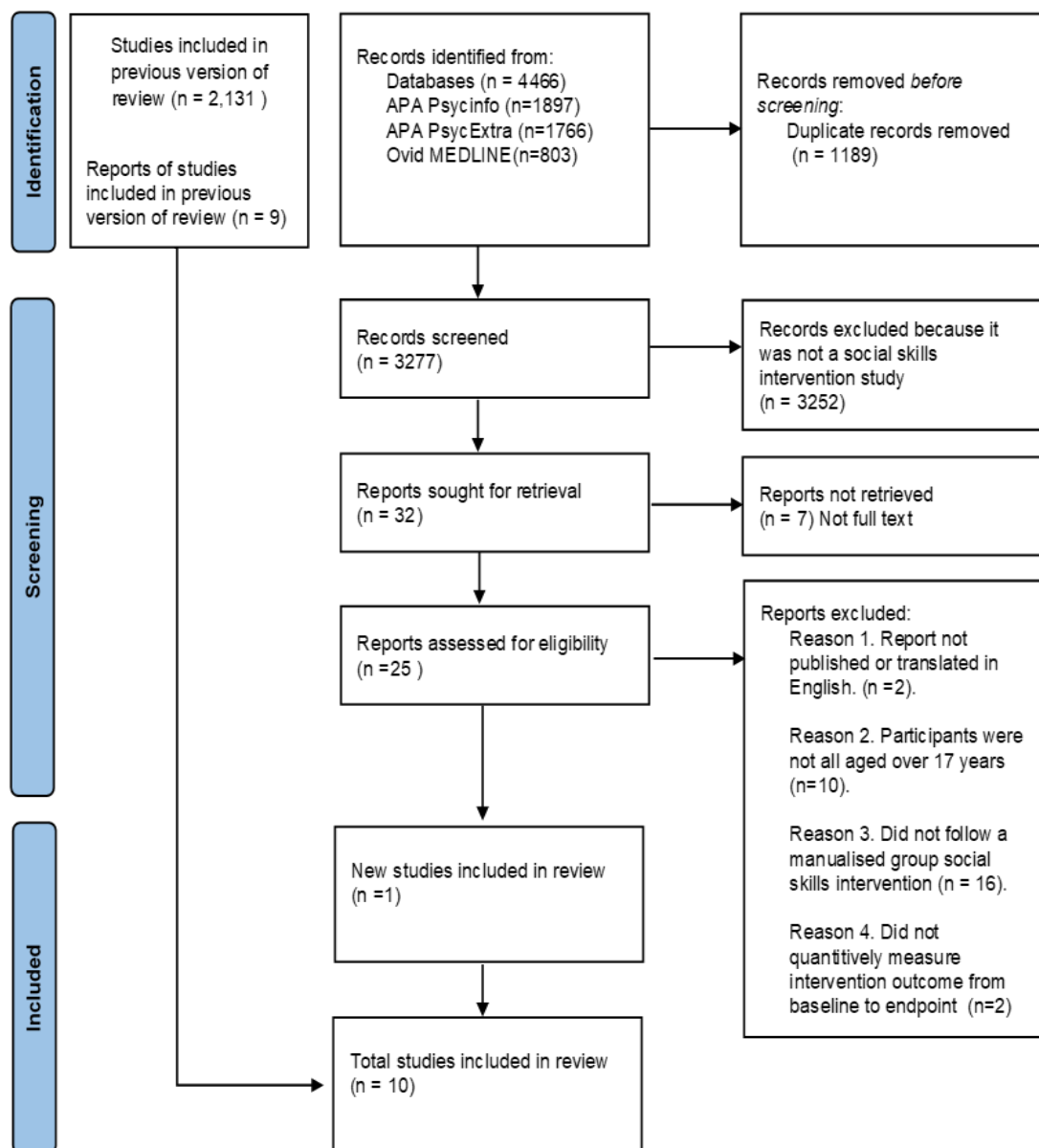
This was assessed by examining the probability that the authors of the study omitted some of the collected data when presenting the results. The following judgements were based on a comparison of the measures described in the methods section of each study and the measures on which data was reported in the results section of the study. A judgment of 'low risk' was given when total collected data appears to have been reported and all expected outcome measures were reported; 'unclear' was given when it is not clear if additional data was collected and not reported; 'high risk' was given when the data from some measures used in the study were not reported or when expected primary outcome measures were not reported.

4. Results

4.1 Study Selection

A total of 10 studies, involving seven separate social skills interventions were identified as meeting the inclusion criteria. Using a comprehensive list of terms, the search returned 4,466 results. After adjusting for duplicate results, 3,277 remained. Following the screening of titles and abstracts, the remaining studies, a further 3,252 studies were excluded as they clearly did not meet all inclusion criteria. The full text of the remaining 25 studies were examined in detail. A further 15 studies were excluded as they did not meet the following criteria: they did not employ a manualised social skills group intervention; They did not measure intervention effects from baseline to endpoint or the sample included participants under 17 years of age. The remaining 10 studies met all criteria and were included in this review (see Figure 1).

Figure 1 Study selection PRISMA diagram



4.2 Design

Out of the 10 studies included in this review, five were described as randomised controlled trials (RCT), four adopted a pre-test post-test design and there was one quasi-experimental study (see Table 2). In the single study that utilised a quasi-experimental design, the authors acknowledge an original intention to implement a RCT, however two participants requested to be allocated to the control group which resulted in a non-randomized controlled trial (Turner-Brown et al., 2008). Overall, five studies compared the

intervention group with a control group. Four studies compared the intervention group to a delayed treatment control group (Gantman et al., 2012; Laugeson et al., 2015, McVay et al., 2016; Oswald et al., 2018), one study compared the intervention group to a treatment-as-usual (TAU) control group (Turner-Brown et al., 2008), and one study (Ashman et al., 2017) compared the social skills intervention group to an intervention control group (e.g. social interaction group) with no specific or explicit social skills training but rather an emphasis on allowing natural social interactions between participants.

4.3 Participants

For participant demographic details see Table 2. Across the 10 studies there were a total of 238 participants. Most participants were young male adults. Ages of participants ranged from 17-61 years with a mean age of 22.2 years. All participants had been previously diagnosed with ASD by a qualified professional. All studies utilised a validated IQ test to eliminate the possibility of intellectual disability. No study utilised a validated clinician-administered measures to establish co-morbid mental health disorders. However, one study did utilise self-report questionnaires to examine expressions of social anxiety (see McVay et al., 2016).

4.4 Measures

There was considerable heterogeneity in the measures used for assessment across all studies reviewed (see Table 2). No study reported the blinding of participants and personnel or the blinding of outcome assessments. Questionnaire scales were the most widely used primary outcome measure and were administered to participants as a self-report or to individuals that were well known to the participants. The Social Responsiveness Scales (SRS; Constantino 2005; SRS-2; Constantino & Gruber, 2012) was the most widely used instruments across studies and was used as primary outcome measure in half of the studies reviewed (Ashman et al., 2017; Gantman et al., 2012; Hartmann et al., 2019; Laugeson et al., 2015; McVay et al., 2016) but only one study (Ashman et al., 2017) used the validated adult version of the SRS (SRS-2; Constantino & Gruber, 2012). Other modes of assessment included tests of social cognition e.g. The Reading the Mind in Eyes test (Baron-Cohen et al., 2001) and observer-rated behavioural assessments e.g. the Contextual Assessment of Social Skills (CASS; Ratto, Turner-Brown, Rupp, Mesibov, & Penn, 2011). No study utilised detailed interviews or observational diagnostic instruments as an outcome measure.

Standardised and non-standardised clinical screening instruments for individuals with ASD were used across studies to assess participant inclusion (see Table 3). Social impairment within the autism spectrum (e.g., SRS-2) and ASD symptom severity (e.g., Autism Spectrum Quotient; Baron Cohen et al., 2001) were frequently used for a global assessment of social impairment. Other popular instruments measured more specific impairments such as empathy (e.g., Empathy Quotient; Baron Cohen et al., 2001) and social cognition (e.g., The Hinting Task; Corcoran et al., 1995). Although limited, some instruments were used to measure quality of life (e.g., Social and Emotional Loneliness Scale for Adults; DiTommaso & Spinner, 1993), and mental health symptom severity (e.g., Beck Depression Inventory; Beck et al., 1996).

Table 2 Study characteristics

Study	Participants	Intervention/Control	Outcome measures	Results
Ashman et al., 2017	Adults with ASD Gender Males n=13 Females n=6 Mean Age	I- Structured social skills training group C- Non-specific social interaction group	- RME (Baron-Cohen et al., 2001) - RMV (Rutherford et al, 2002) - SRS-2 (Constantino & Gruber, 2012) - WFIRS-S (Weiss & Weiss, 2004)	At post testing both the Treatment Group (TG) and the Intervention Control Group (ICG) demonstrated significant improvements on RME. Analysis of SRS-2 informant rated data indicated that participants demonstrated significantly improved social responsiveness in both groups. There were no significant differences found between the TG and the ICG.
Design RCT	Intervention group = 36.1 years Comparison group = 31.78 years			
Gantman et al., 2012	Adults with ASD Gender Males n=12 Females n=5 Mean Age	I- PEERS treatment for young adults C- Delayed treatment group	- EQ (Baron-Cohen & Wheelwright, 2004). - SELSA (DiTommaso & Spinner, 1993) - SSI (Riggio, 1989). - SRS (Constantino, 2005) - SSRS (Gresham & Elliott 1990). - QSQ (Adapted from Frankel et al., 2010).	At post testing the TG improved significantly over the Delayed Treatment Control (DTC) group in social and emotional loneliness as measured by the SELSA. Participants significantly improved their knowledge of social skills as measured by the TYASSK post treatment. Informant reports of TG social functioning showed significant improvements for social responsiveness as measured by the SRS Total score. The TG also significantly improved in social skills as measure by the SSRS and empathising as measured by the EQ.
Design RCT	Intervention group = 19.9 years Comparison group = 20.9 years			

Table 2 *Continued*

Study	Participants	Intervention/control	Outcome measures	Summary of findings
Hartmann et al., 2019	Adults with ASD Gender Males n=4 Females Design n=3 PP Mean Age 21 years	I- Manualised DBT group intervention C- No control group	- SRS-2 (Constantino & Gruber, 2012) - ERQ (Gross & John, 2003) - SPAI-23 (Roberson-Nay et al., 2007) - BPAQ (Buss & Perry, 1992)	There were significant improvements reported on subscales of the SRS in social communication, social interaction, social awareness and social cognition. No significant changes were found measures of the ERQ, BPAQ, or SPAI-23.
Hillier et al., 2007	Adults with ASD Gender Males n=11 Females n=2 Design PP Mean age 19 years	I- Aspiration group intervention C- No control group	- IPR (Hudson, 1982). - AQ (Baron-Cohen, et al., 2001). - EQ (Baron-Cohen & Wheelwright, 2004)	Participant scores on the modified EQ demonstrate significant improvements post treatment.

Table 2 Continued

Study	Participants	Intervention/Control	Outcome measures	Summary of findings
Hillier et al., 2011	Adults with ASD Gender Males n=42 Females n=7 Mean Age 21 years	I- Aspiration group intervention C- No control group	- BDI-II (Beck et al., 1996) - IPR (Hudson, 1992) - STAI (Spielberger et al., 1983)	Participants demonstrated significant reductions in anxiety post treatment on the STAI. Participants reported a significant reduction in depression post treatment on the Becks Depression Inventory-II.
Design PP				
Laugeson et al., 2015	Adults with ASD Gender Males n=17 Females n=5 Mean Age Intervention group = 21 years Comparison group = 19.7 years	I- PEERS treatment for young adults C- Delayed treatment group	- EQ (Baron-Cohen & Wheelwright, 2004). - SRS (Constantino, 2005) - SSRS (Gresham & Elliott, 1990). - TYASSK (Laugeson & Frankel, 2010). - QSQ (Laugeson & Frankel, 2010).	At post testing, knowledge of social skills on TYASSK significantly increased in the TG. The TG demonstrated a significant increase in monthly get-togethers on QSQ. Informant reports of social functioning showed significant improvements in the TG over the DTC group for social responsiveness on SRS. Improvements were reported in the TG over the DTC group in overall social skills on SSRS. Follow-up analyses indicate that treatment gains were maintained for all outcome measures except for QSQ hosted get-togethers and the SSRS Co-operation subscale.
Design RCT				

Table 2 Continued

Study	Participants	Intervention/Control	Outcome measures	Summary of findings
McVay et al., 2016	Adults with ASD Gender Males n= 47 Females n=9 Mean Age	I- PEERS treatment group C- Delayed treatment group	-EQ (Baron-Cohen & Wheelwright, 2004). -LSAS-SR (Fresco et al., 2001) -SELSA (DiTommaso & Spinner 1993) -SPIN (Connor et al., 2000). -SRS (Constantino, 2005) -SSIS-RS (Gresham & Elliott, 2008), -QSQ (Adapted from Frankel et al., 2010).	At post testing, the TG demonstrated significant improvements over the DTC group in Social Skills and Social Responsiveness on the SSIS-RS, SRS, Social skills knowledge on TYASSK, empathy on EQ, and Direct Social Interaction on QSQ-YA. The treatment group also demonstrated significant improvement in expressions of social anxiety on LSAS-SR.
Design RCT	Intervention group = 20.9 Comparison Group = 19.5			
Turner-Brown et al., 2008	Adults with ASD Gender Males n=10 Females n=1 Mean Age	I- SCIT treatment group C- Treatment as usual group	-FEIT (Kerr & Neale, 1993). -The Hinting Task (Corcoran et al., 1995) -SCSQ (McGann et al., 1997). -SSPA (Patterson et al., 2001).	At post testing, FEAT scores show that the TG significantly improved in emotional perception over the Treatment as Usual (TAU) group. The Hinting task score shows that the TG significantly improved in Theory of Mind skills over the TAU group.
Design QE	Intervention group 42.5 years Comparison Group 28.8 years			

Table 2 Continued

Study	Participants	Intervention/Control	Outcome measures	Summary of findings
Oswald et al., 2018	Adults with ASD Gender Males n=31 Females n=13 Mean age Intervention group = 24.9 years Comparison group = 25.5 years	I-ACCESS treatment group C-Delayed treatment group	-ABAS-3 (Harrison & Oakland, 2015). -ASR (Achenbach & Rescorla, 2003). -Seven Component Self Determination Skills Survey (Carter et al., 2013b). -CSES (Chesney et al., 2006).	At post testing, informant rated improvements on the ABAS-3 were significant in global adaptive functioning and self-determination in the TG when compared to DTC. Participants in the TG self-reported a significantly higher belief in their ability to cope with stress by seeking social support at post treatment.
White et al., 2015	Adults with ASD Gender Males n=5 Mean age 24.9 years	PEERS treatment group = 24.9 years	-CASS (Ratto et al., 2011).	Improvements were reported on Asking Questions sub-scale, the Topic Changes sub-scale, overall Involvement, overall Quality of Rapport sub-scale, Gestures sub-scale, Vocal Expressiveness sub-scale and the Social Adaptation Index of CASS.
	Design PP			

Key: Study design: PP-pre/post-test; RCT-randomised controlled trials; QE-quasi experimental. I-Intervention group; C-Control group. Outcome measures: ABAS-3-Adaptive Behavior Assessment System Adult Form, Third Edition; ASR-ASEBA Adult Self-Report; AQ-Autism Spectrum Quotient; BDI-II-Beck Depression Inventory; BPAQ- The Buss and Perry Aggression Questionnaire; CASS-Contextual Assessment of Social Skills; CSES-Coping Self-Efficacy Scale; EQ- Empathy Quotient; ERQ- Emotion Regulation Questionnaire; FEIT-Face Emotion Identification Test; IPR-Index of Peer Relations; LSAS-SR -Liebowitz Social Anxiety Scale-Self-Report; QSQ-Quality of Socialization Questionnaire; RME-Reading the Mind in Eyes test; RMV-Reading the Mind in the Voice' task; SCSQ-Social Communication Skills Questionnaire; SELSA-Social and Emotional Loneliness Scale for Adults; SPIA-The Social Phobia and Anxiety Inventory; SPIN-Social Phobia Inventory; SRS-Social Responsiveness Scale; SRS-2-Social Responsiveness Scale 2nd edition; SSIS-R-Social Skills Improvement System Rating Scales; SSI-Social Skills Inventory; SSPA-The Social Skills Performance Assessment; SSRS-Social Skills Rating System; STAI-State-Trait Anxiety Inventory; TYASSK-Test of Young Adult Social Skills Knowledge; WFIRS-S-Weiss Functional Impairment Rating Scale Self-Report

Table 3 *Screening instruments*

Study	ASD Screening Instruments	IQ Screening instrument (cut off score)
Ashman et al., 2017	Clinical diagnosis not supported by assessment within study	WAIS verbal (IQ \geq 70) Full-scale IQ: Mean = 109.0 (TG) 103.6 (ICG)
Gantman et al., 2012	Clinical diagnosis supported by the AQ	KBIT-2 (IQ \geq 70) Full-scale IQ: Mean = 97 (TG) 109 (DTC)
Hartmann et al., 2019	Clinical diagnosis supported by the ADOS-2	WAIS-II (IQ \geq 80) Full-scale IQ Mean = 99
Hillier et al., 2007	Clinical diagnosis supported by GADS	WAIS (Cut off score not reported) Full-scale IQ: Mean = 109

Table 3 *Continued*

Study	ASD Screening Instruments	IQ Screening instrument (cut off score)
Hillier et al., 2011	Clinical diagnosis not supported by assessment within study	No standardised IQ administered. IQ scores were used for those with available IQ data. Full-scale IQ: Mean = 99
Laugeson et al., 2015	Clinical diagnosis supported by the AQ	KBIT-2 (IQ >70) Full-scale IQ: Mean = 107 (TG) 102 (DTC)
McVay et al., 2016	Clinical diagnosis support by the ADOS	KBIT-2 (IQ ≥ 70) Verbal-scale IQ: Mean = 93 (TG) 91 (DTC)
Turner- Brown et al., 2008	Clinical diagnosis support by the ADOS	WAIS (Cut off not reported) Full-scale IQ: Mean = 113 (TG) 111 (TAU)

Table 3 *Continued*

Study	ASD Screening Instruments	IQ Screening instrument (cut off score)
Oswald et al., 2018	Clinical diagnosis supported by DSM-5 checklist and the ADOS-2	WAIS-II (IQ \geq 70) Full-scale IQ: Mean = 101 (TG) 103 (DTC)
White et al., 2015	Clinical diagnosis supported by SRS-2	KBIT-2 (Cut off score not reported) Full-scale IQ: Mean = 92

Key: ADOS/ADOS-2-Autism Diagnostic Observation Schedule (Lord et al., 2000; 2012); AQ-Autism Spectrum Quotient (Baron-Cohen et al., 2001); DSM-5-Diagnostic and Statistical Manual 5th ed. (APA, 2013); GADS-Gillam Asperger's Disorder Scale (Gillam, 2001); KBIT-2 Kaufman Brief Intelligence Test-Second Edition (Kaufman & Kaufman 2005); SRS 2nd ed.-Social Responsiveness Scale (Constantino & Gruber, 2012); WAIS/WAIS-II- Wechsler Adult Intelligence Scale/ Wechsler Abbreviated Scale of Intelligence-Second Edition (Wechsler, 1997; Wechsler & Zhou 2011)

4.5 Facilitators

Five of the 10 studies which met the inclusion criteria included one or more doctoral level psychologists to facilitate social skills groups (e.g., Gantman et al., 2012; Hartmann et al., 2019; Hillier et al., 2011; Laugeson et al., 2015; Turner-Brown et al., 2008). Five of the studies used one or more graduate or undergraduate psychology student research assistants to either facilitate or assist in facilitating groups (Gantman et al., 2012; Hillier et al., 2011; Laugeson et al., 2015; McVay et al., 2016; White et al., 2015). Only one intervention was designed to require a single group facilitator (an assistant psychologist), although sessions were video recorded for the purpose of supervision by a doctorate level clinical psychologist (Ashman et al., 2017).

There were also variations between the personnel facilitating the social skills groups in the Aspirations intervention studies and the *PEERS* intervention studies. In two studies, a clinical psychologist, a post-doctoral psychology fellow and a number of research assistants (graduate or undergraduate psychology students) facilitated groups (Gantman et al., 2012; Laugeson et al., 2015). In contrast, one study utilised two graduate student clinicians to facilitate groups, although they were supervised by two clinical psychologists trained in the delivery of *PEERS* by the developer of the intervention (White et al., 2015). McVay and colleagues (2016) trained six graduate students in a clinical psychology doctoral program to lead the groups. Training and supervision were provided to the six students by the principle investigator who had a postgraduate degree in clinical psychology and attended training to become a certified *PEERS* instructor. Likewise, in an early trial of the Aspirations program, groups were facilitated by personnel with graduate degrees and experience in managing social skills support groups (Hillier et al., 2007). In a later trial, groups were facilitated by a doctoral level psychologist, a graduate student and undergraduate student (Hillier et al., 2011).

4.6 Intervention

In total, six group social skills interventions were included in this review. All interventions were manualised, however they differed in terms of structure, duration, technique, and curriculum. For more details see Table 3.

4.7 Structure

Intervention group sizes varied across studies. Group sizes were as few as five and as large as 14 participants per group. While MGSSI typically make use of didactic instruction from a trained clinician to teach social skills (e.g. Ashman et al., 2017; Gantman et al., 2012; Laugeson et al., 2015; McVay et al., 2016; Turner-Brown et al., 2008), one program employed a group directed approach where the clinician was instructed to simply facilitate the sessions by keeping the participants on topic (Hillier et al., 2007, 2011).

4.8 Frequency and Duration

Social skills groups were arranged to meet weekly, however the length of each session varied between intervention programs with durations ranging between 50-90 minutes per session. Interventions ranged widely from 8 to 19 weeks with total treatment time ranging from 8 to 28.5 hours.

4.9 Techniques and Curriculum

Manualised interventions were structured and included various techniques and curriculums which covered several topics (see Table 3). Commonly used techniques included providing psychoeducation, interactive tasks, role-play, social problem-solving, group discussions and homework tasks to be completed between sessions. More novel techniques included adopting a support group approach where the members led the sessions (Hillier et al., 2007; 2011), video evaluations conducted by group members (Turner-Brown et al., 2008), group activities using photographs (Ashman et al., 2017) and the facilitation of concurrent parent/caretaker groups which aim to provide participants social support and monitoring outside the confines of the group setting (Gantman et al., 2012; Laugeson et al., 2015; McVay et al., 2016; White et al., 2015).

Curriculums varied to some degree between MGSSI, with each program including unique topics. For instance, the Aspirations program curriculum heavily focused on improving social functioning and included vocational and social skills topics such as employment, independence and university life (Hillier et al., 2007, 2011). The DBT group intervention utilised in-vivo exposure to address social and emotional competencies (Hartmann et al., 2019). Social functioning was more broadly addressed in the *PEERS* intervention for young adult's (Laugeson, 2017) which included social relationship topics

such as electronic communication with others, avoiding exploitation, conflict management, employment skills and dating.

Table 4 *Intervention characteristics*

Intervention	Duration	Training Techniques	Curriculum
Name: Social Skills Intervention (Ashman et al., 2017) Group size: 10	60 minutes group sessions 1x/weekly for 16 weeks	Techniques included psychoeducation, problem solving, group activities, role-play, group discussions and homework.	Topics included, defining social skills, theories of ASD, emotional recognition and responding, language and communication, family, friendships, employment and dating.
Name: Program for the Education and Enrichment of Relational Skills for young adults (Laugeson et al, 2017). Group size: 5-10	90 minutes group sessions 1x/weekly for 14 weeks	Techniques included didactic lessons, Socratic questioning, role-play demonstrations, social cognitive strategies (e.g. social perception questioning, perspective taking questions, & social problem solving), behavioral rehearsal exercises, performance feedback, homework and caretaker involvement.	Curriculum included topics on conversation skills, electronic communication, developing and maintaining friendships, appropriate humour, peer entry and exit strategies, managing teasing, feedback and peer rejection, avoiding exploitation, managing disagreements, employment and dating.
Adapted Dialectical Behaviour Therapy (Hartmann et al., 2019)	90 minutes group sessions 1x/weekly for 12 weeks	Techniques included didactic instructions, mindfulness exercises, handouts and worksheets based DBT and CBT approaches revised for ASD, imagined and in vivo exposure situations and use of videos	Topics included emotion regulation, anxiety feelings, coping strategies, distraction skills, self-soothing skills, and physical anger management skills

Table 4 *Continued*

Intervention	Duration	Technique	Curriculum
Aspirations Social and Vocational Skills Program (Hillier et al., 2007; 2011). Group size: 5-7	60 minutes 1x/weekly for 8 weeks	Techniques included a group design directed by the group members with the facilitators guiding the discussion and ensuring participants remained on topic. Intervention methods included group lead discussion and group problem solving.	Curriculum included topics on social communication, relationships, social event, independent living, independence and university, employment, and conclusion and topic reviews.
The Acquiring Career, Coping, Executive control, Social Skills Program (Oswald et al., 2018). Group size: 14	90 minutes 1x/weekly for 19 weeks	Techniques included psychoeducation, cognitive restructuring, and behavioural activation: reviews of the previous week topic and homework, presentation and group discussion, role-plays, small group activities and caretaker involvement	Curriculum included four modules: Introduction and Core Skills for Group Work, Stress and Anxiety Coping Skills, Self-Determination Skills and Adaptive and Social Skills.
Social Cognition and Interaction Training (Turner-Brown et al., 2008). Group size: 6-8	50 minutes 1x/weekly for 18 weeks	Techniques included concept instruction, group discussion, response identification, role-play, skills practice and homework.	Curriculum- focused on three phases which included: emotions training, understanding situations and social integration

4.10 Risk of Bias Report

Five RCTs and one non-randomised control trial in this review were eligible for risk of bias assessment (see Table 5). Across studies selection bias was low risk except for one quasi experimental trial which had more than one participant request to be reallocated to the control condition after randomisation had been completed (Turner-Brown et al., 2008). Randomisation was completed after baseline assessments across all studies. One study used a random number generator to allocate participants (Ashman et al., 2017), three used a flip of the coin method (Gantman et al., 2012; Laugenson et al., 2015; McVay et al., 2016) and two did not specify the randomisation strategy.

The lack of blinding of outcome of participants, personnel and outcome assessors was rated 'high risk' for five studies apart from Turner-Brown et al (2008) which was deemed unclear. In all of the studies reviewed, key personnel were involved in the final assessment of outcomes. Incomplete data criteria were rated 'low risk' in only two (Ashman et al., 2017; Gantman et al., 2012) out of the six studies. Incomplete data was due to participant attrition in one or both groups or conditions. Across all six studies the most common missing data were self-reports. No studies reported differences at baseline, and all collected data appears to have been reported. Although still at risk of detection bias, Ashman et al., (2017) and Gantman et al., (2015) appear to have the lowest overall risk of bias across the studies reviewed.

Table 5 *Risk of bias report for randomised and non-randomised trials*

Included studies	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Baseline assessment
Ashman et al., 2017	Low risk	Low risk	High risk	High risk	Low risk	Low risk	Low risk
Gantman et al., 2012	Low risk	Unclear	High risk	High risk	Low risk	Low risk	Low risk
Laugeson et al., 2015	Low risk	Low risk	High risk	High risk	High risk	Low risk	Low risk
McVay et al., 2016	Low risk	Low risk	High risk	High risk	High risk	Low risk	Low risk
Turner- Brown et al., 2008	High risk	High risk	Unclear risk	High risk	High risk	Low risk	Low risk
Oswald et al., 2018	Low risk	Low risk	High risk	High risk	High risk	Low risk	Low risk

4.11 Efficacy of Interventions

Improvements varied across interventions and there was considerable variability in the outcome measures used, making a direct comparison of findings difficult. Additionally, the technical approach and topic focus of each manualised curriculum varied, further limiting any possibility of a direct comparison of findings between intervention studies. For this reason, the findings of each study will be qualitatively described based on their respective reported results.

Four studies evaluated the *PEERS* intervention within clinical and community settings and all were found to be effective in improving social skills in an adult ASD population (Gantman et al., 2012; Laugeson et al., 2015; McVay et al., 2016; White et al., 2015). Three of these studies reported improvements in social skills knowledge, improvements in overall social skills, increased empathy, frequency of get-togethers, improvements in ASD symptoms related to social responsiveness, reduced social anxiety and reduced loneliness (Gantman et al., 2012; Laugeson et al., 2015; McVay et al., 2016). Only one study reported follow-up data which suggests the original gains were maintained at 16-week follow-up assessments (Laugeson et al., 2015).

Dialectical behavioural therapy (DBT) and CBT informed group intervention was adapted for improving emotional regulation and social communication in young adults with ASD without ID (Hartmann et al., 2019). At a group level significant improvement were found in social communication and interaction, social awareness (AWR) and social cognition (COG). Individual results indicate that three group participants improved on AWR, two improved on COG, one improved on social communication, five improved social motivation, four improved on RRBs, three improved on verbal aggression, one improved levels of hostility. three participants improved suppression and two improved in reappraisals.

A pilot randomised controlled trial by Ashman and colleagues (2017) was the only controlled intervention design which compared a manualised structured social skills group with a non-structure social interaction intervention group. Findings show there were improvements in social cognition and social function in both groups. There were no significant differences between groups. However, the structure of the social skills intervention group may have impacted on adherence as this group reported higher

attendance (70% versus 55%). The structured social skills group also reported greater treatment satisfaction. While results are preliminary, this study suggest a more structured approach was the participants preferred intervention.

The SCIT intervention, which was developed to target social cognitive improvements (Turner-Brown et al., 2008) found that participants in the treatment group demonstrated improvements in social cognition, empathy and emotional recognition. Observer-rated assessments of social function demonstrated no significant difference between pre/post-test analyses which suggested that social function was not impacted by treatment. Although, social function was an additional assessment and was not the primary focus of the intervention. Feasibility for the intervention was supported as attendance was at 92% and satisfaction reports were primarily positive.

The Aspirations program was the only manualised approach designed to be directed by the group members. The group facilitator's role was to guide group discussions and ensure participants remained on topic. Across two studies, researchers evaluated the effects of the intervention on core ASD symptoms, social functioning, depression and anxiety (Hillier et al., 2007; 2011). The Aspirations program was shown to significantly improve self-reported symptoms of anxiety and depression (Hillier et al., 2011). Changes in ASD symptoms, empathy and social function failed to reach significances (Hillier et al., 2007). Analysis also included non-standardised assessments such as interviews, observations and therapist notes which provides support for the feasibility of the intervention (Hillier et al., 2007)

5. Discussion

The aim of this review was to explore the evidence base for MGSSI in an adult ASD without ID population. Improvements were reported in generalised social impairments associated with ASD (Ashman et al., 2017; Gantman et al., 2012; Hartmann et al., 2019; Laugeson et al., 2015; McVay et al., 2016), conversational skills (White et al., 2015), empathy (Gantman et al., 2012; Hillier et al., 2007; McVay et al., 2016, White et al., 2015), social cognition (Ashman et al., 2017; Hartmann et al., 2019; Turner-Brown et al., 2008), life satisfaction (Gantman et al., 2012) and comorbid mental health symptoms (Hillier et al., 2011; McVay et al., 2016). Unfortunately, there were variations in the remit of each intervention and no single outcome measure was used to assess change across all studies, thus limiting any direct comparisons.

This review was unique in that the aim was on investigating the efficacy of only manualised group interventions which target social impairments in adults with ASD. An earlier review conducted by Spain and Blainey (2015) only identified five group social skills interventions for adults, and only four of them were manualised, leaving a great deal of speculation about efficacy of a manualised approach. The findings of this review were largely consistent with the findings from earlier reviews. For instance, a review of group social skills interventions for adolescents, which included a number of MGSSI, also reported various delivery formats with some combination of didactic teaching and group discussion (Miller et al., 2014). Also in-line with the findings of this review, role-plays, modelling and skills rehearsals were also specifically identified as commonly used techniques across the group social skills literature for youths and adults with ASD (Gates, et al., 2017; Miller et al., 2014; Spain & Blainey, 2015). For improving social competencies, this review found that most group interventions aim for more extensive improvements in core ASD symptoms, with only a smaller number of studies targeting more specific social impairments.

5.1 Clinical Implications and Recommendations

The current findings suggest there is some evidence demonstrating efficacy for MGSSI for improving social competencies, however there is currently a scarcity of research supporting the use of MGSSI for adults with ASD. There was a lack of RCTs within the literature and a noticeable trend in the high risk of detection bias and performance bias across studies reviewed. The two studies. (Ashman et al., 2017; Gantman et al., 2012) appear to

have the lowest risk of bias across all studies reviewed and they both report improvements in social skills over the time of the intervention. However, Ashman et al (2017) did not find improvements when compared to a non-specific social interaction group who had frequent social interactions but did not received structured social skills sessions. The authors did however report less attrition rates within the structured training session suggesting there may be some benefit to more predictable interventions

When considering a social model of development for ASD (see Michelle et al., 2021) it could be that experiencing frequent positive social interactions may be equally beneficial on social development when compared to MGSSI. Unfortunately, no other MGSSI study for this population has been compared to an intervention control group. Future research may provide further insight into any extra benefits MGSSI may have over other intervention e.g., lower attrition rates. Considerations for the delivery and assessment of MGSSI still need further investigation and discussion. Further consideration of participants characteristics, contemporary theory, novel research methodologies and ASD specific outcomes need further reflection before routine clinical practises and/or delivery within the community can be recommended.

5.1.1 Gender and Age

There is a considerable gender imbalance amongst the current MGSSI literature which provides little evidence to suggest that MGSSI are suitable for both males and females with ASD. Past studies have shown that males and females can often differ in the presentations of ASD symptoms and, as a consequence, they may differ in treatment response (see Chapter 1, Section 2.4). Females with ASD are more prone to internalising symptomatology (Goldman, 2013; Head, McGillivray, & Stokes, 2014; Mandy et al., 2012), and often exhibit differing social difficulties (Bargiela et al., 2016). To optimise treatment response, it may be pragmatic for some intervention topics (e.g. avoiding exploitation) to be delivered in gender specific context. While there is some evidence to suggest that female and male ASD patients have a similar response to group social skills interventions (McVey et al., 2017), future studies would benefit from including larger female samples and directly investigating differences between genders in response to distinctive intervention components.

It is also important to give consideration to possible intervention group age constraints dependent on the aims and remit of an intervention program. Most MGSSIs tailored the

content for young adults (18-25 years) and only two studies reviewed (e.g. Ashman et al., 2017; Turner-Brown et al., 2008) included older participants in their intervention groups. It is relatively unclear if particular MGSSI content would be relevant or effective for an older ASD population. The age range and intervention topics may need to be considered by clinicians. Although difficulties remain in adulthood, as the individual with ASD ages, strategies begin to develop in order to manage symptoms, causing the severity of social impairments to be less evident (Howlin, Moss, Savage, & Rutter, 2013).

It is possible that older ASD individuals would benefit more from the social interactions that group treatments provide, oppose to specific social skills training. It may also be important to consider content specific interventions which may be more pertinent to life situations which may arise later in adulthood. For instance, adults with ASD have been shown to be more likely to engage in inappropriate courting behaviours (Stokes, Newton, & Kaur, 2007), therefore teaching appropriate social and romantic functioning may have a positive impact on those seeking more intimate relationships. There is also some evidence for the effectiveness of supported employment programs (Burke, Andersen, Bowen, Howard, & Allen, 2010) which help to teach targeted social vocational skills which are important for maintaining and progressing in an occupation. However, many adults with ASD have no access to specialist interventions unless they are supported by ID or a comorbid mental health disorder, and even then, provisions can be restricted or ineffective (Taylor & Seltzer, 2011).

5.1.2 Methodologies

Over the years, methodologies have varied in terms of design and assessment. Many of the early trials lack the use of a control group (e.g., Hillier et al., 2007) and some have utilized outcome measures which were not validated in an ASD population. As such, these measures may not accurately detect functional impairments related to ASD symptomology (e.g., Ashman et al., 2017). Additionally, there is little evidence to suggest that improvements go beyond the clinical setting and few studies have attempted to demonstrate the impact on real life social function or life satisfaction and wellbeing. Only one study included in this review reported follow-up data which suggested that treatment effects were long lasting (Laugeson et al., 2015). While it is possible that the practise of newly acquired social skills post treatment may lead to further reductions in core ASD symptoms over time, there is limited evidence to support long-term benefits.

It is also currently difficult to establish if manualised group interventions have any additional treatment benefits over alternative approaches (e.g., manualised directive vs non-manualised self-directed interventions). There was a single study which included a control intervention design and while gains were reported in both groups, there were no significant differences between them (Ashman et al., 2017). The authors did note that while efforts were made to not provide explicit social skills training in the control intervention group, the nature of a facilitated social interaction group itself may have contained components which were conducive to social skills acquisition. It is possible that a MGSSI approach holds limited added benefit for the group members receiving treatment.

5.1.3 Standardised and Non-Standardised Clinical Instruments

On the whole results across the studies investigating MSSGI should be interpreted with some level of caution. There was a noticeable risk of detection bias and performance bias across all the studies reviewed. Unfortunately, the nature of intervention studies can make avoiding both detection and performance bias very difficult as research participants and personnel are usually deeply involved, making blinding methods often difficult or not a possibility (Reichow et al., 2012). Accurate assessments can also be difficult to obtain as access to well-validated assessment instruments for an adult ASD population are limited.

Many MGSSI studies have relied on non-ASD specific measure and many of the ASD specific measure were not developed for an adult ASD population (Brugha et al., 2015). For instance, the SRS (Constantino, 2005) was used to measure change in social impairments related to ASD in a number of studies included in this review (e.g., Gantman et al., 2012, Laugeson et al., 2015, McVay et al., 2016), yet this version of the instrument was developed as a screening tool and was not designed to measure change in adults with ASD. However, there is an adult version of the scale (SRS-2; Constantino & Gruber, 2012) which was used in two studies (Ashman et al., 2017; Hartmann, et al., 2019) but with it being a relatively short scale, the instrument may arguably have limited sensitivity to change (Brugha et al., 2015).

It is also still unclear how well MGSSI actually improve the symptoms related to the diagnostic criteria of ASD. Despite concerns about validity (Bishop & Seltzer, 2012; Brugha et al., 2015), a number of studies used the AQ (Baron-Cohen et al., 2001), a low cost self-report ASD screening tool which was used to assess for symptom severity (Gantman et al., 2012; Hilliar et al., 2007) and symptom improvements (Hilliar et al., 2007). Few MGSSI

studies used well validated standardised comprehensive diagnostic instruments such as the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2001) to assess symptom severity (e.g., McVay et al., 2016; Turner- Brown et al., 2008) and no study attempted to use such an instrument to assess symptoms change. There has been some promising research on the sensitivity of change in ASD symptom severity using the ADOS (e.g., Shumway et al., 2011), but the potential utility of this instrument as an outcome measure needs further investigation.

There are similar limitations in assessing the mental health symptoms of adults with ASD. While self-report instruments have a long-established practise in mental health research (Uher et al., 2012), popular measures such as the Beck Depression Inventory (BDI-II; Beck et al., 1996) were not designed for individuals with ASD. Therefore, normative scores are not based on a population with ASD. When considering the difficulties those with ASD have in recognising and understanding emotions (Howlin & Moss, 2012), obtaining reliable scores may be problematic. A possible solution may be adopting parallel self-report and clinician-rated scales with matching content to facilitate the translation of a diagnosis. Previous studies suggest that self-report and clinician-rated versions of the same instrument can each uniquely contribute to the prediction of treatment outcomes amongst a neuro-typical population (Rush et al., 2006). While self-reports combined with clinician rated assessments may be a promising notion, evidence for such an approach for an ASD population does not appear to exist. Large-scale studies would be needed to establish correlating standard threshold scores between self-report and clinician-rated instruments in order to provide a reliably expression of symptom.

5.2 Research Limitations

This review has some potential limitations. For instance, screening of titles and abstracts was largely carried out by one reviewer and the review only included studies which were published in the English language. In order to investigate study homogeneity, only group interventions were included which eliminated individually driven focused interventions, virtual reality training or wider ranging treatments with elements of social skills training. Additionally, the reviewers did not include unpublished reports or grey literature. These noted limitations may have led to not reporting studies which included

meaningful evaluations of outcome measures or potentially effective social skills intervention components.

5.3 Future Research Direction

There are a limited number of validated instruments which exist for adults with ASD without ID. It is essential that future studies attempt to establish normative ASD thresholds for existing social skills and mental health measures or develop and validate new instruments that are sensitive to change. Before efficacy can be established for MGSSI, future studies need to involve a range of validated sensitive instruments which measure change in ASD symptomology within an adult population. Recently, there has been a strong argument that no one instrument can be used solely to make a diagnosis of ASD (Sappok, Heinrich, & Underwood, 2015) and it is likely that this argument extends to measuring change in ASD symptoms. Future studies should consider employing multiple methods of assessment. Standardized diagnostic instruments (e.g., ADOS and the ADI-R) combined with third party informant questionnaires (e.g., SRS-2 parent report) or blinded third party observer-rated assessment (e.g., CASS) may provide a better representation of observed behavioural progression.

The current MGSSI literature has also provided little evidence to elucidate the intervention components which are most effective and to what extent the impact of newly acquired social skills may have on social functioning after the treatment ends. Future studies should consider combining a component analysis and long-term follow-up assessments. It is important to establish if there are unique intervention components which related more to the acquisition and maintenance of specific social skills. It may be that some components are more effective at producing long lasting gains, whereas others may only produce short-term gains or no gains at all.

Lastly, future studies should consider evaluating the MGSSI content based on the age and gender of the target population. To optimise treatment response, some intervention topics may be better delivered based on gender specific context. As males and females can often differ in the expression of their ASD symptoms, they may also respond in different ways to interventions. Likewise, future research should consider investigating the appropriateness of specific content in relation to age. It is important to understand if specific topics may be more

relevant for different age groups (e.g., young adults with ASD may benefit more from topics which focus on transitions from adolescence into adulthood).

6. Conclusion

Social impairments can have a significant impact on life functioning during adulthood for many individuals with ASD. The studies identified in the present review highlight the limited evidence-base for manualised group interventions which aims to improve social impairment in adults with ASD. Thus far, only nine studies have investigated the efficacy of MGSSI to reduce social impairment in and adult ASD without ID population. While the current literature provides some preliminary support for intervention effectiveness, there is only marginal evidence to suggest that improvements have a long-lasting effect or impact on quality of life. For most of the interventions included in this review, it is unclear to what extent improvements can be translated into improved well-being or social functioning in daily life. More robust methodologies and improved instruments of assessment are greatly needed when moving forward with research. As the demands for social skills interventions grow, it is likely that both specialist and non-specialist professionals will be responsible for providing social care in the community and MGSSI may provide the specific guidance needed for effective intervention facilitation.

Chapter 3. Study 1: Evaluation of CBSCTI-ASD

1. Introduction

This chapter provides information about the five participants who received intervention and their response to CBSCTI-ASD. Case studies are valuable records of the clinical practices undertaken by professionals and offer descriptive and clinical assessments of a given intervention (Budgell, 2008). This case study aims to provide a record of noteworthy clinical interactions and assess multiple data sources. A case study analysis can help to frame the future direction of more rigorously designed clinical and community research. Details provided in the case studies are based only on factual information and modest descriptions of what was reported in the case notes. No new diagnoses were provided as part of this case study and suggestions regarding any underlying mechanisms were restrained to the individual's presentation of formerly diagnosed symptoms/disorders.

2. Background

Social behaviours may come naturally for typically developed individuals, yet those with ASD can struggle to have reliably successful social interactions (Tantam, 2014). Social competence is a multidimensional construct which typically involves social communication and interaction, social cognition, social awareness, social knowledge and relationship maintenance and management (Dodge, 1985; Goldman, 1998; Nangle, Grover, Holleb, Cassano, & Fales, 2010). Social competence involves the ability to maintain a sense of agency (self) and communion (others) as a part of social function (Goldman, 1998; Rubin & Rose-Krasnor, 1992). The term "social competence" has been used in a large number of studies and there have been a wide variety of definitions published (see Table 6).

Table 6 *Working definitions of social competence*

Authors	Definitions
Ford (1982)	“The attainment of relevant social goals in specific social context, using appropriate means and resulting in positive developmental outcomes (p. 323)
Rubin & Rose-Kransnor (1992)	“The ability to achieve personal goals in social interaction while simultaneously maintaining positive relationships with others over time and across settings” (p. 285)
Semrud-Clikeman (2007)	“Social competence is an ability to take another’s perspective concerning a situation and to learn from past experience and apply that learning to the ever-changing social landscape.” (p.1)
Taylor & Asher (1984)	“the formulation and adoption of personal goals that are appropriate and adaptive to specific social situation and implementing effective behavioural strategies for achieving goals. (p. 57)
White (1959)	“an organism’s capacity to interact effectively with its environment” (p. 775)
Yeates & Selman (1989)	“ the development of the social-cognitive skills knowledge, including the capacity from emotional control, to mediate behavioural performance in specific context, which in turn are judge by the self and others to be successful and thereby increase the likelihood of positive psychosocial adjustment” (p. 66)

A workable definition of social competence may be useful at the theoretical level, but it provides little in terms of operationalising social competence. Approaches to understanding social competence have been heavily reliant on the assessment of children's social interactions (Lim & Rogers, 2008). Rose-Krasnor (1997) identified four common approaches used in psychology to gain a better understanding of social competence. First is the social skills approach to social competence. This approach views social competencies as a desirable set of skills (Gresham & Elliott, 1990) which are typically assessed using psychometric measures (Gresham, Elliott, & Vance, 2011). Second is the peer status approach. This approach adopts the idea that being popular and accepted by others is an effective measure of social competence (Dodge, 1985; McConnell & Odom, 1999). Typically, sociometric assessments are used as they reflect the judgement of others during social interactions (e.g., Odom, Munson, Schertz, & Brown, 2004). Third, competence is assessed by the quality of a person's relationships (e.g., making and keeping friendships). This is a more challenging assessment approach due to the difficulties identifying and operationalising the important conceptual components of friendships (Bagwell & Schmidt, 2011). Lastly, the functional approach, where the focus is on identifying and measuring performance on context specific social tasks. For instance, Mostow and colleagues (2002) study assessed children's ability to identify emotions from photos and vignettes.

Over the years, several comprehensive models were developed to help conceptualise the components of social competence and provide targets for intervention (for a more comprehensive review see, Nangle et al., 2010 pp. 3-19). Influential models have focused on context and situational specificity (e.g., Goldfried & D'Zurilla, 1969; McFall, 1982), cognitive social information processing (e.g., Crick & Dodge, 1994), and the integration of operationalised multi-level models such as the Tri-Component Model (Cavel, 1990) and the Prism Model (Rose-Krasnor, 1997). However, the Prism Model appears unique in that it places importance on both the "self" (intrapersonal) and "others" (interpersonal).

The Prism Model represents a multi-level framework which separates skills components from summary indices. The Prism Model of social competence consists of three levels: motivation and skills level, index level and theoretical level. The Prism model places the theoretical level at the top of the model. The theoretical level is simply defined as an

individual's effectiveness in social interactions. The theoretical level identifies social competence as a molar paradigm which cannot be reduced to a single index or behaviour. The theoretical level is the most important in relation to conducting research as it takes the perspective that social competence encompasses four major features, namely, transactional interactions, context dependant behaviours, performance and goal achievement (Rose-Krasnor, 1997).

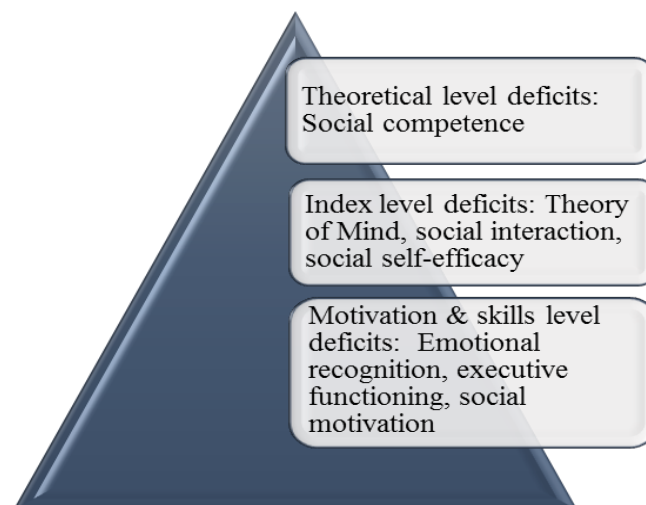
The central level consists of indices of social competence which reflect the quality of interaction sequences, social self-efficacy, social group status and relationships. Index level elements are socially based as they are determined through transactional interactions (e.g., back and forth conversations) with others. The index level consists of two domains: "self" and "others". The "self" domain refers to the aspects of social competence by which priorities of the person are central to achieving personal goals. The "others" domain is central to competencies involved during interpersonal interactions. Both domains are further divided into contexts which reflect the situation-specific nature of the indices (e.g., making friends). Yeates and Selman (1989) argue that in order to achieve the highest level of social competence, an individual will need to integrate the "self" and "others" perspectives into a collaborating strategy.

At the bottom of the Prism model is the motivation and skills level which includes the social, emotional and motivational factors which are related to social competence. Unlike the social nature of the index level, this level contains components of social skills which predominantly exist within the individual (e.g., conversation skills). The motivation and skills level is the most important to master as it provides the scaffolding for successful social interaction, relationships, and group acceptance, which are factors located in the index level. For individuals with ASD, this is likely the most critical level as impaired social skills may affect the ability to competently perform at the index level. For example, some findings suggest that difficulties in decision making, flexibility, and emotional regulation, can have a profound impact on attempts to establish romantic relationships (Urbano, Hartmann, Deutsch, Bondi Polychronopoulos, & Dorbin, 2013). Motivation is an equally important factor of the skills level. Studies have shown that social motivation can be an important factor for developing social skills in both typically developed individuals and individuals with ASD (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012; Dubey, Ropar, & Hamilton, 2017; Rabinet & Gordon, 1992). For those individuals lacking the social skills needed to

proficiently navigate social interactions, the experience of social rejection is likely to impact on factors related to social motivation (Mazurek & Kanne, 2010). A recent study (Neuhaus, Webb, & Bernier, 2019) which included 2,079 children and adolescents with ASD found that dysregulation in several domains moderated the association between social motivation and social skills.

Differences in motivation during adolescence relative to childhood and adulthood in ASD populations have also been recently tested (Bos et al., 2020). Both typically developed individuals and ASD individuals took part in a “go/no-go” motivation task with social and non-social cues. In-line with past research, typically developed adolescents and young adults demonstrated more false alarms for positive social cues than they did neutral social cues. However, individuals with ASD demonstrated no changes in attention across age for social or non-social cues. Findings suggest reduced motivation for the ASD group during late adolescence and early adulthood. The findings further highlight the challenges experienced by adolescents with autism transitioning to adulthood. However, some have recently argued that there is a need to consider alternative explanations as unconventional or idiosyncratic behaviours may not truly represent ways in which autistic individuals express their social interest (Jaswal & Akhtar, 2019; Kapp, Goldknopf, Brooks, Kofner, & Hossain, 2019). Until further understanding of unconventional or idiosyncratic behaviours are gained or changes to assessment measures are made, the debate on social motivation in ASD will likely continue.

Figure 2 *The Social Competence Prism Model for ASD*



Developed by the researcher, adapted from Rose-Krasnor, 1997

Some researchers have theorised that there are three core social competence constructs in which difficulties manifest in ASD individuals: ToM, executive functioning and emotional regulation (Solomon et al., 2004; Stichter et al., 2010). Social cognitive impairment would fall within the skills level and index level of the Prism model of social competence (see Figure 2). Impaired ToM effects the ability to understand the thoughts, intentions and feelings of others (Baron-Cohen, Leslie, & Frith, 1985). The ability to acknowledge that others' thoughts and beliefs are distinct from their own is a key component of social competence and is the base for the index level. Individuals with ASD often have great difficulty taking the perspective of others and predicting their related behaviours and actions (Kimbi, 2014). Skills level impairments which are related to ToM include the ability to differentiate between fact and fiction, social etiquette (e.g., being polite) and turn-taking in a conversation (Frith, 2009; Miller, 2009; Myles & Southwick, 2005).

Executive functioning is another common impairment which can be found within the motivation and skills level of social competence. Definitions of executive function are based on the distinction between automatic and effortful processing. Effective automatic processing provides an ability to respond to everyday situations, whereas effortful processing involves a range of higher-order cognitive processes associated with functioning in the prefrontal cortex (PFC) and are required for adapting behaviours to novel and complex conditions (Happé, Booth, Charlton, & Hughes, 2006). Many individuals with ASD have difficulty with a number of executive functions such as impulse control, cognitive inflexibility, social problem solving, poor planning and self-monitoring (Happé, et al., 2006; Hill, 2004; Pennington & Ozonoff, 1996). Since executive functioning requires the integration and processing of information from both internal and external stimuli, the inability to successfully perform these functions signifies a critical limitation in utilising the contextual cues which are essential for appropriate social and emotional behaviours (Happé et al., 2006).

An important social skill needed to have effective social interactions is the ability to recognise and understand the emotions of others. Emotional recognition involves the cognitive ability to differentiate the diverse number of affective expressions (facial, gestural and verbal) in self and others, as well as having an understanding of the social-contextual meaning (Bauminger, 2002). Often individuals with ASD have the ability to distinguish

between the basic emotional expressions such as happiness and anger (Capps, Yirmiya, & Sigman, 1992; Loveland et al., 1997) but have difficulty recognising more complex emotions such as surprise and sadness (Boraston, Blakemore, Chilvers, & Skuse, 2007; Jones et al., 2011). The recognition of emotional expressions overlaps with ToM to the extent that proficient emotion recognition requires the attribution of understanding the mental state of others. As emotional recognition requires the ability to infer a mental state, there is an obvious overlap with impairments of ToM (Stitcher et al., 2010).

The complex nature of empathy can lead to additional challenges which go beyond simple deficits in understanding of others mental and emotional states. Social models of development have begun to shed light onto ontological factors which may bring greater understanding to the way reactions and responses influence social interactions. The double empathy hypothesis states that typically developed individuals can find it just as difficult empathising with individuals with ASD and that empathy difficulties arise from different ways of communication (Milton, 2012; Chown, Hughes & Baker-Rogers 2020). For typically developed individuals, first impressions of ASD behaviours can often be perceived negatively or unfavourably and these negative first impressions have been linked to a reduced motivation to socially interact (Sasson et al., 2017; Alkhalidi et al., 2019).

While the recent research suggests that individuals with ASD are better and more comfortable interacting with ASD peers (Alkhalidi et al., 2019), there is little evidence to explain this occurrence. Such research suggests that there are distinct characteristics and mechanisms shared by individuals with ASD which help them understand the world and connect with others similar to themselves. Greater awareness of social experiences may help researchers understand the reasons for the mutual misunderstandings often experienced between ASD and typically developed individuals. Mutual misunderstandings will continue to be problematic and hindered by negative perceptions until a greater awareness is achieved within society.

Individuals with ASD can often exhibit difficulties in their social skills knowledge and performance which also frequently elicits negative judgments by others (Merrell & Gimpel, 1998). Social skills are defined as the verbal and non-verbal behaviours which are necessary for effective social interactions (Rao, Beidel, & Murray, 2008). With the appropriate education and skills training, individuals with ASD can learn to integrate

meaningfully into the community (Wehman, 2006) and work competitively amongst their peers (Gerhardt & Holmes, 2005; Hurlbutt & Chalmers, 2004; Wehman et al., 2014). However, the specific mechanisms responsible for changes in social behaviour in an ASD population are not fully understood. Social skills interventions which have been shown to be the most efficacious have followed behavioural and social learning principles. The key elements of evidence based social skills interventions typically include both behavioural and social learning techniques which have been regularly used for the teaching and reinforcement of skills (Miller et al., 2014).

With the exception of a limited few (e.g., Epp, 2008; Hillier et al, 2012), the majority of social skills interventions reflect a ‘deficit model’ of ASD. Deficit models are popular in the field of clinical psychology and view psychopathology as the result of distress or dysfunctions attributed to an individual’s social impairment (Anglin & Polanco-Roman, 2017). Deficit model interventions are typically more directive and aim to improve underlining social impairments as opposed to a ‘social model’ which aims are geared towards empowerment and self-directed choice (Lornec et al., 2017). Traditional social skills interventions have typically adopted a behavioural approach (e.g., Applied Behavioural Analysis or Cognitive Behavioural Therapy) within a clinical or educational setting (Rao et al., 2008). However, social skills interventions can differ in terms of content and assessment depending on the individuals age and level of functioning (McMahon, Vismara, & Solomon, 2013; Rao et al., 2008).

Social skills interventions which include directive instructions and behavioural components have the strongest evidence-base for adolescents and adults with ASD (Ke et al., 2018; Lornac et al., 2017). Social skills interventions which utilise a behavioural approach attempt to target either specific or generalised skills deficits. For example, the *PEERS* programme (Laugeson & Frankel, 2010) is a comprehensive group treatment manual which targets improvements in a generalised set of social skills which relate to social functioning. Others have used validated assessment instruments pre-treatment to identify specific target skills for participants and then incorporated these into treatment plans (Mitchell et al., 2010).

The most common delivery approaches for social skills interventions for individuals with ASD can be broadly categorised in three ways: Adult-mediated, peer-mediated and adult-and-peer mediated (Reichow & Volkmar, 2010). Adult-mediated approaches are

facilitated by a teacher or clinician (Brady, Maccarrone, Holloway, Gunning, & Pacia, 2020), whereas peer-mediated approaches incorporate peer models or mentors (Chang & Locke, 2018). Adult-and-peer mediated is simply a combination of these two approaches. While these approaches have a substantial evidence-base amongst children and adolescents with ASD, their impact on adults are not as well established.

Delivery strategies and techniques can vary between interventions, but many have been found to be promising for the teaching of social skills. The most effective techniques used in group social skills interventions for adolescents have been reported to be corrective and positive feedback, skills modelling, behavioural shaping, and scaffolding (Miller et al., 2014). Other evidence-based interventions which have focus on behaviour change have also included: video modelling and video feedback (Apple et al., 2005; Ozonoff & Miller, 1995; Simpson et al., 2004), self-management skills (e.g., Morrison et al., 2001), behaviour modelling (Laugeson et al., 2012), group discussions (MacKay et al., 2007), script writing (Krantz & McClannahan, 1993, 1998), social stories (Broderick et al., 2002; Thiemann & Goldstein, 2004), skills rehearsal (Minihan et al., 2011), pivotal response training (Pierce & Schreibman, 1995), role-play activities (Tse et al., 2007), peer support (White et al., 2013) and incentive systems (Mitchell et al., 2010). Other non-behavioural intervention methods have also been identified such as interpersonal therapy (Mishna & Muskat, 1998), art therapy (Epp, 2008) and music therapy (Hillier et al., 2012), however the evidence-base for these interventions are limited.

Given that individuals with ASD often display difficulties with adaptive functioning, cognitive flexibility and generalisation of skills (Brunsdon & Happé, 2014; Kanne et al., 2011; Wilson et al., 2014), individualised social skills training alone may not easily translate to social functioning in real-world situations. Social skills groups for individuals with ASD have been shown to have long-term positive effects on an individual's social development which can extend to real-world social functioning (Karst et al., 2014; Laugeson et al., 2015; Mandelberg et al., 2014). A naturalistic group setting, where social interaction is encouraged in a safe environment will better promote appropriate social interactions outside the confines of the clinical setting (Barry et al., 2003). This may be due to a number of factors in the utility of group interventions. One such factor is that the facilitators of social skills groups are given the opportunity to provide instructions to group members on specific social skills, which allows for immediate rehearsal and practice of skills between group members. The

social skills group setting also provides an opportunity for facilitators to deliver immediate reinforcement with positive and corrective feedback, thus increasing the probability of the skill being practised with corrections.

In the past, social skills interventions have been a popular and an effective intervention modality for some adults with ASD (Lornec et al., 2017). A great deal of support is offered to children and adolescents with ASD, yet appropriate group based social skills interventions for adults with ASD are few (Roux et al., 2015). Despite a growing need, gaining access to effective evidence-based group social skills interventions which are delivered in clinical and community settings can be extremely difficult for many (Howlin, 2014; Taylor & Seltzer, 2011; Thompson, Bolte, Falkmer, & Girdler, 2018). In order to increase access to support and improve the lives of those adults which struggle due to their social impairments, it is important to develop tailored and comprehensive social skills interventions in the future.

2.1 Research Aims and Objectives

Study objective 1: Develop a cognitive behavioural social competence intervention and create the CBSCTI-ASD manual for use with young adults with ASD without ID.

Study objective 2: To establish the feasibility of delivering CBSCTI-ASD to young adults with ASD without ID.

Qualitative aims: To explore young adults with ASD without ID and their parents experience of receiving CBSCTI-ASD. To explore the CBT therapists experience of delivering CBSCTI-ASD.

Quantitative aims: To investigate the feasibility and potential efficacy of CBSCTI-ASD.

2.2 Research Questions

Q1: What were the experiences of the young adults that received CBSCTI-ASD?

Q2: What were the views and opinions of the parent which had an active involvement in CBSCTI-ASD

Q3: What were the CBT therapists' experiences of delivering CBSCTI-ASD to young adult with ASD without ID.

2.3 Hypotheses

H1: Participants in the treatment group will find the intervention acceptable.

H2: As a result of the intervention, the participants will demonstrate a significant increase in scores from pre-test to post-test as measured by the Interaction Rating Scale Advanced (IRSA; Anme et al., 2014) and the Multidimensional Social Competence Scale (MSCS; Yager & Larocci, 2013).

3. Method

3.1 Design

A case study design which adopted a pragmatic mixed-methods approach was used to evaluate the feasibility of CBSCTI-ASD. Quantitative data were used to assess participants' satisfaction and capture behavioural changes in social competence. There were three strands of qualitative data collection; semi-structured interviews of participants who received CBSCTI-ASD, semi-structured interviews of parents involved in CBSCTI-ASD and a focus group with the CBT therapists who delivered CBSCTI-ASD. The aim was to explore subjective experiences relating to participant satisfaction and the effectiveness of the intervention.

Quasi-experimental design: Quantitative analysis was used only to explore the preliminary effects of CBSCTI-ASD and was not intended to prove or validate the efficacy of the intervention. As such, in chapter four only descriptive analyses and repeated measures analysis were conducted. The independent variable was CBSCTI-ASD, and the dependent variables were scores from the Interaction Rating Scale Advanced (IRSA; Anme et al., 2014), and the Multidimensional Social Competence Scale (MSCS; Yager & Larocci, 2013). Analysis were preformed using the Statistical Package for Social Sciences (SPSS, v24.0).

Qualitative data analysis: This case study had a qualitative, exploratory and descriptive design. A qualitative inquiry using single person semi-structured interviews were selected to explore the experiences of five young adults with ASD which received CBSCTI-ASD and their parents. Two parents which had an active involvement in the CBSCTI-ASD

individual sessions were also interviewed and their views and opinions of CBSCTI-ASD were explored. A focus group was used to achieve a group discussion between the CBT therapists so they could express their opinions and experiences of CBSCTI-ASD delivery. The interview was naturally a social experience which fostered a collaborative discussion where the therapists could build upon their comments (Krueger & Casey, 2009).

For study 1 an inductive or “bottom up” approach to Thematic Analysis (TA) was used to describe or understand the human experience, context or phenomenon (Polit & Beck, 2014). Boyatzis (1998) describes TA as bringing together the language of qualitative research and quantitative research. TA is a useful and flexible method which has been used regularly in recent cognitive behavioural intervention research to explore the experiences and views of the therapists (van Rooij, Zinn, Schoenmakers, & Van de Mheen, 2012), service users (Dittmann, & Jensen 2014; Stawarz, Preist, Tallon, Wiles, & Coyle, 2018) and parents of service users (Shahnavaz, Rutley, Larsson, & Dahllöf, 2015). TA can be used to explore a range of epistemologies and is a valid method for identifying, analysing, organising, describing, and reporting themes in qualitative research (Braun & Clarke, 2006; Nowell, Norris, White, & Moules, 2017).

3.2 Participants

3.2.1 Intervention group participant characteristics

Four male participants and one female participant with a diagnosis of ASD were recruited to take part in the intervention (see Table 7). Two parents, both mothers, volunteered to take part in the study with their adult child. The participants age range was between 18-29 years with a mean age of 22.2 and standard deviation of 4.1. All participants were classified as White British. Four of the participants reported comorbid diagnosis of a mental health disorder. Mood disorders were the most common with four participants identifying a depressive disorder. Combined anxiety and depressive disorders were reported in three participants and while only one participant reported no comorbid mental health disorders, he self-identified social anxiety as an undiagnosed issue. Selective serotonin reuptake inhibitors (Fluoxetine and Sertraline) were the only medications reported and all doses remained stable over the course of the intervention.

Inclusion and exclusion criteria were initially assessed during an initial telephone interview (see Appendix F). Screening was further carried out during the intake assessment interview which took place at the University of Salford approximately two weeks after the telephone interview. Inclusion criteria for entering the intervention required participants to be between the ages of 18-30 years and be proficient in the English language. Participants were required to have had a past clinical diagnosis of ASD without ID from a reliable health professional. Additionally, diagnosis had to be supported by a self-report score of 32 or greater on the Autism Spectrum Quotient (Baron-Cohen et al., 2001) which was administered during the intake interview. Capacity to provide informed consent was established through clinical observations at the time of gaining consent in accordance with the British Psychological Society (BPS) guidelines (Assessment of Capacity in Adults: Interim Guidance for Psychologists, 2006).

Only participants that did not report a comorbid intellectual disability at the time of the telephone interview were included in the study. Participants were excluded if they reported the presence of a medical condition which may affect their ability to complete the full study or a history of neurological injury such as head trauma, seizure disorder (i.e., seizure within the preceding six-month period), stroke, prior neurosurgery, or were under the care of a neurologist or neurosurgeon. In addition, participants were excluded if they reported a primary (most severe) mental health disorder (e.g., panic disorder or OCD) or were experiencing significant drug or alcohol intoxication at the time of the intake interview as assessed by self-report or interviewer observation

Table 7 Participant demographic data

Participant Pseudonym	Age	Gender	Occupation or Education Status	Co-morbid Diagnosis	Psychotropic Medications	IQ scores	AQ scores
Rick	22	Male	University student	Depression, anxiety, OCD, IBS	Fluoxetine 20mg*	122.00	41
Clare	21	Female	Unemployed	Depression, anxiety, PTSD, hypermobile, Irene Rett syndrome	None	107.00	41
Jim	21	Male	University student	Depression	Fluoxetine 40mg* & Sertraline 100mg*	103.00	38
Ken	29	Male	Part time employment	Depression, anxiety, dyspraxia	Sertraline 100mg*	91.00	38
Alex	18	Male	University student	None	None	124.00	32

Note: Taken once daily*; OCD - obsessive compulsive disorder; PTSD - post-traumatic stress disorder

3.2.2 CBT therapist characteristics

There were two therapists which assisted the researcher in the delivery of CBSCTI-ASD. Both were qualified as CBT therapists, aged in their 30's, with post-graduate educations. The pseudonyms Sandy and Alan were used to identify the therapist in the current study. At the time of the study, Alan was working as a CBT Therapist in a busy community clinic and primarily worked with individuals with common mental health disorders. Alan had no prior experience of working with individuals with ASD. Sandy was working in the volunteer sector as a CBT therapist, and had prior experience of working with young adults with ASD.

3.3 Materials

3.3.1 Screening Instruments

Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). The AQ (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) instrument is a self-evaluation scale that measures autistic traits across five subscales: social skills, attention shifting, attention to detail, communication and imagination. Participants respond to statements such as "I prefer to do things on my own than with others" with definitely agree, slightly agree, slightly disagree, or definitely disagree as response options. Responses marked on the scoring key are given one point and responses which are not marked receive a score of zero. "Definitely agree" or "slightly agree" responses scored 1 point, on the following items: 1, 2, 4, 5, 6, 7, 9, 12, 13, 16, 18, 19, 20, 21, 22, 23, 26, 33, 35, 39, 41, 42, 43, 45, 46. "Definitely disagree" or "slightly disagree" responses scored 1 point, on the following items: 3, 8, 10, 11, 14, 15, 17, 24, 25, 27, 28, 29, 30, 31, 32, 34, 36, 37, 38, 40, 44, 47, 48, 49, 50. To acquire a total score, the sum of all items are calculated to provide a level of symptom severity. Higher scores represent more ASD related traits. Adolescents and adults with ASD and typically developed participants reported good internal consistency (.82) and test-retest reliability (.70) in a validation study (Baron-Cohen et al., 2001). The AQ has good discriminative validity and screening properties for ASD in clinical samples with a minimum threshold scores ranging between 26-32 have been found to support the presence of ASD (Woodbury-Smith et al., 2005). This instrument was administered to participants with ASD at baseline to support the self-reported clinical diagnosis.

Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000). The WRIT (Glutting, Adams, & Sheslow, 2000) is an individually administered test of ability designed for use with individuals between the ages of 4 and 85 years. The WRIT can be administered in less than 30 minutes and consists of four subtests (Verbal Analogies, Vocabulary, Matrices, and Diamonds). These subsets can be combined to form three IQ scores which include Verbal IQ, Visual IQ and General IQs ($M= 100$, $SD = 15$). Scores below 70 may indicate an intellectual disability (Canivez, Konold, Collins, & Wilson, 2009) and as such a cut-off score of 70 was used in the current study. As noted in the technical manual, the WRIT's standardisation design covered the variables of age, gender, race / ethnicity, parent/individual education level and region of residence. The technical manual provides reliability estimates (e.g., internal consistency and test-retest reliability) for each of the scales for the WRIT (Glutting et al., 2000). Internal consistency estimates (alpha coefficients) ranged from .76 to .97 across all age levels for the WRIT's subtests. Reliability estimates were found to be higher for General IQ with a range of .93 to .97. Test-retest stability ranged from .70 for the Matrices subtest to 1.0 for Verbal Analogies; and from .63 for Matrices to .90 for Verbal Analogies (uncorrected for attenuation). Convergent validity and construct validity has also been reported to be high for the WRIT (Canivez, Konold, Collins, & Wilson, 2009).

