# THE DESIGN AND IMPLEMENTATION OF A NEW COGNITIVE BEHAVIOURAL THERAPY (CBT) BASED INTERVENTION FOR THE MANAGEMENT OF SENSORY EXPERIENCES IN ADOLESCENTS WITH AUTISM

Louise Jane Edgington

Institute of Education, University of London

Doctorate in Professional Educational Child and Adolescent Psychology

#### ACKNOWLEDGEMENTS

First, I would like to thank my supervisors Liz Pellicano and Vivian Hill, who have provided invaluable commentary, ideas, and insight throughout this project.

I would also like to thank the adolescents, parents, SENCO, and staff at the school where the research was carried out. Without their participation and time, this study would not have been possible. I am particularly grateful for having had the opportunity to run the intervention with the adolescents in the current study; their engagement, demeanour and humour made the group sessions thoroughly enjoyable to deliver.

Finally, I would also like to thank my fellow Trainee Educational Psychologists, who have been a source of moral support throughout. Most importantly, I thank Alex for his proof reading, encouragement, and support at home.

#### ABSTRACT

**Background.** There is growing recognition of the impact of sensory difficulties in autism. However, traditional 'sensory integration therapies' lack empirical support and behaviour-based measures may misrepresent some sensory experiences in autism, meaning that sensory atypicalities are poorly understood and supported. There is therefore a need for a new self-regulatory approach to understanding and managing sensory experiences, which is consistent with theory, and draws upon self-reports of individuals with autism.

**Aims.** 1) To expand the evidence base of self-reports of sensory experiences of adolescents with autism. 2) To evaluate the effectiveness of a new 8-week CBT-based group intervention for self-regulation of sensory experiences.

**Methods.** Twelve adolescents aged 11 to 16 years with diagnoses of autism and IQs above 70, from one mainstream secondary school completed the study. A randomised controlled trial (RCT) design was used. To address Aim 1, self-reports were elicited pre-intervention, in a semi-structured interview and analysed thematically. To address Aim 2, quantitative measures of sensory behaviours, anxiety and repetitive behaviours were taken at baseline, postintervention and follow-up, together with qualitative interview data from experimental groups and parents, post-intervention.

**Results.** Aim 1) Thematic analysis revealed 5 main themes: 'need for control', 'resonance with stimulus affects reactivity', 'self in-relation-to others', 'barriers to coping relate to consciousness', and 'features of adaptive coping strategies'. Aim 2) Quantitative analysis revealed no significant intervention effects,

although qualitative reports indicated the intervention raised meta-conscious awareness of sensory experiences, expression and use of language, sense of self in-relation-to others, and adolescents' use of new coping behaviours.

**Conclusion.** Striking qualitative data suggest the intervention was effective in raising meta-conscious awareness and self-regulation. Results indicate the future need for larger sample sizes, and for the development of more sensitive and valid sensory measures. Implications for EPs include facilitating supportive group dynamics, and developing parent and staff understanding.

**Declaration:** 

I hereby declare that, except where explicit attribution is made, that the work presented in this thesis is entirely my own.

Logizton

Word Count: 34,864

# TABLE OF CONTENTS

1.	СНАРТ	FER ONE: INTRODUCTION	13
2.	СНАРТ	TER TWO: LITERATURE REVIEW	17
2.	1. Litera	ature Review	17
	2.1.1.	Autism Terminology	17
	2.1.2.	Sensory Terminology and Theory	18
	2.1.3.	Measures of Sensory Reactivity	21
	2.1.4.	Sensory Reactivity in Different Clinical Groups	25
	2.1.5.	Sensory Processing, Reactivity and Experiences in Autism	27
	Theo	ories of sensory processing in autism.	27
	Rese	earch using sensory reactivity measures in autism	31
	Rese	earch in self-reports of sensory experiences in autism.	39
	2.1.6.	Additional Impact and Outcomes of Sensory Processing	
	Atypica	alities in Autism	50
	Autis	sm symptoms	51
	Enga	agement, behavioural difficulties and academic attainment	51
	Anxi	ety and depression	52
	2.1.7.	Coping Strategy Interventions for Sensory Experiences	53
	The	Alert Program for Self-Regulation	54

Sensory Stories56
2.2. The Current Study: Rationale59
2.3. The Current Study: Research Questions64
3. CHAPTER THREE: METHODOLOGY
3.1. Methodology65
3.1.1. Epistemological Stance65
3.1.2. Experimental Methodology and Research Aims
3.2. Participants69
3.3. CBT- Based Sensory Intervention77
3.3.1. Overall Structure and Features77
Relevance to CBT model77
Modifications for individuals with autism79
3.3.2. Pilot Studies
Pre-intervention interview84
Intervention sessions84
3.3.3. Intervention Session Outlines85
Session 1: Introduction85
Session 2: Introduction to CBT model: Positive experiences
Session 3: Introduction to CBT model: Difficult experiences
Session 4: Outcomes of sensory experiences: Helpful or unhelpful?86
Session 5: Behaviour coping tools87

Ses	sion 6: Body coping tools	87
Ses	sion 7: Thinking coping tools	88
Ses	sion 8: Review and celebration	88
3.3.4.	Engagement with the Setting	91
3.3.5.	Qualifications and Experience of Intervention Leader	93
3.4. Mea	sures	93
3.4.1.	Background Measures	93
Wed	chsler Abbreviated Scale of Intelligence – Second Edition.	95
Soc	ial Responsiveness Scale – Second Edition	95
3.4.2.	Outcome Measures	96
Prim	nary outcome measures	96
Sec	ondary quantitative outcome measures.	99
Qua	litative measures	101
3.5. Gen	eral Procedure	107
3.5.1.	Step 1: Pre-Intervention, Baseline Data Collection	107
3.5.2.	Step 2: Randomisation	108
3.5.3.	Step 3: Pre-Intervention Interviews	109
3.5.4.	Step 4: Experimental Intervention	109
3.5.5.	Step 5: Post-Intervention	109
3.5.6.	Step 6: Follow-Up	110
3.5.7.	Step 7: SaU Intervention	110

3.6. Ethical Considerations111
3.6.1. Informed Consent111
3.6.2. Sensitivity to Adolescents' Needs111
3.6.3. Anonymity and Data Protection112
3.6.4. Confidentiality112
3.7. Data Analysis113
4. CHAPTER FOUR: RESULTS OF AIM 1) SELF-REPORTS OF SENSORY
EXPERIENCES
4.1. Theme 1: Need for Control118
4.2. Theme 2: Resonance with Stimulus Affects Reactivity
4.3. Theme 3: Awareness of Self in-Relation-to Others
4.4. Theme 4: Barriers to Coping Relate to Consciousness
4.5. Theme 5: Features of Adaptive Coping Strategies
5. CHAPTER FIVE: RESULTS OF AIM 2) EFFECTIVENESS OF CBT-BASED
SENSORY INTERVENTION131
5.1. Initial Data Analysis131
5.1.1. Characteristics of Sample131
WASI-II131
SRS-2132
AASP132
SSP134

RBQ
SCAS-P136
5.1.2. Randomisation and Comparison of Group Means136
5.2. Group Analysis of Intervention Effectiveness
5.2.1. Primary Outcome Measures141
AASP141
SSP143
5.2.2. Secondary Outcome Measures143
RBQ
SCAS-P144
5.3. Individual Analysis of Intervention Effectiveness
5.4. Fidelity and Attendance148
5.1. Participant Perceptions of the Effectiveness of the Intervention
5.1.1. Adolescent's Perceptions of the Intervention
Theme 1: Raised awareness of sensory experiences150
Theme 2: New-found self-expression152
Theme 3: Motivation for using coping strategies
Theme 4: Generalising learning154
Theme 5: Improvements to programme155
5.1.2. Parents' Perceptions of the Intervention
Theme 1: Challenges to parental involvement

Theme 2: Importance of communication with parents158
Theme 3: Parents' perspectives of change post intervention158
Theme 4: Importance of group dynamics159
Theme 5: Improvements in future support and delivery
6. CHAPTER SIX: DISCUSSION
6.1. Self-Reports of Sensory Experiences163
6.1.1. Awareness of Behavioural, Physical and Emotional Response163
6.1.2. Awareness of Sensory Difference164
6.1.3. Awareness of Coping Strategies165
6.2. Effectiveness of CBT-Based Intervention167
6.2.1. Participant Characteristics and Randomisation
6.2.2. Group and Individual Analyses of Intervention Effectiveness170
6.2.3. Participant Perceptions of Intervention Efficacy174
6.3. Further Limitations and Strengths of the Study176
6.4. Relevance to Professional EP Practice178
6.4.1. Facilitating Understanding in Teaching and Learning178
6.4.2. Application of CBT-Based Sensory Intervention179
6.5. Future Directions181
6.6. Conclusion
7. REFERENCES
8. APPENDICES

# LIST OF TABLES

Table 1. Individual participant demographics	74
Table 2. Stratified Expt and SaU group demographics	74
Table 3. Participant groups, measures and intervention schedule	94
Table 4. Expt, SaU group and normative means	138
Table 5. Means of Expt and SaU primary outcome measures	142
Table 6. Means of Expt and SaU secondary outcome measures	143
Table 7. RCI coefficients for AASP subscale and total scores	146
Table 8. RCI coefficients for SSP, RBQ and SCAS-P total scores	147

# LIST OF FIGURES

Figure 1 Flow diagram showing participant numbers73
Figure 2. Sensory picture template used in intervention sessions80
Figure 3. Exemplar emotion sheet available to participants
Figure 4. Exemplar body feelings sheet available to participants83
Figure 5. Relaxation exercises used in session 6
Figure 6. Visualisation exercise used in session 790
Figure 7. Image of Sensory School Cards102
Figure 8. Adolescent pre-intervention semi-structured interview schedule 104
Figure 9. Adolescent post-intervention semi-structured interview schedule106
Figure 10. Parent post-intervention semi-structured interview schedule107
Figure 11. Themes from analysis of adolescent pre-intervention interviews119

Figure 12. Individual scores on AASP subscales,	.133
Figure 13. Individual scores on AASP total.	.134
Figure 14. Individual scores on SSP total	.134
Figure 15. Individual RBQ subscale and total scores	.135
Figure 16. Individual SCAS-P total scores	.136
Figure 17. Example of one adolescent's Sensory pictures.	.149
Figure 18. Themes from analysis of adolescent post-intervention interviews	.151
Figure 19. Themes from analysis of parent post-intervention interviews	.157

# LIST OF APPENDICES

Appendix A. Information sheet and consent form for parents	209
Appendix B. Weekly intervention session outlines	212
Appendix C. Adolescent information and consent form	220
Appendix D. Pre-intervention adolescent interview transcript exemplar	222
Appendix E. Adolescent focus group post-intervention transcript exemplar	223
Appendix F. Parent post-intervention interview transcript exemplar	224

#### **1. CHAPTER ONE: INTRODUCTION**

This research was undertaken to fulfil the research component of the Doctorate in Professional, Educational, Child and Adolescent Psychology (DEdPsy) at the Institute of Education (IOE). It was carried out during years 2 and 3 of the programme, whilst on placement in a central London local authority (LA) as a Trainee Educational Psychologist (TEP). Over the course of the DEdPsy, I have worked with several schools and families in supporting children with autism, an activity widely acknowledged to be a key part of the Educational Psychologists' (EP) role (Fallon, Woods & Rooney, 2010). During this time, recognition of the impact and prevalence of sensory-related difficulties in autism has grown, as indicated by the inclusion of atypical sensory behaviours for the first time in the American Psychiatric Association's (APA) diagnostic criteria for autism spectrum disorders (DSM-5) (2013). There is also growing awareness of the need to focus research efforts on issues of immediate practical concern to the autism community themselves, including the amelioration and/or accommodation of sensory sensitivities, rather than on the underlying biology and causes of autism (Pellicano, Dinsmore, & Charman, 2014). The relative absence of research on treatments, interventions, and education approaches means that many autism practitioners have limited understanding of how to support sensory-related difficulties that affect daily life.

Several schools in my LA refer to Ayres' (1972) theory of sensory integration dysfunction, which describes atypical reactions to stimuli that many children with special educational needs (SEN) exhibit, categorising these as: sensory-

seeking (e.g. spinning), over-responsive (e.g. high sensitivity to fluorescent lights) or under-responsive (e.g. fails to respond to name being called). However, there is no evidence that sensory integration dysfunction exists as a separate disorder, leading the American Academy of Pediatrics (2012) to recommend that the diagnosis should not be used. In addition, the vast majority of 'sensory' related interventions are based on Ayers' (1972) theory of sensory integration dysfunction and have focussed on attempts to re-organise neurological sensory processing by providing sensory input (Ashburner, Rodger, Ziviani & Hinder, 2014). Included in these class of interventions are 'sensory integration therapies' involving a clinic-based programme of play activities designed specifically for the child, which may incorporate activities using specialist equipment such as therapy balls and swings (Baranek, 2002: Case-Smith, Weaver & Fristad, 2014). Also in this category are 'sensory-based interventions', which use single sensory strategies such as weighted vests and auditory integration therapy (where selected sound frequencies are played to the child) (Case-Smith et al., 2014). However, there is limited evidence for the effectiveness of 'sensory integration therapies' and no conclusive evidence for single sensory strategies (Baranek, 2002; Case-Smith et al., 2014; Dawson & Watling, 2000).

These therapies are further limited by the assumption that some sensoryrelated behaviours are driven purely by a neurological sensory sensitivity. Behavioural reactions to sensory stimuli may also be driven by cognitive and emotional factors, an argument illustrated by Ashburner et al. (2014), who use the example of a child with a tactile or auditory sensitivity to hair clippers, also

being influenced by a fear from past experiences or uncertainty around the expectations for social interaction with the hairdresser. There is thus a need for a fresh examination of these issues, one which draws on an understanding of sensory experiences in autism to enable practitioners to support children to overcome sensory-related difficulties.

The current research topic builds on key findings from my year 1 research project (Edgington, 2012). This initial project focussed on eliciting the perspectives of 7 to 11 year-old children with autism on their sensory preferences and found that these self-reports often differed from teacher or caregiver reports. In addition to highlighting the importance of self-reports of sensory experiences in autism, the study also indicated that children had limited awareness of their sensory differences and had not yet developed the coping strategies used by some autistic<sup>1</sup> adults (e.g. Jones, Quigney & Huws, 2003). The key implication was that children might benefit from support in developing their awareness of their sensory-related difficulties and in developing strategies to compensate for these (Edgington, 2012). The current study set out to address just that, eliciting adolescents self-reports of sensory experiences and using the framework of cognitive behavioural therapy (CBT) in the design of a new approach to sensory intervention. It sought to build individuals' existing meta-conscious awareness of the cognitive, physiological, emotional, and behavioural aspects of sensory experiences, then uses this framework to

<sup>&</sup>lt;sup>1</sup> The term 'autistic' person is used in addition to person-first language (e.g., person with autism) because the former reflects the preferred language of many people on the autism spectrum (Sinclair, 1999).

provide the individual with self-regulatory coping strategies. With its focus on developing understanding of how autistic people think and intervention to ameliorate or accommodate salient sensory issues, this thesis directly addresses the research priorities identified by individuals with autism, their families and those that work with them (Pellicano et al. 2014).

## 2. CHAPTER TWO: LITERATURE REVIEW

This chapter describes the literature review that informed the study rationale and research questions. First, autism terminology are defined, followed by the sensory terminology of 'processing', 'reactivity' and 'experiences', defined within the context of the theory of typical sensory processing. Next, common measures used to capture sensory difficulties and what is known about sensory atypicalities in other clinical groups are discussed. Then, theories of autistic sensory processing, studies using behaviour-based measures and self-reports of sensory experiences in autism are considered and critically evaluated. Evidence for additional outcomes related to sensory symptoms in autism is also reported. Finally, the existing 'coping strategy' interventions for sensory difficulties are critically evaluated, leading to the study rationale and research questions.