3.3.2 Feasibility Measures

Client Satisfaction Questionnaire (CSQ-8; Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The CSQ-8 (Larsen, Attkisson, Hargreaves, & Nguyen, 1979) is a field standard measure of treatment satisfaction that has been widely employed to assess the acceptability of psychotherapy programs. This measure consists of 8 items rated between 1 (“quite dissatisfied”) and 4 (“very satisfied”) to assess self-reported satisfaction with treatment programs. Initially item were drawn from a pool of 81 statements developed to address nine hypothesized aspects or component dimensions of satisfaction. Upon reviews by panels of experts the pool of 81 items was reduced to 31. The remaining items were tested on 248 mental health clients and from these the final eight items were selected based on their factor loadings. Predictive validity has been hypothesised and demonstrated by the presence of higher satisfaction scores for service completers as compared to non-completers. The internal consistency of the CSQ-8, as measured by coefficient alpha, ranges from .83 to .93, with values of .86 and .87 being reported in the two largest studies (Attkisson & Greenfield

1995). The CSQ-8 is scored by calculating scores from individual items which produces a range of 8 to 32. The higher scores indicating greater client satisfaction rates. Means, modes, medians, and standard deviations involving a variety of approximately 8,000 clients have been reported between 26.35 and 27.80 (see Attkisson & Greenfield, 2004). As no set cut-off scores have been distinguished for specific boundary levels of satisfaction, the current study used a cut-off score of 28 to represent high satisfaction rates.

Fidelity check lists. Fidelity check lists were developed by the researcher. Each item on the checklist corresponded to the components being delivered within each session. A yes/no response option was provided for each check list item based on the following: Yes (if activity was performed and for the time allocated); No (if activity is not performed or not within the time allocated). In addition, observations were noted if the programme format was not adhered.

3.3.3 Social Competence Measures

Interaction Rating Scale Advanced (IRSA; Anme et al., 2014). The IRSA (Anme et al., 2014) is a 92-item instrument designed as a brief but comprehensive observation measure that assesses basic social competence for individuals over the age of 15. Social competence is examined through five-minute observations of a social interaction. The advantage of the IRSA is that evaluations of interactions can be completed in a short period within a naturalistic environment. The IRSA has demonstrated a Cronbach's alpha value of 0.89 and a moderately high correlation ($r = 0.58$) between IRSA scores and professionals' practical evaluation. The IRSA includes a behavioural score and six subscale scores that combined provide an impression score: "self-control," "expressivity," "sensitivity," "assertiveness," "responsiveness," and "regulation". Two different variables are scored: behaviour and impression. For the behaviour variable, items are assessed in terms of the presence of a behaviour (0 = no, 1 = yes), and the sum of all subscale items provides the overall score. The total score can range from 0 to 92 (Anme et al., 2014). As for the impression, each observed behaviour is rated on a five-point scale where 1 is "not evident at all," 2 is "not clearly evident," 3 is "neutral," 4 is "evident," and 5 is "highly evident." The rating procedure is as follows: the evaluator completes the checklist, focusing on the participant's behaviours (e.g., expressing his/her own feelings to the partner). A second observer provides a separate impression score for each observed behaviour. Higher scores represent greater levels of social competence. While the authors of this measure have already started to employ the IRSA for

assessing children with ASD with ID, no normative scores for adults ASD without ID have been reported.

Multidimensional Social Competence Scale (MSCS; Yager & Larocci, 2013). The MSCS (Yager & Larocci, 2013) is a measure administered to primary caregivers or as a self-report. The scale includes 77 items rated on a Likert scale ranging from 1 (“not true or almost never true”) to 5 (“very true or almost always true”). Items are coded such that higher scores reflected higher levels of social competence. Internal consistency has been supported with coefficient alpha reliabilities for domain, subscale, and total scores being reported above 0.84. Convergent validity has been reported with significant large correlation being reported between the MSCS total score and the SRS (Constantino & Gruber, 2005) in a total sample of typically developed and ASD demonstrated a correlation ($r = -0.89$, $n = 132$, $p < 0.001$) and in the ASD sample ($r = -0.78$, $n = 87$, $p < 0.001$). Mean scores on the MSCS were compared for the individually matched ASD and typically developed populations using t-tests. Significant group differences were found for all MSCS domains, subscale, and total scores with higher levels of social competence reported in a typically developed population compared with an ASD population. The mean score for an ASD population has been reported for total MSCS scores at 216.23 with a standard deviation of 38.94. Mean scores found in a typically developed population were reported at 317.31 with a standard deviation of 30.06.

3.3.4 CBSCTI-ASD Manual

CBSCTI-ASD is a manual-based program (see full description in Appendix K) which is delivered over six weeks (15 hours) through two therapy modalities: individual therapy (CBT sessions), and group therapy (social skills group). Individual and group sessions were delivered each. Individual sessions took place 48 hours prior to the delivery of group sessions. Individual therapy sessions were approximately 30 minutes in length, with the optional inclusion of parents toward the end of each session for approximately 10 minutes. The group therapy sessions each lasted approximately two hours with a 10-minute break. Common intervention techniques employed included: behaviour modelling, roleplay, problem-solving and psychoeducation.

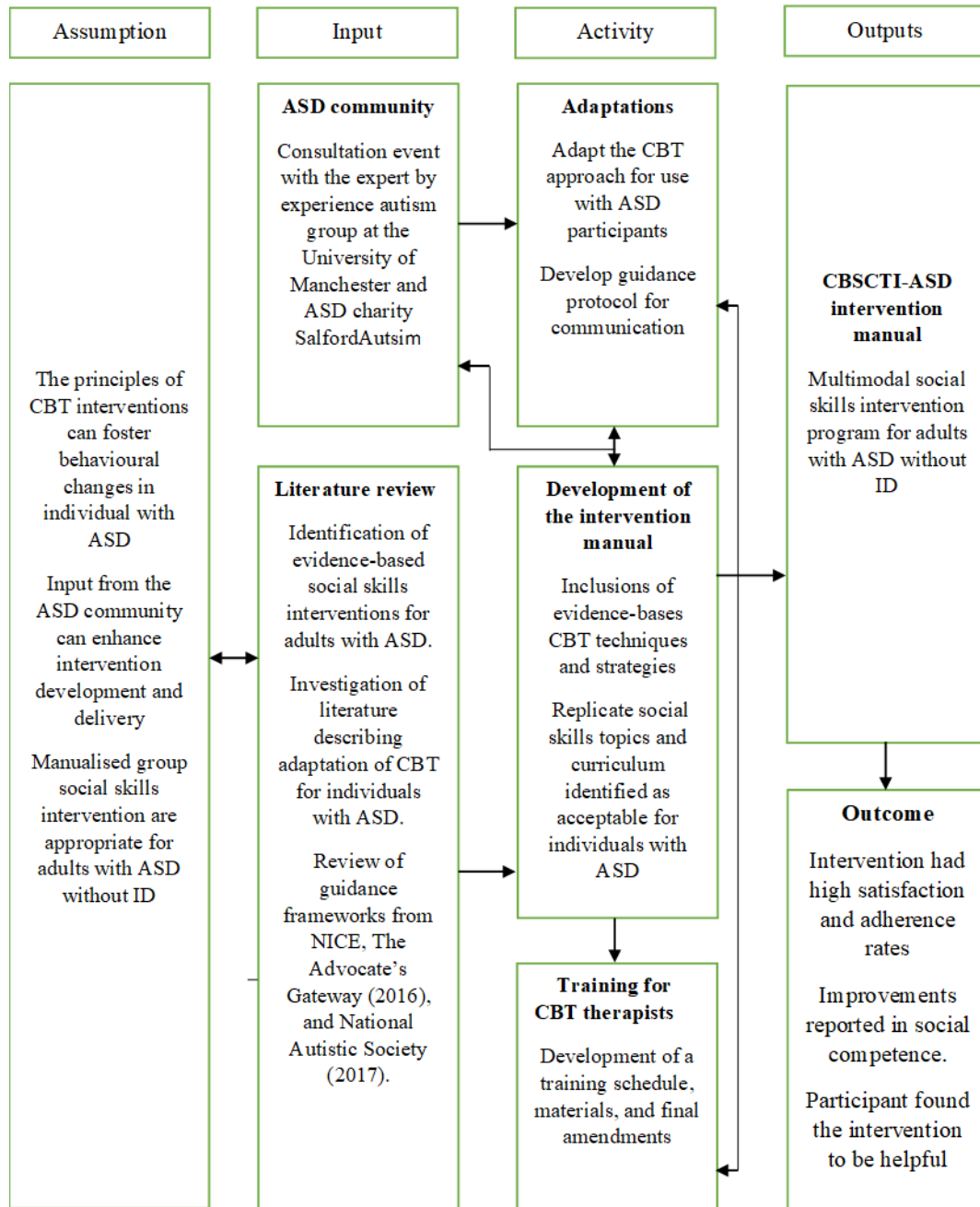
CBSCTI-ASD psychoeducation curriculum includes only the operational definitions of social skills (verbal and non-verbal) found in the literature with an evidence-base. The curriculum combines a number of non-verbal and verbal communication skills which have

been shown to increase the chances of successfully starting and maintaining a conversation. Psychoeducation lessons cover six social interaction topics which include: starting a conversation and exchanging information, making a request, active listening, sharing a conversation, entering a conversation and good sportsmanship.

3.4 Intervention development

The development of CBSCTI-ASD is outlined using the logical model for program development (Savaya & Waysman, 2005) which acts to communicate and support the actions that were required to achieve the intervention objectives (see Figure 3). The process of the logical model development consisted of four stages: inputs, activities, outputs and outcomes. The first stage was exploratory with the objective of assessing existing data sources and collecting input through consultations with the ASD community. At this stage the main objectives were to: identify and define specific evidence-based strategies, techniques, and topics adapted for ASD and to collect project feedback from the ASD community.

Figure 3 Logical model for program development



3.4.1 Autism Community Involvement

On December 6th, 2017 the Autism@Manchester expert by experience steering group were consulted on the design and appropriateness of the research project. There were approximately 18 members in attendance, including the Chairperson of the group. The members of the group included a director of a local autism charity, an expert in ASD, adult group members with ASD and several caregivers to individuals with ASD. At this meeting a 30-minute presentation was delivered covering the research project and an outline of the intervention manual topics. Following the presentation, the group discussed the rationale/justification for why the study was important, the feasibility of the research methodologies, the intervention and the recruitment process. The researcher took notes during the discussion and collected recommendations from several group members (see appendix M for impact statement).

The group were also provided with a copy of the PIS and consent form. One group member felt that sensory issues which may arise during assessment needed to be more clearly stated within the PIS. Minor amendments to the wording in the PIS were made to ensure it was very clear that the assessment may affect sensory issues and the study would stop if any discomfort or distress was experienced by participants. Advice on the language used in the PIS around ASD was mixed e.g., some preferred Autism Spectrum Condition, while others felt that Autism Spectrum Disorder was a more accurate descriptor. As there was no clear consensus on terminology, the original language used to describe participants was not changed. Recently, best practise guidelines were published by the BPS (2021) which discusses the use of terminology when working with people with ASD. Similar to the feedback from the Manchester expert by experience group, there still appears to be mixed views and no universally accepted language for this population e.g., BPS Guidance for working with autism states:

“Terminology is widely debated in the autism field. There is no single universal way for practitioners to describe autism, apart from reference to the diagnostic criteria. Commonly used terms include autism, autism spectrum disorder and autism spectrum condition. Some autistic people object to being referred to as ‘disordered’ and see autism as a different way of being, while others feel that autism seriously challenges their lives and wish to retain the term ‘disorder’ so that their needs are recognised” “For some, autism is a core part of their identity and they see themselves as autistic, rather than ‘someone with

autism'. Other individuals who do not see autism as central to their identity prefer the term 'with autism' (BPS, 2021 p9.).

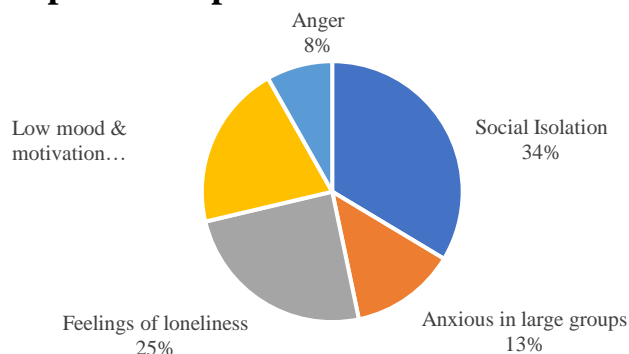
Intervention topics preselected by the researcher were also discussed with the group. The aim was to ensure topics within the intervention manual were viewed as appropriate and relevant to young adults with ASD transitioning into adulthood. No objections were raised for the inclusion of the chosen social skills topics, however several adults with ASD shared their positive and negative experiences of receiving both standard CBT treatments and ASD specific CBT treatments. These group members were provided with a feedback form asking questions about receiving CBT interventions based on their knowledge and personal experience. Several members of the group responded and returned their forms to the researcher. Unfortunately, none of the group members had experience of receiving CBT for social skills development. All responses were discussed within the research team and further considered during the intervention manual development stages (see Appendix N for table of responses).

3.4.2 Autism Related Adaptations

Past reviews have suggested that when adapted, Cognitive Behavioural Therapy (CBT), can be efficacious in reducing mental health problems and improving challenging behaviours in an ASD population (e.g. Weston, Hodgekins, & Langdon, 2016). The Five Areas CBT model (Williams, 2001a) formulation was adapted to fit within the remit of the CBSCTI-ASD multi-modal programme (i.e. focus on ASD related problems). Since individuals with ASD have often been described as visual learners (Rao, & Gagie, 2006; Scattone & Mong, 2013), changes to the model included providing a visual representation of issues related to social impairment (see Figure 4). The pie chart provides a visual representation which should, theoretically, be more helpful for fostering greater comprehension between clients with ASD and their therapist.

Figure 4 Pie chart of social impairment developed by the researcher

Impact of Impaired Social Communication



In addition, the length of each session was adapted to be only 30 minutes, include structured worksheets (see Appendix K) and limited to six weekly sessions. Generally, brief and intensive CBT interventions have been modified for those with ASD by reducing the number of sessions/the time period over which the sessions are delivered, include visual aids and provided structured worksheets (Öst and Ollendick 2017; Scattone & Mong, 2013). In addition, a guidance protocol for communicating with adults with ASD was developed for the CBT therapists (see Appendix G). The guidance protocol for communication was developed in-part based on responses collected on 6th of December 2017 during the meeting with the Autism@Manchester expert by experience advisory group. Additional considerations were taken from existing recommendations from the following recognised national guidance documents: the Advocate’s Gateway (2016) tool kit for questioning someone with ASD, the West Midlands Police Federation (n.d.) interview guidance notes for people with ASD and the National Autistic Society (2017) guidance for recruiting an autistic employee.

To help ensure the appropriateness and utility of the CBSCTI-ASD intervention manual, improvements were also made to the CBSCTI-ASD training activities that were delivered to the CBT therapists involved in the study. During the CBSCTI-ASD training the therapists were asked to provide feedback on the delivery and formulation of the intervention manual. Discussions and feedback were provided by the therapists following each of the 10 training sessions. The therapists highlighted issues with some of the language used in the sessions and suggested a more simplified delivery formulation to the ABC assessment model (see Appendix M). A number of the questions were adapted to focus on thoughts instead of feelings and some language was simplified to make the task instructions clearer. It was also agreed that in order to scaffold skills development through specific examples, where possible

modelling of social skills should be combined to run alongside psychoeducation lessons. All changes to improve the original manual were made before the start of the intervention.

3.5 Procedure

3.5.1 Participant Recruitment and Screening

Ethical approval was granted before participant recruitment (see Appendix E). To develop interest in participation in the study, recruitment materials were provided to ASD groups in the North West of England. The University of Salford, University of Manchester, Axia-ASD, SalfordAutism charity group, Greater Manchester Autism Consortium and the National Autism Society (NAS) were primary collaborators in the recruitment process. There were a total of nine respondents that met the initial phone screening criteria. Two parents made opening contact with the researcher to express interest on behalf of the potential participants. The other seven respondents were self-referred and made direct e-mail contact with the researcher.

All respondents were contacted to arrange a telephone meeting within two days of their initial email. During the telephone meetings, the researcher followed an interview script which focused on a number of screening questions (see Appendix F). Despite meeting the initial inclusion criteria, one respondent had two telephone conversations with the researcher before deciding not to participate. One participant failed to attend the intake interview and did not respond to emails until after the close of intake. One respondent had scheduling conflicts with employment which resulted in her ineligibility. Another respondent was excluded due to logistical problems of attending twice a week for the intervention sessions. Individuals who were excluded based on a failure to meet the study's inclusion criteria were offered an optional referral to Salford Autism and the Together Trust, North West. Salford Autism provide social support for individuals with ASD and offer an open contact line 24 hours, 7 days a week, including all holidays. Together Trust is a charity that offers care, support and special education to children, adults and families with ASD. Their services are based in the North West of England and they accept referrals. No respondent chose to accept the referral offer. The final five participants that met the initial inclusion criteria volunteered to take part in the study.

The five respondents that declared interest in participation in the study and met initial inclusion criteria were sent an invitation letter and an information sheet via email. The information sheet outlined the purpose of the study, details of the participants' involvement and the ethical rights of participation in research (see Appendix F). Intake interviews were held with the researcher in the Allerton Building on the University of Salford campus. The information sheet was handed out again in person during the intake interview. Participants were told by the researcher that they had a minimum of 24 hours to consider whether they wished to take part in the study following the intake interview. The researcher gained consent following a guidance protocol for obtaining informed consent of someone with ASD (see Appendix G). Participants were ensured in the information sheet and also the consent form that they had the right to withdraw at any time and that all data that they have given up until the point of withdrawal will be used in analysis and will be securely stored for a minimum of five years. Before screening assessment commenced participants were again provided the opportunity to ask any questions and/or request further details of the study. Once all questions had been addressed to the satisfaction of each participant, the researcher then began the screening assessment.

The screening assessment began by conducting a medical history interview on general and specific health issues (e.g., current ASD diagnosis, other diagnoses, physical health and medication use). To screen for the presence of ASD, the AQ was administered to support participants clinical diagnosis of ASD. The AQ is a commonly used self-report screening instrument which only took the participants approximately 20-30 minutes to complete. Due to minor visual impairment, one participant requested that the researcher administering the assessment assist with reading the questions and recording responses. Before marking the answer on the questionnaire, the researcher repeated the answer back to the participant in an attempt to ensure that the correct Likert response option was chosen. All other individuals assessed answered the questionnaire independently. Participants who met the inclusion criteria were required to score above 26 on the AQ.

The Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000) was administered to establish an IQ score. The WRIT required the participants to answer questions based on verbal and visual IQ. The WRIT manual was adhered to by the researcher and the test took approximately 20-30 minutes for participants to complete. An overall IQ score equal to or above 70 was the threshold score to eliminate the presence of a comorbid

ID. Verbal and visual IQ were measured and no participant with ASD scored below an 80 on combined verbal and visual IQ, nor did any participant score below an 80 on verbal IQ. It must be noted that one participant scored a 69 on visual IQ but verbal IQ was within the normal range and when verbal and visual IQ were combined, the overall score exceeded 80.

3.5.2 Research Assistant Recruitment

To complete this study a total of six volunteer research assistants were recruited from the University of Salford. Volunteer research assistant positions were advertised to undergraduate and postgraduate psychology students. Recruitment for the research assistant positions began immediately upon ethical approval. Psychology program leaders were approached and asked to recommend suitable candidates based on the criteria of each role. With the permission of psychology program leaders, students were also directly approached by the researcher in lecture and seminar settings. All recommendations from psychology program leaders were considered. However, recruitment was aimed at individuals who had studied to a minimum of 2nd year undergraduate level, demonstrated a high level of engagement on the course (e.g., high registered attendance) and had some knowledge of ASD.

Four research assistants were recruited to help facilitate the social interaction tasks. Each of the research assistants were required to devote approximately four hours of assistance over two days of assessments. As the task was developed to assess a first-time interaction (interaction with a person they did not know) the research assistants were required to participate in only the pre-test condition or either the post-test condition. The role of the research assistant was to participate in two social interaction tasks during the assessments. Two research assistants were recruited to complete observer-rated assessment following the IRSA manual. Researcher assistants viewed a total of 10 video recordings (pre/post; 5/5) of a five-minute dyad interaction task. Both research assistants were blind to the condition (pre/post) of the test. Ratings were compared and disagreements were discussed until 100% agreement was established.

3.5.3 CBT Therapist Recruitment

Only applicants that had experience of working with individuals with ASD or that had worked in a clinical setting were considered. Two research assistants (one male and one female) recruited to help deliver the multi-modal CBSCTI-ASD intervention. Due to budget

constraints (i.e., no funding was provided for this PhD project), the CBT therapists who took part in this study were volunteers and received no financial compensation for their participation. The CBT therapists recruited for this study had previous experience as research assistants, but only one had experience of working with an ASD without ID adult population. However, both therapists reported to have had success of working with individuals with social anxiety, a condition which is often comorbid to ASD.

3.5.4 CBT Therapist Training

The two CBT therapists who delivered CBSCTI-ASD were provided with a copy of the intervention manual and several training workshops in advance of delivery. Training was conducted on a weekly basis and workshops were approximately an hour long. Training workshops were broken down into two phases of delivery: individual CBT session delivery and group therapy delivery. The first phase of training included three workshop sessions which focused solely on the delivery of individual CBT sessions. These training session workshops included an overview of the five areas CBT model, role-play, mock formulations, and a final session focusing communication. There were seven training session workshops which focused on delivering of group sessions and adhering to the CBSCTI-ASD manual.

Workshops 1-3

Training sessions were delivered using PowerPoint presentations and supplementary materials from the CBSCTI-ASD manual. The first session provided an overview of the Five Areas CBT model and formulation. Both CBT therapists were provided research literature on the Five Areas Model, reviewed diagrams of the model and were provided examples of the possible utility of the model. In the second session, the CBT therapists were provided with a hypothetical case study and were asked to formulate treatment using the Five Areas Model. This task was followed by a group discussion on the possible strengths and limitations of the model and how challenges may be addressed (e.g., time limited sessions). In the third and final session the focus was on effective communication. This session included providing psychoeducation on being aware of some ASD features which may be misinterpreted by the therapist (e.g., a lack of eye contact does not always suggest avoidance), along with addressing how to adapt communication towards individuals with ASD (e.g., avoid the use of non-literal terms and metaphors which are commonly used in CBT therapy).

Workshops 4-10

Each of the training workshops for the group social skills sessions were delivered using PowerPoint presentations and practical skills activities such as behavioural skills modelling. Training workshop 4 was an introduction session to the CBSCTI-ASD intervention manual. The topic focus of workshop 4 covered: intervention preparation, how to follow and use the CBSCTI-ASD intervention manual (e.g., understanding the manual key) and a brief overview of the curriculum, strategies and techniques covered in the CBSCTI-ASD manual. The subsequent two workshops (5 and 6) aimed to provide a comprehensive review of the phases and content of each group therapy session according to the intervention manual. The focus of workshops 7-10 were to provide training on key strategies (e.g., problem solving) and techniques (e.g., providing didactic instruction) used in the intervention manual. The final workshop involved a summary of training and a group discussion to voice concerns and ask any questions. In total, the CBT therapists completed approximately 10-hours of training before the commencement of the intervention.

3.5.5 Social Interaction Task

As part of participation in this study, and for the purpose of assessment, the participants were asked to complete two brief, five-minute social interaction tasks. The social interaction tasks were administered in an observation suite at the University of Salford campus. One of the tasks was video recorded for the purpose of observer-rated assessments. This task was developed specifically for use with the IRSA observer-rated assessment instrument manual. Participants were asked to start a conversation while playing a classic game of Tumble Tower (which is similar to the game Jenga).

Tumble Tower consists of 54 precision-crafted hard wooden blocks (see Figure 5). Players take turns removing one block at a time from the tower which is followed by placing that block on the top of the tower. Before participants began the game, the researcher provided detailed instructions on how to set up the tower and play the game. During this task the participants had five minutes to play the game and converse. If the game ended (the tower falls) before the five minutes were over, participants were instructed to simply reset the blocks and play again until the remaining time expired. The researcher provided instructions on when to begin and end the task over a loudspeaker from the control room of the observation suite. The social interaction during the task was video recorded with four video cameras and timing for each video were predefined and automatically stopped recording after

a five-minute duration. All video recordings were stored on a secure password encrypted computer.

Figure 5 *Image of tumble tower game used during observer rated assessment*



3.5.6 Parent Participation

Parents/Caretakers were invited to attend the individual CBT sessions but only two parents volunteered to take part in the study. The parents joined at the end of each individual session and were asked to play the supportive role of social coach (e.g., encourage homework completion or help towards achieving predefined SMART goals). Parents were also asked to complete the Multidimensional Social Competence Scale questionnaire (MSCS: Yager & Larocci, 2013) as a third-party assessment.

3.5.7 Setting

The University of Salford's psychology department facilities were utilised for conducting the intervention and all assessments. The therapy room which was used to facilitate the intervention was a large open space equipped with a white board, a computer

and a projector screen. In the middle of the room eight chairs formed a circle in which the whole group joined. This area of the room did not change over the course of the intervention and was used to facilitate group discussions and psychoeducation. In each corner of the room chairs were strategically placed so they could be easily accessed for break-out group activities. The break-out areas of the room were changed weekly in order to adapt to the needs of a task or group activity.

The observation suite was used to conduct all assessments. The suite was complete with a comfortable testing laboratory and a control room with multi-recording video from controllable cameras and a microphone to communicate with participants in the testing lab from the control room. The control room also included a one-way mirror for observation-based investigations in the testing laboratory. The testing lab was furnished with a soft armchair, a couch and a small table with four chairs. The suite was secured with a combination door lock and the testing lab and the control room required an electronic key for entry.

3.6 Data Collection and Analysis

3.6.1 Participant Semi-Structured Interviews

All interviews were recorded using an Olympus WS-853 digital recorder device. Semi-structured interviews were transcribed by the researcher using intelligent verbatim and the analysis process involved typical strategies such as coding, categorising chunks of data and making sense of the essential meanings of the phenomenon (Bernard et al., 2016). The transcripts were analysed using thematic analysis. The stages of the analysis involved familiarisation of the data, initial code generations, searching for themes, reviewing themes, defining and naming themes, and generating the final report (Braun & Clark 2006). An inductive approach to thematic analysis aimed to keep emerging themes grounded to the original data and to help reduce the influence of the researchers' existing knowledge and preconceptions.

Coding and analysis were conducted primarily on a semantic level. The study adopted a pragmatic mixed methods approach as the aim of the research was to capture lived experiences. Appose to adopting post-positivism or constructivism in two different ontological and epistemological camps, pragmatism ask the researcher to focus on the two

different approaches to inquiry (Morgan, 2014b). The foundations behind pragmatist epistemology is that knowledge is always based on experience and an individual's perceptions of the world are shaped by social experiences (Kaushik & Walsh, 2019). Pragmatist epistemology views knowledge as constructed with a purpose to better manage one's existence and to take part in the world (Goldkuhl, 2012) using both formal and informal rhetoric (Creswell & Clark, 2011).

3.6.2 Feasibility

Feasibility was assessed by monitoring fidelity, recording attendance and analysing participant satisfaction. In order to record intervention adherence rates the researcher kept an attendance log for all individual CBT sessions and group social skills training sessions. For data to be included in the study analysis, participants had to maintain a minimum of 80% overall adherence rate (a minimum of 12 out of 15 hours of therapy). Upon the completion of treatment, the participants were administered a short client satisfaction questionnaire (CSQ; Larsen et al., 1979). The CSQ was a self-report instrument only takes about five minutes to complete. Four out of the five participants also agreed to take part in a post-intervention interview. The semi-structured interviews were scripted with several questions (see Appendix J) which concentrated on the participant's personal experience and satisfaction with CBSCTI-ASD. All interviews were audio recorded and transcribed for analysis.

To ensure rigor of the intervention, adherence to the CBSCTI-ASD manual was monitored by a single observer using a fidelity checklist (see Appendix I). Case notes were taken for both the individual CBT therapy sessions and group therapy sessions (see Appendix H). Individual CBT case notes included the follow criteria: an attendance log, updated progress review, response to homework, preparations, session notes on formulations, future actions (e.g., new homework) and supervisor consultation (issue to bring to supervision). Similarly, the group session case notes criteria included: the group agenda, notes on individual contributions, a group behavioural rating and a weekly evaluation rating. Group behaviour ratings were provided on a five-point scale (1=low and 5=high). Weekly evaluations were provided at the end of each group session. Ratings were discussed and agreed upon by the therapists at the end of each group session. The scores were not used for data analysis but rather for the therapists to monitor progression and highlight any engagement issues.

3.6.3 Efficacy

The MSCS and the IRSA assessment measures were carried out approximately one week before and one week after the delivery of CBSTI-ASD. Reliable change indices (RCI; Jacobson & Truax, 1991) were computed to determine whether change in MSCA and IRSA scores from pre-treatment to post-treatment were significant for each of the participants. RCIs are usually regarded as standardized scores, and therefore, an RCI larger than 1.96 will occur in less than 5% of cases (Zahra & Hedge, 2010). Therefore, RCI values greater than 1.96 indicate statistically significant and clinically meaningful change. Advantages of RCI are that scores can be calculated for individuals without reference to control group data and they account for test reliability at both baseline and follow-up assessments which means less reliable tests will demonstrate a larger test-retest difference score to require a significant change (Zahra & Hedge, 2010). Related *t*-tests were conducted on the pre and post intervention scores of the MSCS and IRSA to determine changes at a group level were statistically significant.

4. Case Study Analysis

To protect the anonymity of those involved in the intervention, pseudonym names were used to identify participants and CBT therapists.

4.1 Case 1- Jim

4.1.1 Case History

Jim is a 22-year-old male. Jim was attending university undertaking a undergraduate degree and lived independently. Jim presented to therapy with a past diagnosis of Asperger's syndrome and depressive disorder. Jim had previously received counselling for depression, but he had never received specialist treatment for his ASD symptoms. The Asperger's syndrome diagnosis was supported by scores on the AQ. Intelligence assessments suggested that Jim had an above average verbal and visual IQ. During the six weeks of CBT therapy, Jim failed to attend two individual CBT sessions and one group therapy session. He also did not respond to a request to attend a post intervention interview. Reasons for missing sessions were due to a period of social isolation caused by symptoms of his comorbid depressive disorder. Jim did not have a parent with active involvement in the intervention and was solely responsible for adhering to the intervention sessions. During participation in the intervention,

Jim was receiving Fluoxetine and Sertraline to reduce symptoms of depression. Medication dose and treatment were managed by his General Practitioner (GP). In total, Jim received two hours of individual CBT and 10 hours of group therapy as part of the intervention.

4.1.2 Systematic Assessment

Jim presented with difficulties demonstrating empathy, understanding social inferences, and emotional regulation. Jim expressed a motivation to achieve more fulfilling relationships with others which included, entering romantic relationships. Jim expressed interests in music and instruments which he had often used as a coping mechanism to deal with problems in the past. However, this coping behaviour was often non-social and did not help with his ASD symptoms. Jim said he recognised social motivation issues were a barrier to practising social skills. In the past he had quit several choirs and instrument groups due to ASD symptoms leaving him feeling exhausted. Physical travelling, sensory overload and difficulties accepting others were all noted as barriers to proficiently navigating social situations. Jim's CBT therapist noted frequent fidgeting, limited eye contact, limited conversation (e.g., only responds, does not initiate), and flat affect in tone.

4.3 Case 2- Clare

4.3.1 Case History

Clare was a 21-year-old female. Clare lived with her parents and receives a considerable amount of support from her mother. Clare's mother participated in the intervention and took on a supportive role. Clare presented to therapy with a diagnosis of ASD, general anxiety disorder, Post Traumatic Stress Disorder (PTSD), and depressive disorder. The ASD diagnosis was consistent with her score on the AQ and Clare received an IQ score within the average range. Clare had received talking therapy for mental health issues in the past, but she had never received treatment for ASD. Clare was not receiving any pharmacological treatments for any of her diagnosed disorders before or during the intervention. Clare had a 100% attendance rate, completing the entire course of therapy.

4.3.2 Systematic Assessment

During the initial case formulation Clare reported issues with traumatic thoughts, sensory overload, independence, shame, and socialising with others. Clare suffered from a germ phobia and sensory overload which were barriers to social engagement. Clare's primary

issue was that she suffered from distorted thought which have manifested from negative school experiences during childhood and adolescents. She expressed feelings of shame and low self-esteem for having ASD and worried about judgment from others. The therapist noted that Clare was engaged and expressed a motivation to change which became greater over time. Eye contact and body postures were attentive and direct. Her CBT therapist noted some immature mannerisms during therapy, and she had a clear difficulty in managing vocal tone and pitch in conversations.

4.2 Case 3- Rick

4.2.1 Case History

Rick is a 21-year-old male attending university and living independently. Rick presented to therapy with a past diagnosis of Asperger's syndrome, depressive, anxiety, and obsessive-compulsive disorders. His diagnosis of Asperger's was consistent with his score on the AQ screening tool and his IQ assessment scored within the average range. Rick had received some CBT for anxiety and depression in the past and reported to have found it helpful. Rick had not received any past treatment for ASD, however during the intervention he was assigned an autism mentor by a separate support provider. During participation in the intervention Rick was receiving Fluoxetine for the treatment of a depressive disorder. Medication dose and treatment were managed by his GP. Rick had 100% adherence to the intervention and received the full course of therapy. Rick did not have a parent with active involvement in the intervention.

4.2.2 Systematic Assessment

Case formulation revealed that Rick was experiencing intrusive dark thoughts which caused low mood and high levels of anxiety. Rick would often experience ruminating negative thoughts of the world after reading/listening/watching stories in the media. In addition, large group social situations were particularly difficult, and he would avoid them whenever possible. Rick expressed feelings of shame and reported that his lack of daily structure exacerbated his negative thought patterns. The therapist noted that motivation was not an issue and nonverbal communication difficulties were limited to occasional evasive eye contact.

4.5 Case 4- Ken

4.5.1 Case History

Ken was a 28-year-old male. Ken lived at home with his parents and held down a part time job. Ken presented to therapy with Asperger's syndrome, anxiety disorder and depressive disorder. Scores from the AQ were consistent with an ASD diagnosis and IQ assessment scores for verbal IQ were within the average range, however his visual IQ score were below average. In the past, Ken had received talking therapies for mental health, but he had never received treatment for ASD. Ken was prescribed Sertraline for the treatment of depression and anxiety symptoms. Medication dose and management was handled by his psychiatrist. Ken's mother had an active involvement in the intervention and played a supporting role. Ken and his mother had 100% attendance and completed the full course of therapy.

4.5.1 Systematic Assessment

Early case formulation uncovered Ken's issues in the workplace which were causing significant amounts of frustration and high levels of stress. Ken acknowledged that his primary problem was work related stress and a lack of goal achievement. Ken struggled with social interactions and he often found it difficult to see problems within his own behaviour. The therapist used a SMART goal formulation with Ken to develop realistic short-term goals. In the short-term, Ken wanted to improve workplace issues causing stress. Ken also said he wanted to move to Rome so he could see his family and attend university. Ken's CBT therapist noted that he struggled to control his tone and he showed signs of stimming behaviour in conversations (e.g., nodding his head in a rapid manner when listening to a response).

4.4 Case 5- Alex

4.4.1 Case History

Alex was an 18-year-old male. Alex attended university and lived independently in student accommodation. Alex presented to therapy with ASD. No other co-morbid conditions or pharmacological treatments were reported. Scores from the AQ were consistent with an ASD diagnosis and IQ scores demonstrated an above average intelligence. Alex has a family history of ASD and received diagnosis in childhood. He was provided a place at a special

boarding school which provided him with social skills training and specialised support for ASD. Alex attended all sessions and completed the entire course of therapy. He did not have a parent with active involvement in the intervention.

4.4.2 Systematic Assessment

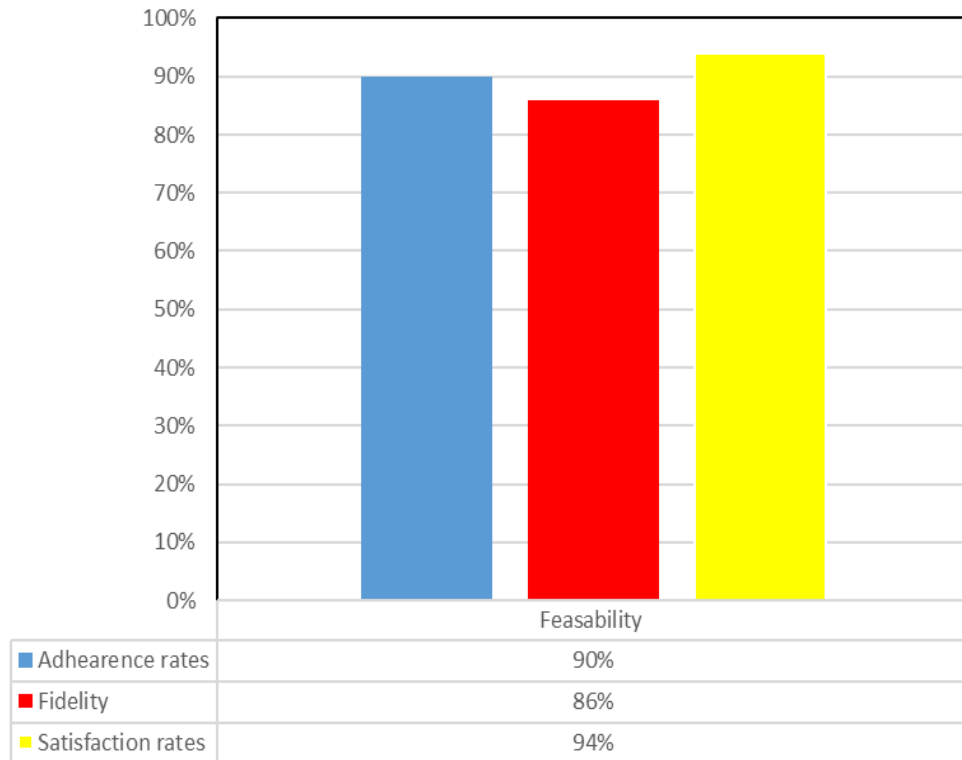
Alex was very clear from the start that he wanted to work on his social anxiety. The therapist started carrying out a formulation based on a recent event in which Alex had suffered from high levels of anxiety. Alex suffered symptoms of anxiety since childhood but recently these symptoms have worsened since starting university. As a result of his anxiety, Alex suffered from sleep disturbance and at times social isolation. The primary goal of therapy was to reduce levels of social anxiety relating to his university experiences and improve social interactions when in social situations with new people. Alex made proficient eye contact when in a single conversation, but he would often look down in group discussions. He would also exhibit stimming behaviour when talking in the group (e.g., sketching on paper) to help his concentration.

5. Quantitative Results

5.1 Feasibility Analysis

Feasibility of the CBSCTI-ASD program was supported within three fields as shown in Figure 6. Fidelity to the intervention manual objectives for each session ranged from ~86% to 100% over the six group therapy sessions. Overall, client satisfaction rates were very high based on scores from the CSQ-8 (mean score 30.20 / standard deviation 1.09). For all five participants, overall satisfaction was calculated at 94% post intervention. Adherence rates were also high with four of the five participants attending ~100% of all the intervention sessions. One participant failed to attend two individual CBT sessions and one group session which accounted for missing 3 out of 15 hours of therapy. For all five participants, overall adherence rates were recorded at 90%.

Figure 6 Feasibility assessment as measured from fidelity, adherence and participant satisfaction rates



5.2 Data Screening and Analysis

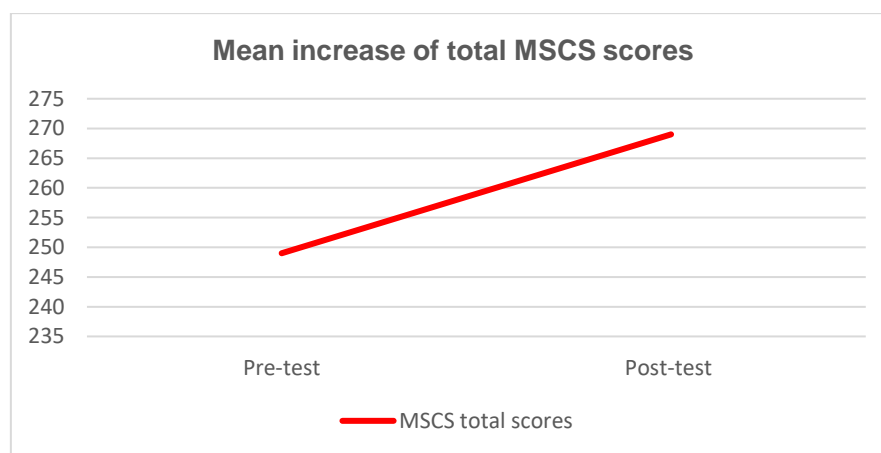
5.2.1 Related *t*-Test Analysis of MSCS Self-Report

The mean and standard deviation for the MSCS total scores and sub-set scores were calculated and are shown in Table 8 (see Appendix A for raw data).

Table 8 *The mean and standard deviation of MSCS scores*

MSCS Domains	<u>Mean (Standard Deviation)</u>	
	Pre-test	Post-test
Social Motivation	31.40 (10.62)	36.20 (8.79)
Social Inferencing	35.40 (8.33)	37.20 (7.89)
Empathy	38.20 (8.29)	41.40 (4.72)
Social Knowledge	40.60 (8.68)	42.80 (3.90)
Verbal Conversation	35.00 (7.28)	34.80 (1.10)
Non-Verbal Conversation	39.40 (3.21)	42.20 (3.83)
Emotional Regulation	29.00 (9.41)	34.40 (10.41)
Total MSCS scores	249.00 (34.02)	269.00 (19.01)

Inspection of the mean total MSCS scores of both conditions (see Figure 7) suggests that there were linear increases in social competence. Inspection of the sub-set domain scores also suggest that the group increased mean scores across all domains with the exception of verbal conversation. The standard deviation values suggest that the group had a greater spread of scores at pre-test compared to scores calculated at post-test.

Figure 7 *Mean increase of total MSCS scores*

In order to check whether the data met the assumptions for parametric analysis, the level of measurement of dependant variables were considered, the shape of frequency of

histograms and the standard deviations were compared (see Appendix B). The data was then analysed by a related t -test (see Table 9) which demonstrated that participants significantly increased total MSCS scores from pre-test to post-test $t(4) = -2.85, p = 0.02$. On the subscale domains participants demonstrated significantly higher scores from pre-test to post-test in social motivation $t(4) = -0.73, p = 0.02$, emotional regulation $t(4) = -.2.43, p = 0.04$., and non-verbal conversation $t(4) = -2.06, p = 0.05$.

Table 9 *Related t -test analysis results of MSCS total and subset domains*

Variable	t -values	Effect size	Significance
Social Motivation	-2.848	0.49	.02
Social Inferencing	-.726	0.22	.25
Empathy	-1.573	0.47	.10
Social Knowledge	-.736	0.25	.25
Verbal Conversation	.058	0.03	.48
Non-Verbal Conversation	-2.064	0.79	.05
Emotional Regulation	-2.425	0.54	.04
Total MSCS	-.545	0.72	.02

Note. bases on 1-tailed t -test analysis. Effect size measured using Cohen's d

5.2.2 Related *t*-Test Analysis of IRSA Observer-Rated

The median and interquartile range for IRSA total scores and sub-set scores were calculated and are shown in Table 10 (see Appendix A for raw data).

Table 10 *The median and interquartile range of the IRSA scores*

Variable	Pre-Test Median	Post-test Median	Pre-test Interquartile Range	Post-test Interquartile Range
Expressivity	7	8	6	3
Assertiveness	4	8	5	3
Sensitivity	4	6	3	4
Acceptance	8	8	3	3
Interpersonal Relationship	8	12	1	2
Self-control	15	18	6	2
Total IRSA	47	56	12	10

Inspection of IRSA median values suggest that total IRSA scores increased from pre-test to post-test. Inspection of the sub-set domain median values suggest that there was an increase in all domains with the exception of the Acceptance domain. The interquartile range values suggest that the spread of scores was similar between the pre-test and post-test conditions. In order to check whether the data met the assumptions for parametric analysis the level of measurement of dependant variables were considered and the shape of frequency of histograms were visually inspected (see Appendix B). As the normality assumption appeared to be violated on a number of sub-set scores, a non-parametric test was carried out (see Table 11).

A Wilcoxon Signed-Rank Test indicates that the median post-test rank IRSA total scores were statistically significantly higher than the media pre-test rank scores $Z= 15 p = 0.02$. Analysis of subscale scores indicate that there was a statistically significant increase from pre-test to post test in domains of Assertiveness $Z= 15 p = 0.02$, Interpersonal Relationships $Z= 15 p = 0.01$, Self-control $Z= 10 p = 0.03$ and sensitivity $Z= 6 p = 0.05$.

Table 11 Results of the pre/post-test Wilcoxon Signed-Rank Test

Pre/Post-test variables	Z statistic	Significance
Expressivity	5	0.14
Assertiveness	15	0.02
Sensitivity	6	0.05
Acceptance	2	0.29
Interpersonal Relationship	15	0.01
Self-control	10	0.03
Total IRSA Pre-test	15	0.02

Note. bases on 1-tailed analysis

5.2.3 Reliable Change Analysis

Reliable change for the MSCS and IRSA pre/post intervention scores are reported in Table 12. For MSCS self-report assessment, only Jim, Clare, and Rick demonstrated significant pre/post intervention improvements when calculating total MSCS scores. Clare demonstrated the greatest improvements overall (RCI=4.11), however significant improvements on sub-domains were limited to social knowledge (RCI=2.65) and verbal conversation (RCI=2.57). Jim demonstrated improvements in empathy (RCI=2.70) and emotional regulation (RCI=3.17). Rick showed improvements in social inference (RCI=2.59) and non-verbal conversation (RCI=2.05). Ken also demonstrated significant improvements in non-verbal conversation (RCI=3.59). Alex did not demonstrate any significant improvements.

For the IRSA observer-rated assessment Jim, Rick, Ken and Alex all demonstrated significant improvements on IRSA total scores. Ken demonstrated the greatest overall improvements (RCI=5.83) and was the only participant to have significant improvements in expressivity (RCI=3.82). For assertiveness Jim and Ken showed significant improvements (RCI=2.22). The largest significant gains for Ken (RCI=8.73), Jim, Clare, Alex and Rick (RCI=6.55) were in the sub-domain of interpersonal relationships. Ken (RCI=4.06), Jim and Clare (RCI=2.03) all showed significant improvements in sensitivity. Only Ken demonstrated significant improvements in acceptance however Jim showed significant declines in the acceptance sub-domain (RCI= -3.90). Rick was the only participant to show improvements in self-control (RCI=2.53).

Table 12 RCI values of pre-post intervention for each MSCS and IRSA domain

Participants	MSCS RCI values									IRSA RCI values					
	Social motivation	Social inference	Empathy	Social knowledge	Verbal conversation	Non-verbal conversation	Emotional regulation	MSCS total	Expressivity	Assertiveness	Sensitivity	Acceptance	Interpersonal relationship	Self-control	IRSA total
Jim	1.30	0.24	2.70*	0.408	-1.07	0.51	3.17*	3.16*	1.53	2.22*	2.03*	-3.90*	6.55*	0.84	2.38*
Clare	1.48	-0.94	1.35	2.65*	2.57*	1.54	0.45	4.11*	0.00	1.48	2.03*	0.00	6.55*	0.00	1.85
Rick	1.30	2.59*	-0.54	-1.02	-0.21	2.05*	1.13	2.00*	0.00	0.74	0.00	-1.30	6.55*	2.53*	2.38*
Ken	-0.19	0.00	0.27	0.41	0.21	3.59*	0.91	1.48	3.82*	2.22*	4.06*	2.60*	8.73*	1.69	5.83*
Alex	0.56	0.24	0.54	-0.20	-1.71	-0.51	0.45	-0.21	-0.76	3.70*	0.00	0.00	6.55*	0.42	2.12*

Note. RCI = reliable change indices; RCI > 1.96*.

6. Qualitative Findings 1: Participants Response

Thematic analysis identified the following four overarching themes from the interview data: 1. satisfaction with CBSCTI-ASD, 2. important components of CBSCTI-ASD, 3. challenges and critiques, 4. recommendations. These themes and combined sub-themes (see Table 13) are set out in the following section.

Table 13 *Study 1 themes and subthemes*

Themes	Sub-themes
Satisfaction with CBSCTI-ASD	Enjoyed the intervention Intervention was helpful Would recommend to others
Important components of CBSCTI-ASD	Parent involvement Group discussions Individual sessions
Challenges and critiques	Felt individual sessions were less helpful Improvements seen in individual therapy were not long-term. Some group sessions were less helpful.
Recommendations	Include new topic Should include more girls More one-to-one support Change phone roster task.

6.1 Theme 1. Satisfaction with CBSCTI-ASD

Enjoyed the intervention. Experiences of the intervention which were discussed by the participants were mostly positive. Many comments provide a description which elucidated specific aspects of what they enjoyed most about the intervention. Making friends and socialising were discussed by both Ken and Clare.

“I enjoyed the social element, alongside having various weekly goals. We became a good group and we have kept in contact since.” (Ken)

“I made friends that I would not have made otherwise.” (Clare)

Rick and Alex separately expressed their satisfaction of working in a group and learning about other people in the group.

“It was great to meet like-minded autistic people who I could really get to know over a number of sessions. It was very heart-warming to see how everyone progressed over the number of weeks. It was also interesting to learn more about autistic people and what they struggle with.” (Rick)

“I liked meeting the group. It was good talking and listening to other and hearing about their examples in the group discussion.” (Alex)

Ken’s mother, Anne, recalled seeing good social interaction with others and a positive attitude towards the other people in the intervention.

“Well I was glad that it was done, it was good seeing his interaction with the other people that were there, he was just so positive about the people who he was with.” (Anne)

Intervention was helpful. Everyone interviewed described some part of the intervention as helpful. Rick described finding the individual CBT sessions as the most helpful part of the intervention.

“There was lots that was helpful about the intervention... I think the counselling sessions were most helpful... Sandy educated me about the world of OCD, which is something I suffer from. We worked together over a number of weeks to build understanding of the condition and what I can do to prevent such frustration. She was very helpful.” (Rick)

Ken believed that the intervention helped him accept his condition and increase his social motivation.

“I would say that I have been more up-front about having Asperger’s and I have also noticed that I have made more of an effort in social situations, especially at work.” (Ken)

Ken's Mother, Anne, also expressed positive changes in his behaviour since the intervention.

"Yeah, he is trying to do more than I think ever before. He is trying so hard to move on and be fulfilled. See there were times when he would be down for months. He is doing better since being with you. He is trying to get paid work and doing more. We have opened a bank account now for him and he has his own money."

While Anne believes other factors are likely to also play a role in his behaviour change, she thinks that the intervention was helpful.

"He has turn 30 and it is probably a number of things, but it has definitely helped him coming to you and the group." (Anne)

Alex also describes no longer avoiding social situations and having increased motivation for social interactions since the intervention.

"I do more socialising such as eating in the kitchen in the halls when others are around. Before the intervention I would avoid the kitchen if others were around and wait to eat until everyone was gone." (Alex)

Alex continued to describe having increased motivation for social interactions and more control of negative thoughts since completing the intervention.

"I have more motivation to be around others and I try not to think negatively about what they may think of me." (Alex)

Clare reported that she had started dating since completing the intervention, however she did note that she did not know if it was the intervention which motivated such behaviour.

"So, friendship wise not much has changed but dating wise, um I never really understood the whole process of it but I am getting better at it somehow. I can't say it is because of the intervention but it has been since the intervention." (Clare)

However, Clare later described how she would have likely not started dating if it were not for the intervention and that her most recent experience was unpleasant but she felt that she coped better than she would have before the intervention.

“I would not have been able to sit there and be awkward, I would of actually ended up screaming at them, and then crying and shoving them out the door. Plus, the thing wouldn’t have happened in the first place. I have been trying to go out of my comfort zone which was why he was invited back to my house for the Doctor Who date. He asked for the second date and normally I would have said, “I’m not ready yet” or “I don’t know what we are going to do, blah blah blah. Inviting him over was a big “out of my comfort zone” because my house is my safe space, but I wasn’t going to go over to his place!” (Clare)

Clare expanded on what she found helpful and she highlighted a specific session which seems to have had long-term effects. Clare response below was in reference to a group session where strategies were taught for making a polite successful request.

“I couldn’t do it the entire session and I would have said it didn’t help me, but it did. For example, when you sent me that email the other day asking if we could move it, I went to write a response and when I was writing it at the end I thought about writing “I really appreciate it” like you taught us.” (Clare)

Clare’s Mother Sam reported that the intervention had a positive impact on Clare’s polite communication. Sam also believed that the intervention increased Clare’s confidence when communicating with other people.

“She became more confident, she definitely became more confident, and as I said before, her niceties came out. She started to use her please and thank you. She now says, “can I have” or will it be ok”. And definitely she is better at talking to other people once she is used to their faces and the environment.” (Sam)

Would recommend to others. All of the participants interviewed said that they would recommend the intervention to others. Rick expressed his reasons for why he would recommend the intervention to other autistic people.

“I would definitely recommend this intervention to other autistic people. It builds confidence but also polished my social skills. You are a very knowledgeable practitioner and it was good to get to know you. Sandy and Alan were also a delight to get to know and their counselling was most useful” (Rick)

6.2 Theme 2. Important Components of CBSCTI-ASD

Parent involvement. There were benefits to having a parent involved in the intervention which were highlighted in the interviews with Sam and Anne. Both parents played a supportive role for their children during the intervention. Anne believes that without her support, Clare would not have attended the group component due to her anxiety.

“For me it was helping Clare to get there, she would not have gone to the group session unless I had taken her in, and I had been in the building. She needs to know I was in the building.” (Sam)

“I had to always ask him, and I would do thing with him, but I think it was more about what you did and the group.” (Anne)

Group sessions. Group sessions account for approximately 80% of the intervention. The group sessions were a key component for learning and practising new social skills. Each comment highlights the participants perception of the group.

“I preferred the group... learning different techniques were quite useful.” (Ken)

“...the group sessions let me practise social skills, which I eventually used to help be more social in the halls of residence.” (Alex)

“Whilst I would like to think I am fairly competent in social interaction, the intervention was reassuring and polished up my communication skills.” (Rick)

While Clare had apprehensions and anxiety when starting the group sessions, by the end of the study they were her favourite modality of the intervention.

“I always liked the groups sessions the most. It was easier sitting and talking in the group setting rather than doing activities that were not natural to us. I think it was always easier in the group setting too because it wasn’t always pressured to keep the conversation going by yourself, because there is only two of you, instead there are a bunch of you, and you can take your go when you were ready to talk, or you have something important to say.” (Clare)

Individual CBT sessions. Individual sessions were reported to be helpful for setting targets and working on anxiety. Most notably, some participants expressed feeling less anxiety because of this modality.

“The individual sessions were really good to set targets and work on my anxiety and the group session let me practise social skills, which I eventually used to help be more social in the halls of residence.” (Alex)

Rick found the individual CBT sessions helpful for working on his anxiety. In particular, he highlights psychoeducation and finding the therapist helpful in his response.

“I think the counselling sessions were most helpful...Sandy educated me about the world of OCD, which is something I suffer from. We worked together over a number of weeks to build understanding of the condition and what I can do to prevent such frustration. She was very helpful.” (Rick)

6.3 Theme 3. Challenges and Critiques

Individual sessions were less helpful. Ken expressed mixed feelings for individual CBT sessions. He found a goal orientated approach more helpful than psychoeducation.

“Yes, I kind of felt that Alan was more generalised, rather than focusing on individual issues. Like the one week that Sandy took over she told me about Improv Comedy Workshops and she seemed to be more goal orientated in her approach, rather than just, here are some sheets on this have a read.” (Ken)

Ken highlights the importance of building a strong therapeutic alliance. He believed that individual CBT sessions would have been more helpful with a different therapist who better understood his needs.

“I think I would have like to have Sandy because the one week she took over because Alan wasn't in, she had me learning about different things in Manchester that I wasn't aware of that were beneficial socially.” (Ken)

Ken's Mother expressed a similar opinion in her separate interview. She was upset that he did not benefit more from the individual CBT therapy sessions

“No disrespect to the other chap, he was very good, but I think Ben would have done better with Sandy. I was a little sad about that to be honest, see been needs one-to-one.” (Anne)

Clare expressed a dislike for the individual sessions because of the CBT approach.

“I didn't like it because the type of counselling it was, well it was the face everything directly, that sort of stuff.” (Clare)

Improvements seen in individual therapy were not long-term. Clare felt that while she did improve when attending sessions, these improvements were not long lasting. Clare believed that the root of the problem had not changed. However, Clare also acknowledged that she did

not continue the gradual exposure exercises once the intervention ended and since then the anxiety had returned.

“I had to go stand outside my old school which wasn’t nice. I do feel that even though I did get better at doing it over time and I did do it a lot, it is not like the reason for not wanting to do it disappeared. So now that I have stopped doing it daily, the anxiety is back every time we pass the school. So, nothing has changed like that, and I still try to dodge teenagers, I still don’t like touching things, so yeah, it just wasn’t the type of counselling that worked on me.” (Clare)

Some group sessions were less helpful. Rick reported that he felt some parts of the intervention were repetitive and too basic for his level of social skills ability.

“There may have been a few moments during the intervention where it was a little repetitive and a little basic. However, I appreciate why this was required.... The skills training was interesting, but slightly repetitive as I am well practised at this and feel assured in this setting.” (Rick)

Clare said she enjoyed the group sessions more than the individual sessions. However, she highlighted her preference for the group discussions component of the group sessions because she felt less comfortable participating in the practical social skills activities.

“It was easier sitting and talking in the group setting rather than doing activities that were not natural to us.” (Clare)

Ken reported enjoying the final session, however he found it the least helpful part of the intervention because he felt the group did not learn anything new.

“The last one was the least helpful in the fact that we didn’t really do many techniques, but it was also very fun because it was more informal.” (Ken)

6.4 Theme 4. Recommendations

Include new topics. During her interview, Clare discussed her experience of starting to date and she expressed that the topic of romantic relationships was very important and reported how little she understands about dating behaviours.

“It is a big part of life and you don’t get lessons on it in school and for an autistic person that doesn’t understand socialising in the first place, well then it’s a whole different ball game. You just don’t understand how to do it.” (Clare)

Clare’s Mother Sam shared her feelings about how challenging dating can be for her autistic daughter. Sam describes the emotional impact of watching her daughter struggle.

“...but her biggest challenge is that she wants a boyfriend, and this is where we are struggling. It is heart breaking to a parent to watch your daughter go, oh I want a boyfriend, I want to get married and have children.” (Sam)

Should include more girls. Sam believed that more girls were needed in the social skills group. Sam felt that having more girls would have helped Clare feel more comfortable.

“I would say there was only one thing and that was the Clare was the only girl. I know you had problems getting girls in but I think, we both thought, it would have been good for her to have another girl. She would have felt more comfortable quicker and settled.” (Sam)

More one-to-one support. Ken’s Mother, Anne, felt he would benefit from an intervention with more individualised support.

“I think Ken could have done with more one to one support. He saw that chap and that lady once didn’t he, but more of that would have been good.” (Anne)

Change phone roster task. Rick found the phone roster task anxiety provoking and he believed providing a topic to discuss each week could have made the task easier.

“The request to ‘speak on the phone’ may have been aided with subjects to talk about. It was a little too broad, which I think created anxiety for participants” (Rick)

7. Qualitative Findings 2: Therapist Response

Rich qualitative data was gathered to reflect the therapist’s experiences of delivering the intervention manual. The patterns which emerged from the data include three themes: Training and delivery, successes and challenges and therapist recommendations.

7.1 Theme 1. Training and Delivery

Sandy and Alan both expressed satisfaction with training and delivery of the CBSCTI-ASD intervention. Alan felt the training made it easier to understand and follow the manual during group sessions.

“Without the training we did before the start, I don’t think I would have had the knowledge or the confidence to facilitate the group sessions.” (Alan)

Alan described how he found it helpful to use what he learned from training.

“You taught me to focus more on thoughts than emotions which was really helpful when working with Alex.” (Alan)

Sandy remarked about the benefits of reading the manual in advance of delivery.

“I found that reading the manual before we started was helpful.” (Sandy)

Sandy also found the training sessions helpful for discussing the content of the manual and asking questions.

“The meetings we had were also really good to discuss what was in the manual and I thought you did well to answer our questions.” (Sandy)

Both therapists found the intervention manual clear and easy to deliver. Sandy also expressed that she believed others would also find the manual easy to deliver.

“I thought the manual was clear and concise and anyone can follow it, and not just myself. But any person could pick it up without prior experience could still understand it and follow through with implementing it.” (Sandy)

“I felt the manual was well structured and I didn’t note anything difficult about it.” (Alan)

Sandy discussed her satisfaction with using the five areas formulation as a visual approach to identifying symptoms in individual CBT therapy.

“I used it at first as an initial symptom indicator. It was a good visual representation of the issues we would work with to start. It allowed us to go straight into the assessment and discussing interventions... they were quick at catching on because it was more of a visual thing. I like to use visual notes when working with people with autism. It’s the diagram and the flow of information that makes it work. Visual representation as well and verbal is really important because for some it’s hard to follow just verbal instruction.” (Sandy)

Alan described the formulation model as helpful for keeping formulation simple.

“I did find it helpful, it let me keep the formulation simple.” (Alan)

Sandy and Alan shared the opinion that adherence to time was sometimes difficult during group session activities and group discussions. Sandy also believed that the “check-in activity” could have taken a more directive approach at times.

“The only one thing is possibly time keeping, there can be a lot of push and pull between the therapist and the clients and this can make it difficult to cover everything without being time rigid. I feel because our group jelled really well, they wanted to express a lot about their life, but this may not always be the case. I also think that check-in sometime could have been more specific rather than a general discussion.” (Sandy)

“I agree about the time issue, some of the discussions could have been longer after completing an activity.” (Alan)

Alan recalled some resistance during the phone roster homework task and suggested that it be modified.

“I would change the phone roster homework. It may be that phone calls are less common with young people but no one in the group constantly engaged with it and they all ended up communicating on a Facebook group. Maybe suggest a social media group or text messages.” (Alan)

Alan described how he believed that individual and group sessions were both important for achieving change in Alex.

“Yes, with Alex he showed more confidence as the session progressed and I believe that was more because of the group work. While he had a great understanding and self-awareness it was the behavioural aspect that he needs to work on. It was good because we would talk about change in the individual sessions and I could see changes occur in later group sessions.” (Alan)

Sandy believed there was a benefit to having group therapy alongside individual CBT therapy.

“Especially those that found it difficult to verbalise for long periods of time. The group setting allowed everyone to share,

so the focus was not always just on one person, unlike the individual sessions”.

Alan and Sandy both expressed satisfaction with the group therapy curriculum and believed keeping things simple was of benefit to the group.

“we covered a lot, but the skills overlap, so it felt like less work. I had no issues with the curriculum at all.” (Alan)

*“I agree, don’t underestimate the power of simplicity...”
(Sandy)*

7.2 Theme 2. Successes and Challenges

Alan and Sandy discussed working with participants during individual CBT sessions and the successes and challenges they experienced. Alan discussed the challenges Alex faced with his anxiety symptoms. He described working collaboratively with the social anxiety model and how Alex had a positive response to therapy.

“With Alex the main aim was to reduce his social anxiety and face some issues he was apprehensive about. From the start of therapy to the finish I noticed, and he reported less anxiety in social situations. Alex said in the closing session that he felt he had achieved the goals set out in therapy. We explored the social anxiety model and we collaboratively identified behaviours which he was reinforcing with ruminating thoughts.” (Alan)

Alan described using mini exposure tasks to help Alex reduce his social anxiety.

“A prominent social situation that was very anxiety provoking for Alex was socialising in the university halls of residence. Before the start of therapy Alex would wait to enter the kitchen until it was empty and would avoid eating a times when other were around. After a few weeks of rationalising and exploring different perspectives he started to see the benefit to meeting others in the halls. After the 3-4 mini exposure tasks, he started

sitting and eating with other residence in the halls with limited anxiety.” (Alan)

Alan discussed how the work in individual therapy had a positive impact on group therapy.

“For Alex, it was a combination of rationalising and exposure which helped to overcome some of the earlier anxiety. It was also evident in the group sessions that his anxiety had reduced, and he was seeking more social interaction with others in the group.” (Alan)

Alan also believed the group sessions were helpful and provided Alex with more confidence.

“Yes, with Alex he showed more confidence as the sessions progressed and I believe that was more because of the group work.” (Alan)

While challenges were few when working with Alex, Alan described working with Ken to be more challenging. In the early stages of individual therapy, Alan experienced some difficulties collaborating and communicating with Ken.

“A challenge I had was due to communication. Ken in particular, at times felt that I wasn’t listening to him, but as the therapist, I was aware of the time focused aspect and that we only had time to work on short-term goals. There were issues that the client wanted to focus on that were beyond the scope of realistic achievements.” (Alan)

Alan reported difficulties in setting realistic goals, even with the help of Ken’s Mother.

“Ken had a lot of goals at the start and some seemed out of reach. I used SMART goals and invited his mum into the session to help set his goals. Unfortunately, Ken was not very flexible, however he did acknowledge that some of his goals seem a bit wild.” (Alan)

Alan described how he worked with the challenges experienced with Ken and there was some noticeable resistance at the start.

“We tried breaking the goals down into; short, medium, and long term. Ken wanted to learn to control his anger and deal with conflict in a better way. We implemented the STOPP technique, but he was rather resistant at the start.” (Alan)

Alan explained that having the involvement of Ken’s Mother in the intervention was helpful.

“Overtime he engaged more, and his mother was very helpful, and I felt having his mother involved was very helpful. By the end of therapy Ken had memorised the techniques and was using it frequently at work. Other techniques we used involved funny imagery.” (Alan)

Alan described that Ken reported believing that he had reached some of his goals in individual therapy.

“Ken did say he felt he achieved his short- and medium-term goals. He had started to join new social groups and at the end Ken also anecdotally reported feeling better mentally and emotionally”. (Alan)

Sandy did not experience communication issues when working with Clare, however she did report that progress was at a slow rate.

“Now with Madison I found her change more gradual and progress was a little slower, but her goals were defined and clear. We worked on fear and social anxiety.” (Sandy)

Sandy describes the problems Clare faced, her motivation for change, and the interventions used which aimed to help reduce symptoms of anxiety.

“She responded well to gradual exposure, we explored her behavioural activations and her motivations. She wanted to see her friends more and the reward of dealing with these issues would be that she could see them more in person. She had

agoraphobia and PTSD from past experiences in school, she received a lot of bullying.” (Sandy)

Sandy explains the process of the gradual exposure intervention and how Clare completed the task.

“She wouldn’t even drive past the school even though it was just up the road, the homework tasks progress so one week she was to walk past the school on the weekend, then on a weekday, she eventually stood outside while school let out”. (Sandy)

Sandy also described her work with Rick and how he eventually reached his primary goal of reducing his anxiety.

“He wanted to work on shame and guilt causes by ruminating thoughts, or intrusive thoughts which he could not stop thinking about. We worked on his feeling about the thoughts and by removing the strong emotion, so taking the heat out of the thoughts which were quite shocking and triggering, and rather taboo. We talked through this issue and Rick said in the final session, that from the start till the end, intrusive thought and negative emotions have reduce by 90% for me”. (Sandy).

Both therapists discussed challenges keeping the group focused and engaged. Alan suggested more scaffolding for those which struggle to hold attention or stay on topic.

“I don’t think it was necessarily always difficult, but some tasks were harder than others. ... someone like Ken, that is so likely to go off and have difficulty focusing, sometimes made it difficult.” (Sandy)

“Yes, I agree and possibly more scaffolding for those individuals that need more guided focus.” (Alan)

Sandy believed that some tasks were difficult and created anxiety for those which felt uncomfortable completing a task.

“I don’t think it was necessarily always difficult, but some tasks were harder than others... In the task where they had to enter a

group conversation, Rick was nervous and apprehensive... I think that the more out of the comfort zone you take a client the harder it is to get them to engage.” (Sandy)

7.3 Theme 3. Therapists Recommendations

Both therapists also made several recommendations based on their experience of intervention delivery. Adapting communication style was highlighted as an important factor for effective intervention delivery. Alan believed that it was important to have clear communication and ensure discussions are appropriately paced.

“I think it’s important to seek constant clarification with an Autistic client and allow time to respond or take mini-break.” (Alan)

Sandy described how she used specific probing questions to help her quickly identify problems during formulation.

“I found with my group, identifying problems to work on quit quickly and easily because I was very direct with my probing questioning. It was important to be very specific and avoid being general. You let them connect the dots to make their own general conclusions”. (Sandy)

During the group sessions some individuals struggled to stay focused on the topics. Sandy suggested that it may be helpful to introduce some grounding exercises to refocus those with attention difficulties.

“I think there were times where excitability may have had an impact on Ken in particular. May some grounding exercises would have helped with this. It’s just a suggestion but someone like Ken that is so likely to go off and have difficulty focusing sometime made it difficult”. (Sandy)

In addition, Sandy recommended expanding the intervention to include components which focus more on emotional awareness and recognition.

“There could have been more focus on emotion in terms of understanding expressions and identifying emotions in others. Although we did do some work on non-verbal behaviour, we really didn’t discussed expressions of emotion which would fit in well, I think.” (Sandy)

Alan found benefits to adapting formulations in order to place greater emphasis on identifying thoughts and understanding the perceptions of others.

“Yes, it was mainly thoughts that were clearly identified. I think this approach was particularly useful with Alex when we were discussing what it would be like for other. I asked what he thought it would be like for others.” (Alan)

Sandy also described how she adapted formulations to focus more on thoughts and behaviours, however at times emotions were still an important part of the discussion.

“I agree, there was way more focus on behaviour and thoughts and a lot less on emotion. I found the only time that emotions were really discussed were to assess how they were feeling in relation to a specific anxiety provoking activity or situations which made them depressed. Often emotions were discussed in terms of a contrast of before and after a situation to encourage that they can complete an activity that was anxiety provoking. Also, when discussing emotions, I found this to be done by highlighting examples of behaviour and assessing what emotion were felt, so if they describe going out a lot in the week, I would link this to feelings such as being motivated, happy or in just in a good mood.” (Sandy)

Alan did not have experience of working with an ASD population before the intervention and he provided some recommendations based on the challenges he faced. Alan believes knowledge of ASD and working with an experienced supervisor is important. He also recommended that a collaborative understanding should be established and verified with the individual with ASD before progressing to new discussions.

“They should learn about autism. You should also ensure you have been understood and that you understand them before moving forward. It is also helpful to have a supervisor with experience of working with autism to be as effective as possible.” (Alan)

Alan struggled to set goals with Ken, and he believed that more time spent on visualising SMART goals could be helpful to challenge unrealistic targets.

“In hindsight, I would have spent more time on SMART goals as a visually demonstration of the challenges of unrealistic targets.” (Alan)

Sandy has worked with ASD individuals in the past and draws upon her experience delivering the current and past intervention. Sandy points out the importance of clear communication and building a strong therapeutic relationship early in the therapeutic process.

“I also advise to establish a strong therapeutic relationship early and set clear goal at the start. When communicating, be clear with speech and avoid using metaphor.” (Sandy)

Sandy also believed that it may be beneficial to have a less intensive intervention. She suggested that shorter sessions over a longer time period may reduce fatigue and increase engagement.

“Yes definitely, and maybe even shorter sessions but over a longer time frame. I think it’s a demanding interaction and some may be more disengaging if the task or discussion is too long. Many said they were tired at the end of the sessions, and so was I.” (Sandy)

In their final remarks, Sandy and Alan both expressed that they would recommend the intervention to others.

“I have actually informed my workplace that I have worked on this project and that we could possibly use it for our service users with ASD.” (Alan)

“After the improvements that I saw in my clients, I would definitely advice others to use it.” (Sandy)

8. Discussion

The primary objectives of this study were twofold: 1. To develop the CBSCTI-ASD manual. 2. To assess the feasibility of delivering CBSCTI-ASD to young adults with ASD without ID. The participant satisfaction rates and adherence to treatment were recorded at 94% and 90%, respectively. High attendance rates were particularly promising as most of the participants in the sample lived independently or semi-independently and were responsible for their own attendance. In addition to participant self-report questionnaires which demonstrated very high treatment satisfaction, semi-structured interviews revealed that the participants would recommend the program to other young adults with ASD without ID. All participants interviewed (including two parents) believed the intervention or parts of the intervention were helpful. In addition, therapist fidelity to adhere to the CBSCTI-ASD objectives within group sessions were calculated to be high at 86%. Additionally, the CBT therapists who delivered the intervention reported that they would recommend CBSCTI-ASD to other professionals.

A separate objective of this study was to investigate the efficacy of the CBSCTI-ASD program on social competencies in an adults ASD without ID population. Assessment of individual improvements from pre-post intervention were analysed using RCI. Only Jim, Clare, and Rick made significant pre/post intervention social competence improvements based on total MSCS scores. Clare demonstrated the greatest overall improvements. With the exception of Alex, all participants demonstrated significant improvements on at least one of the sub-domain scales. Clare significantly improved scores in social knowledge and verbal conversation. Jim also improved scores in empathy and emotional regulation sub-domains. Rick showed improvements in social inference and non-verbal conversation. Ken only demonstrated significant improvements in non-verbal conversation. Alex did not demonstrate any significant improvements. For group changes, *t*-test analysis indicated that there were significant increases in overall social competence as measured by the MSCS total change

scores. However, only the sub-domains of social motivation, non-verbal conversation and emotional regulation reached levels of statistical significance. A medium to large effect (Cohen's *d*) was found for total MSCS cores and the sub-domain non-verbal conversation. A small size effect was seen on the sub-domain of social motivation and a medium effect was reported for emotional regulation. Verbal conversation, social knowledge and social inferences did not reach significant levels of change.

The IRSA observer-rated assessment showed that Jim, Rick, Ken and Alex all individually demonstrated significant improvements on IRSA total scores. Ken demonstrated the greatest overall improvements in observed social competence and he was the only participant to have significantly improved in the sub-domain of expressivity. Jim and Ken both demonstrated significant improvements in assertiveness. Across participants there were significant improvements in the sub-domain of interpersonal relationships. Rick was the only participant to show significant improvements in the sub-domain of self-control. Ken, Jim and Clare demonstrated significant improvements in sensitivity. Ken was the only participant to demonstrate significant improvements in acceptance. Unexpectedly, Jim demonstrated a significant decline in the sub-domain of acceptance. As a group, total IRSA scores demonstrated significant increases from pre-test to post-test in all participants. Statistically significant increases were found from pre to post-test on IRSA sub-scales in Assertiveness, Interpersonal Relationships, Self-control and Sensitivity. However, the sub-scale scores of Expressivity and Acceptance did not reach significance as a group.

There are a number of possible explanations for the findings. First, it is possible that the process of being taught social skills may have actually caused the participants to reflect on their difficulties and become more aware of their symptoms at post-test. Since the intervention was somewhat brief (only 6 weeks of sessions) and the assessment was conducted in a relatively short time period, after the completion of the intervention there may have been a delay in perceived improvements. Laugeson and colleagues (2015) found that while most improvements in their sample were maintained at a 16-week follow-up assessment, over time new improvements were also observed (e.g., additional treatment gains were reported in the domains of problem behaviours, externalising behaviour, self-control and social awareness). The results found in this study are consistent with previous research. Manualised group social skills interventions for adults have been found to improve overall social skills (Ashman et al., 2017; Gantman et al., 2014; Laugeson et al., 2015), social

motivation, assertion (Laugeson et al., 2015), empathy (Ganman et al., 2014; McVay et al., 2016), self-control (Gantman et al., 2014) and social communication (Laugeson et al., 2015; Turner-brown et al., 2008).

Anecdotal data also revealed some support for intervention feasibility. CBSCTI-ASD was seen by participants as a bonding experience which fostered friendships. During the intervention participants even took it upon themselves to meet up socially outside the confines of therapy. Alex, Clare, Rick and Ken all expressed satisfaction with the intervention and all reported feeling the intervention was of benefit. Notably, in relation to the group modality, active listening skills and conversation skills were highlighted as areas which participants felt improvements were made. Alex and Rick both found the individual sessions helped to set targets and work on symptoms of anxiety, while the group sessions encouraged the practise of social skills. Some participants also said they felt more motivated to engage in social interactions as a result of the interventions. Reductions in anxiety were also reported, however Clare did not believe that her improvements in her anxiety levels were long lasting. During their separate interviews, both parents (Anne and Sam), believed that improvements were made as a result of CBSCTI-ASD. Their subjective evaluations were in-line with the finding from the quantitative arm of this study. Parents reporting that they noticed increased social motivation, acceptance, independence and improved social etiquette after completing CBSCTI-ASD. Overall, findings support the feasibility and efficacy of CBSCTI-ASD for improving social competencies in young adults with ASD without ID.

8.1 Recommendations and Remediations for CBSCTI-ASD

Some intervention preferences were expressed by the participants in their separate interviews. Rick found the individual CBT sessions to be most helpful for his problems because some of the skills taught in group sessions were seen as remedial for his level of social competence. Although feeling the groups sessions were less helpful, he did express enjoying the social aspects of these sessions. Social competence can often vary significantly between individuals with ASD (Howlin & Moss, 2012; Rattaz, et al., 2018) and Rick's experiences highlight one of the difficulties of developing a "one size fits all" group curriculum for improving social competencies in an ASD population.

In its current form, the CBSCTI-ASD manual did not include a peer-mediated social skills approach in any of the components. A peer-mediated approach is where individuals

with greater social abilities help teach social skills to their socially impaired peers (Chang, & Locke, 2016). This approach may have been beneficial for those individuals, like Rick, that have a higher level of mastery in some social skills, but still take great benefit from the group social interactions. Recently, a small pilot study delivered a peer-mediated intervention to four adults with comorbid Down Syndrome and ASD with ID (Davis, Spriggs, Rodgers, & Campbell, 2018). Peer mediators in this intervention study had a diagnosis of Down Syndrome with ID and were able to reliably deliver the peer-mediated social skills intervention to those with comorbid ASD/ Down Syndrome with ID. When further developing the CBSCTI-ASD manual, inclusion of a peer-mediated approach deserves further consideration. Including more peer-mediated activities (e.g., behaviour modelling or use of video feedback to examine social interactions) could increase levels of engagement, especially at times when individuals feel more competent with a particular skill or skill set being taught.

Rick also felt that the phone roster homework task caused anxiety and would be improved by providing a predefined topic to discuss each week. During the group therapy sessions, group members all expressed feeling uncomfortable with the phone roster task and reported taking it upon themselves to set up a Facebook group for their communication. The group was set up by one group member and included only those completing CBSCTI-ASD. As the Facebook group was not part of CBSCTI-ASD, group facilitators did not have any involvement. Further consideration should be given to making adaptations to the phone roster task to reduce the anxiety of engaging with others. Structure is a fundamental concept in teaching individuals with ASD (Mesibov et al., 2004) and as such, the CBSCTI-ASD manual could be adapted to provide more structure to the phone roster task by including a list of specific topics to discuss on the phone each week (e.g., my hobby, favourite music). In addition, internet access has provided a new format for social support groups and recently there has been a significant swing in the ASD community towards computer-based Facebook social support groups (Mustafa, Short & Fan, 2015; Roffeei, Abdullah, & Basar, 2015).

A significant amount of consideration would be needed to ensure safety and appropriate group behaviours when developing a internet-mediated social interaction group activity for the CBSCTI-ASD manual. However, once included, future participants may find the interaction less stressful, leading to more frequent social contact. An internet-mediated social interaction group could also be used as a springboard to address the topic of online

behaviours more broadly (e.g., online dating). Online training interventions provided to children with ASD and their parents are becoming increasingly more popular in school settings (Good & Fang, 2015), yet interventions such as these for adults with ASD are still in their infancy (Backman et al., 2018). There also appears to be only a limited few evidence based social skills intervention for adults with ASD which address the topic (e.g., Laugeson, et al., 2015).

It is believed that symptoms associated with ASD place adults at a high risk for victimization from others (Eldeson, 2010; Hannah & Stagg, 2016). Even in other clinical populations characterized by social skills impairments (e.g., Attention-Deficit/Hyperactivity Disorder), the symptoms specific to ASD appear to increase risk of victimisation (Ohlsson Gotby, Lichtenstein, Långström, & Pettersson, 2018). In particular, impairments in verbal (e.g., pragmatic language) and nonverbal (e.g. understanding social cues) social communication can lead to difficulties interpreting social cues and differentiating between safe and unsafe individuals (Hannah & Stagg, 2016; Sevelever, Roth, & Gillis, 2013). Addition risk factors for victimization in ASD populations are a lack of independence (e.g. reliance on others), social isolation, obedient compliance, and limited sex education (Eldeson, 2010; Sevelever et al., 2013). In addition, both male and female adults with ASD have been found be more likely to experience unwanted sexual contact, sexual coercion, and rape when compared to a typically developed adults (Brown-Lavoie et al., 2014). It is apparent that there is a need to help support individuals with ASD to safely navigate social interaction on the internet and avoid the dangers of either being a victim or even unintentionally victimising others using online platforms.

It has also been argued that clinical factors associated with ASD can impact on culpability when committing crimes such as online sexual offenses (Allely, Kennedy, & Warren, 2019). While less is known about how ASD symptoms manifest into offending behaviours, a recent study conducted interviews on nine sexual offenders with ASD and finding suggest that social difficulties, misunderstandings, limited experience of sexual relationships and inadequate self-control possibly contributed to offending behaviours (Payne, Maras, Russell, & Brosnan, 2020). Intervention has been shown to reduce the risk of individuals with ASD reoffending (Railey, Love, & Campbell, 2020) and early intervention during the transition into adulthood may reduce the risk of an offence being committed. Expanding CBSCTI-ASD to include a component addressing internet safety and risk of

victimisation may go some way to reducing vulnerability. This topic could either be developed as a singular component or be interwoven throughout the different CBSCTI-ASD components, complimenting a variety of social competence topics, in particular, romantic relationships and sexual behaviours.

The only female participant which received CBSCTI-ASD believed it was important to include a component on relationships and dating. After completion of CBSCTI-ASD, Clare had a motivation to begin dating but struggled with the actual experience. Research has shown that concerns for social and romantic relationships are common for individuals with ASD. For example, a large study which included 232 individuals diagnosed with ASD found that while there were similar levels of interest in relationships between both typically developed and ASD populations, individuals with ASD reported less opportunities to engage in romantic relationships, more short-lived relationships, and greater concern for long-term relationships (Hancock, Stokes, & Mesibov, 2020). It is likely these relationship difficulties are due to several factors. For example, when compared to a typically developed population, individuals with ASD have been shown to have less understanding of sexual behaviour and rely more on sex education from non-social sources such as browsing the internet and less sex education from social sources such as teachers and parents (Mogavero, 2016). Developing a component within CBSCTI-ASD which addresses appropriate and inappropriate behaviour regarding friendships, dating, sexuality and longer-term relationships could be helpful for improving dating experiences and relationship outcomes.

Clare also expressed a preference for the group sessions because she did not like the individual CBT approach. She did highlight that the collaborative discussions and listening to other's experiences were her favourite aspect of the group sessions. Clare reported that the "*face everything directly*" nature of CBT is what she disliked the most. She found that the gradual exposure activities did help her with handling stressful events during therapy, however CBT strategies were not maintained, and social distress returned after therapy ended. In the future, modifications to weekly review formulations during the CBSCTI-ASD individual sessions may help to better identify strategies which are unlikely to be maintained. Explicitly addressing satisfaction of a given intervention approach or activity could help the therapist collaboratively identify alternative CBT interventions such as: reading self-help CBT literature, internet-based CBT, psychoeducation or mindfulness CBT (Bennett-Levy et

al., 2010). This minor modification could possibly improve communication and increase maintenance strategies.

Ken also expressed a preference for the group sessions because he found it difficult to work with his CBT therapist during individual sessions. Ken's therapist Alan had no experience of working with individuals with ASD and while Alan completed all CBSCTI-ASD training, his lack of experience may have affected communication with Ken. The therapeutic relationship has been shown to be an important predictor of the development of social skills in children with ASD, most notably, communication and language (Mössler et al., 2019). However, clinicians with less experience of working with ASD may miscommunicate or even overstimulate an individual with ASD and therefore risk inhibiting the therapeutic relationship which fosters change (Lerner et al. 2012). While there are advantages for clinicians with less experience to participate in training workshops, it is clear that clinical experience significantly improves their ability to yield more positive treatment outcomes in an ASD population (Bennett-Levy, McManus, Westling, & Fennell 2009; Kuyken & Tsivrikos, 2009, Mannix et al., 2006; Westbrook, Sedgwick-Taylor, Bennett-Levy, Butler, & McManus, 2008). For best outcome results, it has been highly recommended to provide clinicians with a theoretical understanding of an intervention, combined with applied experiential activities (Beidas & Kendall, 2010).

The CBSCTI-ASD training for the CBT therapists included many of the strategies discussed in the literature, however the remit of training primarily focused on delivery and learning the CBSCTI-ASD manual content. Remediations to the training workshops should include a greater emphasis on supervision, reflective practices and barriers to building a therapeutic relationship. In addition, the training workshops for CBSCTI-ASD are not currently provided in the CBSCTI-ASD manual. Including these workshops within the current CBSCTI-ASD manual or developing a separate training manual will be key for ensuring high fidelity and the best possible outcomes. Unfortunately, there is little guidance for clinicians about the implementation (e.g., feasibility, effectiveness) of evidence-based interventions for adults with ASD (Wainer et al., 2017) and there are no universal guidelines for the training and supervision of CBT therapists delivering ASD interventions (Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015). Ensuring effective delivery is an imperative factor to consider when evaluating the efficacy of CBSCTI-ASD. As there are no known

studies which systematically compare the training strategies provided to clinicians delivering CBT interventions for adults with ASD, further investigations are greatly needed.

8.2 Research Limitations

There are several potential limitations that warrant consideration. The first notable limitation of this study is the small sample size, limiting the certainty with which quantitative results can be interpreted. Although the small sample size may have limited the power to detect potentially meaningful clinical effects, the primary objective of this study was to assess feasibility before conducting larger trials to test efficacy. A further limitation is the non-normal distribution of outcome variable data on the IRSA. Caution should be taken in comparing effect sizes directly to effect sizes from other samples. It is also worth highlighting that all participants opted into the study by self-referral and as a result may likely represent a subset of adults with ASD who have more intrinsic motivations for sociability and are able to better cope with group situations without the need for caregiver support.

Limitations of the study also include the quasi-experimental nature of the research design. A general issue with a case study design is that the results are difficult to generalise to the wider population. In addition, the IRSA outcome measure was designed to be used by a range of professionals as a practical assessment of social competence and was not specifically developed for blinded assessments of individuals with ASD. As the IRSA is also not a standardised measure for use within an ASD population, findings should be interpreted with caution. While the IRSA subscales do appear to cover some of the most common social competence components addressed in previous ASD studies, the measure does not comprehensively represent all dimensions of social competence (Anme et al., 2014). In addition, sensitivity to change has yet to be established for the IRSA. Although, change was found in this study, large-scale clinical studies are needed to demonstrate normative change scores for an adult ASD without ID population. As mentioned earlier, the IRSA instrument has only been previously used in one clinical trial with ASD participants and they all had comorbid ID (Munesue et al., 2016).

It should also be noted that the researcher had direct involvement in the intervention which may have caused subjective feelings which could have influence the case study (e.g., researcher bias). In addition, due to the first-time delivery of CBSCTI-ASD manual, there

were some notable difficulties in delivering the intervention as intended according to the manual. Difficulties were primarily caused by the need to adjust the amount of time for participants to complete a specific task or discuss a particular topic during group sessions. Despite this limitation, all of the content from each session were delivered by the group facilitators and all tasks were completed by the group members.

It is possible that difficulties in adhering to the intervention manual were due to the characteristics of the participants (e.g., longer processing time) rather than the therapist's ability to follow the protocol structure. It is apparent that the researcher failed to account for the variability of the participants social competencies during CBSCTI-ASD development. Finally, the CBSCTI-ASD manual cannot be recommended for use across all cultures since much of the skills content is based on social behaviour norms in western cultures. For example, Chinese international students studying at university in the US have been found to be less comfortable with overt social behaviours (Yan & Berliner, 2011) and social protocols such as maintaining eye contact during conversations or negotiations, can be viewed as inappropriate in other cultures (Woo & Prud'homme, 1999).

8.3 Future Research Direction

Moving towards robust large-scale trials will be necessary before conclusions of efficacy can be established. It is important to implement CBSCTI-ASD in different settings with more diverse samples. A true randomised control design with multiple control conditions (e.g. TAU control group, intervention control group and wait list control group) would be the most rigorous way to test the efficacy of CBSCTI-ASD. To establish the broader utility of CBSCTI-ASD, research needs to move beyond clinical settings. Delivery of CBSCTI-ASD in community and educational settings where young adults are more likely to be preparing for the transition into adulthood will be important in future studies. Funding and policies play a significant role in many educational and community settings, so it is important to be able to deliver interventions within a reasonable budget. Further investigations should investigate the feasibility of parents and caretakers either leading or helping to facilitate the group sessions. Past research has shown that the utility of a manualised parent-lead social skills intervention is feasible for improving social interaction skills in children and youths with ASD (Pugliese et al., 2020; Radley, Jenson, Clark, & O'Neill, 2014). Adapting the

CBSCTI-ASD group sessions to be delivered by trained parents may increase the utility of CBSCTI-ASD while also reducing the cost of delivery within a community setting.

It is also important to include a more diverse participant population (e.g., include more females with ASD) in future studies. In the study presented in this chapter, there was only one female with ASD which limited any investigation into gender differences in response to CBSCTI-ASD. Additionally, it may be worth investigating if a mixed gender group provides an added component for social change. Males and females alike may benefit from learning about the shared experiences expressed by each other, which could possibly improve confidence and social motivation for those interested in establishing future relationships with the opposite sex.

Validated assessment materials which measure behavioural changes in adults with ASD are also greatly needed (Brugha et al., 2015). Future studies should aim to adapt existing youth instruments or develop new instruments for assessing ASD behavioural outcomes specifically for adults with ASD. Costly ASD screening instruments have been used in past social skills intervention (e.g., Ashman et al., 2017; McVay et al., 2016; White et al., 2015), but many of such instruments were not designed to be sensitive to change. Additionally, only social competencies outcome measures were used to determine efficacy and it is possible CBSCTI-ASD impact may be further reaching. Research has shown that group CBT has the potential to reduce stress in individuals with ASD (McGillivray & Evert, 2014; Weston et al., 2016). Further investigations on the impact of CBSCTI-ASD on mental health symptoms may further support the anecdotal data which suggest anxiety reduction were experienced.

Assessment of the efficacy of CBSCTI-ASD was also limited to pre/post-testing alone. It is important for future studies to conduct follow-up assessments to measure the longer-term impact of CBSCTI-ASD. However, follow-up assessments should not be limited to experimental methods. Qualitative investigations of the experiences gained since the delivery of CBSCTI-ASD may help to provide more specific details of why the intervention either did or did not have long lasting effects for a specific individual. Future research could also benefit from providing a more robust assessment of the training given to the CBT therapist delivering CBSCTI-ASD. Interview responses by the CBT therapist provide some

anecdotal data about the training experience but future research should also investigate if different training approaches impact on intervention delivery.

Further investigations of CBSCTI-ASD should also include the addition of multiple control groups (e.g., more than one intervention group and a no treatment control). Comparing different groups may help to determine if improvements were specific to the components of the CBSCTI-ASD program or to other factors (e.g., self-motivated social interactions external to the intervention). Ashman and colleagues (2017) utilised an intervention control group and found no benefits to a structured manualised group social skills intervention when compared to a non-specific social interaction intervention group. It is possible that social skills can be improved by simply increasing the number of social interactions experienced. It is possible that for some adults with ASD, the nature of social interactions includes working components which can improve social competence without the need to be completely directed.

9. Conclusion

There are very few evidence-based social competence interventions with a group component which have been developed specifically for adults with ASD. Most intervention efforts have focused on youth populations (Gates et al., 2017), yet many individuals with ASD encounter significant challenges in adulthood. Unemployment or difficulties at work, poor academic performance, limited social interaction and poorer quality of life are not uncommon factors for those with ASD which are struggling to cope with the demands of adulthood (Miller et al., 2014). It is imperative that evidence based adult ASD interventions are highly accessible and cost effective before they can be considered for use within community and clinical settings. This study provides both qualitative and quantitative evidence to support the use of a CBSCTI-ASD within an adults ASD population. CBSCTI-ASD was found to be acceptable and beneficial for those with difficulties in social functioning and may have the potential to improve the outcomes of this increasingly recognised population.

Chapter 4: Study 2: Neuroplasticity of the Social Brain Following CBSCTI-ASD

1. Introduction

The study within this chapter was primarily interested in investigating the neuroplasticity of CBSCTI-ASD. A simple social conversation task which resembled a real-life two-way conversation was developed for this study. Naturalness of the conversations were an important element to consider for ecological validity during non-invasive optical imaging of the brain. Participants in the ASD intervention group and the typically developed control group completed the conversation task while having their brain scanned using a novel neuroimaging technique. Findings from brain scans during the conversation task were used to identify neurological biomarkers which served as regional brain targets for assessing changes in neurological function over time. Finding patterns linking to neurological biomarkers using brain scanning technology could be effective in identifying specific pathways which could serve as objective theragnostic tools alongside gold standard ASD assessment instruments (Yang et al., 2017).

1.1 Background

One possible explanation for the core ASD symptoms associated with social and communication impairment is the social brain hypothesis (Dunbar, 1998). The social brain hypothesis is a strongly supported theory which suggest the social brain is responsible for the mediation of social cognitive functions, however the exact relationship between impaired social cognition and impaired brain function remains somewhat unclear (Peng et al., 2020). Social cognitions can include; identifying and perceiving emotions, understanding the viewpoint of others, demonstrating joint attention, face perception and understanding and responding to other autonomous agents (Patriquin et al., 2016). There have been attempts to map the social brain using neuroimaging technologies and the medial prefrontal cortex (MPFC) has been shown to play a significant role in social brain function (Di Martino et al., 2009). More specifically, the MPFC appears to play a role during the natural social interactions of having a conversation with others (Suda et al., 2011).

It has been shown that individuals with ASD can have structural and functional brain differences when compare to typically developed participants (Nickl-Jockschat et al., 2012;

Patriquin et al., 2016). A great deal of focus has been given towards investigating social cognitive processes related to potential functional neuroendophenotypes in ASD (Patriquin et al., 2016; Phillip et al., 2012). In clinical research biomarker refers to objective biological signs which can be accurately measured and may influence and predict the incidence and outcome (Uddin, Dajani, Voorhies, Bednarz, & Kana 2017). Neuroanatomical and neurofunctional biomarkers provide a visual map of the social brain in ASD and some biomarkers are essential for the function of the social brain networks (Pelphrey, 2014). These networks can include function in the MPFC, orbitofrontal cortex, anterior cingulate cortex, amygdala, temporoparietal junction, inferior frontal gyrus, superior temporal sulcus (STS), and the fusiform gyrus (Blakemore et al., 2007; Easton & Emery, 2004; Frith & Frith, 2008; Kennedy & Adolphs, 2012; Nomi & Uddin 2015; Oberwelland et al., 2017; Pelphrey & Carter, 2008).

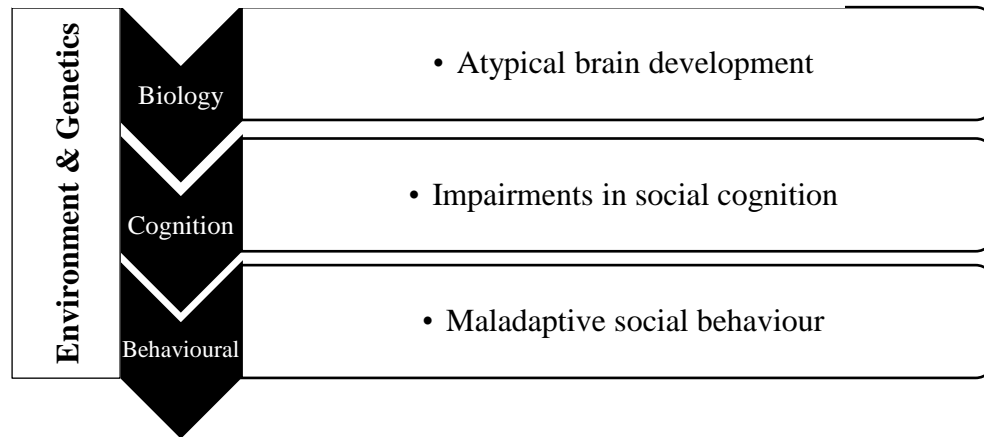
The utility of biomarkers has been gaining interest in recent years and researchers have even demonstrated a map of functional connectivity within the ToM network of individuals with ASD (Deshpande et al., 2013). Additionally, a study by Kana and colleagues (2017) utilised Functional Magnetic Resonance Imaging (fMRI) to examine the role of social brain networks in self-others processing in young adults with ASD. Participants in the study completed a task where they were asked to make “yes” or “no” assessments of whether a visual adjective described themselves (self) or their favourite teacher (others). During self and other processing both the ASD group and the typically developed control group demonstrated a significant increase in activity in the MPFC. Contrary to past research findings (e.g., Di Martino et al., 2009; Sugranyes et al., 2011), functional differences in the MPFC were not significant between groups. Group differences were found in other social brain regions. Between groups analysis showed significantly reduced activity in the left inferior frontal gyrus and left inferior parietal lobe in the ASD group when compared to the typically developed control group. Additionally, while processing self-related words, the ASD group demonstrated significantly weaker functional connectivity of the anterior cingulate cortex. Although findings were somewhat mixed, this study help further identify important functional frontal lobe regions associated with the social brain in individuals with ASD.

Despite some mixed findings amongst the research, meta-analyses findings on the social brain in ASD have consistently shown that MPFC is typically less active across a

variety of social task demands when compared to typically developed individuals (Di Martino et al., 2009; Sugranyes et al., 2011). Individuals with ASD have demonstrate hypoactivation in the MPFC in response to social cognitive task demands when compared to typically developed controls in a number of studies (e.g., Sugranyes et al., 2011; Peng et al., 2020). However, group differences in MPFC activation may relate more to specific social stimuli and it is possible that the MPFC is a less reliable marker for measuring social impairment under certain conditions than previously believed (Kanna et al., 2017). It is apparent more evidence is needed to support the MPFC as a viable target for measuring the effects of interventions on social cognition.

1.2 Neuroimaging and Social Skills Interventions

Understanding the brains response to psychological interventions is an important advancement in clinical research (Faja et al., 2012; McPartland & Pelphrey, 2012; Van Hecke et al., 2015; Yang et al., 2017) and may contribute to understanding a causal chain for ASD. The model in Figure 8 describes a causal chain, which in its simplest form, involves the influence of environmental and genetic factors on three levels of interaction: biology, cognition and behavioural. Measuring activity of the neuro-biological markers potentially associated with ASD, may provide convergent validity between biological and behavioural assessments. A multiple assessment approach may provide a more accurate indication that the intervention is acting on brain mechanisms associated with social cognition and social behaviour. To date, only a select few psycho-social intervention studies have attempted to measure brain plasticity leaving low external clinical validity.

Figure 8 *Causal model of ASD*

There has been some ASD social skills intervention research which has revealed that there may be a significant degree of plasticity in the neural systems associated with social impairments (Van Hecke et al., 2015; Yang et al., 2017). In a study by Yang and colleagues (2017), fMRI was used to successfully identify pre-treatment neurological biomarkers which accurately forecasted the response to Virtual Reality-Social Cognition Training (VR-SCT) in a sample of young adults with ASD. The VR-SCT was a novel five-week intervention which totalled 10 hours of computerised social cognitive training. Functional connectivity analyses revealed that within the adults with ASD which improved performance on social cognitive tasks, the general increase in connectivity was found in the right STS and the MPFC.

The only evidenced-based comprehensive manualised group social skills program to measure neurological change in response to intervention comes from a randomised controlled trial of the *PEERS* (Laugeson & Frankel, 2010) intervention (Van Hecke et al., 2015). Assessment using EEG provided instantaneous feedback of brain activity while adolescents with ASD focused on a fixation point displayed on a computer monitor. Researchers found that adolescents with ASD who completed the *PEERS* intervention demonstrated a shift from right hemisphere to left hemisphere dominant EEG asymmetry (Van Hecke et al., 2015). Findings show the magnitude of left dominant EEG asymmetry was related to fewer reported ASD symptoms, increased social contact and increased knowledge of social skills. The authors also reported that EEG data for adolescents with ASD no longer significantly differed from that of the typically developed controls following successful completion of the intervention. Unfortunately, the main disadvantage of EEG recordings are they produce poor spatial resolution, limiting the identity of exactly which areas in the left hemisphere of the brain were most active.

Interventions which specifically target the neural mechanisms associated with social competencies in adults with ASD may greatly improve intervention outcomes. As research advances and neuroimaging techniques improve, it is possible that neuroimaging assessment methods may provide greater accuracy for measuring symptoms and treatment outcomes for individuals with ASD (Ansel et al., 2019; Bölte et al., 2015). Although neuroimaging studies have shed light on potential neuroendophenotypes of ASD, it has been argued that they have not yet established sufficient validity to translate into reliable biomarkers that can be used in clinical practice (Goldani, Downs, Widjaja, Lawton, & Hendren, 2014).

The emerging evidence from a range of current neuroimaging studies indicate several areas of the social brain to be potential neural bio markers of ASD. Across the studies published on the social brain of individuals with ASD, there is a lack of consensus on a specific region or network that may serve as neurobiological indicators. Identifying neural markers is essential to understanding the biological underpinnings between both typically developed and ASD individuals alike. It is possible that reliable biomarkers can support a diagnosis of ASD (Ecker & Murphy, 2014; Ecker, Bookheimer, & Murphy, 2015), and improve the assessment and design of targeted interventions which aim to enhance social competence, more specifically, the social cognition abilities needed to be socially proficient when interacting with others (Patriquin et al., 2016).

1.3 Objective Assessments of Neural Function in ASD

Assessments of adult ASD interventions can often be difficult because very few objective methods exist for reliably measuring ASD related outcomes. For instance, a recent review of outcome measures in intervention trials for adults with ASD found that the current data on the validity or reliability of ASD instruments to assess change in adult populations is limited (Brugha et al., 2015). In addition, most assessment methods used in the ASD intervention research rely on the subjective perceptions of change by others (e.g., caretaker, clinician or teachers). This brings further concerns since research has shown that many individuals who are less knowledgeable about ASD will often overestimate the performance of individuals, while those who are actually most knowledgeable about ASD often underestimate performance (McMahona, Stolla, & Linthicum, 2020). As such, levels of knowledge could have a significant impact on self-reported assessments which brings further concerns for use as a single proxy for outcome assessments.

To reduce the reliance and limitations of subjective assessments of ASD, more objective measures are greatly needed. Biomarkers have the potential to increase our pathological understanding of ASD by highlighting the processes behind this heterogeneous disorder (Di Martino et al., 2017; Hiremath et al., 2021; McPartland, 2016). In intervention research, validation of biomarkers to measure change provides researchers with the ability to avoid reporting biases and distinguish between actual change or placebo effects (Masi et al., 2017). Learning the differences in brain function between individuals with ASD and typically developed controls can aid researchers in the development of broader models of ASD, provide an objective measure to reduce diagnosis waiting times and help further validate intervention outcome assessments (Grecucci, Siugzdaite & Job 2017).

Using advanced technologies with innovative neuroimaging protocols may one day help clinicians to accurately detect and clearly characterise features of ASD. In a recent review (Hiremath et al., 2021) of emerging behavioural and neuroimaging biomarkers related to ASD revealed that neuroimaging research can play a crucial role in the early detection and accurate characterisation of irregular brain functioning. However, this research is still in its infancy as many of the studies included in the review rely on very small ASD samples. The conclusions from the review were heavily based on ASD related behavioural impairments associated with structures of the brain, brain volume and functional brain connectivity using Magnetic Resonance Imaging technology. Due to assessment challenges specific to individuals with ASD (e.g., sensory issues), it is important to ensure that neuroimaging assessments are feasible for this population. fMRI is a non-invasive neuroimaging technique that uses a strong magnetic field to measure hemodynamic change and provide high-resolution images of brain activity. Data from fMRI studies has also identified functional brain patterns in ASD which can be distinguish from typically developed individuals. However, there continues to be some questions on the feasibility of using fMRI within the literature, thus limiting the reliability of fMRI for identifying specific biomarkers for ASD assessment (McPartland et al., 2021).

There are several limitations which need to be noted when considering the use of fMRI assessments within ASD research and clinical practise. A recent study investigated the feasibility of using fMRI scanning in a clinical trial for children with ASD aged from 3-12 years (DeMayo et al 2021). Children were reported to have no functioning constraints for participation at the start of the research, however only 24 children out of 71 recruited

successfully completed both an fMRI scan and other assessments at baseline. High volume noise during scanning and feelings of confinement were issues reported which could have possibly affected the brains response to assessment. For those who did complete the assessment it was important to have flexibility and tailor the experience for each of the participants. Dependent on the paradigm used during assessment, this may be more difficult for researchers to achieve. While fMRI does provide a tool for gathering objective assessment data, it does not appear feasible for use with children (McPartland et al., 2021) and feasibility for use with adolescents and adults with ASD has yet to be established.

In recent years, electroencephalogram (EEG) has been a popular objective neuroimaging assessment used in ASD research (Brihadiswaran, Haputhanthri, Gunathilaka, Meedeniya, & Jayarathna, 2019). EEG is a safe non-invasive direct method of measuring neural activity by strategically placing electrodes which measure electrical activity of the brain on the scalp. EEG has recently been used to identify ASD characteristics and help to predict appropriate treatments. For instance, a recent study used EEG and eye-tracking technologies to assess both typically developed and ASD children (Kang et al., 2020). For all 97 children, their resting state EEG data was recorded, and they also performed eye-tracking tests individually on stimuli of own-race and other-race stranger faces. Findings revealed that combining the two types of data, the accuracy to classify groups reached approximately 85%.

Similarly, a very recent study combined EEG and facial thermographic data into several computerised learning models in an automated approach to ASD classification. The integration of EEG and thermographic data achieved approximately 94% accuracy when classifying individuals with ASD from control subjects (Haputhanthri et al., 2020). EEG has also been used to assess improvements in children with ASD after receiving intervention. Pivotal Response Treatment (PRT) is a ASD intervention based on applied behaviour analysis (Lei & Ventola, 2017) and has growing empirical support for producing therapeutic gains in social communication skills (Koegel, Ashbaugh, & Koegel, 2016; Verschuur et al., 2014). A recent pilot study (Hegarty et al., 2019) utilised EEG to assess 18 children's response to a PRT program. The researchers observed associations between baseline structural properties in language regions of the brain and improvements in language abilities following PRT (Hegarty et al., 2019). Unfortunately, due to the limitation of EEG, the precise mechanism behind neurological change could not be established in this study.

Compared to fMRI, EEG appears to be a more feasible objective ASD assessment since it does not have the limitations of loud noise and containment during neuroimaging (Amaral et al., 2018; D’Croz-Baron, Baker, Michel, & Karp, 2019). However, the low spatial resolution of EEG means data is not useful for pinpointing exact locations of brain activity, and it does not allow researchers to distinguish between sources of activities which are closely related. Functional near-infrared spectroscopy (fNIRS) is also a non-invasive, optical neuroimaging device which looks similar to EEG in its application, but it provides better spatial resolution by assessing hemodynamic changes similar to fMRI. An additional benefit to fNIRS over EEG is that it requires less setup time and includes a less intrusive application process e.g., eliminated the need for cream scrub and gel application to the scalp.

There have been two systematic reviews which have reported on the feasibility of using fNIRS as an objective assessment within an ASD populations (Butler, Kiran, & Tager-Flusberg, 2020; Zhang & Roeyers, 2019). Across the studies in both reviews, methods included a variety of tasks which aim to assess features such as executive functioning, language and speech, and social perceptions. Resulting patterns of cortical level activity in individuals with ASD have been similar across several cognitive, social, and language assessments. Similar to other neuroimaging research, the current fNIRS findings suggests that there is reduced activity in the MPFC, inferior frontal gyrus, and/or STS activation in both children and adults with ASD when compared to closely matched typically developed controls (Butler et al., 2020; Su et al. 2020; Yeung et al. 2019; Zhang & Roeyers, 2019). It appears that similar to EEG, fNIRS is more feasible to use with an ASD population than fMRI but also benefits from providing more location accuracy than EEG.

Currently, there appears to be no one assessment measure or set of assessment methods or instruments that can be considered a standardised measure for outcome evaluations in adult ASD intervention trials. Developing studies that can measure both biomarker and behavioural change in response to psychological interventions has become an important goal in recent ASD research (Faja et al., 2012; McPartland & Pelphrey, 2012; Van Hecke et al., 2015; Yang et al., 2017). A multiple assessment approach may provide a more accurate indication that the intervention is acting on brain mechanisms associated with social cognition and social behaviour. To date, only a select few psycho-social intervention studies have attempted to objectively measure the brains response to intervention. It is important for researchers to provide evidence towards the feasibility and validity of neuroimaging

techniques before they can be regularly used to objectively assess and evaluate change in ASD.

1.4 Aims and Objectives

Aim 1. To measure the neurological activity of participants during a conversation task in order to identify viable neurological biomarkers of the social brain.

Aim 2. Investigate the utility of Functional Near-Infrared Spectroscopy (fNIRS) to measure changes in neural function over time.

Objective: The primary objective of the study is to measure the brains response to CBSCTI-ASD.

1.5 Hypotheses

H1: Demand from the conversation task will significantly increase oxy-HB activation in the MPFC, an area implicated in the social brain and the pathology of ASD.

H2: During task demand, the intervention group will demonstrate decreased activation in the MPFC when compared to the typically developed control group.

H3: As a result of completing CBSCTI-ASD, over time the intervention group will demonstrate greater increases in oxy-Hb concentration during task demand in the MPFC when compared to the control group

1 Method

3.1 Design

A quasi-experimental design was used in an attempt to quantify the neurological response to CBSCTI-ASD. Functional Near Inferred Spectroscopy (fNIRS) assessed social brain function in the ASD intervention group (participants from study 1) and a typically developed control group. During the conversation task there were three scanning conditions: 1. Resting brain 2. Entering a conversation 3. Maintaining a conversation. The fNIRS devise uses near-infrared light to measure associated changes in hemodynamic responses related to the neural activity in cortical regions of the brain. More importantly, fNIRS is a validated instrument for measuring hemodynamic response in human brain imaging research during naturalistic tasks

(Noah et al., 2015). The oxy-hemoglobin (oxy-Hb) signal was selected as the signal source due to superior sensitivity in detecting task-related changes, along with a high correlation with oxy-Hb level-dependent signals in fMRI (Toronov, Zhang, & Webb, 2007).

The brains response to stimuli within the three conditions during the conversation task were measured for associated increased levels of local oxygen consumption which increases cerebral blood flow and blood volume in the brain. Measurements of oxy-Hb were taken during a simple conversation task at pre and post intervention testing. Pre and post-test task activation oxy-Hb estimates were calculated and converted to change values. Multivariate analysis of variance (MANOVA) were run to measure between-group differences in oxy-Hb change values. Post hoc *t*-tests analysis were run to measure within-group differences. MANOVA analysis were performed with group (intervention group vs typically developed control group) as the independent variable and oxy-Hb concentration task activation change values were the dependent variables. In addition, to investigate differences in social competence between groups, pre-test and post-test social competence assessment scores were converted to change values and analysed with MANOVA.

3.2 Participants

See Chapter 3, Section 3.2 for intervention group characteristics

3.2.1 Inclusion Criteria for the Control Group.

Inclusion criteria for the control group required that participants were typically developed and between the ages of 18 and 30 years. During the intake interview participants reported no presence of a current medical or mental health condition that could impact their ability to be involved in the study. Participants were administered the MSCS (Yager & Larocci, 2013) self-report questionnaire and the IRSA (Anme et al., 2014) observer rated assessment. All control participants social competence scores fell within the range found in a typically developed sample. To control for basic demographic differences, control participants with a close match of age and gender to that of the intervention group were selected.

3.2.2 Control Group Characteristics.

Participants were recruited from an undergraduate psychology cohort. The researcher advertised by strategically placing poster around the university campus. Four typically

developed males and one typically developed female respondents who were closely matched in age were recruited to take part in the control group. The age range between control group participants were 19-30 years with a mean age of 21.4 and a standard deviation of 4.8. Control group participants were British second year undergraduate psychology students recruited from a University in the North West of England.

3.3 Materials

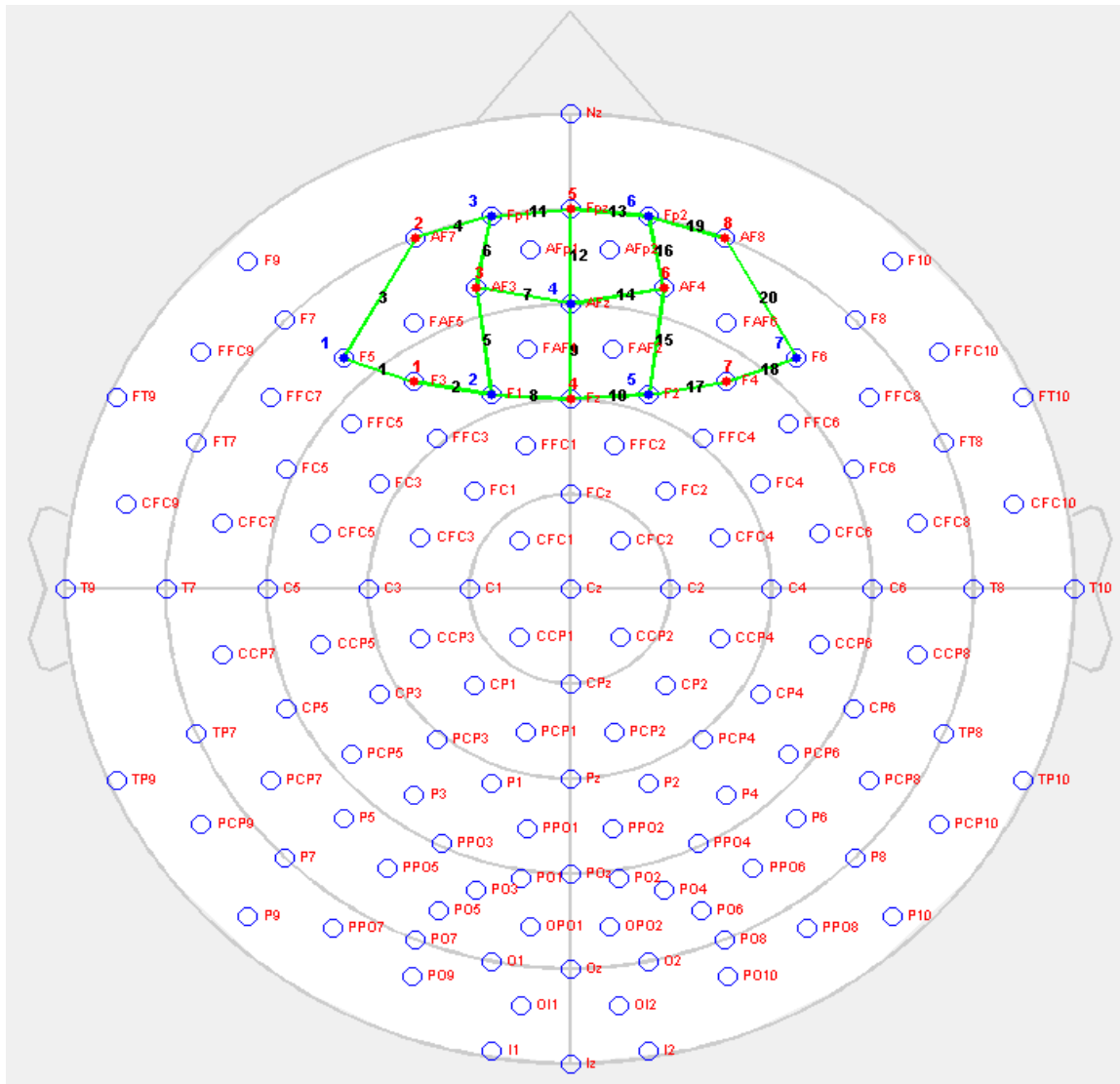
3.3.1 Functional Near Infrared Spectroscopy (fNIRS)

EEG and fMRI have been popular neuroimaging techniques which have been widely used for decades, however advancements in technology have led to the development of several other neuroimaging techniques which includes fNIRS (Liu et al., 2017). In recent years, EEG and fMRI have been vital for investigating brain function, however there are several disadvantages when compared to fNIRS techniques. For instance, fNIRS provide superior spatial resolution compared to EEG, and is more accurate at locating the signal source from the brain (Liu et al., 2017). The benefit of the fNIRS device is its compact, mobile and demonstrates more tolerance of movement than fMRI, which allows researchers to create tasks with more ecological validity (e.g., Suda et al., 2011; Liu et al., 2016). Furthermore, fNIRS is more cost-effective than using fMRI, making it more accessible to use for interventions which may involve several scanning sessions.

Changes in oxygenated haemoglobin were measured using a 52- Channels (Chs) NIRSport device and NIRStar program (NIRx Medical Technologies, 2015). As a region of the brain becomes functionally active, the metabolic activity of neurons increases and cerebral blood flow to that region increases (Attwell & Iadecola, 2002). In addition, cerebral blood volume, oxygen metabolic rate, and oxy-Hb will increase (Liu et al., 2017). Near infrared light is moderately transparent to biological tissues. fNIRS requires low-intensity near-infrared light in the range between 650 nm and 950 nm to penetrate the skull. Released infrared light passes through the scalp tissue and the skull to a maximum depth of approximately 3 cm which is detected by a light receptor that measures the intensity of relative changes (Gratton et al., 2010; Noah et al., 2015). Twenty channels cover the prefrontal cortex. The source-detectors were set up at distance of 3 centimetres apart. The fNIRS probes used in the study were placed in accordance to the 10–20 international system for EEG recording (Liu et al., 2017). Source emitters were positioned on F3, AF7, AF3, Fz,

Fpz, AF4, F4, AF8, detectors were positioned on F5, F1, Fp1, AFz, F2, Fp2, and F6 (see Figure 9).

Figure 9 Probe positioning used to scan the prefrontal cortex.



Note: Red are sources, blue are detectors, green are channels

This study focuses on the results based on the oxy-Hb chromophore. A couple of factors were considered for the selection of oxy-Hb as representative of brain activity: Firstly, there are some researchers which suggest that oxy-Hb is the most sensitive parameter of task-related hemodynamic response (Doi, Nishitani, & Shinohara, 2013; Hoshi, Kobayashi, & Tamura, 2001; Strangman et al., 2002). Secondly, another factor for choosing oxy-Hb was due to the data analysis approach used. A correlation between the blood-oxygen-level-dependent signal and oxy-Hb in the PFC has been shown during cognitive tasks using

Statistical Parametric Mapping (SPM), however the effects have been shown to be stronger for oxy-Hb (Cui, Bray, Bryant, Glover, & Reiss, 2011). Since the aim of this study was to investigate the brains response to CBSCTI-ASD, the selection of oxy-Hb was more in-line with the research aims of this study.

3.3.2 Social Competence Measures

See chapter 4, section 3.4 for full details of the MSCS and the IRSA

3.4 Procedure

3.4.1 Social competence assessments

One week before the commencement of the intervention both the intervention group and the control group were asked to complete the MSCS questionnaire, take part in the IRSA observer-rated social interaction task (see chapter 4, section 3.5 for task details) and complete a five-minute conversation task with brain monitoring using fNIRS. Post-testing assessments were also completed approximately one week after the intervention was completed. The social interaction task was administered in an observation suite at the University of Salford campus. In order to improve ecological validity, the experimental suite was designed as a small lounge with an adjacent chair and sofa for participants to have a comfortable conversation. The observation area was equipped with multi-recording video from controllable CCTV cameras and a one-way mirror for observation-based investigations (see Figure 10). The aim of the conversation task was to provide an assessment of brain function during a naturalistic conversation. The intervention and control groups completed the task one week before the start of the intervention (pre-test) and once again at the end of the intervention (post-test). All participants completed the task at two separate time points which were approximately eight weeks apart. During the eight weeks between testing, the control group were provided no intervention or training and reported no change to their normal routines.

Figure 10 *Image of University of Salford observation suite*

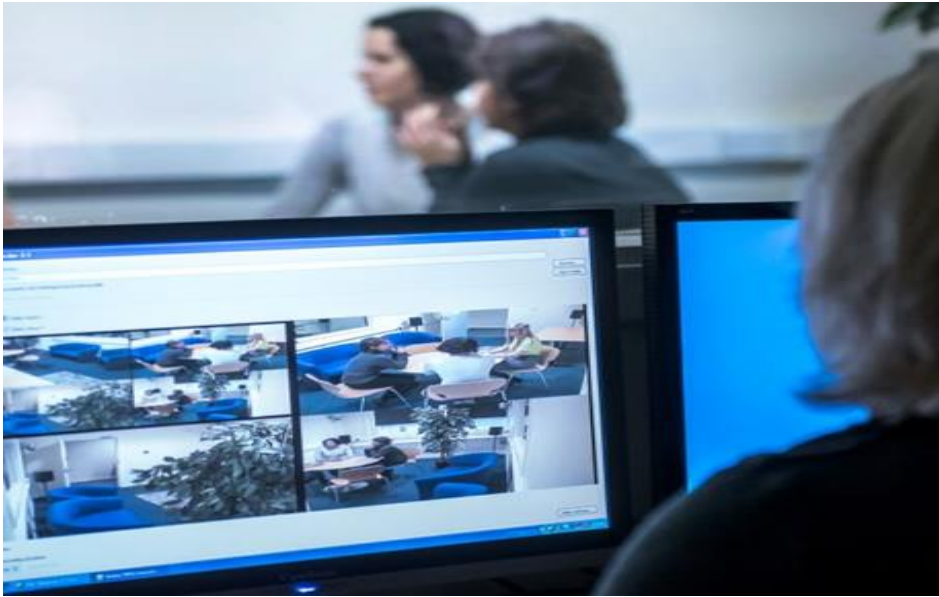


Image taken from the University of Salford website <https://www.salford.ac.uk/health-and-society/facilities-and-services/psychology-laboratories>

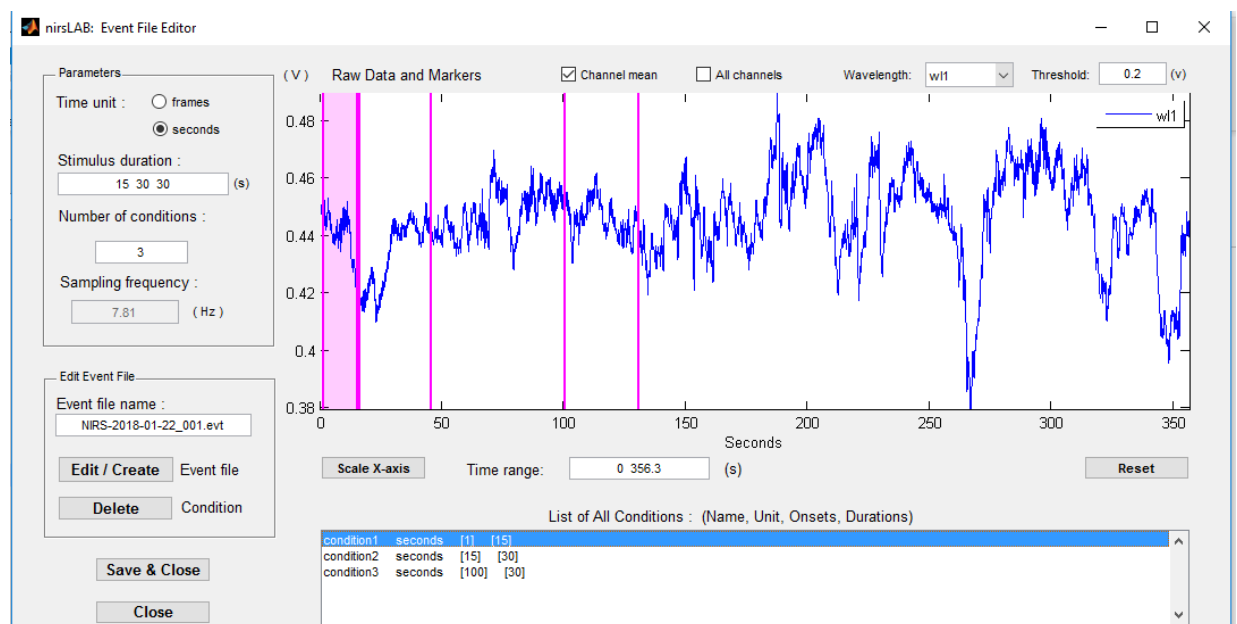
The task aimed to replicate a natural first-time conversation between the participant and a person unfamiliar to them (a confederate). During this conversation task participants were required to wear the fNIRS device for approximately five minutes. The fNIRS is a small non-invasive device that was simply placed on the head of each participant similar to a swimmer's cap (see Figure 11).

Figure 11 *The fNIRS cap with probs and sensors attached.*



There were only three instructions to follow for the conversation task: 1. the topic was to be chosen by the prior to the start of the conversation 2. each person was to speak in turns during the conversation 3. participants were instructed to attempt to stay on topic. The confederate was instructed to attempt to facilitate a balanced conversation by keeping their responses to within approximately 30 seconds. Conditions were monitored and time markers were used to separate each condition. Time markers to measure brain function were taken at three intervals (see Figure 12). Participants were aware of the resting brain condition interval, however, to increase the ecological validity of producing a natural conversation, they were blind to the specific time intervals of the other two data measurement points.

Figure 12 Image of event file for three conditions: resting brain, entering the conversation and maintaining the conversation.



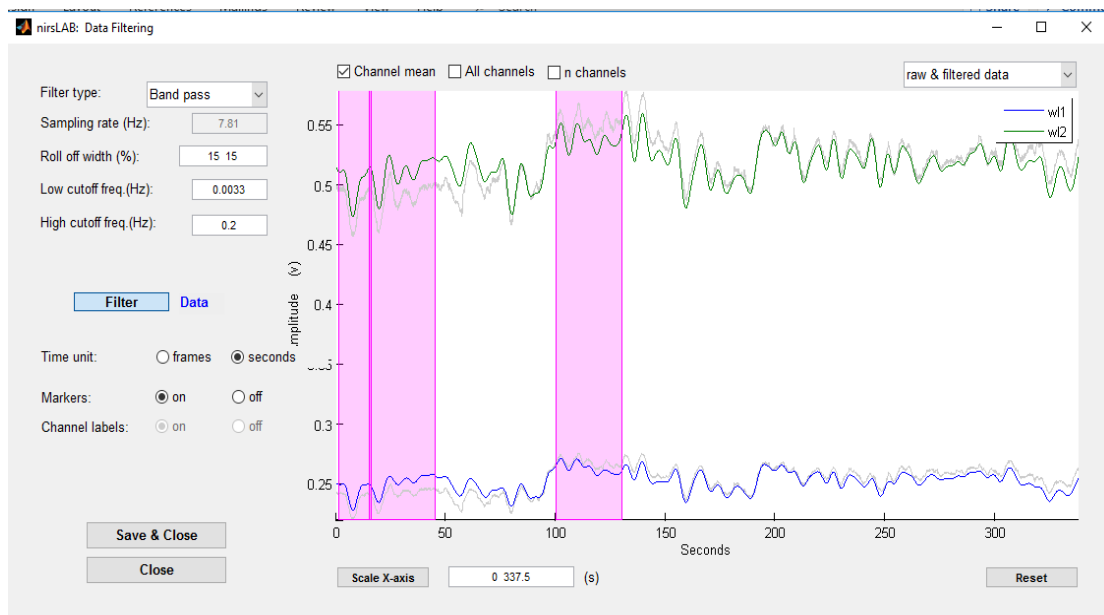
3.4.2 Data analysis

SPM analysis was used to statistically assess the study hypothesis about regionally specific effects in the functional brain. Analysis of fNIRS data was conducted using the SPM approach. SPM is a standard technique for the analysis of functional brain images (Penny, Friston, Ashburner, Kiebel, & Nichols, 2011). In addition, SPM has been considered a gold standard technique for the analysis of fMRI data (Friston, 2007) which is comparable to fNIRS data (Cui et al., 2011). The data analysis portal functions in the SPM package were used to include statistical analysis of hemodynamic-state time series to compute the time

series of O, tissue blood volume, and Oxy-Hb2 saturation, from the filtered data produced by the pre-processing utility (Xu, Graber, & Barbour, 2016).

To pre-process fNIRS measurement data, the nirsLAB toolboxes were used to exclude data channels having excessive noise, delete experimentally irrelevant time intervals, remove any artefacts from the data (artificial spikes) and filter data to exclude experimentally irrelevant frequency bands (see Figure 13). Discontinuities were removed from the filtered data and Chs that clearly contained artefacts were excluded from further analyses. The waveforms of haemoglobin concentration changes for all 52 Chs under conversation and control conditions were calculated for all participants. Data quality was checked with 15% confidence intervals and data was filtered with a band pass filter (low-pass filter and a high-pass filter combined into a single operation) with a sampling rate of 7.81 (Hz) and low cut-off frequency of 0.0033 (Hz) and a high cut-off frequency of 0.2. Bad channels effected by noise were identify and excluded.

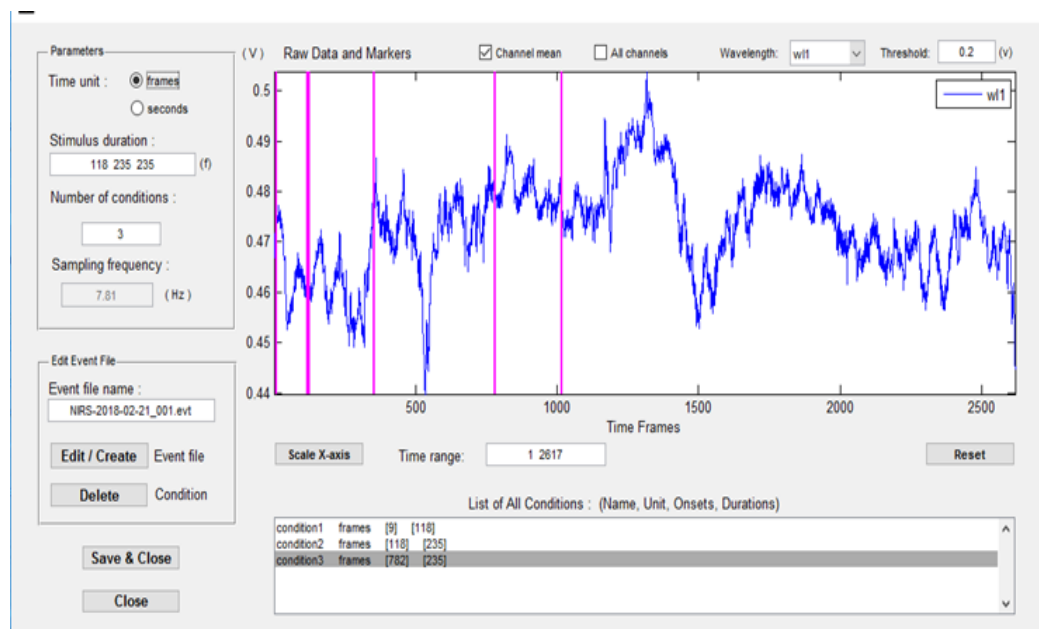
Figure 13 *Data Quality Checking Tool*



3.4.3 SPM General Linear Model Analysis

Interpretations of neuroimaging data collected during designed experiments were used for SPM Level 1 and Level-2 (within subject and between multiple conditions) analyses. Level-1 general linear model (GLM) analysis of fNIRS hemodynamic-state time series were generated to evaluate the position-dependent relationships between computed data-channel responses and user-specified temporal models. Scans were taken of the resting brain between 9 and 118 frames; entering a conversation between 118-235 frames; maintaining a conversation between 782-1017 frames (see Figure 14). Level-2 analysis provided t-contrasts to create statistical parametric maps of activation of oxy-Hb concentration changes.

Figure 14 Event file demonstrating time frames markers



3.4.4 Regions of Interest

Four Regions of Interest (ROI) were examined and defined on the basis of the BA atlas (Brodmann, 1909). The BA atlas map represents cortical areas of the brain and is commonly used for localisation of activations using fMRI (Zilles, 2018). Chs 1, 3, 5 and 7 represent the Left DLPFC; 14, 15, 18 and 20, Right DLPFC; 6 and 11, Left MPFC; 13 and 16, Right MPFC. Averaged change between conditions (resting brain vs maintaining a conversation) within each of the ROI were calculated. Data extraction for each of the ROI channels was required to provide estimates of oxy-Hb concentrations for the time frames between 782-1017 (maintaining a conversation condition). For both pre-test and post-test

conditions, average oxy-Hb concentration estimates for each of the Chs were combined and calculated to provide a single oxy-Hb activation estimate for the separate ROI (Poldrack, 2007). Post-test oxy-Hb concentration estimates were then subtracted from pre-test oxy-Hb concentration estimates for each participant to provide a single oxy-Hb concentration change value for each ROI. The four ROI were further analysed by multivariate analysis of variance (MANOVA).

2 Results

4.1 Analysis of Social Competence

The mean and standard deviation for the MSCS total scores were calculated for the ASD intervention group and the typically developed control group. Descriptive statistics are shown in Table 14. Inspection of the mean scores of all variables suggests that there were greater increases in social competence scores in the intervention group compared to the control group. Inspection of the sub-set domain scores also suggest that the intervention group increased mean scores across all domains with the exception of verbal conversation on MSCS and acceptance on the IRSA. The control group mean scores suggest that scores were similar from pre-test to post-test across all variables. The standard deviation values suggest that the intervention group had a greater spread of scores compared to the typically developed control group.

Table 14 Mean and standard deviation (SD) of variables

Variable	<u>Intervention Group</u>		<u>Control group</u>	
	Mean (SD)		Mean (SD)	
	Pre-test	Post-test	Pre-test	Post-test
MSCS				
Social motivation	31.40 (10.62)	36.20 (8.79)	41.80 (6.30)	42.80 (7.40)
Social inferencing	35.40 (8.33)	37.20 (7.89)	42.40 (2.30)	42.80 (1.10)
Empathy	38.20 (8.29)	41.40 (4.72)	43.00 (4.80)	42.40 (3.72)
Social knowledge	40.60 (8.68)	42.80 (3.90)	42.80 (3.56)	43.00 (3.81)
Verbal conversation	35.00 (7.28)	34.80 (1.10)	33.00 (6.82)	35.20 (5.07)
Non-verbal conversation	39.40 (3.21)	42.20 (3.83)	42.20 (4.60)	40.00 (4.00)
Emotional Regulation	29.00 (9.41)	34.40 (10.41)	39.00 (6.89)	39.80 (4.87)
Total MSCS scores	249.00 (34.02)	269.00 (19.01)	284.20 (16.77)	286.00 (10.89)
IRSA				
Expressivity	6.40 (2.79)	7.60 (1.57)	9.40 (1.14)	9.40 (0.89)
Assertiveness	5.60 (2.88)	8.40 (2.07)	9.80 (0.83)	9.60 (1.57)
Sensitivity	4.60 (1.51)	6.20 (1.92)	9.40 (1.14)	10.20 (0.84)
Acceptance	8.20 (1.64)	7.80 (1.10)	12.20 (1.48)	10.20 (1.48)
Interpersonal relationships	8.40 (0.55)	11.60 (0.54)	13.00 (1.58)	13.80 (1.92)
Self-control	14.60 (3.50)	17.20 (1.30)	17.80 (0.83)	16.40 (0.89)
Total IRSA	47.80 (8.07)	58.80 (5.81)	71.60 (2.70)	69.60 (3.13)

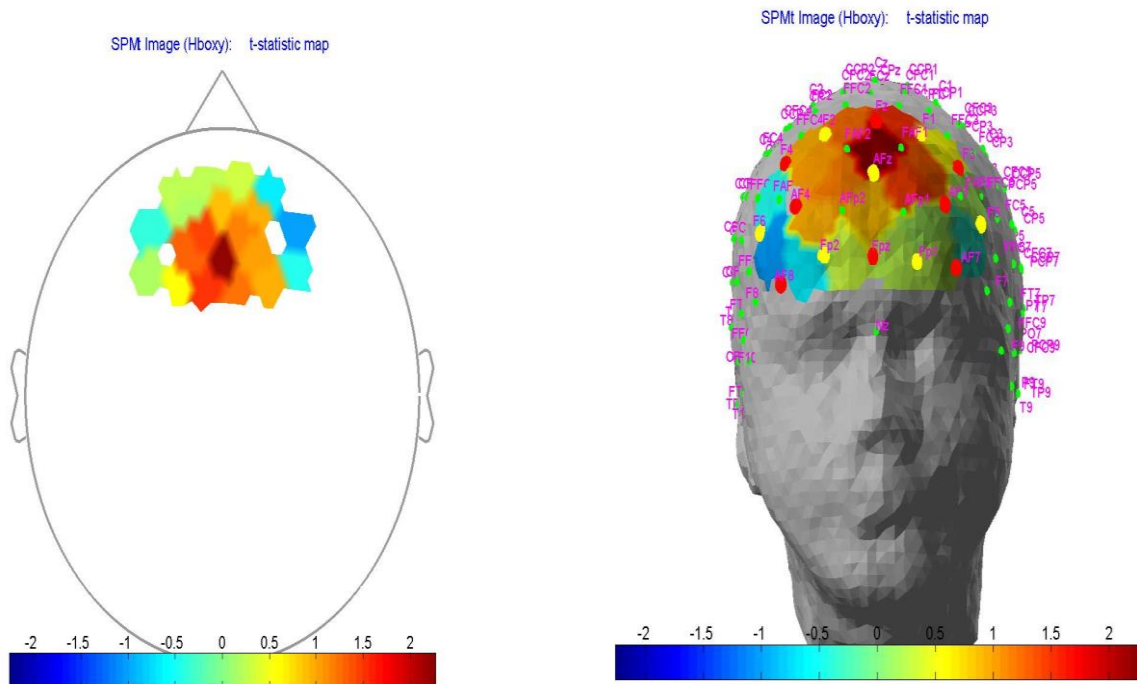
Scores from pre and post intervention testing variables were calculated and converted to change scores for both groups. There were no statistically significant differences in social competence between groups based on change scores of the MSCS, $F(7, 2) = 48.83$, $p = .21$, Wilk's $\Lambda = 0.003$, partial $\eta^2 = .99$. There was a trend towards reaching the significance threshold in the subscale domain of social motivation $F(1, 8) = 3.57$, $p = .10$, partial $\eta^2 = .30$; non-verbal conversation $F(1, 8) = 4.25$, $p = .07$, partial $\eta^2 = .34$ and emotional regulation $F(1, 8) = 3.20$, $p = .11$, partial $\eta^2 = .28$. Total change scores on the MSCS also neared the significance threshold $F(1, 8) = 3.50$, $p = .10$, partial $\eta^2 = .30$. There were no significant changes in subscale domains of social inference $F(1, 8) = .26$, $p = .63$, partial $\eta^2 = .03$; empathy $F(1, 8) = 2.00$, $p = .19$, partial $\eta^2 = .20$; social knowledge $F(1, 8) = .39$, $p = .55$, partial $\eta^2 = .05$ and verbal conversation $F(1, 8) = .38$, $p = .56$, partial $\eta^2 = .05$.