## 2.1. Literature Review

## 2.1.1. Autism Terminology

The newly-revised diagnostic criteria for autism in the DSM-5 (APA, 2013) describes a single diagnostic category of 'autism spectrum disorder'<sup>2</sup>, reflecting the considerable variability inherent between individuals with the condition.

<sup>&</sup>lt;sup>2</sup> This term reflects the APA's (2000) previous diagnostic categories of autism, Asperger's (which may indicate relatively intact language and intellectual functioning) and Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS) (which may indicate late onset or atypical symptomatology, below the diagnostic threshold for autism). As individuals involved in both the current study and studies discussed below would have been diagnosed under DSM-IV criteria, the term *autism* will be used to denote autism, Asperger's, autism and PDD-NOS.

The revised DSM-5 (APA, 2013) criteria describe two core domains. The first are 'social' difficulties, indicating difficulties in social-emotional reciprocity, nonverbal communicative behaviours and in developing and maintaining relationships. The second DSM-5 criteria (APA, 2013) are the 'non-social' difficulties of restricted and repetitive patterns of behaviour, including difficulties at least two of the following areas: stereotyped or repetitive speech (e.g. frequently repeating back phrases), movement or use of objects (e.g. spinning or flicking objects, rocking the body), excessive adherence to routines or ritualised patterns of behaviour or resistance to change (e.g. insistence on taking the same route to school), restricted or fixated interests (e.g. an obsession with trains), and – of most interest to the current work – 'hyper or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment'. Hyper-reactivity describes a strong reaction or aversion to often unexpected stimuli from different modalities (e.g. bright lights, rough clothing, strong smells, certain foods, and noises such as hairdryers, toilet flushes or sirens). Hypo-reactivity describes the reduced capacity to notice or orient to a stimulus (e.g. fail to respond to their name, insensitivity to pain or temperature, bumps into things). An unusual interest in sensory stimuli involves seeking-out certain experiences (e.g. fascination with twinkling lights, mouthing or banging objects). The inclusion of this sensory category implicates atypical sensory behaviours as part of the core of autism.

## 2.1.2. Sensory Terminology and Theory

Throughout the literature, the terms 'processing', 'symptoms', 'difficulty', 'atypicality', 'reactivity', 'sensitivity', and 'experiences' are used with the term

'sensory' to indicate the presence of atypical behavioural responses to sensory stimuli. Sensory *processing* is conceptualised here as the process through which we perceive stimuli in our environment. This is comprised of the detection and interpretation of external sensory stimuli (Bremner, Lewkowicz & Spence, 2012). The number and categories of our detective 'senses' are not clearly defined (Gordon, 2012) but current accounts tend to describe seven sensory modalities: auditory, visual, tactile, olfactory (smell), gustatory (taste), proprioception (joint and limb position), and vestibular (balance) (e.g. Reebye & Stalker, 2008). However, evidence suggests that there is much overlap between the senses (e.g. some sounds may induce a tactile sensation on the skin) (Gordon, 2012). Therefore, while the above seven sensory modalities may serve as useful indicators of the type of sensory experience, sensory processing is perhaps best conceptualised as a complex and multimodal experience.

Typical sensory processing involves both 'bottom-up' and 'top-down' processing (Bernstein, 2010). When incoming sensory stimuli are detected by receptors in the sensory cortex, this information is sent to the pre-frontal cortex (bottom-up processing), the area believed to be involved in a range of higher cognitive functions including focussing attention, and inhibiting, initiating and monitoring actions which together are often referred to as 'executive' functions (Pennington & Ozonoff, 1996). The brain then draws upon past experience and knowledge to modulate or filter the incoming information, thereby providing an interpretation of it (top-down processing) (Bernstein, 2010).

This ability to detect and interpret sensory stimuli has been hypothesised by early psychologists to form the basis of human consciousness (e.g. James, 1890; Jaynes, 1976). This idea is elaborated in a more recent review of the neural correlates of consciousness. Crick and Koch (2003) hypothesize two modes of sensory processing: the 'Zombie' mode and a 'conscious' mode. The Zombie mode describes an unconscious, rapid and often stereotyped response to stimulus where information flows 'bottom-up'. In the 'conscious' mode, information flows both bottom-up and top-down, which Crick and Koch (2003) describe as a slower response to stimuli that allows time for conscious thought and the planning of an appropriate response. Most recently, consciousness has also been described as a construct of the neural networks specialised for social perception (Graziano & Kastner, 2011). In other words, the neural systems that allow us to detect and interpret social cues and become aware of others' minds also gives us awareness of our own minds. 'Top-down' processing or interpretation of sensory information may therefore be likened to consciousness and underlie our sense of self in-relation-to others.

Once a stimulus has been processed, a behavioural or physiological response may occur, with varying degrees of automaticity. The term *sensory reactivity* is used here to indicate behavioural responses that are frequently outside 'typical' expectations, including both under and over-responsive and seeking (e.g. fails to respond to name, covering ears with hands in everyday situations and spinning). However, it is acknowledged that sensory reactivity may actually be a proxy measure for what is primarily a difference at level of sensory processing. Finally, the term *sensory experience* is used for the whole sequence of sensory

processing, reactivity and any subsequent outcomes as they are felt by the individual.

While there are some experimental paradigms that are beginning to emerge to capture some aspects of sensory processing in autism at a perceptual (e.g. Pellicano & Burr, 2012) and neurological level (Brandwein et al., 2013), consideration of these methods is beyond the scope of this study. Instead, the focus is on sensory reactivity (being that which is readily observed or perceived to be problematic to others) and on sensory experiences (being salient to the individuals themselves).

#### 2.1.3. Measures of Sensory Reactivity

As yet, there is no agreed conceptualisation or description to capture sensory reactivity differences. As the full range of atypical sensory behaviours are unlikely to be observed in a clinical setting, studies have generally relied on caregiver questionnaires or interviews which focus on observable behaviours.

Most standardised measures are based on Ayres' (1972) categories of overresponsive/hyper-sensitive, under-responsive/hypo-sensitive and sensoryseeking (Ben-Sasson et al., 2009; Dunn, 1999). The most commonly used measures are Dunn's Sensory Profile (SP), Short Sensory Profile (SSP) and the modified versions for infants and school settings (Dunn, 1999; Dunn, 2006; Dunn & Daniels, 2002). These measures are based on Dunn's (1997) model of sensory processing which assumes an interaction between response type (active or passive) with 'neurological threshold', the assumed level of stimulation required for a neuron to respond. In the SP, caregivers rate the

frequency (on a 5-point scale) of 125 different behaviours organised in sensory modalities (e.g. visual, tactile, auditory etc.), which, when scored are categorised into 4 quadrants: hyper-sensitive, active response ('avoiding', e.g. holds hand over ears to protect from sound); hyper-sensitive, passive response ('sensitivity', e.g. has trouble completing tasks when the radio is on); hyposensitive, active response ('seeking', e.g. touches people and objects); hyposensitive, passive response ('low registration', e.g. leaves clothes twisted on body) (Dunn, 1999). In the reduced 38-item SSP (Dunn, 1999), scores are simply given in 7 sensory modalities (e.g. tactile sensitivity). These questionnaires were developed using clinical observations of sensory reactive behaviours from several different special needs populations and norms are based on a typically developing population.

One caregiver questionnaire that was designed specifically around the observed sensory reactivities in autism is the Sensory Experience Questionnaire (SEQ) (Baranek, David, Poe, Stone & Watson, 2005), standardised for use with children aged 5 to 80 months. Like the SP, the SEQ also uses the assumption of neurological thresholds and the hyper/hypo-sensitive classification, but subdivides these into social and non-social behaviours (e.g. 'hypo-social': ignores new person, 'hypo-non-social': flaps arms, 'hyper-social': dislikes tickling, 'hyper-non-social': averse to water). For 21 items, caregivers a) rate the frequency of behaviours on a 5-point scale, b) state whether or not they attempt to change the behaviour and c) describe what they do to change the behaviour. This measure therefore has the advantage of providing information on how sensory experiences may be influenced by others,

although, like the SP it does not measure the intensity or impact of sensory behaviours.

Another significant critique of both the SP and the SEQ lies in the underlying assumption of 'neurological thresholds' which are inconsistent with some theories of sensory processing in autism (see below, Frith, 2003; Pellicano & Burr, 2012), as they assume a difference in sensory detection at the neuronal level, rather than differences in interpretation. Owing to the difficulty in measuring neural responses in the brain directly, there is only indirect support for the theory of neurological thresholds (Dunn, 1997), however, these are limited and inconclusive. In studies using measures of electro dermal activity (skin conductance) to record physiological arousal, children with autism have been found to have both lower (Schoen, Miller, Brett-Green & Nielsen, 2009), and higher (Chang et al., 2012) physiological arousal responses to sensory stimuli, when compared to typically developing children. This might indicate that the neuronal excitation and subsequent physiological response are indeed atypical in autism. However, as noted by Schoen et al. (2009), electro-dermal responses are influenced by several different systems in the brain, so are hypothesised to be the result of the 'perceived' significance of the sensory stimlus and associated psychological responses. As such, findings from these studies can infer little about the 'neuronal thresholds' for excitation or response. Moreover, the validity of the SP could be further questioned, as Schoen et al. (2009), found no correlation between SP scores and electrodermal responses. The SP may therefore not represent the sensory expereince as it is perceived by the individual.

Because items are fixed in questionnaires, it cannot be guaranteed that every respondent has interpreted the question in the same way. Caregiver interviews can overcome this difficulty by being more flexible and allowing for topics to be clarified. The Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing, Leekam, Libby, Gould & Larcombe, 2002) is a clinical interview schedule designed to assess autistic symptoms in people of all ages and autism types. It contains 21 items on sensory reactivities specific to clinical observations of sensory behaviours in autism in different sensory domains (e.g. distressed by sounds that do not affect others, refuses food that is lumpy or needs chewing). Just over half of the sensory items on the DISCO are also represented on the SP (Leekam, Nieto, Libby, Wing & Gould, 2007), providing an indication of the variability between measures. Behaviours are marked as 'severe'/marked abnormality', 'minor abnormality' or 'no problem' by the clinician, using guidelines according to frequency of behaviour and severity of impact. As such, scoring may be subject to the judgement of individual clinicians. However, the SEQ has the advantage of asking about both 'ever' and 'current' behaviours, providing a richer picture of development.

All of the above measures rely on caregiver reports. However, caregivers may not necessarily be exposed to every sensory behaviour or may misjudge the frequency or severity of sensory-related responses. The only self-report questionnaire is the 60-item Adolescent/Adult Sensory Profile (AASP) (Brown & Dunn, 2002), based on the SP, using the same quadrants of avoiding, sensitivity, seeking and low registration to categorise behaviour (Dunn, 1999), using a 5-point frequency rating scale. While it is ostensibly a behaviour-based

questionnaire on sensory reactivity, there are 16 items that tap more internal sensory experiences, including preferences and emotions (e.g. I am bothered by the feeling in my mouth when I wake up). The AASP therefore has the ability to measure some aspects of the sensory experience, which may not necessarily be evident in behaviour. However, the validity of the AASP depends on the respondent's ability to reflect upon and judge their own sensory experiences. It is therefore only suitable for intellectually able individuals with the ability to complete a questionnaire and self-reflect (Brown & Dunn, 2002).

The variability between the items within different behaviour-based measures means that any one individual may score differently on different sensory measures. As such, the type of measure employed should be considered when comparing findings from sensory reactivity studies.

#### 2.1.4. Sensory Reactivity in Different Clinical Groups

Sensory reactivity is not unique to autism, being observed in several different clinical groups, such as developmental delay (DD), Fragile X syndrome and Attention Deficit Hyperactivity Disorder (ADHD) (Emmons & Anderson, 2005; Reebye & Stalker, 2008; Rogers & Ozonoff, 2005). While there is no clear consensus on the profile of sensory reactivity within each group, some studies have found differences between clinical groups.

Rogers, Hepburn and Wehner (2003) used the SSP (Dunn, 1999) to measure sensory behaviours in toddlers of comparable mental age with autism, Fragile X, DD and typically developing children. Children with DD had similar sensory reactivity to typcially developing toddlers, whereas children with autism and

Fragile X had higher overall levels of sensory reactivity, with no difference between the two groups on total score. Children with autism had more atypical taste and smell behaviours than other groups, while children in the Fragile X group were reported to have more behaviours indicative of low energy/ weak muscles (Rogers, Hepburn & Wehner 2003).

In a study with older children aged 3 to 10 years, Cheung and Siu (2009) found that children with ADHD and with autism had greater sensory reactivity than typically developing children on parent-report measures of sensory behaviours using a Chinese version of the SP, but found no difference between the ADHD and autism groups. However, this study did not control for intellectual functioning, which may have confounded findings.

Using the SEQ (Baranek et al., 2005) and observational measures of 'hyper (over) and hypo (under) reponsiveness' to sensory stimuli, Baranek et al. (2013) found that differences between clinical groups were moderated by intellectual functioning in children aged 11 to 105 months. For those with a mental age (MA) around 6 months, autistic children demonstrated more hyporeponsiveness to sensory stimuli than DD or typically developing groups. However, there were no significant differences across groups for those with higher MA (around 60 months).

From the few studies comparing sensory reactivity between clinical groups, taste and smell sensitivities, and hypo-responsiveness may be expected to be a feature of autism. However, there would appear to be a limited and inconsistent picture likely to be due to the different sensory measures employed by each study, cultural and contextual influences, and methodological limitations such as a failure to control for intellectual functioning. Moreover, it remains unclear whether or not the sensory symptoms in different groups have a shared underlying aetiology. As such, sensory reactivity has largely been viewed as a co-occurring difficulty in these groups, rather than a core or underlying feature.

## 2.1.5. Sensory Processing, Reactivity and Experiences in Autism

Descriptions of abnormal responses to sensory information (e.g. 'hypersensitivity' to some sounds) are evident in the earliest descriptions of autistic children (Kanner, 1943). However, as it was not considered a core feature of autism until recently, the nature of sensory-related difficulties in autism has been relatively under-researched (Ben-Sasson et al., 2009). In the absence of a way to capture sensory processing, researchers relied on behavioural reports or observations of sensory reactivity (Ben-Sasson et al., 2009) which have produced a highly incoherent and heterogeneous picture. More recently, research has turned its attention to self-reports of sensory experiences in autism. Although subjective, these self-reports offer a more informative picture of the phenomenon as they have the potential to incorporate information about the interpretation and response to stimulus. Together with sensory perceptual data self-reports offer support to theories of sensory processing in autism, which identify sensory processing as the root cause of autistic symptoms (Pellicano, 2013). The literature on theories of sensory processing, reactivity studies and self-report experiences in autism is described below.