There were statistically significant differences in IRSA observer-rated scores between groups, $F(7, 2) = 25.56, p = .004$; Wilk's $\Lambda = 0.011$, partial $\eta^2 = .99$. The intervention group demonstrated statistically significant gains in total IRSA scores compared to the control group $F(1, 8) = 21.12, p = .002$, partial $\eta^2 = .73$. Between groups analysis showed that the intervention group demonstrated statistically significant increases in sub-scale domains of assertiveness $F(1, 8) = 3.20, p = .11$, partial $\eta^2 = .283$; interpersonal relationships $F(1, 8) = 12.00, p = .009$, partial $\eta^2 = .60$ and self-control $F(1, 8) = 12.121, p = .008$, partial $\eta^2 = .60$ compared to the control group. No statistically significant differences were found for sub-scales of expressivity $F(1, 8) = 1.00, p = .34$, partial $\eta^2 = .67$; sensitivity $F(1, 8) = .80, p = .39$, partial $\eta^2 = .09$ and acceptance $F(1, 8) = 1.45, p = .26$, partial $\eta^2 = .15$.

4.2 SMP Analysis- Neural Activation During the Conversation Task

Figure 15 shows the results for fNIRS SPM analysis: resting brain condition vs maintaining a conversation condition. The significance threshold level ($p = .05$) for SPM contrast group analysis only revealed significant increase in oxy-Hb concentration during maintaining a conversation condition when compared to the resting brain condition. No significant differences were found between the resting brain condition vs entering a conversation condition for either group. As SPM channel-wise analysis revealed participants demonstrated significantly higher levels of oxy-Hb concentration during the “maintaining a conversation” condition, analysis of this condition was further conducted. Unfortunately, NIRSLab provides no option to compare between separate scanning sessions, limiting the ability to investigate mean differences in oxy-Hb concentration changes between groups (intervention and control) and condition (pre-test/post-test). Due to the limitations of the NIRSLab software, further analysis of group differences were conducted using SPSS v23.

Figure 15 SPM Activation *t*-map of oxy-Hb concentration during the conversation task.



Note: The colour scale represents the *t*-value for each channel without threshold limit. The 3D map to the left shows probes according to the 10-20 system.

4.3 Analysis of Change in Brian Activity

MANOVA analysis were conducted to compare regional oxy-Hb change between groups over time. Consistent with SPM I analysis, MANOVA demonstrated a statistically significant group effect in brain activation based on oxy-Hb estimate change values when all factors were averaged together, $F(4, 6) = 6.63$, $p = 0.03$; Wilk's $\Lambda = 0.159$ partial $\eta^2 = .84$. Unexpectedly, between groups analysis demonstrated statistically significant increases in oxy-Hb in the left MPFC of the control group when compare to the intervention group $F(1, 8) = 15.23$, $p = .005$ partial $\eta^2 = .65$. No statistically significant difference in oxy-Hb concentration in the left DLPFC $F(1, 8) = 1.99$, $p = .20$ partial $\eta^2 = .20$, the right DLPFC $F(1, 8) = .63$, $p = .45$ partial $\eta^2 = .07$. or the right MPFC $F(1, 8) = .002$, $p = .96$ partial $\eta^2 = .00$ for either group.

In order to investigate where the statistically significant differences are with respect to the rate of oxy-Hb change within each group independently, a series of post hoc paired

sample *t*-tests were performed (see Table 15). Observations of the *t*-test analysis show statistically significant increases in oxy-Hb concentration from pre-test to post-test in the left MPFC of the intervention group $t(4) = -2.376, p = .04$, (one-tailed). There were also trends toward the significance threshold for increased oxy-Hb concentration in the left DLPFC for the intervention group $t(4) = -1.699, p = .08$ (one-tailed) but not the control group $t(4) = -1.015, p = .36$ (one-tailed). There were also significant increases found in oxy-Hb concentration between pre- and post-testing in the left MPFC for the control group $t(4) = -4.462, p < 0.01$, (one-tailed).

Table 15 Paired sample *t*-test results for each ROI. All *p* values .05 threshold.

ROI	Group	Mean	SD	<i>t</i> -value	<i>p</i> -value
Left DLPFC	Intervention	-.00018000	.00010597	-1.699	0.08
	Control	-.00002600	.00005727	-1.015	0.36
Right DLPFC	Intervention	-.00072600	.00181522	-.894	0.22
	Control	-.00007800	.00022231	-.785	0.48
Left MPFC	Intervention	-.00150600	.00141737	-2.376	0.03
	Control	.00117200	.00058734	4.462	0.01
Right MPFC	Intervention	-.00011820	.00091318	-.289	0.39
	Control	-.00009800	.00018833	-1.164	0.30

Note: All *p* values .05 threshold.

3 Discussion

This chapter was part of the wider evaluation of CBSCTI-ASD for adults with ASD without ID. Investigating the effects of CBSCTI-ASD on neurological function required the monitoring of regional cerebral blood volume changes in the PFC using a 52-channel fNIRS device during a conversation task. SPM general linear model analysis was used to run an assessment of the statistical significance of the GLM model-fitting coefficients. The findings from SPM analysis suggests that there were significant task activation increases in oxy-Hb concentration in the left MPFC for both the ASD and typically developed control group, thus supporting the first hypothesis. Oxy-Hb concentration estimates were higher in the typically developed control group, but there were no statistically significant differences between groups, leading to a rejection of the second hypothesis. In addition, the third hypothesis was also rejected as there were no significant differences in oxy-Hb concentration during task

activation between groups over time. Post-hoc *t*-test analysis revealed that the intervention group demonstrated significant increases of oxy-Hb in the left MPFC and a trend toward significant increases in the left DLPFC after completing CBSCTI-ASD. However, the control group also demonstrated significantly increased oxy-Hb concentration in the left MPFC at post-test. As both groups demonstrated greater oxy-Hb at post testing it is not possible to determine the impact of the intervention on brain function.

The activation areas which were found in the current study have been implicated in the social brain and are characteristic of the pathology of ASD. The DLPFC has been shown to play a crucial role in the genesis and maintenance of the alerting state (attention) and learning processes (Mannarelli et al., 2015). The left DLPFC in particular has been suggested to be part of a complex cortical network associated with language processing (Klaus, Dennis, & Schutter, 2018), sentence comprehension (Hashimoto & Sakai, 2002; Cooke et al., 2006; Makuuchi et al., 2009; Stephens et al., 2010; Hsu et al., 2017) and sentence production (Humphreys & Gennari, 2014). The trend level oxy-Hb increases in these areas are likely due to the nature of the conversation task which involved paying attention and listening to what the other person is saying, talking to the other person and learning about the person.

The increased activation in the left MPFC may be due to the social cognitive demands which come from having a social interaction. The MPFC has been shown to have associations with social cognition (Mitchell, Banaji, & Macrae, 2005) and emotional processing (Etkin, Egner, & Kalisch, 2011). To some degree, Suda and colleagues (2011) reported similar findings in a typically developed sample of individuals with high trait ASD. The participants in their study did not have a diagnosis of ASD but did score above the ASD diagnostic threshold on the AQ (all their participants score greater than 32). The authors similarly monitored regional cerebral blood volume changes using a 52-channel fNIRS apparatus over the prefrontal cortex (PFC) and found significant activation in the DLPFC but not the MPFC during face-to-face conversations in individuals with high trait autism.

5.1 Research Limitations

The most notable limitation is the relatively small sample size. Sample size power calculations are more complicated in neuroimaging studies because the data recorded contains tens of thousands of correlated channels (voxels), making typical power calculations less appropriate for estimating the sample size (Hayasaka, Peiffer, Hugenschmidt, &

Laurienti, 2007) and to date, there are no known tools to estimate a power and sample size for fNIRS studies. However, in fMRI studies, some researchers have determined that a minimum of twenty-four participants are required for a sufficient level of power to develop an accurate brain activation map (Desmond & Glover, 2002). With a small sample of only ten, it is likely the sample size was not sufficient enough to determine accurate results.

Another limitation of the study is that the control group consisted of only typically developed participants. While it was essential to include typically developed participants for establishing differences in brain function between typically developed and ASD populations, comparison of change in social competence as measure by the IRSA and MSCS was less clinically relevant. The inclusion of a second group of ASD participant such as a ‘treatment-as-usual’ or ‘waiting list’ ASD control group would have provided a more direct comparison of ASD behavioural changes and produced more clinically meaningful results.

There are also some potential limitations in the technique used to assess neural functioning in the present study. Specifically, fNIRS has limited spatial resolution and lacks the ability to assess deep brain structures. The pathological substrate of ASD and the brain area reliable for social cognition are mostly considered to be the medial PFC, not the entire PFC. However, it is not possible to fully differentiate the MPFC from the other regions of the PFC because of the low spatial resolution of the fNIRS technique. For this reason, it is logical to argue that in the current study, the main functions of the PFC were likely in regard to executive functions and/or social cognition, which correspond to both the DLPFC and the MPFC.

5.2 Future Research Direction

The method for measuring neural function should be further considered in future research. Until there are advances in fNIRS technology, in the short-term, technology such as fMRI may provide a more precise picture of the brain’s response to behavioural interventions. The use of fMRI has the advantage of investigating the important subcortical areas which have been related to the social brain of individuals with ASD. However, fMRI is considerably more costly, and replication of the conversation task would be difficult as fMRI can only capture a clear image if the individual being scanned stays completely still. A major benefit of the fNIRS device was that it is a non-invasive mobile unit which could be used in a natural environment (e.g., sitting comfortably on a couch while having a conversation) which

would be impossible to achieve using fMRI. In the future, if fNIRS can achieve higher spatial resolution it may be able to accurately distinguish between neural activation in the medial PFC and the DLPFC. In addition, using a different or perhaps a larger probe set-up may be helpful to investigate other areas of the social brain. The probes in the present study covered only the region around the PFC and as such it could not presently be determined if other important cortical regions of interest (e.g., temporal lobe) were involved during the conversation task.

4 Conclusion

There are only a limited few social skills intervention studies which have investigated the neuroplasticity of adults with ASD without ID. Most notable, no studies have measured the brains response to a multi-modal cognitive behavioural social skills intervention for adults with ASD. This study included a unique combination of ecologically valid brain imaging and behavioural assessments as part of the CBSCTI-ASD evaluation. This study indicates that fNIRS can be used to provide quality data on the brain response to a conversation task. Social competence improvements were found, and neural function increased in the ASD group after completing CBSCTI-ASD. However, there were also significant increases in neural activation in the control group over the same time period. As both groups significantly increased activation in the left MPFC over time, it cannot be ruled out that other factors may have been responsible for the increase in neural activation. Despite the authors best efforts to provide a unique first encounter, the conversation task was a repeated measures design and the first time wearing the fNIRS deviced was a novel experience. Nonetheless, this study supports previous findings suggested that the MPFC is a vital functional region in the social brain.

Chapter 5. Study 3: Exploring the Experiences of Parents' with an Adult Child with Autism Spectrum Disorder

1. Introduction

The primary objective of this chapter was to explore the lifetime of experiences held by a small group of parents directly affected by ASD. Parents of adult children with ASD have encountered a wide range of rich experiences which deserve consideration when improving or developing new interventions. This qualitative study aimed to examine parents' experiences to better understand their perceptions of the challenges, coping strategies, and support services encountered over their adult child's lifetime. In addition, the study aimed to ascertain parents' views about which interventions they believe would be the most beneficial for adults with ASD.

1.1 Background

The parental experiences of living with an individual with ASD are becoming increasingly more recognised in the literature (e.g., Mostafa, 2019; Mount & Dillon, 2014; Hines, Balandin, & Togher, 2014). Over the past two decades, some literature has provided rich accounts of the challenges which parent's experience (e.g., Benson, 2012; Mostafa, 2019; Osborne & Reed, 2008 Solish & Perry, 2008). Parents have reported difficulties which include, decreased parenting efficacy, increased parenting stress (Kuhaneck et al., 2015) and reduced quality of life (Karst & Van Hecke, 2012). The effect of being a parent of a child with ASD can also impact on marriages, parent-child relationships (Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011) and relationships with other members of the family (Welch et al., 2012). Exploring the shared experiences of parents may provide greater insight into the most effective ways to support individuals and families experiencing challenges related to ASD (Mount & Dillon, 2014).

Parents of children with ASD also often worry about the future outcomes of their children once they enter adulthood (Sosnowy, Silverman, & Shattuck, 2018; Thompson, Bölte, Falkmer, & Girdler, 2018). Research including parents of individuals with ASD suggests that they believe the most important outcomes are in relation to education, physical safety, happiness, acceptance, making and maintaining friendships, financial security, community involvement, employment and living independently (Ivey, 2004; 2007; Poon et

al., 2013; Sosnowy et al., 2018). Many of these outcomes are a constant worry for some families, which is understandable when considering the percentage of adults with ASD with poorer outcomes (e.g., a lack of or limited friendships, limited social integration, poor employment prospects mental health problems and difficulties with independent living) have changed very little over the years (Henninger & Taylor, 2013; Howlin & Magiati, 2017). However, by exploring the lived experiences of those impacted by ASD, researchers can begin to gain insight into the issues which halt adults with ASD from achieving the important milestones associated with more positive outcomes.

1.2 Experience of Diagnosis

One of the early challenges a parent of a child with ASD encounters involves acknowledgment of the problem and the process of diagnosing the disorder. Parents are often responsible for managing their child's difficult behaviours while also navigating through numerous services when seeking help for their child's condition (Blanche, Diaz, Barretto, & Cermak, 2015). Furthermore, a diagnosis can often be a prolonged which can cause significant frustration, anxiety and delays in treatment and support. The process of a diagnosis is rarely straightforward, and many parents have expressed the need for a quicker and easier procedure which provides accurate information and a more coherent structure (Osborne & Reed, 2008). The process of diagnosis is a critical stage which often impacts heavily on the parent's experience and their response to professional services in the future (Potter, 2017; Russell, & Norwich 2011).

Delays are considerably profound in the UK. On average, after initial contact with service professionals, parent waiting times for a formal diagnosis has recently been estimated to be three and a half years (Crane, Chester, Goddard, Henry, & Hill, 2015). The manner of communication during diagnosis has also emerged as a significant problem for many parents of children with ASD. In a qualitative study, 184 fathers' responses to open-ended questions were analysed and it was found that they were often unsatisfied with the level of communication in terms of briefness, insensitivity and over emphasis on the negative aspects of ASD (Potter, 2017). This is particularly concerning as an overly negative experience may cause avoidance or resistance to form future relationships with professionals, limiting the level of support received. Overly focusing on future difficulties and negative outcomes can

impact on a parent's perception about their ability to cope with the challenges faced in the future (Taanila, 2002).

Parents responses towards a diagnosis can also vary considerably. Some parents can become more worried about their child's future after an ASD diagnosis (Mansell & Morris, 2004), whereas others become more proactive and even encourage other parents to seek an ASD diagnosis (Russel & Norwich, 2011). Differences in parental views about ASD also seems to impact on a parent's response to a diagnosis. Recently, cultural family norms have been highlighted as a significant factor to how parents respond to a formal diagnosis (Lopez, Magaña, Yue Xu, & Guzman, 2018). For example, in a study of 44 Latina mothers and 52 white mothers, researcher found white mothers were more likely to experience a great sense of relieve after diagnosis, while Latina mothers experienced more feelings of guilt and placed blame on themselves (Lopez et al., 2018). Differences in response due to cultural perspectives may prove to be a significant challenge for professionals attempting to communicate after diagnosis. To reduce the stigma, guilt and stress of those which have different views about ASD, professionals may need to develop interventions which provide plenty of time for discussions, subject sensitivity and education about positives and negatives of the disorder.

1.3 Parents Experience of Coping Strategies

After receiving a diagnosis, some families may require a significant level of support. Researchers have often turned to parents to gain a better understanding of the hardships within families struggling to cope. For example, Mount and Dillon (2014) conducted semi-structured interviews with nine parents (five mothers and four fathers) living with an adolescent child (one girl and five boys), aged between 11 and 16 (mean 13) diagnosed with ASD without ID. The themes found were deeply insightful. The challenges which were reported to impact on their families were extensive and included the need to maintain predictability in their children's lives, mediate communication and social difficulties, manage outbursts of physical or verbal abuse towards parents, and intense mother-child relationships. Mental and physical fatigue were reported amongst many parents and all parents described using some form of coping strategy or the need for social support at times.

It is also not unusual for parents to react differently to their child's condition, with mothers typically experiencing more anxiety and depressive symptoms, while fathers are

more likely to feel frustration, anger and denial (Burrell et al., 2017; Hastings et al., 2005). However, both mothers and fathers of children with ASD tend to report higher levels of parenting problems and psychological distress when compared to parents of typically developing children (Davis & Carter 2008; Hastings et al., 2005) and children with intellectual disability (Eisenhower, Baker, & Blacher 2005; Weiss, 2002). Elevated levels of psychological distress can make both mothers and fathers feel like incompetent parents and this can significantly impact on parental attachment (Goodman & Glenwick, 2012).

Parents of children with ASD have been shown to use a range of both adaptive and maladaptive coping strategies. Adaptive strategies may include acceptance, problem-solving, cognitive reframing and seeking social or religious support, whereas maladaptive coping strategies tend to centre on active avoidance, denial and disengagement (Lai & Oei, 2014; Mostafa, 2019; Tzoy et al., 2007). A number of factors have been shown to impact on whether parents adopt more adaptive or maladaptive coping strategies. The nature of the problem, age of the child and types of social support can often be a determining factor for the types of strategies which are employed (Grey, 2006). Other concurrent factors which effect family are financial strains, time burden of supporting a child with ASD and limited social activities (Ludlow, Charlotte, & Rohleder, 2011., 2011). However, the research on how parents cope is more balanced towards exploring the experience of mothers, with relatively fewer studies addressing the father's experiences (Burrell, Ives, & Unwin, 2017).

Less is known about the experiences of fathers of children with ASD, however qualitative investigations have provided some insight into their often, overlooked experiences. In a qualitative inquiry of ten fathers (Frye, 2016), findings showed that their needs were in relation to parental co-operation, active involvement, finances, honesty/information, and time with loved ones. Fathers also describe feelings of grief and loss that are like those experienced when there is a death. Fathers often feel that support is lacking after diagnosis and that their needs are not recognised as much as the needs of mothers (Potter, 2016). Similarly, in another study (Burrell et al., 2017) eight fathers of children with ASD participated in semi-structured interviews and fathers reported feeling that they had to fight against obstructive services to receive appropriate support. It was also found that fathers placed great amount of importance on fostering their child's integration and independence. These finding suggest that the experiences of father's are somewhat similar to mothers of children with ASD. For example, past research which explored mostly mothers'

experiences have also reported dissatisfaction with professional services and feelings of grief and loss comparable to a death after diagnosis (Gray 2006; Hock et al., 2012; Sosnowy et al., 2018).

Parents of adult children with ASD have considerable experiences of coping with the challenges associated with the disorder, however it appears coping strategies do change over time. Later in life parents must contemplate how they will care for their child's needs when they no longer have the capability to provide support and this can cause a great deal of emotional stress (Grossman & Webb, 2016). Such stresses on aging parents may be why there is a shift from using more problem-solving strategies towards more emotion-focused strategies (Grey, 2006). The long-term role of caring responsibilities placed on parents with adult children with ASD can impact on social networks, with many reporting only a limited few friends and family members involved in their life (Oti-Boadi, Asante, & Malm, 2020).

Understanding the transformations of challenges and coping strategies adopted over time seems essential for the wellbeing of both the parents and the aging ASD population. To assist parents in planning for their adult child's future, Marsack-Topolewski and Graves (2019) found that educating professional services about the changing needs of ageing parents is crucial for providing appropriate support. The authors suggested that parents should be helped when working through their planning and the process should be separated into easy to manage steps. Providing emotion-focused intervention (e.g., an emotional support group for aging ASD caregivers), alongside future planning may also reduce the worry and stress.

1.4 Intervention and Support

Parents often play a vital role in the outcome assessments of ASD support services and intervention programs. For example, group-based social skills interventions are the most widely used for social impairment in school-age children with ASD and parental responses are vital for assessing the impact of an intervention on their child's behaviour (Gates, Kang, & Lerner, 2017). However, intervention efficacy is often assessed without considering the rich subjective experience of the service user or those individuals close to them. Qualitative investigations have revealed that some parents believe that interventions should aim to improve life satisfaction, independence and integration, safety and security and social skills (Burrell et al., 2017; Ivey, 2004; Poon et al., 2013) but how such interventions are subjectively experienced in terms of delivery and outcomes is relatively unexplored.

Gathering the perspectives of parents can help to draw conclusion on the social feasibility or “social validity” of an intervention (Callahan, Henson, & Cowan, 2008). Exploring the user satisfaction of an intervention is often used as an indicator of its acceptability, and in some cases, they have even been used as an outcome measure (e.g., Jamison & Schuttler, 2017). Detailed accounts of intervention satisfaction can provide information about service users’ views and these may be very important for addressing issues with intervention content and delivery. More specifically, recording experiences and collecting opinions from parents is important for the purpose of developing appropriate and effective interventions which address concerns for an individual with ASD and the loved ones which provide such crucial support (Swaab et al., 2017).

While the majority of intervention research has focused on the evaluation of quantitative data, some have attempted to provide a rich qualitative account of an intervention (e.g., Grindle, Kovshoff, Hastings, & Remington, 2009) to help establish intervention acceptability. For instance, a qualitative study by Buchanan and Miedema (2017) utilised phenomenological interviews to explore the parent’s perspective of Physical Activity (PA) in their adult ASD children’s lives. Findings highlighted intrapersonal, interpersonal and community factors which were important for engagement in PA. While these subjective experiences of parents may not provide information which can be generalised, these findings can provide greater insight into personal barriers to PA and may be significant when considering the feasibility of delivering future community-based PA interventions.

Due to the complexities of social impairment, parents are also often involved in managing the health care treatments of their child well into adulthood (Lake, Milovanov, Sawyer, & Lunskey, 2015). Parents qualitative evaluations have help provide a richer understanding of intervention efficacy and service user issues for adults with ASD (Grindle et al., 2009; Lake et al., 2015). A study investigated UK father’s views and feelings about the experience of their child’s ASD diagnosis (Potter, 2017). Fathers reported feeling that they were given limited attention during diagnosis and treatment planning stages. Nine of the fathers interviewed in the study described feeling excluded to some extent because the focus was on the need of their partner. Many also felt there were little or even no service support offered to them after their child was diagnosed. These findings are extremely important for ensuring current service provisions offered by professional services are more inclusive and take into account the needs of both parents.

Parent's perspectives have also helped researchers to better understand some of the more unique challenges associated with ASD. A recent qualitative study (Mademtzi, Singh, Shic, & Koenig, 2018) investigated the largely overlooked experiences and needs of females with ASD. The study explored the parents' perspectives of the challenges which they believed their daughters encounter. There were some issues discussed which were common to ASD (e.g., challenges in social interactions) but there were also issues highlighted that were unique to girls with ASD. Issues parents reported were, problems socialising with other girls, barriers to appropriate intervention, sexual vulnerability and issues related to sex-specific puberty. This rich and clinically useful data provided by the parents could be used to develop more topic specific interventions, which can benefit females with ASD in particular.

Living with a person with ASD can require a significant amount of family support (Seltzer et al., 2004; Swaab, McCormack, & Campbell, 2017) and findings across the ASD outcome literature have commonly shown that parents continue to play a supportive role well beyond the time period observed in typically developed populations (Hines et al., 2014; Krauss, Seltzer, & Jacobson, 2005). Parents can feel the need to continue helping their adult children with ASD in order to help them secure an acceptable future but often worry about how they will cope after they can no longer provide care (Hare, Pratt, Burton, Bromley, & Emerson, 2004; Marsack-Topolewski & Graves, 2020). To ensure that outcomes for adults with ASD are continuing to improve, it is essential to develop and provide intervention which can support their individuals throughout their life.

1.5 Access to Intervention

It is clear that parents and their adult children with ASD can often benefit from supportive interventions but accessing appropriate services can be a significant challenge (Anderson, Lupfer, & Shattuck, 2018). Past research has shown that insight into accessing adult ASD services can be gained by exploring the experiences of parents with adult children with ASD (Marsack-Topolewski & Weisz, 2020). Past research has mostly investigated the benefits and effects of more formal support services which are directed at adults with more severe ASD symptoms or for those with additional disabilities (Caldwell & Heller, 2007; Esbensen & Seltzer, 2011), however these services are rarely readily available for those who maybe struggling to cope (Marsack-Topolewski & Weisz, 2020). For instance, as previously discussed in chapter one, adults with ASD without ID are often offered less support than their

adult peers with ASD and a comorbid ID (Roux et al., 2017; Taylor & Seltzer, 2011). A number of studies have explored the effectiveness of services for parents and children with ASD, but the experiences of service users ability to access appropriate ASD services and interventions has been somewhat overlooked (Marsack-Topolewski, 2019).

It has clearly been established that access to support is important to avoid experiencing negative outcomes. For instance, limited access to social support during adulthood has been linked to a reduction in quality of life for adults with ASD and increased worries for their parents (Shivers, Sonnier-Netto, & Lee 2019; Tobin et al., 2014). There is a continued need to support the growing population of parents and adults with ASD, however it appears support needs later in life are not currently being met as there is a significant decrease in the number of individuals with ASD receiving support services past adolescence (Marsack-Topolewski & Weisz, 2020; Roux et al., 2017; Shattuck et al. 2011; Turcotte et al. 2016). For example, the percentage of individuals with ASD receiving intervention (e.g., speech-language therapy in schools) has been shown to be reduced by up to 40% when transitioning from adolescence into adulthood (Turcotte et al., 2016).

Many parents and their adult children with ASD who continue to face challenges in procuring appropriate services often attribute this to limited financial assistance, long waitlists for access to services, and most notably, the lack of available age-appropriate support programs specifically designed for adults with ASD without ID (Anderson & Butt, 2018; Anderson et al., 2018; Marsack-Topolewski, 2019; Taylor & Henninger, 2015). Very little is known about the experiences and perceptions of parents who must source and advocate for appropriate support services for their adult children with ASD. Most of the literature in this area has focused on social communication support and services for children with ASD, with little attention to services for adults with ASD and their parents (Wright et al., 2013).

More recently, parents have further highlighted the problem when describing the need to stop using services due to their inadequacy (Marsack & Hopp 2019). Parents are often placed in a position where they have to pay for more appropriate services they could not access through other means (Wilson et al., 2021). Inadequate services have been shown to make some individuals with ASD experience feelings of failure and many parents experience stress from being burdened with the financial and emotional responsibility of acquiring

services to meet their adult children's needs (Wilson et al., 2021). A lack of sufficient funding has consistently been reported as a common barrier to accessing ASD support and intervention (Anderson & Butt, 2019; Marsack & Hopp, 2019; Wilson Kaminski-Mainardi, Tenbus & Marsack-Topolewski, 2021). It is a significant challenge for researchers to develop effective ASD interventions, however it appears that a greater challenge is making them accessible and affordable for those who need support.

There are several other barriers worth noting that have received lesser attention within the research. A very recent qualitative study (Wilson et al., 2021) utilised focus groups to explore parents' perceptions of social communication support services for their adult children with ASD. Seven barriers emerged from the study. While a lack of funding was the most prominent barrier to social communication support, parents also reported inadequate agency staff, lack of understanding from employers and issues related to comorbid diagnoses (e.g., mental health issues) also had a serious impact on access to support. Parents felt that they often lacked information about existing support and transportation was an additional barrier even when support was offered (Anderson et al., 2018; Wilson et al., 2021).

Recently, research findings have started to shed some light on parents' perceived access to support for their adult children with ASD. Exploring the experiences of parents offers a way to collaboratively devise future ideas and solutions for how to make support more accessible. Very few studies have focused on providing solutions for more community engagement and increasing access to social support for adults with ASD and their families. Financial costs seem to be a common barrier experienced by parents seeking help, but it is likely that there are several other barriers which have been shown little attention within the research. It is important to continue to explore experiences related to accessing and receiving support so future researchers can find the best ways to develop and provide access the most appropriate interventions.

The primary aim of this study was to explore the experiences of parents with adult children with ASD. In order to provide a combination of relevant and effective interventions to those adults with ASD who struggle with daily life, it is essential to continue consulting with parents and those with experiences of living with the disorder. While some very recent qualitative studies have explored the experiences of parents with adult children with ASD, their investigations have mostly been focused on the experiences of ageing parents of young

adults with ASD (e.g., Marsack & Perry, 2018; Marsack-Topolewski & Graves, 2020; Oti-Boadi, et al., 2020). This study is unique in that it attempted to explore parents' experiences over the lifetime of their adult child with ASD. There was further anticipation that the investigation would provide rich qualitative data that may be found useful to further guide the development of CBSCTI-ASD.

1.6 Study Objectives

- To investigate the lived experiences of being a parent of an adult child with ASD.
- To identify some of the challenges and difficulties that parents of young adults with ASD face.
- To explore the parents' opinions of social support interventions provided over the lifetime of their adult child with ASD.
- To elucidate which interventions are believed to be important for adult children with ASD.

1.7 Research Questions

- What are the lived experiences of being a parent of an adult child with ASD?
- What are parents' opinions of social support interventions provided over the lifetime of their adult child with ASD?
- What interventions do parents believe are important for their adult children with ASD?

1 Method

3.1 Design

A qualitative inquiry using interviews and TA were selected to explore the experiences of being a parent of an adult child with ASD. Single semi-structured interviews were conducted which aimed to capture the participant's unique experience of diagnosis, support, challenges, and successes. The aim of the research was to capture the lived experiences of parents which have been the primary caregiver of an adult child with ASD. With this aim in mind, the ontological framework adopted by the researcher was critical realism and the epistemological framework was contextualism (Henwood & Pidgeon, 1994). An inductive approach to thematic analysis was used and the researcher utilised semantic level coding and analysis (Braun & Clark, 2006). Predetermined codes (e.g., recommendations to improve intervention support) were used alongside codes that emerged from the data. The objective was to identify patterns in the lived experience of the participants who were interviewed. Predetermined and emergent codes were then reviewed to identify patterns and similarities within them. This process led to identifying and narrowing down themes within those codes.

3.2 Participants

Ethical approval was provided by the university ethics committee prior to recruitment (see Appendix E). Along with advertising through social media, a recruitment call was sent to a number of local ASD organisation in Greater Manchester. Respondents contacted the research via email, and they were provided participant information sheets and consent forms (see Appendix F). In total, seven parents were which meet the inclusion criteria responded and were recruited to participated in short semi-structured interviews. For this study, a parent was defined as a person which had legal guardianship until the age of 18 years. For inclusion all parents involved were required to have an adult child with ASD without ID over the age of 18 years living in the United Kingdom at the time of diagnosis (see Table 16). Parents were required to have adequate English language skills in order to participate in the telephone interviews. All parents which took part in this study were mothers.

Table 16 *Demographic details of participants and their adult children with ASD*

Guardian ID	Adult child (pseudonym)	Guardian Role	Age of adult child	Age of diagnosis	Adult child's education level	Current status
P1	Ellie	Mother	20 year	13 year	Post-secondary education	University student
P2	Joey	Mother	22 years	14 year	Secondary education	Full-time employment
P3	Ali	Mother	36 years	29 years	Post-secondary education	Full-time employment
P4	Clare	Mother	22 years	20 year	Some post-secondary education	Unemployed
P5	Clark	Mother	26 years	8 years	Post-graduate education	Unemployed
P6	Ken	Mother	30 years	28 years	Post-secondary education	Part-time employment
P7	Hank	Mother	18 year	11years	Post-secondary education	University student

3.3 Data Collection

Semi-structured telephone interviews were carried out by the researcher. All telephone interviews were recorded using an Olympus WS-853 digital recorder device. The interview schedule (see Appendix J) was developed following protocols defined by Jacob and Furgerson (2012). Using a series of open-ended questions (see Table 17), the researcher aimed to elicit the narratives of the parental experience of having an adult child with ASD without ID. Field notes were written up at the beginning and end of each interview, and in an attempt to avoid impressionistic interpretation, most coding categories included the language used by the participants themselves up to the point of final refinement of a theme (Russel & Norwich, 2012).

Table 17 *Interview schedule questions*

Background questions	Central questions	Follow-up questions	Commonly used probes/prompts
Can you tell me what you know about your family medical history?	How does your experience of support currently compare to when XX was a child?	Did you feel the support offered was helpful?	Can you recall anyone in the family without formal diagnosis but struggled with social skills during their life?
What are some of the challenges of being a parent of an autistic young adult?	Can you describe any positive aspects of being a parent/caregiver of an autistic young adult?	What advice would you give to a parent with a child currently approaching the transitioning into adulthood?	How did you handle these challenges? Do you feel the support offered since your child became 18 has been adequate?
Can you tell me about your experience of the diagnosis procedure?	Can you describe what kind of interventions or treatment your child has received for autism since entering adulthood?	What are your biggest fears/worries about XX's future?	
How does the support or treatment in adulthood compare to when XX was a child?	What were the kinds of support or treatments offered after diagnosis? What skills and topics do you think would be most important to address in a social skills intervention for young adults with autism?	Can you tell me about anything in particular that was helpful or unhelpful from treatment?	

3.4 Data Analysis

Interviews were transcribed using intelligent verbatim and all personal identifiers were removed. To preserve anonymity, each participant was provided with a personal identification code (e.g., P1, P2) and their adult child provided with a pseudonym. The analysis process involved; coding, categorising chunks of data and making sense of the essential meanings of the phenomenon (Bernard et al., 2016). The transcripts were analysed using a data driven six stage thematic analysis (Braun & Clark, 2006). The stages of analysis involved familiarisation of the data, initial code generations, searching for themes, reviewing themes, defining and naming themes, and generating the final report (Braun & Clark, 2006). Transcripts were initially coded, an iterative process which led to the review and finalisation of themes and sub themes. Extracts were selected to demonstrate evidence of a theme

followed by a final analytic review of patterns to support a theme. Prior to inclusion in the results section some of the data was minimally edited to remove non-words, occurrences of partial sentence repetition and superfluous information to improve the readability of the extracts. Great care was taken to preserve content accuracy. This method was chosen as a means of drawing themes from across the full set of interviews.

2 Findings

Transcripts from parent interviews generated rich data on their life experiences of raising and living with an adult child with ASD. Thematic analysis identified six main themes and 12 sub-themes which are reported in Table 18 (see Appendix K).

Table 18 Study 3 themes and sub-themes

Themes					
Process of receiving a diagnosis	Support and treatment	Challenges	Parent coping strategies	Positive parenting	Recommendations for intervention
Sub-themes					
Family noticed problems before diagnosis	Barriers to accessing support	Worried about the future	Acceptance Management	Pride of character	Life skills
Barriers to receiving a diagnosis	Inadequate support	Strain on parents		Pride of achievements	Education and psychological therapy

4.1 Theme 1. Receiving a Diagnosis

Family noticed problems before diagnosis. Most of the parents interviewed recall either themselves or someone else noticing ASD symptoms long before receiving a formal diagnosis.

“She wasn’t diagnosed until she was 13, as a child we knew things weren’t quite right but as parents we didn’t know what was going on.”
(P1)

I didn’t know until he was 29. I had not heard of autism. I only knew of people who were severely disabled and looked disabled, even though I had been a nurse on and off. However, I noticed Ali had a weird laugh when he was 2 weeks old, so much so that his dad and I tried to video him in the bath to see if he did it again. His laugh, at that time, reminded me of what I thought an autistic child would sound like!”
(P3)

“Hank use to belong to an adventure group, something like the scouts, but he didn’t get on very well with it. We had an evening with them, and someone said to me, “is that the autistic kid in the group?”, talking about Hank but it wasn’t him at all. They said it to me because he was sitting in the corner not socialising, fiddling, and obviously anxious.” (P7)

“Starting in primary school I said there was a problem, he wouldn’t engage with anybody, speak to people and things, he wouldn’t look at anyone of authority in the eyes, he would just blank them.” (P2)

Barriers to receiving a diagnosis. Getting along with other children in school was a common problem but support was not always forthcoming. One mother describes how her son did not start speaking until 4 years old, and although his teacher highlighted issues at school and a specialist psychologist noticed delays in his learning, her son did not receive an official diagnosis until he was 29 years old.

“There were different symptoms on his way to being a young adult that frustrated me and his dad, like standing on the feet of other kids that annoyed them. He didn’t speak until age 4. It was a relief when his nursery teacher, a qualified infant teacher told me Ali was odd. At last, someone could see what I could see. The teacher even had her friend, a

child psychologist, meet him, then tell me Ali was 6 months behind his peers.” (P3)

Delays in diagnosis were common amongst all parents. All parents felt that they had to fight for a diagnosis, which was a long and difficult process. Problems at school were noted as a major catalyst for diagnosis. However, some schools were reported to be less likely to recognise and support ASD, even though problematic behaviour was addressed with parents.

“Well he didn’t get a formal diagnosis until he was 11. He just didn’t get along with others at school... That’s when I finally opened my eyes and said, you know what, I am being called into school all the time because he has fallen out with someone or not socialising. But you know the school never said anything about autism...”. (P7)

“It was his behaviour at school and...but I was waiting, I was told at that time, Asperger’s could not be diagnosed until that age.” (P5)

“The primary school picked up that something wasn’t quite right also, but they couldn’t put their finger on it.” (P1)

“It was challenging because he never fitted in and teachers did not understand his behaviour.” (P3)

“The school knew there was a problem, they just didn’t do anything with it. They said he was lazy and needed to concentrate more. He had problems with processing also, I picked up early on that he was dyslectic, but the primary school were having none of that either. Yet within two or three weeks of being in high school, they referred him to CAHMS.” (P2)

Resistance to being diagnosed also caused a barrier towards receiving an official diagnosis statement. Some parents reported that either a doctor or their child showed some form of resistance to diagnosis. One parent reported that she was provided incorrect information by an NHS general practitioner.

“That ended with us seeing the head of services who turned around and said, we think you may have autism. So, we went to our doctor to make a request and they said “well you would have to pay for it.” (P4)

Another mother was not provided a diagnosis due to the psychiatrist’s belief about diagnostic labelling.

“...the psychiatrist that had seen Ken for years said he didn’t want to put a “label on him”. Those were his words.” (P6)

Other parents discussed how they had struggled during the time of diagnosis because of their child’s difficulty accepting the condition.

“...we met a very sensible doctor at CAHMS who said this is ridiculous, there is something obviously wrong and we need to get to the bottom of it. But she then didn’t engage with anyone at CAHMS or anybody anywhere... Well, it took a long time to get her diagnosed.” (P1)

“The problem, in some ways was getting the diagnosis, because adults have a choice to say no, to be social enough to survive, stay in their comfort zone.” (P3)

Parents highlighted “masking” as a barrier to receiving a formal diagnosis. Intelligence was expressed by two parents as a “mask” that caused a barrier to receiving early diagnosis.

“He just didn’t get along with others at school. I think when he was actually diagnosed the consultant said to us that we masked it quite a bit.” (P7)

“He did not have “bad” behaviour, but he had poor coordination in sports so was very unpopular in a team. He suffered a lot of bullying, but he was very stoic about it. Every time I expressed my concern to family, teachers, doctors or health visitors, there was nothing wrong, he was intelligent/” (P3)

“It was always accepted that he was on the autism spectrum and Asperger’s was always mentioned, but throughout his schooling he never was what they call “statemented”. It was called “statement in leu” he had and for one reason or another, I think it was because he was clever and could do his work, so it never proceeded.” (P6)

4.2 Theme 2. Challenges

Worried about the future. Parents expressed several challenges experienced as a parent of an individual with ASD. A major concern parents expressed were in relation to their adult child’s future welfare. Issues such as employment, relationships and living independently were highlighted concerns amongst many of the parents interviewed.

“That’s right, and when I am not here, I just don’t know how he will cope.” (P6)

“You go through life assuming everything is going to be OK, you know, you’re going to have a child and it’s going to grow up and meet someone and get married and a family. But I am not sure that going to ever happen... oh god loads, will they be by themselves? Will they be able to take care of themselves? Are they going to be financially OK? What happens if there is nobody around to support them? Plus, my other two children, my god they are going to have to deal with these issues, their youngest and eldest sisters, you know! There is just so much.” (P4)

“I am concerned about her going away to university, not the academic side but as usual the social side of things.” (P1)

“I have huge concerns about his future. Since I didn’t know for sure he has autism until he was 29, the entrenched isolation damage was done.” (P3)

“I am hoping some woman will take him on at some point or he will live with me forever. You at the moment he is not interested in girl, he’s quit immature for his age, so he is not interested in going out to

pubs, he doesn't see the point in socializing in the pub, he doesn't drink. I guess I just hope he will settle and find something he likes to do. You know I don't want him sitting at home on the DOLE. You know I worry about interviews for when he enters the workplace and stuff like that.” (P7)

Strain on parents. Caring for a person with ASD throughout a parent's life can add substantial amounts of stress on parents. Significant amounts of time were reported to be spent on providing care and support to their child. Some parents reported experiencing psychological distress, social isolation and self-blame.

“...the isolation, for one to keep them protected and an you know, getting into mishaps so they can't be a part of the usual social circles. You also have family difficulties with understanding... certainly, with Clark 's condition, because it wasn't so obvious, it was just seen as everything he did was misbehaving. So, you pull yourself away because you don't want them to always be on the receiving end of blame.” (P5)

“...when she was a child without a diagnosis, it felt very isolated, it felt obvious that we were doing something wrong, and we were crap parents.” (P1)

Some family members were less accepting of their child's behaviours and this added further distress to some mothers. One mother describes how some family members will not see her adult son anymore.

“...the sad thing is because of the way he has behaved, some of the family won't see him anymore. But it is absolutely their loss.” (P6)

“You also have family difficulties with understanding. Certainly, with Clark 's condition, because it wasn't so obvious, it was just seen as everything he did was misbehaving.” (P5)

Parents also reported that their employment was affected when having to provide extra support.

“Yeah, but a few years ago when things were difficult, I was working, so I would get really stressed with work and when we both got stressed, we really clashed. It’s one of the reasons I quit my job in the end and I have not gone back yet.” (P7)

“But I had to pick Clark up every other day with his difficulties, I brought him back to work with me were of course I could protect him and look after him...”. (P5)

“I also went to my doctor after nearly having a breakdown and he told me, well you can’t work and take care of Clare and do everything else you’re doing.” (P4)

4.3 Theme 3. Parent Coping Strategies

Acceptance. Interview’s highlighted several coping strategies which helped to improve some of the problems experienced by parents. Some parents described the importance of acceptance, taking on the viewpoint of the autistic person and flexible ways of thinking.

“The most important thing is to except the person, you can’t change the person, just accept them. As a parent I always thought I could change his behaviour, but I can’t. You need to change the way you think because you will just go around in circles trying to explain how to do it a different way, but Ken ’s just does things his own way. And he has succeeded in doing things in his own way.” (P6)

“I think you need to be led by the child, I think acceptance... There is nothing wrong with your child, their brains wired slightly differently. And support them but allow them to be themselves. When the school were trying to change Ellie, to mould her do what they need to fit into their system things were worst, but when things started improving, was when health teams and psychologists started saying, “what do we need to do to fit into Ellie’s way of thinking, how can we help her develop, grow, and succeed.” (P1)

“I think I would say, just don’t worry about what other people think, have to be more hardy and you know, be a little more like, they are going to be different.” (P7)

Parents seeking and accepting help was also noted as critical in coping with the stresses of being a parent of an individual with ASD. Help from charities were discussed by two parents interviewed.

“For me too, we joined the local charity and they have been brilliant. I don’t know how I would have gotten through the years without them, you know, with their advice and talking to other parents.” (P7)

“Clare’s support is through CHAPS... CHAPS is Cheshire Autism Practical Support, it’s a volunteer organisation.” (P4)

Two mothers recalled accepting help from family members.

“Oddly enough my daughter was a great support... Yeah, so she was a big support really.” (P2)

“I talk to my husband about what we will do in like, five years’ time, and we have his grandparents to help...” (P7)

Management. Management strategies were commonly used to help deal with problems and prevent issues from arising. Planning and organisation were important for prevention which often included family discussions and scenario mapping.

“...we are having to do a lot of planning because she is planning to go to university in September so. There was so much planning even before applying, like going and staying overnight in like Edinburgh, St Andrews, the places she might want to go, just so we could get a feel for the place, which was very much part of her making her decision.” (P1)

“...we would talk openly when things had gone wrong. We would pull it a part together and see where that happened and why that happened, so we spent lots of time together.” (P5)

“Well, you’re always well prepared and organised because you have to be... Yeah, like for his driving licence, it took him 18 months... and it like for the first few sessions we just sat around the table talking about driving and getting in the car. The instructor said everything was just going to need to go a bit slower and he just needed to take more time.” (P7)

Some parents discussed strategies for managing their own wellbeing. Engaging in recreational activities, and counselling were reported as ways of taking care of self and coping with stress.

“No, I was actually very depressed. It was only after I got married to Joey’s dad, when Joey was about three years old, he turned to me and said, “you need to start doing something for yourself.” You know, because I was always depressed. I told him I would really like to start cycling again. So, I joined a club and got the whole family into it.” (P2)

“For me, walk away, yoga.” (P4)

“I was put on the list for counselling which I am now 8 weeks into, and they told me this was not going to just be 8 weeks, but it will be long term”. (P4)

“I also go to the gym...” (P7)

4.4 Theme 4. Support and Treatment

Barriers to accessing support. Barriers to treatment and support differed between families. Experience of limited or inadequate options were common barriers to gaining appropriate treatment and support. When parents were asked about the types of treatment and support offered since their child entered adulthood, they expressed feeling that there was either inadequate or no support offered. Parents also expressed concerns about support ending after adolescence or that their adult child would likely resist help if offered.

“No, but she would reject it if it was offered.” (P1)

“No, in fact when your 16 CAMHS discharge you.” (P2)

“...Ali had no treatments or interventions.” (P3)

“No, there are pockets of support by places like this, but this group was actually started by an “Aspi” Mum... we would just be subject to social care and social care are just useless. I mean Clare’s report, we asked for a residential one so we could get her into Langdon Community. The report came back saying she needed seven sleep-ins and she wouldn’t leave the house. So, they had nothing more to do with her and they were completely useless for us.” (P4)

“No, we had a couple of appointments with Dr. Black, but he was only training, so he moved on and then we had maybe a couple more appointments. There was absolutely nothing!... Nothing at all. Well, other than the support at the university, which I paid for...” (P5)

“Oh, before that (diagnosis), I didn’t get any help... Now he has had counselling for different things, but the counselling is for if there is something wrong with you. There is nothing wrong with him, he is just Ken ...The only thing that was offered was a place he could go in Thameside, where he could go and meet up with other people the same as him, but he has never bothered. So, there is something there, where he can tell his thoughts or whatever, but he has never took that up.” (P6)

“Well nothing really, well I dunno, I don’t think there is any. He hasn’t been moved on to adults’ services yet, but I only know this because of his ADHD. So, I assume that his autism will also be passed on to adult services, but what they will do, I have no idea. No one has seen him since he was 11 so I don’t think they will be rushing to see him anytime soon.” (P7)

Some of the individuals with ASD were only offered help when they were children.

“Well, it took a long time to get her diagnosed, she was in the unit for five months. She actually had spent her 13th birthday in there and they did so much work with her, about social skills and behaviour and they worked with us. She would come home every weekend with her key worker for the day and they were teaching me different things with Ellie and the key worker would leave on Friday evening and Ellie would go back on a Monday morning. So, while she was still in there, she was referred for home treatment for children with complex needs. They saw her while she was still in Alder Hay and they came out with her when she was discharged. They worked with us, initially it was six months but after six month they said although things are moving on, we don't think we are as far as we can get, and we want to finish this. So, they stayed with us for a year.” (P1)

“Oh yes, children get the support and adults don't.” (P4)

“No, not on the NHS. He did end up in an autism unit. He went to high school and struggled for a couple of years and it just so happens we were in the right place at the right time. They had decided that at his school they were going to open an autism unit and the school were told they could choose one pupil from the whole school and the rest would be sent in from other places. So, they chose Hank, so he ended up getting into this autism unit.” (P7)

Inadequate support. Difficulties accessing adequate autism specific treatment in childhood even after diagnosis was experienced by one parent.

“In Trafford it was a nightmare. Even though we had a supportive GP to start with, before we moved house due to divorce, Dr Simpson could not access support from the then Primary Care Trust. After moving I tried to get advice from 2 further GP's. One told me that autism was just a “new-fangled syndrome” and the second dismissed me from the consultation and then gave Ali a PHQ-9 form, said he was depressed, and would not discuss with me further. I periodically would phone around but was passed from pillar to post. Suspected autism was not

learning difficulties, so they passed me to mental health, then they rightly said autism was not in their field either. Ali did access CBT for a short while, but he did not feel it helped.” (P3)

4.5 Theme 5. Recommendations for Intervention

Life skills. Parents provided rich insight into what they believe their autistic adult child would benefit from in an intervention. Training of life skills was recommended by some parents.

“It’s everything really, relationships, making friends, how to behave, and just social skills for someone her age.” (P1)

“I just think social skills in social situations, Joey had the national autistic society come to the school and they put them into small groups and learned social skills and that really helped.” (P2)

“Both my girls really struggle to understand social cues, so understanding when to start talking, when it’s safe to interrupt and not. ...when you don’t have those social cues in a social environment, whether they are in a work environment or even talking to strangers in the street, or answering a phone, they’re not able to do that and I don’t know if that’s something that can be taught because it a basic autistic problem.” (P4)

Employment and independence were deemed important and one parent believed relationship skills such as dating need to be addressed.

“I wish that the Jobcentre had a properly trained disability support person with sensitivity to these issues. I tried ringing them again last year and they clearly did not understand at that point. If I could trust the system, then I think Ali would engage more if he was financially rewarded by “working”, albeit only a couple of hours, in something he might engage with out of the confines of his own room.” (P3)

“Well, he’s 26, and now looking at it, clearly, he needs workshops for employment. Again, it that preparation, the more preparation, the more confidence you have going forward.” (P5)

“Yeah, well in the unit, I think they should have done more everyday skills. Sorry, I just remembered that he just finished with this charity that gave him interview skills and CV skills, but I did have to fight for it. It wasn’t just for autism it was also for people with mental health issues. It was also great because it got Hank out, he had to make his own way to the job centre and meet a stranger.” (P7)

Some parents described a need for an advocate to help with supporting independence.

“Yeah because Ken needs someone throughout his life, he’s not going to change or get better, he has a condition doesn’t he, you know what I mean? It’s not an illness, it is just something that is different. And he’s vulnerable, no matter what he may say, he is vulnerable.” (P6)

“Yeah, I mean there are just so many forms to fill-in and everything you do, you have to jump through hoops. Without a person on your side to help, I think it would be really difficult.” (P7)

Education and psychological therapy. Support for parents, psychoeducation, pet assisted therapy, and counselling were also discussed.

“I think that some of the courses we have been on were great like understanding sensory overload....., one thing that helped Ellie tremendously was, well at the time it was call dogs for the disabled and they did some research, this thing called PAWS which stands for parent of autism workshop and support. The research brought parents of autism together to see the potential a pet dog might have with the family and recognising the incredibly calming effect a dog can have on a child with autism. Our pet dog had such a calming influence on Ellie when she was very angry or frustrated. It was all about her having to take care of him, grooming him, and it was just brilliant.” (P1)

“For this group of patients, I think gradual and closely counselled reengagement is needed. As highly intelligent and insightful human beings, they cannot be deceived or manipulated, yet there is great difficulty from his previous counselling and CBT in adhering to the goals of the person with autism, often not wanting to engage out of their comfort zone and imposing on increasingly elderly parents being swept along in their child’s resistance to responsibility... I often wonder how many parents themselves are struggling with a high level of autistic traits?”. (P3)

4.6 Theme 6. Positive Parenting

Pride of Achievement. Expression of pride in achievements were reported by parents interviewed. Two parents spoke of how achievements are more pronounced and celebrated because of the challenges they experienced. One parent discussed how their adult child had even exceeded her expectations.

“Oh yes, definitely. There achievements are just so much more special. Seeing Joey works fulltime, he has friends and he has a partner now. You know when he was 14, I wouldn’t have envisioned any of this.” (P2)

“...And also, not that my expectations were low, but because he struggled so much, when he achieved, I would just think, wow, you’ve just done amazing, you know going through college, applying for Uni, and passed his driving test. Just, things that I thought three or four years ago, when he was going through adolescents, you know, I never thought he’d get there.” (P7).

Pride of character. Parents highlighted positive characteristics of their adult children. Insightfulness, creativity and academic achievement were all expressed.

“Often very insightful angles on situations. When he was stuck in the car with me in a bad traffic jam (I had done counselling training) and I was ending my marriage, and Ali asked me very skilful questions about my motives and rationale. He has taken on tasks more since his dad

and I split 12 years ago... understanding the central heating boiler and monitoring the pressure. He has A level electronics and is keen on monitoring electrical consumption of gadgets to keep our bills down.” (P3)

“Oh god yeah, Clare’s artistic side is amazing, her writing...” (P4)

“My son has done remarkably well in the sense that he went to university and has a first masters.” (P5)

Being naturally caring and helpful to others were positive characteristics that were drawn attention to by three parents.

“He has an amazing relationship and understanding of his sister’s border collies. He cares for his sister when she is ill... She is often stuck in bed due to having ME.” (P3)

“So even though they feel strong emotions, they also have a lot more to give.” (P4)

“Dave has classic autism with learning difficulties and doesn’t speak. I would understand Dave’s needs but Clark’ was very sensitive to Dave’s needs, Dave could do no wrong, he would give up anything and everything to him...”. (P5)

3 Discussion

Many of the themes found in the current study were broadly comparable to other past studies (e.g., Ludlow et al., 2011; Mount & Dillon, 2014; Sosnowy et al., 2018). Participants spoke at length about their experiences of being a parent to an adult child with ASD. Many parents described how they were proud of their child’s accomplishments in light of the challenges they had experienced. Some parents felt their adult child had even exceeded their expectations, with some providing examples of accomplishments in education, vocation, and artistic talent. Focusing on the positives and celebrating progress have been reported as helpful coping strategies for caretakers of an adult with ASD (Hillman & Anderson, 2019; Kayfitz, Gragg, & Orr, 2010). However, all parents interviewed also provided insightful

details about some of the challenges experienced over the lifetime of their adult child with ASD.

The findings show that all parents at some stage were faced with the reality that there was something different about their child. Many of the parents interviewed describe how either they or someone else noticed a problem before the process of diagnosis. Past research has shown that it is common for a parent or family member(s) to express an early sense of a problem before receiving a diagnosis (Howlin & Moor, 1997). Many of the parents in the current study discuss long delays in receiving a diagnosis and reported finding it difficult to access appropriate support and that most of the support they received they had to source themselves. Some parents even expressed how they faced such barriers that a formal diagnosis statement was not provided until after their child had entered adulthood. These findings are consistent with past research which suggests that many parents often wait up to three years for a formal diagnosis but hope for a much “faster and easier” process (Crane et al., 2015; Osborne & Reed, 2008). Mount and Dillon (2014) also reported similar experiences were parents of adolescent children with ASD found a need to push for a diagnosis or source support themselves. When considering delays in diagnosis are common and tend to increase parental stress (Blanche et al., 2015; Mansell & Morris, 2004), it appears greater access to support during the diagnosis process is greatly needed.

Many parents expressed their difficulty getting a diagnosis was contributed by either a professional or their child’s resistance to diagnosis. Broadly in-line with past research (e.g., Ludlow et al., 2011; Osborne & Reed, 2008, Potter, 2016), parents felt that some of the professionals they encountered provided unsatisfactory support or provided incorrect information about ASD. Parents reported a range of experiences which include being told that autism was a “*new-fangled syndrome*” or how the professionals personal views on the effects of diagnostic “*Labelling*” hindered receiving an ASD diagnosis. Some of the experiences reported by the parents in this study predate the impact of National Autism Awareness Month, televised reports on ASD and an increase in online searches related to ASD, which have all significantly increased awareness of the disorder over the past two decades (DeVilbiss & Lee, 2014). It appears that levels of social support can influence the ability of both parents and their adult children with ASD to cope later in life (Oti-Boadi et al., 2020), so families without support may have an increased vulnerability. It is important that

professionals strive towards a more collaborative approach which offers clear communication of knowledge and considers the needs of both parents.

Parents of children who received late diagnoses believed that “masking” of symptoms contributed to late acknowledgment of the problem. Intelligence being specifically highlighted as a way to mask symptoms. These findings are in-line with the results from autobiographical descriptions and clinician observations which have shown that some individuals with ASD ‘camouflage’ their symptoms (Lai et al., 2017). Individuals who receive a diagnosis in childhood have been shown to have reduced symptoms as adults (Howlin et al., 2013), while individuals diagnosed later in life tend to go without help for many years so they develop coping strategies to “mask” or “camouflage” social impairment (Lai et al., 2017). Those individuals diagnosed later in life also tend to struggle more with mental health issues caused by trying to adapt to the demands of life in society (Lai & Baron-Cohen, 2015). A greater awareness of “masking” by professionals can help to ensure that individuals with ASD and their families, do not suffer from the unnecessary stress caused by not having a diagnosis.

The challenge of providing care to their adult child with ASD placed substantial amounts of strain on parents. During their interviews, parents described spending large amounts of time providing care and support towards their child’s needs well into adulthood. These findings are broadly in-line with findings from a very recent qualitative study which explored the unique experiences of nine ageing parents and their young adults with ASD (Oti-Boadi et al., 2020). Of the nine participants interviewed in their study, seven reported feeling fully responsible for the child even in adulthood and report having to put in extra time into caring and nurturing the needs of their adult children. It is not uncommon for parents to express feelings of guilt, self-blame (Lopez, et al., 2018) psychological exhaustion, and social isolation (Oti-Boadi et al., 2020). Offering interventions such as community counselling groups, may provide a better platform to educate parents about ASD in adulthood and work through the psychological challenges that can arise among caregivers of individuals with ASD (Mills, Vimalakanthan, Sivapalan, Shanmugalingam, & Weiss, 2020).

Parents in this study also expressed concern for the future well-being of their adult child. Concerns discussed were related to employment prospects, social and romantic relationships and independent living. Independent living outcomes are a large concern for

many young adults with an ASD (Anderson et al., 2014) and many of the parents interviewed in this study expressed concern about their adult children living on their own. In a recent qualitative inquiry, fathers of children with ASD revealed that they felt integration and independence were key areas for professionals to provide further support (Potter, 2016). Similarly, a study exploring parents' perspectives on transition outcomes of young adults with ASD found that living independently and employment were considered the most important for achieving larger overarching goals (Sosnowy et al., 2018).

During their interviews parents also described how having a child with ASD had at times caused relationship difficulties and that some relationships had completely broken down over the years. Research has shown that one family member with ASD can have a significant impact on other members of the family (Hines et al., 2014; Welch et al., 2012). Similar findings were reported by Mount and Dillion (2014) after they interviewed parents of adolescent children with ASD. Eight out of the nine parents interviewed reported having experience some form of effect on relationships e.g. strong attachment towards the mother and not the father or the need to justify ASD related behaviours to siblings

Many parents may find that they need to find ways to manage their problems without access to professional services and the current study sheds some light on how older parents have learned to cope. Many parents reported using several coping strategies which they found to be useful during their most difficult times. Acceptance and management of the condition were important for coping with life as a parent of an individual with ASD. Parents felt that accepting the condition helps see things from the autistic persons point of view, which can then lead to more flexible thinking. Acceptance and management of ASD has also been discussed in past research which explored experiences of parents with children diagnosed with ASD (Altiere & von Kluge, 2009; Burrell et al., 2011; Ludlow et al., 2011). Analysis of interviews with 14 mothers and six fathers of children with ASD revealed that while both mothers and fathers experiences of coping were similar, many mothers felt that fathers had more difficulty with acceptance of the disorder and some even experience denial (Ludlow et al., 2011). One reason for greater acceptance in mothers could be due to a receiving a greater level of social support from family and friends than fathers (Altiere & von Kluge, 2009) and that fathers can place less value on both informal support and formal support (Burrell et al., 2011). Once a parent has come to accept the condition, coping strategies such as positive reframing and structured planning can become more manageable (Bonis, 2016).

Accepting help from others during difficult times was also found to alleviate some of the stress and strain on parents. Help from family members and charities were the most commonly reported forms of social support provided to the parents. Charities were described by some parents as vital resources which provided important information and contact with the ASD community. Similar findings were reported by Ludlow and colleagues (2008) where the parents in their study felt that grandparents and other parents of children with ASD were important social support resources. For those individuals who do not have the option of family support (recently moved or estranged from family), charities and other forms of ASD community groups may provide a supportive alternative.

The most common management strategies reported by parents were in reference to being structured and organised. Being prepared and talking about an event in advance helped to plan for adverse reactions or unexpected occurrences. Likewise, parents of adolescents with ASD have also reported the need to use more practical management strategies such as keeping to routines and planning in advance (Mount & Dillon, 2014). Parents in the current study also described having to manage quality time for themselves and the family. Recreational activities such as going to the gym, doing yoga and cycling were found to help parents relax. Collectively, present and past findings have provided greater insight into the things that help parents cope with the additional pressures associated with having a child with ASD. Unfortunately, recreational activities may be seen as a lesser priority when even finding the time to connect with a partner can be difficult (Frye, 2015). Nevertheless, the information gained from these findings can help push towards developing new interventions which provide advice and promote the resources which have helped other parents when struggling to cope.

During their interviews, all of the parents believed that more ASD specific support should be provided in adulthood. Parents stated that they had been offered little or no intervention since childhood and those which received an adult diagnosis were being offered even less support. Parents expressed concerns that their adult child may not accept help even if offered. It is plausible that one reason for this is in-part, due to past experiences of working with professionals. A recent study found that adults with ASD find it difficult to access effective interventions and that they often felt that professionals had very poor knowledge of autism and needed better training (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy,

2019). Early positive experiences of interventions for ASD seems to be vital to increase the likelihood of individuals with ASD accepting support in adulthood.

It is still not fully clear what level of impact adult ASD interventions have on long-term outcomes, however older parents are in a unique position to provide insight into the challenges faced by their adult children with ASD. Drawing from their own experiences, parents can help to identify the most appropriate forms of support and intervention. Different types of support were discussed with parents during their interviews and many involved some form of psychoeducation or skills training. Social skills were believed to be very important for functioning adequately in adulthood. Parents also believed that training adults with ASD to make friends, behave at work or in social gatherings, enter romantic relationships and living independently were all important topics for intervention. In past research, parents and young adults have described similar topics in terms of desirable outcomes to be achieved over a lifetime, such as physical safety, friendships, employment, and living independently (Ivey, 2004; 2007; Poon et al., 2013; Sosnowy et al., 2018). It seems clear that in order to assist the best possible outcomes for young people with ASD, it is imperative that topics which are seen as personally important are at the centre of future intervention development.

5.1 Recommendations and Remediations for CBSCTI-ASD

Findings from this chapter should be taken into account when further developing CBSCTI-ASD. Providing support towards independence and employment were believed to be very important by parents. Several studies have suggested that social impairment related to ASD can impact upon adaptive living skills and this may contribute to the lack of independence and poor quality of life found in young adults with ASD (see review by Palmen et al., 2012). Adults with ASD have been shown to face significant challenges entering, maintaining and advancing in employment, however using behavioural techniques to train employment skills in individuals with ASD appears to be promising (Hedley et al., 2017).

Similar to other MGSSI for adults with ASD (see Chapter 2), it is possible to extend CBSCTI-ASD to provide employment and daily living skills. Behavioural techniques for teaching employment and life skills have included: tablet-based video modelling (Burke et al., 2013), covert audio employment coaching (Bennett et al., 2013) and discrete-trial training (Lerman et al., 2015). Although it is well established that employment rates for individuals with ASD are rather bleak, extending CBSCTI-ASD to include topics on adaptive

functioning such as daily living skills (e.g., hygiene, handling money, cooking) and employment skills (e.g., performing in interviews) may improve some individuals chances of finding and retaining employment and even progressing in their careers.

All parents that were interviewed also discussed a long diagnosis process where limited or no support was offered. Apart from a limited few early intensive behavioural interventions for young children (e.g., Early Start Denver Model; Vismara & Rogers, 2008), interventions for adults and caretakers awaiting diagnosis do not yet appear to exist. Receiving a diagnosis can take an average of three and a half years (Crane et al., 2015) and feeling misinformed or displeased with medical and other professionals can increase stress during this time (Wong, Yu, Keyes, & McGrew, 2017). When further developing CBSCTI-ASD, the inclusion of a pre-diagnosis consultation which provides accurate information in a positive style, may help alleviate some of the stress associated with the diagnosis process (Abbott et al., 2012).

Many parents often have misconception about the nature of ASD and this can affect bonding and serve to be an obstacle to accurate ASD education (Castillo, Cohen, Miguel, & Warstadt, 2020; Chan et al., 2021). Recently research has shown anti-autism bias and stigmatization can be reduced when providing educational messages and specific bias training (Bast et al., 2020; Jones, DeBrabander, & Sasson, 2021). Parent intervention prior to diagnosis may be effective in reducing misconception, improve communication, and strengthen bonds between both typically developed and ASD family members. A very recent study (Jones et al., 2021) investigated the effects of autism acceptance training program on both explicit bias (conscious level bias) and implicit biases (unconscious bias) toward individuals with ASD. The training involved showing typically developed participants videos which included topics on diagnostic characteristics of ASD, sensory issues, strengths of ASD, challenges an individual experienced at university, neurodiversity, and increasing inclusion and acceptance of individuals with ASD. Training was found to significantly reduce explicit bias but did not impact upon implicit bias, nor was it measured for long-term effects. Nonetheless, such a training modality could be incorporated into the CBSCTI-ASD manual to help parents improve awareness and provide more positive perceptions about ASD. However, it appears changing beliefs about the condition maybe more challenging.

The CBSCTI-ASD pre-diagnosis consultation should cover details about other experiences and provide an honest appraisal for families trying to prepare for the process. Expectations need to be addressed, and accurate information should be provided about the process such as working with multiple professionals, communication, the timely process of diagnosis and getting support from an ASD specialists. Consultations could also be used to address parents' concerns about "masking" symptoms and avoiding engagement with professionals when help is offered. Tackling the topic of "masking" within CBSCTI-ASD may provide a communication platform to concentrate on individual barriers to accepting professional help (e.g., masking the truth until social demands exceed capacity to cope). In addition to consultations, CBSCTI-ASD could also include psychoeducation seminars for caretakers which discuss feeling anxiety, stress, sadness and anger during and after the diagnosis process (Keenan et al., 2010; Wong et al., 2017).

There also appears to be a demand for CBSCTI-ASD to include a caretaker component for those parents struggling to cope after diagnosis. Some parents reported needing help to improve their own wellbeing at times, with support groups and physical activities being popular and helpful interventions. Charities and community groups often run a number of popular activities which can help people relax by breaking down psychological barriers between people and encouraging mutual support for each other during difficult times (Lyons et al., 2016). For many older parents, they will likely have already developed some helpful coping strategies for handling problematic behaviours related to ASD but may still benefit from more emotion-focused strategies to help them plan and come to terms with the possibility of their child living without their support (Grey, 2006). Planning should be collaborative and separated into manageable steps and each step should include a significant level of support (Marsack-Topolewski & Graves, 2020).

Delivering a concurrent caretaker component may prove to place a higher demand on resources and may impact upon providing CBSCTI-ASD more widely. However, collaboration with community groups, charities or government services (e.g., NHS) could possibly be a cost-effective solution. CBSCTI-ASD could be adapted to include a single session which provides information about support and activity groups in their local community. Caretakers would potentially be introduced to multiple resources which could be self-tailored to their specific needs and interests. In addition to informing the expansion of CBSCTI-ASD, the information gained from the PhD project could contribute towards the

development of new community interventions which provide advice and some direction towards appropriate resources (e.g., counselling services, self-help activities, and support groups).

5.2 Research Limitations

There are some research limitations in this chapter which should be addressed. The first noteworthy limitation of this qualitative study is that it lacks generalisability. Broad generalisations from the findings of this study should be considered with extreme caution. Despite this limitation, the findings do provide an indication of shared experiences through the rich subjective accounts of parents' views. The study provided insight into what support they had received and what support they believe to be important for their adult child with ASD.

A second limitation is that the study did not explore the different experiences by age of parents and adult children. It is possible that the experiences of the diagnosis process and support have differed over time. Due to greater awareness, there have been changes in professional practise and early detection and intervention has been the focus of a number of investigations (James & Smith, 2020). Lastly, only mothers were interviewed in this study, however they did provide information about how they perceived events which included the entire family. Since there are differences in the way parents experience events, interviews with fathers or siblings may shed further light on way to support families in need of more help.

5.3 Future Research Direction

Future studies would benefit from the inclusion of fathers where possible. The experiences of mothers' and fathers' in the diagnosis and support planning has been shown to differ for parents of children with ASD (Potter, 2017) Therefore, the experience of fathers caring for their adult's child with ASD deserves to be explored further. In the future, focus groups may provide a better platform for collecting accounts from multiple sources (e.g., mothers, fathers, parenting couples, other family members), broadening the number of experiences likely to be shared. Furthering qualitative investigation of service user views on policy and experience of diagnosis is greatly needed. Dissatisfaction with service providers has increase over the years with reports showing 61% of parents expressing dissatisfaction in

2015 compared with just 37% in 1997 (Crane et al., 2015; Howlin & Moore, 1997). More accounts of the subjective experiences of service users may provide a better understanding of why perceptions of services are more often negative.

4 Conclusion

The findings from this study highlight some important and complex issues which parents and individuals with ASD experience over a lifetime. Ensuring healthy and safe outcomes for those with ASD is of the greatest priority. Community and clinical support services should consider developing a collaborative working relationship with the families of those with ASD that are finding it difficult to adapt to the demands of adulthood. It is important for professionals offering support to understand some the unique challenges which they may face when providing intervention, such as individuals “masking” their problems. A particular focus should be given to those individuals who have reported to have inadequate or no prior support and still struggle to cope and “mask” their problems. Parents and family members need to be provided with information about a range of relevant resources which engage the needs of those individuals who are struggling but are more resistant to accepting help. Intervention should include a range of important topics, provide helpful information and teach the necessary skills for individuals with ASD to achieve their desired outcomes. Moving forward, it is vital to further consider the findings of the study within this chapter when further developing CBSCTI-ASD.

Chapter 6. General Discussion

1. Summary of Findings

1.1 Introduction

Several modalities have been used to improve social competencies in youths and adults with ASD (e.g., CBT therapy, virtual reality training, leisure activities), however group-based behavioural interventions appear to be the most popular format (Ke, Whalon, & Yun, 2018). While early studies on social skills interventions for ASD with a group component provide only anecdotal data to support efficacy, (e.g., Mesibov, 1984), over the past four decades a significant evidence-base has been produced (see reviews by Gates et al., 2017; Ke, Whalon, & Yun 2018, Reichow et al., 2013; Spain & Blainey, 2015). Despite the large evidence-base to support the use of group social skills interventions for youths with ASD, efficacy on adults with ASD is still in question.

There is also little information on which components of a given social skills intervention may be most appropriate for adults with ASD. Chapter 2 provides a comprehensive review of nine MGSSI for adults and no or very limited information was provided about the development process of the social skills intervention being delivered. Additionally, of the nine studies only one had the manual published (e.g. *PEERS*; Laugeson & Frankel, 2010). This project attempted to address this limitation by providing a detailed overview of each CBSCTI-ASD component and the rationale for inclusion. Unfortunately, analysis of each component of the intervention was beyond the scope of this PhD project but should be considered in future research.

This PhD project was unique in that it adopted a mixed methods approach to evaluate the feasibility and efficacy of a multimodal cognitive behavioural social competence intervention for adults with ASD without ID. To the authors knowledge, this is also the first attempt to investigate the neural response to a multimodal CBT social competence intervention for adults with ASD without ID using fNIRS technology. In addition, embedded in this project was a nested study which explored the rich experiences of parents with adult children with ASD. Qualitative findings can help provide some level of insight into the needs of adults with ASD and the parents which provide them with essential support. The results from this PhD project build upon the existing knowledge of interventions for social

competencies in adult ASD populations, the neuroscience of the social brain in adults with ASD without ID and the complex needs of those with ASD.

1.2 Feasibility and Efficacy of CBSCTI-ASD

The primary objective of this PhD project was to establish the feasibility of delivering CBSCTI-ASD to adults with ASD without ID. Through qualitative and quantitative investigation, the findings were promising and feasibility of the delivery of CBSCTI-ASD were supported. Markedly, participant satisfaction rates and adherence to the intervention were at a very high level. In addition, the therapist adherence to CBSCTI-ASD manual objectives suggest that the method of delivery was suitable. In addition to quantitative data, qualitative analysis of semi-structured interviews provided anecdotal evidence of intervention feasibility. The participants in the intervention group and their parents expressed that they believed that CBSCTI-ASD was helpful for improving social interaction and increasing social motivation. All four of the participants interviewed said that they would recommend CBSCTI-ASD to others with ASD in the future.

Preliminary results supporting efficacy of CBSCTI-ASD were also somewhat promising. Reliable change scores for individual participants showed that three out of the five participants demonstrated significant improvements in overall MSCS self-report scores. Four participants reported significant improvements on IRSA observer-rated assessment. Participants also increased scores on social competence sub-domain across measures. However, individual improvements across social sub-domains were considerably variable between participants. The only significant improvement found across all participants were in the interpersonal relationship sub-domain of the IRSA.

Group analysis of social competencies through self-report measures also suggest that CBSCTI-ASD may help to improve social motivation and emotional regulation. Group analysis of observer-rated IRSA assessments suggests that participants were more assertive and demonstrated more self-control after the completion of CBSCTI-ASD. There were also significant improvements observed in interpersonal relationship skills and social sensitivity. Findings from qualitative analysis also revealed anecdotal support for the efficacy of CBSCTI-ASD. Improved prosocial behaviour, increased social motivation, greater acceptance, new gained independence and improved social etiquette were drawn attention to as areas participants believed to be improved after receiving CBSCTI-ASD.

1.3 Impact of CBSCTI-ASD on Brain Function

Investigation of the neurobiological effects of CBSCTI-ASD were somewhat mixed. Results from neuroimaging data found that there was significant increased oxy-Hb in the left MPFC for both the ASD and typically developed control group during the conversation task. These findings suggest that the left MPFC is highly active during a naturalistic social interaction and may provide a suitable target for assessing brain activity related to the development of social competence. Surprisingly, between groups comparison revealed some unexpected results. There were no significant differences found in any regional brain activity during the conversation task between the ASD intervention group and the typically developed control group. Group comparison also revealed no significant differences between groups in self-reported social competence. However, analysis of observer-rated assessment did show there were gains in the domains of assertiveness, interpersonal relationships, and self-control for the intervention group but not the control group.

Post hoc tests demonstrated that the intervention group demonstrated a significant increase in oxy-Hb in the left MPFC and a trend toward significant increases in the left DLPFC over the time in which CBSCTI-ASD was delivered. However, over this same timeframe there were also significant increases of oxy-Hb in the left MPFC in the typically developed control group. Increases in brain activity in both groups make it impossible to establish if CBSCTI-ASD had any impact on increasing neural activity. Nevertheless, these findings provide some evidence to support the role of the MPFC and possible the DLPFC as part of the social brain. Further research will be needed to establish if these regions are viable targets for measuring therapeutic change in response to interventions for individuals with ASD.

1.4 Experience of Parents and Recommendations for Future Intervention Development

Most of the themes found when exploring the experiences of parents with adult children with ASD were related to the challenges they faced and their ability to access clinical and community support over their adult child's lifespan. In addition to these themes, parents also expressed pride in their adult child's accomplishments, despite the challenges encountered along their journey into adulthood. Some parents felt their children even exceeded their own expectations. However, parents described the long and arduous process of diagnosis which some individuals did not receive until adulthood. It was common for parents

to feel unsupported by professional services or that they were given misinformation. Parents highlighted that “masking” of symptoms, in particular the use of intelligence as a “mask”, often created the impression that nothing was wrong.

Parents expressed their belief that it is important to support the entire family effected by ASD. All parents interviewed were primary caregivers who described the necessity to devote significant amounts of time providing support towards their child’s needs, even after entering adulthood. Parents reported feeling psychological distressed, socially isolated and some even place blame on themselves for their child’s condition. However, several coping strategies were reported to help during difficult times. Acceptance and management of the condition and accepting help from other people were crucial coping mechanisms. Family support and help from the ASD community were common avenues for social support. Management strategies included having a daily structure and being organised, prepared and have willingness to communication with your child were essential for adapting to confirmed and conceivable changes to the daily routine. Parents felt that interventions were crucial for teaching topics relating to employment skills, social skills, making friends, entering romantic relationships and independent living.

It was important for parents to manage quality time for themselves. Self-help physical activity strategies which included practising yoga, going to the gym and cycling helped the parents improve their wellbeing. Alongside self-help strategies, some parents found that professional services such as counselling, were also helpful for coping with problems. Parents also believed more ASD specific support should be provided to young adults with ASD which are struggling to cope with the demands of adulthood. Most parents interviewed had been offered little or no intervention since their child entered adulthood. Profoundly, individuals with an adult diagnosis seem to have been offered limited clinical follow-up or were offered no intervention once receiving their ASD diagnosis. The clinical implication of the findings from this PhD project are further discussed.

2. Clinical Implications and Recommendations

The initial findings of CBSCTI-ASD appears promising, but the scope for delivering the intervention to community, clinical or educational settings needs further consideration. There are considerable challenges when delivering a multi-modal therapeutic intervention. Co-ordinating combined group social skills therapy and individual CBT therapy sessions may

present distinctive logistical and care provider challenges. CBSCTI-ASD currently requires more than one specialist clinician, and the duration and frequency of sessions may limit application across settings. It could be possible to deliver the manualised group component in a community setting with non-specialist professionals, while the individual component is delivered in a clinical setting by a trained CBT therapist. This would also reduce the demand placed on professionals attempting to deliver both modalities. Although, separation of modalities may come with additional communication and co-ordination challenges between the professionals delivering separate modalities of the intervention. CBSCTI-ASD could be adapted to be delivered exclusively under a group therapy framework which would eliminate such challenges, yet those which need more individual support would benefit less from the intervention. Before adaptations to the intervention are made, a more extensive analysis of CBSCTI-ASD would help to determine which modalities and components of the intervention are most effective for improving social outcomes.

Since the conception stage of CBSCTI-ASD in 2016, evidence has emerged to support the double empathy problem and studies have started to show that social difficulties go beyond just addressing social impairments through social skills intervention. Evidence is growing in support of social perspective models of ASD which heavily focus on the factors that impact upon social experiences (Michell et al., 2017; 2021). In contrast to the causal model position taken within this research project, a social developmental model account of ASD would pose that social development is shaped by the experiences shared when encountering others (Mitchell et al., 2021). Social interactions are multifaceted and while difficulties making inferences about others has been commonly reported in individuals with ASD, typically developed individuals have likewise been shown to find it difficult to read individuals with ASD (Alkhaldi et al., 2019; Sheppard, 2016; Sasson et al., 2017).

Empathy problems for typically developed individuals can also impact upon the perceptions and the motivation to socially engage with individuals with ASD. Understanding both sides of a negative social experience may provide greater insight into the social phenomena which occurs during interactions between ASD and typically developed individuals. It is still not clear to what extent negative social experience and being hard to read/interpret has on the social difficulties commonly encountered by individuals with ASD. Establishing external indicators that impact on social development may help to better

understand the aetiology of ASD and develop the most appropriate interventions for those who need greater awareness and understanding.

In addition, recent research investigating the double empathy hypothesis suggests that individuals with ASD are possibly better and more comfortable communicating with ASD peers, however there is little evidence to explain this occurrence. The double empathy theory suggests that there are distinct mechanisms shared by individuals with ASD which help them understand the world and connect with others with ASD (Milton, 2012). Understanding these mechanisms may bring further clarification to the reasons for mutual misunderstandings. Further research investigations may also provide ways to address the double empathy problem within society.

When developing CBSCTI-ASD, the goal was to support natural change and not try to change individuals to better fit into society. Some social skills behavioural interventions maybe at risk of simply teaching individuals how to camouflage features of ASD (Michell et al., 2021). It is well documented that efforts to “camouflage” or attempt to mask ASD characteristics in order to blend in with others is common and that camouflaging has been identified as a potential risk factor for mental health issues and even suicide (Hill & Katusic 2020). While not the intention of any researcher developing social skills interventions, these views should be considered to avoid the risk of inadvertently contributing to future mental health problems, or more concerning, increasing the risk of suicide within this vulnerable population.

The use of non-specialist professionals carries further additional risk to the delivery of CBSCTI-ASD. During this PhD project, when interviewed, both CBT therapists acknowledged that communication was a significant challenge during collaboration in individual therapy sessions. This was not a surprising revelation amongst the findings when considering the nature of communication difficulties experienced between ASD and typically developed individuals, however this does pose concern for those therapists without specialist training or experience working with individuals with social communication difficulties. Poor communication can affect the therapeutic alliance (Attwood & Scarpa, 2013) and this may lead to reduced engagement. A possible solution would be to invite parents with experience of having a child with ASD to help facilitate the groups alongside the non-specialist

professional. This approach has the dual benefit of improving the ability to effectively communicate and reduce the financial costs of delivery.

The age and gender of the participants who took part in CBSCTI-ASD, may have also impacted on intervention evaluation. The participants in this project which completed CBSCTI-ASD were all young adults transitioning into adulthood. Older adults with ASD without ID often learn both helpful and unhelpful coping strategies for dealing with social difficulties (Taylor & Seltzer, 2011) and they may not share the same benefits from CBSCTI-ASD as younger adults with fewer adulthood experiences. For example, older adults with ASD may need more time to address unhelpful coping strategies and replace these with more helpful ways of coping. As for gender differences, unfortunately little can be inferred about gender response as there was only one female participant in the intervention group. However, the female participant demonstrated the highest level of social competence improvements as measured by self-report. However, it should be noted that the same levels of improvement were not reflected in the results of the observer-rated assessment.

A further limitation is that the researcher could not know the extent of the participants social impairments without using gold standard screening measures (Brugha et al., 2015). During the CBT therapists focus group interview, there was acknowledgement that some components may have been too difficult or daunting for those with more specific needs or more limited social capabilities. It was suggested that these individuals may benefit from more scaffolding during skills training in group sessions. Unfortunately, due to budget limitations of the PhD project, screening measures to support an ASD diagnosis were limited to measuring trait ASD symptoms using the AQ. The AQ screening instrument is limited in its ability to adequately distinguish very low or very high levels of ASD traits (Murray, Booth, McKenzie, & Kuenssberg, 2016) and many individuals with an ASD diagnosis can often still score below the AQ cut-off threshold (Ashwood et al., 2016).

Using more sensitive assessment instruments, may offer a more detailed picture for the therapist, providing a greater awareness of those which may need more focused help. The CBT therapists also believed that reducing the number of problem areas targeted in individual therapy would help the therapist provide a greater level of support towards one problem while also benefiting those that find it difficult to address multiple issues at once. One parent expressed a similar notion and said she feels her son would have benefited from more one-to-

one support during the intervention. It is important to investigate if the components of the intervention adequately foster the learning of new skills for those with more idiosyncratic difficulties or those with more severe social impairments.

Assessing ASD-specific intervention effects in adults may offer some difficulties that are not typically found with interventions for non-ASD adults. The severity of ASD symptoms tends to be less evident in adulthood than in childhood (Howlin et al., 2013) and social skills improvements may be more subtle and difficult to detect. While the MSCS has been used with an adult ASD population in recent research (e.g., Weiss & Fardella 2018), the instrument was initially validated for use with child and adolescent ASD populations. Therefore, the MSCS measure may be limited due to the fact it was developed for use with adolescents with ASD ages 11 to 17 years and may not be as sensitive to detecting changes in an adult ASD population. A number of studies have indicated that observational measures often do not correlate with self-report outcome measures because self-assessments can produce a bias evaluation of self (Rao et al., 2008). However, in the current study more improvements were detected in the observational assessments and the ability to detect change may have been a factor.

Age related change may explain why observed changes were more pronounced using the IRSA measure. The IRSA observer-rated assessment tool was specifically designed as a brief, yet comprehensive measure to assess basic social competence in an adult population. However, as discussed in chapter 2, there are relatively few instruments which have been specifically designed to measure change in social competence for adults with ASD (Brugha et al., 2015). To robustly investigate the efficacy of ASD interventions, a single assessment instrument or set of standard outcome measures to detect ASD specific treatments are greatly needed for adults with ASD (Brugha et al., 2015).

It is also possible that CBT-SCT-ASD could help towards improving mental health symptoms. Similar cognitive behavioural interventions with a group component have been shown to improve mental health symptoms of both adolescents and young adults alike (e.g., McVey et al., 2016; Schiltz et al., 2017; White et al., 2013). Interviews with the CBT therapists provided some qualitative accounts of working toward improved mental health symptoms. These accounts were supported by anecdotal data which suggests that some

participants in the intervention group also felt their mental health symptoms improved during and after the completion of CBSCTI-ASD.

Since CBSCTI-ASD was not developed to directly address mental health problems, it is not completely clear how the intervention impacted upon participants mental health. The transactional model of development (Michelle et al., 2017) suggests that an individual's behaviour impacts on how they are perceived by others, and these perceptions then influence how others behave toward them within the interaction. Since typically developed individuals can find it difficult to read individuals with ASD (Edey et al., 2016) and have less favourable perceptions of them (Sasson et al., 2017), individuals with ASD likely encounter more negative social experiences which can impact on mental health. Individuals with ASD have also been shown to be better than typically developed individuals at understanding and reading others with ASD (e.g., Sheppard et al., 2016). Over the time of the intervention, it is possible that changes were due to having a combination of more positive social experiences along with a shared understanding of ASD behaviours. These experiences may have had a positive impact on participants mental health, however measuring changes in mental health symptoms and exploring the possible reasons for change were beyond the remit of this PhD project. The impact of CBSCTI-ASD on mental health symptoms is still unclear and at this stage should not be considered for those with comorbid mental health disorders.

Expanding CBSCTI-ASD to be a more comprehensive intervention for both adults with ASD and parents also has its challenges. Delivering a caretaker component may prove to be costly as it would require more professional involvement. Collaboration with community groups could possibly be a more cost-effective solution to extending the utility of CBSCTI-ASD. Furthermore, anecdotal findings from study 3 suggest that parents differed in the activities used to help them cope during difficult times. It could be beneficial to simply offer a single session for parents/caretakers where information about the support and activities in their local community are provided. While there would be a considerable amount of logistical planning needed by clinicians delivering CBSCTI-ASD, this approach would introduce multiple external resources which could be self-tailored to the specific needs and interests of the individual caretaker. Collectively, the present and past findings have provided greater insight into the things that help parents cope with the additional pressures associated with having an adult child with ASD.

This PhD project also indicates the role of the MPFC during social interactions consistent with previous studies (e.g., Di Martino et al., 2009; Suda et al, 2011; Kana et al 2017). The ability to identify social impairment in ASD related to levels of brain functioning could possibly impact on prescribing, delivering and assessing the most appropriate evidence-based interventions. Chapter 6 provides some supporting evidence towards the use of the fNIRS device as a mobile way to measure brain activity in response to treatments. In the past, the ability to measure the brains functional response to treatments have been costly and assessment tasks often have limited ecological validity.

While popular for its good spatial resolution, fMRI is limited by the strict methods needed to measure the brains response to a given task. The poor temporal resolution of fMRI requires the participant to avoid movements during scanning procedures and the machine can be very noisy. These limitations provide significant challenges when attempting to develop an ecological valid social interaction task for use with fMRI. There are clear benefits to using fNIRS to measure brain function during social interaction tasks. The mobility and superior temporal resolution of the fNIRS device impacts on the ecological validity of the assessment. The lower associated financial cost of use also means fNIRS is a promising assessment tool for more routine clinical assessments. Unfortunately, fNIRS only measures cortical functioning, eliminating many of the social brain biomarkers which may be more sensitive to change in neurological functioning. However, investigations into fNIRS ability to accurately predict and monitor clinical outcomes should be considered in the future.

3. Conclusions

The research carried out during this project provides the first evidence of the feasibility of CBSCTI-ASD and adds to a limited database of research on manualised cognitive behavioural social skills interventions for adults with ASD without ID. Furthermore, study 2 provides some evidence towards showing that the MPFC is an important functional region of the social brain and maybe a viable target for intervention assessment. Further adapting or expanding the CBSCTI-ASD manual will need a great deal of consideration and it is vital to take into account the rich experiences and recommendations reported in this PhD project. In addition to informing the expansion of CBSCTI-ASD, the information gained from study 3 could contribute towards the development of new community interventions which provide advice and direction towards supportive resources (e.g., counselling services, self-help activities, and support groups) for parents struggling to

cope. As parents grow older, they can often be filled with worry about their adult child's future, however effective interventions may help to reduce dependence and ease away the burden of care placed on loved ones (Marsack-Topolewski & Graves, 2020). While the results of this project have been promising, due to several methodological limitations, the evidence to support efficacy of CBSCTI-ASD should be taken with some level of caution. Nevertheless, there is a considerable amount of merit towards efforts to further the development CBSCTI-ASD and larger, more robust clinical trials in the future are warranted.

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Appendices

Appendix A. Raw data

Oxy-Hb Estimates for Each Regions of Interest

Intervention group					Post-Test Scores				
Pre-Test Scores									
Regions of Interest – Oxy-Hb estimates									
Participant Number	Left DLPFC	Right DLPFC	Left MPFC	Right MPFC		Left DLPFC	Right DLPFC	Left MPFC	Right MPFC
1	-.00070	-.00010	-.00051	-.00048		-.00063	-.00025	.00020	-.00001
2	-.00022	-.00045	.00001	-.00023		-.00019	-.00040	.00034	.00023
3	.00013	-.00001	.00012	.00081		.00021	-.00011	.00220	.00011
4	-.00048	-.00350	-.00034	-.00012		.00012	.00047	.00340	.00116
5	.00021	-.00011	-.00045	.00113		.00033	-.00025	.00022	.00021
Control Group									
Pre-Test Scores									
Regions of Interest - Oxy-Hb estimates									
Participant Number	Left DLPFC	Right DLPFC	Left MPFC	Right MPFC		Left DLPFC	Right DLPFC	Left MPFC	Right MPFC
1	.00023	-.00013	.00150	.00056		.00029	.00033	.00021	.00078
2	.00028	.00022	.00236	.00113		.00034	.00017	.00024	.00096
3	.00041	.00021	.00124	.00023		.00049	.00027	.00041	.00053
4	.00011	-.00012	.00079	.00045		.00009	-.00022	.00019	.00044
5	.00023	.00011	.00124	.00098		.00018	.00013	.00022	.00113
Interaction Rating Scale Advanced									

Control group

Pre-Test Scores									Post-Test Scores						
Participant Number	Expressivity	Assertiveness	Sensitivity	Acceptance	Interpersonal relationships	Self-control	Total Scores	Expressivity	Assertiveness	Sensitivity	Acceptance	Interpersonal relationships	Self-control	Total scores	
1	9	11	11	13	15	17	76	8	12	10	12	16	17	75	
2	8	9	10	12	12	19	70	10	9	11	11	11	17	69	
3	9	9	9	14	14	17	72	9	10	11	8	15	15	58	
4	11	10	9	12	11	18	71	10	8	10	10	14	17	69	
5	10	10	8	10	18	18	69	10	9	9	10	13	16	67	

Intervention group

Pre-Test Scores									Post-Test Scores						
Participant Number	Expressivity	Assertiveness	Sensitivity	Acceptance	Interpersonal relationships	Self-control	Total Scores	Expressivity	Assertiveness	Sensitivity	Acceptance	Interpersonal relationships	Self-control	Total scores	
1	4	4	4	11	9	15	47	6	7	6	8	12	17	56	
2	9	10	7	8	9	18	61	9	12	9	8	12	18	68	
3	9	7	5	7	8	9	45	9	8	5	6	11	15	54	
4	3	4	3	7	8	14	39	8	7	7	9	12	18	61	
5	7	3	4	8	8	17	47	6	8	4	8	11	18	55	

Multidimensional Social Competence Scale

Intervention Group

Participant	Pre-Test Scores					Post-Test Scores					Total scores					
	Social Motivation	Social Inference	Empathy	Social Knowledge	Verbal Conversation	Non-verbal Conversation	Emotional regulation	Social Motivation	Social Inference	Empathy		Social Knowledge	Verbal Conversation	Non-verbal Conversation	Emotional regulation	
1	17	30	25	45	40	35	29	221	24	31	35	47	35	36	43	251
2	23	33	40	27	24	42	18	207	31	29	45	40	36	45	20	246
3	39	28	45	46	34	41	27	260	46	39	43	41	33	45	32	279
4	39	49	45	37	34	37	27	268	38	49	46	39	35	44	31	282
5	39	37	36	48	43	42	44	289	42	38	38	47	35	41	46	287

Control Group

Participant	Pre-Test Scores					Post-Test Scores					Total scores					
	Social Motivation	Social Inference	Empathy	Social Knowledge	Verbal Conversation	Non-verbal Conversation	Emotional regulation	Social Motivation	Social Inference	Empathy		Social Knowledge	Verbal Conversation	Non-verbal Conversation	Emotional regulation	
1	44	44	48	46	26	43	31	282	48	44	47	49	32	45	36	301
2	45	44	44	38	27	49	35	282	43	41	44	41	29	43	35	276
3	49	39	47	45	39	43	48	310	51	43	41	44	35	35	45	294
4	33	44	38	45	41	39	44	284	32	43	37	42	42	39	45	280
5	38	41	38	40	32	37	37	263	40	43	43	39	38	38	38	279

Appendix B. SPSS Outputs

Statistical Outputs of Oxy-Hb Estimates

Descriptive Statistics				
	Group	Mean	Std. Deviation	N
Pre_left_DLPFC	Intervention group	-	.00038893	5
		.0002120		
	TD_control group	.0002520	.00010826	5
	Total	.0000200	.00036365	10
Pre_right_DLPFC	Intervention group	-	.00149974	5
		.0008340		
	TD_control group	.0000580	.00017254	5
	Total	-	.00111081	10
		.0003880		
Pre_left_MPFC	Intervention group	-	.00028237	5
		.0002340		
	TD_control group	.0014260	.00058127	5
	Total	.0005960	.00097522	10
Pre_right_MPFC	Intervention group	.0002220	.00070432	5
	TD_control group	.0006700	.00037477	5
	Total	.0004460	.00058194	10

Multivariate Tests ^a								
Effect			Value	F	Hypothesis	Error		Sig.
					is df	df		
pt	Interce	Pillai's	.774	4.28	4.000	5.00	.07	
		Trace		0 ^b		0	1	
		Wilks'	.226	4.28	4.000	5.00	.07	
		Lambda		0 ^b		0	1	
		Hotelling	3.42	4.28	4.000	5.00	.07	
		's Trace	4	0 ^b		0	1	
		Roy's	3.42	4.28	4.000	5.00	.07	
		Largest Root	4	0 ^b		0	1	
Group	Trace	Pillai's	.833	6.23	4.000	5.00	.03	
		Wilks'	.167	6.23	4.000	5.00	.03	
		Lambda		4 ^b		0	5	
		Hotelling	4.98	6.23	4.000	5.00	.03	
		's Trace	7	4 ^b		0	5	
		Roy's	4.98	6.23	4.000	5.00	.03	
		Largest Root	7	4 ^b		0	5	

			Univariate Tests					
Dependent Variable			Sum of Squares	df	Mean Square	F	Sig.	
C	Pre_left_DLPF	Contrast	5.382 E-7	1	5.382 E-7	6.605	.033	
		Error	6.520 E-7	8	8.150 E-8			
FC	Pre_right_DLP	Contrast	1.989 E-6	1	1.989 E-6	1.746	.223	
		Error	9.116 E-6	8	1.140 E-6			
C	Pre_left_MPF	Contrast	6.889 E-6	1	6.889 E-6	32.993	.000	
		Error	1.670 E-6	8	2.088 E-7			
C	Pre_right_MPF	Contrast	5.018 E-7	1	5.018 E-7	1.577	.245	
		Error	2.546 E-6	8	3.183 E-7			

The F tests the effect of Group. This test is based on the linearly independent pairwise comparisons among the estimated marginal means.

Post Hoc t-test analysis-intervention group

		Paired Samples Test						
		Paired Differences			95% Confidence Interval of the Difference		Sig. (2-tailed)	
Mean	Std. Deviation	Std. Error Mean	Lower	Upper	t			
air 1	Pre_left_DLPFC - Post_left_DLPFC	.00018000	.0023696	.0010597	-.0004742	.0011422	1.699	.165
air 2	Pre_right_DLPFC - Post_right_DLPFC	.00072600	.0181522	.0081179	-.0029799	.0152790	.894	.422
air 3	Pre_left_MPF - Post_left_MPF	.00150600	.0141737	.0063387	-.0032658	.0025389	2.376	.076
air 4	Pre_right_MPF - Post_right_MPF	.00011820	.0091318	.0040839	-.0012520	.0101567	.289	.787

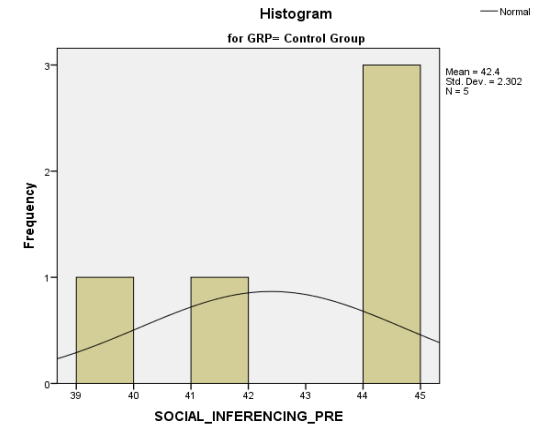
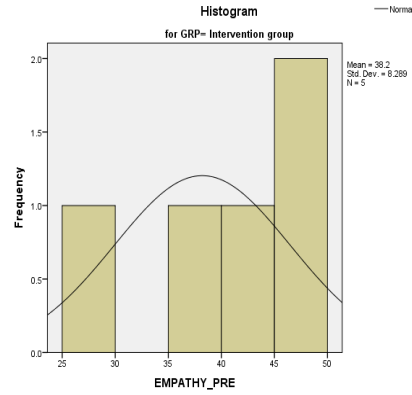
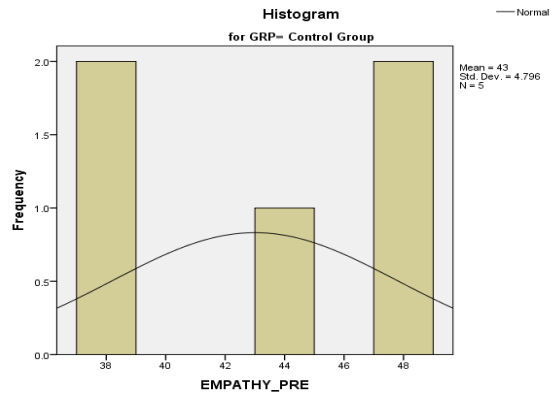
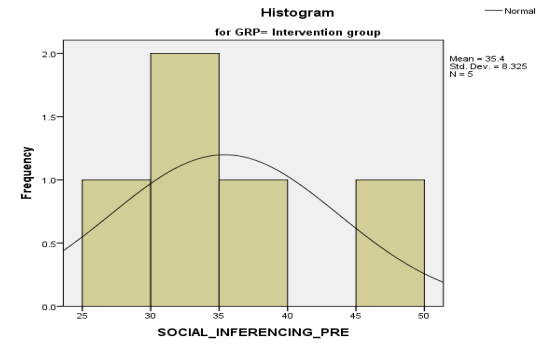
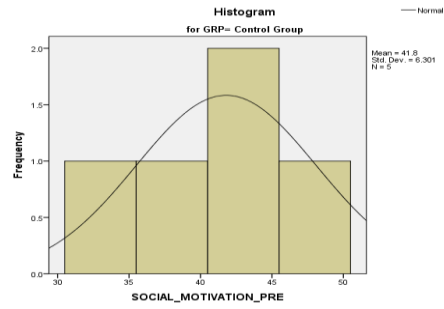
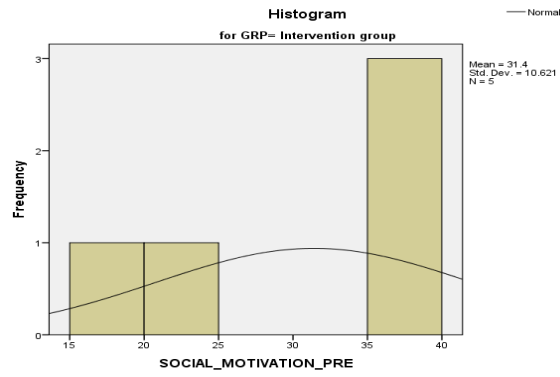
Post Hoc t-test analysis-control group

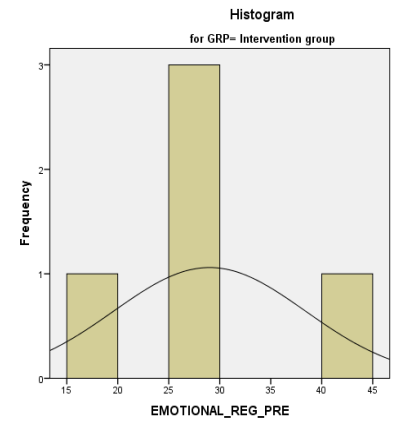
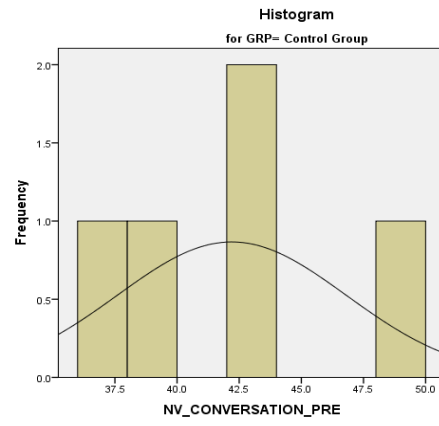
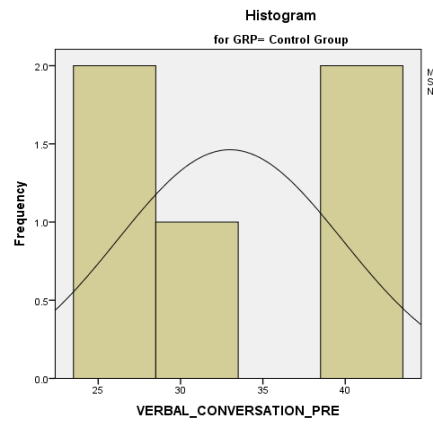
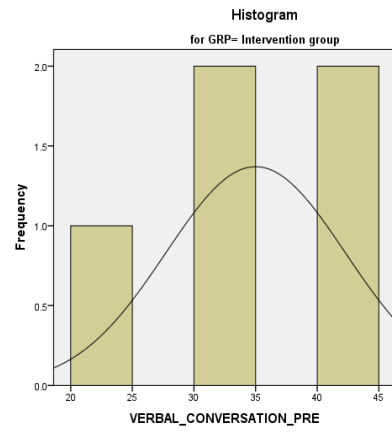
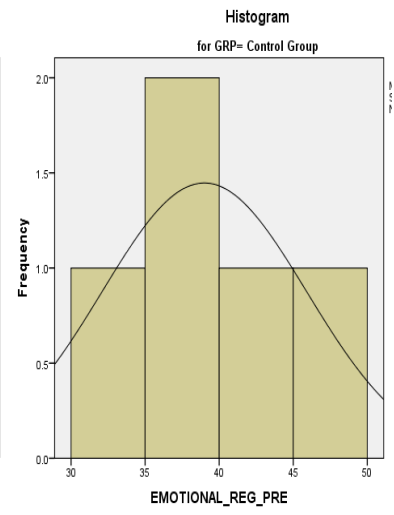
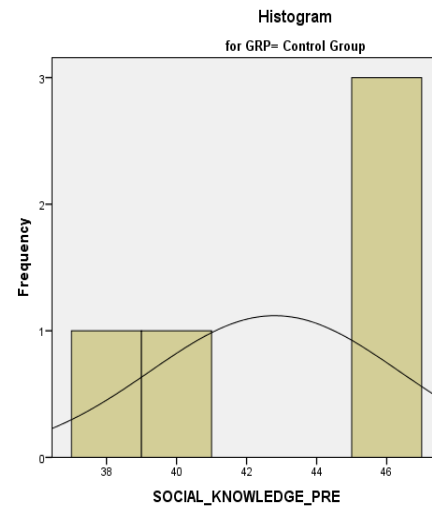
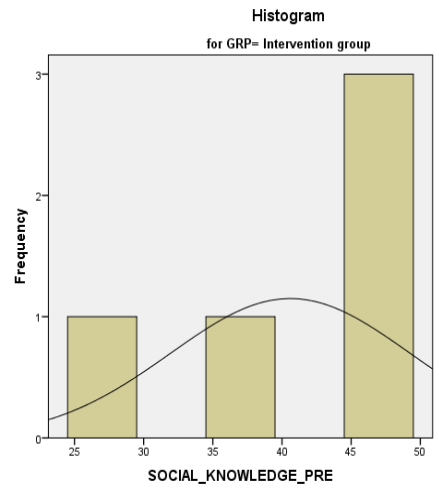
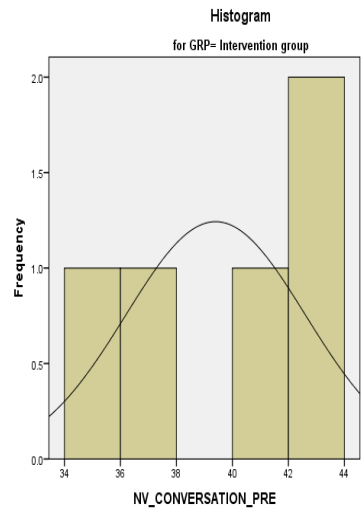
		Paired Differences					Sig. (2-tailed)	
Mean	Std. Deviation	Std. Error Mean	Lower	Upper	t			
air 1	Pre_left_DLPFC - Post_left_DLPFC	.00002600	.00005727	.00002561	-.00009711	.00004511	1.015	.367
air 2	Pre_right_DLPFC - Post_right_DLPFC	.00007800	.00022231	.00009942	-.00035403	.00019803	.785	.477
air 3	Pre_left_MPF - Post_left_MPF	.0017200	.00058734	.00026267	-.00044272	.00190128	.462	.011

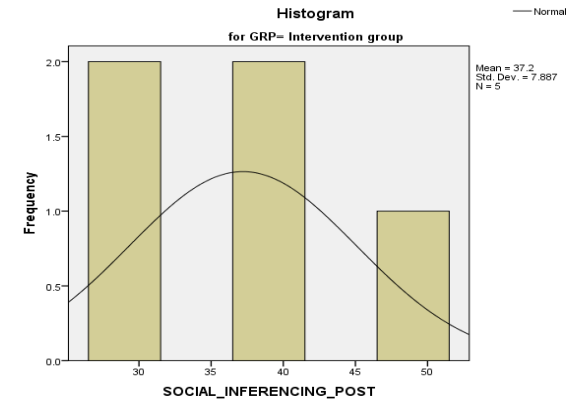
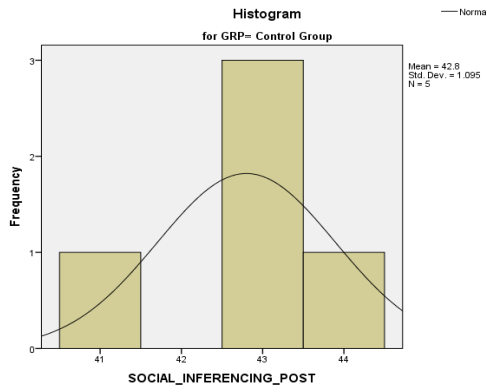
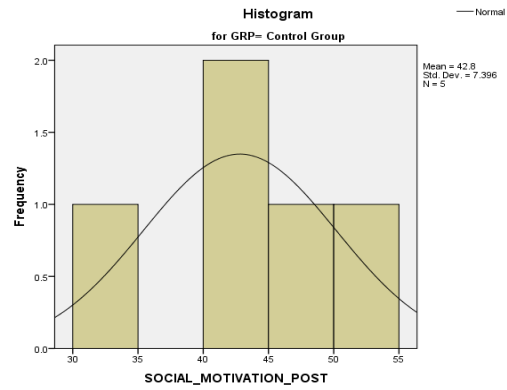
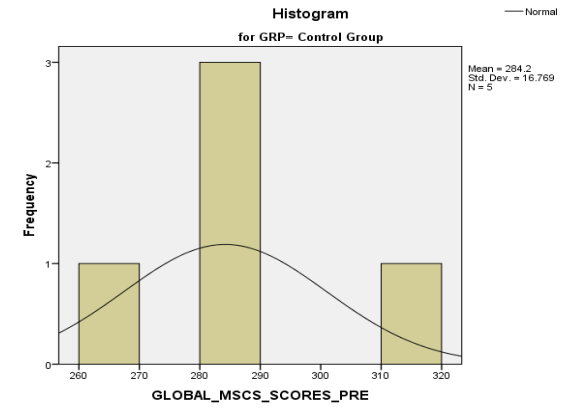
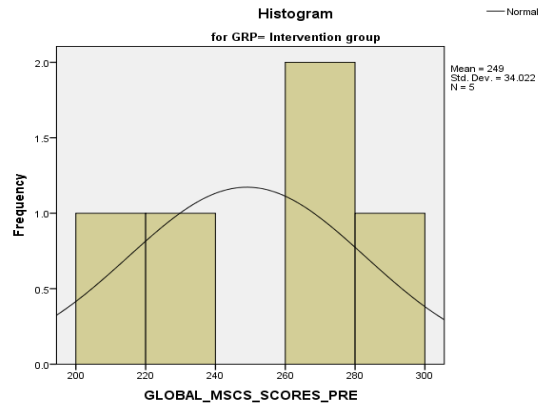
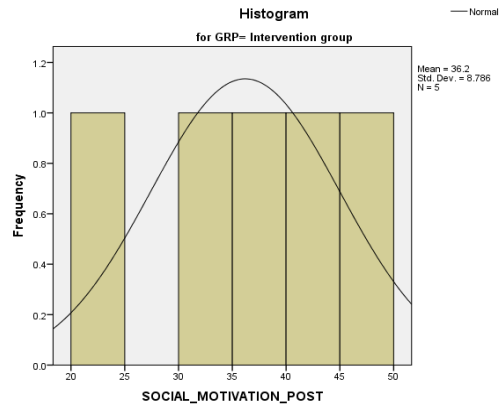
air 4	re_righ_M PFC - Post_right_ MPFC	.00009800	00018833	00008423	.00033185	00013585	1.164			.30 9
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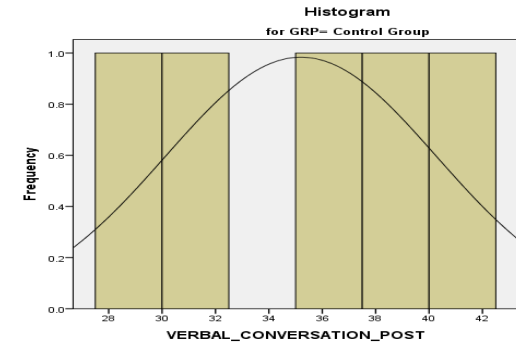
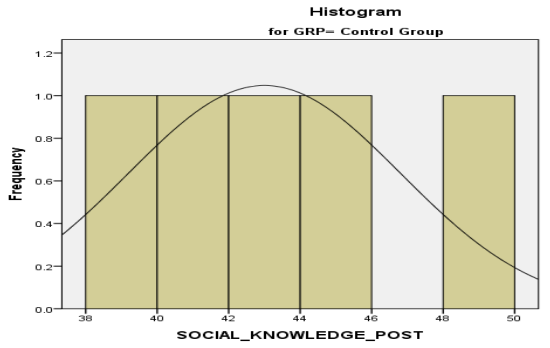
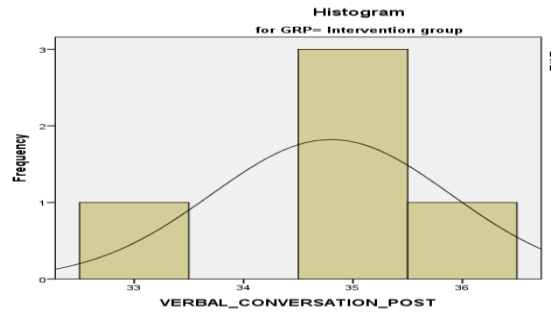
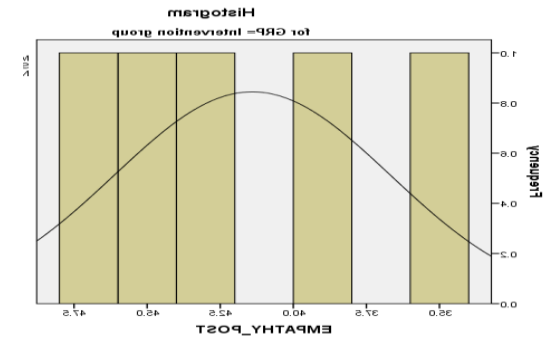
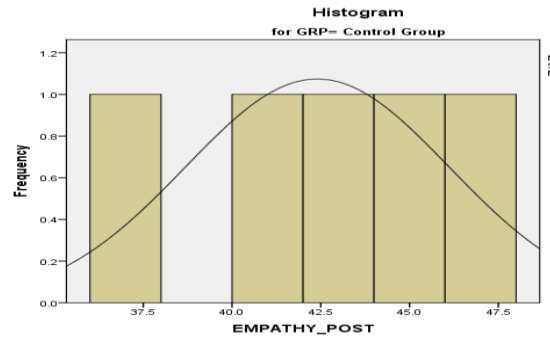
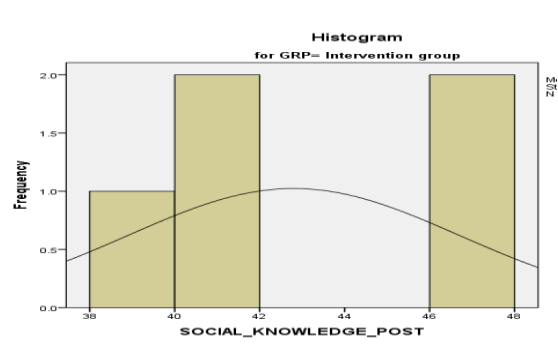
Multidimensional Social Competence Scale

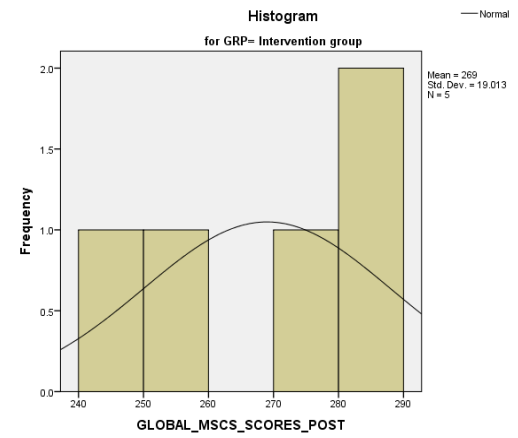
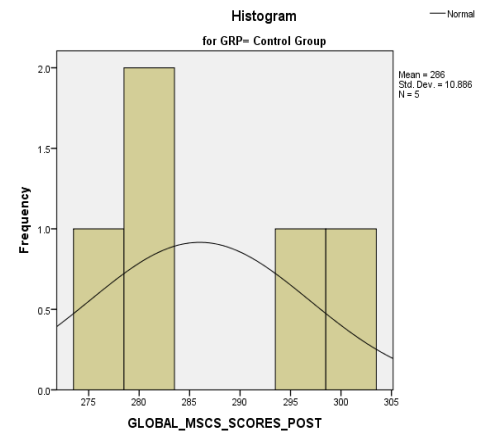
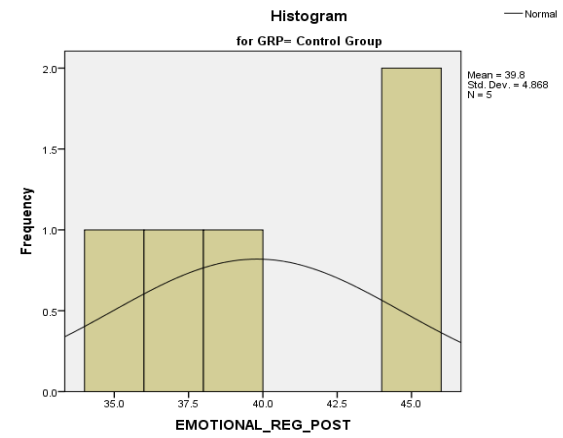
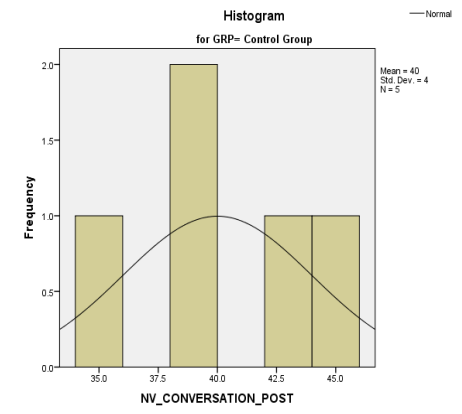
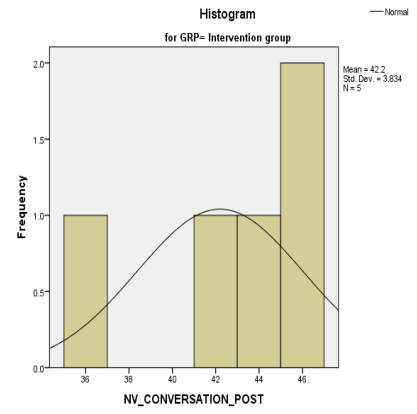
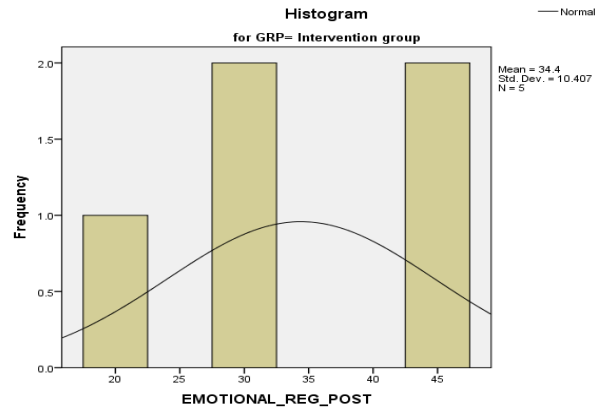
	GRP	Tests of Normality					
		Kolmogorov-Smirnov ^a			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
SOCIAL_MOTIVATION_P RE	Intervention group	.363	5	.030	.757	5	.035
	Control Group	.237	5	.200 [*]	.956	5	.783
SOCIAL_INFERENCING_P RE	Intervention group	.224	5	.200 [*]	.883	5	.324
	Control Group	.356	5	.037	.773	5	.048
EMPATHY_PRE	Intervention group	.206	5	.200 [*]	.870	5	.268
	Control Group	.251	5	.200 [*]	.845	5	.180
SOCIAL_KNOWLEDGE_P RE	Intervention group	.294	5	.182	.864	5	.242
	Control Group	.331	5	.076	.838	5	.159
VERBAL_CONVERSATIO N_PRE	Intervention group	.245	5	.200 [*]	.935	5	.628
	Control Group	.211	5	.200 [*]	.890	5	.357
NV_CONVERSATION_PR E	Intervention group	.291	5	.193	.833	5	.147
	Control Group	.231	5	.200 [*]	.943	5	.685
EMOTIONAL_REG_PRE	Intervention group	.300	5	.161	.891	5	.364
	Control Group	.214	5	.200 [*]	.955	5	.774
GLOBAL_MSCS_SCORES _PRE	Intervention group	.227	5	.200 [*]	.936	5	.641
	Control Group	.305	5	.145	.895	5	.381
SOCIAL_MOTIVATION_P OST	Intervention group	.181	5	.200 [*]	.967	5	.853
	Control Group	.159	5	.200 [*]	.969	5	.867
SOCIAL_INFERENCING_P OST	Intervention group	.210	5	.200 [*]	.932	5	.607
	Control Group	.372	5	.022	.828	5	.135
EMPATHY_POST	Intervention group	.233	5	.200 [*]	.908	5	.457
	Control Group	.164	5	.200 [*]	.984	5	.955
SOCIAL_KNOWLEDGE_P OST	Intervention group	.278	5	.200 [*]	.807	5	.093
	Control Group	.204	5	.200 [*]	.937	5	.642
VERBAL_CONVERSATIO N_POST	Intervention group	.372	5	.022	.828	5	.135
	Control Group	.136	5	.200 [*]	.990	5	.980
NV_CONVERSATION_PO ST	Intervention group	.281	5	.200 [*]	.821	5	.118
	Control Group	.199	5	.200 [*]	.964	5	.833
EMOTIONAL_REG_POST	Intervention group	.196	5	.200 [*]	.940	5	.664
	Control Group	.257	5	.200 [*]	.820	5	.117
GLOBAL_MSCS_SCORES _POST	Intervention group	.301	5	.159	.834	5	.150
	Control Group	.309	5	.133	.864	5	.243











Paired Samples correlation

		N	Correlation	Sig.
Pair 1	SOCIAL_MOTIVATION_PRE & SOCIAL_MOTIVATION_POST	5	.942	.017
Pair 2	SOCIAL_INFERENCING_PRE & SOCIAL_INFERENCING_POST	5	.768	.130
Pair 3	EMPATHY_PRE & EMPATHY_POST	5	.898	.038
Pair 4	SOCIAL_KNOWLEDGE_PRE & SOCIAL_KNOWLEDGE_POST	5	.677	.209
Pair 5	VERBAL_CONVERSATION_PRE & VERBAL_CONVERSATION_POST	5	-.282	.646
Pair 6	NV_CONVERSATION_PRE & NV_CONVERSATION_POST	5	.642	.243
Pair 7	EMOTIONAL_REG_PRE & EMOTIONAL_REG_POST	5	.878	.050
Pair 8	GLOBAL_MSCS_SCORES_PRE & GLOBAL_MSCS_SCORES_POST	5	.984	.002

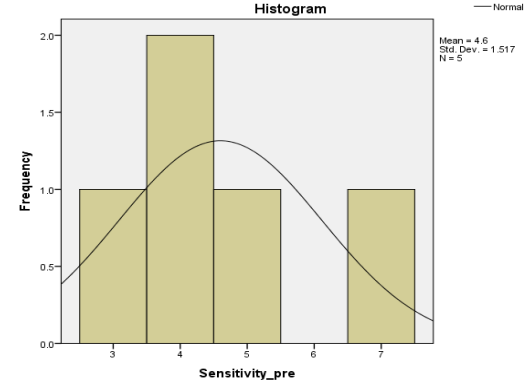
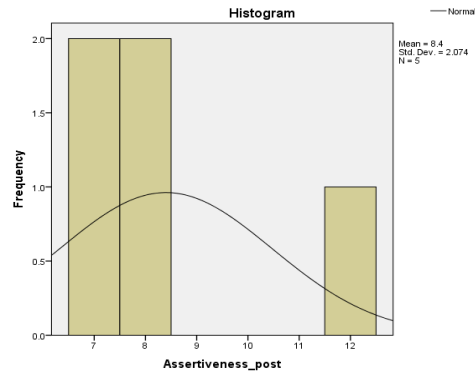
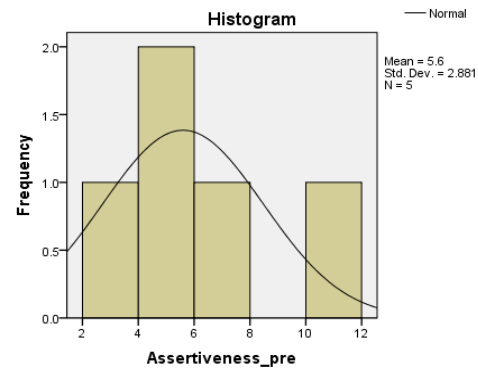
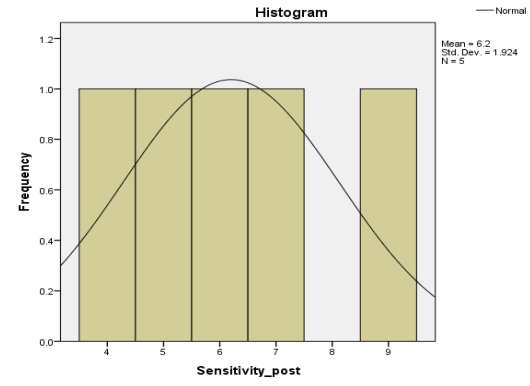
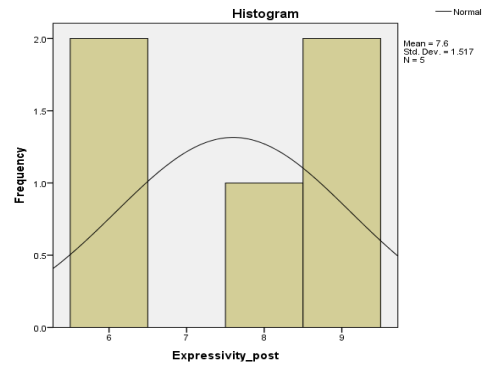
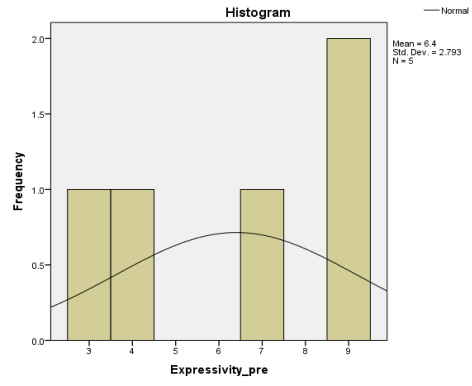
Paired Samples Test

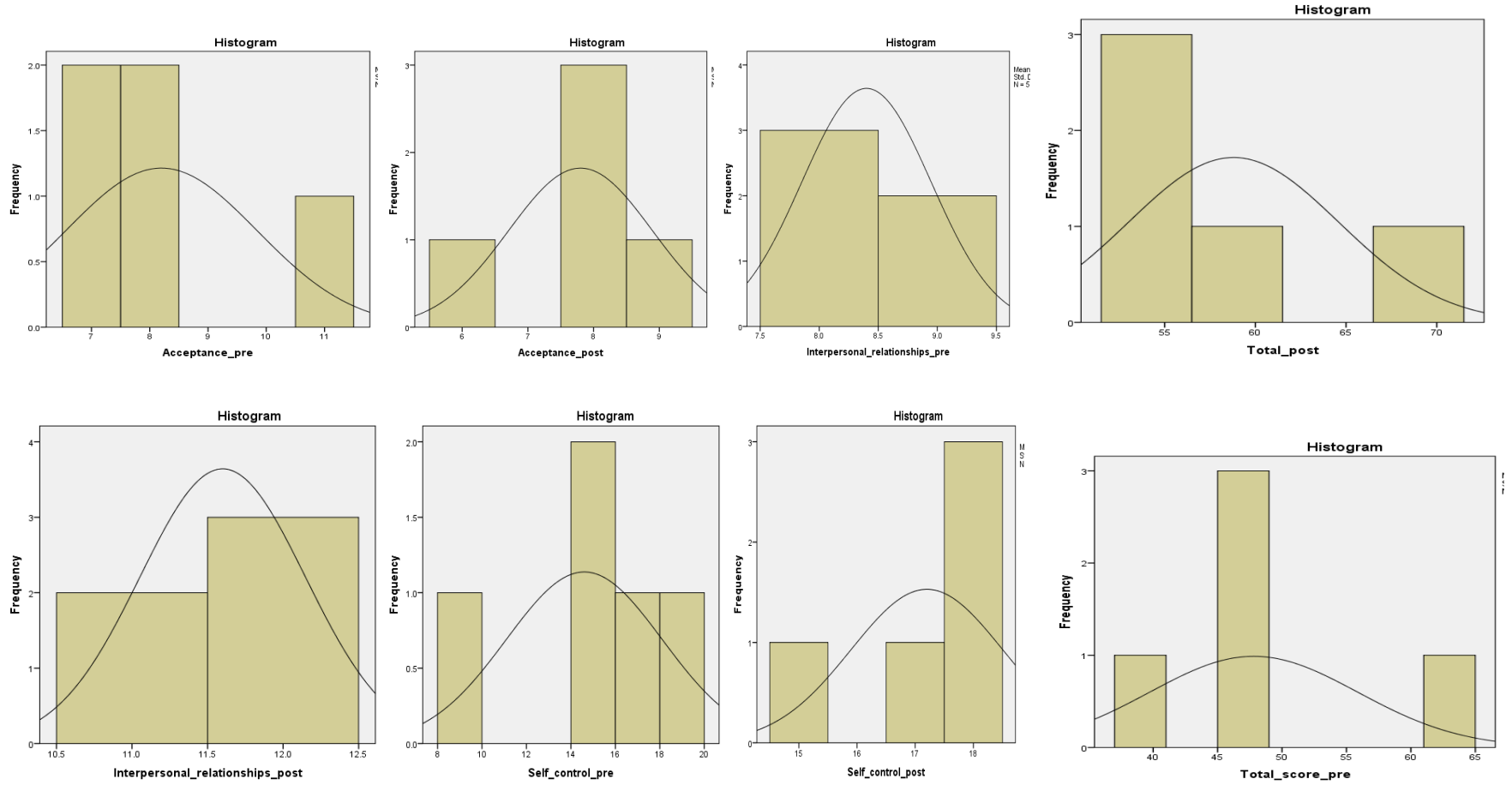
		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
1	Pair SOCIAL_MOTIVATION_PRE - SOCIAL_MOTIVATION_POST	4.800	3.768	1.685	-9.479	-.121	2.848	4	.046
2	Pair SOCIAL_INFERENCING_PRE - SOCIAL_INFERENCING_POST	1.800	5.541	2.478	-8.680	5.080	.726	4	.508
3	Pair EMPATHY_PRE - EMPATHY_POST	3.200	4.550	2.035	-8.849	2.449	1.573	4	.191
4	Pair SOCIAL_KNOWLEDGE_PRE - SOCIAL_KNOWLEDGE_POST	2.200	6.686	2.990	10.502	6.102	.736	4	.503
5	Pair VERBAL_CONVERSATION_PRE - VERBAL_CONVERSATION_POST	.200	7.662	3.426	-9.313	9.713	.058	4	.956
6	Pair NV_CONVERSATION_PRE - NV_CONVERSATION_POST	2.800	3.033	1.356	-6.566	.966	2.064	4	.108
7	Pair EMOTIONAL_REG_PRE - EMOTIONAL_REG_POST	5.400	4.980	2.227	11.583	.783	2.425	4	.072
8	Pair GLOBAL_MSCS_SCORES_PRE - GLOBAL_MSCS_SCORES_POST	20.000	15.668	7.007	39.455	-.545	2.854	4	.046

Interaction Rating Scale Advanced

Expressivity_pre	Intervention group	.224	5	.200*	.865	5	.246
	Control Group	.237	5	.200*	.961	5	.814
Assertiveness_pre	Intervention group	.311	5	.129	.871	5	.269
	Control Group	.231	5	.200*	.881	5	.314
Sensitivity_pre	Intervention group	.254	5	.200*	.914	5	.492
	Control Group	.237	5	.200*	.961	5	.814
Acceptance_pre	Intervention group	.348	5	.047	.779	5	.054
	Control Group	.246	5	.200*	.956	5	.777
Interpersonal_relationships_pre	Intervention group	.367	5	.026	.684	5	.006
	Control Group	.136	5	.200*	.987	5	.967
Self_control_pre	Intervention group	.232	5	.200*	.914	5	.492
	Control Group	.231	5	.200*	.881	5	.314
Total_score_pre	Intervention group	.339	5	.061	.875	5	.287
	Control Group	.241	5	.200*	.903	5	.427
Expressivity_post	Intervention group	.254	5	.200*	.803	5	.086
	Control Group	.349	5	.046	.771	5	.046
Assertiveness_post	Intervention group	.376	5	.020	.739	5	.023
	Control Group	.254	5	.200*	.914	5	.492
Sensitivity_post	Intervention group	.141	5	.200*	.979	5	.928
	Control Group	.231	5	.200*	.881	5	.314
Acceptance_post	Intervention group	.372	5	.022	.828	5	.135
	Control Group	.246	5	.200*	.956	5	.777
Interpersonal_relationships_post	Intervention group	.367	5	.026	.684	5	.006
	Control Group	.141	5	.200*	.979	5	.928
Self_control_post	Intervention group	.330	5	.079	.735	5	.021
	Control Group	.349	5	.046	.771	5	.046
Total_post	Intervention group	.285	5	.200*	.858	5	.220
	Control Group	.376	5	.020	.788	5	.065

Histograms





Related Samples Wilcoxon Signed Ranking Test

Note: Significance levels of the Wilcoxon Signed Ranking Test are 2-Tailed. Significance was adjusted for 1-Tailed analysis.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Expressivity_pre and Expressivity_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.285	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Assertiveness_pre and Assertiveness_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.042	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Sensitivity_pre and Sensitivity_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.102	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Acceptance_pre and Acceptance_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.593	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Interpersonal_relationships_pre and Interpersonal_relationships_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.034	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Total_score_pre and Total_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.042	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of differences between Self_control_pre and Self_control_post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.068	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix C. Ethics Application

This form should **only** be completed by staff and PGRs from the **School of Health Sciences** and the **School of Nursing, Midwifery, Social Work and Social Sciences**. For queries please contact Health-ResearchEthics@salford.ac.uk

For all other schools, please visit <http://www.salford.ac.uk/ethics>

School Research Ethics Approval FILTER Form

No research can be started without full, unconditional ethical approval. There are a number of routes for obtaining ethical approval depending on the potential participants and type of study involved – please complete the checklists below to determine which is the most appropriate route for your research study.

Teaching & Learning Research (STAFF ONLY)		
1.	Is the proposed study being undertaken by a member of UoS staff ?	No
2.	Is the purpose of the study to evaluate the effectiveness of UoS teaching and learning practices by identifying areas for improvement, piloting changes and improvements to current practices or helping students identify and work on areas for improvement in their own study practices?	No
3.	Will the study be explained to staff and students and their informed consent obtained?	N/A
4.	Will participants have the right to refuse to participate and to withdraw from the study?	Yes
5.	Will the findings from the study be used solely for internal purposes? <i>e.g. there is no intention to publish or disseminate the findings in journal articles or external presentations</i>	No

If you have answered **YES to all Qs1-5** your study does not require UoS ethics approval as the work sits under enhancing quality of teaching and learning.

If you have answered **NO to any of Qs1-5** you should complete the checklists below to determine which route you should use to apply for ethics approval of your study.

To find out if your study requires ethics approval through NRES answer the

National Research Ethics Service (NRES)		
1.	Does your study involve access to NHS patients or their data, or involve participants identified from, or because of, their past or present use of NHS services?	No
2.	Does your study include adults who lack capacity to consent as research participants and/or those under 18 years of age?	No
3.	Does your study involve the collection and/or use of human tissue as defined by the Human Tissue Act 2004?*	No

If you have answered **YES to any of Qs 1-3** you should complete this application form, for University of Salford ethics review, you will normally have a response within 4-6 weeks of submission. Once you have UoS approval you can then complete and submit the relevant NHS National Research Ethics Service (NRES) form (the information from the UoS forms can be transferred onto the NRES forms). For further information and details of how to apply to NRES can be found at <http://www.nres.nhs.uk/>

* For more information, please discuss with your supervisor or Research Lead

If you have answered **NO** to Qs1-3 complete the checklist below to determine whether your application is eligible for Fast Track (proportionate) review or full review.

Full versus 'Fast Track' (Proportionate Review)		
1.	Expose participants to high levels of risk, or levels of risks beyond those which the participant is likely to encounter in their everyday activities? These risks may be psychological, physical, social, Economic, cause legal harm or devalue a person's self-worth. <i>E.g. untrained volunteers exposed to high levels of physical exertion; participants purposefully exposed to stressful situations; research where participants are persuaded to reveal information which they would not otherwise disclose in the course of everyday life.</i>	No
2.	Involve the administration of drugs, medicines or nutritional supplements as part of the research design?	No
3.	Include adults who may be classed as vulnerable? <i>E.g. adults with learning disabilities or mental illness; drug/substance users; young offenders; prisoners/probationers; those in a dependent relationship with the researcher</i>	No
4.	Include children or young adults (below 18 years of age)?	No
5.	Involve the discussion or disclosure of topics which participants might find sensitive or distressing? <i>E.g. sexual activity; criminal activity; drug use; mental health; previous traumatic experiences; illness; bereavement</i>	yes
6.	Use questionnaires which focus on highly sensitive areas? <i>e.g. illegal activity; criminal activity; disclosure and analysis of findings based on sensitive personal information as defined by Data Protection Act e.g. racial or ethnic origin; political opinions; religious beliefs; trade union membership; physical or mental health; sexual life</i>	No
7.	Incorporate interviews or focus groups which involve the discussion of highly sensitive areas? <i>e.g. illegal activity; criminal activity; disclosure and analysis of findings based on sensitive personal information as defined by Data Protection Act e.g. racial or ethnic origin; political opinions; religious beliefs; trade union membership; physical or mental health; sexual life</i>	Yes
8.	For research accessing and analysing existing datasets. Will the dataset include information which would allow the identification of individual participants?	No
9.	Involve deliberately misleading participants in any way?	No
10.	Involve recruiting participants who have not been provided with a participant information sheet and asked to sign a consent form? <i>Please note that for questionnaire based studies where the questionnaire is completed by the participant, a consent form is generally not required as consent is implied by the completion of the questionnaire. Applicants conducting questionnaire-only studies should answer NO</i>	No
11.	Involve the collection and/or use of human tissue from healthy volunteers? <i>Under these circumstances human tissue is as defined by the Human Tissue Act 2004 - "Any, and all, constituent part/s of the human body formed by cells." Research studies involving the use of plasma or serum are not covered by the HTA.</i>	No
12.	Involve high levels of risks to the researcher? <i>e.g. lone working at night; interviewing in your own or participants homes, observation in potentially volatile or sensitive situations</i>	No

School	Health Sciences
Course of Study	PhD
Title of proposed research project	The Development and Feasibility Trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

The checklist **MUST BE COMPLETED**. It is designed to help you to ensure that you have all the supporting documents submitted with your ethics application form. This information is necessary for the committee to be able to review and approve your application. Please complete the relevant boxes indicating whether a document is enclosed and where appropriate identifying the **date and version** number allocated to the specific document (*in the header/footer*). Additional documents can be recorded in the boxes provided or extra boxes added to the list if necessary.

Document	Enclosed?	Date	Version
			No.
Application form	Mandatory	16/03/18	6
Protocol	no		
Risk Assessment Form	No		
DBS Check	No		
Participant Invitation Letter	no		
Participant Information Sheet	Yes	16/03/18	5
Participant Consent Form	Yes	16/03/18	5
Participant Recruitment Material – <i>e.g. copies of Posters, newspaper adverts, website, emails.</i>	no		
Organisation Management Consent/Agreement Letter	Not Required		
Research Instrument, non-validated questionnaire			
Draft interview guide/Topic guides for participants	Not Required		
	Select		
Click here to enter text.	Select		

NOTE: If the appropriate documents are not submitted with the application form then the application will be returned directly to the applicant and will need to be re-submitted at a later date,

School Research Ethics Approval APPLICATION Form

Ethics approval must be obtained by all applicants prior to starting research with human subjects, animals or human tissue.

Postgraduate students **must** discuss the content of this form with their PhD supervisor(s). A final copy of this application form should be agreed between the student and supervisor(s).