**Theories of sensory processing in autism.** Theories which describe a fundamental sensory processing atypicality in autism are gaining popularity. Frith (2003) was the first to hypothesize a weak, or absence of, 'top-down' processing in autism. Mottron et al.'s (2006) model of 'Enhanced Perceptual Functioning' built upon Frith's account, and similarly implicates weak 'top-down' processing, but also greater functional activation of the regions in the sensory cortex, suggesting an enhanced (bottom-up) sensory detection system. Frith's account (2003) goes on to relate the absence of top-down processing to the idea of an 'absent self', which, in typically developed individuals is the awareness of self in-relation-to others, located in the prefrontal cortex. Frith suggests that this description may unify the predominant cognitive theories of autism, namely Executive (dys) Function (Pennington & Ozonoff, 1996) (weak top-down processing), Weak Central Coherence (Frith & Happé, 1994) (bias for local processing or 'bottom-up' processing) and Theory of Mind (Baron-Cohen, Leslie & Frith, 1985) (an inability to impute the thoughts of others, represented by the absent or weak self). When these accounts are compared with Crick and Koch's (2003) aforementioned model of typical sensory processing involving a 'conscious' and a 'Zombie' mode, the description of autistic sensory processing appears to resemble the unconscious, bottom-up, 'Zombie' mode, which might suggest that autism is related to a poorly developed 'consciousness'. This suggestion would also be consistent with Graziano and Kastner's (2011) theory of consciousness as linked to social perception, providing one explanation as to why an awareness of others' minds, as well as conscious awareness of the 'self' may be compromised in autism.

The suggestion that autism may be related to a poorly developed 'consciousness', fits with Donna Williams' (1998) first-hand account of her life with autism. She describes herself as inhabiting a 'preconscious' state, of 'no

self, no other', which she refers to as the 'system of sensing' without the interpretation of 'mind':

"I would hold what was otherwise a comb but perceive a flat, solid form that could be scraped with teeth...I would perceive it not by its functional purpose but by its sensory one. It was a 'rih-rih' sounding instrument" (Williams, 1998, p. 15)... "When the system of sensing came naturally to me, 'I' was purely will and had little, if no, conscious mind... I lived in a relatively constant sleep walking state, a bit like a zombie" (Williams, 1998, p. 42).

Williams goes on to describe how she gradually moved from the 'system of sensing' into the 'system of interpretation', with a period of switching between the two. She would switch into the 'system of interpretation' if she felt 'body connectedness', or if prompted by others. Williams would switch back into the 'system of sensing' as a means of coping with overwhelming sensory information:

"I have known the adaption of shutting down mind – sensory experience is no longer chaotic or bombarding once the mind no longer strives to file or make sense of it. Yet had I remained constantly in that state...I'd not have become functionally capable." (Williams, 1998, p. 83)

First-hand accounts such as Williams' can therefore offer some indirect support for the idea of autism as a bottom-up, somewhat unconscious processing style, where top-down processing is deployed only occasionally, which may account for the day-to-day variability in behavioural response. This is consistent with Lai, Parham and Johnson-Ecker's (1999) suggestion that hyper and hyposensitivities are really "two sides of the same coin" due to 'shutting down' of sensory processing. With the help of assistive technologies, first-hand anecdotal accounts such as Williams' are increasingly being reported by younger children with more severe autism (e.g. Higashida, 2013). However, the majority of self-reports do tend to come from a handful of cognitively able adults, who have developed sufficient language to express whatever they do recall of their previous experiences. There is a lack of empirical evidence to support the theoretical accounts directly, as the constructs are difficult to operationalise.

Nevertheless, the process through which we may develop our 'system of interpretation' has been operationalised (Pellicano, Jeffery, Burr & Rhodes, 2007). Pellicano (2013) refers to 'priors' as our internal working models of the world, which are used for sensory interpretation in top-down processing. Priors are constantly updated or adapted as we gather more experience of the world; exposure to a stimulus (e.g. a face) is believed to alter the response properties of the neurons responsible for detecting that stimulus. Drawing on evidence of face processing in autism (Pellicano et al., 2007), Pellicano and Burr (2012) suggest that this process of adaptation and the refinement of 'priors' is significantly impaired or delayed in autism, leading to 'hypo-priors': fewer internal constraints on perception, leading the individual to perceive the world 'just as it is'. Such an account is in line with self-reports of perception in autism, such as Williams' (1998) aforementioned description of a comb. However, further empirical evidence of the development of 'priors' in typical and autism populations is needed to support this theory.

Indirect support for the theories of sensory processing in autism may also be seen in correlational studies, which have found links between measures of

sensory reactivity and general autism symptoms in autistic children, (Kern et al., 2007, described in more detail below) and in non-autistic adults (Robertson & Simmons, 2012). Together, these studies suggest a continuum over which sensory reactivities correlate with, and potentially underlie, features of autism within the general population.

From the above theoretical accounts, one might expect that an individual with autism perceives more incoming sensory information and is less able to 'get used to' certain stimuli, relate them to past experience, or predict them (Pellicano & Burr, 2012). In light of the possible unconscious nature of some autistic sensory processing, it would also be likely that individuals have a limited meta-awareness of how their perceptual processes compare to others'. It is these aspects of autistic sensory processing that sensory reactivity measures such as the SP (Dunn, 1999) are unable to capture. What these measures do find is reported below.

**Research using sensory reactivity measures in autism**. In addition to the variability from different measures, the picture of sensory reactivity in autism is further complicated by variations with age, intellectual functioning and level of autism symptoms (Ben-Sasson et al., 2009). Some studies indicate prevalence of sensory reactivities across culture, ethnicity and gender (e.g. Baranek et al., 2005), although links between these factors are rarely examined. Individuals are also likely to exhibit sensory reactivity in multiple sense modalities, which can vary from day-to-day (Kern et al., 2007; Leekam et al., 2007). The overall picture is therefore highly heterogeneous, with prevalence estimates of sensory behaviours more than 1 standard deviation (*SD*) different from typically

developing age norms ranging between 45 to 95% (Baranek, Boyd, Poe, David & Watson, 2007; Ben-Sasson et al., 2009; Crane et al., 2009; Leekam et al., 2007).

One of the few studies to try and disentangle the picture was Ben-Sasson et al.'s (2009) meta-analysis of 14 studies of parent-reports of sensory reactivity in individuals with autism aged 7 months to 56 years. Of these 14 studies, 11 employed versions of Dunn's (1999) SP (Ben-Sasson et al., 2009). When compared to typical populations, autistic groups showed the greatest differences in 'under-responsivity', followed by 'over-responsivity', then 'seeking' behaviours. However, Ben-Sasson et al. (2009) noted significant variability in sensory reactivity findings across studies and attributed this to sampling characteristics, including age, severity of autism and intellectual functioning.

*Variation with age.* Ben-Sasson et al. (2009) found an increase in total sensory reactivity scores for autism groups relative to typical children up to 9 years old and a decrease with age thereafter. However, studies in the metaanalysis had differing inclusion criteria on the basis of autism diagnosis, while only some employed typical age-matched comparisons that were also matched on intellectual functioning, meaning that level of autism symptom severity and intellectual functioning was not accounted for in Ben-Sasson et al. (2009). In fact, of the adolescent and adult studies reviewed in Ben-Sasson et al. (showing a decrease in sensory reactivity with age, e.g. Kern et al., 2007), none employed a typical control group matched on intellectual functioning. The apparent reduction in sensory reactivity in adolescents and adults may therefore

have been due to typical control groups with non-matched (higher) intellectual functioning, rather than indicating a reduction in sensory reactivity with age.

The need to control for intellectual functioning was addressed in a separate study with 18 adults with Asperger's or autism and IQs above 70 (Crane et al., 2009). Crane et al. (2009) found that the autistic group had significantly more atypical sensory reactivity scores on the self-report AASP measure than a typical control group matched on age, gender, and intellectual functioning. All but one of the autistic group showed extreme sensory reactivity scores (greater than 2 SD from norms) and no correlation was found between age and AASP score for either group, suggesting that sensory reactivity does not dissipate with age in adulthood. However, the use of the AASP in Crane et al.'s (2009) study might be expected to indicate greater levels of sensory reactivity than the parent-report measures in Ben-Sasson et al. (2009), as parents may underestimate some unobservable or internal items that self-report questionnaires pick up. Nevertheless, Crane et al.'s (2009) findings suggest that sensory processing differences in autism do persist into adulthood for individuals with intact intellectual functioning, but that the kind of sensory reactivity may change as individuals learn to respond differently.

In one of the only studies with adolescents with autism, De la Marche, Steyaert and Noens (2012) gave the AASP to 80 adolescents with autism and without intellectual disability aged 11 to 18 years. Responses indicated autistic adolescents were more likely to avoid and less likely to seek sensations than typically developing adolescents. However, the level of autism severity and intellectual functioning of participants was not reported in this study.

Variation with autism severity. As noted by Ben-Sasson et al. (2009), there is a paucity of studies that account for autism severity in measures of sensory reactivity. Using the SP with 104 people with autism, aged 3 to 56 years, Kern et al. (2007) found a positive correlation between SP-measured sensory reactivity and severity of autistic symptoms (using the Childhood Autism Rating Scale (CARS), Schopler, Reichler, & Renner, 1994) in individuals aged 3 to 12 years, but not for individuals aged 13 to 56 years. However, this study is limited by its failure to account for the potentially confounding effect of intellectual functioning and the use of scales designed for children, with adolescents and adults. Nevertheless, this finding is consistent with that of Crane et al. (2009) in their group of adults with Asperger's, finding no correlation between AASP scores and autism symptoms as measured by the Autism-Spectrum Quotient (AQ, Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001) .

Other studies have found correlations between sensory reactivity and certain repetitive behaviours (as defined in DSM-IV) (APA, 2000) in toddlers (Baranek, Foster & Berkson, 1997), children and adolescents with autism (Chen, Rodgers & McConachie, 2009; Gabriels et al., 2008). Similarly, research has also correlated sensory reactivity with severity of social symptoms in 6 to 10 year-olds (Hilton et al., 2010), and 'communication apprehension' college students with autism (Gearhart & Bodie, 2012). While the picture is inconsistent, there would appear to be some links between autistic features and sensory reactivity, that is, those showing a greater degree of autistic symptoms, also show more sensory reactivity.

Other studies focus on sensory reactivity in autistic subgroups. In comparisons between 50 verbal and 29 non-verbal children with autism aged 2 to 7 years, Patten et al. (2013) found no difference in 'hyper-responsive' behaviours, but did find 'hypo-responsive' and 'sensory-seeking' behaviours to be more likely in the non-verbal group. However, the groups were not matched on age or intellectual functioning, which would also include non-verbal cognitive skills (Patten et al., 2013).

Focussing on a group of 25 'intellectually able' (IQ above 70) children aged 6 to 11 years attending mainstream school, Hochhauser and Engel-Yeger (2010) found all children to have sensory reactivity scores in the 'definite difference' range of the SSP, scoring higher than typically developing age-matched children. Taken together with Crane et al.'s (2009) adult study, this would suggest that atypical sensory reactivity is present in both children and adults with less severe autism symptoms. The studies of Kern at al. (2007) and Pattern et al. (2013) might suggest that more severe autism symptoms are linked with increased presentation of sensory reactivity in young children. However, more studies are needed to separate autism severity effects from differences in intellectual functioning.

Variation with intellectual functioning. In the meta-analysis of parentreport questionnaires, Ben-Sasson et al. (2009) found sensory reactivity differences between autistic and typical groups were reduced when studies used typical comparison groups that were matched on intellectual functioning, as opposed to being matched on age alone. This suggests that higher

intellectual functioning is associated with reduced presentation of sensory reactivity.

Using the DISCO to examine the prevalence of sensory reactive behaviours in 200 children and adults aged 2-38 years, Leekam et al. (2007) divided participants into 4 groups on the basis of age (younger and older than 10 years) and IQ (above and below 70). All 4 groups had equivalent rates (91-94%) of participants with sensory abnormalities in all domains. However, the younger, low IQ group had a higher mean 'atypical domains' score, such that they displayed more atypical behaviours in visual, oral and 'mixed' sensory domains than the other 3 groups. This finding would indicate that intellectual functioning might affect presentation of sensory reactivities in younger children only. However, in scoring the DISCO, Leekam et al. (2007) collapsed the 'minor abnormality' and 'no problem' categorisations, meaning that the measures had reduced power to detect differences between groups.

Using clinical observations and the more sensitive SEQ parent-report questionnaires, Baranek et al. (2013) found that 'hyporesponsive' behaviours were negatively correlated with IQ, in children with autism aged 1 to 9 years. Similarly, higher IQ has been associated with reduced AASP scores in adults with Asperger's, on all domains except sensory-seeking behaviours (Crane et al., 2009). While the overall picture is again confused by methodological limitations and differences between studies, higher intellectual functioning seems to be linked with reduced presentation of sensory reactivity in autism.

Limited validity of sensory reactivity measures. Sensory reactivity measures may be criticised on the grounds that some were not developed for

the sensory behaviours seen in autism (e.g. SP, Dunn, 1999), some are based on unfounded assumptions about neurological thresholds (e.g. SEQ, Baranek, David, Poe, Stone & Watson, 2006) or some caregivers and clinicians may have inaccurate and subjective views about the frequency or existence of different behaviours (e.g. DISCO, Wing et al., 2002). For those that have sufficient literacy and intellectual functioning to complete them, self-report questionnaires such as the AASP (Brown & Dunn, 2002) may be better able to estimate the true frequency or severity of behaviours and begin to tap more internal sensory experiences, including preferences and emotions. However, even the AASP is based on Dunn's (1999) unfounded 'neurological thresholds' model, which raises questions regarding construct validity.

Self-report accounts indicate that sensory experiences in autism are more complex than the observable sensory reactivity in measures described above. For example, if Williams' (1998) aforementioned adaption of 'shutting down mind' in response to an overload of sensory information were to be coded with the SP, it would most likely be observed with item number 6: 'appears to not hear what you say (for example, does not "tune-in" to what you say), appears to ignore you' (Dunn, 1999). As this item is categorised as indicating a 'hyposensitive', passive (low registration) behaviour, the SP may indicate that the individual has an innate 'hypo-sensitivity' to sounds and requires more stimulation. However, Williams' explanation demonstrates that the individual's perceptual experience may be quite the opposite: a difficulty interpreting and managing high levels of auditory information, suggesting they would require less stimulation.

Bogdashina's 'Sensory Perceptual Checklist – Revised' (SPC-R) (Bogdashina, 2003) goes some way towards acknowledging this limitation, being formed from analysis of sensory self-reports in autism and clinical observations of behaviours. However, Bogdashina (2003) only draws on the experiences of the handful of (commonly female) adults with autism who have documented their experiences (e.g. Grandin, 2006), which may not be generalisable to the wider autism population. Moreover, the SPC-R still requires development, it has not been standardised or used in research and its structure has also been questioned in a factor analytic study (Robinson, 2010). A deeper understanding of the different sensory experiences in autism is needed before the full range of 'sensory experiences' may be captured accurately in a questionnaire.

Measures of sensory reactivity may therefore reveal the behaviours that are most problematic to observers, but obscure the details of the underlying sensory experience that is most relevant to the individual experiencing it. The implications are that sensory reactivity measures may actually underestimate the prevalence and impact of sensory-related difficulties in autism as they only tap observable behaviours. This potential underestimation would account for why prevalence estimates of 'sensory difficulties' in autism (Ben-Sasson et al., 2009) fall below the universality predicted by theories of sensory processing in autism (Frith, 2003; Mottron et al., 2006). As sensory reactivity is considered here to be a result or marker of internal sensory processing, it is perhaps not surprising that there is no coherent pattern found, given the difference between measures and the limited number of studies that account for the co-varying factors of age, intellectual functioning and autism severity.

# **Research in self-reports of sensory experiences in autism.** Research is increasingly turning to self-reports of sensory experiences for their increased validity over parent-reports (Ashburner et al., 2013), for ethical reasons of representing the 'autistic voice' (Milton, Mills & Pellicano, 2012), and for the potential to provide explanatory links between observed sensory reactivity and theories of sensory processing in autism.

*Explanatory power of self-reports.* Self-reports of coping strategies such as only looking at objects out of the side of the eye to reduce visual overload, tapping objects in a room to compensating for unreliable vision, or rocking to 'shut out the world' (Bogdashina, 2003; Grandin, 2006; Williams, 1998) provide clues as to how and why idiosyncratic sensory reactivity may develop and vary with age, autism presentation and intellectual functioning.