Staff must submit a fully anonymised version to Research Centres Support Team (Health-ResearchEthics@salford.ac.uk). Students must have their fully anonymised application submitted by their supervisor (from the supervisors email account) to Research Centres Support Team (Health-ResearchEthics@salford.ac.uk)

Is this application a resubmission?	
Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> If YES, please indicate Ref No. (if known) HSR1617-166	
Is this an amended version of the original application?	
<i>(Please ensure that the changes are highlighted within the documents)</i> Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	
Staff/PGR Student experience/qualifications:	Msc Applied Psychology (therapies), Bsc (Hons) Psychology and Counselling, diploma in therapeutic counselling with 450 client contact hours, and I am a graduate member of the British Psychological Society. Background: Integrative counsellor with experience in individual and group therapy. I am contracted as a part-time associate lecturer teaching on various psychology modules.
School	Health Science
Course of study: <i>(PGR use only)</i>	PhD
Start date of project:	Upon ethical approval
End date of project:	08-31-2019
Proposed start date for participant recruitment:	Upon ethical approval

Will this project take place on University premises?	
Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> <i>If you answer 'yes' to any of the above questions, a risk assessment of the project is required and MUST be submitted with the application.</i>	
Is a DBS check required?	
Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Have you read the Lone Worker Policy?	
Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	

The form must be completed electronically; the sections can be expanded to the size required. To assist you with the completion of this form there are [Guidance Notes for Completing the School Research Ethics Approval Form](#), which indicate what is required for each section.

Title of proposed research project: <i>(refer to guidelines in section 1)</i>	The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Interventions for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)
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Project Summary

This project's focus is to develop and evaluate a cognitive behavioural therapeutic social competence intervention for adults with Autism Spectrum Disorder (ASD) without an Intellectual Disability (ID). The study will aim to recruit 10 individuals with ASD without ID and their parent/caretaker to participate in a six week group intervention. The intervention will utilise a small group format with a focus on social communication. Group sessions will include didactic lessons, Socratic questioning, role-play and rehearsal, social skills tasks that promote problem solving, feedback using positive and corrective instruction, homework assignments and parent/caretaker active involvement. To further scaffold group therapy, each participant will attend six individual CBT sessions following the five areas CBT model. Ideally, individual sessions will be conducted each week on Mondays and Tuesdays between 9 am and 4 pm and group session will be held the same week on a Thursday afternoons between 1 pm and 3 pm. Logistical arrangement will be made based on facility available upon ethical approval. Pre and post assessments for the experimental group will be conducted within the two weeks prior to the start of the intervention and again no more than two weeks after the intervention end date. The control group will complete pre and post assessments approximately 7-8 weeks apart in line with assessment timescale for the intervention group. Using a quasi-experimental design the project aims to evaluate the following:

Feasibility will be analysed by monitoring attendance over the six week intervention and administering a post intervention self-reported participant satisfaction questionnaire. The lead researcher will keep an attendance log for individual CBT sessions and group social competence sessions to record intervention adherence rates. The CSQ (Larsen et al., 1979) will be administered upon completion of the intervention and scores will be used to demonstrate participant satisfaction rates.

Outcomes assessments will be measured using a parent/caretaker questionnaire and a self-report questionnaire (Multidimensional Social Competence Scale; Yager & Larocci, 2013) for both the experimental and control groups. For the experimental group an observer rated behavioural measure of social competence (Interaction Rating Scale Advanced; Anme et al., 2014) will be utilised to evaluate the performance of a video recorded five minute dyad interaction task.

To assess neurological activity participants will be required to complete a five minute natural interaction task while wearing the 52 channel functional near infrared spectroscopy (fNIRS).

The relationship between neurological activity and ASD symptom severity will be investigated.

The lead researcher will conduct and video record selective interviews upon the completion of the six week intervention.

Research Hypotheses

H1: Participant in the treatment group will find the intervention acceptable.

H2: Participants will demonstrate a significant increase in social competence scores post intervention as measured by the Interaction Rating Scale Advanced (Anme et al., 2014) and the Multidimensional Social Competence Scale (Yager & Larocci, 2013).

H3: Participants will demonstrate increased activation over the course of the intervention in the medial prefrontal cortex an areas implicated in social cognition and the pathology of ASD

H4: As a result of the intervention an increase in neural brain activation in the prefrontal cortex will correlate with reductions in ASD symptoms.

Research Questions:

What are the experiences of a parent living with an adult child with ASD without ID?

What were the experiences of the parents involved in the SCTI-A intervention?

3. Project Objectives (refer to guidelines section 3)

Primary objectives:

To investigate the feasibility of the SCTI-A

Explore the plasticity of neuroanatomical markers related to social cognition in ASD.

To investigate the relationship between neural activation and ASD symptoms

Secondary objectives:

To investigate the efficacy of the SCTI-A.

To explore the parental experience of living with an adult child with ASD

To investigate the subjective experience of the parents which had active involvement in the intervention and their subjective opinion of behavioural change seen in their child during and after the SCIT-A intervention

To explore the experience of parents living with an adult child with ASD without ID

4. What is the rationale which led to this project? (refer to guidelines section 4)

Introduction: Autism spectrum disorder (ASD) is a developmental disability defined by criteria that includes deficits in social communication and interaction and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association,

2013). Many adults with ASD often find it challenging in adulthood as social impairments can interfere with building interpersonal relationships, functioning in a career and connecting with the community (Hendrick & Wehman, 2009). Recent findings by Howlin and Moss (2012) indicate that as adults individuals with ASD, including those with an IQ within the normal range, are significantly disadvantaged in terms of employment, social relationships, physical and mental health, and quality of life. Reports have shown that individuals with ASD without an intellectual disability (ID) were three times more likely to have no day activities and suffer social isolation compared to young adults with ASD and a comorbid ID (Taylor & Seltzer, 2011).

A number of investigations have shown that social deficits for an individual with ASD are often long term and can span a lifetime (Palmen, Didden, & Lang, 2012; Schall & McDonough, 2010). There is a growing demand for effective intervention for individuals with ASD but establishing efficacy can often be a difficult process. One potentially effective assessment is to monitor levels of brain function, specifically marker associated with social impairment. There is a growing body of literature which demonstrates that neurological disturbance and connectivity has an association social cognition (Alaerts et al., 2015; Redcay et al., 2013; Suda et al., 2011; Tamura et al 2012; Van Hecke et al 2013). Effective interventions may increase the connectivity in associated regions, reducing neurological disturbance and social impairment.

To the author's knowledge, no study has examined and evaluated the effects of a group cognitive behavioural social competence intervention on neurological functioning in adults with ASD without ID. When considering the challenges that young adults with ASD without ID face, it seems important that future studies further validate social competence interventions by investigating both any changes in ASD symptoms and associated neural function.

Background: Although ASD was not a recognised disorder in the diagnostic manuals until 1980, it has since become an extremely popular research topic (Reichow, Steiner, & Volkmar, 2012). Over the years there has been a significant rise in the detection of ASD and it appears to be a more common disorder than previously believed. The rise in detection of ASD has been most pronounced in individuals with typical or above average cognitive abilities (Reichow et al., 2012). It seems that this increased rate of detection has brought heightened public awareness which is prompting greater scientific interest in ASD (Hansen, Schendel & Palmer, 2015).

ASD research has shown that social impairments often develop in early childhood and persist into adulthood irrespective of cognitive abilities (Barnhill, 2007; Klin et al., 2006). It seems that maturation alone will not improve some of the social impairments associated with ASD (Schall & McDonough, 2010). In studies on adaptive functioning, data on adolescents and young adults with ASD without ID have often found adaptive skills to be lower than would be predicted by cognitive ability and this discrepancy between cognitive ability and adaptive functioning may grow as individuals increase in age (Bolte & Poustka, 2002; Kanne et al., 2011; Klin et al., 2007). Similarly, in a long-term investigation of adolescents and young adults with ASD, the authors noted that while there were general improvements in communication, social communication deficits continued to persist throughout childhood, adolescence and adulthood (Schall & McDonough, 2010). These findings suggests that without intervention ASD symptoms will continue to persist or may even worsen over time. These findings highlight the need to develop effective adult interventions.

Researchers have utilised a number of techniques to enhance a range of social cognitive function and social interaction skills. In a recent review of social skills group interventions, Reichow and Volkmar (2010) identified empirically supported methods that have been used to improve social skills. The authors reported cognitive behavioural therapy (CBT), video modelling, peer training, group treatment and visual supports to be effective interventions for teaching social skills to children and adolescents with ASD.

Unfortunately, there is limited intervention research on adults with ASD. While CBT, video modelling, peer training, group treatments and visual supports are suggestively effective interventions for children and adolescents, these recommendation cannot be transferred to an adult ASD populations without further research. Furthermore, efficacy is still in question for even the most validated social skills programs for ASD. For example *The Program for the Education and Enrichment of Relational Skills (PEERS)*; Laugeson & Frankel, 2010) is one of the most empirically validated manualised social skills intervention for ASD (e.g. Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012; Gantman, Kapp, Orenski, & Laugeson, 2012; Van Heck et al., 2013), yet the majority of outcome data has been obtained through the self-report measures of participants that were directly involved with the treatment, suggesting that the current findings on *PEERS* are at high risk of performance bias. This is not to say that the *PEERS* program, and others like it, are not effective but it does suggest that more rigorous testing is needed.

Neuroimaging and ASD: Neuroimaging technology is arguably a significant step towards further validating interventions for individuals with ASD. Recent neuroimaging studies have indicated that the prefrontal cortex (PFC), the temporo-parietal junction (TPJ), the superior temporal sulcus (STS), the insula, the posterior parental cortex (PPC) and the fusiform face area, are regions of the brain commonly identified as neurobiological markers of ASD (Alaerts et al., 2015; Iwanaga et al., 2013; Olson, McCoy Klobusicky, & Ross, 2013; Patriquin et al., 2016; Redcay et al., 2013). Measuring the neurological marker associated with ASD, alongside the utilisation of behavioural assessments, may provide convergent validity that demonstrates the intervention is acting on the brain mechanisms that are associated with observed and self-reported social and communication impairments associated with ASD.

Although limited, there is research that suggests interventions can increase neural activation in some individuals with ASD (Van Hecke et al 2013; Yang et al., 2017). Van Hecke and colleagues (2013) found that implementing the *PEERS* treatment manual, (Laugeson & Frankel, 2010) affected neural function, via EEG asymmetry, in a RCT of adolescents with ASD. There was a shift from right-hemisphere gamma-band EEG asymmetry before treatment to left hemisphere EEG asymmetry after treatment compared to a waitlist ASD control group. Left-hemisphere EEG asymmetry was associated with more social contacts and knowledge, and fewer symptoms of ASD.

Recently, Yang and colleagues (2014; 2017) utilised a well-validated biological motion neuroimaging task to identify pre-treatment biomarkers that can accurately forecast the response to an evidence-based behavioural treatment (Virtual Reality-Social Cognition Training; VR-SCT). In preliminary samples of young adults with high-functioning ASD, the authors identified neural predictors of change in emotion recognition and social cognition after VR-SCT. This study demonstrates neuroimaging-based predictive biomarkers for treatment effectiveness in adults with ASD. These results revealed a remarkable degree of malleability in the neural systems involved in social cognition in adults with high functioning ASD.

It could be suggested that interventions which specifically target the neural mechanisms associated with social cognition in adults with ASD, may lead the way forward towards developing more precise and effective interventions. For example, those individuals that do not demonstrate an increase in brain activity from a behavioural intervention on its own, future researchers may benefit from the administration of intranasal oxytocin which has been shown to increase brain activity (which includes the PFC, an area of the brain under

investigation in this proposal) and improve performance on higher-level social cognitive tasks (Davis et al, 2013; Domes et al 2014; Gordon et al, 2016).

Social competencies are a complex, multi-dimensional construct that arguably requires multiple methods of assessment. Overall, it could be argued that the current data available in the literature is not sufficiently robust enough to determine intervention efficacy. It could be suggested that neurological biomarkers may have potentially far-reaching implications for ASD diagnosis and treatment (Yang et al., 2014; Patriquin et al., 2016). The benefits of identifying and measuring neurological markers may provide more transparency as to the extent of intervention efficacy and help inform the development of future interventions.

5. Research Methodology (refer to guidelines section 6)

Design:

Quasi-experiment: The study will incorporate a repeat measures quasi-experimental design. The independent variable is SCTI-A. The dependent variables are the change scores from the Interaction Rating Scale Advanced (IRSA; Anme et al., 2014), the change scores from the Multidimensional Social Competence Scale (MSCS; Yager & Larocci, 2013), the perceived rating from the Client Satisfaction Questionnaire (CSQ-8; Larsen et al., 1979) and the demonstrated changes in neurological activity from successful fNIRS brain function monitoring.

Correlation study: A related design will be utilised to investigate the relationship between the demonstrated changes in neurological activity from successful brain function monitoring using fNIRS and the self-reported scores of the Autism Spectrum Quotient (AQ-50; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).

Qualitative interviews: Semi-structured interviews (appendix B) will be conducted on participants involved in the intervention. In addition, to investigate the experience of accessing and receiving of treatment (e.g. possible barriers), between 6-10 semi-structured interviews will be conducted with a primary caregiver (e.g. a parent) of an adult child with ASD that did not participate in the intervention. Thematic analysis will be conducted on the transcripts.

Recruitment: Non-intervention participants:

A snowball sample approach will be taken to recruit parents/caretakers of young adults aged 18-29 years of age with a diagnosis of ASD without ID. Information sheets will be provided to existing contacts that have aided in the initial recruitment process.

Intervention Participants:

Participants will be recruited through the University of Salford and the Autism Spectrum Database-UK and Autism Research UK. Currently, the lead researcher has applied with the National Autism Society (NAS) on a collaboration. A key role of the collaboration with the NAS is participant recruitment. Additionally, advertising for recruitment (see appendix I) through the disability and learner support team at the University of Salford may provide suitable candidature. Providing recruitment advertisement material to local autism groups in the local area would be advantageous for recruitment. Please see list of possible groups below:

[Axia-ASD Salfordautism](#) [Greater Manchester Autism Consortium](#) [Next steps](#) [Bolton Adult Autism Support](#)

Recruitment of control participant will take place on the University of Salford campus. Student will be approached by the lead researcher with the approval of module lead of various psychology programs

All of these groups have been involved with research at other local universities (e.g. University of Manchester and Bolton University) and I believe they would make for a reliable recruitment partnership.

Individuals will declare their interested in participation by communicating with the lead researcher via e-mail (University of Salford e-mail address will be provided on all recruitment materials).

Any individual that has interest in participation in the study will be sent an invitation letter (see appendix H) and will be provided with an information sheet (see appendix C) that will outline the details of the study, the intervention involvement and the participant's rights. This information sheet will be handed out in person and/or via e-mail. Participant will be given a minimum of 24 hours to consider whether they wish to take part to the study following contact with the lead researcher and being sent the participant information sheet.

Once the participant has agreed to proceed with the study, the participant will be given a chance to ask any questions before informed consent (see appendix E) is obtained. The researcher gaining consent will follow a guidance protocol for gaining informed consent of someone with ASD (see appendix G). Participants will be ensured in the information sheet and consent form that they have the right to withdraw at any time and that all data that they have given up until the point of withdrawal will be used in analysis and will be securely stored for a minimum of five years.

Participants: Non-intervention Interviews:

Parent or caretaker of an adult child aged between 18-29 years with a diagnosis of ASD without an ID. This may include a past diagnosis of: high functioning autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS).

Intervention:

The intervention study will aim to recruit male and female participants (n=10) adults (18-29 years) and their care takers.

Inclusion and exclusion criteria will be assessed during an initial telephone interview (see appendix A) and again during an intake interview. Researchers gaining consent will follow a guidance protocol for gaining informed consent of an individual with ASD.

Inclusion criteria:

Adults between the age of 18-29 years that are proficient in the English language and report a past diagnosis of high functioning ASD.

Capacity to provide informed consent. This will be established through clinical observations at the time of gaining consent, in accordance with the British Psychological Society (BPS) guidelines (Assessment of Capacity in Adults: Interim Guidance for Psychologists, 2006).

Adults must have a current verbal IQ equal or above 80 as measure by the Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000).

Exclusion criteria:

Self-reported presence of an organic brain disease.

History of neurological injury: head trauma, seizure disorder (i.e. seizure within the preceding six month period), stroke, prior neurosurgery, or under the care of a neurologist or neurosurgeon as determined by interview

Inability of caretakers to speak English

Absence of a consistent caretaker to participate in the intervention and report on symptoms

Significant drug or alcohol intoxication at the time of interview as assessed by self-report or observed by the interviewer.

Individuals that report a primary (most severe) mental health disorder (e.g. panic disorder or OCD) comorbid with ASD will be excluded but will be offer a referral to Salford Autism or the Together Trust North West. Salford Autism provide social support for individuals with ASD and offer an open contact line (0771 390 3224) 24 hours, 7 days a week, including all holidays. Additional support:

The Together Trust is a charity that offers care, support and special education to children, adults and families. Their services are based in North West England and they accept referrals from all over the UK. Contact details: 0161 283 4848 8.30am – 5.00pm or 0800 013 0014 for out of hours support.

Setting:

The University of Salford's psychology department facilities will be utilised for conducting the intervention and all assessments. Rooms will be booked in advance to ensure continuity for participants.

Assessment measures: Screening:

The Autism Spectrum Quotient (AQ-50; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) measure is a self-evaluation on a range of traits known to be associated with ASD, such as specific behaviours, responses to social situations, and making friends; it has a test-retest reliability of $r = 0.7$. Participants respond to statements such as "I prefer to do things on my own than with others" with *definitely agree*, *slightly agree*, *slightly disagree*, or *definitely disagree*. Two points are given for responses of definitely or slightly agree on questions referring to behaviours typically associated with ASD, and 1 point is given for responses of definitely or slightly disagree for behaviours not typically associated with ASD, such as "I am good at social chitchat." The AQ will also be utilised as a secondary outcome measure.

The Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000) is an individually administered test of ability designed for use with individuals between the ages of 4 and 85 years. The WRIT's four subtests (Verbal Analogies, Vocabulary, Matrices, and Diamonds) can be combined to form Verbal, Visual, and General IQs ($M = 100$, $SDs = 15$). The WRIT's standardisation plan spanned the variables of age, gender, race / ethnicity, parent/individual education level, and region of residence. Each stratification variable conformed to U.S. population data from the 2000 Census within $\pm 5\%$. Reliability estimates (e.g., internal consistency and test-retest reliability) are provided in the technical manual for each scale. Internal consistency estimates (alpha coefficients) ranged from .76 to .97 across all age levels for the WRIT's subtests. Reliability estimates were highest for the General IQ, ranging from .93 to .97. Test-retest stability (corrected for attenuation) ranged from .70 for the Matrices subtest to 1.0 for Verbal Analogies; and from .63 for Matrices to .90 for Verbal Analogies (uncorrected for attenuation). Interscorer reliability was also assessed for the two subtests that require examiner judgment (Vocabulary, Verbal Analogies) using 40 randomly selected cases from the normative sample, which were then independently scored by three raters. Agreement was high as evidenced by intraclass correlation coefficients (Vocabulary had an ICC of .98, and the coefficient for Verbal Analogies was .99).

Feasibility:

Client Satisfaction Questionnaire (CSQ-8; Larsen et al., 1979) is a field standard measure of treatment satisfaction that has been widely employed to assess the acceptability of psychotherapy programs. This measure consists of 8 items rated between 1 ("quite dissatisfied") and 4 ("very satisfied") to assess self-reported satisfaction with treatment programs. The CSQ-8 is easily scored by summing the individual item scores to produce a range of 8 to 32, with high scores indicating greater satisfaction.

Outcome measures: Social competence:

Interaction Rating Scale Advanced (IRSA; Anme et al., 2014).

The IRSA is a 92-item instrument designed as a brief but comprehensive observation measure that assesses basic social competence for individuals over the age of 15. Social competence is examined through five-minute observations of a social interaction. One advantage of the IRSA is that evaluations of interactions can be completed in a short period within normal, daily situations. The IRSA includes a behavioural score and 6 subscales scores that combined provide an impression score: "self-control," "expressivity," "sensitivity," "assertiveness," "responsiveness," and "regulation". Two different variables are scored: behavior and impression. For the behaviour variable, items are assessed in terms of the presence of a behaviour (0 = no, 1 = yes), and the sum of all items in provides the overall score. The total score can range from 0 to 92. As for the impression, each observed behaviour is rated on a five-point scale where 1 is "not evident at all," 2 is "not clearly evident," 3 is "neutral," 4 is "evident," and 5 is "highly evident." The rating procedure is as follows: the evaluator completes the checklist, focusing on the participant's behaviours (e.g., expressing his/her own feelings to the partner).

Multidimensional Social Competence Scale (MSCS; Yager & Larocci, 2013).

The MSCS is a recently developed measure administered to participants and primary caregivers. The scale includes 77 items rated on a Likert scale ranging from 1 (“not true or almost never true”) to 5 (“very true or almost always true”). Items are coded such that higher scores reflected higher levels of social competence. Simon Fraser University’s WebSurvey software will be used to administer a secure electronic version of the MSCS to participants via the Internet.

Neuroimaging:

Functional near infrared spectroscopy (fNIRS) will be utilised to measure brain functioning. In the proposed study, changes in oxygenated haemoglobin and deoxygenated haemoglobin will be measured using a 52-channel NIRS machine. fNIRS is a somewhat recently developed functional brain imaging technique that involves emission of near infrared light that can be detected through the scalp (Boas et al., 2003). fNIRS allows monitoring of cerebral blood volume changes in cortical regions of the brain. fNIRS detects increases and decreases oxygenated haemoglobin concentration using a small apparatus which is placed on the scalp. The major benefit of fNIRS is that compared to other functional brain imaging techniques it enables brain activity measurement in a more natural setting, making it a suitable choice for the proposed study.

Procedure

To complete this study a total of at least four volunteer research assistants will need to be recruited. Ideal candidates may be attained via the undergraduate and postgraduate psychology courses at the University of Salford. Psychology program leaders will be approached and asked to recommend suitable candidates. Recruits will have studied to a 2nd year undergraduate level or higher. Although, all recommendations from psychology program leaders will be considered (e.g. recommendation for a first year undergraduate student with relevant past experience). With the permission of psychology program leaders, it may also be advantageous to garner interest by approaching students in lectures and seminars. Recruitment for the assistant researchers will begin upon ethical approval.

Two of the assistant researchers will be recruited to help facilitate the group therapy sessions. Applicants that have experience working with individuals with ASD or that have worked in a clinical setting may provide the best candidature. Minimal training will be required for the assistant researchers. Assistant researchers will be required to become familiar with the intervention manual and attend a two day training session totalling approximately 8 hours. The focus of training will be on the rehearsal of role play and modelling strategies outlined in the intervention manual. Volunteer assistant researchers will be required to devote approximately 20 hours to fulfil these two positions.

Assistant researchers will also be recruited to help facilitate the fNIRS conversation task. Assistant researchers will be required to participate in approximately 20 pre/post-test five minute conversations with five participants in the experiential group and five in the control group. Prior to the task the assistant researcher will meet with the participant so that they can mutually agree upon a topic of conversation. The volunteer assistant researcher will be required to devote approximately eight hours over two days to fulfil this position.

To complete the observer-rated assessment one assistant researcher will be required to view a total of 10 video recordings (pre/post; 5/5) of a five minute dyad interaction task. To score behaviours, two evaluators (the lead and assistant researcher) will need to code the participants’ interactions following the IRSA manual (Anne et al., 2014). The volunteer assistant researcher will be required to devote approximately five hours to fulfil this position.

Recruitment respondents will receive a 10 minute pre-screening phone interview which will help establish if initial criteria is met and if the treatment is appropriate for the individual. The interviewer will utilise a generalised phone screening script (see appendix A) to ensure all requirements are met for participation. An intake interview for the potential participant and caretaker will be completed within the two weeks prior to commencement of the intervention. The intake interview will consist of a verbal review of the content of the information sheet (see appendix C), address any questions and administer the WRIT (Glutting, Adams, & Sheslow, 2000) and the AQ-50 (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). In the event that a participant is found to not be appropriate for the intervention a full explanation will be provided i.e. the researcher will repeat the criteria requirements and explain which of the criteria(s) caused the participant to be ineligible. Once eligibility has been established and participants express an interest to continue, a signed consent form (see appendix E) will be obtained following a guidance protocol for gaining informed consent of an individual with ASD (see appendix G). After a 24 hour consideration period, informed consent will be accepted by the researcher.

Feasibility

Feasibility will be analysed by monitoring attendance over the six week intervention and administering a post intervention self-reported participant satisfaction questionnaire. The lead researcher will keep an attendance log for individual CBT sessions and group social competence sessions to record intervention adherence rates. The CSQ (Larsen et al., 1979) will be administered upon completion of the intervention and scores will be used to demonstrate participant satisfaction rates.

Interviews

To gather data for future intervention development, interviews (see appendix B) will be utilised upon completion of the intervention. Participants with a minimum of 80% attendance during the intervention and their caretakers will be asked to take part in semi-structured interviews. The lead researcher will conduct and video/audio record interviews upon completion of the intervention and again at 6-8-month follow-up assessment. Interview data will be utilised to steer further intervention development.

In addition, the researcher aims to conduct between 6-10 semi-structured interviews (see appendix B) with a primary caregiver (e.g. a parent) of an adult child with ASD that did not participate in the intervention. Interviews will aim to investigate the experiences of living with an adult child with ASD (e.g. accessing and receiving of support/treatment). Interviews will be conducted in person at the university of Salford’s observation suite or via skype telecommunication video link. All interviews will be video/audio recorded.

Focus group

Assistant researchers (co-therapists) will be invited to the observation suite in the Allerton Building which is in room L802 on the 8th floor to have a semi-structured focus group discussion. Topics covered in the discussion will relate to: 1) a review and discussion about the group therapy case notes 2) Their subjective experience of delivering group sessions 1-6 of the SCTI-A manual. 3) Their experience of the facilitation of 1-1 CBT sessions guided by case notes. 4) Therapists perception of what was effective and what could

be improved. 5) Expressions of how training on the delivery of SCTI-A for therapist can be improved. The discussion will be video recorded for the purpose of assessment, intervention development and improving therapist training.

Parent/caretaker and self-assessments

Parent/Caretaker assessments will be completed on a University of Salford laptop in the Allerton observation suite where a researcher will be on hand to help and answer questions. Parent/Caretaker-reports will be completed using the online version of the MSCS (Yager & Larocci, 2013). Scores will be calculated by collaborating colleagues at Simon Fraser University, Canada. Observer-rated data will be collected by assistant researchers using the IRSA (Anme et al., 2014). Optional paper version will be offered to those participants that do not wish to complete the measure online. Paper versions will be scored by the lead researcher

Brain imagining

Participants in the experimental group and the control group will be required to complete a pre/post-test social interaction task. The tasks will aim to replicate a natural conversation between a participant and a research assistant (topic to be agreed upon by both parties before the commencement of the conversation). Participants will be given specific details of the task before being guided into the room where the conversation will take place. The conversation will be initiated by the assistant researcher at the beginning of each conversation task. During this conversation task the participants will be required to wear the 52 channel fNIRS device for approximately six minutes. The 52 channel fNIRS data will provide a measure of neurological activity during the five minute conversation task and the conversation summary. There are only three criteria that must be met before the five minute conversation begins:

- 1) The topic is chosen by the participant and the assistant researcher prior to the commencement of the conversation
- 2) Attempt to speak in turns during the conversation.
- 3) Stay on topic

At the end of the conversation the participants will be asked to give a brief 60 second summary of the conversation, describing the assistant researcher viewpoint on the topic discussed.

Observer rated assessment

Participants in the experimental group will also be required to complete a naturalistic five minute dyad interaction task for the purpose of observer-rated behavioural assessment. Participants will be told that they are going to have a conversation while playing a game. In dyads participants will be escorted into the Allerton observation suite which will be furnished with a small table and two chairs. The participants will then be instructed that they are going to play a classic game, Tumble Tower. Tumble Tower consists of 54 precision-crafted, hard wood blocks. Players take turns removing one block at a time from the tower and placing that block on the top of the tower. The participants will be provided with instructions from the researcher on how to set up and play the game. Participants have five minutes to play the game and converse. If the game ends (the tower falls) before the five minutes is over, participants are instructed to reset the blocks and play again. The interaction will be video recorded with four video cameras which can assess the interaction from four angles. Video recordings will be viewed to rate social competence based on observations as described by the IRSA manual

Intervention overview

The following program was developed in line with the clinical guidelines from the National Institute for Health and Care Excellence on Autism Spectrum Disorder (ASD) in adults: diagnosis and management (NICE; 2012). The SCTI-A intervention manual utilises Cognitive Behavioural Therapy (CBT) principles to approach therapeutic change in social competence. Evidence based CBT techniques are considered to be instrumental to the SCTI-A program and are further discussed below:

Group therapy format

A recent meta-analysis suggests that group CBT interventions can be as effective as individual CBT for young people with ASD (Weston, Hodgekins & Langdon, 2016). Group social skills paradigms typically have a trend of 6-10 participants per group. One of the largest yields for an evidence based group CBT format for adults was 10 participants per group (Gantman, Kapp, Orenski & Laugeson, 2014; Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015). As there is limited research, there does not seem to be a consensus recommendation for an optimal number of participants per group, although it does appear that groups as large as 10 can be effective. Larger groups are not recommended as the results are unknown.

Therapeutic alliance

Research strongly suggests that the therapeutic alliance has an association with positive treatment outcomes (Haug, et al., 2016). A good therapeutic relationship is important in CBT as it helps the client and therapist to work collaboratively towards a shared goal (Jones, Peters, & Barker, 2009). It is important for the therapist to build the foundations of the therapeutic alliance by providing empathy, positive regard, and congruence early in the therapeutic process. Studies have shown that when the CBT therapists demonstrate empathy and trust they have a better working alliances and obtain more positive outcomes (Jones et al., 2009).

Social Cognition

Social cognition is therapeutically targeted by focusing the questioning on taking the perspective of others. CBT sessions utilise perspective taking questions such as “*I know how you feel about the situation but what do you think it was like for the other people involved?*” Taking on the perspective of others or “Theory of Mind” (ToM) is a well document social deficit for individuals with ASD and has been targeted in a number of social skills interventions (Miller, Vernon, Wu & Russo, 2014). Perspective taking questioning should be done repeatedly and predictively (Laugeson, 2013), with the same line of questioning each week. Laugeson and Park (2014) suggest using the following three perspective taking questions when modelling good and bad social behaviour: “*What do you think that was like for other people?*” “*What do you think they thought of me*” and “*are they going to want to talk to me again?*” This repeated line of questioning aims to develop a schema which will provide content dependant meaning when social demands are experienced.

Problem solving

Social problem solving is a collaborative process to test and challenge the rationality of specific cognitions and to modify associated maladaptive behavioural patterns (Hofmann et al., 2012). Mutually identifying the problem and consider the cause is the first

line of investigation. Discussing the details of what happened to cause the problem and reflect on what could have been done differently should follow. Collaborate and explore the differing possible outcomes, identify accommodating strategies that may provide a solution to the problem and mutually agree on naturalistic practise of strategies as homework. It is important to review these strategies and be flexible with adaptation when needed.

Socratic questioning

The Socratic Method is ubiquitous in the psychotherapy literature and is a fundamental technique in CBT (Carey & Mullan, 2004). In SCTI-A, the overall purpose of Socratic questioning, is to challenge the accuracy and comprehensiveness of reasoning in a way that acts to move an individual towards their eventual goal. Corsini (2002) defined the Socratic dialogue/method as in two ways:

In counselling, a carefully constructed series of questions designed to arrive at logical responses to a problem and proper conclusions about future actions.

Inductive dialectic procedure leading a person to accept or admit the desired conclusion by means of a progressive series of leading questions that are answered in turn. (p. 921)

Focused lines of questioning should aim to investigate a specific viewpoints or perspectives. Conceptual clarification questions should be commonly used to make an individual think more about what exactly they are asking or thinking about. Questioning aims to build evidence of the concepts and provide a rationale for learning while challenging any irrational arguments.

Modelling, role-play and repeated rehearsal

It seems that one the largest consequences of social isolation in adults with ASD is that they lack practise of social skills (Tantam, 2014). There is growing research supporting the use of modelling and role-play practise for teaching social skills to an ASD population (e.g. Gantman et al., 2014; Laugeson et al., 2015; Stichter et al., 2010; White et al, 2013). Modelling is a common technique used in CBT and typically involves the therapist demonstrating a strategy or skill. Role-play involves the participants repeatedly rehearsing social skills in a safe, non-threatening environment. In SCTI-A, role-play and modelling are used to support the practical application of the psychoeducation lesson content. During repeated rehearsal, scaffolding is fundamental to fostering new skill development. Wood et al. (1976) found that the most effective scaffolding resulted in those who combined general and specific interventions according to the progress of an individual e.g. provide general feedback until the individual faces difficulty, then implement more specific instructions.

Psychoeducation

Didactic instruction is another typically used technique in CBT. In an investigation of which CBT training methods are perceived to be most effective, Bennett-Levy and colleagues (2009) found didactic instruction to be one of the most useful methods for teaching declarative knowledge. Psychoeducation lessons are used to teach clearly structured strategies that aim to improve social competence. Psychoeducational curriculum was steered by evidence based behavioural skills training packages used to teach conversation skills to adolescents and young adults with ASD (Dotson, Leaf, Sheldon, & Sherman, 2010; Kornacki, Ringdahl, Sjoström & Nuernberger, 2013; Nuernberger, Ringdahl, Vargo, Crumpecker, & Gunnarson, 2013) and research identifying ecologically valid social skills typically used by socially capable adolescents and young adults (Laugeson, 2013).

Parent/Caretaker involvement

There is growing evidence to support the inclusion of parent and caretaker involvement in CBT social skills interventions for adolescents and adults with ASD (White et al., 2013; Gantman et al., 2014). Parents/Caretakers act as a social coach between sessions, promoting the practise of skills in a natural setting. Parents/Caretakers are provided with a weekly curriculum outline of the group session content and play an active supporting role throughout the intervention e.g. ensuring the completion of homework assignments. Additionally, parents are asked to encourage the use of newly learned skill/strategies (as outlined in the psychoeducation handouts) and consult with the therapist on progression towards reaching the goals set in therapy.

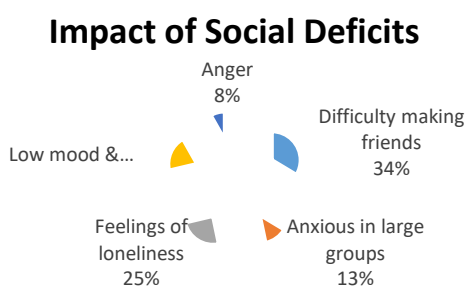
Intervention procedure

Sessions will be attended over a 6 week time frame. The intervention will comprise of weekly individual sessions and weekly group sessions.

Individual therapy session

The individual sessions will last approximately 30 minutes and will utilise a five areas CBT formulation. In the final 10 minutes of each individual session, parent/caretakers are asked to join the session to discuss mutually agreed goals and homework tasks that will encourage practise of social skills outside of the clinical setting. Individual session will be facilitated by a Masters level psychologist with qualifications in therapeutic counselling.

The Five Areas CBT approach utilise a collaborative process for identifying targets for future change. This should be done using a pie chart where each target is a piece of the pie and the size of each piece represents the magnitude of problem



The pie charts will be used to identify and prioritise the focus of therapy. Once the five main areas have been clearly defined, the clinician has a perfect starting point for choosing a problem for further discussion and formulation. The role of the clinicians is to focus on managing change through a series of case formulations which revolve around:

Problem solving, Coping strategies Support networks , Skills practice Homework Overcoming problems/issues Group therapy sessions Group session will be approximately 120 minutes and will follow the SCTI-A intervention manual (see appendix L). Group sessions will be conducted in a seminar room at the University and will be facilitated by the lead researcher and at least one assistant researcher. Two undergraduate or postgraduate psychology student from the University of Salford will be recruited for this role.

Group sessions are structured and are tailored to enhance verbal and non-verbal social communication deficits that are commonly reported in an ASD population. Using a small group format, each social session utilises didactic instructions and the delivery of information is broken down into easy to understand steps/rules. These steps/rules are repeatedly reinforced when undertaking session activities. Following the principles of CBT, Socratic questioning is utilised in a systematic line of investigation that guides reasoning, encouraging participants to encode new information and gain a greater understanding of each social skill developed. Group therapy sessions involve psychoeducation, skills modelling, role-play and rehearsal and task reinforcement. At key stages of each session, the therapist provides positive and corrective feedback. Feedback should aim to enhance key cognitive skills such as social perception (information processing), social cognition (taking on the perspective of others), and social problem solving (identifying and adjusting maladaptive behaviours).

Analysis:

A repeated measures ANOVA will be utilised to measure change. Due to a small sample size ($n=10$) there may be a need to analyse the mean difference in scores with 95% confidence intervals.

A correlation analysis will be performed on the demonstrated levels of brain activity as measured by fNIRS and self-report ASD symptoms as measure by the AQ-50. If a significant correlation between variables is found, a regression analysis will be performed. Effect size will also be analysed. All analysis will be performed using SPSS.

6. How many participants will be recruited and/or involved in the study, and give the rationale for this number? (*refer to guidelines section 7*)

An audit of sample sizes for pilot and feasibility trials was undertaken in the United Kingdom, registered in the United Kingdom Clinical Research Network (UK-CRN) database (Billingham, Whitehead & Julious, 2013). Pilot trials were found to have a smaller sample size per arm (median = 30, range = 8 to 114 participants) than feasibility trials (median = 36, range = 10 to 300 participants). By type of endpoint, across feasibility and pilot trials, the median sample size per arm was 36 (range = 10 to 300 participants) for trials with a dichotomous endpoint and 30 (range = 8 to 114 participants) for trials with a continuous endpoint.

Based on a Randomized Controlled Trial (RCT), a power analysis was performed using the Clinical and Translational Science Institute sample size calculator. Based on, $p=0.05$, $\beta=0.80$, $E=0.8$, $SD=1.960$ the sample size for a clinical trial is recommended at $N=30$. Because the formula used here is based on approximating the t statistic with a z statistic, it will slightly underestimate the sample size when N is about 30.

When taking into account the range reported in the audit of sample size for pilot and feasibility trials (Billingham et al 2013) and the power analysis of an RCT (Pilot studies recommended at 10%-20% of RCT sample size), a sample size of 10 is suggested for this feasibility study.

7. Please describe how you plan to obtain organisational agreement for your project (if required). (*Refer to guidelines section 8*)

I have completed and submitted a National Autism Society research collaboration form (see appendix K).

8. Please identify which Code of Conduct and/or Governance Framework you will be adhering to? (*Refer to guidelines section 9*)

British Psychological Society (BPS) code of Human Research Ethics (2014)

9. Please describe the data protection issues that you need to address? (*Refer to guidelines section 10*)

All information / data will be kept confidential. Data will only be handled by the principle researcher, research assistants, research supervisors and a psychology technician. Video data will be recorded by the researcher using cameras within the observation room and will not be shared publicly. Conversation tasks and selective interviews will be video recorded for the purpose of observer assessment. Video data will be uploaded to a secure password encrypted computer and video files will be encrypted with a digital password. Participant will be identified by a unique participant number to ensure anonymity when gather data. The data gathered from questionnaires and neuroimaging will be entered into a secure database in accordance with ISO/IEC27002 (Information Technology – Code of Practice for Information Security Management, 2013). All hard copies will be stored in a locked filing cabinet located in an auto lock office secured with a five digit key code within a secure building. Participants are free to withdraw from the study at any time without giving a reason and all data collected up to the point of withdrawal will remain part of the study. All collected data will be kept for minimum of five years on password secured encrypted disk drive.

All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. Participants will be provided with the unique identification number in order to ensure anonymity. Data will be kept for a minimum of five years and secured on password secured computer on encrypted disk at the university campus accessed only by research team.

10. Please describe how other ethical issues will be considered (*Refer to guidelines Section 12*)

In the event that a participant is found to not be appropriate for the treatment a full explanation and appropriate referral will be provided. Accepted participants will be provided with the information sheet describing the nature of the experiment, potential risks factors and detailed information about the intervention. In the case that the participant feels distress during the intervention the participant will be asked if they would like participation to cease and withdraw from the study.

In the case of a participant experiencing any discomfort or distress during the use of fNIRS, the participant will be asked if they feel alright to proceed. If the participant feels they can no longer proceed the experiment will be terminated immediately and the participant will be given a debriefing by the principle researcher. As the fNIRS device can cause discomfort for prolong periods of time (approximately 15 minutes or more), participants will only be required to wear the device during a 5 minute conversation task.

In the case of participants exhibiting behavioural problems which cannot be resolved by the researcher or if distress or discomfort continues during any part of the study the researcher will contact security as they are the central point of contact if participants are in need of physical and/or psychological first aid. As a failsafe, in the case where contact with security fails there will be a contingency plan for the principle researcher to contact student life for further support. The contact details for security (0161 295 4773) and for student life (0161 295 0023) will be kept at all times by the facilitating researcher during the study in the case of emergency.

11. Please identify if reimbursements and/or incentives will be provided to participants. (*Refer to guidelines Section 13*)

None will be provided

12. Please describe the dissemination strategies for your project findings. (*Refer to guidelines Section 13*)

e.g. reporting of incidental findings from assessments, reporting adverse event, addressing sensitive issues, dealing with vulnerable populations or working alone.

When the study is completed a lay version of the results will be offered to individuals that opt to participate at the consent stage. All affiliates of the study will be sent a copy of the anonymised final results.

Final reports will be developed for the intent of publication in academic peer reviewed journals and will be submitted to relevant journals. Abstracts will be submitted to national and international conferences/ events. E-mail contact will be made with national and international autism organisations that promote excellence in autism research (e.g. Nation Autism Society & Autism Research UK. The authors also aim to disseminate information via academic social media platforms (e.g., Researchgate.net)

13. References – provide full list of all references used.

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I certify that the above information is, to the best of my knowledge, accurate and correct. I understand the need to ensure I undertake my research in a manner that reflects good principles of ethical research practice.*

****By submitting your application via email you are confirming you will comply with the above***

*Please note that whilst the School indemnifies PGR student research projects, the supervisor is signing that they are satisfied that the student has considered the ethical implications of their work and to confirm for the PGR student's project to proceed subject to approval by the ethics panel.***

*****By submitting your students' application you are confirming you will comply with the above***

PRIOR TO SUBMITTING THE APPLICATION FORM:

Please refer to the 'Application Checklist' and ensure appropriate supporting

Risk Assessment Form

All projects must include a risk assessment. If this summary assessment of the risk proves insignificant, i.e. answer no to all questions, no further action is necessary. However, if you identify risks you must identify the precautions you will put in place to control these.

1. What is the title of the project?

The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder

2. Is the project purely literature based? NO

If YES, please go to the bottom of the assessment and sign where indicated. If NO, complete question 3 and list your proposed controls.

3. Please highlight the risk/s which applies to your study:

Hazards	Risks	If yes, consider what precautions will be taken to minimise risk and discuss with your Supervisor
<i>Use of ionising or non-ionising radiation</i>	<i>Exposure to radiation</i> <i>NO</i>	<i>Obtain copy of existing risk assessment from place of research and attach a copy to this risk assessment summary.</i>
<i>Use of hazardous substances</i>	<i>Exposure to harmful substances</i> <i>NO</i>	<i>Obtain copy of existing risk assessment from place of research and attach a copy to this risk assessment summary.</i>
<i>Use of face-to-face interviews</i>	<i>Interviewing;</i>	<i>NB: Greater precautions are required for medium & high risk activities</i>

<p><i>Interviewees could be upset by interview and become aggressive or violent toward researcher</i></p>	<p><i>Own classmates=Low risk</i> No</p> <p><i>Other University students=Medium risk</i> Yes</p> <p><i>Non-University personnel=High risk</i> Yes</p>	<p>Consider:</p> <ul style="list-style-type: none"> • <i>How will contact with participants be made - i.e. do not give out personal mobile no., home number or home email, etc.</i> • <i>Location of interviews – to be held in a safe environment, e.g. University building, workplace</i> • <i>What support will be available, i.e. will anyone else be available to assist if you call for help, etc. e.g. colleague knows where interview to take place and telephoned when completed and safe- what action to take after certain time if not phoned</i> • <i>How to deal with aggressive/violent behaviour, what precautions will be taken to prevent this from happening?</i>
<p><i>Use of face-to-face interviews</i></p> <p><i>Participants or interviewees could become upset by interview and suffer psychological effects</i></p>	<p>yes</p>	<p>Consider:</p> <ul style="list-style-type: none"> • <i>What initial and subsequent support will be made available for participants or interviewees?</i> • <i>What to do if researcher uncovers information regarding an illegal act?</i> • <i>What/who will be used to counsel distressed participants/ interviewees, what precautions will be taken to prevent this from happening?</i>
<p><i>Sensitive data</i></p>	<p><i>Exposure to data or information which may cause upset or distress to Researcher</i></p> <p>No</p>	<p>Consider:</p> <ul style="list-style-type: none"> • <i>What initial and subsequent support will be available to the researcher</i>
<p><i>Physical activity</i></p>	<p><i>Exposure to levels of exertion unsuitable for a individuals level of fitness</i></p> <p>No</p>	<p>Consider:</p> <ul style="list-style-type: none"> • <i>Health Questionnaire/ Medical declaration form / GP clearance.</i> • <i>Trained First Aid personnel/ Equipment.</i>
<p><i>Equipment</i></p>	<p><i>Exposure to faulty unfamiliar equipment.</i></p> <p>No</p>	<p>Consider:</p> <ul style="list-style-type: none"> • <i>Equipment is regularly checked and maintained as manufactures instructions.</i> • <i>Operators receive adequate training in use of.</i>

		<ul style="list-style-type: none"> Participants receive induction training prior to use.
<p><i>Sensitive issues</i> i.e. Gender / Cultural</p> <p>e.g. when observing or dealing with undressed members of the opposite sex</p>	<p><i>Exposure to vulnerable situations/ sensitive issues that may cause distress to interviewer or interviewee</i></p> <p>No</p>	<p>Consider:</p> <ul style="list-style-type: none"> Use of chaperones/ Translators. What initial and subsequent support will be made available for participants or interviewees?
<p><i>Children</i></p>	<p>No</p>	<ul style="list-style-type: none"> Adhere to local guidelines and take advice from research supervisor
<p><i>Manual Handling Activities</i></p>	<p><i>Exposure to an activity that could result in injury</i></p>	<ul style="list-style-type: none"> Adapt the task to reduce or eliminate risk from manual handling activities. Ensure that participants understand and are capable of the manual handling task beforehand. Perform health questionnaire to determine participant fitness prior to recruitment

If you have answered yes to any of the hazards in question 3, please list the proposed precautions below:

Interviewees could be upset by interview and become aggressive or violent toward researcher

In the case of participants exhibiting behavioural problems which cannot be resolved by the researcher, the researcher will contact security as they are the central point of contact. As a failsafe, in the case where contact with security fails, there will be a contingency plan for a researcher to contact student life for further support. The contact details for security (0161 295 4773) and for student life (0161 295 0023) will be kept at all times by the facilitating researcher during the study in the case of emergency.

Participants or interviewees could become upset by interview and suffer psychological effects

In the unlikely event that a participant becomes upset and suffers psychological effects the participant will be given a referral to Salford Autism or the Together Trust North West. Salford Autism provide social support for individuals with ASD and provide an open contact line (0771 390 3224) 24 hours, 7 days a week, including all holidays. Additional/Alternative support: The Together Trust is a charity that offers care, support and special education to children, adults and families. Their services are based in North West England and they accept referrals from all over the UK. Contact details: 0161 283 4848 8.30am – 5.00pm or 0800 013 0014 for out of hours support.

Signature of student David Tate Date 05-07-2017.....

Signature of Supervisor Date

Appendix E. Ethical Approval Letters

 Research, Innovation and Academic Engagement Ethical Approval Panel
Research Centres Support Team
G.03 Joule House
University of Salford
M5 4WT
T +44(0)161 295 2280
www.salford.ac.uk/

12 September 2017

Dear David,

RE: ETHICS APPLICATION–HSR1617-166 – ‘The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A).’

Based on the information you provided, I am pleased to inform you that application HSR1617-166 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

A Clark

Andrew Clark
Deputy Chair of the Research Ethics Panel

Appendix F. Recruitment materials

Participant Information Sheet 1

Participant Information Sheet

Study Title

The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Invitation paragraph

We would like to invite you to participate in this study, which forms part of my PhD project. Before you decide whether you want to take part, please take time to read the following information carefully as it is important for you to understand why the research is being done and what your participation will involve. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to investigate the feasibility and effectiveness of a cognitive behavioural intervention which was developed as part of my PhD project.

Why have I been invited?

We are looking for volunteers that have a diagnosis of autism spectrum disorder without an intellectual disability and your parent/caretaker to take part our study. This may include a past diagnosis of: high functioning autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS). Parents or caretakers will have minimal involvement and will mainly play a supporting role.

Do I have to take part?

Participation in this study is voluntary. You should read this information sheet and if you have any questions or need clarification you should contact the researcher using the details at the end of this document. You should not agree to take part in this research until you have had all your questions answered to your satisfaction. If you decided to take part in the study, you are free to withdraw at any time without giving a reason and all data up to the point that you withdraw will be stored for a minimum of five years.

What will happen to me if I take part?

Initially you will receive a brief phone call from a researcher to make sure the intervention is appropriate for you. If you are interested in participating in the study, you will be invited to the Allerton Building on the University of Salford campus to meet with a researcher where you can ask any questions and further discuss the details of the study. Once all your questions have been answered to your satisfaction, we will then ask you to take an IQ test and answer a questionnaire. The Autism Spectrum Quotient (AQ-50; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) is a popular questionnaire which will take you about 20-30 minutes to complete. The questionnaire will assess your autism symptoms and provide support for your autism diagnosis. The Wide Range Intelligence Test will be used to establish your IQ score and it also takes about 20-30 minutes to complete (WRIT; Glutting, Adams, & Sheslow, 2000). An IQ score of 80 or above is needed to participate in this study (typically people have an IQ of 90-110). Altogether, this meeting is expected to last no more than two hours. If it is determined that you are suitable to participate in the study and you wish to take part, a signed consent form will need to be returned to the researcher following a 24 hour consideration time period.

As part of your participation in this study you will need to complete two brief social interaction tasks (see below for Task A & B) before the start of the intervention and once again at the end of the intervention. Both tasks will be completed on the same day and will take place in the observation suite and a small meeting room on the 8th floor of the Allerton Building on the University of Salford campus.

Task A

One of the tasks will aim to replicate a natural conversation between you and another person. During this conversation task you will be required to wear the 52 channel functional near infrared spectroscopy (fNIRS) device for about six minutes. The fNIRS is a small non-invasive device that will be simply placed on your head similar to a swimmers cap as seen in the picture below. There are only three rules for this conversation task:

- 1) The topic is chosen by you and the other person prior to the start of the conversation
- 2) Speak in turns during the conversation.
- 3) Stay on topic

At the end of the conversation you will be asked to give a brief 60 second summary of the conversation describing the other person's viewpoint on the topic you both discussed.



Task B

You will also be asked to complete a second tasks which involve you playing a game. You will not be required to wear the fNIRS cap for this task. For this task you will play a classic game, Tumble Tower. Tumble Tower consists of 54 precision-crafted, hard wood blocks. Players take turns removing one block at a time from the tower and placing that block on the top of the tower. Before you begin the game, you will be provided with instructions on how to set up and play the game. You will have five minutes to play the game and talk with the person you are playing against. If the game ends (the tower falls) before the five minutes is over, you will simply reset the blocks and play again. The interaction will be video record with four video cameras and video recordings will only be viewed by researchers involved in the study.



On the final day of the intervention, you will also be given a short questionnaire to complete and you may be randomly selected to participate in a very brief interview. The

questionnaire will be completed at the University of Salford in a meeting room in the Allerton building and the interview will take place in the observation suite which is also located in the Allerton building. The Client Satisfaction Questionnaire (Larsen et al., 1979) requires you to answer only eight questions and only takes about five minutes to complete. The Short interview is scripted with six questions that are focused on your personal experience of the intervention. The interview will roughly take between 5-10 minutes. An example of one interview question is “*What did you like about the intervention?*”

Parent/Caretaker participation

Parents/Caretakers play a very important role in the study. Along with providing social support during the intervention, the parents/caretakers will complete The Multidimensional Social Competence Scale online questionnaire (MSCS: Yager & Larocci, 2013) which will help determine if there were any improvements in your social competencies as a result of the intervention. A researcher will set up a university laptop in a meeting room in the Allerton Building on the University of Salford campus. Questionnaires will need to be completed before the intervention begins and again when the intervention ends. In the event that a parent/caretaker would prefer not to answer the questionnaire online, a paper version can be provided. Should a parent/caretaker decided to withdraw from their role and not answer their questionnaire, it will not affect you from continuing on with the study.

Expenses and payments?

There is no financial incentive to participate in this research.

What will I have to do?

If you and your parent/caretaker are happy to participate in the research you will be told the full purpose of the study and you will need to sign the consent form and return it to the researcher. For participation in this study you will need to provide a commitment twice a week to therapy. All sessions will be attended in the Allerton Building on the University of Salford campus over six weeks. The intervention involves six weekly individual sessions and six weekly group sessions (two therapy session a week). The total time you will need to commit to therapy over the six week intervention is 15 hours (2.5 hours a week).

The individual sessions (just you and one other therapist) are at the beginning of the week and will last about 30 minutes. These session will follow the five areas cognitive

behavioural therapy (CBT) model. In the final 10 minutes of the individual CBT sessions your parent/caretaker will be invited to join the session as we recap on any mutually agreed goals and/or homework tasks. Parents/caretakers will play a supportive role in helping you to complete your homework tasks and achieve your goals. Individual CBT will total three hours of therapy over six sessions and will run alongside the group sessions.

Group sessions are held at the end of the week and will last approximately two hours. The group size is small and will not exceed more than ten participants. The group sessions are aimed at improving general social communication skills. Activities in the group often involve socialising with others, which makes participation very important. Group therapy sessions will involve learning new skills, watching the therapists modelling behaviours, role-play and rehearsal of social skills and social problem solving. There are six group sessions requiring a commitment from you of 12 hours of group therapy.

What are the possible disadvantages and risks of taking part?

We do not anticipate that you will experience risk or disadvantages, however you may experience a slight discomfort or pressure whilst wearing the fNIRS device. This device can be easily adjusted or removed in the event that discomfort becomes distressing. This will not affect your participation in the intervention.

What are the possible benefits of taking part?

The data gathered will be used to further develop social skills interventions for individuals with ASD. This study will help to increase the understanding of the brain's response to a specialised therapeutic intervention.

What if there is a problem?

If you have a concern about any aspect of this study you can contact the lead researcher David Tate (D.Tate@edu.salford.ac.uk) or Dr Clare Allely (c.s.allely@salford.ac.uk).

If you would like to make a complain, you can contact

Dr Sue McAndrew

Room Mary Seacole 1.91

T: 0161 295 2778

E: s.mcandrew@salford.ac.uk

University of Salford,

Salford,

M5 4WT

Will my taking part in the study be kept confidential?

All information / data will be kept confidential. Video data will be recorded by the researcher using cameras within the observation suite and will not be share publicly. Conversation tasks and selective interviews will be video recorded for the purpose of assessment. Video data will be uploaded to a secure password encrypted computer and video files will be encrypted with a digital password.

The data gathered will be entered into a secure database in accordance with ISO/IEC27002 (Information Technology – Code of Practice for Information Security Management, 2013). All hard copies will be stored in a locked filling cabinet located in an auto lock office secured with a 5 digit key code within a secure building. All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. You will be provided with the unique identification number in order to ensure anonymity and your data will be kept for a minimum of five years.

What will happen if I do not carry on with the study?

You are free to withdraw from the study at any time and without giving reasons for withdrawing. All of the data collected up to the point of withdrawal will be stored for a minimum of five years.

What will happen to the results of the research study?

Details and results of this study will be published in scientific publications, such as journals, and/or presented at conferences and seminars, and/or research website depositories.

They will be used in the researcher's PhD dissertation. Any and all information will be anonymised.

Who is organising or sponsoring the research?

University of Salford

Long-term support

This study is unlikely to cause any persistent distress or discomfort but if you do feel continued distress or discomfort and cannot continue, the researcher will telephone security who are now the central point of contact for both physical and psychological first aid. The number for security is 01612954773 and for student wellbeing 01612950023. We can also offer a referral to Salford Autism or the Together Trust North West. Salford Autism provide social support for individuals with ASD in Salford and provide an open contact line (0771

390 3224) 24 hours, 7 days a week, including all holidays. The Together Trust is a charity that offers care, long-term support and special education to children, adults and families. Their services cover the North West of England and they accept referrals from all over the UK. Together Trust Contact details are: 0161 283 4848, 8.30am – 5.00pm or 0800 013 0014 for out of hours support. In the case of needing immediate support contact your GP or NHS helpline for advice by calling the free number 111.

Participant Information Sheet 2

Participant Information Sheet

Study Title

The Development and Feasibility Trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Invitation paragraph

We would like to invite you to participate in this study, which forms part of my PhD project. Before you decide whether you want to take part, please take time to read the following information carefully as it is important for you to understand why the research is being done and what your participation will involve. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to investigate the feasibility and effectiveness of a cognitive behavioural intervention which was developed as part of my PhD project.

Why have I been invited?

You have been invited to participate in a focus group discussion because you had a direct involvement in the delivery of SCTI-A.

Do I have to take part?

Participation in this study is voluntary. You should read this information sheet and if you have any questions or need clarification you should contact the researcher using the details at the end of this document. You should not agree to take part in this research until you have had all your questions answered to your satisfaction. If you decided to take part in the study, you are free to withdraw at any time without giving a reason and all data up to the point that you withdraw will be stored for a minimum of five years.

What will happen to me if I take part?

You will be video recorded while participating in a small group discussion.

Expenses and payments?

There is no financial incentive to participate in this research.

What will I have to do?

You will be invited to the observation suite in the Allerton Building which is in room L802 on the 8th floor to have a semi-structured focus group discussion. Topics covered in the discussion will relate to; 1) a review and discussion about the group therapy case notes 2) your subjective experience of the delivery of group sessions 1-6 of the SCTI-A manual. 3) Your experience of facilitation of the 1-1 CBT sessions, feedback and case notes review. 4) Therapist perception of what was effective and what could be improved. 5) Expressions of how training on the delivery of SCTI-A for therapist can be improved.

The discussion will be video recorded for the purpose of assessment, intervention development and improving therapist training.

What are the possible disadvantages and risks of taking part?

We do not anticipate that you will experience risk or disadvantages by your participation.

What are the possible benefits of taking part?

The data gathered will be used for the further development of SCTI-A for adults with ASD and inform best practise for the training of therapist that wish to implement the intervention within a clinical or community setting

What if there is a problem?

If you have a concern about any aspect of this study you can contact the lead researcher David Tate (D.Tate@edu.salford.ac.uk) or Dr Clare Allely (c.s.allely@salford.ac.uk).

If you would like to make a complain, you can contact

Professor Sue McAndrew

Room Mary Seacole 1.91

Frederick Road Campus, University of Salford, Salford, M6 6PU.

T: 0161 295 2278

E: s.mcandrew@salford.ac.uk

Will my taking part in the study be kept confidential?

All information / data will be kept confidential. Video data will be recorded by the researcher using cameras within the observation suite and will not be share publicly. Video data will be uploaded to a secure password encrypted computer and video files will be encrypted with a digital password.

The data gathered will be entered into a secure database in accordance with ISO/IEC27002 (Information Technology – Code of Practice for Information Security Management, 2013). All hard copies will be stored in a locked filling cabinet located in an auto lock office secured with a 5 digit key code within a secure building. All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. You will be provided with the unique identification number in order to ensure anonymity and your data will be kept for a minimum of five years.

What will happen if I do not carry on with the study?

You are free to withdraw from the study at any time and without giving reasons for withdrawing, however your contribution to the focus group discussion will remain part of the study. All of the data collected up to the point of withdrawal will be stored for a minimum of five years.

What will happen to the results of the research study?

Details and results of this study will be published in scientific publications, such as journals, and/or presented at conferences and seminars, and/or research website depositories.

They will be used in the researcher's PhD dissertation. Any and all information will be anonymised.

Who is organising or sponsoring the research?

University of Salford

Support and first aid

This study is unlikely to cause any physical or psychological distress but if you do feel distressed and cannot continue, the researcher will telephone security who are now the central point of contact for both physical and psychological first aid. The number for security is 01612954773.

Participant information sheet 3

Study Title

The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Invitation paragraph

We would like to invite you to take part in this study which forms part of my PhD project. Before you decide whether you want to take part, please take time to read the

following information carefully as it is important for you to understand why the research is being done and what your role will involve.

What is the purpose of the study?

The purpose of this study is to develop and evaluate our newly developed cognitive behavioural social skills intervention for young adults with autism.

Why have I been invited?

Because you are the parent or caretaker of an adult child (18+) with a diagnosis of autism spectrum disorder (ASD) without an intellectual disability. This may include a past diagnosis of: high functioning autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS).

Do I have to take part?

It is voluntary for you to take part in the study. You should read this information sheet and if you have any questions or need clarification you should contact the researcher using the details at the end of this document. In the event you decided to take part, you are free to withdraw from the study at any time without giving a reason and all data up to the point that you withdraw will be stored for a minimum of five years.

What will happen to me if I take part?

You will participate in an interview that will take approximately 30 minutes to complete. The researcher will conduct the interview in person or via telecommunication. The interview aims to gain valuable insight into your family history, your past and current challenges related to autism, and your experience(s) of accessing and/or participating in autism interventions/treatments throughout your child's life. You will also be asked to provide your opinion about the most helpful topics/skills to teach when providing social skills support to young adults with ASD (For example, avoiding victimisation in adulthood)

What are the possible disadvantages and risks of taking part?

We do not anticipate that you will experience risk or disadvantages. However, if you feel you cannot continue at any time, the interview will be stopped until you feel ready to continue again.

What are the possible benefits of taking part?

The interviews aims to gain valuable qualitative insight into your experiences of support offered to autistic individuals in adulthood. The data gathered will also be used to further the developments social skills interventions for adults with ASD.

What if there is a problem?

If you have a concern about any aspect of this study you can contact the lead researcher David Tate (D.Tate@edu.salford.ac.uk) or Dr Clare Allely (c.s.allely@salford.ac.uk).

If you would like to make a complain, you can contact

Professor Sue McAndrew

Room Mary Seacole 1.91

Frederick Road Campus, University of Salford, Salford, M6 6PU.

T: 0161 295 2278

E: s.mcandrew@salford.ac.uk

Will my taking part in the study be kept confidential?

All information / data will be kept confidential. The data gathered will be entered into a secure database in accordance with ISO/IEC27002 (Information Technology – Code of Practice for Information Security Management, 2013). All hard copies will be stored in a locked filling cabinet located in an auto lock office secured with a 5 digit key code within a secure building. All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. You will be provided with the unique identification number in order to ensure anonymity. Data will be kept for a minimum of five years and on password secured computer on encrypted disk accessed only by the research team.

What will happen if I do not carry on with the study?

All of the data collected up to the point of withdrawal will be stored for a minimum of five years.

What will happen to the results of the research study?

Details and results of this study will be published in scientific publications, such as journals, and/or presented at conferences and seminars, and/or research web site depositories.

They will be used in the researcher's PhD dissertation. Any and all information will be anonymised.

Who is organising or sponsoring the research?

University of Salford

For further information or to ask questions contact:

Mr. David Tate

PhD Student and Lecturer in Psychology | School of Health and Society

Allerton L526, University of Salford, Salford, M6 6PU

t : 07594 047 472

Email: D.Tate@edu.salford.ac.uk

Consent Form 1

CONSENT FORM

Title of study: The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Name of Researcher:
David Tate

Please complete and sign this form **after** you have read and understood the study information sheet. Read the statements below and yes or no, as applicable in the box on the right hand side.

1. I confirm that I have read and understand the study information sheet Version 3, dated 05/09/2017, for the above study.
I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.
3. If I do decide to withdraw I understand that the information I have given, up to the point of withdrawal, may be used in the research and will be stored for a minimum five years
4. As described in the information sheet version 3 I agree to participate by completing a series of third party and self-assessments, participating in the SCTI-A program, and an brief interview
5. I agree to be video recorded for the purpose of assessment.
6. I agree to participate in a conversation task while wearing a non-invasive brain imaging devise (functional near inferred spectroscopy)
7. I understand that my personal details will be kept confidential and will not be revealed to people outside the research team *[add, if appropriate - However, I am aware that if I reveal anything related to criminal activity and/or something that is harmful to self or other, the researcher will have to share that information with the appropriate authorities].*
8. I understand that my anonymised data will be used in (the researcher's thesis/ research report) other academic publications and conferences presentations.
9. I agree to take part in the study:

_____ Name of participant	_____ Date	_____ Signature
_____ Name of person taking consent	_____ Date	_____ Signature

Consent Form 2

CONSENT FORM

Title of study: The Development and feasibility trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Name of Researcher:
David Tate

Please complete and sign this form **after** you have read and understood the study information sheet. Read the statements below and yes or no, as applicable in the box on the right hand side.

1. I confirm that I have read and understand the study information sheet Version 5, dated 16/03/2018, for the above study.
I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.
3. If I do decide to withdraw I understand that the information I have given up to the point of withdrawal **will be used in the research and will be stored for a minimum five years**
4. As described in the information sheet version 5 I agree to take part in a focus group discussion and for this to be video recorded
5. I **agree to keep what is discussed in the group confidential**
6. I understand that my personal details will be kept confidential and will not be revealed to people outside the research team *[However, I am aware that if I reveal anything related to criminal activity and/or something that is harmful to self or other, the researcher will have to share that information with the appropriate authorities].*
7. I understand that my contribution in the focus group will be used in the researcher's thesis, other academic publications and conference presentations.
8. I **agree to take part in the studies focus group discussion**

_____ Name of participant	_____ Date	_____ Signature
_____ Name of person taking consent	_____ Date	_____ Signature

Consent Form 3

CONSENT FORM

Title of study: The Development and feasibility trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability

Name of Researcher:
David Tate

Please complete and sign this form **after** you have read and understood the study information sheet. Read the statements below and yes or no, as applicable in the box on the right hand side.

- 1. I confirm that I have read and understand the study information sheet Version 6, dated 25/03/2019, for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily. Yes/No
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected. Yes/No
- 3. If I do decide to withdraw I understand that the information I have given up to the point of withdrawal will be used in the research and will be stored for a minimum five years Yes/No
- 4. As described in the information sheet version 7 I agree to take part in the interview and for this to be Video/Audio recorded Yes/No
- 5. I understand that my personal details will be kept confidential and will not be revealed to people outside the research team [However, I am aware that if I reveal anything related to criminal activity and/or something that is harmful to self or other, the researcher will have to share that information with the appropriate authorities]. Yes/No
- 6. I understand that my contribution in interview will be used in the researcher's thesis, other academic publications and conference presentations. Yes/No

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Phone Screening Interview

Q. Are you the parent or caretaker of an adult over the age of 18 with a past diagnosis of ASD without ID or are you a self-referral for the intervention program?

Q. How did you find out about the study?

The interviewer will then explain a brief overview of the intervention using the following script.

Before we go any further let me tell you a little more about the program. CBSCTI-ASD is a 6- week intervention that uses the principles of cognitive behavioural therapy to help improve social skills in adults with ASD. The intervention requires meeting twice a week and will involve an individual session and a group session. The individual CBT sessions are aimed at improving social deficits that are specific to each individual. Weekly individual sessions will last approximately 30 minutes and the parents/caretakers is required to attend the final 10 minutes. The group sessions are two hours long and will focus on social communication. The sessions are on the same day and time each week and will be held at the University of Salford. The next intake will be on _____ and will end on _____. Regular attendance is a requirement for acceptance onto the program.

Q. Is this something you (or the young adult in question) would be interested in?

If no then thank them for their interest and end the interview.

If yes, confirm the following information

- The participants first and surname
- The participants age and date of birth

Q. Do you have a parent or caretaker that can regularly attend the end of the individual session them.

Q. Do you foresee any difficulty attending all of the allotted sessions between ____ and ____.

Check list: Can I just confirm that (use young adult's name) meet the criteria for the study.

- Are you over 18 years of age, proficient in the English language and have a past ASD diagnosis?
- Have you been diagnosis with organic brain disease?
- Do you have severe speech or communication issues?
- Were you diagnosed as lower functioning ASD (IQ below 80)?
- Do you have a severe physical disability or a comorbid mental disability which would prevent participation?
- Do you have visual or hearing impairments?
- Do you have a comorbid mental illness such as schizophrenia, bipolar or depressive disorder, an anxiety disorder?

Q. Who will be regularly attending the program with you and what is there relationship?

It seems at this point you are appropriate for the intervention and we would like to invite you to an intake interview. If all criteria is met upon completion of the interview you will be allocated to the next treatment intake which will commence on _____

Q. Do you have any questions at this point in time?

Great, an intake interview appointment date will be sent to you in the next few days. Once you receive the packet please return promptly as enrolment is limited. May I please request a current e-mail address to send the information packet over to you?

Recruitment Poster



Participants Needed!



University of
Salford
MANCHESTER

Study Title: The Development and Feasibility trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

We are seeking to recruit young adults aged 18-25 that are on the high functioning autism spectrum to pilot a new six week group cognitive behavioural social competence intervention. If you have a past diagnosis of High Functioning Autism Spectrum Disorder, Asperger's Disorder, Childhood Disintegrative Disorder or Pervasive Developmental Disorder-Not Otherwise Specified, then you may be interested in participating in our study

In this study we aim to:

- Investigate if the intervention is acceptable for high functioning adults that are on the autism spectrum.
- Investigate if the intervention has an effect on brain function.
- Investigate the relationship between brain functioning and ASD symptoms.
- Investigate if the intervention was effective at improving social skills.