For age, one explanation for the change in sensory reactivity with age may lie in a passive or subconscious accrual of 'priors' (Pellicano & Burr, 2012). Alternatively, individuals may simply develop conscious coping strategies following the experience, which develops with age. How far coping strategies are deployed consciously at different ages may therefore help clarify how age affects sensory reactivity.

For autism symptoms, self-reports would support theories of sensory processing in autism which suggest that sensory processing underlies presentation of both social and non-social symptoms (Frith, 2003). Drawing on the accounts of individuals with autism, Bogdashina (2003) argues that repetitive behaviours themselves may be defensive (e.g. insistence on sameness to minimise unexpected stimuli), self-stimulatory (e.g. spinning

around), compensatory (e.g. holding fingers in front of eyes to reduce visual input) or pleasurable experiences (e.g. echoing or repeating sounds). Under this view, non-social autistic symptoms could therefore be understood as sensory coping strategies themselves. Likewise, the development of social symptoms may be better understood through self-reports. Williams (1998) describes how fragmented sensory perception interfered with her ability to read emotions in faces and understand language, while not understanding that others processed sensory information differently to her led to increased feelings of isolation.

For intellectual functioning, the directionality of the relationship with sensory reactivity is less clear. While reduced sensory reactivity is likely to facilitate engagement with the environment and therefore cognitive development, many researchers have suggested that the relationship is bi-directional; that intellectual functioning may facilitate the development of conscious coping strategies, causally influencing sensory reactivity (Crane et al., 2009; Leekam et al., 2007). The question of whether individuals have conscious awareness of their own sensory coping strategies or of their behavioural response being 'atypical' may therefore provide an indication of how far sensory experiences and reactivity in autism are related to differences in age, autism symptoms and intellectual functioning.

*Methodological considerations in self-report studies.* In order to be representative of the autistic experience, self-report accounts should be self-chosen, covering a wide range of topics and not constrained by language or social inhibitions. Such accounts are seen by the handful of autistic authors, who have chosen to document their experiences in books or online (Grandin,

2006; Grandin & Scariano, 1986; Williams, 1998). However, there are difficulties inherent in eliciting such accounts from people with autism who may have limited cognitive or linguistic ability. Perseveration on a topic and difficulties with recall may further inhibit the ability of individuals with autism to recount their sensory experiences (larocci & McDonald, 2006). To overcome these limitations, several of the studies reviewed below employed interview formats, in which sensory experiences are partially recreated in order to stimulate discussion. However, in such researcher-led formats, the full range or saliency or the autism sensory experience cannot be assumed. In addition, studies vary in their approach to analysis, which may be inductive or driven by the search for pre-defined topics. These issues, including the age, autism severity, and intellectual functioning of participants are considered in discussion of the studies of self-reports, below.

*Findings in adults.* In a grounded theory analysis that aimed to discover a theory of adult sensory experiences from a dataset of online first-hand accounts of 5 adults with autism, Jones, Quigney and Huws (2003) identified 4 main themes: turbulent sensory perceptual experiences, coping mechanisms, enjoyable sensory perceptual experiences and an awareness of being different. Coping mechanisms included; shutting out the world, avoiding unpleasant stimuli, using touch in place of other senses, rubbing objects and focussing on one aspect of an unfamiliar environment or on one sensory modality at a time (Jones et al., 2003). Four out of the 5 accounts examined also revealed awareness that their sensory processing was different to that of other people (Jones et al., 2003). However, as accounts were taken from

unverified online sources, they cannot be assumed to be genuine and the age, autism type and intellectual functioning of the contributors is unknown. Similarly, pre-existing autobiographical accounts of 10 adults aged 33 to 67 years with autism have also been analysed by Elwin, Ek, Schroder and Kjellin (2012). However, in their analysis, Elwin et al. (2012) applied predetermined categories of 'hyper' and 'hypo –sensitivity' to sensory information, which is likely to have constrained the analysis to descriptions of behaviours in these categories.

More recently, Smith and Sharp (2012) conducted a grounded theory analysis of self-reports of 9 adults aged 29 to 45 years with a verified Asperger's diagnosis. Participants' education levels ranged from GCSEs to bachelor's degrees. Interviews were conducted using open-ended, response-led questions, via online instant messaging, so had the advantage of facilitating communication by reducing the demands of social interaction (Smith & Sharp, 2012). Responses were categorised into the experiences of: heightened senses (e.g. everything seems louder), sensory stress (including fear and anger), the stress avalanche (where stress leads to heightened sensitivity and further stress), moderating factors (e.g. being calm beforehand), coping strategies, other people, self-acceptance, fascination (e.g. with music), and isolation (Smith & Sharp, 2012). Coping strategies included blocking out sensory input (e.g. by avoiding eye contact), dampening the intensity of sensory input (e.g. through covering the ears or listening to music), making their environments more ordered and predictable (e.g. mentally preparing for situations) and calming strategies (e.g. being squeezed). Although there was no separate theme suggesting an awareness of their atypical sensory processing, this was

identified as an important coping strategy in itself, as it allowed some participants to explain themselves to others and identify areas for change (Smith & Sharp, 2012). However, 6 of the 9 participants were reported to be on psychotropic medications; it is unclear how far this may influence sensory experiences. In addition, as with the Jones et al. (2003) study, the sample size is small and limited to individuals with an Asperger's diagnosis. It is not clear whether these experiences would generalise to other autism diagnoses.

Using a larger sample size of 15 adults aged 19 to 55 years and including 2 participants with a PDD-NOS diagnosis, 13 with an Asperger's diagnosis, Elwin et al. (2013) analysed the interview responses of a broader range of individuals. Participants' education ranged from pre-GCSE to bachelor's degree equivalent and all participants had an IQ above 70. Analysis of the interview responses revealed the themes of hyper and hypo-sensitivities, reacting to sensory overload, strong preferences, managing attentiveness, managing sensory stimuli and dealing with the consequences of sensory reactions. Within the theme of 'dealing with consequences', coping strategies of: avoiding, 'getting used to' stimuli, calming and compensatory strategies (e.g. listening to music and structure) were reported. However, as acknowledged by the authors, the topics of conversation were pre-defined by the interview questions, even though these were designed to be open-ended. The use of medication was not reported, but all participants had a co-occurring diagnosis, with ADHD and depression being the most commonly reported. While the analysis did not focus on individuals' awareness of their differences, 5 of the participants' reported examples did indicate this awareness.

Together, these studies indicate that most adults with autism have a conscious awareness of their sensory processing being different, which is likely to have helped in the creation and application of the reported coping strategies. These coping strategies were behavioural (e.g. covering ears, avoidance), physical (e.g. being squeezed, rubbing items) and cognitive (e.g. preparing for new situations, focussing on one aspect of the environment). However, it is worth noting that several unhelpful avoidance coping strategies were also reported in these studies, such as retreating 'inside my head' (Jones et al., 2003) and staying indoors to avoid unpleasant stimuli (Smith & Sharp, 2012).

*Findings in children and adolescents.* Systematic reviews of previous research into the self-report accounts of sensory experiences in children were carried out in March and September of 2013 and again in March 2014<sup>3</sup>. Of these studies only 2 pertained to the qualitative self-reports of sensory experiences of children with autism (Ashburner et al., 2013; Kirby, Dickie & Baranek, 2014). These 2 studies, my year 1 DEdPsy research project (Edgington, 2012) and one further unpublished doctoral thesis are discussed below (Robertson, 2012).

Edgington (2012) elicited the perspectives of 10 children with autism aged 7 to 11 years on their sensory processing preferences and experiences. All children had a diagnosis of autism, which was supported by elevated scores on the

<sup>&</sup>lt;sup>3</sup> An 'all time' abstract search using these terms: [autis\* OR ASD OR autism OR Asperger\* OR PDD-NOS OR Pervasive developmental disorder] AND [sens\* OR multisensory] AND [self report OR first hand OR autobiograph\* OR own] AND [child\* OR adolescen\* OR school age OR young] yielded the following results: PubMed: yielded 37, Web of Science (topic search): yielded 98, ProQuest: yielded 27 (which searches the databases Applied Social Sciences Index and Abstracts, British Humanities Index, ERIC, International Bibliography of the Social Sciences, Social Services Abstracts)

Social Communication Questionnaire (SCQ) (Rutter, Bailey & Lord, 2003). although details of the diagnoses were not confirmed. All children had a statement of special educational needs, with 6 attending a special school for autism and 4 attending mainstream education. Three children were working slightly below UK National Curriculum attainment levels and the remainder were working significantly below. To elicit the children's sensory preferences, cards depicting images of sensory stimuli (e.g. flicking pages) ('Sensory School Cards'; Gaudion & Edgington, 2012) were presented. They were asked what they do, think and feel when they encounter the stimulus presented on each card. Thematic analysis of responses revealed some awareness of pleasant and unpleasant emotional feelings (e.g. 'happy' at having a hug and an 'annoying' toilet flush), body sensations (e.g. Velcro was described as 'skinny', making skin feel funny) and behaviours related to control or helplessness (e.g. 'when it gets really loud, I feel I can't do nothing'). Some children were able to identify coping mechanisms of avoiding (e.g. for heights), controlling the sensory input through tidying-up or the use of ear defenders (Edgington, 2012). What was not evident was an awareness of the children's sensory processing being different to others', or reports of more complex coping mechanisms, such as those discussed above. However, the responses gleaned in this study were limited by the cognitive and linguistic ability of the children, by them being distracted or uncomfortable within the interview setting (with an unfamiliar adult), and by the saliency of the stimuli used, being limited to visual images preselected by the interviewer, rather than the child.

In three separate focus groups, Robertson (2012) interviewed 10 children with autism aged 9 to 14 years about 'sensory processing issues'. Completion of the SCQ (Rutter et al., 2003) indicated the range of overall autistic symptomatology being 12 to 25 (where 15 is considered the indicative 'cut-off' for autism). There was no reported measure of intellectual functioning. To facilitate recall of sensory experiences, participants took part in interactive activities, including listening to sounds, smelling scents and feeling items hidden in a box. Inductive thematic analysis revealed positive and negative sensory experiences and extremely strong reactions to sensory stimuli (Robertson, 2012). Reference was made to avoidance (e.g. covering ears) or distraction techniques and positive sensory experiences being used as a calming mechanism (e.g. squeezing something). Analysis of children's responses did not include reference to an awareness of their sensory processing being different to others', meaning that conclusions about conscious coping strategies at different ages cannot be formed. Furthermore, as Robertson only reports asking children about their sensory preferences (rather than the internal experience) it is unclear how far these responses are representative of children's full sensory experiences.

More recently, Ashburner, Bennett, Rodger and Ziviani (2013) interviewed three adolescents with autism aged 12, 13 and 16 years about their sensory experiences. Two had a diagnosis of autism and one Asperger's. Intellectual functioning was not collected, but 2 participants attended a mainstream school and one attended an autism-specific school. Using a semi-structured interview format and visual cues as prompts, participants were asked to describe their reactions to sensory input and consider whether they differ to others'.

Responses were analysed using an 'a priori' coding system, searching for pleasant, unpleasant and distracting experiences as well as coping mechanisms. Three common coping mechanisms were identified. The first was avoiding, controlling or blocking out unpleasant or distracting stimuli (e.g. leaving the room), some of which lead to unhelpful outcomes for the child (e.g. avoiding eating). The second was increasing predictability or control (e.g. cooking own food, asking someone to stop whistling). The third category was of meta-cognitive coping strategies, including self-talk, focussing on one aspect of the environment, imagination and planning ahead. Again, there was no indication that children were aware of their sensory processing being different to others'. Ashburner et al. (2013) also noted that all participants preferred predictable and controllable sensory input and suggested that children may benefit from being encouraged to identify the controllability of stimuli. For stimuli that cannot be controlled, participants reported 'getting used to it' as important in reducing their discomfort, consistent with the role of 'priors' as important for sensory interpretation (Pellicano & Burr, 2012). Interestingly, Ashburner et al. (2013) also report one boy overcame a fear of hand-dryers by playing and experimenting with them, suggesting that a more conscious acquisition of 'priors' is also possible. While the pre-defined categories for analysis resulted in a comprehensive discussion of coping strategies, some other aspects of sensory experiences, such as the extent of participants' awareness of being different, may have been omitted from the analysis. Moreover, in addition to the small sample size, 2 of the 3 participants had a co-occurring diagnosis of ADHD and were on stimulant medications, which may limit the generalisability of these findings.

Most recently, Kirby, Dickie and Baranek (2014) elicited the perspectives of 12 children aged 4 to 13 years. Children's autism severity scores ranged from 4 to 10 on the ADOS, (where 4 to 5 is indicative of autism and 6 to 10 of autism spectrum disorder, Gotham, Pickles & Lord, 2009) and mental ages ranged from 4.5 to 15 years, all children were 'verbal'. Kirby et al. (2014) used a semistructured interview format and personalised examples of video clips to facilitate discussion. Children were asked about sensory preferences, thoughts, feelings and behaviours in response to sensory stimuli and perceptions of difference to others. Questions were open-ended, based on both previously known and open to other sensory preferences. In analysing responses, Kirby et al. (2014) focussed on how individuals share their sensory experiences, recording their behavioural responses and facial expressions through video recordings. This analysis led to 3 main themes, including 'normalising' experiences, 'story-telling' (e.g. anecdote and demonstration) and 'describing responses'. Within the 'normalising' theme, Kirby et al. (2014) suggest that 3 subthemes of 'likes and dislikes', 'change over time', and 'same as others' indicate children were motivated to convey they have typical sensory experiences and suggest that this may indicate some self-consciousness about sensory differences. However, the authors did not consider the possibility that children already consider their experiences to be normal because they had not yet developed a sense of their sensory experiences being different. Nevertheless, they do note that children were motivated to change their sensory experiences in order to overcome unpleasant everyday experiences (e.g. brushing hair).

Within the theme of 'describing responses', coping 'strategies' were noted, including a need to respond by avoiding or modifying the exposure to sensory input. 'Uncontrollable physical responses' (including nausea and pain) and 'fear' of unknown or past unpleasant sensory experiences were also described within this theme. Kirby et al.'s (2014) methods of using individualised video clips to both prompt and record responses would appear to facilitate eliciting responses from individuals from a wide range of autism severity and MA. However, it is perhaps due to the range of abilities presented in this sample that it is difficult to say how different experiences may vary with these parameters.

The small number of qualitative studies of self-reports of sensory experiences indicates that both pleasant and unpleasant sensory experiences are common to both adults and children with autism (e.g. Robertson, 2012; Smith & Sharp, 2012). Coping strategies of avoiding or controlling an unpleasant stimulus are also present even in the youngest participants studies reviewed (Edgington, 2012; Kirby et al., 2014), though can sometimes result in unhelpful outcomes for the individual (Ashburner et al., 2013; Smith & Sharp, 2012). As participant ages increased between studies, increasingly sophisticated coping strategies emerge, including distraction techniques and physical calming mechanisms (9 to 14 years, Robertson, 2012), and cognitive strategies including planning and focussing attention (12 to 16 years, Ashburner et al., 2013). Kirby et al. (2014) and Ashburner et al. (2013) were the only authors to ask participants about their awareness of their sensory experiences in relation to others; neither included reports that indicated a conscious awareness of a sensory difference. The lack of reports of self-awareness of difference may indicate that this meta-cognitive

awareness develops atypically or relatively late, this suggestion is supported by anecdotal self-reports:

"When I was a child and teenager, I thought everybody thought in pictures. I had no idea that my thought processes were different." (Grandin, 2006, p. 4)

This perspective would fit with theories of sensory processing which may suggest a limited conscious awareness of self in-relation-to others (Frith, 2003, 2006). Most studies have yet to relate self-report sensory experiences to theories of sensory processing in autism. Moreover, with such small sample sizes these experiences cannot be assumed to be generalisable. How far the development of these strategies is related to age, experience, intellectual functioning or awareness of sensory processing being different is unclear as many fail to adequately describe the degree of autistic features or the intellectual functioning of participants.

# 2.1.6. Additional Impact and Outcomes of Sensory Processing Atypicalities in Autism

A difficulty in interpreting or perceiving sensory stimuli is likely to impact on several other developmental outcomes, additional to sensory reactivity. Additional outcomes are defined here are those features which might be expected to be causally influenced by atypical sensory processing, which correlate with measures of sensory reactivity. It has been argued that some 'talents' in autism, such as hyper-attention to detail, may be additional outcomes of sensory processing (Baron-Cohen, Ashwin, Ashwin, Tavassoli & Chakrabarti, 2009). However, those outcomes that are generally regarded to interfere with daily functioning, and therefore most relevant for potential interventions, are considered below.

Autism symptoms. As discussed above, studies of sensory reactivity have found correlations with the social (Gearhart & Bodie, 2012; Hilton et al., 2010) and non-social symptoms of autism (Chen et al., 2009; Gabriels et al., 2008). Autobiographical accounts of sensory experinces have suggested how atypical sensory processing may at least in part, causally affect autism symptom severity (Grandin, 2006; Williams, 1998). As such, both social and non-social autism symptoms could be considered additional outcomes.

Engagement, behavioural difficulties and academic attainment. Selfreport accounts describe how some stimuli may cause extreme distress or pain, while others may be soothing or mesmerising (Grandin, 2006; Grandin & Scariano, 1986; Williams, 1998). Both positive and negative sensory experiences may therefore prevent the child from interacting with the environment and other people (Suarez, 2012). Accordingly, correlations have been found between sensory reactivity and behavioural difficulties in toddlers (Tseng, Fu, Cermak, Lu & Shieh, 2011) and children with autism (Ashburner, Ziviani & Rodger, 2008; Baker, Lane, Angley & Young, 2008; O'Donnell, Deitz, Kartin, Nalty & Dawson, 2012), which Bogdashina (2003) attributes to a difficulty in explaining distress in the face of uncomfortable or painful stimuli. Similarly, Ashburner et al. (2008) report correlations between sensory reactivity and measures of inattentive behaviours and teacher-rated academic attainment in children with autism aged 6 to 10 years in mainstream school. While these findings are limited by a failure to control for variation in intellectual functioning,

the impact on engagement, behavioural difficulties and subsequent academic attainment are perhaps one of the more immediately recognisable additional outcomes.

Anxiety and depression. Studies have found associations between sensory reactivity and anxiety or negative mood in toddlers (Ben-Sasson et al., 2009), 3 to 7 year-olds (Brock et al., 2012) and 2 to 18 year-olds with autism (Mazurek et al., 2012). The directionality of the relationship between sensory behaviours and anxiety has since been demonstrated in a longitudinal study of toddlers with autism where sensory hyper-sensitivity predicted changes in anxiety over a year, controlling for child age, maternal anxiety, developmental level and autism symptom severity (Green, Ben-Sasson, Soto & Carter, 2012). Autistic self-reports of 'fear' at certain sensory experiences (Kirby et al., 2014) would corroborate this link with anxiety and support the claim of Hollocks et al. (2013) that anxiety in autism is due to interpretational biases, rather than the attentional biases seen in typical populations.

Looking more specifically at the type of sensory behaviours involved, Pfeiffer, Kinnealey, Reed and Herzberg (2005) found correlations between sensory hyper-sensitivity and anxiety and hypo-sensitivity and depression in 6 to 17 year-olds with autism. While this study fails to account for intellectual functioning, self-reports (e.g. Williams, 1998) would support the notion of overwhelming and feared environmental stimuli causing anxiety, while the protective coping mechanism of 'shutting down' to block out too much information may resemble the lethargy and lack of responsiveness evident in depression (Lai, Parham & Johnson-Ecker, 1999; Pfeiffer et al., 2005).

Interventions that focus on sensory experiences therefore have the potential to affect sensory reactivity and also impact on these additional outcomes.

## 2.1.7. Coping Strategy Interventions for Sensory Experiences

In view of the role that sensory experiences may play in the development of autistic symptoms and their impact on additional outcomes as discussed above. there is a pressing need for interventions aimed at this level, that is, the conscious awareness and interpretation, cognitions, emotions and responses involved in sensory experiences. Thus far, sensory integration therapies have ignored the internal 'sensory experience' as it is felt by the individual and the highly limited evidence base is testament to the ineffectiveness of this approach (American Academy of Pediatrics. 2012; Case-Smith et al., 2014). Intervention focussing on environmental adaptations to suit the sensory needs of individuals (e.g. Gaudion & Brand, 2011) is a promising alternative approach, suitable for settings such as schools. However, 'self-regulatory' interventions that equip the individual to cope in unfamiliar situations are also needed (Ashburner et al., 2014). Interventions that draw upon self-reports of sensory experience in autism, empower the individual to consciously cope with their difficulties and offer a more ethical and potentially more effective framework in which to design an intervention.

Systematic reviews of previous coping strategy interventions for the sensory experiences of children and adolescents with autism were carried out in March

of 2013 and 2014<sup>4</sup>. Of these studies only one purported to employ a 'psychoeducational programme', finding significant treatment effects on autism severity, but not sensory reactivity (Papauasiliou, Nikaina, Rizou & Alexandrou, 2011). However, the intervention programme also included social skills, sensory integration and language interventions, making it difficult to comment on the effectiveness of any one component. Nevertheless, within the literature on occupational therapy interventions (Ashburner et al., 2014; Gal, Cermak & Ben-Sasson, 2007) there are 2 programmes known for use with children with 'sensory difficulties' (i.e. not autism specific) which are designed to equip children and adolescents with coping strategies that they implement themselves. These are discussed below.

The Alert Program for Self-Regulation (Williams & Shellenberger,

**1994)**. The Alert Program consists of 8 weekly sessions and associated activities that use the analogy of an engine to help children think about how their body is 'running' to minimise disruption from sensory reactivity and 'stay on task' (Williams & Shellenberger, 1994). Children are taught how to identify and change their 'engine speeds' using sensory-motor calming strategies (e.g. petting a cat, stretching, watching the sunset), taking increasing responsibility for monitoring and regulating their own 'engine speeds'. The programme was initially intended for children with attention and learning difficulties aged 8 to 12

<sup>&</sup>lt;sup>4</sup> An 'all time' abstract search using these terms: [autis\* OR ASD OR autism OR Asperger\* OR PDD-NOS OR Pervasive developmental disorder] AND [sens\* OR multisensory] AND [intervention OR treatment OR therap\*] AND [coping OR cope OR managem\* OR regulat\*] AND [child\* OR adolescen\* OR school age OR young] yielded the following results: PubMed: yielded 26, Web of Science (topic search): yielded 75, ProQuest: yielded 14 (which searches the databases Applied Social Sciences Index and Abstracts, British Humanities Index, ERIC, International Bibliography of the Social Sciences, Social Services Abstracts)

years and has been adapted for use with younger children. Williams and Shellenberger (1994) note that it is appropriate for use with 'verbal and interactive' autistic populations, who can engage in reciprocal conversation, but less suitable for children who are 'concrete thinkers' who have difficulty with imagination or abstract thought, as they may have difficulty with the engine analogy.

The effectiveness of the programme has been investigated by Barnes, Vogel, Beck, Schoenfeld and Owen (2008) in one school with 7 children receiving the intervention and 5 typical children aged 9 to 11 years. Children were selected for having an 'emotional disturbance', a term used by the school psychologist to denote behaviours 'not conducive to learning'; all took medication for this. IQs of all children ranged from 77 to 123, with one additional child having an IQ of 57; the group allocation of this child was not reported. Using the SP to measure sensory reactivity pre and post-intervention Barnes et al. (2008) report a slight improvement to the mean intervention group score, but a worsening of typical group scores. However, teachers completed the SP, which is designed for use by caregivers. Moreover, numerical scores and statistical analyses were not reported on this measure. Two intervention-group children showed a significant improvement on a standardised behaviour measure, although numerical scores and statistical analyses were again not reported. A significant intervention-group effect was found for teacher-reported 'self-regulation self-efficacy' using a measure designed for the intervention, but not on the child-reported equivalent. While there is little information reported about the content of this measure, a greater criticism lies in the fact that teachers in the intervention group were

trained on the programme and encouraged to implement it, so the significant finding may be attributed to teachers' increased understandings and behavioural expectations (Ashburner et al., 2014). Although this study has several methodological limitations and intervention has not been evaluated with autism populations, the emphasis on building up conscious self-awareness and monitoring address that which both theory (Frith, 2003; Mottron et al., 2006) and self-reports (Ashburner et al., 2013; Edgington, 2012; Robertson, 2012) suggest is atypical in autism. In addition, the strategy of using pleasant sensory experiences to self-soothe has good face validity as a coping strategy, reportedly employed by individuals with autism (Robertson, 2012; Smith & Sharp, 2012).

Sensory Stories (Therapro Inc., 2011). These consist of 30 customisable stories that are read several times a day to children with sensory difficulties to prepare them for different activities, such as brushing teeth. Stories suggest calming sensory strategies such as self-hugs for children to use during the activity, which the children are encouraged to implement. The authors suggest that children aged 5 to 7 years with sensory overresponsiveness may benefit most from the approach.

In an unpublished thesis, Sherick (2004) investigated the effect of being read personalised, daily Sensory Stories on the 'targeted behaviours' of a convenience sample of 5 children with (unconfirmed) autism aged 5-10 years, attending a summer camp for autism. Children were reported to have a minimum of a 2 year-old level of language understanding, however, there were no other reported measures of cognitive or language abilty. Three out of 5

children had significant sensory reactivity difficulties on the SP, at baseline. Behaviours were recorded using daily interval time sampling observations over pre-intervention (1 week), intervention (2 weeks) and follow up (1 week) periods and were specific to each child, including: repetitive movements, spontaneous vocalisations and 'non-purposeful behaviour'. Binomial analysis showed a reduction in group targeted behaviours during the intervention, but an increase during post-intervention and no change in behaviours on an individual level (Sherick, 2004). However, Sherick acknowledges that findings are limited as participants showed inconsistent patterns of behaviour during the base-line period of this 'ABA' design, so without a control group, who did not receive the intervention, reduction in observable behaviours may not necessarily be attributed to the intervention. In a similar study using an ABA design, Marr, Mika, Miraglia, Roerig and Sinnott (2007) selected 5 children with autism aged 4 to 5 years, attending a preschool programme for autism. Improving on Sherick's (2004) design, Marr et al. (2007) ensured that children were read to (not sensory stories) during the pre-intervention phase, and found that 3 out of 4 children showed a decrease in their 'targeted behaviours' during the intervention phase as measured using time sampling observations. In this way improvements may be more likely attributed to the content of sensory stories, rather than the attention afforded by being read to individually. However, in both Marr et al. (2007) and Sherick's (2004) studies, generalisability is limited by the use of a small, convenience sample. Nevertheless, the coping strategies of sensory self-calming and cognitive strategy of mental preparation or visualisation resemble some of the self-reported coping strategies of individuals

with autism (Ashburner et al., 2013; Smith & Sharp, 2012), so have good face validity.

Despite their limited evidence base, the above programmes aim to improve sensory awareness and provide self-soothing and cognitive coping strategies so represent a self-regulatory approach that is compatible with theories of sensory processing in autism (Frith, 2003) and self-reported sensory experiences (e.g. Ashburner et al., 2013). However, this self-regulatory approach may be better suited to older and more cognitively able individuals with autism, who perhaps receive fewer intervention hours and have a greater level of independence required to implement the strategies (Gal et al., 2007). Such populations may also be able to consider a more comprehensive and flexible approach offered within the framework of Cognitive Behavioural Therapy (CBT), which involves the conscious consideration of cognitions, emotions, physiology and behaviour involved in sensory experiences.

#### 2.1.8. CBT and its use in Autism Interventions

CBT is one of the most widely used forms of therapeutic intervention (Reid & Westergaard, 2011). It is time-limited, has strong empirical support and is commonly applied to anxiety and other psychiatric difficulties (Graham, 2005). All CBT therapies are based on the idea that maladaptive cognitions or faulty interpretations of events are causally linked to behaviours, emotions and physiology, which interact with each other and contribute to the maintenance of psychiatric problems (Hofmann, 2011; Westbrook, Kennerley & Kirk, 2007). The aim of CBT is to empower the recipient to understand and manage their thoughts, feelings and behaviours (Reid & Westergaard, 2011). With autistic

populations, CBT programs require adaptions that might take account of difficulties in: establishing relationships with the therapist, high level language, taking turns in group situations, and understanding emotions (Donoghue, Stallard & Kucia, 2011). Accordingly, CBT programmes for children with autism include adaptions such as; emotional education (Clarke, 2012; Sofronoff, Attwood & Hinton, 2005), parental involvement (Chalfant, Rapee & Carroll, 2007; Reaven, Blakeley, Smith, Culhane, Shelburne, & Hepburn, 2012); Sofronoff, et al. 2005.; Wood et al., 2009), visual materials and reward systems (Chalfant, et al. 2007), and the teaching of friendship skills (Wood et al., 2009), relaxation exercises, emotional regulation and cognitive self-control (Sofronoff et al., 2005; Sung et al., 2011). There is evidence from randomised control trial (RCT) studies with groups of autistic children, ranging in age from 8-16 years, that such adapted CBT programmes are effective in reducing anxiety, as measured by clinical interview (Chalfant et al., 2007; Reaven et al, 2012; Wood et al., 2009), and parent and child questionnaires (Chalfant et al., 2007; Sofronoff et al., 2005; Sung et al., 2011; Wood et al., 2009). For autistic adolescents with sufficient verbal ability, CBT might therefore be considered a suitable intervention approach for anxiety.

#### 2.2. The Current Study: Rationale

There is growing recognition of the role that atypical sensory processing may play in the development of autism. Sensory reactivity seems to be a cooccurring feature of some individuals with autism but the true prevalence of sensory-related difficulties is likely to have been obscured by parent-report measures of sensory reactivity, which are based on assumptions about hyper

and hypo-reactivity, rather a theoretically-informed understanding of sensory processing in autism. Although theories of sensory processing have yet to be empirically verified, they nevertheless suggest that sensory reactivity in autism arises from an enhanced bottom-up processing style (Mottron et al., 2006), with limited 'interpretation' due to weak or intermittent top-down processing (Frith, 2003), potentially arising from a difficulty in building up internal models of the world or 'priors' (Pellicano & Burr, 2012). Qualitative self-report accounts of sensory experiences in autism are consistent with these theories and also provide clues about sensory processing styles in autism that may causally influence the social and non-social autism symptoms and other difficulties such as engagement with the environment, behavioural difficulties and anxiety. Ultimately, a richer understanding of sensory experiences through self-report accounts should inform the development of behaviour-based questionnaires and sensory-based interventions.