For further information please contact

Lead Researcher David Tate D.Tate@edu.Salford.ac.uk or Researcher Supervisors Dr Clare Allely c.s.allely@salford.ac.uk and Dr Linda Dubrow-Marshall L.Dubrow-Marshall@salford.ac.uk

Appendix G. Guidance Protocol for Communication

Guidance protocol for communication with an ASD individual

Considerations for the researcher gaining consent:

- The researcher gaining consent should talk calmly in a natural voice, keeping language as simple and clear as possible. Use only necessary words.
- Be aware of your own facial expressions. Try not to exaggerate your facial expression or tone of voice as this can be misinterpreted.
- Keep gestures to a minimum, as they may be a distraction. If gestures are necessary, accompany them with unambiguous statements or questions that clarify their meaning.
- Use the individual’s name at the start of each question so that they know they are being addressed.
- Cue the individual in to the language you are about to use, preparing them for the instructions or questions that might follow. For example, “John, I am going to ask you a question.”
- Give time for the person to respond, do not assume that silence means there is no answer forthcoming.
- People with autism have a very literal understanding of language. Avoid using non-literal language such as irony or sarcasm.
- Back up questions with the use of visual aids or supports. People with autism often understand visual information better than words. For example show images in the information sheet while reading the instructions.

Response considerations

- Allow the individual extra thinking time to respond to each question.
- People with autism may have better expressive language skills than receptive language skills.
- Don’t expect the individual to necessarily make eye contact during the interview.
- Remember that people with autism may speak in a monotone, and/or use very stilted language.

Appendix H. Assessment measures sample

The Adult Autism Spectrum Quotient (AQ-50)

The Adult Autism Spectrum Quotient (AQ)

Ages 16+

SPECIMEN, FOR RESEARCH USE ONLY.

For full details, please see:

S. Baron-Cohen, S. Wheelwright, R. Skinner, J. Martin and E. Clubley, (2001)
[The Autism Spectrum Quotient \(AQ\) : Evidence from Asperger Syndrome/High Functioning Autism, Males and Females, Scientists and Mathematicians](#)
 Journal of Autism and Developmental Disorders 31:5-17

Name:..... Sex:.....

Date of birth:..... Today's Date:.....

How to fill out the questionnaire

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

Examples

E1. I am willing to take risks.	definitely agree	slightly agree	slightly disagree	definitely disagree
E2. I like playing board games.	definitely agree	slightly agree	slightly disagree	definitely disagree
E3. I find learning to play musical instruments easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
E4. I am fascinated by other cultures.	definitely agree	slightly agree	slightly disagree	definitely disagree

Client Satisfaction Questionnaire (CSQ-8)

CLIENT SATISFACTION QUESTIONNAIRE (CSQ-8)

- Purpose:** To assess client satisfaction with treatment.
- Scoring:** The CSQ-8 is easily scored by summing the individual item scores to produce a range of 8 to 32, with high scores indicating greater satisfaction.
- Description:** The CSQ-8 is an 8-item, easily scored and administered measurement that is designed to measure client satisfaction with services. The items for the CSQ-8 were selected on the basis of ratings by mental health professionals of a number of items that could be related to client satisfaction and by subsequent factor analysis. The CSQ-8 is unidimensional, yielding a homogeneous estimate of general satisfaction with services.
- The CSQ-8 has been extensively studied, and while it is not necessarily a measure of a client's perceptions of gain from treatment, or outcome, it does elicit the client's perspective on the value of services received. The CSQ-8 seems to operate about the same across all ethnic groups. This also is true for a version of the CSQ-8 that was translated into Spanish.
- Primary Reference:** Larsen, D.L., Attkisson, C.C., Hargreaves, W.A., and Nguyen, T.D. (1979). Assessment of client/patient satisfaction: Development of a general scale, *Evaluation and Program Planning*, 2, 197-207. Instrument reproduced with permission of C. Clifford Attkisson.
- Availability:** Dr. C. Clifford Attkisson, Professor of Medical Psychology, Department of Psychiatry, Box 33-c, University of California, San Francisco, CA 94143.

CLIENT SATISFACTION QUESTIONNAIRE

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.* We also welcome your comments and suggestions. Thank you very much; we really appreciate your help.

Circle your answer:

1. How would you rate the quality of service you have received?

4	3	2	1
Excellent	Good	Fair	Poor

2. Did you get the kind of service you wanted?

1	2	3	4
No, definitely	No, not really	Yes, generally	Yes, definitely

3. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met

4. If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

5. How satisfied are you with the amount of help you have received?

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied

Interaction and Rating Scale Advanced (IRSA)

International community care and lifespan development: Empowerment science, University of Tsukuba

The Manual of Interaction Rating Scale Advanced

Outline

The Interaction Rating Scale Advanced (IRSA) is an international scale used to measure the various aspects of social ability easily and accurately. The IRSA enables us to measure interactions between persons easily in everyday settings, measure outcomes of the social skill, and evaluate the quality of the relationships based on their behaviors. In addition, it can be used as a tool for an early detection of anxiety eliciting situation and an early support for professionals at their place of practice.

Implementation method

Subjects: over 15 years old

Setting: It is desirable to set the implementation challenges where interactions are likely to occur, such as games (ex. sticky) and daily conversation.

Observation time: Approximately 1-5 minutes

1) Utters or vocalizes toward a partner while watching the task tools

Vocalizing, laughing, making a noise, chatting with the partner, etc. This item does not include the following situations: the subject looks at the hand, looks down clearly, or does not see the materials.

2) Expresses his/her own thoughts to the partner regardless of positive or negative remarks

The subject expresses his/her own thoughts through clear words to a partner. He/she expresses either positive thoughts about oneself and the partner (e.g. suggestion for a partner, own strategy) or negative thoughts (ex. doubting a partner, denial).

3) Attempts to elicit help or consolation from the partner using words

The subject attempts to elicit help or consolation proactively in a situation, which needs feeling control such as when a task does not go well or when the subject is opposed to the partner.

* The item includes asking a partner, e.g., "How should I ...?"

* Check × when the subject cannot control feeling, for example without expression or irritation obviously (none)

* If there are no situations which needs feeling control, evaluate positive (more than twice).

* If there are no situations which needs help or consolation (more than twice).

4) Shows self-assertiveness to the partner through a gesture

Evaluate once when the subject does some kind of self-assertion for a partner in intentional movement such as the movement of a hand, the face, or the head.

5) Casts the partner a glance to seek sympathy

The subject looks at the partner and attempts to convey his/her feeling. Distinguish intentional one from accidental one.

6) Shows the change of his/her feelings through facial expressions

Identify an expression that indicates the changes in his/her feelings, for example smiles when the task goes well, expression of surprise, and expression of regret.

* the item does not include if a change is not seen.

Multidimensional Social Competence Scale (MSCS)

I understand that by completing this questionnaire I am giving consent to take part in research

MSCS- Parent Report Jodi Yager, PhD and Grace Iarocci, PhD Pg. 1 of 4

Child's/ Adolescent's Name (First, Middle, Last): _____

Child's Birth Date (Month, Day, Year): _____ Sex: Male Female Other

List any developmental disorders/ learning disabilities that you are aware of:

Your Name (First, Middle, Last): _____

Relationship to Child/ Adolescent: Mother Father Other _____

Today's Date (Month, Day, Year): _____

Instructions: For each item, circle the number that best describes your child's/ adolescent's behaviour over the past six months.

- 1 = Not True or Almost Never True
- 2 = Rarely True
- 3 = Sometimes True
- 4 = Often True
- 5 = Very True or Almost Always True

Many of the items may seem similar to one another, but your response on each one is very important. If you are unsure of an item, please put your best estimate.

1 = NOT TRUE OR ALMOST NEVER TRUE	2 = RARELY TRUE	3 = SOMETIMES TRUE	4 = OFTEN TRUE	5 = VERY TRUE OR ALMOST ALWAYS TRUE
-----------------------------------	-----------------	--------------------	----------------	-------------------------------------

1. Prefers to spend time alone (e.g., may seem most content when left on his/her own).	1 2 3 4 5	9. Is sensitive to the feelings and concerns of others.	1 2 3 4 5
2. Enjoys meeting new people.	1 2 3 4 5	10. Initiates friendly social "chit-chat" with people (e.g., asks about what's new with other person, talks about the weather or events). These are casual conversations that often have no specific purpose.	1 2 3 4 5
3. Recognizes unfriendly actions. For example, he/she knows when someone is making fun of him/her in a mean-spirited way. Or, he/she recognizes when a peer is pressuring him/her to do something he/she shouldn't or doesn't want to do.	1 2 3 4 5	11. Appears visibly upset when he/she sees people suffering (in real life or on tv/film).	1 2 3 4 5
4. Can disagree with people without fighting or arguing.	1 2 3 4 5	12. Has trouble joining conversations appropriately (e.g., he/she may interrupt or "butt in" without waiting for a good time to join in; or, he/she may start talking about a topic of interest to him/her regardless of the ongoing conversation).	1 2 3 4 5
5. Apologizes after hurting someone (without being prompted or told to).	1 2 3 4 5	13. Misreads social cues.	1 2 3 4 5
6. Talks "over" people in conversations (e.g., interrupts a lot, doesn't wait for others to finish speaking).	1 2 3 4 5	14. Stays in the "background" in group social situations (e.g., keeps to him/herself, may not be noticed).	1 2 3 4 5
7. Shifts conversations to his/her favourite topic or interest.	1 2 3 4 5		
8. Talks about the same things over and over ("gets stuck" on certain topics).	1 2 3 4 5		

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Appendix I. Case Note Templates for CBSCTI-ASD

Individual Session Case Note Template

Participant Name(s):

Date:

Session #:

ATTENDANCE: YES / NO

If no please provide details of reason the session was not attended:

Was the session rescheduled within the same week: Yes/No

Date of rescheduled session

DD

MM

YEAR

UPDATE AND PROGRESS:

SIGNIFICANT OBSERVATIONS:

REVIEW AND RESPONSE OF
HOMEWORK:

PREP FOR THE SESSION:

--	--

SESSION NOTES: (PLEASE PROVIDE DETAILS OF THE MAIN TOPIC AND GOALS DISCUSSED)

Next Actions and
Homework:

Supervisors consult needed?
YES / NO

If "yes" please provide brief
description:

Counsellor name: _____ Counsellor Signature:

Group Session Case Note Templet

Group Therapy Case Notes

Participant: _____ Session #: _____ Date:

AGENDA: GROUP TOPICS

GROUP BEHAVIOR RATINGS

WEEKLY EVALUATION

INDIVIDUAL CONTRIBUTIONS THIS SESSION

Therapist _____

Attendance: Yes/No

Co-therapist _____

<p>Reason for absence: _____</p> <p>_____</p> <p>_____</p> <p>_____</p>

Appendix J. Examples of interview schedules and transcripts with codes

Intervention Group Interview Schedule

Post intervention participants interview schedule

1. *What did you like about the intervention?*
2. *What did you not like about the intervention?*
3. *Which session did you find the most helpful?*

Prompt: *What in particular did you find helpful.*

4. *Which session did you find the least helpful?*

Prompt: *What in particular did you find unhelpful?*

5. *How do you feel your social skills have improved since the intervention?*

Probe: *What kind of impact do you think these improvements have had on your life?*

6. *Can you tell me about any social challenges you have had in the past six months?*

Probe: *How did you deal with these challenges?*

7. *How would you have handle these kinds of challenges in the past before the intervention?*

8. *Where there any skills you learned from the intervention which may have helped you achieve your goals over the past six months?*

Probe: *Was this what you expected?*

Survey questions

1. Over the past 6 months have you sought or received social skills training apart from the intervention we provided?
2. Over the past 6 months have you increased the amount of social interactions with others? Yes/No
3. Do you feel that your social interactions with others has improved?
Yes/No
4. Would you recommend the intervention to others?
Yes/No

Intervention Group Interview Transcripts with Codes

Respondent: Participant 4	ID reference Clare
Interviewer: David	Date: 23/05/2018
Length of interview: 19 minutes 07 seconds	Codes
Transcripts	Refined Codes
I: What did you like about the intervention?	
R: I made friends that I would not have made otherwise.	Liked making friends
I: Making friend was a definitely a good thing. What did you not like about the intervention?	
R: The type of counselling that we had while doing it, I didn't like that.	Didn't like the individual CBT sessions
I: Ok, can you tell me a little more about that?	
R: I didn't like it because the type of counselling it was, well it was the face everything directly, that sort of stuff. I had to go stand outside my old school which wasn't nice. I do feel that even though I did get better at doing it over time and I did do it a lot, it is not like the reason for not wanting to do it disappeared. So now that I have stopped doing it daily, the anxiety is back every time we pass the school. So, nothing has changed like that, and I still try to dodge teenagers, I still don't like touching things, so yeah, it just wasn't the type of counselling that worked on me.	Didn't like the counselling approach Anxiety got better when in therapy doing exposure tasks Anxiety returned after therapy ended Type of counselling did not have long-term benefits Deeper reason for anxiety did not change during therapy
I: so let me just make sure I understand, while you were doing the CBT sessions the challenges did get easier but when the sessions stopped, the root of the problem was still there. Is that correct?	
R: Yeah, they got easier but not in the sense of my mental state, it's just that I am good at pushing myself to do something.	Mental state did not improve
I: I understand thanks for clarifying.	
I: I know it has been a long time and you struggle with your memory, but can you remember which session you found the most helpful?	
R: I don't know, I always liked the groups sessions the most. It was easier sitting and talking in the group setting rather than doing activities that were not natural to us. I think it was always easier in the group setting too because it wasn't always pressured to keep the conversation going by yourself because there is only two of you, instead there are a bunch of you, and you can take your go when you were ready to talk, or you have something important to say.	Liked group session most Preferred the group discussion over the group activities Like that the pressure to talk was shared by the group
I: Was there something about the group that made you feel more comfortable?	
R: Yeah, they were all autistic which made it easier.	Being a group with other autistic people was helpful
I: Good to know, thank you.	
I: Were there any sessions you did not find very helpful?	
R: I don't remember any of them, erm, I mean well the only one I really remember was the one where we said how we appreciate.	
I: I believe you are talking about is the session on making a successful request.	
R: I couldn't do it the entire session and I would have said it didn't help me, but it did. For example, when you sent me that email the other day asking if we could move it, I went to write a response and when I was writing it at the end I thought about writing "I really appreciate it" like you taught us.	Making a polite requests group session was helpful Still uses the strategy for making a request
I: That's fantastic, you should have written it. Can I ask, how do you feel your social skills have improved since the intervention?	
R: I still don't do talking to people in the shops unless they speak to me first.	Still avoids social conversation unless prompted
I: What about friendship are you socialising much?	
R: Well I don't have that many people like that in my life. I mean, well, I have 40 odd people in my Facebook group, but I have always been good at talking to them because its just an open group and I always feel safe. So, friendship wise not much has changed but dating wise, um I never really understood the whole process of it but I am getting better at it somehow. I can't say it is because of the intervention but it has been since the intervention.	Not many close people in life Lots of Facebook friends Facebook group is safe place to socialise Started dating since the intervention Struggles to understand dating behaviour
I: So, you started dating since the intervention?	

<i>R: I just was not comfortable, yeah but it was a learning curve, an experience, so you can find the right person, who is not going to make you feel uncomfortable.</i>	<i>Learned from the dating experience</i>
<i>I: What a wonderful way of looking at it. Thank you for sharing that experience with me.</i>	
<i>I: Where there any skills you learned from the intervention which may have helped you achieve your goals over the past six months?</i>	
<i>R: I would say that in some way it did help, I go to a lot of CHAPS events now, obviously because I am autistic and they do lots of things and I feel comfortable with the main person that runs a lot of the stuff but I been even going to things that she is not there and I am getting better at walking in and getting comfortable with the new people a lot quicker.</i>	<i>Increased social interaction since the intervention</i> <i>Now find it easier to get comfortable with new people</i>
<i>I: So the experience of being a part of the intervention has had an impact on your confidence joining other groups?</i>	
<i>R: Yes, yeah</i>	
<i>I: That's wonderful. It's nice to know you getting out there</i>	
<i>R: And being social, Monday I am going to crafting club.</i>	<i>Increased social activities</i>
<i>I: Fantastic.</i>	
<i>I: Was this what you expecting after the intervention?</i>	
<i>R: I don't know what I was expecting, I don't look that far into the future.</i>	
<i>I: Ok that fair enough. Now I am just going to ask you a few yes or no questions.</i>	

Parents Interview Schedule

Introduction

Thank you for agreeing to take part in today's interview. I just want to remind you that everything you say today will be kept confidential and all responses reported will be anonymised. If at anytime you feel you need stop the interview just let me know and we can take a break. If you feel ready, we can now begin the interview.

Part 1

1. Can you tell me what you know about your family medical history e.g. are there others in the family with a diagnosis of autism or a related medical/developmental condition?
 - a. **Prompt/probe:** Can you recall anyone in the family without formal diagnosis but struggled with social skills during their life?
2. What are some of the challenges of being a relative/parent of an autistic young adult?
 - a. **Prompt/probe:** Can you tell me about how you handled these challenges?
3. How does your experience currently compare to when X was a child?
 - a. **Prompt/probe:** What advice would you give to a parent with a child currently approaching the transitioning into adulthood i.e. any lessons learned from your own experience?
4. Can you describe any positive aspects of being a parent/caregiver of an autistic young adult?
 - a. **Prompt/probe:** Can you describe how these positive aspects impact on your role as a parent/caregiver?
5. What are your biggest fears/worries about X's future?
 - a. **Prompt/probe:** In hindsight, is there any recommendations you would give to others to help reduce such fears/worries?
6. Can you tell me about your experience of the diagnosis procedure?
 - a. **Prompt/probe:** Did you feel supported at this time e.g. did you have questions which weren't answered, or did you feel adequately informed?
7. What were the kinds of support or treatments offered after diagnosis?
 - a. **Prompt/probe:** Did you feel the support offered was helpful?
8. How does the support or treatment offered now compare to when X was younger?
 - a. **Prompt/probe:** Do you feel the support offered since X turned 18 has been adequate?
9. Can you describe what kind of interventions/treatment your child has received since entering adulthood?
 - a. **Prompt/probe:** Can you tell me about anything in particular that was helpful or unhelpful from treatment?
10. In your opinion, what skills/topics do you think would be most important to address in a social skills intervention for young adults with autism?
 - a. **Prompt/probe:** e.g. conversation skills, dating behaviour, employment skills, independent living skills, internet/electronic communication skills, making friends.
11. Can you tell me why you feel these topics are important to address?
 - a. **Prompt/probe:** finding a partner, living on their own, finding a job, socialisation, social support

Part 2- Only for parents which took part in the intervention

1. Can you describe your experience of being a part of the intervention?
 - a. **Prompt/probe:** Did you find it helpful to be invited into the individual CBT session?
2. What role do you feel you had in the intervention?

Prompt/probe: active, passive, supportive, no role at all? Can you expand with examples?

3. What do you feel was the most beneficial aspect of the intervention for XX?
 - a. **Prompt/probe:** how did this impact upon you and/or family life?
4. During the intervention did you notice any changes in XX Behaviour.
 - a. **Prompt/probe:** communication, mood, understanding others, motivation to socialize
5. Since the end of the intervention 12 month ago, has there been any noticeable changes in XX behaviour
 - a. **Prompt/probe:** improvements, regression, stayed the same
6. How do you think the intervention could have been improved?
 - a. **Prompt/probe:** more parental support, longer duration for the skills training, lower intensity (such as meeting only once a week), different treatment plan (such as just a group or individual therapy sessions)

End of interview

You have now completed the interview. I would like to thank you again for participating in the interviews and if you have any questions at this point I will happily attempt to answer them.

Parent Interview Transcript with Codes

Respondent: Participant 4	ID reference P4
Interviewer: David	
Length of interview: 42 minutes 28 seconds	Codes
<i>I: Thank you for agreeing to take part in today's interview. I just want to remind you that everything you say today will be kept confidential and all responses reported will be anonymised. If at any time you feel you need stop the interview just let me know and we can take a break. If you feel ready, we can now begin the interview.</i>	
<i>R: Yep fine</i>	
<i>I: Can you tell me what you know about your family medical history e.g. are their others in the family with a diagnosis of autism or a related medical/developmental condition?</i>	
<i>R: Ok so... me and my husband are cousins, but I was adopted so I have his family medical history and a little of myself as well. Ok well Madison my daughter was diagnosed, and we are in the process of getting Abby a diagnosis. When I think back to when Abby was a child, she was very similar but more detail, in fact I could see more autism in Abby than I could in Madison, if you know what I mean.</i>	Family history on both side
<i>I: Anyone from further back?</i>	
<i>R: Well if I go backwards, my mother-in-law told me when my husband was little he would scream with noises, he didn't have any social life, he didn't like other people and at a party he would sit in a corner and wouldn't join in. And his behaviour is very much Asperger's</i>	Husband and girls father is undiagnosed but has autistic traits
<i>I: But he has never had a formal diagnosis is that correct?</i>	
<i>R: He has never had a diagnosis but has every possible symptom you can think of, even now he doesn't have a social group.</i>	
<i>I: Was there anyone else in the family that fit that description?</i>	
<i>R: Yes, I can go back two generations here, my mother-in-laws brother and sister, who were twins, both showed signs of Aspergers as well.</i>	
<i>I: Definitely sound like there is a link.</i>	
<i>R: Oh yeah, I can go back one more generation to my grandmother brother who also as atypical Asperger's. I remember you could see it in him and I remember thinking, this is not normal.</i>	Autism traits link back to three generations
<i>I: oh really.</i>	
<i>R: Now in my own genetic family now, um I know she is diagnosed, she a few years older than Madison and I have been told by the family she has been diagnosed with Asperger's/autism.</i>	Cousin with autism diagnosis
<i>I: So, it sounds like the link is definitely on both side of the family.</i>	
<i>R: Yes, definitely on both sides, but it is more pronounced on my husband's side.</i>	Link more pronounced on husbands' side of family

<i>I: Ok thanks, moving on a little bit, can I ask you what are some of the challenges of being a relative/parent of an autistic young adult?</i>	
<i>R: Well where to begin, it is extremely hard work. It gets really loud and trying to get them to understand to be a little bit quieter, she was not just loud in her speech but also in her language and manner, so it was difficult controlling that. It can be very frustrating.</i>	<i>Parents have to work really hard</i> <i>It can get loud in language and manners</i> <i>Feeling frustrated</i>
<i>I: I can imagine</i>	
<i>R: but it can also be very frustrating to them, I know this. There are a lot of time when I simply want to run away because it is just such hard work.</i>	<i>Child can also get very frustrated</i> <i>Mother just wants to run away because it is so hard</i>
<i>I: Oh really.</i>	
<i>R: Honestly, there are times when I Just want to run away.</i>	
<i>I: How do you handle those times?</i>	
<i>R: For me, walk away, yoga. Just get out, the thing is Clare will just follow me about. Even when I go to my room and if I close the door, she will just open it. And Abby was the same, although she is not living at home anymore. But even now, when Abby gets upset, she cries like a baby. You know like when a child cries and they hold their breath?</i>	<i>Handle stress by walking and doing yoga</i> <i>Hard to get alone time as a parent</i> <i>Adult child of 31 years can still get up set and cry like a baby and behave like a child</i>
<i>I: Yes, I do.</i>	
<i>R: Yeah, she does that.</i>	
<i>I: And how old is Abby now?</i>	
<i>R: She is 31.</i>	
<i>I: Well this lead into the next question nicely because I want to ask, how does your experience currently compare to when your girls were a children?</i>	
<i>R: Well Abby didn't talk until she was nearly five to be honest. She did grunt language and pointing. And that is how we communicated for most of her preschool, basic language. The word "Mama" could range from me, to the nanny we had at the time, or to my mother-in-law, my next-door neighbour who was female. So, anyone female was mamma and dada was anyone male.</i>	<i>Abby didn't talk until five year and most communication was non verbal</i>
<i>I: So that is a big difference, being a child that was basically non-verbal to a full verbal adult.</i>	<i>Big difference between childhood and adulthood for Abby was communication ability</i>
<i>R: Yes, "it" could mean tea, water, food, you name it. It was very basic, she had about 12 words.</i>	
<i>I: What age did her language really develop?</i>	
<i>R: She was about five, yes it was when she started school. It was about four months but like Clare she had problems with eating. She had problem keeping anything down. Anything she ate she chocked on. At one point she was on cystic vibriosis medications because they thought there was a blockage. So she missed school for a month and she went back (unclear....) you see she has speech therapy from the age of three. She had two sessions a week, one at the hospital and one at special needs nursery. And even then we still didn't get language until she was five.</i>	<i>Both girls have issues with eating</i> <i>With speech therapy language developed at five for Abby</i>
<i>I: wow, a lot of work</i>	
<i>R: Yeah but Clare was a chatter box, the complete opposite. Everything was a demand. Both the girls were always attached to me, everywhere I went they had to go, if I went to the toilet, or had a bath, they had to be with me. I couldn't do anything by myself.</i>	<i>Clare was the opposite and spoke a lot</i> <i>Both girls were very attached</i>

	<i>Mother felt she could not do anything alone</i>
<i>I: I imagine that was a large strain on you.</i>	
<i>R: It was with Abby but by the time Clare came it was like, I can deal with that, I can deal with that, because I was used to it.</i>	<i>Mother felt more confident with the younger child because of her past experiences</i>
<i>I: So you were used to it because you had already faced the challenge with Abby?</i>	
<i>R: Yes that right, I mean Abby wouldn't sleep for more than two hours before needing a feed and Madison was the same, (unclear statement...), they were both long term breast feeders and just extremely demanding. Speech was a problem, Clare had a hearing problem, she had a cyst behind her ear when I was pregnant, and we think it affected her hearing.</i>	<i>Both children struggled with sleep One child had a hearing problem</i>
<i>I: Oh, right.</i>	
<i>R: Yes, so she couldn't hear properly till she was about three or four.</i>	
<i>I: I see, so do you think there could have been some issue with communication because of this?</i>	
<i>R: Well we decided that this is why she is loud.</i>	
<i>I: I guess it was difficult at a young age to determine if it was due to hearing or a symptom of autism.</i>	<i>Difficult to know if symptoms were due to hearing or autism</i>
<i>R: Yeah true, and while it was different for Abby who was given a statement at three which said she had verbal learning delays and it was never change which is why we are fighting it now.</i>	<i>Fighting to get statement up dated in adulthood from verbal learning delays to autism</i>
<i>I: So you would like a more accurate statement now she is an adult?</i>	
<i>R: Well she does still have a language problem, she muddles up words, so she will use similar sounding word in places which she thinks are correct but they are not. She still does that to this day.</i>	<i>Abby still has language problems</i>
<i>I: That is very interesting, thanks for sharing. I have a more positive question for you coming up if that OK</i>	
<i>R: Yeah sure.</i>	
<i>I: So, can you describe any positive aspects of being a parent/caregiver of an autistic young adult?</i>	
<i>R: Oh god yeah, Clares artistic side is amazing, her writing (not clear...), and they are both emotionally attached. So even though they feel strong emotions, they also have a lot more to give.</i>	<i>Both children have a lot of positive emotions to share and Clare is very artistic</i>
<i>I: And how does that feel and impact on you as a parent, you know, your role as a parent?</i>	
<i>R: It can make things easier sometimes, take Clare, when she is flying off the handle and is on her high, when she comes down, I know she is going to be nice. She will apologise now which she never did before. She will apologise, she does realise what she has done. She is very much like, "I am sorry Mum, I love you Mum." and that's a great response when you have had someone furious at you for no particular reason. It make things, worthwhile.</i>	<i>Can be easier when you understand and can expect child's behaviour Clare is more polite in adulthood</i>
<i>I: So when she was younger this was something she struggled with but as she has become an adults is more understanding?</i>	
<i>R: Yes, social ques are still difficult you know, and in Clare's case it always been one of the most difficult things for her. But they are both just very caring.</i>	<i>Both adult children are very caring Social cue are still a problem</i>
<i>I: That definitely comes across when you meet them. So for my next questions I want to know what are your biggest fears/worries about their future?</i>	
<i>R: Oh god loads. Will they be by themselves? Will they be able to take care of themselves? Are they going to be financially OK? What happens if there is nobody around to support them? Plus, my other two children, my god they are going to have to deal with these issues, their youngest and eldest sisters you know. There is just so much.</i>	<i>A lot of fears and worries about their future Worried about their financial future</i>

	<p>Concerns about who will support them later if life</p> <p>Worried about the burden on the older children</p>
I: I can only imagine.	
R: Yeah, its every little thing. You go through life assuming everything is going to be OK, you know, your going to have a child and its going to grow up and meet someone and get married and a family. But I am not sure that going to ever happen.	<p>Go through life assuming everything will be alright.</p> <p>Worried that daughters may never get married and have families of own</p>
I: As a parent myself I would have the same concerns.	
R: Yeah, I mean its every little thing, like what if they lose there job, will some else give them a chance, (unclear...), are they going to understand, so often you come across people who are like, oh it's a mental health disorder and it's not.	<p>Worried about employment</p> <p>Concerned about other people's ignorance of autism</p>
I: I know its not, but others do commonly get confused. I come across that issue all the time.	
R: Exactly, and in the end of the day when I am not around, what are they going to put Clare into a mental institution because they still have the hospitals, you hear about them being put in because they can't control their temper. And with Abby you have to make sure she has understood what you have said. You have to say, "did you understand that Abby?" But they look like anyone else on the street so unless you know her, it's a problem.	<p>Concerns of welfare after parents death</p> <p>Worried about being institutionalised after parent's death</p> <p>Concerned about other people's ignorance of autism</p> <p>The problem is they look normal</p>
I: I agree, that is a difficulty with autism.	
R: Yeah, when you say high functioning people look at them as if there is nothing wrong with them and that's where the misunderstanding comes from.	Worried that people think there is nothing wrong because they are high functioning
I: Based on your experience of dealing with your worries, do you have any advice for a mother or parent with an autistic child?	
R: Oh, every mother I meet with an autistic child are mainly in their teenage years. We have CHAPS here, and CHAPS supports autistic's parents, children, adults, the whole lot. Their lovely CHAPS, but one thing I notice is they don't want us to say, "well I have this problem". So there are a couple of Mums I have been talking too and one has just been diagnosed with autism herself.	Mother talks mostly to other parents with autistic teens
I: Oh OK.	
R: Yes she just turn 30 this week and she was only just diagnosed two months ago. When I talk to them, they ask questions like "how do I deal with this?", or "I don't know what I am doing." I just say to them that they are not different to any other mother.	Important to let other parents know they are the same as other parents
I: Sounds comforting.	
R: I tell them that I am a mother to a 31 and 22 year old and each one is different and I also have three other children and you will treat them all different because they all have different problems. Because they are individuals. So this is what a say to these mothers "If you need the support, there are people out there, but your have to find those people and your have to work with them.	<p>All children are individuals and need to be treated differently</p> <p>Advise other parents that there is support but you have to find it yourself and work with them.</p>
I: Yeah that is good advice.	
R: Now it is a struggle and a fight but you have to go out and find the people that can help you. Now when they are adults, well if they are diagnosed as children, there is a bit more support there. It worse if diagnosed as an adult.	<p>It is a struggle and fight to get help</p> <p>Worse for people diagnosed in adulthood</p> <p>More support for children</p>

I: This leads on nicely to my next question. Can you tell me about your experience of the diagnosis procedure?	
R: Absolute nightmare.	
I: Oh yeah,	
R: Yeah, the only reason Clare got diagnosed was because they sent her to CAMHS because as I said, they decided she had a mental disorder. OK, the woman she was seeing, she saw for 10 weeks. It started in winter so Clare had her winter clothes on because it was cold and when it ended she was wearing brighter clothes because it was summer. And at the end of the session this woman came out and said "well that's the end of it, you can go pick her up." David ask, "did Clare discuss the eating problem she has got?" and they responded, "what eating problems?".	<p>Negative experience of diagnosis procedure</p> <p>Only received a ASD diagnosis because originally referred daughter for a mental health disorder</p> <p>CAMHS specialist did not pick up in daughters co-morbid eating disorder</p>
I: Oh wow.	
R: So we made Clare make a complaint, That ended with us seeing the head of services who turned around and said, we think you may have autism. So we went to our doctor to make a request and they said "well you would have to pay for it".	<p>Parents made a complaint because of missed eating disorder</p> <p>Complaint led to further assessment which suggested autism symptoms</p> <p>GP suggested parent would need to pay for private diagnosis</p>
I: Really, you have to pay for it on the NHS?	
R: But I happen to be told by the head of services at mental health, told me the name of the services, whether it be NHS or private. I don't know but I call them up and said "look my daughter needs seeing, how much is it?" An the lady said, "don't be silly, you don't pay for it." She said it was funded by your doctor and you use this phrase. So I went to my doctor and used the phrase that I was told, I think its patients charter or something, I might be wrong but I have that in my head for some reason. So I said I want a NHS funded diagnosis please and luckily it came through very quickly.	<p>GP provided incorrect advice as NHS did fund diagnosis</p> <p>Parent had to go back to GP and fight their corner</p> <p>Once GP was correctly informed the assessment came through quickly</p>
I: It sound like you really had to fight and were lucky to figure that out. If you hadn't you would have been out a lot of money wouldn't you?	
R: Yeah basically, I paid privately for Abby's assessment and that wasn't even a formal diagnosis of autism, it just said she had learning difficulties. But that did trigger the local authority to do one for themselves which is how she got her statement, um so it was a totally different situation which is now why we are fighting to get a autism diagnosis for Abby. So when we went to AXIA, David was with me and we went in together but Abby was sitting outside. Interestingly throughout the process if diagnosis they were asking her questions and David would say, "Yeah, I agree with that", and "well, I would agree".	<p>As a child parents paid for private assessment which triggered local authority to provide a statement</p> <p>Still fighting to get Abby a statement for autism at age 31</p> <p>Recently went private again to get a statement for Abby</p>
I: So you could see a similarity between your husband and daughters behaviour?	
R: Well by the end of the session they said she does have autism and your husband may too.	Abby was given a diagnosis, but parents are still awaiting an official statement
I: Just to be Clear AXIA are private specialist in autism is that correct?	
R: Yes, they do autism diagnosis and counselling as well and other various supports. They are private so they do cost unless you get funding and that's the problem	
I: Of course, yes.	
R: Now we started the diagnosis for Abby in January and we are still waiting.	
I: So that's Abby but Clare was diagnosed, so what were the kinds of support or treatments offered after diagnosis?	
R: Well there was a follow up appointment following diagnosis and they gave us various places to go for support such as social services. So they told	Information was provided with details of some further support

<i>me to ask for a social care report, they told me about PIP, they told me about ESA, you know all those thing but the social care report was horrendous.</i>	<i>Support was limited</i> <i>Social care report was a negative experience.</i>
<i>I: Did you feel the supported during this time help was being offered?</i>	
<i>R: Yes in that they gave me information that I could walk away and say I need to do this this and this. I also went to my doctor after nearly having a breakdown and he told me, well you can't work and take care of Clare and do everything else your doing. I was put on the list for counselling which I am now 8 weeks into and they told me this was not going to just be 8 weeks but it will be long term.</i>	<i>Provided information that the parent could action themselves</i> <i>Mother visited doctor due to psychological breakdown</i> <i>Difficulty working and taking care of special needs of children</i> <i>Mother receives counselling to cope</i> <i>Mother was taking on too much responsibility</i>
<i>I: It nice to hear they are offering you support as well and Clare.</i>	
<i>R: Well this support is through my Doctor and Clare's support is through CHAPS but when I had this breakdown my doctor said to me, you need to join CHAPS and register as a Carer. CHAPS is Cheshire Autism Practical Support, it's a volunteer organisation.</i>	<i>Support for Clare and parent are from different sources</i>
<i>I: I have heard of the charity.</i>	
<i>R: Yeah they have been amazing, they have a social group for Clare and offer parent support, they have meeting once a month for me, they do yoga they do craft club every two weeks.</i>	<i>Found CHAPS charity to be amazing support</i>
<i>I: That really sounds great.</i>	
<i>R: Yes she is actually making friends in this group.</i>	<i>Support group has been good for making friends for Madison</i>
<i>I: Do you feel lucky to have found this support group?</i>	
<i>R: God yes, they are amazing, I have been telling others about them</i>	<i>Feels lucky to have this particular charity supporting her family</i> <i>Often tells other local parents about the support group</i>
<i>I: So is this a local charity or is this kind of support offered by them nationwide.</i>	
<i>R: No there are pockets support by places like this but this group was actually started by an "Aspi" Mum.</i>	<i>CHAPS support is limited to a few select location</i>
<i>I: So, from you experience, other geographical areas may not offer this kind of support.</i>	
<i>R: Yes exactly, we would just be subject to social care and social care are just useless. I mean Clare's report, we asked for a residential one so we could get her into Langdon Community. The report came back saying she needed seven sleep-ins and she wouldn't leave the house. So they had nothing more to do with her and they were completely useless for us.</i>	<i>Social care offered by the government is not adequate</i> <i>Support offered from social care was not flexible</i>
<i>I: So what they offered was not practical for Clare?</i>	
<i>R: Yeah and the computer system they use for diagnosis was also a load of rubbish and so many people I know have said the same thing.</i>	<i>Parents not satisfied with the computerised diagnostic system used by social care team</i>
<i>I: And these are the free serviced the government offer, is that right.</i>	
<i>R: Yes, it's the social care offered. (Unclear...) their advice to me was to actually make her homeless because then she would have to be re-diagnosed and we could get the statement. They actually said I should abandon her where one of my other children lived because that area could do a better re-assessment.</i>	<i>Social care advised to make my daughter homeless and then she would get better support</i>

<i>I: Wow those were the actual words used?</i>	
<i>R: Yes I complained about how useless the staff was and they just closed the case.</i>	<i>When mother complained about the services, no more support as offered</i>
<i>I: Really they just closed the case...</i>	
<i>R: Yeah, they initially said that we would get six hours a week, but they gave two and then they just took it away. So social care in my opinion are a waist of time. I had the same think happen when Abby was a baby with IBS and we lived in London, Harrow, and she was in hospital when she was little. They told us to contact social care, that's what I was told to do, and they came round to the house and I was throwing away so many pairs of underwear because they just start to smell and cant be cleaned. So they came round while I was cleaning and they said, well you don't need our help. So here I am, living in a new place with a special needs child, I don't know anyone, and they came in and said, well you're a coper, you don't need use and they walked out.</i>	<i>Social care did not deliver the service they said they would</i> <i>Mother has had poor support from social care more than once</i> <i>Social care suggested that the mother could cope and that she did not need their help.</i> <i>Mother believed she needed social care help but felt abandoned when they left</i>
<i>I: That does not sound like a good level of support.</i>	
<i>R: No, I think your always told you're a coper because financially they can't afford to help people that need the help.</i>	<i>Feels like that social care can't financially afford to help</i>
<i>I: I think you are correct in that budget is a huge problem.</i>	
<i>I: I know Clare was diagnosed in adulthood but can you tell me how does the support or treatment offered now compare to when the girls were younger?</i>	
<i>R: Well with Abby we were lucky because we met a neighbour and we talked a few time and she asked if Abby ever spoke and I said no. Well she said, I am speech therapist and we had an appointment within a week. I couldn't have been any luckier so from that she got speech therapy, occupational therapy, physio therapy and a special needs nursery placement. So she got speech therapy from the school and hospital.</i>	<i>One daughter had a statement as a child and was offered a lot of support</i>
<i>I: So, would you say you were offered more support when they were children?</i>	
<i>R: Oh yes, children get the support and adults don't. But saying that, I was very luck, because at that point I was being ignored by the doctors. So it was pure fluke that everything got triggered.</i>	<i>Children are offered more support than adults</i>
<i>I: Wow, it sounds like you had some good fortune in deed. For my next questions can I get your opinion on what skills/topics do you think would be most important to address in a social skills intervention for young adults with autism?</i>	
<i>R: Both my girls really struggle to understand social cues, so understanding when to start talking, when it's safe to interrupt and not. Even when in a group, Abby will just barge in and start talking.</i>	<i>Learning social cue are important</i> <i>Important to understand when to start talking and when it is safe to interrupt.</i> <i>Daughter will barge into conversations</i>
<i>I: Yes, conversation skills can be a difficulty for autistic people.</i>	
<i>R: Yes, when you don't have those social cues in a social environment, whether they are in a work environment or even talking to strangers in the street, or answering a phone, they're not able to do that and I don't know if that's something that can be taught because it a basic autistic problem.</i>	<i>Conversation skills are important</i> <i>Worried some skills can't be taught due to autism</i>
<i>I: So, I hear you highlighting skills, but you also describe them in terms of adult social context such as employment. Do you think it is important to include specific social contexts like employment when teaching social skills so they can integrate them into independent living?</i>	
<i>R: Yes that is exactly, I mean Abby's been trying to date and is really not coping with it and Clare is vaguely trying to do things but it all online. She doesn't always understand what is being said to her, some of the letters like LOL, she just doesn't understand them, she cant deal with them, it doesn't translate in her head. Even if you tell her she doesn't get it. It also that it not just the autistic person needs to know social cues but other also need to understand that autistic adults need more time. They can process things at a</i>	<i>Important topic is dating</i> <i>Daughter has struggled to date because of autism traits</i>

<i>different speed, so like Clare can have a great conversation with someone but then she will need to go away and process what's been said to her. Then she will decide whether something feels right to her or feels wrong to her. Whereas I can tell if somethings off quit quickly, they can't.</i>	<i>Important for other to be educated about autism also</i> <i>Autistic adults need more time to process conversation and how they feel</i>
<i>I: and this is all down to their communication deficits?</i>	
<i>R: Yes, it a major stoppage to everything they try to do.</i>	
<i>I: Definity, it's a problem. If it is ok with you, we will move on to part two of the interview which is about the social skills intervention which as you know, I developed, and I just want to know how you experienced it.</i>	<i>Communication problems are a major barrier to everything</i>
<i>R: Yes (unclear....)</i>	
<i>I: Please just be as honest as you can, don't worry, you won't hurting my feeling whatsoever. So for the first question, can you describe your experience of being a part of the intervention?</i>	
<i>R: Well as a parent taking her every week and her discussing everything with me, it was quite good because the "please" and "thank you" and the making requests, prior to your intervention we didn't have much of that. She is much more polite now.</i>	<i>Mother liked attending and discussing issues every week</i> <i>Mother feels daughter has improved on making a request and is more polite since the intervention.</i>
<i>I: Well that good to hear.</i>	
<i>R: Yes it was interesting watching the way she changed, she didn't have the politeness she has now, the niceties were not there.</i>	<i>Mother found it interesting to see the changes in her daughter</i> <i>Daughter is more polite than before the intervention</i>
<i>I: Did you find it helpful to be invited into the individual CBT session?</i>	
<i>R: I found it interesting, I think you have an idea in your head how your child is going to answer things, and when they kinda surprises you with something you didn't expect them to say, you learn more.</i>	<i>Mother was sometime surprised at what daughter would say in therapy</i> <i>Mother learned more about her daughter in the CBT sessions</i>
<i>I: What role do you feel you had in the intervention?</i>	
<i>R: For me it was helping Clare to get there, she would not have gone to the group session unless I had taken her in, and I had been in the building. She needs to know I was in the building.</i>	<i>Mother played a supportive role</i>
<i>I: So, you provided a supportive role?</i>	
<i>R: Yes, she would never have come to the group sessions. The individual one's she was ok with but not the group. After the first meeting she would have started to go in by herself, well she would with you because she felt comfortable with you. But her fear and OCD were very high, her anxiety were very high.</i>	<i>Mother ensured that her daughter participated.</i> <i>Daughter would not have participated if it wasn't for mother</i> <i>Daughter would have eventually settled but was very anxious in the beginning</i>
<i>I: Sounds like you really need to be there</i>	
<i>R: Its is a struggle for her to feel safe in the room, so I also have to be there</i>	<i>Daughter finds it hard to feel safe at first</i>
<i>I: That must be a challenge.</i>	
<i>R: It isbut her biggest challenge is that she wants a boyfriend and this is where we are struggling. It is heart breaking to a parent to watch your daughter go, oh I want a boyfriend, I want to get married and have children. And especially with Abby, I look at Abby and think she is 31 now, is it ever going to happen.</i>	<i>Biggest challenge is daughter want romantic relationship</i> <i>Daughter wants a relationship and family</i> <i>Worried eldest daughter at 31 will never make a family</i>
<i>I: Such a worry, the stress must be great.</i>	
<i>I: I know you may have already answered this but during the intervention, did you notice any changes in Clare's behaviour?</i>	

<i>R: She became more confident, she definitely became more confident, and as I said before, her niceties came out. She started to use her please and thank yous. She now says, "can I have" or will it be ok". And definitely she is better at talking to other people once she is use to their faces and the environment.</i>	<i>During the intervention Clare became more confident</i> <i>Finds it easier to talk to other once comfortable</i> <i>More polite than before the intervention</i>
<i>I: Yes that is nice to hear, Clare did really well in some of the sessions but she really thrived in the session on making requests.</i>	
<i>R: Yes I remember because she was practising it at home.</i>	<i>Clare practised skills at home to improve on them.</i>
<i>I: That's great, it was relatable to her everyday life so she had the opportunity to practise at home.</i>	
<i>I: I always like critical feedback to make improvements so in your honest opinion do you think the intervention could have been improved in any way at all?</i>	
<i>R: I would say there was only one thing and that was the Clare was the only girl. I know you had problems getting girls in but I think we both thought it would have been good for her to have another girl. She would have felt more comfortable quicker and settle.</i>	<i>More girls needed in the group social skills training</i> <i>Would have felt more comfortable with more girls</i>
<i>I: I completely agree that it would have been nice to have more girl, thank you for that feedback. Well we have now completed the interview. I would like to thank you again for participating in the interviews and if you have any questions at this point I will happily attempt to answer them.</i>	
<i>End interview</i>	

Therapist Focus Group Interview Schedule

Part 1: Individual CBT sessions

1. *I'd Like to start off by asking to describe how you found the training?*
Probe: *Is there anything you think could be improved?*
2. *What was your experience of using the five arear formulation model helpful?*
Probe: *Did you think the five areas model provided too many issues to focus on at once?*
3. *Where there any challenges in formulating sessions?*
Prompt: *Did you find that your experience of working with autism helped you?*
4. *Did you find you had to adapt your approach when working with ASD participants?*
Prompt: *How did you adapt your approach?*
Probe: *Are there any suggestions or advise you have for a CBT therapist that has not work with clients with autism?*
5. *Looking back at your notes, how do you think the participants responded to the intervention*
Probe: *Can you provide some examples*

Group Sessions

1. *Were there any difficulties adhering to the intervention manual*
Prompt: *Please provide detailed examples.*
2. *Did you feel that the group sessions complemented the individual sessions?*
Probe: *Did you perceive any benefits or limitations to combining modes*
3. *Did you find it difficult to get the clients to engage with the content and activities?*
Probe: *can you provide more detail about any challenges*
4. *Did you think that the curriculum was suitable for young adults with ASD?*
Probe: *Did you feel we addressed important social skills?*
5. *Were there any parts of the intervention manual which you would have changed?*
Prompt: *For example, the length of the sessions*

Would you recommend this intervention to other CBT practitioners working with adults with ASD?

Therapists Interview with Codes

Interviewee: Alan and Sandy [Pseudonym]	
Interviewer: David Tate	
Date and Time: 20/07/2018 Duration: approximately 64 minutes	
Location: University of Salford Allerton build room L524]	
CBT therapist group interview	
Interviewer = I	
Part 1:	Codes
I: I'd Like to start off by asking you to describe how you found the training?	
R1: Without the training we did before the start, I don't think I would have had the knowledge or the confidence to facilitate the group sessions. You taught me to focus more on thoughts than emotions which was really helpful when working with Alex.	Training was perceived as helpful for adhering to treatment Built knowledge and confidence
R2: I agree, I found that reading the manual before we started was helpful. The meetings we had were also really good to discuss what was in the manual and I thought you did well to answer your questions	Training was perceived as helpful for adhering to treatment Meetings were good for discussion and asking questions
I: Is there anything you think could improve the training	
R1: I can't think of anything, no.	
R2: It wasn't a problem for me, but others may need time spent on communication skills. I am used to speaking to autistic peoples, but others maybe need to understand differences in communication style better. It is easy to misunderstand or to be misunderstood.	Spending more time on communication barriers in training
I: So spending more time on common communication issue which may arise for both the therapist and client?	
R2: Yeah, I think so anyway.	
I: Again, this question is for both of you. What was your experience of using the five arear formulation model?	
R1: I did find it helpful, it let me keep the formulation simple.	Five areas CBT was helpful for keeping formulation simple
I: Did you think the five areas model provided too many issues to focus on at once?	
R1: It did feel like it may have been overwhelming for Ken..	Five areas may have been to much for some autistic people
I: How did you deal with this issue?	
R1: I just narrowed the problems down by importance and using a simply ABC model...	Helpful to priorities problems and use simple formulation
I: And did this help?	
R1: Yes, a little I think.	
I: Sandy, did you find the five arear formulation model helpful during the individual CBT sessions?	
R2: I did yes. I used it at first as an initial symptom indicator. It was a good visual representation of the issues we would work with to start. It allowed us to go straight into the assessment and discussing interventions.	Five areas was good as a symptom indictor Provide visual representation of problems. Fast process to assessment and intervention
I: So you found it a good tool to provide a visual assessment which the participant could understand, is that right?	

<i>R2: Yes, they were quick at catching on because it was more of a visual thing. I like to use visual notes when working with people with autism. It's the diagram and the flow of information that makes it work. Visual representation as well and verbal is really important because for some its hard to follow just verbal instruction.</i>	<i>Visual aid was helpful for autistic person.</i> <i>Visual and verbal instruction provided better communication</i>
<i>I: Thank you for those answers, they are insightful. Let's move on. Where there any challenges in formulating sessions, for example adhering to treatment?</i>	
<i>R2: I found with my group identifying problem to work on quit quickly and easily because I was very direct with my probing questioning. It was important to be very specific and avoid being general. You let them connect the dots to make their own general conclusions.</i>	<i>Direct probing questions were helpful in identifying problems</i> <i>Being very specific was important part of communication</i> <i>Important to let the autistic person make their own general conclusions</i>
<i>I: Did you find that your experience of working with autism helped you?</i>	
<i>R2: Yes, it likely did.</i>	<i>Helpful to have experience of working with ASD</i>
<i>I: How about you R1, did you come across any challenges.</i>	
<i>R1: A challenge I had was do to communication. Ken in particular at times felt that I wasn't listening to him but as the therapist I was aware of the time focused aspect and that we only had time to work on short term goals. There were issues that the client wanted to focus on that were beyond the scope of realistic achievements. In hindsight I would have spent more time on SMART goals as a visually demonstration if the challenges of unrealistic targets. I think it important to seek constant clarification with an Autistic client and allow time to respond or take mini-break.</i>	<i>Challenges in communicating with autistic person</i> <i>Difficulty setting realist goal</i> <i>May have helped to spend more time on visual SMART goals.</i> <i>Important to seek constant clarification and allow time to respond or take short breaks</i>
<i>I: Did you address this with Ken</i>	
<i>R1: I did, but he really didn't respond well. He was very focused on unrealistic goals so I would have to remind him each week. This only made him feel like I wasn't listening to him which made things more challenging.</i>	<i>Poor response to refocusing techniques used by therapist.</i> <i>Participant was overly focused on unrealistic goals</i> <i>Participant did not feel listened too.</i>
<i>I: That's great, thanks you both for that feedback.</i>	
<i>I: The next question I wanted to ask related to what we discussed in training about the treatment focusing more on thoughts than emotions. Did you modify your treatment approach in this way?</i>	
<i>R1: Yes, it was mainly thoughts that were clearly identified. I think this approach was particularly useful with Alex when we were discussing what it would be like for other. I asked what he thought it would be like for others.</i>	<i>Thought were more clearly identified and challenged.</i>
<i>R2: I agree, there was way more focus on behaviour and thoughts and a lot less on emotion. I found the only time emotion that were really discussed were to assess how they were feeling in relation to a specific anxiety provoking activity or situations which made them depressed. Often emotions were discussed in terms of a contrast of before and after a situation to encourage that they can complete an activity that was anxiety provoking. Also when discussion emotions I found this to be done by highlighting examples of behaviour and assessing what emotion were felt, so if they describe going out a lot in the week, I would link this to feelings such as being motivated, happy or in just in a good mood.</i>	<i>Focus was more on behaviours and thoughts and less on emotion</i> <i>Emotions were only discussed as part of assessment of anxiety provoking or depressive events</i> <i>Emotions were often discussed as a way to compare feeling before and after an event</i> <i>Discussion of behaviours were linked to emotions felt</i>
<i>I: Are there any suggestions or advise you have for a CBT therapist that has not work with clients with autism?</i>	
<i>R1: They should learn about autism. You should also ensure you have been understood and that you understand them before moving forward. It is also helpful to have a supervisor with experience of working with autism to be as effective as possible.</i>	<i>It is important to ensure both therapist and client have understanding before moving forward.</i> <i>Its helpful having a supervisor with autism experience</i>
<i>R2: I agree with what Alan said completely. I also advise to establish a strong therapeutic relationship early and set clear goal at the start. When communicating be clear with speech and avoid using metaphor.</i>	<i>Developing a good bond early is important.</i> <i>Set clear goals, communicate clearly and avoid metaphors</i>

<p><i>I: Thanks for that insight, I have just one more question about the individual CBT sessions. Looking back at your notes, how do you think the clients responded to the treatment. For example, did you note any specific improvements/declines or goal achievements/failures?</i></p>	
<p><i>R1: With Alex the main aim was to reduce his social anxiety and face some issues he was apprehensive about. From the start of therapy to the finish I noticed, and he reported less anxiety in social situations. Alex said in the closing session that he felt he had achieved the goals set out in therapy. We explored the social anxiety model and we collaboratively identified behaviours which he was reinforcing with ruminating thoughts.</i></p>	<p><i>Individual therapy was helpful for working on and reducing anxiety</i></p> <p><i>Goals of therapy were achieved</i></p> <p><i>Worked collaboratively</i></p>
<p><i>I: Can you provide a specific example?</i></p>	
<p><i>R1: A prominent social situation that was very anxiety provoking for Alex was socialising in the university halls of residence. Before the start of therapy Alex would wait to enter the kitchen until it was empty and would avoid eating a times when other were around. After a few weeks of rationalising and exploring different perspectives he started to see the benefits to meeting others in the halls. After 3 or 4 mini exposure tasks, he started sitting and eating with other residence in the halls with limited anxiety. For Alex it was a combination of rationalising and exposure which helped to overcome some of the earlier anxiety. It was also evident in the group sessions that his anxiety had reduced, and he was seeking more social interaction with others in the group.</i></p>	<p><i>Mini exposure tasks were helpful social tasks</i></p> <p><i>Rationalising thoughts and exposure therapy helped reduce anxiety</i></p> <p><i>Increased social interaction over time</i></p>
<p><i>I: Can you tell me a little about your work with Ken?</i></p>	
<p><i>R1: Ken had a lot of goals at the start and some seemed out of reach. I used SMART goals and invited his mum into the session to help set his goals. Unfortunately, Ken was not very flexible, however he did acknowledge that some of his goals seem a bit wild. We tried breaking the goals down into; short, medium, and long term. Ken wanted to learn to control his anger and deal with conflict in a better way. We implemented the STOPP technique, but he was rather resistant at the start. Overtime he engaged more, and his mother was very helpful. I felt having his mother involved was very helpful. By the end of therapy Ken had memorised the techniques and was using it frequently at work. Other techniques we used involved funny imagery. Ken did say he felt he achieved his short and medium-term goals. He had started to join new social groups. At the end Ken also anecdotally reported feeling better mentally and emotionally.</i></p>	<p><i>Goals were set using the SMART techniques</i></p> <p><i>Client somewhat inflexible and resistant</i></p> <p><i>Used STOPP technique and funny imagery to help with anger management</i></p> <p><i>Mother was helpful in therapy</i></p> <p><i>Increased social interaction</i></p> <p><i>Goals of therapy were achieved</i></p> <p><i>Client feels better mentally and emotionally after therapy</i></p>
<p><i>I: R2, can you tell me about your cases?</i></p>	
<p><i>R2: Sure, well, everyone achieved what they wanted to achieve in some way.</i></p>	
<p><i>I: Can you be more specific? What were Ricks main goals and how did he achieve them?</i></p>	
<p><i>R2: He wanted to work on shame and guilt causes by ruminating thoughts, or intrusive thoughts which he could not stop thinking about. We worked on his feeling about the thought and by removing the strong emotion, so taking the heat out of the thoughts which were quite shocking and triggering, and rather taboo. We talked through this issue and Rick said in the final session that "from the start till the end, intrusive thought and negative emotions have reduce by 90% for me". Now with Clare, I found her change more gradual and progress was a little slower, but her goals were defined and clear. We worked on fear and social anxiety. She responded well to gradual exposure, we explored her behavioural activations and her motivations. She wanted to see her friends more and the reward of dealing with these issues would be that she could see them more in person. She had agoraphobia and PTSD from past experiences in school, she received a lot of bullying. She wouldn't even drive past the school even though it was just up the road, the homework tasks progressed so one week she was to walk past the school on the weekend with mum, then on a weekday, she eventual stood outside while school let out.</i></p>	<p><i>Worked on ruminating and intrusive thoughts</i></p> <p><i>Client felt intrusive thoughts and negative emotions reduced during therapy</i></p> <p><i>Set clear goals</i></p> <p><i>Slow and gradual progress</i></p> <p><i>Gradual exposure was helpful</i></p> <p><i>Client wanted more social interaction</i></p> <p><i>Worked with anxiety</i></p> <p><i>Social anxiety around a specific event reduced through gradual exposure tasks</i></p> <p><i>Parent involvement was helpful</i></p>
<p><i>I: Thank you very much to you both, we are going to take a short break and then we will talk about the group sessions.</i></p>	
<p><i>Part 2:</i></p>	
<p><i>I: Alright, lets get started with the next phase of the interview. So we are going to talk about the group work we did and I have just a few question to ask. You both took part in the group and contributed to the activities and</i></p>	

<i>group discussion, so I want to know, did you find any difficulties adhering to the intervention manual?</i>	
<i>R2: I thought the manual was clear and concise and anyone can follow it and not just myself, but any person could pick it up without prior experience could still understand it and follow through with implementing it. The only one thing is possibly time keeping, there can be a lot of push and pull between the therapist and the clients and this can make it difficult to cover everything without being time rigid.</i>	<i>Manual was clear, concise and easy to follow Non-specialist could use the manual Time allotted for task completion was an issue</i>
<i>I: Great feedback, was there any part that you thought more time should be devoted?</i>	
<i>R2: No, but I think that will depend on the nature of who you will be working with. I feel because our group jelled really well they wanted to express a lot about their life but this may not always be the case. I also think that check-in sometime could have been more specific rather than a general discussion.</i>	<i>Group bonded well Maybe better to be more specific about discussion topics</i>
<i>I: How about you Alan, same question.</i>	
<i>R1: I felt the manual was well structured and I didn't not anything difficult about it. I agree about the time issue, some of the discussions could have been longer after completing an activity.</i>	<i>Manual was well structured and easy to follow More time for discussions after the activities</i>
<i>I: Awesome guys thanks, now for the next question. Did you feel the group sessions complimented the individual session?</i>	
<i>R1: Yes, with Alex he showed more confidence as the sessions progressed and I believe that was more because of the group work. While he had a great understanding and self-awareness it was the behavioural aspect that he needs to work on. It was good because we would talk about change in the individual sessions and I could see changes occur in later group sessions.</i>	<i>Group work help build confidence Discuss change in individual sessions Observed changes in the group session overtime</i>
<i>I: So, you though it was helpful for him to practise skills in the group before using them in the real world</i>	
<i>R1: Well yes.</i>	
<i>I: Good stuff thanks. Sandy, did you feel the group session complimented your individual sessions.</i>	
<i>R2: Absolutely, I think so. Especially those that found it difficult to verbalise for long periods of time. The group setting allowed everyone to share so the focus was not always just on one person, unlike the individual sessions.</i>	<i>Group sessions were helpful for those that struggle with verbalising for long periods Group sessions allowed everyone to share the focus</i>
<i>I: ok moving on to the next question, did you find it difficult to get the clients to engage with the content and activities?</i>	
<i>R2: I think there were times where excitability may have had an impact on Ken in particular. Maybe some grounding exercises would have helped with this. Its just a suggestion but someone like Ken that is so likely to go off and have difficulty focusing sometimes made it difficult.</i>	<i>Challenges working with client Grounding exercises recommended Difficulty getting client to focus</i>
<i>R1: Yes I agree and possibly more scaffolding for those individuals that need more guided focus.</i>	
<i>R2: I don't think it was necessarily always difficult, but some tasks were harder than others.</i>	<i>Some group tasks were difficult</i>
<i>I: Can you provide an example?</i>	
<i>R2: In the task where they had to enter a group conversation, Rick was nervous and apprehensive.</i>	<i>Some task cause anxiety and apprehension</i>
<i>I: That was a particularly challenging task, and no one really moved without being prompted, did they?</i>	
<i>R2: No and I think that the more out of the comfort zone you take a client the harder it is to get them to engage.</i>	<i>Feeling comfortable is important for engagement</i>
<i>I: What about the content of the intervention, did you guys think that the curriculum was suitable for young adults with ASD?</i>	
<i>R1: Yes, I did, we covered a lot but the skills overlap so it felt like less work. I had no issues with the curriculum at all.</i>	<i>Curriculum was suitable Covered a lot of content but skills overlapped</i>
<i>R2: I agree, don't underestimate the power of simplicity. What we may find easy in terms of multitasking and joint attention [not clear....].</i>	<i>Good to keep it simple</i>

<i>I: Were there any parts of the intervention manual which you would have changed or added too?</i>	
<i>R2: There could have been more focus on emotion in terms of understanding expressions and identifying emotions in others. Although we did do some work on non-verbal behaviour we really didn't discuss expressions of emotion which would fit in well I think.</i>	<i>Skills training could include more emotions training</i>
<i>I: So, you think in the future the treatment manual should include a emotions component?</i>	
<i>R2: Yes definitely, and maybe even shorter sessions but over a longer time frame.</i>	<i>Shorten the length of the sessions Included more session over a longer period of time</i>
<i>I: Great suggestion, did you think 2hr was to long of a session?</i>	
<i>R2: Yes, I think it's a demanding interaction and some may be more disengaging if the task or discussion is too long. Many said they were tired at the end of the sessions and so was I.</i>	<i>Group sessions were tiring for both clients and therapist</i>
<i>I: R1, would you have added or changed anything?</i>	
<i>R1: I would change the phone roster homework. It may be that phone calls are less common with young people but no one in the group constantly engaged with it and they all ended up communicating on a Facebook group. Maybe suggest a social media group or text messages</i>	<i>Group did not engage with the phone roster Replace phone roster with a text-based platform</i>
<i>I: One last question and then we can finish. Would you recommend this intervention to other CBT practitioners working with adults with ASD?</i>	
<i>R1: Yes, I have actually informed my work place that I have worked on this project and that we cold possibly use it for our service users with ASD.</i>	<i>Would and has recommended the intervention to others</i>
<i>I: wow that's great, would you recoomend it R2?</i>	
<i>R2: Yes, after the improvements that I saw in my clients, I would definitely advice others to use it.</i>	<i>Would recommend based on the improvement made in therapy</i>
<i>I: Well that the end of the interview, thanks you so much....</i>	

Appendix K. Example of Thematic Map



Appendix L. Example of Fidelity Check List

Therapist _____

Co-therapist(s) _____

Session number _____ 1 _____

Response options: Yes (if activity is performed and for the time allocated); No (if activity is not performed or not for the time allocated).

(Yes/No) Ice breaker: The interview and group rules (Time 30 minutes).

(Yes/No) Group activity: complete the “why change” worksheet followed by a group discussion (20 minutes).

(Yes/No) Break (10 minutes).

(Yes/No) Psychoeducation Lesson and Skills Modelling 1: Exchanging Information (20 minutes).

(Yes/No) Role-play & Repeated Rehearsal (30 minutes)

(Yes/No) Closing Session Activity “My journal” (10 minutes)

If the programme format was not followed, what are your reflections on why this occurred?

Observer: _____ Signature: _____

Appendix M. Intervention Manual

Overview of intervention

Terminology

In the section of this overview which describes the individual CBT therapy modality, the terms “client” and “therapist” are used when referring to the participants receiving the intervention and the CBT therapists, respectively. Description of the group therapy modality adopts the terms “group member(s)” when referring to the participants and “group facilitator(s)” when referring to the CBT therapists leading the group sessions.

The following program was developed in line with the clinical guidelines from the National Institute for Health and Care Excellence on Autism Spectrum Disorder (ASD) in adults: diagnosis and management (NICE; 2012). The Cognitive Behavioural Social Competence Therapeutic for adults with ASD (CBSCTI-ASD) intervention manual utilises Cognitive Behavioural Therapy (CBT) principles to approach therapeutic change in social competence. CBT techniques are considered to be instrumental to the CBSCTI-ASD program and are further discussed below:

	Components	Intervention	Description	
Session 4	Session Opening	1. Check-In group discussion, skills recap 2. Activity-Brief conversation	1.6 Group discussion 1.7 Collaborative problem solving	
	Psychoeducation lesson	Conversation skills- Sharing the conversation	1.9 Psychoeducation	
	Role-play & repeated rehearsal	Take turns exchanging information to find out each other's hobbies	1.11 Role-play activity	
	Group activity- Talker & listener	Mirroring talk- Paraphrasing	1.8 Social cognition activity	
	Close session	Buddy System and Journal	1.12 Homework	
	Session 5	Session Opening-Recap	Check-In group discussion-evaluation	1.7 Collaborative problem solving
Psychoeducation lesson		Conversation skills- Entering a conversation	1.9 Psychoeducation	
Role-play & repeated rehearsal		Conversation loops- Entering an open conversation	1.11 Role-play activity	
Group activity- observer		Observer Feedback Worksheet	1.10 Behaviour modelling	
Close session		Buddy System and Journal	1.12 Homework	
Session 6		Session Opening-Recap	Check-In- reflection on ending therapy	1.4 Therapeutic alliance 1.5 Group cohesion
	Skills review	Group Discussion	1.7 Collaborative problem solving	
	Psychoeducation lesson	Introduction to good sportsmanship	1.9 Psychoeducation	
	Group activity- social games	Social interaction games	1.5 Group cohesion	
	Close session and say goodbyes			

Individual Therapy Modality

Cognitive Behavioural Therapy (CBT), if adapted, has been shown to be efficacious in reducing mental health problems and improving challenging behaviours in an ASD population (Weston, Hodgekins, & Langdon, 2016). The Five Areas CBT model (Williams, 2001a) was adapted to fit within the remit of the CBSCTI-ASD multi-modal programme (see Table 6). The Five Areas assessment model was developed as part of an NHS commission to provide an easy to deliver and accessible model of CBT for use in high demand clinical settings (Williams, 2001a). The Five Areas CBT approach begins with the therapist providing an assessment and a structured consultation. The role of the therapist is to try to summarise the problems expressed by the client into areas that provide clear targets for therapeutic change. For individuals with ASD, common areas may include; social problem-solving, maintaining relationships, identifying and modifying extreme and unhelpful thoughts, overcoming social isolation and dealing with RRBs.

The Five Areas CBT approach is collaborative, and negotiations are ongoing throughout the individual therapy sessions. It is important to allow for some therapeutic flexibility during formulation e.g. changes to the formulation based on expressed progression or regression (Beck, 2011). The first step of the Five Areas CBT approach is to utilise a collaborative process for identifying targets for future therapeutic change. In order to systematically identify these target areas, the therapist uses a pie chart where each target is a piece of the pie and the size of each piece represents the magnitude of which the individual finds challenging or difficult (see Figure 2). Individuals with ASD are often described as visual learners (Rao, & Gagie, 2006) and the pie chart provides a visual representation which should, theoretically, be helpful for an ASD population.

One of the greatest challenges early in therapy is attempting to collaborate with the client to identify targets for future change (Wright et al., 2002). The therapist uses a systematic line of questioning to identify expression of symptoms which then need to be combined in order to factor down the number of targets for therapeutic change. It is important for the therapist to limit the targets down to five areas or the chart will contain a large number of small targets which may not be adequately addressed within the timeframe of therapy. Individuals with ASD may initially find it difficult to collaboratively identify and conceptualise problems, but to aid this process the Five Areas Model has the benefit of providing a verbal and visual representation model which systematically identifies the short-term, medium-term and longer-term targets.

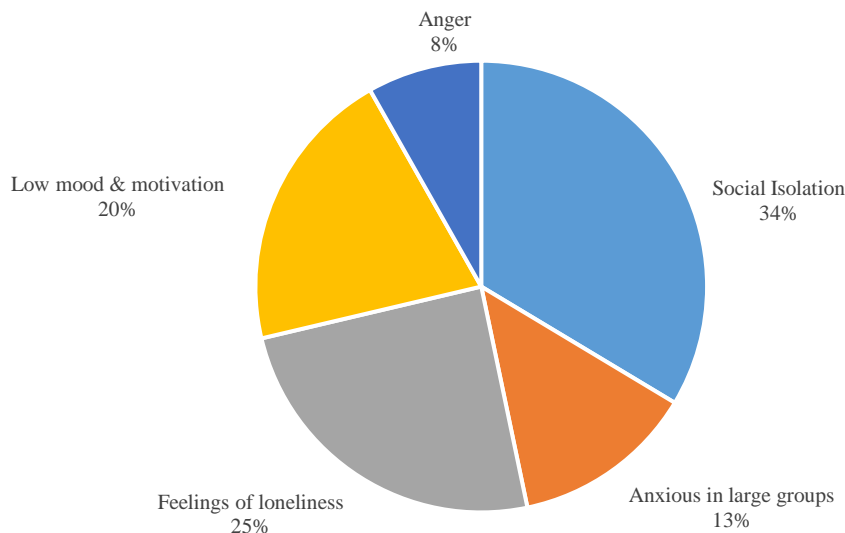
Five Areas CBT model adapted for CBSCTI-ASD

Five Areas Model	CBSCTI-ASD Five Areas Model
-Session of approximately 20 minutes	-Session of approximately 30 minutes
Brief update, mood/mental state examination, symptom review and medication check	Homework review, brief update and assessment of social skills practice and progression (i.e., are you having any struggles or negative feelings or thoughts)
-Case formulation: agenda is very limited (e.g. focus on one problem area in each session)	-Case formulation: agenda is limited (e.g. focus on one problem or two related problem areas at a time). Formulation emphasis is on identifying and understanding thoughts and behaviour
Practical Review	Therapy Review
-Summary of the current session with brief feedback, identify key thing learned and review tasks to complete before the next session.	-Optional: Parent/caretaker involvement in the final ten minutes of the session (social coaching)
	-Summary of the current session with brief feedback, identify key strategies for social problem solving and review homework to be completed before the next session.