To date, this understanding has largely come from the self-report accounts of a handful of cognitively able autistic adult authors. However, studies suggest experiences may be different for children and adolescents, as sensory reactivity may change with age, autism severity and intellectual functioning, which may be due to the development of a conscious awareness of a sensory processing difference and coping mechanisms (Crane et al., 2009; Kern et al., 2006; Leekam et al., 2007). The self-reported sensory experiences of children and adolescents have only been investigated by a handful of studies (Ashburner et al., 2013; Edgington, 2012; Kirby et al., 2014). These studies have included limited information about the autistic profile and intellectual functioning of

participants, except for Kirby et al., who included a wide range of ages and autism types, making it difficult to infer how experience differs between profiles. Analyses of experiences so far have focussed on sensory preferences and behaviours (Edgington, 2012; Robertson, 2012), or *how* experiences are shared (Kirby et al., 2014). The development of coping mechanisms has only been directly explored in one study with 3 adolescents (Ashburner et al., 2013), while the extent to which children and adolescents have conscious awareness of a sensory processing difference remains unclear (Kirby et al., 2014). There is therefore a pressing need to explore further the process of conscious development of awareness in children and adolescents with known autism severity and intellectual functioning.

A first-hand understanding of sensory experiences in autism has the potential to inform self-regulatory interventions, which may help individuals manage their cognitive, emotional, physiological and behavioural responses. Such an approach, targeted at the level of the conscious awareness, stimulus interpretation and planning for responses involved in sensory experiences, more closely resembles the 'top-down' conscious processing that is implicated to be absent in theories of sensory processing (e.g. Frith, 2003). This approach is therefore a more direct way of influencing behaviour than traditional sensory integration therapies that provide sensory input to try and 'integrate' sensory processing. These traditional therapies ignore the internal experiences of the autistic individual, are based on a theory lacking in empirical support (American Academy of Pediatrics, 2012), and have been revealed to be ineffective (Case-Smith et al., 2014). There are only two known programmes which adopt a

different approach and try to teach sensory coping strategies in the form of selfawareness and self-calming (the Alert Program, Williams & Shellenberger, 1994), and mental preparation (Sensory Stories, Therapro Inc., 2011) with young children. However, the evidence for the effectiveness of these is extremely limited. Moreover, self-reports of sensory experiences in autism would suggest that this self-regulatory approach may be more suited to older and more cognitively able individuals with autism.

There is a need for an evidence-based sensory intervention programme for individuals who are more capable of meta-cognition and self-regulation, which offers a more comprehensive and flexible approach than the existing selfregulatory programmes and draws on theories of sensory processing in autism and the self-reports of existing coping behaviours in sensory experiences. More work is needed to examine the feasibility of awareness-building and coping strategies with older autistic populations and the impact that such an approach may have on measurable outcomes of sensory atypicalities. There is also a need to address methodological issues in previous studies, through the use of a control group who do not receive intervention, matched on intellectual functioning and autism symptomatology.

CBT offers a promising framework within which to design such an intervention, as it is a self-regulatory intervention, focussed on the development of selfawareness of the interaction between thoughts, feelings and behaviours in response to environmental triggers (Hofmann, 2011). In programmes that use suitable adaptations, CBT has already been demonstrated to successfully

reduce anxiety in adolescents with autism (Chalfant, Rapee & Carroll, 2007; Clarke, 2012; Sofronoff, Attwood & Hinton, 2005; Wood et al., 2009).

However, as discussed above, some researchers have suggested that some anxieties in autism stem from the unpredictable nature of sensory stimuli (Mazurek et al., 2013) and difficulties in sensory interpretation (Hollocks et al., 2013). It could therefore be argued that using a CBT approach to help manage sensory experiences may also act as a more direct approach to address anxiety in autism, as well as problematic sensory behaviours.

Adolescents of secondary school age, 11 to 16 years were considered the most suitable age range for two reasons. First, previous research into the sensory experiences of children and adolescents with autism would indicate that the secondary school years are when children may be beginning to develop coping strategies and an awareness that they perceive the world differently (Ashburner et al., 2013; Edgington, 2012; Robertson, 2012). At this age, adolescents are also experiencing hormonal and other transitional life changes and challenges, such as school transition and external exams, all of which require them to adapt to the demands of the environment. An intervention aiming to accelerate or anticipate the adaptive process may also be most effective at this age. Second. adolescents are also more likely to have the requisite meta-cognitive and language ability to engage in a CBT-based intervention. Previous research using CBT with individuals with autism has involved participants with a mean age of around 10 years (Chalfant et al., 2007; Clarke, 2012; Sofronoff et al., 2005; Wood et al., 2009). Children above this age, at secondary school are therefore more likely to be able to engage with and benefit from the intervention.

## 2.3. The Current Study: Research Aims

The current study expands the evidence base of sensory self-report accounts of adolescents aged 11-16 years with autism, using a semi-structured interview format with visual sensory images as prompts (Gaudion & Edgington, 2012). This study builds on the work of Ashburner et al (2013) and Kirby et al. (2014), by asking adolescents of known intellectual functioning and autism severity about their experiences, coping mechanisms and their belief about how their experiences compare to others'. While analysis of responses was influenced by an interest in individuals' conscious awareness and coping, an inductive approach was taken to capture the experience as it is felt by adolescents, rather than descriptions of sensory behaviours and preferences.

In addition, this study is the first to design a CBT-based intervention to help adolescents' conscious awareness and management of their behavioural, emotional, physiological and cognitive responses to sensory stimuli, and to assess the feasibility of such an intervention.

The main aims of current study were therefore:

- To expand the evidence base of self-reports of sensory experiences of adolescents with autism aged 11-16 years.
- 2) To evaluate the effectiveness of an 8-week CBT-based group intervention for adolescents with autism to help build awareness and coping strategies for sensory experiences, associated behaviours and anxiety.

#### 3. CHAPTER THREE: METHODOLOGY

This chapter begins with a statement of the epistemological stance of the research, then outlines experimental methodologies used to answer the research questions above and further research sub-questions. Participants and recruitment procedures are then described, followed by a detailed description of the intervention design and rationale, including modification to the setting. Next, the psychometric properties of measures used are reported, followed by an outline of the data collection procedures, ethical considerations and data analysis procedures.

#### 3.1. Methodology

#### 3.1.1. Epistemological Stance

This study centres on the belief that individuals with autism may perceive the world differently, due to differences in their sensory perception and interpretation; a belief which would fit with Burr's (2003) description of a constructivist position. Accordingly, this study also views self-report data as the most valid source of information on sensory experiences in autism, yet acknowledges the difficulties inherent in using self-reports to measure the internal processes that underlie sensory processing and behaviour in autism. This study therefore adopts a pragmatic stance: the most helpful thing we can hope to do is to assist individuals with autism develop the skills to adapt their chosen behaviours and function in society. The subjective self-reports of individuals with autism and their families are considered important to understand the sensory experience and evaluate the intervention, while the

objective measures of sensory behaviours, repetitive behaviours and anxiety provide a practical measure of how far the intervention is useful in allowing them to behave in a manner consistent with integration into society. As argued by Teddlie and Tashakkori (2009) a pragmatic perspective would allow for both the more qualitative, constructivist approach and the quantitative, positivist approach to be combined in order to answer the research questions in this mixed methods study.

#### 3.1.2. Experimental Methodology and Research Sub-Questions

A mixed methods design was chosen to ensure that both the perspectives of observers and individuals with autism were presented, thereby enriching understanding of sensory experiences (Teddlie & Tashakkori, 2009). To address Aim 1, adolescents with autism in one mainstream school were interviewed individually about their sensory experiences, using a semi-structured interview format. Adolescents' responses were analysed thematically using an inductive approach that aimed to draw out the aspects of the adolescents' experiences that would be most useful in allowing educators and their families to support the adolescents in coping and adapting to their environments. In light of the literature review, aspects of the sensory experience also of interest were: the most salient thoughts feelings and behaviours (given the CBT framework of the intervention in Aim 2), the extent to which their own sensory experiences are considered 'different' and how far this knowledge may be related to the use and development of coping strategies. Aim 1 therefore included the following research sub-questions:

- *i.* To what extent are adolescents conscious of how sensory experiences relate to thoughts, emotions, physical sensations and behaviours?
- *ii.* To what extent are adolescents conscious of having different sensory experiences in relation to other individuals?
- iii. To what extent are conscious coping strategies employed by autistic adolescents prior to intervention and what do they consist of?

To address Aim 2, a CBT-based intervention was designed specifically to build awareness of the areas identified in Aim 1 and for the management of sensory experiences for more able children with autism. As this is a new intervention, the rationale for the structure and content of the intervention is described with reference to the literature. A pilot randomised controlled trial (RCT) was carried out to assess the effectiveness of this intervention. Participants' background data were measured prior to the intervention. These included intellectual functioning as measured by IQ, autism severity, and other characteristics known to co-vary with sensory reactivity or affect autism presentation. Participants were randomly allocated to experimental (Expt) or services as usual (SaU) groups. Evaluation of the intervention was based on a mixed methods approach with outcomes measured using quantitative approaches examining group changes over time, and qualitative approaches to capture participant perspectives. Due to the individual variability inherent in sensory reactivity, within-participant analyses of change were also carried out for individual cases on outcome measures, to examine any effects which may not be evident at a group level.

Sensory reactivity was identified as the primary outcome, measured on 3 occasions: pre-intervention, post-intervention, and follow-up. The follow-up data

collection point was chosen for 2 reasons; 1) to determine whether any changes would be maintained 8 weeks after the intervention; 2) to determine whether there is a delay prior to any impact of the intervention becoming visible in observable behaviours. In light of the potential discrepancy between the sensory behaviours most salient to parents and adolescents themselves, as argued above, both a parent-report and a self-report questionnaire were chosen to index the primary outcome variables, following Consolidated Standards of Reporting Trials (CONSORT) criteria of primary outcomes that hold 'greatest importance to relevant stakeholders' (Schulz, Altman & Moher, 2010).

Secondary outcomes not directly targeted by the intervention were chosen from the 'additional outcomes' discussed above: social and non-social symptoms of autism, engagement, behaviour, attainment, anxiety, and depression. From this list, the non-social autism symptoms and anxiety were chosen as 2 secondary outcome measures, being those most likely to be causally influenced by a sensory processing atypicality, easy to operationalise and with the strongest evidence for correlations with sensory reactivity (Chen et al., 2009; Gabriels et al., 2008; Mazurek et al., 2012; Pfeiffer et al., 2005). Secondary outcome measures were collected at follow-up only, 8 weeks after the intervention ended (i.e. not post-intervention), to limit the number of questionnaires parents had to complete.

Participant perspectives were gathered via post-intervention semi-structured interviews with 2 focus groups of adolescents who had received the intervention and individual interviews with their parents. Parents' perspectives were sought to ascertain the extent to which behavioural changes were evident in the home

context and to triangulate data with adolescents' reports. All interventions and interviews were carried out by the researcher and took place within the adolescents' school setting, an all-boys mainstream secondary school. Aim 2 was therefore divided into the following research sub-questions:

- Was there a change in adolescents' group-level sensory symptoms, as measured by a self-completed sensory questionnaire and a parentcompleted sensory questionnaire at post intervention and follow-up?
   [primary outcome measures]
- ii. Does the intervention have secondary consequences for adolescents' group-level repetitive behaviours and anxiety, as measured by a caregiver completed questionnaires at follow-up? [secondary outcome measures]
- iii. Are there impacts on adolescents' individual-level measures of sensory reactivity, repetitive behaviours and anxiety?
- *iv.* What were adolescents' perceptions of the effectiveness of the intervention?
- v. What were parents' perceptions of the effectiveness of the intervention?

# 3.2. Participants

Twelve male adolescents aged between 11 and 16 years (*M*=13.91 yrs., *SD*=1.45) took part in the study. Criteria for inclusion in the study were (1) both parent and adolescent signed consent for participation, (2) an independent clinical diagnosis of autism or Asperger's Syndrome (confirmed by parents and documentation supporting the diagnosis), (3) reported functional hearing and vision, (4) aged between 11 and 16 years in July 2013, (5) sufficient language

and literacy to answer some written and oral questions, and (6) IQ of above 70 (as measured by the Full Scale IQ-II subtest measure of the Wechsler Abbreviated Scale of Intelligence – II; WASI-II). The exclusion criterion was the use of psychotropic medications. Participants were not excluded for having a co-occurring diagnosis in addition to autism, due to the high degree of overlap with other conditions, such as ADHD (Simonoff et al., 2008).

The Social Responsiveness Scale (SRS) (Constantino, 2012) was used to gain an overall measure of autistic symptomatology. Since it is not itself a diagnostic tool and it is known that presentation of autistic symptomology can change with age (e.g. Fein et al., 2013), SRS scores were not used as an exclusion criterion. Furthermore, the scores on the behaviour-based sensory questionnaires (see measures section) employed in this study were not used as exclusion criteria, for the following reason. In light of the literature review, the current study takes the position that all individuals with autism may have atypicalities in sensory processing. Self-report or parent-report sensory questionnaires do not measure these internal processing atypicalities, but observable behaviours and preferences. Moreover, any questionnaire is only able to tap a few specific common examples, rather than the range of sensory experiences that is relevant to the individual. Participants were therefore included in the study irrespective of their SRS and sensory reactivity scores.

Adolescents with autism and their parents were recruited through one secondary mainstream school in London. The school was initially identified as one known for having a high number of pupils with autism, located within the LA in which the researcher was employed. Special schools were excluded from the

study as the pupils may have limited cognitive or language ability for engagement with the intervention. The Special Educational Needs Co-Ordinator (SENCO) was contacted to gain permission for recruitment via the Head Teacher.

The school itself (Gradewood<sup>5</sup>) is unlike many other maintained mainstream schools in London, being selective on the grounds of religious faith and free to follow its own curriculum as per its Academy status. The SENCO reported that there were 1351 pupils on role, which includes a primary-age and sixth form provision, spanning academic years 3 to 13 (ages 7 to 18 years). Gradewood accepts boys-only up to academic year 11 and is co-educational in the sixth form. The school's pupils come from all over London, with pupils resident in 23 different LAs. Key demographics of Gradewood indicate that it has higher attainment and a lower Special Educational Needs (SEN) prevalence than the national average, as measured by the percentage of pupils classified as School Action (SA), School Action Plus (SA+) or with a statement of SEN (SSEN) (Department for Education, 2014; Education Adviser, 2014). As might be expected for London school, Gradewood has a higher percentage of pupils with English as an additional language (EAL) or from non-'white British' ethnic backgrounds in comparison to national averages. While Gradewood has a relatively high proportion of pupils who live in 'deprived areas', the number of pupils eligible for free school meals (FSM) is lower than the national average. The SENCO reported that Gradewood is often favoured by parents of pupils with autism, due to the high levels of structure and behavioural expectations

<sup>&</sup>lt;sup>5</sup> All names are pseudonyms

within the school. Initial discussions were held with the SENCO to identify potential candidates, arrange timings, details of the project and the measures to be collected. The CONSORT flow diagram in Figure 1 shows participant numbers at the stages of enrolment, group allocation and subsequent data collection and analysis. One participant in the SaU\_older group dropped out due to personal difficulties. In the SaU group, 2 participants experienced personal, familial and medical difficulties, meaning that they did not take part in the intervention.

Initial contact was made with 16 parents of children who met the inclusion criteria through postal distribution of information sheets and consent forms (see Appendix A), in which parents were additionally asked to confirm their child's diagnoses and functional hearing and vision. Autism diagnoses were confirmed by visually inspecting the multidisciplinary report confirming the diagnosis, held in the school's files. For 3 pupils, the original document was not available; instead, diagnoses were confirmed through inspection of the pupil's SSEN (for which original documentation would have been required).

Participants were assessed with the baseline measures at pre-intervention. Characteristic background data presented for individual participants are shown in Table 1. Randomisation was stratified within the Expt and SaU groups on the basis of academic years in September 2013 into 'younger' (years 7-9) and 'older' (years 10-12) groups (more detail in 'General procedure' section, below). The total number of participants in the Expt and SaU groups is presented in

Table 2, along with group demographics and characteristics.

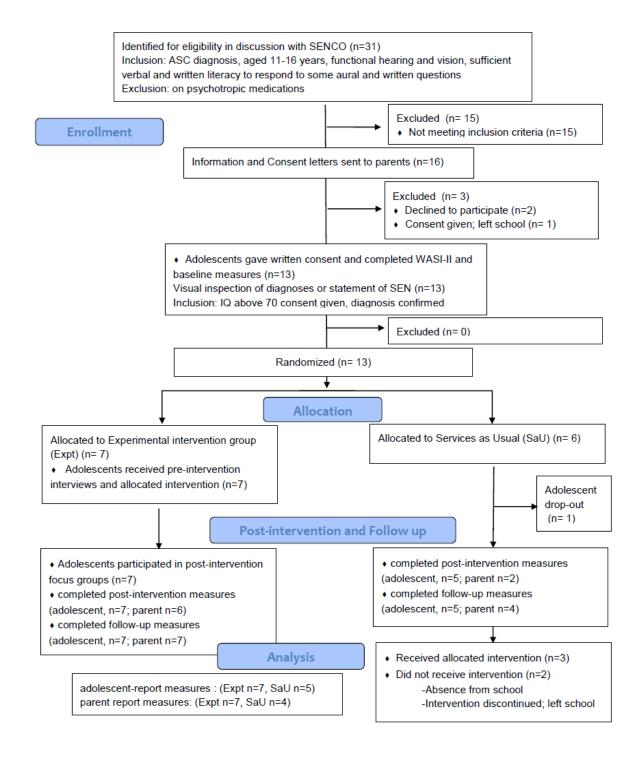


Figure 1 Flow diagram showing participant numbers at selection, group allocation, post intervention, follow up and analysis.

. Individu		ipant de	mog	raphic	s.				1			1			1
eceived	acade mic		~							-		-		~	ition, oort
ervices re	BESD	~				~	~				~	~		~	school ac ming supp
upport se s usual	SLT					~	~			-		~			eds, SA: LSA: lea
Areas for which support services received as usual	Autism specialist support	~	-		~										ducational ne ation needs,
Areas f	LSA support	-			-	~		-				-		~	: special e communic
	Additional areas of SEN	BESD	none	BESD	SLCN	none	none	none		BESU	none	SLCN	none	BESD	disorder, SEN language and
	SEN status	SSEN	SA	SA+	SSEN	SSEN	SA+	SSEN	Č	+A2	SA+	SSEN	SA+	SSEN	yperactivity c CN: speech,
	Additional Diagnosis	ADHD	none	none	none	none	physical or motor	none		none	physical or motor	ADHD	none	none	attention deficit h I difficulties, SL
	Diagnosis	Aspergers	Aspergers	Aspergers	Autism	Autism	Aspergers	Autism		Aspergers	Aspergers	Autism	Aspergers	Aspergers	meals, ADHD: a tional and socia
Entitle	ment to FSM	8	С С	8	2	yes	6	2		2	2	9	2	6	ee school oural, emo
	Ethnicity	WBR	WBR	WBR	WBR mixed asian	WBR	WBR	WBR		WBK	WBR	WBR	WBR	WBR	Expt: Experimental group, SaU: Services as Usual group, WBR: White British, FSM: Free school meals, ADHD: attention deficit hyperactivity disorder, SEN: special educational needs, SA: school action, SA+: school action plus, SSEN: statement of special educational needs, BESD: behavioural, emotional and social difficulties, SLCN: speech, language and communication needs, LSA: learning support A4 A4
Academic	year group 2013-24	6	80	7	5	10	11	10	c	ת	8	6	10	12	p, WBR: Whit ducational nee
	Gender	male	male	male	male	male	male	male	-	male	male	male	male	male	Usual grou of special e
Age	(years) in July 2013 Baseline	13.50	12.75	11.58	15.58	13.83	15.42	14.33		c7.21	11.83	13.50	14.58	16.33	: Services as I: statement o
	(years) in Participant July 2013 pseudonym Baseline	Timo	Angus	Freddie	Milo	Rupert	Frank	Abel		Artnur	Otis	Victor	Winston	Harvey	tal group, SaU on plus, SSEN
		I	Expt_younger	I	1	Expt older	- - -	I	I	:	saU_younger	I		040-044	Expt: Experiment SA+: school active <b>A</b>

Table 1. Individual participant demographics.

#### Table 2. Stratified Expt and SaU group demographics

		Expt_younger	Expt_older	Expt Group		SaU_younger	SaU_older	SaU Group
	N	3	4	7	•	3	2	5
A	Μ	12.61	14.79	13.86		13.03	15.46	14
Age in years* July	SD	0.97	0.85	1.43		1.04	1.24	1.64
2013 2013	Range	11.58-13.50	13.83- 15.58	11.58- 15.58		11.83- 13.75	14.58- 16.33	11.83- 16.33
Gender**	Male	3	4	7	•	3	2	5
Gender	Female	0	0	0		0	0	0
	Year 7	1	0	1		0	0	0
Year Group	Year 8	1	0	1		1	0	1
in academic	Year 9	1	0	1		2	0	2
year 2013-	Year 10	0	2	2		0	1	1
2014***	Year 11	0	2	2		0	0	0
	Year 12	0	0	0		0	1	1
<b>F</b> (1, .''), +++	White British	3	3	6	-	3	2	5
Ethnicity***	White British, mixed Asian	0	1	1	-	0	0	0
Socio-	FSM	0	1	1		0	0	0
economic status***	Non-FSM	3	3	6		3	2	5
Diagnosis***	Asperger's	3	1	4	-	2	2	4
Diagnoolo	Autism	0	3	3		1	0	1
	None	2	3	4	-	1	2	3
Additional diagnoses***	physical or motor difficulties	0	1	1		1	0	1
	ADHD	1	0	1	-	1	0	1
SEN	SA	1	0	1		0	0	0
status***	SA+	1	1	2		2	1	3
	SSEN	1	3	4	-	1	1	2
Additional	None	1	3	4		1	1	2
areas of	BESD	2	0	2		1	1	2
need***	SLCN	0	1	1	-	1	0	1
	Individual LSA support in class	1	3	4		1	1	2
Services as	Autism specialist input	2	1	3		0	0	0
Usual****	SLT input	0	2	2		2	0	2
	BESD support	1	2	3		2	1	3
	Academic and cognitive support	1	0	1		2	1	3

For tests of difference between Expt and SaU groups:\* t(10)=.16; p=.88 (2 tailed). \*\* chi-square not calculated as gender is a constant. \*\*\* All chi-square 'exact' p values were non-significant (p>.05) \*\*\*\* chi-square not calculated as assumption of mutually exclusive and collectively exhaustive categories was violated.

Expt: Experimental group, SaU: Services as usual group, FSM: Free school meals, ADHD: attention deficit hyperactivity disorder, SEN: special educational needs, SA: school action, SA+: school action plus, SSEN: statement of special educational needs, BESD: behavioural, emotional and social difficulties, SLCN: speech, language and communication needs, LSA: learning support assistant, SLT: speech and language therapist.

An independent samples t-test confirmed no significant difference in age between Expt and SaU groups, t(10)=.16; *p*=.88 (2 tailed). Chi-squared tests were carried out on the categorical variables of year group, ethnicity, socioeconomic status, autism diagnosis, additional diagnoses, SEN status and additional areas of need. The chi-square assumption of less than 20% of cells with expected frequencies less than 5 was violated, therefore Fischer's 'exact' p-values were calculated, which are appropriate with smaller sample sizes (Kinnear & Gray 2009). All exact p-values were non-significant (at *p*>.05), suggesting no significant difference between groups.

While some pupils were bilingual, all spoke English as their first language. All adolescents in the study received support for their SEN associated with their diagnosis of autism, in the form of extra time in exams and specific advice and training given to class teachers to make reasonable adjustments in class.

In addition, selected pupils received additional 'services', some of which were related to additional needs in the areas of behavioural, emotional, and social difficulties (BESD) and speech language and communication needs (SCLN). For the purposes of comparison, the additional services have been categorised as: individual support in class from a Learning Support Assistant (LSA), input from an autism specialist service, input from Speech and Language Therapists (SLT), BESD support (including involvement from the Child and Adolescent Mental Health Service (CAMHS), pastoral support, counselling, and specialist behaviour teacher support) and academic or cognitive support (including study skills, participation in homework club, and computer based memory training).

Experimental groups received the intervention in the first half of the autumn term 2013, and SaU groups received the intervention in the spring term 2014 as an ethical measure, following data collection (see Table 3 for participant groups, measures and intervention schedule). Younger and older groups were delivered separately to facilitate small-group dynamics in light of Clarke's (2012) conclusion that larger groups of individuals with autism reduce engagement in the CBT intervention.

## 3.3. CBT- Based Sensory Intervention

The intervention consisted of pre-intervention individual interviews, followed by 8 weekly group sessions, of 45 minutes duration each. The intervention was designed to address several of the issues arising from self-reports of sensory experiences, but was also modified in light of pilot testing and the context in which it was delivered.

#### 3.3.1. Overall Structure and Features

The overall design for the intervention is reported below, making reference to principles of CBT and those interventions that have been adapted for use with autism populations. During development of the programme, ideas were discussed and refined in five supervision sessions.

**Relevance to CBT model.** The intervention structure was based loosely on typical elements of regular CBT interventions, namely establishing rapport, problem discussion, identifying goals for change, problem formulation using the CBT model, examining evidence for maladaptive beliefs, and experimenting with new thoughts, feeling states and behaviours (Hofmann, 2011). Pupils were interviewed individually in 'pre-intervention' interviews, primarily to address Aim 1, expanding the knowledge base of autism experiences. However, the interviews were considered part of the intervention as they also addressed the CBT stages of establishing rapport, problem discussion, and identifying goals for change, but also started the process of bringing some sensory experiences and coping to consciousness. In addition, information from pre-intervention interviews was used to prompt adolescents if they were without a self-chosen example in sessions.

The first 4 intervention sessions addressed the next CBT stage of 'problem formulation' by building adolescents' awareness of their own thoughts, feelings and behavioural responses to sensory situations. The aforementioned CBT element of 'examining evidence for maladaptive beliefs' was not represented in the current intervention as faulty cognitions are not implicated in the literature review of sensory processing in autism. The final 4 sessions focused on identifying and experimentation with new behaviours, feelings and thoughts, reflecting the order in which they emerge through development in self-reports of coping strategies in autism (Ashburner et al., 2013; Edgington, 2012; Jones et al., 2003; Smith & Sharp, 2012).

CBT is a transparent therapy; the structure and length of sessions are shared with individuals, who are encouraged to take ownership for new responses during 'homework' tasks (Hofmann, 2011; Westbrook, Kennerley & Kirk, 2007). The structure of each session in the current intervention consisted of: 'checkingin' (sharing recent progress and events), the session outline, introduction and demonstration of ideas, opportunity for the participants to 'have a go', and a

plenary where the ideas were shared and a homework task set. Since homework can create additional anxiety for participants with autism (Clarke, 2012), this was presented as optional.

**Modifications for individuals with autism.** The format of each session and resources used remained consistent, to accommodate 'the desire for sameness', held by many individuals with autism (APA, 2013). Some of the modifications used in previous interventions for children with autism were also incorporated into the current intervention.

In pre-intervention interviews, the 'School Sensory Cards' (Gaudion & Edgington, 2012, used in Edgington, 2012) were used to stimulate discussion around several different sensory experiences. These beer-mat sized cards depict images of sensory stimuli (e.g. flicking pages), thereby accommodating a strength for visual information in autism. Further details on the pre-intervention interviews are reported in the Measures section, below.

As in Chalfant et al.'s CBT intervention (2007), a sticker-based visual reward system was used to motivate engagement. In all sessions, participants wrote on paper templates of a 'stick-man' representation of the interplay between thoughts, feelings (body and emotional) and behaviours and outcomes (see Figure 2). These 'sensory pictures' are similar to the drawings used by Clarke (2012) to visually represent body sensations. As the 'sensory pictures' were created specifically for the intervention, their use was first validated with a typically developing pupil aged 12 years old, of average academic ability at a different mainstream school. With minimal prompting, the pupil was able to Sensory Picture

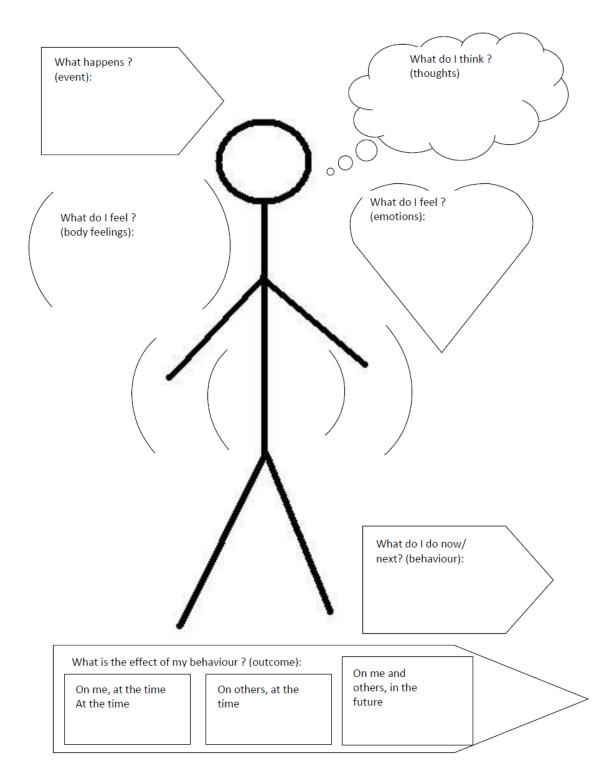


Figure 2. Sensory picture template used in intervention sessions

complete a sensory picture for his chosen example of 'chairs scraping the floor'.