The therapist must actively choose a single problem area for their initial focus for therapy. Short-term targets are those which focus on changes which can be made in time for the following session. Medium-term targets are changes to be put into place over the course of the intervention. These targets are addressed during formulation reviews and are the primary focus of individual therapy. Long-term targets are the goals that are hoped to be achieved in 6-12 months after the intervention ends and requires the therapist to put in place

strategies to support the client in the absence of meeting with the therapist (Cully & Teten, 2008). Once the initial list of symptoms is complete, the therapist and the client discuss ways of trying to combine symptoms into fewer, more general problem areas which can then be systematically addressed. This is achieved by identifying and combining separate thoughts (e.g., “People don’t like me” and “I am not good at conversations”, and “I notice people avoid talking to me”) which can be summarised as a general problem (e.g., problems with making friends). The problems can then be characterised as a “need to modify”.

Impact of Impaired Social Communication



of the time limitation. The therapist and client then prioritised problems and formulated the session targets down to one, or two agenda items based on symptom severity. Events related to the agenda items are explored using a simple appraisal formulation such as the ABC model (see Table 7) which aimed to conceptualise and examine specific events through cognitive appraisal (Ziegler, 2001). The ABC model is a fundamental tool which is often used in CBT for analysing presenting problems (Skinner & Wrycraft, 2014) and it has been shown to be an acceptable model for clinical use with individuals with ASD (Gelbar, 2017). This model is one of the most commonly used in CBT for helping individuals clarify their problems and gain a greater understanding of the interplay between thoughts, emotions and behaviours which are central to their psychological distress (Lam & Gale, 2000; Teater, 2013). After formulation, irrational thoughts are challenged and then disputed with facts, evidence of the facts and alternative ways of thinking (Beck & Haigh, 2014).

ABC formulation model for CBSCTI-ASD

A - Activating Event	B – Belief/Thoughts	C - Consequences
Describe the event or situation which caused distress or concern.	Identify the negative thinking behind initial thought. Choose one or more from the list of common types of negative thinking.	Identify the short-term and long-term consequences
<i>What is the situation?</i>	<i>What thoughts went through your head during or after the activating event occurred?</i>	<i>How did your actions affect others? How did they affect you?</i>
Describe any initial thought.	Identify source of negative belief.	Disputing thoughts and behaviours. Look at the evidence both for and against beliefs and actions.
<i>What thought first crossed your mind?</i>	<i>Can you trace your thinking back to a situation or person? Is there a deep belief or fear driving your thinking?</i>	<i>Have you been in a similar situation before? What did you learn from it? Does it happen every time you are in that type of situation?</i>

Other popular CBT intervention techniques utilised by the therapist include, but are not limited to; engaging in imagery, relaxation techniques (e.g. controlled breathing), distraction strategies (e.g. fidget device), behaviour modelling, and adopting competing behaviours to counteract negative outcomes (Beck & Haigh, 2014). The therapist concludes each session by conducting a therapy review of each agenda item in-turn with a summary of key points from the session. The aim of the review is to identify key things learned and discuss any planned activities before the next session.

Group Therapy Modality

Group formats have a growing evidence-base in the social skills intervention literature (Gates et al., 2017; Miller et al., 2014; Spain & Blainey, 2015). Group formats have often been used for direct and indirect social skills training through facilitated group discussions or specific skills teaching (e.g., Ashman et al., 2017; Hillier et al., 2011). The CBSCTI-ASD group sessions aimed to facilitate social interactions and the sharing of experiences in a safe and comfortable setting. The group format is essential for supporting ecologically valid skills practise and increased social support.

In-line with past CBT group interventions, CBSCTI-ASD group sessions are approximately two hours in length with a ten-minute break (e.g. Thimm & Antonsen, 2014). Each group session is delivered in components which include; check-in group discussions, psychoeducation lessons, behaviour modelling, role-play and rehearsal, group social skills activities and homework. When combined, these components aimed to nurture the therapeutic alliance, build group cohesion, enhance social problem-solving skills and foster the practise of social skills in a safe environment.

Socratic Questioning Technique

The Socratic Method is ubiquitous in the psychotherapy literature and is a fundamental technique in CBT (Carey & Mullan, 2004). In CBSCTI-ASD, the overall purpose of Socratic questioning is to challenge the accuracy and comprehensiveness of reasoning in a way that acts to move an individual towards learning new social skills. Corsini (2002) defined the Socratic method in two ways:

4. In counselling, a carefully constructed series of questions designed to arrive at logical responses to a problem and proper conclusions about future action.
5. Inductive dialectic procedure leading a person to accept or admit the desired conclusion by means of a progressive series of leading questions that are answered in turn.

The CBSCTI-ASD manual provides focused lines of questioning which aim to investigate specific viewpoints or perspectives. Conceptual clarification questions are used as a meta-cognitive technique to make an individual think more about what exactly they are asking or thinking about (Cully, & Teten, 2008). Socratic questions used in sessions are developed to build evidence of concepts, provide a rationale for learning, and to challenge any irrational beliefs or distorted thoughts.

Socratic questions and responses adapted by the researcher for the CBSCTI-ASD manual

Session	Questions	Rationale response
Session 1. Exchanging information	<i>“Why would you not want to get personal in the first meeting?”</i>	<i>“This can make people feel uncomfortable and this may stop the conversation from progressing further”</i>
Session 2 Making a request	<i>“Why is it important to be clear when making a request?”</i>	<i>“If the other person does not clearly understand your request, they are more likely to reject your request.”</i>

Session 3. Active listening	<i>“What kind of body language may show the talker that you are distracted?”</i>	<i>“The active listener should try to refrain from facing away, fidgeting, looking at a clock or watch, doodling, playing with their hair or picking their fingernails. These signs may lead the talker to believe you are not interested in having a conversation or that you have somewhere else you need to be.”</i>
Session 4. Sharing the conversation	<i>“Why is it better to use open ended questions?”</i>	<i>“Open questions are designed to encourage thoughtful, expressive answers. You are more likely to learn more about a person by asking open ended questions.”</i>
Session 5. Conversation entry	<i>“What happens if you try and join a group discussion without knowing the topic of conversation?”</i>	<i>“You could interrupt the conversation, and this may be perceived as bad mannered. A topic related statement or question is more likely to be accepted by the group.”</i>
Session 6. Good sportsmanship	<i>“What is the importance of being a good sport if you lose a game?”</i>	<i>“If you congratulate a person or group/team for winning, it is more likely that they will want to play with you again in the future.”</i>

Therapeutic Alliance

Research strongly suggests that the therapeutic alliance has an association with positive treatment outcomes in typically developed and ASD individuals (Albaum, Tablon, Roudbarani, & Weiss, 2020; Haug et al., 2016). A strong therapeutic relationship is important as it helps the client and therapist work collaboratively towards a shared goal (Jones, Peters, & Barker, 2009). It was important for the therapist to build the foundations of the therapeutic alliance by providing empathy, positive regard and congruence early in the therapeutic process. Research has shown that when CBT therapists demonstrate empathy and trust, they have a better working alliance and their clients obtain more positive outcomes (Jones et al., 2009).

In order to build the therapeutic relationship, multiple communication, cognitive and emotional skills need to be considered when adapting CBT interventions for an ASD population (Attwood, & Scarpa, 2013). A guidance protocol for communicating and working with adults with ASD was developed by the researcher for the CBT therapist delivering CBSCTI-ASD (see Appendix G). In part, the guidance protocol for communication was developed using responses collected on 6th of December 2017 during a consultation meeting with the Autism@Manchester University expert by experience advisory group. Advisors of the group involved, experts in the field, adults with ASD and family members effected by ASD. During the meeting member comments were collected, collated and documented. Comments by both experts and individuals with experience of ASD were used to help inform the development of the guidance protocol for communication with ASD participants (see Table 9). Recommendations were also considered from recognised national guidance documents which includes; the Advocate’s Gateway (2016) tool kit for questioning someone with ASD, the West Midlands Police Federation (n.d.) interview guidance notes for people with ASD and the National Autistic Society (2017) guidance for recruiting an autistic employee.

Responses from consultation with ASD experts and individual effected by ASD

Input from experts of ASD	Input from those with ASD experience
<i>“Clarity of phrasing is important.”</i>	<i>“Use literal speaking or we are likely to have a big misunderstanding”</i>
<i>“Keep language clear and simple and check for understanding regularly.”</i>	<i>“Don’t assume we understand you. We may think that we understand what you are saying even when we do not.”</i>
<i>“Avoid multi-layered questioning.”</i>	<i>“Only ask me one question at a time. Give time to think about the answer and don’t assume a slow response is a way of avoiding the question being asked.”</i>
<i>“Do not use ‘tag’ questioning.”</i>	<i>“Keep the questions simple and repeat them to make sure I understand what you are asking me.”</i>
<i>“More focus on thoughts and behaviours.”</i>	<i>“Don’t ask how I feel but rather focus on what I think. If you ask me how I feel in the past, I’ll most likely answer with how I feel in the present moment. I am more accurate at discussing my thoughts rather than feelings.”</i>
<i>“Build a strong therapeutic relationship.”</i>	<i>“Give time to talk about special interests within the session as this will help build a better relationship even if it is not directly related to the current topic of therapy.”</i>
<i>“Training should focus on practical social skills which lead to better social functioning.”</i>	<i>“Conversation is my biggest challenge when meeting new people. It is often difficult to understand my own emotions and the emotions of other people.”</i>
	<i>“I get frustrated when I am not understood. I am always angry.”</i>

Group Cohesion

The group sessions are tailored to foster the therapeutic alliance and build trust within the group. To help aid early group cohesion, two icebreaker activities were used to encourage appropriate self-disclosure and establish clear group boundaries. The first icebreaker was taken from the University of Manchester *Peer Support Icebreakers* booklet (n.d.). This icebreaker activity involves the facilitators dividing the group members into pairs. Pairs are asked to interview each other, and each interviewer is instructed to find out three interesting facts about their partner. After the completion of the interviews, group members present the three facts about their partner to the rest of the group. This task provides group members their first experience of exchanging information and sharing within the group therapy setting.

The second ice breaker termed “group rules” is a commonly used technique in group CBT (Bieling, McCabe, & Antony, 2009). This activity forms the basis for the group’s working agreement which helps members to come to an arrangement on how they will work together respectfully and effectively (Flores & Georgi, 2005). This activity aims to enable group members to interact in a co-operative manner and maintain respect for other group members (Estes & Henry 1976). The task requires the group members to collaboratively discuss and write down what rules they would like to suggest for their group working agreement. This task provides an opportunity for early interactions and a platform to use a group voice for the first time. A brief group discussion follows allowing each participant to give a reason why a particular rule is important. Once the task is complete, the group facilitator contributes by adding predefined boundaries from the CBSCTI-ASD manual (see Table 10). Group rules for the CBSCTI-ASD working agreement were developed in alignment with the APA Procedures and Guidelines for Group Therapy (Breskin, 2011).

CBSCTI-ASD group rules for the working agreement

Rules	Description
Confidentiality	What is said in the group, stays in the group
Respectful and helpful	Be polite and if others struggle, support and help them
Commitment to therapy	Attend all six group sessions
Take breaks	10-minute breaks after an hour
Arrive on time	Try and arrive on time and if you are going to be late enter the room and join the group without disruption. Wait to speak until you are addressed by the group facilitator(s)
Phone us if you can't attend	If you know you cannot attend let the facilitators know with a text or phone call as soon as possible
No phones	All mobile phone to be turned off and left in pockets during each session
Speak clearly	Speak loud enough so everyone can hear you
Homework completion	Complete any tasks assigned on time

There is a well-established relationship between bonding and therapy outcomes (Maltzman, 2016). The final group therapy session aimed to encourage lasting bonds between group members, while ending therapy in an enjoyable social context. Providing the group with a fun social activity was important for demonstrating how they can continue to grow their bonds outside the confines of the therapy group. Social games have been shown to help aid in social skills development (Tse et al., 2007) and they can also provide the platform for group members to practise their social skills together after therapy ends. All the games offered must encourage both verbal and nonverbal communication during social interactions. The CBSCTI manual provides two examples of such games: 1). Headbandz “who am I” is a game where the aim is for a player to figure out if the cartoon card on a player’s head is a specific animal, food or man-made object by asking as many questions as possible in a short time period. 2). Charades is a parlour game which requires a person to act out while the rest of the group guess each syllable of a word or phrase in order to learn the whole phrase.

Group Discussions

Group discussions aim to address any anxiety provoking thoughts, help consolidate knowledge, develop coping strategies and reflect on performance. Group discussions are used to provide concrete reasoning for learning new skills. During psychoeducation lessons, group discussions provide the rationale for why the skills are being taught and why they are important to learn. The beginning of all group sessions started with a check-in group discussion. Check-in discussions aimed to encourage group members to share, reflect and evaluate their weekly social experiences. Group discussions provide the platform for gaining insight into social difficulties and formulating problem-solving strategies (Howlin & Yates, 1999). Problem-solving discussions were essential after completion of social skills tasks and activities. Discussions facilitate the development of problem-solving strategies which can be used by group members outside of the therapeutic setting (Oradee, 2012).

Collaborative Social Problem Solving

Group discussions often include “social autopsies” to aid group members with social problem solving. The social autopsy formulation breaks down social problems so the individual can gain a deeper understanding of the problem (Bieber, 1994). Collaborative

social problem-solving strategies were developed to find possible solutions, monitor progress, evaluate and select options, and if relevant, agree on contingencies. Social problem solving is a collaborative process to test and challenge the rationality of specific cognitions and to encourage or foster the modification of associated maladaptive behavioural patterns (Hofmann et al., 2012). Mutually identifying issues and considering the causes are the first line of investigation. Discussing the details of what happened during a problematic event are explored using a rational problem-solving formulation (see Table 11). Rational problem-solving formulations are the constructive application of rational, deliberate, and systematic problem-solving strategies (Chang, D’Zurilla, & Sanna, 2004). Exploring the differing possible outcomes and identifying accommodating strategies, in part, forms the basis of mutually agreed goals.

Problem solving formulation adapted from D’Zurilla, Nezu & Maydeu-Olivares, (2004) social problem-solving model

Stages	Description
Identify the problem	Break the problem down into smaller steps and decide what you need to action first
Explore possible solutions	Generation of alternative solutions
Decision making	Choose a solution
Implementation	Collaborate to identify coping strategies and available resources
Verification	Evaluate how well the solution worked. Review strategies and be flexible with adaptation.

Social Cognition Intervention

Social cognition is therapeutically targeted by addressing the perspectives of others during social skills activities. Taking on the perspective of others, or “Theory of Mind” (ToM), is a well-documented social impairment for many individuals with ASD and has been the focus of several social skills interventions (Miller, et al, 2014). First-order false belief tasks were developed to help members understand that it is possible to hold false beliefs about events in the world (Wellman & Liu 2004). Second-order false belief tasks were developed to help group members realise that it is possible to hold a false belief about other’s beliefs (Miller, 2009). Throughout group therapy, the group facilitators utilise perspective taking questions such as *“I know how you experienced the situation but what do you think it was like for the other people involved?”* Perspective taking questions were asked repeatedly and predictively with a similar line of questioning being used each week. The following three perspective taking questions were commonly used when having group discussions: *“What do you think that was like for the other people around you?”*, *“What do you think they thought of you”* and *“Do you think they are going to want to talk to you again?”*. Such repeated lines of questioning aim to develop a schema which provided some context dependant meaning when social demands are experienced (Laugeson & Park, 2014).

Three tasks were developed in the CBSCTI-ASD program which aimed to enhance social cognition (see Table 12). The “time for change” activity was developed to enhance motivation for change and challenge second order ToM, a common deficit in adults with ASD (Baron-Cohen, 2000). The activity was introduced in the first session and required members to list what they believe their three largest difficulties are when communicating with others. Group members are then asked to think of a person that they have regular social interactions. They then write down what the person they chose would believe their largest difficulties are in communication with others. Group members are then asked to share if the challenges in both lists were the same or different. Once all members of the group share their list of difficulties, they are required to then complete the following statement. *“If these difficulties in communicating with others’ were not a struggle I could...”*. This activity followed with a problem-solving discussion about the items on their list.

Social cognition activities developed by the researcher

Session	Activity	Social Cognition	Demands of the task
Session 1	Time for change worksheet	Second order ToM	The realization that it is possible to hold a false belief about someone else's belief.
Session 3	Active listening activity	First order ToM	Reflect on what someone is thinking or feeling
Session 4	Mirror talk paraphrasing activity	First and second order ToM	Paraphrasing fosters reflection of what others are feeling or thinking and aids in the recognition that other can hold a false belief.

The third session included a popular active listening activity known as the “The Best Holiday Ever?” (see Exercise C., Birmingham City University, n.d.). The activity aims to enhance listening skills and enhance the ability to make inferences based on a conversation. For this task the group members were paired and given the title of either “the talker” or “the listener”. The talker must describe what they want from a holiday but without mentioning a destination. The listener must be attentive to what is being said and what is not quite being said. After a few minutes the listener must summarise the three or four main perspective points that they heard the talker express and then make a tentative sale of a suitable destination based on the listeners perspective of an ideal holiday. Then roles are reversed, and the activity is repeated.

To target a combination of first and second order ToM, a mirroring exercise (Mirror talk paraphrasing activity) for session four was developed. This exercise includes verbal and nonverbal mirroring techniques (Clabby, & O'Connor, 2004; Manusov, 1992) and requires group members to use paraphrasing and appropriate body language during a conversation. Group members must attempt to demonstrate how to appropriately read a person’s expression and how to demonstrate an understanding of the talker’s message. Interventions commonly teach facial mirroring and paraphrasing skills for having a shared conversation (e.g., Kingsep & Nathan, 2003; Laugeson & Frankle 2010). The activity requires group members to have a conversation following the topic of “my hobbies”. While each pair takes turns attempting to use mirroring and paraphrasing during their conversation, the group facilitators are responsible for providing positive and corrective feedback.

Psychoeducation

Didactic instruction is a popular CBT technique used in therapy to aid learning. Kennett-Levy and colleagues (2009) investigation into which CBT training methods were perceived to be most effective and they found didactic instruction to be one of the most useful methods for teaching declarative knowledge. Psychoeducation lessons are used to clearly teach structured strategies and techniques which aim to improve social competence (see Table 13). Psychoeducation lessons always provide a rationale for learning new social skills. Each lesson includes a description of skills, contextual application of skills and skills appraisal. Socratic questioning is used after every skills description, followed by the group facilitator providing a rationale response as outlined in the CBSCTI-ASD manual. There is a significant amount of skills overlap in the psychoeducation curriculum and this aimed to enhance skills through repetitive practise. Since repetition may not always translate into the learner applying the knowledge across different situations (Harris et al., 2015), lessons are designed to aid rote learning through repetition, while role-play provides the opportunity to practise skills across various situations.

CBSCTI-ASD psychoeducation curriculum includes only the operational definitions of social skills (verbal and non-verbal) with an evidence-base. Psychoeducation lessons cover six social interaction topics which include: 1. starting a conversation and exchanging information, 2. making a request, 3. active listening, 4. sharing a conversation, 5. entering a conversation 6. good sportsmanship. Skills which are included in the psychoeducation lessons aim to provide the strategies for achieving a competent and meaningful social interaction during conversation exchanges. The curriculum for the psychoeducation lessons combine a number of non-verbal and verbal communication skills which have been shown to be effective in starting and maintaining a conversation.

The first lesson aims to teach the skills for starting a conversation and exchanging information. The skills taught in the lesson include; staying calm when approaching others (Kornacki, et al., 2013; Laugeson & Frankel, 2010; Tse et al., 2007), standing or sitting an arm’s length away during a conversation (Kornacki, et al., 2013; Nuernberger et al., 2013; Ryan et al., 2017), making eye contact with the

person (Dotson et al., 2010) and occasionally moving your gaze so you seem not to stare (Laugeson & Frankel, 2010). Show an interest in others by posing a question about the other person (Ryan, Brady, Holloway, & Lydon, 2017; Nuernberger et al., 2013) and share similar information about yourself (Dodge et al., 1983; Laugeson & Frankel 2010; Tse et al., 2007). Maintenance strategies were taught for when a conversation goes silent, such as making a new comment or pausing to assess how well the conversation is going (Laugeson & Frankel 2010). Each lesson combines newly learned social skills with the social skills taught in prior sessions.

The aim of the second psychoeducation lesson is to combine the skills of exchanging information with the skills of making a request. Group members are taught that a successful request must be stated clearly, followed by telling the person how you would feel if your request was accepted (Laugeson & Frankel, 2010). It is important to be polite even if the request is denied (Tse et al., 2007), and avoid pressing the person once you have been denied or they may not help in the future (Laugeson & Frankel, 2010).

Advancing nonverbal communication was an important focus of lesson three. Effective listening skills require individuals to avoid distractions (Dotson et al., 2010), provide appropriate facial expressions (Tse et al 2007), making eye contact when the person is speaking (Kornacki et al., 2013), provide encouraging body language or verbal cues to show you are interested in what the person is saying (Fitzgerald & Leuda, 2010) and mirroring body language (Kingsep & Nathan, 2003). Group members are also taught that it is important to ask clarifying questions when listening to others and take time to consider what the other person is saying (Nuernberger et al., 2013).

The fourth lesson aims to develop the verbal abilities needed to share and maintain a conversation. Verbal and Nonverbal social skills for sharing a conversation include; using open-ended questions to gain more information about others (Dodge et al., 1983), taking turns speaking (Dotson et al 2010; Kornacki et al., 2013), changing the topic from time to time, avoiding repetitive questioning (Laugeson & Frankel, 2010), not interrupting the speaker (Dotson et al 2010; Kornacki et al., 2013) evaluating the conversation by reading the body language of others (Laugeson & Frankel, 2010) and ending the conversation politely (Dotson et al 2010; Nuernberger et al 2013).

The aim of lesson five is to provide skills for the successful entry into a conversation. to successfully enter a conversation requires a sequence of tactics which are broken down into either low-risk or high-risk tactics (Dodge et al., 1983). The low Attempts risk tactics for conversation entry include; looking and listening, showing an interest by moving closer and hover until the right opportunity appears e.g. a pause in the conversation (Dodge et al., 1983; Gottman, 1977). High risk tactics are typically verbal responses, however successful entry requires the individual to ascertain a "frame of reference" (Phillips, Shenker, & Revitz, 1951) common to the group members. This can be achieved by making a topic related statement or asking a question which is relevant to the group conversation, provide a group-oriented statement, or imitate the actions of others in the group such as laughing (Dodge et al., 1983; Putallaz, 1983; Putallaz & Gottman, 1981). When combined, these tactics provide group members with a strategic approach to entering the conversations of others.

In the sixth and final psychoeducation lesson, the topic of good sportsmanship was addressed. Due to social impairment, it is unlikely that children with ASD ever get to possess adequate sportsmanship skills due to a lack of participation (Ferguson, Gillis, & Sevlever, 2013). It is likely that adults with ASD will still be unaware of appropriate sportsmanship behaviours and this may impact on future group social interactions e.g. group games or competitive activities with friends. A list of rules for good sportsmanship were developed using recommended guidelines for good behaviour during group activities (Stanford Children's Health: Teaching Children Good Sportsmanship). The rules for good sportsmanship aim to ensure all group members are respectful toward each other and engaged in appropriate communication.

Group psychoeducation lessons curriculum

Psychoeducation lesson	Social skills curriculum
Lesson One: Starting a conversation and exchanging information	<ul style="list-style-type: none"> ➤ Calmly approach with a greeting and do not get too personal in the first meeting ➤ Keep an appropriate distance ➤ Make variable eye contact i.e. eye contact but do not stare ➤ Show an interest in the other person by posing a question about the person ➤ Share similar information about yourself ➤ Share the conversation and take turns speaking ➤ Allow the other person to lead the conversation and avoid interrupting ➤ If the conversation goes silent ask a question or make a new comment based on the other person's interests or share an interest of your own ➤ Stop and assess how well the exchange is going. Is the other person making eye contact with you and showing an interest back?
Lesson Two: Making a request from others	<ul style="list-style-type: none"> ➤ Make variable eye contact i.e. eye contact but do not stare ➤ Be clear and say exactly what you are requesting ➤ Tell the person how you would feel if your request is carried out ➤ Be polite, even if your request is denied ➤ Avoid repeating the request if you are denied as this may be seen as badgering or nagging
Lesson Three: Active listening skills	<ul style="list-style-type: none"> ➤ Mirror facial expression ➤ Make variable eye contact i.e. eye contact but do not stare ➤ Minimal encouragers ➤ Body posture and Mirroring ➤ Asking a clarifying question ➤ Reflect on what the person is saying ➤ Avoid distractions
Psychoeducation lesson	Social skills curriculum
Lesson Four: Sharing a Conversation	<ul style="list-style-type: none"> ➤ Using open-ended questions ➤ Pause, listen and do not interrupt ➤ Take turns exchanging information ➤ Avoiding repetitive questioning ➤ Change the topic from time to time ➤ Use and read body language ➤ Ending the conversation
Lesson Five- Entering a conversation	<p>Step 1: Look and listen before entering into a conversation</p> <p>Step 2: Show interest by moving closer</p> <p>Step 3: Wait for the right opportunity to enter a conversation</p> <p>Step 4: Ask a question or make a topic related comment</p> <p>Step 5: Read the body language of others once you have entered the conversation</p>
Lesson Six- Good sportsmanship	<ul style="list-style-type: none"> ➤ Avoid arguing. ➤ Everyone should have a chance to play. ➤ Play fair. ➤ Follow directions and rules. ➤ Respect others. ➤ Encourage teammates. ➤ Respect the decisions of referees and other officials. ➤ End with a handshake or a comment such as good game (even if you lose the game).

Behaviour Modelling

There is growing research supporting the use of modelling strategies for teaching social skills to an ASD population (e.g., Gantman et al., 2014; Laugeson et al., 2015; Stichter et al., 2010; White et al., 2013). Modelling is a common technique used in CBT (Laugeson & Park, 2014) and typically involves the therapist effectively demonstrating the strategy or social skill being taught. In the CBSCTI-ASD program, modelling is typically used to support the practical application of the psychoeducation lesson content. Modelling is predominantly performed by the group facilitators, however at times it is encouraged to include the active involvement of group members (e.g., when modelling a two-way interaction).

Skills modelling typically provides examples of both acceptable and unacceptable behaviour. Fostering the principles of “Social Learning Theory” (Bandura, 1977), the modelling activity in session five was developed to improve social competencies through observational learning. The activity requires group members to model the skills for entering a conversation. The activity begins with two group members entering a conversation based on a predefined topic (e.g., watching football). Other group members then observe the group facilitator model both a successful entry and an unsuccessful entry (e.g., failed entry demonstrated with an abrupt interruption and an off-topic comment). Following the demonstration, in turn, group members are asked to then model a successful and unsuccessful conversation entry. This activity ends with a brief discussion about group entry strengths and weaknesses.

Role-Play Activity

One of the greatest consequences of social isolation in adults with ASD is that they have had limited opportunity to practice their social skills (Tantam, 2014). There is substantial evidence supporting the use of role-play as an aid to teaching social skills to adolescents and adults with ASD (e.g., Gantman et al., 2014; Laugeson et al., 2015; Stichter et al., 2010; White et al., 2013). Role-play activities involved a repeated run through of social skills in a safe, non-threatening environment. Dependent on the aim of the skills being taught, role-play activities are performed in pairs or small groups. Role-play requires the group members to perform social skills which are introduced during the psychoeducation lessons. Facilitators monitor progress and provide both positive and corrective feedback during role-play activities. Facilitators adopted a scaffolding approach whereby combining general and specific instructions are provided based on the level of support needed to help a group member successfully complete a task (Wood et al., 1976).

Role-play activities have also been used by clinicians to rate performance or measure levels of social competencies in individuals with ASD (e.g., Webb, Miller, Pierce, Strawser, & Jones, 2004; White et al., 2015). This concept was taken to develop an observer-rated group activity where group members are asked to rate other group members social skills performance. In the fifth session, group members were required to enter a conversation between two group facilitators. The facilitators engage in a conversation with a predetermined topic and one group member attempts to enter using the appropriate steps. All other group members observing the task then provide a performance rating on a simple Likert scale. At the end of each attempt, the observers are asked to provide a brief explanation for their rating (e.g., what they thought went well and did not go well). This activity provides group members with the opportunity to observe and then practise the skills necessary for entering a group conversation. It also provides an opportunity for the group facilitators to challenge any misconceptions about the steps needed for an appropriate conversation entry.

The role-play activity in session two required the group to work together to brainstorm a list of “social scripts”, Social Scripts are a social narrative that provides direct instructions for social situations. Social scripts have been shown to increase fluency of appropriate social behaviours (Barnhill, 2002). Group members were first asked to complete a list of their ideal occupations and then write some possible requests which they may need to ask in these occupational settings. Group members are then required to write a dialogue on a blank role card which includes one of the requests in their list. Each script was required to include instructions on how to make a polite request in relation to their ideal occupation(s). The group members are then asked to role-play at least one request, ensuring to follow the steps provided in the psychoeducation lesson. Following each role-play request, feedback is then provided by the therapists.

Group Therapy Homework

Homework activities in the group sessions were developed to aid social skills learning and self-reflection. Journals have been shown to increase cognitive processing during writing (Ullrich & Lutgendorf, 2002). Journals are used as weekly homework in group sessions and required group members to keep a log of thoughts and skills practise which occurred during the intervening time between

sessions. During group discussions these logs are explored using cognitive journaling formulations using specific or hypothetical events in which particular skills are utilised.

The “buddy system” was introduced in the second session to encourage group interactions and to provide support outside of the confines of the therapeutic setting. This activity requires group members to stay in contact with a different person each week. Group facilitators organised a phone roster to rotate contact between group members each week. The aim is to encourage the use of skills between sessions and enhance group cohesion between members.

Parent/Caretaker Involvement

There is evidence to support the inclusion of parent and caretaker involvement in CBT social skills interventions for adolescents and adults with ASD (e.g., White et al., 2013; Gantman et al., 2014). Parents acting as social coaches are invited to join the concluding 10 minutes of each individual CBT session so they can help with weekly goal setting, aid skills practise between sessions and encourage the completion of weekly or ongoing homework tasks. Parents/Caretakers have a less active role in group therapy, but they are provided with the weekly curriculum of the psychoeducation lessons. Parents are asked to play a supporting role by reviewing lesson materials and encourage the use of newly learned social skills during family interactions. During individual therapy sessions parents also play a vital role by consulting the therapist on progression and any challenges experienced.

Intervention Preparation

Prior to acceptance onto CBSCTI-ASD, a telephone screening interview is recommended. This interview will aim to establish if the program is acceptable for the applicant.

Intake Consultation

An intake interview for the potential participant and caretaker will be completed prior to commencement of the intervention. The intake interviewer will review the content of the program, address any questions and administer screening measures. In the event that a participant is found to not be appropriate for the treatment a full explanation needs to be provided. It is important to ensure that the participant wants to be a part of the program and equally there is a substantial commitment from the parent/caretaker to have regular involvement in the individual sessions and to provide skills support outside the confines of the treatment room.

Once completed and eligibility has been established the consultant will provided an official placement offer. At this point a welcome letter will be given which will specify the exact start day and time for the intervention. **Participants will be asked to sign and return documents within 48 hours to secure the program placement.**

Session Key

☞ = Provide Handout

☞ = Therapist Instructions

Italic print = Read Out Loud

Session 1. Group Introduction & Exchanging Information

Component 1. Introductions

👉 **Provide** the loose leaf folder for handout/worksheet storage📁

🌀 The formation of this group may represent a new and possibly anxiety-provoking experience. To reduce the anxiety of participants in the first session, the first Component of group interaction will involve two “ice breaker” tasks that together will last no longer than 30 minutes in total.

Ice breaker 1. The interview

Time: 10 minutes

🌀 Divide the young people into pairs. Ask them to take three minutes to interview each other. Each interviewer has to find 3 interesting facts about their partner. Bring everyone back to together and ask everyone to present the 3 facts about their partner to the rest of the group. Watch the time on this one, keep it moving along.

Ice breaker 2. Group rules

Time 20 minutes

🌀 The second ice breakers is a “group rules” activity. The group works together to write down what rules they would like to suggest for the 6 week working agreement. This encourages early interactions and allows the therapist to encourage each participant to contribute. Go around the room and ask each participant to suggest a rule. If the participants struggle with this task, consider suggesting the follow:

Suggested Group Rules:

- *Confidentiality*
- *Respectful and helpful*
- *Commitment*
- *Breaks*
- *Arrive on time*
- *Phone if you can't attend*
- *Turn off mobile phones during session time*
- *Speak clear and loud so everyone can hear you*
- *Homework completion*
- *Buddy system*
- *Commitment to therapy*

Component 2. Group Activity- Time for change

Self-Disclosure: The “Time for change” Handout is needed for this activity

Time: 10 minutes

🌀 The purpose of SCTI-A is to enhance social competence using a therapeutic approach. In order for participants to become accustomed to the process of opening up, it is important to ensure this is occurring in a safe environment. Although self-disclosure is an important group goal, the primary therapeutic goal involves improving participant’s social skills. In order to combine these two elements, participants are provided with a “time for change” handout and are asked to take a few minutes to complete it.

📌 **Provide:** “Time for change” handout:

Awareness

A) ‘My biggest difficulties in communicating with other people (friends, family and people I don’t know that well) ARE...’

B) ‘what do others think of my communication skills...’

Reflection

A) “What would my life be like without these difficulties?”

👉 Take a few minutes to take suggestion from the group and write them down on the white board.

Component 3. Psychoeducation Lesson One: Learning to Exchange Information

Lesson Time: 40 min

Rationale for learning how to exchange information.

Question: Ask the group why they think it’s important to exchange information in a conversation?

👉 Provide Rationale: *Explain that exchanging information is a naturally occurring event during conversation. Typically conversation exchanges involve discussing ideas, interests and thoughts. Exchanging information will allow you to find a common interest and hold a meaningful conversation.*

📌 **Provide** the handout “Tips for exchanging information”.

👉 Go through each strategy for exchanging information and model (provide a micro-demonstration for each item) the appropriate behaviour. Ensure to repeat the demonstrations upon request from the group members.

- Calmly approach and introduce yourself (Name exchange) or supply a friendly greeting (exchange of pleasantries). Do not get too personal in the first meeting as this can make some people feel uncomfortable.

Question: Why would you not want to get personal in the first meeting?

Answer: This can make people feel uncomfortable and this may stop the conversation from progressing further.

- Start a conversation by showing an interest in the other person. Pose a question to the other person (e.g. interests, activities, hobbies).

Question: Why is it important to show interest in someone else?

Answer: This is a good way to get to know more about an individual and see if you have any common interests.

- Keep an appropriate distance, make variable eye contact and smile occasionally when exchanging information

Question: Is body language important when talking to another person?

Answer: Yes. It show the other person you are actively listening and want to keep the conversation going. It’s important to stand or sit at a minimum of an arm’s length. When participating in the conversation ensure you are look at or looking towards the other persons face.

- Share similar information about yourself (e.g. interest, hobbies).

Question: Why would you share similar information about yourself?

Answer: This exchange may help you to establish a common interest.

- Conversation is a two way street. Share the conversation and take turns speaking

Question: Why should you take turns speaking?

Answer: Sharing the conversation allows the continuation of information exchange and allows bonds to be build. You should aim to make a statement or pose a question based on the topic. To avoid shifting the topic, it is recommended that you make a minimum of three statements on the same topic

- Pause and give the other person time to answer or ask a question (do not interrupt even if you think you know the answer to the question).

Question: If you interrupt, how may others see you?

Answer: Interruptions are typically seen as rude behaviour and can suggest to the other person that you do not want to listen to what they have to say.

- Ensure to pause and allow the other person to lead the conversation. If the conversation goes silent ask a question or make a new comment based on the other persons interests.

Question: Why is it important to allow the other person a chance to lead the conversation?

Answer: Only talking about what you are interested may become boring for the other person and could lead to the other person ending the interaction.

- Stop and assess how well the exchange is going. Is the other person making eye contact with you and showing an interest back?

Question: What should you do if you notice the other person is no longer showing an interest in you?

Answer: If a person does not seem interested, politely end the conversation (it was nice talking to you, goodbye) and move on.

Component 4. Role-play & Repeated Rehearsal

Activity: Role-play

Time: 30 minutes

☞ Once you have modelled how to exchange information correctly ask the participants to get into dyads (If odd number use one triad). Ask each pair to practise exchanging information with the goal of finding something in common. Remind the participants to use the handout and tell them you and the assistants (use names) will be moving around the room helping to facilitate the interaction with positive and corrective feedback. Time permitting, end this activity by having volunteers demonstrate a good exchange and a bad exchange to the group.

Component 5. Close Session

Practice makes perfect

Time: 15 minutes

☞ At this point, the therapist introduces the need for practice outside of session times. It might be useful to point out that practice involves changing behaviours using the skills learned. Foster perseverance and persistence and explain that with practise over time they will begin to think, behave and feel differently as they become more socially competent.

👉 **Provide** “My Journal” handout

☞ This activity ends the session. Take the final 5-10 minutes to introduce the “My journal” handout and explain that at the end of each session participants are encouraged to write down a few things they feel were important to learn. Remind the group to practise what they have learned and as they practise, record thoughts and feeling in their journal entry. Finally, thank the group for their participation and have the participants add all the handouts to their folder before they leave.

Session 2. Conversation Skills-Making Requests

Component 1. Session Opening-Recap

Recap Time: 10 minutes

☞ Begin the session with a recap of the first session. Briefly remind the participants of the group rules and review the exchanging information worksheet. Allow the participant to take ten minutes to again practice having a conversation using the rule on the worksheet. Have the participants work the same dyad as the week before and remind them that the aim is to gain more information about each other.

Component 2. Psychoeducation Lesson Two: Making a request

Lesson Time: 40 min

Rationale for learning how to make a request.

Question: Why is it sometimes important to ask another person to do something or to ask someone to help?

☞ Have each participant write one reason they feel it would be important to make a request. Once the participants have finished, write a few of the participant’s suggestion on the whiteboard. Consider suggesting the following rationale.

☞ Provide Rationale: *A request is an act of asking politely or formally for something. Often people will use a request to make future arrangements or plan activities with friends. More importantly, in anyone’s life, situations come up where it is necessary to ask another person to do something or ask for something. A request that is heard as a demand or as pestering usually does not lead to the person wanting to follow through with the request. Making a request in a positive way, however, is usually less stressful and is more likely to lead to the request being met.*

☞ As a group go through the steps that help you make a successful request and model (provide a micro-demonstration for each item) the appropriate behaviour. Ensure to repeat the demonstrations upon request from the group members.

☞ **Provide** the Making a request handout.

☞ Go through each strategy and ask the suggested questions and answers

1. The speaker needs to look into the listener’s eyes, but it is important that the speaker moves their gaze around the listener’s face to avoid staring.

Question: Why does the listener move their gaze?

Answer: If you are listening, it is important to be mindful not to stare at one single spot on the speaker’s face as this may result in the other person becoming uncomfortable and ending the conversation.

2. Be clear and say exactly what you are requesting e.g. *“I would like you to join me at the science museum next week” or “I don’t drive, may I please have a ride in your car to the museum”?*

Question: Why is it important to be clear when making a request?

Answer: If the other person does not clearly understand your request they are more likely to reject your request.

3. Tell the person how you would feel if your request is carried out e.g. "I would really enjoy your company at the museum" or "I would be very grateful to you for a ride to the museum."

Question: Is it important to express your feeling when making a request.

Answer: Yes. Expressing your feelings lets the other person know that the request is important to you. Additionally, if rejected, it provides the opportunity to politely accept their decision.

4. Be polite, even if your request is denied. Once you have been denied the request it is important to except their answer. Avoid repeating the request as this may be seen as badgering or nagging.

Question: Why would you want to be polite if the request is denied?

Answer: Just because your request was denied the decision was most likely not personal. There may be a time in the future when the other person grants you a request.

☞ Take the next few minutes to discuss the modelled conversation and review the strategies again before starting the role-play activity.

Recommended break

Time: 5-10 minutes

Component 4. Role-play & Repeated Rehearsal

Activity: Role-play

Time: 30 minutes

☞ Once you have modelled how to successfully make a request, ask the participants to get into dyads (If odd number use one triad) just as they did in the previous session. Encourage the group to work with a person they have not yet worked with. Ask each pair take turns practicing exchanging information and finish the conversation by making a request. Remind the participants that you and the assistant will be moving around the room helping to facilitate the interaction with positive and corrective feedback. From time to time the therapist may need to step in and work directly with a participant. Time permitting, end this activity by having volunteers demonstrate to the group "how to make a successful request".

Component 5. Group Activity-Making a Request

Group Activity-Making a request

Time: 20 minutes

☞ **Provide** the activity handout "Could you do me a favour?"

☞ **Provide** each participant with blank role cards.

☞ Have the group work together to brainstorm a list of as many occupations as they can. Once they have completed their list, have them write a dialogue in the blank role card and includes as many requests as possible. Each dialogue should feature one of the careers they listed in their brainstorming session and should use a variety of methods for making polite requests.

Component 6. Close Session

The buddy system

Time: 15 minutes**👉 Provide phone roster handout**

🌀 As a closing activity the therapist now introduces the idea of being paired with another randomly selected participant with whom they will agree to be in phone contact (talk and text) each week. Pairs are encouragingly rotated every week. Encourage the participants to use the skills learned to find a common interest and use that topic to continue and guide the conversation.

🌀 Take the final 5 minutes to take out the “My journal” handout and encourage the participants to write down a few things they feel learned. Remind the group to practise what they have learned and as they practise, record thoughts and feeling in their journal entry. Finally, thank the group for their participation and have the participants add all the handouts to their folder before they leave.

Session 3. Conversation Skills- Active listening skills

Component 1. Session Opening-Recap

Recap Time: 10 minutes

🌀 Begin the session with a friendly greeting and have the participants take out their loose-leaf folders as they will need their handouts for the recap activity. The therapist then recaps strategies learned from the psychoeducation lessons. Allow the participant to take ten minutes to again practice having a conversation following the handouts. Have the participants work in dyads for this recap. Explain to the dyads that the aim of this activity to find a common interest and to make a request based on this interest e.g. “*what is your favourite DVD? I like that DVD also, it is one of my favourite movies. It would really make me happy to see it again, may I please borrow the DVD next week?*”

Component 2. Psychoeducation Lesson Three: Listening Skills

Lesson Time: 30 minutes**What is active listening?**

🌀 Listening is one of the most fundamental component of interpersonal communication skills. Listening is not something that just happens (that is hearing), listening is an active process in which a conscious decision is made to listen to and understand the messages of the speaker.

Rationale for active listening.

🌀 Ask the following two questions and allow the group to answer without corrections. Then provide the rationale below.

Question: Why is it sometimes important to listen to another person or group?

🌀 Provide Rationale: *Explain that actively listening is important for making and maintaining friendships as it show the person that you are not just hearing the words that are being said but you are listening to the details and understand (or are trying to understand) the person. Listening to others also provides an opportunity to enter or start conversations based on an already established topic.*

👉 Provide the participants with the “Active Listening Rules” handout.

🌀 Review the following list of verbal and non-verbal signs of listening. Explain to the participants that “*people who are listening are more likely to display at least some of these signs.*” However remind the participants that “*these signs may not be appropriate in all situations and across all cultures.*”

- Make facial gestures briefly from time to time if appropriate. For example in first time meets and pleasant conversations it may be appropriate to smile).

Question: What will the other person think if you occasionally smile when listening?

Answer: Small smiles can be used to show that the listener is paying attention to what is being said or as a way of agreeing or being happy about the messages being received. Combined with nods of the head, smiles can be powerful in affirming that messages are being listened to and understood.

- Make eye contact but do not stare.

Question: Why is eye contact important when having a conversation?

Answer: It is typical and usually encouraging for the listener to face the speaker and look them in the eyes. This demonstrates to the speaker that you are interested and listening. Ensure to move your gaze around and do not stare as this may make others uncomfortable.

- Minimal encouragers

Question: What do you think minimal encourager are?

Answer: A minimal encourager is using a verbal and nonverbal cues that aims to encourage the talker to continue while also letting them know you are listening to what they are saying e.g. agreeing by saying 'Yes' or nodding your head to encourage them to continue. When exchanging large amounts of information active listening allows the listener to gain a better understanding of what the person is attempting to convey.

- Posture should be appropriate

Question: How does your posture impact on listening to a conversation?

Answer: Posture can tell a lot about the sender and receiver in interpersonal interactions. The attentive listener tends to face the speaker, stand or sit at least an arm's length away, look at the persons face and providing minimum encourager. Bad posture can lead to the speaker feeling like you are not interested in what they have to say, which will often lead to the conversation prematurely ending.

- Mirroring

Question: What is mirroring a person?

Answer: Mirroring is when the listener automatically and naturally mimics the facial expressions of the talker. Automatic reflection/mirroring of any facial expressions used by the speaker can be a sign of attentive listening. These reflective expressions can help to show sympathy and empathy in more emotional situations.

- Questioning the other person

Question: How can asking a question show the other person that you are listening?

Answer: The listener can demonstrate that they have been paying attention by asking relevant questions and/or making statements that build or help to clarify what the speaker has said. The use of open questions enables the speaker to expand on certain points as necessary and gain clarification when unsure. By asking relevant questions the listener also helps to reinforce that they have an interest in what the speaker has been saying.

- Reflect on what the person is saying

Question: What is reflection?

Answer: Reflecting is closely repeating or paraphrasing what the speaker has said in order to show comprehension. Reflection is a powerful skill that can reinforce the message of the speaker and demonstrate understanding.

Question: When could you use reflection during a conversation?

Answer: When you are uncertain about how someone feels or how strongly they feel about what has been said.

- Avoid distractions

Question: What kind of body language may show the talker that you are distracted?

Answer: The active listener should try to refrain from facing away, fidgeting, looking at a clock or watch, doodling, playing with their hair or picking their fingernails. These signs may lead the talker to believe you are not interested in having a conversation or that they are wasting your time.

Component 3. Role-play & Repeated Rehearsal

Activity: Role-play

Time: 20-30 minutes

☞ Once you have modelled how to actively listen, ask the participants to get into dyads (If odd number use one triad) just as they did in the previous session. Encourage the group to work with a person they have not yet worked with if possible. Ask each pair take turn practicing exchanging information and making a request but this time be mindful of your body language and use active listening skills. Briefly remind the participants of the strategies that are outlined in the handouts and the aims of the conversation is to discuss a common interest. Also remind the participants that you and the assistant will be moving around the room helping to facilitate the interaction with positive and corrective feedback.

Component 4. Group Activity- Talker-Listener Activity

Time: 10-15 minutes

The holiday task

☞ **Talker** has to describe what they want from a holiday but without mentioning a destination.

☞ **Listener** has to practice active listening skills – listening attentively to what is being said and what is not quite being said and demonstrating their listening to the talker by their behaviour. After 3-4 minutes the listener has to summarise the three or four main issues or criteria that they have heard the talker express and then make a tentative sale of a suitable destination. Then allow a minute to review how well active listening behaviours was demonstrated. Then swap roles and repeat.

Component 5. Close Session

Three good listeners

Time: 5 minutes

☞ As a closing activity emphasise the importance of listening in a conversation ask all the members to write the names of three people whom they consider to be good listeners. The therapist needs to personally check with each participant if they have written down three names (some may find it difficult).

☞ Then ask the group the following questions

Question: Do the three people you have written down, fall under one of these categories: I like them, I love them or I respect them.

☞ The response normally is yes. Even if someone writes the name of the person whom they don't like, that person will typically still fall in the category of people respected by the participant. Further highlight this "socially desirable trait" by pointing out that good listeners are often described as liked, loved or respected by others.

Time: 5 minutes

☞ Remind the group members to arrange phone contact with a person on the phone roster. Encourage the group to choose a different person each week.

☞ Finally, have participants take out the “My journal” handout and encourage the participants to write down a few things they feel learned. Remind the group to practise what they have learned and as they practise, record thoughts and feeling in their journal entry.

Session 4. Conversation Skills - Sharing the Conversation

Component 1. Session Opening-Recap

Recap Time: 10 minutes

☞ Begin the session with a friendly greeting and have the participants take out their loose leaf folders as they will need their handouts for the recap activity. The therapist and the participants will briefly review the session handouts.

☞ Ask the participants to join up with the person they engaged in role play with in the previous session (if not possible join with someone else or make a triad). Instruct the participants to have a conversation about what they did over the weekend. After just two minutes ask the participants to stop their conversation. If participants continue or seem frustrated, let them know there is a reason for the abrupt ending which will be discussed.

Component 2. Psychoeducation Lesson Four: Sharing the Conversation

Lesson Time: 20-30 minutes

Rationale for sharing the conversation.

☞ By only giving two minutes for the conversation in the opening activity it is likely the person that started sharing first monopolized the conversation.

Question: Ask the participants if they felt that in their last conversation, one person talked more than the other?

☞ Give the participants a few minutes to reflect and comment on the conversation they just had

Question: Why is it important to take turns in a conversation?

☞ Provide Rationale: *If the conversation is not shared, only one person is exchanging information and the goal of finding a common interest to talk about cannot be achieved. It is likely that the person not sharing will lose interest and end the conversation or just walk away.*

☞ Participants may be more custom to conversing using social media were they express their views, and then respond if others comment. It may be that this is a common issue and the therapist may need to address this issue by explaining that when you are face to face, it may be seen as rude to start the conversation by airing their views (especially when first meeting).

👉 **Provide** the sharing a conversation handout

☞ As a group, go through the strategies for sharing a conversation and read the questions and answers.

- Use open-ended questions. Close-ended questions are those which can be answered by a simple "yes" or "no," while open-ended questions are those which require more thought and more than a simple one-word answer.

Question: Why is it better to use open ended questions?

Answer: Open questions are designed to encourage a thoughtful, expressive answers. You are more likely to learn more about a person by asking open ended questions.

- Pause, listen and do not interrupt. Take time to stop talking and allow the other person a chance to contribute.

Question: Can anyone think of a good time to pause and listen in a conversation?

Answer: After you ask a question. It is polite to allow the other person to answer a question you have asked in full. Do not interrupt, even if you think you know how they are going to answer. A great time to practice active listening skills would be after you ask a question.

- Take turns exchanging information

Questions: What happens if you do not take turns?

Answer: If you do not take turns then a monologue occurs, a monologue in either direction, is not conversation. Try to achieve a balance between talking and listening.

- Avoid repetitive questioning. This means do not just ask one question after another.

Question: Why would asking one question after another be important to avoid?

Answer: Although you may feel like you are keeping the conversation going by showing an interest in the other person, but they may feel uncomfortable, like it's an interrogation. After the other person has answered your question you need to contribute something to the conversation yourself. One way would be for you to answer the question yourself.

- Don't just talk about the same thing, change the topic from time to time.

Question: What happens if you always talk about the same topic over and over?

Answer: Just because you share an interest with someone, it does not mean that is all they want to talk about. Repetitively talking about the same topic limits the scope of the conversation and may result in the other person getting bored.

- Use and read body language

Question: What body language do you think may be important when having a conversation?

Answer: It is important to keep an appropriate distance of an arm's length, face the person, make eye contact, speak to be heard, and mirror the other person e.g. smile with them or frown with them. Avoid distractions such as looking around the room and/or avoid staring at the floor when talking. It is also important to read the body language of others as this can be a sign of how well the conversation is going e.g. a lack of eye contact and withdrawn posture may be a sign that the other person is ready to end the conversation.

- End the conversation

Question: How do you know when the conversation has ended?

Answer: A person may overtly end the conversation but there are time when this is less obvious. When there is a long pause in response to the other person ending the conversation or if the other person responds with a yes/no answers or one word response, this suggests that the conversation has come to an end.

Component 4. Role-play & Repeated Rehearsal

Activity: Role-play

Time: 40 minutes

☞ Once you have modelled how to share the conversation, ask the participants to get into dyads (If odd number use one triad) just as they did in the previous sessions. Encourage the group members not to work with the same person as last week. Ask each pair to take

turns sharing a conversation. Briefly remind the participants of the strategies that are outlined in the handouts. Explain that the aims of the conversation is to exchange information to find out each other's hobbies (an activity done regularly in one's leisure time for pleasure). The therapist and the assistant will need to move around the room and help scaffold the interaction with positive and corrective feedback.

☞ Once the activity is over have a group discussion using the following questions to provoke thoughtful reflection and learning (whiteboard optional).

Question: Did anyone experience being interrupted by the other person? How did that make you feel?

Question: Did anyone feel they did not have an equal part in the conversation? Would you have liked to say more?

Question: How many found this activity difficult?

Question: If you had to choose, what were the most difficult rules to follow?

Component 5 Group Activity- Paraphrasing

Time: 10-15 minutes

☞ **Provide** the My Mirror Talk handout

Mirroring—What I See and Hear

☞ This exercise introduces both verbal and nonverbal mirroring. This activity aims to demonstrate how to appropriately read a person's expression, followed by demonstrating an understanding of what they have said. Facial mirroring and paraphrasing are commonly used skills in a shared conversation. It is recommended that the therapist chooses a participant to demonstrate mirroring and paraphrasing before commencement of the exercise. Have the participants get into dyads and take turns mirroring and paraphrasing. Suggest the following conversation topic, "my hobby".

Component 6. Close Session

Time: 8-10 minutes

☞ Remind the group members to arrange phone contact with a person on the phone roster. Encourage members to choose a different person each week.

☞ Take the final 5 minutes to allow the participants to take out the "My journal" handout and encourage the participants to write down a few things they learned from the session. Encourage the participants to practise what they have learned and as they practise, record thoughts and feeling in their journal entry.

Session 5. Conversation Skills-Conversation Entry

Component 1. Session **Opening-Recap**

Check-in: Time: 10 minutes

☞ Begin the session with a check-in, were participants are asked to share in a therapeutic setting. As social competence grows participants may want to share new social experiences with the group. The aim is to give the participants a space to learn from the experience of others and to further gain group cohesion.

Component 2. Psychoeducation Lesson- How to Enter a Conversation

Lesson Time: 25-30 minutes

Rationale for entering a conversation.

☞ In everyday life adults often have to engage in social situations that require entering or beginning a conversation. At times, these conversations are with people we know and at other times we may be meeting someone for the first time.

Question: Why is it sometimes important to enter a conversation?

☞ Provide Rationale: There are times when it may be difficult to start a conversation and it may be necessary to enter into the conversation of others. Or maybe you are interested in something others are discussing and you have something to contribute to the conversation. Entering a conversation can be a way of getting to know others and making friends.

☛ Provide the “Entry Steps” handout

☞ As a group read through the following strategy of entering a conversation and ask the following question.

Step 1: Look and listen before entering into a conversation. Make sure that you are interested in the topic. If you don't understand the conversation then it is likely you will have very little to contribute and it may be best to find a different conversation.

Question: What happens if you look and listen to the conversation before attempting to enter?

Answer: If you look and listen you can find out the topic of conversation. Once you know what the conversation is about, it is important to consider if you have anything to contribute.

Question: What happens if you try and join without knowing the topic of conversation?

Answer: You interrupt the conversation and this may be perceived as bad manners.

Step 2: Show interest by moving closer but not too close, then make eye contact and mirror the person speaking. Body language will be the first move towards showing the pair/group that you are interested.

Question: What may happen if you get too close?

Answer: If you are perceived as eavesdropping, others may not want to accept you into their conversation or they may move away before you can join. Remember, don't get too close and don't listen for too long before joining in.

Question: Why would we make eye contact and mirror the person that is speaking?

Answer: This allows the person speaking to know that you are listening and interested in the topic. Gestures such as smiling and nodding can show that you are in agreement and have something to contribute to the conversation.

Step 3: Wait for the right opportunity to enter a conversation. Make eye contact with the person speaking and wait for a pause as this is an indication that the person speaking has finished.

Question: Why is it important to wait to speak?

Answer: Interrupting will not give off a good impression. Try to avoid talking over someone that is already speaking, even if you have a good point to make and you think that others will be interested in what you have to say.

Step 4: Ask a question or make a comment (topic related) to enter into the conversation. Do not try to change the conversation topic to one that you are interested in and try to avoid making personal comments if there are people in the conversation that you do not know.

Question: Why should we not try to change the topic of conversation?

Answers: If you try to change the topic of the conversation, you are no longer joining the conversation, you are interrupting the conversation. This may lead to others wanting to end the conversation or move away so they can carry on the original conversation.

Question: what kind of question do you think would be appropriate when entering a conversation?

Answer: An open-ended topic related question. Keep on topic and ask an open-ended question as this opens up the conversation and introduces an opportunity for further discussion. Remember you can exchange more information with open ended questions.

Step 5: **Read the body language of others** once you have entered the conversation. This is an opportunity to see if your contribution is welcome. Read the body language of others and if they do not seem interested, try to not take it personally and try again in the future if the opportunity arises.

Question: What are some signals that may tell you that your attempt to join has been unsuccessful?

Answer: There are a lot of signals and some are more subtle than others. Here are some of the more obvious signals: avoid making eye contact with you, they turn away from you when you speak, roll their eyes when you speak, ignore your comment/question or show signs of aggression towards you.

☞ Remind the participants that rejection may not always be personal. It could be that the conversation is personal or maybe they missed an entry step and others did not know that you wanted to join in. It is important to encourage participants that it is alright to try again. Remind them that if they join half the conversation that they attempt, then they have been successful.

Recommended break

Time: 5-10 minutes

Component 3. Role-play & Repeated Rehearsal

Activity: Role-play

Time: 30 minutes

☞ For this role-play activity the therapist will form a triad conversation loops. The therapist will initiate a conversation with a participant and a second participant will follow the steps to enter the conversation. Approximately two minutes after successfully entry into the conversation the therapist will exit and a new participant will enter. This loop will continue until each participant has repeated entering the conversation, exchanging information, and existing the conversation.

Component 4. Group Activity- Observer

Time: 30 minutes

Provide Observer feedback worksheet-entering a conversation.

☞ For this activity each participant will get a chance to enter a conversation between the therapist and the assistant. Attempt to change the topic of conversation for each participant entering the conversation. The other participant is asked to observe the interaction and take notes on what they thought had been done well and what they thought could be improved. Explain the instruction on the feedback worksheet and ensure everyone understands the instructions. At the end of each role-play the participants observing are asked to provide brief feedback on the interaction. It is advised that feedback time is managed closely to ensure everyone gets a chance to enter a conversation.

Component 5. Close Session

Time: 10 minutes

Close the session with a journal review. Ask the participants to share something from their journal e.g. “I practised exchanging information and I found it really hard”. Explain that this is a sharing activity where comments and questions are withheld. Encourage the participants to use their listening skills when others are sharing and avoid interruptions.

Take the final 5 minutes to allow the participants to take out the “My journal” handout and encourage the participants to write down a few things they feel learned recently from therapy. Remind the group to practise what they have learned and after practise, record thoughts and feeling in their journal entry. Also, remind the group that the next session will bring the intervention to an end and that this will be the final week to use the phone rosters.

Session 6. Booster Session: Communication Skills Recap

Component 1. Session opening

Time: 10 minutes

☞ Start the session by reminding the participants that this is the final time we will meet as a group. Start with a 10 minute check-in to see if anyone would like to share how they feel about the group ending and moving forward. It is important to ensure that any and all worries about the group ending are addressed and remind the participants that it is encouraged to stay in touch with each other after the group sessions end.

Component 2. Skills Recap & Group Discussion

☞ The recap will take the form of a group discussion. The participants will need to use all of their psychoeducation session handouts for this discussion. As we recap each psychoeducation session, participants will be encouraged to share their past experiences and how they would handle some of the situations now and in the future. It is important to discuss what improvement they think were made and identify skills that they feel could still be improved upon. Use SMART goals to help members plan work on these areas after the group ends.

Component 3. Psychoeducation Lesson- Good Sportsmanship

Before beginning the game provide the group with the following “Good Sportsmanship” rules and ensure all understand why they are important in social situation such as parties:

- Avoid arguing. ...
- Everyone should have a chance to play. ...
- Play fair. ...
- Follow directions and rules. ...
- Respect others. ...
- Encourage teammates. ...
- Respect the decisions of referees and other officials. ...
- End with a handshake or a comment such as good game (if you lose the game).

Component 4. Games & Social Skills

☞ In this part of the session a series of games will be offered to participant which they can play together. The games offered will all encourage social interactions and provide an enjoyable way to use their social skills. The games offered will be Guess Who, Hedbandz “What am I?” and table top basketball.

Component 5. Close Session

☞ To close the final session, arrange dates to come in for final assessments and then finish by saying our goodbyes.

Active Listening Handout

- Smile briefly from time to time if appropriate (Use when meeting someone for the first time or when having a pleasant conversation).

Notes:

- Make eye contact but don't stare.

Notes:

- Posture should be appropriate

Notes:

- Minimal encouragers

Notes:

- Mirroring

Notes:

- Questioning the other person

Notes:

- Reflect on what the person is saying

Notes:

- Avoid distractions

Notes:

Entering a Conversation Handout

Step 1: **Look and listen** before entering into a conversation. Make sure that you are interested in the topic. If you don't understand the conversation then it is likely you will have very little to contribute and it may be best to find a different conversation.

Notes

Step 2: **Show interest** by moving closer but not too close, then make eye contact and mirror the person speaking. Body language will be the first move towards showing the pair/group that you are interested.

Notes

Step 3: **Wait for the right opportunity** to entering a conversation. Make eye contact with the person speaking and wait for a pause as this is an indication that the person speaking has finished.

Notes

Step 4: **Ask a question or make a comment (topic related)** to enter into the conversation. Do not try to change the conversation topic to one that you are interested in and try and avoid making personal comments if there are people in the conversation that you do not know.

Notes

Step 5: **Read the body language of others** once you have entered the conversation. This is an opportunity to see if your contribution is welcome. Read the body language of others and if they do not seem interested, try to not take it personally and try again in the future.

Notes

Exchanging Information Handout

- Introduce yourself (Name exchange) or supply a friendly greeting (exchange of pleasantries). Do not get too personal in the first meeting as this can make some people feel uncomfortable.

Notes:

- Start a conversation by showing an interest in the other person. Ask the other person about themselves (e.g. interests, activities, hobbies).

Notes:

- Keep an appropriate distance, make eye contact and smile occasionally when exchanging information

Notes:

- Share similar information about yourself (e.g. interest, hobbies).

Notes:

- Conversation is a two way street. Share the conversation and take turns speaking and listen

Notes:

- Give the other person time to ask questions and do not interrupt even if you think you know the answer to the question.

Notes:

- Ensure to pause and allow the other person to lead the conversation. If the conversation goes silent ask a question or make a new comment based on the other persons interests.

Notes:

- Stop and assess how well the exchange is going. Is the other person making eye contact with you and showing an interest back?

Notes:

Making a Request Handout

1. The speaker needs to look into the listener's eyes, but it is important that the speaker moves their gaze around the listener's face to avoid staring.

Notes:

2. Be clear and say exactly what you are requesting e.g. "I would like you to join me at the science museum next week" or "I don't drive, may I please have a ride in your car to the museum"?

Notes:

3. Tell the person how you would feel if your request is carried out e.g. "I would really enjoy your company at the museum" or "I would be very grateful to you for a ride to the museum".

Notes:

4. Be polite, even if your request is denied e.g. that's alright I can make my own way to the museum, thanks anyway.

Notes:

Sharing the Conversation Handout

- Start with a nice greeting and follow with an open questions. Close-ended questions are those which can be answered by a simple "yes" or "no," while open-ended questions are those which require more thought and more than a simple one-word answer.

Notes:

- Pause, listen and do not interrupt. Take time to stop talking and allow the other person a chance to contribute.

Notes:

- Take turns exchanging information

Notes:

- Avoid repetitive questioning. This means do not just ask one question after another.

Notes:

- Don't just talk about the same thing over and over.

Notes:

- Use and read body language

Notes:

Observer Feedback Worksheet-Entering a Conversation

Step 1: Look and listen

Performed task well ← 1-----2-----3-----4-----5 Task performance needs improvement →

Notes

Step 2: Show interest

Performed task well ← 1-----2-----3-----4-----5 Task performance needs improvement →

Notes

Step 3: Wait for the right opportunity

Performed task well ← 1-----2-----3-----4-----5 Task performance needs improvement →

Notes

Step 4: Ask a question or make a comment (topic related).

Performed task well ← 1-----2-----3-----4-----5 Task performance needs improvement →

Notes

Step 5: Read the body language of others

Performed task well ← 1-----2-----3-----4-----5 Task performance needs improvement →

Notes

Making Requests Activity Worksheet

Using the steps below act out the role provided on the cards. Rate your partner on each step.

1. The speaker needs to look into the listener's eyes, but it is important that the speaker moves their gaze around the listener's face to avoid staring.

Tick the box that best describes the rating.

- Attempted to perform all parts of the step
- Attempted to perform some parts of the step
- Did not attempt

2. Be clear and say exactly what you are requesting e.g. "I would like you to join me at the science museum next week" or "I don't drive, may I please have a ride in your car to the museum"?

Tick the box that best describes the rating.

- Attempted to perform all parts of the step
- Attempted to perform some parts of the step
- Did not attempt

3. Tell the person how you would feel if your request is carried out e.g. "I would really enjoy your company at the museum" or "I would be very grateful to you for a ride to the museum".

Tick the box that best describes the rating.

- Attempted to perform all parts of the step
- Attempted to perform some parts of the step
- Did not attempt

4. Be polite, even if your request is denied e.g. that's alright I can make my own way to the museum, thanks anyway.

Tick the box that best describes the rating.

- Attempted to perform all parts of the step
- Attempted to perform some parts of the step
- Did not attempt

Mirror Talk Handout

Short and Clear

Cut through the clutter

Don't guess what they
mean or feel

Own words....NO Parrot
talk

Phone Roster

The Phone roster is used to assign and track of the buddy systems weekly phone call activity. Ensure the phone numbers are up to date and both parties agree to time and day for when the phone conversation will take place.

**PHONE ROSTER**

My Journal Handout

My Journal- Session #__

Take some time to record any important thoughts, and homework assignments. The journal page can be used as a reminder of the things you learned in this session, a way of checking your progress and to remind you of your homework.

DATE:

Some important points I learned today:

HOMEWORK ASSIGNMENTS

HOME WORK FOR PRIOR WEEK COMPLETED

Yes/No

Social Autopsy for group discussion

Use this strategy to review a social encounter by having the child or youth define what occurred, what went wrong, who was affected, and what could be done differently the next time. Conducting social autopsies is useful because it helps the child identify the social error she made and reiterates that other people are affected by the actions that she takes. It provides the opportunity to problem solve and determine what adjustments ought to be made for future social encounters.

Social Autopsy Worksheet

What happened?

What was the social error? Who was hurt by the social error?

What should be done to correct the error?

What could be done next time?

From Myles, B. S., & Adreon, D. (2001). *Asperger syndrome and adolescence: Practical solutions for school success* (p. 109). Shawnee Mission, KS: Autism Asperger Publishing Company. Reprinted with permission.

Appendix N. Impact statement to Autism@Manchester expert by experience group.

This impact statement was formatted following the guidance of Autism@Manchester expert by experience group.

Feedback and Acknowledgement of Group Activity: Impact Report on the Research Project Titled:

The Development and Feasibility Trial of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

On 6/12/2017, I attended the Autism@Manchester expert by experience group meeting where I presented my planned research. I delivered a 30-minute presentation covering the research project objectives and methodology. The theoretical approach and topics for the social skills intervention preselected by the researcher were also presented. The group were also provided with a copy of the PIS and consent form to review.

Following the presentation:

The group debated the importance of the study, the feasibility of the research methodologies, the intervention topics and the recruitment process. The researcher took notes during the discussion and collected recommendations from several group members.

We did.....

I am more aware of the sensory issue that may arise from the neuroimaging device and I will ensure to monitor the participants under testing conditions. Testing will stop if there are any sign of distress or reports of discomfort. The PIS acknowledges this possibility and provides warning to those with sensory sensitivity.

In this session, group members were also asked to provide feedback on a guidance protocol for therapeutic communication when working with young autistic people without an intellectual disability.

The group advised that the therapist should consider:

- Clarity of phrasing, - literal speaking to avoid misunderstanding

- Don't assume we understand you and keep language clear and simple
- Avoid multi-layered questioning
- Do not use tag questioning
- Don't ask how they feel but rather focus on how/what they think. If you ask me how I feel in the past I'll most likely answer with how I feel in the present moment. I am more accurate at discussing my thoughts rather than feelings
- Give time to talk about special interests within the session as this will help build a better relationship even if it is not directly related to the current topic of therapy

We did.....

I developed a guidance protocol (which included the suggestions provided by the group) for the training of all CBT therapists involved in the intervention. This protocol will hopefully have a positive impact on the quality of communication between the therapists and the participants in the intervention group.

Additionally, I have taken many of these points and made appropriate adaptations to the content in the intervention manual e.g. a number of tasks were simplified and instruction was made to be more explicit.

In the group discussion after my presentation, I asked the group if they could provide advice on participant recruitment of young adults with a diagnosis of autism without intellectual disability aged 18 -25 years.

The groups offered a number of contacts such as:

The Together trust

PIPS Stockport

Special Education Schools

SeaShell Trust Manchester

SalfordAutism

We did

I made contact with all suggested recruitment streams and received some positive responses. Ultimately, I did not recruit from these specific organisations. I did benefit from contact as relationships were built and collaborations for future projects are a promising prospect.