His responses suggested an understanding of the difference between thoughts,

body feelings, emotional feelings, behaviour and long term outcomes. Attwood's CBT (2004) programme also incorporates exercises to build up children's emotional language expression, recognising this to be an area of difficulty for several individuals with autism. Throughout the current intervention, adolescents were provided with a 'prompt' sheet of examples of emotions (see Figure 3, Henry, 2013) and a list of examples of body feelings (see Figure 4, adapted from Attwood, 2004). Participants' recall of sensory experiences and engagement in the activities were facilitated by interaction with 'live' sensory stimuli, drawing on Robertson's (2012) approach. A 'feely box' was used, which contained the following: chocolate, chilli, bubbles, nail file, hairdryer, eye mask, pens, headphones (for listening to music), wig, rough material, Velcro, and liquid stock cubes. Half of these items were included in response to participants' sensory preferences expressed during the pre-intervention interviews, thereby personalising some experiences as in Kirby et al. (2014). When recalling or considering sensory experiences during the groups, participants' own examples were prioritised in order to adhere to the CBT position that individuals must be motivated to change in order to be successful (i.e. they must perceive it to be a problem, Hofmann, 2011). This approach is also more ethical and consistent with the neurodiversity movement, which views autism as an aspect of identify and would oppose change imposed by others (Jaarsma & Welin, 2012). If adolescents did have difficulty selecting a sensory experience for consideration, they were prompted with an example from a pupil-specific list of likes and dislikes, collated from their responses during pre-intervention interviews and questionnaires, referred to as 'sensory preference sheets'.

aggressive	Q0 alienated	angry	0,0 annoyed	( ( coo) ) anxious	ور م apainetic	D basnful		
ص <u>ا</u> ح bored	QO cautous	Confident	Confused	Curious	depressed	Hereined determined		
disappointed	discouraged	disgusted	embarrassed	enthusiastic	di G envious	00 ecstanc		
excited	exhausted	Correction fearful	Ö.ð ● frightened	Notes and the second se	guilty	happy		
<b>g</b> helpless	hopeful	hostile	humiliated	60 hurt	hysterical			
interested	iealous	lonely	loved	lovestruck	mischievous	miserable		
A negative	<u><u></u> cptmiste</u>	pained	Paranoid	peaceful	Proud	puzzled		
o o regrettul	· (jo); relieved	K (sad	satisfied	shocked	(T) shy	sorry		
A I stubborn	⊕ → sure	OL O Surprised	suspicious	0,1 thoughtful	undecided	ې withdrawn		

enovs

*Figure 3. Exemplar emotion sheet available to participants during intervention sessions (Henry, 2013)* 

# Examples of Body Feelings

Smiling	Tummy pain
Warmth	Dry mouth
Tingly	Tired
Slow breathing	Muscle tension
Energetic	Headaches
Floppy	Fast breathing
Red cheeks	Shortness of breath
Flappy hands	Light headedness
Yawning	Fast heartbeat
Laughing	Stiff neck
Fidgety	Sweating
Jumping	Upset stomach
Blinking	Lump in throat
Shaky voice	Crying
Ears ringing	Wide eyes
Tense muscles	Butterflies in tummy
Cold	Wobbly knees
Hungry	Goosebumps
Dizzy	Itchy
Chattering teeth	Can you think of any more ?:
Chest pain	

Figure 4. Exemplar body feelings sheet available to participants during intervention sessions

Finally, in view of the role that individuals' awareness of their sensory experiences being different may have in the development of conscious coping strategies (Smith & Sharp, 2012), time for sharing sensory pictures was built in at the beginning and end of sessions, so that adolescents developed a sense of how others may perceive and respond to stimuli differently.

# 3.3.2. Pilot Studies

Pilot studies of pre-intervention interviews and intervention sessions aimed to familiarise the group leader with the materials and ascertain the appropriate level, pace and duration of different activities.

**Pre-intervention interview.** To maximise the chances that the preintervention interview would be pitched at a level accessible to 11-16 year-olds with autism, the pilot was carried out on a younger boy with autism, aged 10 years at Gradewood. Following this pilot, the pre-intervention interviews were adjusted in the following ways: The number of School Sensory Cards presented to participants was limited to 25 to allow more time for discussion. The number of cards selected for discussion was limited to 4 to maximise engagement and allow time for discussion around contingent topics. Some repetitious questions were omitted, and the wording and order of some questions changed. For example, 'how do you calm yourself down?' was clarified by 'lf you're upset, how do you calm yourself down?'

**Intervention sessions.** As timing and practical constraints prevented the intervention sessions from being piloted on the same pupil as above, one 12 year-old pupil with autism in a different mainstream secondary school was

chosen for convenience. After piloting, the following adjustments were made to the sessions: Preferred prompt sheets for emotion and body feeling words were selected (see Figure 3 and Figure 4). Suitable group leader examples for sensory pictures (e.g. rollercoaster) were chosen and worked through. Controlled access to the internet was seen to facilitate recall of some sensory experiences; uncontrolled access was avoided in case adolescents took advantage of this. Some further changes to individual sessions are discussed below.

## **3.3.3. Intervention Session Outlines**

Each weekly session outlined below was positioned within the overall session structure, discussed above (weekly session outlines given Appendix B). While the pre-intervention interview was considered part of the intervention, its primary function was to gather data on participants' experiences, so is discussed in more detail in 'Measures' below.

**Session 1: Introduction**. First, pupils shared ideas around the meaning of the term 'sensory', writing on one large piece of paper to foster a sense of collaborative group work as in Clarke (2012). In a structured 'ice-breaker' game to foster group dynamics (a critical factor in the success of CBT interventions, Clarke, 2012), adolescents 'hi-fived' those with similar answers to the question 'what is your favourite...?' (e.g. food), thereby introducing the idea that individual differences exist within the group. Participants were then introduced to the prompt sheets for emotion and body feeling words (see Figure 3 and Figure 4), using these to describe responses to their 'favourite' things. Group

rules for a supportive session were co-constructed, noted down and signed by all adolescents.

Session 2: Introduction to CBT model: Positive experiences. The interplay between thoughts, body and emotion feelings and behaviours was introduced via demonstration of a sensory picture (see Figure 2) of selected examples (e.g. rollercoaster, having a bath), emphasising that 'pleasant' will be different for different people. For sessions 2 and 3, sensory picture templates were used without the bottom arrow asking: 'what is the effect of my behaviour?' ('outcome arrows', see Figure 2); this graphic was introduced in session 4. Participants were given a piece of chocolate and encouraged to consider thoughts, body and emotion feelings and behaviours while eating, an approach taken from the Mindfulness in Schools Project '.be' programme (2013), which encourages attention on current sensory stimuli. Once participants understood the sensory picture template, they worked on creating more for their own chosen positive experiences.

Session 3: Introduction to CBT model: Difficult experiences. In a

similar format to session 2, unpleasant sensory pictures were demonstrated using selected examples (e.g. filing nails, people talking while I'm trying to work). Chilli was eaten as an optional group demonstration activity (Mindfulness in Schools Project, 2013).

Session 4: Outcomes of sensory experiences: Helpful or unhelpful? Given the self-reports of unhelpful sensory coping mechanisms in autism (Ashburner et al., 2013; Smith & Sharp, 2012), adolescents were encouraged to consider the impact of their reactions on themselves, and others at the time and in the future, sticking new 'outcome arrows' onto previous sensory pictures. Those sensory pictures with helpful outcomes (e.g. having a bath, listening to music) were introduced as 'coping tools' (terminology used in Attwood, 2004) and shared with the group, as drawing attention to existing coping was hoped to foster self-efficacy and motivation for trying out new coping tools.

Session 5: Behaviour coping tools. During this session, the idea of changing a behavioural response to affect thoughts, feelings and outcomes was demonstrated by making a new sensory picture for new coping behaviours (e.g. for 'people talking when I'm trying to work' -- 'ask someone to be quiet' / listen to music'/ 'focus on work'). Adolescents role-played inoffensive ways of tactfully asking someone stop doing something, as pilot studies and initial interviews suggested that this was an area of difficulty. Prior to thinking of their own coping tools, adolescents sorted sensory pictures into controllable and uncontrollable stimuli, following Ashburner's (2013) suggestion. For controllable stimuli, adolescents were supported to think of 'behaviour coping tools' and made new sensory pictures for these scenarios.

Session 6: Body coping tools. For uncontrollable and unpleasant experiences, adolescents considered ways to change the body's state. Appropriate pleasant sensory experiences (e.g. stress ball) and the relaxation techniques introduced as body coping tools, in line with other sensory and CBT interventions (Attwood, 2004; Williams & Shellenberger, 1994). These were included as they may also provide a degree of 'body connectedness', which the autistic author, Williams' (1998) suggests is necessary for conscious sensory processing via the 'system of interpretation'. Relaxation techniques of breathing

exercises and progressive muscle relaxation were carried out using resources from the 'Retracking' pack (see Figure 5, Bates, 1997), chosen for their simplicity and ease of access and level of engagement in pilot testing. Participants then applied the body coping tools to make new sensory pictures.

Session 7: Thinking coping tools. Thinking coping tools were introduced as things 'you can do in your head' to self-calm or motivate in the face of uncontrollable and unpleasant sensory experiences. These included focussing attention and positive self-talk, chosen for their validity as coping tools, already used by adolescents with autism (Ashburner et al., 2013). The use of positive-self talk also resonates with the approach of 'being a friend to yourself in the 'Friends' CBT programme used with typically developing adolescents (Barrett, 2004). To demonstrate the effect of 'focussing attention', adolescents were guided through a 'visualisation' exercise (Figure 6), a similar approach to the use of imagination for calming in the 'Sensory Stories' intervention (Therapro Inc., 2011). An additional thinking coping tool of 'rationalising' or starting a 'project' to understand how a feared stimulus works was included, following Ashburner et al. (2013) and Attwood's (2004) suggestion that this may facilitate conscious sensory interpretation. Adolescents again made new sensory pictures to illustrate the application of coping tools.

Session 8: Review and celebration. The different tools were reviewed and successful uses shared with the group. Adolescents then reviewed their sensory pictures, making new ones for scenarios that may have arisen along the course of the intervention. As appropriate, an unpleasant sensory stimulus (e.g. sticky substance) was introduced, to practise application of coping tools

	WINSCLES II	Sounds a bit daff doesn't kill. We all know how to breathe, it's the first thing that we ever do and we never even have to think about it could be serious if we were to stop!
-	LE DOWN OR SIT SO THAT YOU ARE FEELING REALLY COMPORTABLE.	Actually there are different ways to breathe and sometimes we have to consciously get
e4	CONCENTRATE ON THE FEELINGS IN YOUR MUSCLES AS WE TRY TENSING OR RELAYING THEM.	<ul> <li>* you've been frightened</li> <li>* somebody has been steeping</li> </ul>
ers -	STARTING WITH YOUR HANDS AND ARMS, CLENCH YOUR FIST TIGHTLY AND TENSE THE MUSCLES IN YOUR ARMS, VERY SLOWLY RELAX THEM, REPEAT SEVERAL TIMES.	* you've been ranning * you've teen upset
4	NOW THAN ABOUT YOUR SHOULDERS, PLINCH THEM IP TIGHTLY NEARLY TOUCHNS YOUR EARS. SLOWLY LET THEM RELAX. REPEAT A NUMBER OF TIMES.	There are noticeable variations in our breathing patterns at such times. It is possible to get our breathing under control to decrease termion, to relax our muscles, to decrease our heart and pulse rate or even to increase our alertness by
wi	KEEPNIG YOUR EYES CLOSED SCOEN THEM UP TIGHTIY THEN GRADUALLY RELEASE YOUR EYELDS UNTIL THEY AGE TOTALLY RELAYED, REPEAT	providing more arygen to our brain. Ty the following:
-0	TIGHTEN UP YOUR EYEBROWS BY DRAWING THEM TOGETHER THEN SLOWLY RELEASE THE TENSION IN YOUR FOREHEAD. REPEAT.	.Sit quietly but comfortably on a chair with your hands resting in your lap.
14	TENSE YOUR JAW BY BITNIG YOUR BACK TRETH TOGETHER TIGHTLY THEN	Roop your back straighte but related so that your lungs are able to operate officiently.
	LET YOUR JAN GET HEAVER AND HEAVER UNTIL TOTALLY RELAVED. REPEAT.	Keep your head straight but relayed with your eyes gently closed.
e0	TO RELAY YOUR NECK LET YOUR OW RALL FOOMAD ONTO YOUR OVEST UNTU THE MUSCLES IN YOUR NECK FEEL OUTE TOWT SUDWY PULL IT	Taky a deep, silent breath, through your nose. Feel the breath travelling deeply into your lungs feel your chose expanding slowly.
*	BALX UN L. YUU PEEL KELANEN, KEYEN.	Let the broath out through your mouth, slowly and calmly feeling your lungs empty.
95	PULL YOUR STOMADY NAS TRATED AS YOU CAN THEN GOADUALLY RELAX THOSE MUSCLES AND REPEAT.	Taky another deep breath and feel what is happening to your chest as the air flenss through nour nose, down nour whichtee and terflates were lumas.
位	I. USING HEELS PUSH DOWN HARD AGAINST THE FLOOD UNTL. YOU FEEL THE TOPS OF YOUR LEGS ARE AS TIGHT AS POSSIBLE. SLOWLY RELAX AND THEN REPEAT. FOR THE BOTTOM HALF OF YOUR LEGS	Now breathe out again through your mouth, slowly and quietly
	PONT YOUR TOES AS HARD AS YOU CAN THEN SLOWLY RELEASE AND REPEAT.	Morp repeating the process at your own pace enjoying the feelings
	GO THROUGH THE WHOLE SEDJENCE AGAIN.	standard for standard for

Figure 5. Relaxation exercises used in session 6 (Bates, 1997)



As we have already said, one of the ways to help us relax when we're feeling tense and angry is to use our imagination to picture a pleasant, peaceful scene.

Here is an example of one to help get you started. It is much better however to draw your own imaginary scene, based perhaps on happy memories from your past... be creative, it's your own private world.

Begin by getting yourself relaxed, using the relaxation and breathing exercises that we have already tried. Let all other feelings go... breathe slowly and calmly... close your eyes...

Listen as this is read to you .....

We are going on a short but gentle journey. We are going into the woods... walking along a winding path through the softly waving trees. It is a beautiful, sunny, warm day with a few cotton wool clouds floating gently across a blue sky. The sun is warm on the skin of your arms and you can feel the breeze softly ruffling your hair. By the side of the path colourful, scented flowers grow in small groups. A young rabbit basks in the sunlight, cleaning his soft fur and nibbling on the lush green grass. You can feel the earth warm and firm under your feet. The path ends at the banks of slowly babbling stream. You sit on a mossy tree trunk at the side of the stream, dipping your feet into the tumbling water which bubbles and

the side of the stream, dipping your feet into the tumbling water which bubbles and sings around your ankles. The water is soft and cool upon your feet as the sun continues to warm your face and arms. The breeze blows a leaf from a nearby tree and you watch as it floats silently down coming to rest upon the surface of the water which carries it away downstream. You close your eyes and listen to the sounds of the water, the birds singing cheerfully in the trees and the leaves rustling gently in the late afternoon air. You can stay here for as long as you like, feet dipped in the stream... there are no pressures to leave... you are calm and happy... no worries... all is well...

Figure 6. Visualisation exercise used in session 7 (Bates, 1997)

# 3.3.4. Engagement with the Setting

The intervention must be considered within the context in which it was delivered. Prior to meeting the pupils individually, I spent 3 break-times in the school's Learning Support area, to become a 'familiar face' around the department and build rapport with participants. All interviews and sessions were carried out in a small room adjoining the Learning Support area, with a whiteboard, computer, tables, and chairs. Each session therefore took place in the same familiar space, with minimal interruptions due to the room being 'booked'. The timetabling of the 8 weekly group sessions was arranged in collaboration with the SENCO. In order to minimise impact on the boys' normal curriculum, sessions fitted into one of the 7, 45-minute 'periods' of the school day, being held every Friday and rotated around periods, in line with school 'carousel' systems. Pupils were informed of the period of the sessions by a note in their morning register, a well-established system within the school.

The delivery of the intervention was also adapted to fit the school ethos, which was understood through discussion with staff and a lesson observation. Perhaps more than in most secondary schools in the LA, pupils at Gradewood are expected to follow instruction and attempt all work, expectations which were upheld in the intervention sessions. The intervention also employed a reward system, which fed into the school reward system; 10 star stickers equated to a 'commendation'. In view of the school's expectations around engagement with reading and ownership of learning, initial plans for a visual timetable of session contents (as in Chalfant et al., 2007) were abandoned in favour of rewriting session outlines and providing participants with individual copies.

Modifications were also made to suit the specific needs of the participants. Having met some participants during break-times prior to the intervention, the 'homework' was renamed 'Mission', to appeal to a commonly shared passion for computer gaming. Modifications were also made for Timo, whom staff reported to be 'disruptive' in group situations. I met with him individually prior to the sessions and talked about 'setting an example to the younger boys' in the group. I also attended his annual review to understand how best to interact with him.

Steps were also taken to engage with Learning Support staff and the wider setting of adolescents' homes. Parents were emailed weekly copies of the session outlines, resources and 'Missions' and were encouraged to ask questions or communicate any events or thoughts. Having sought permission from adolescents and parents, sensory pictures were shared with parents and school after the intervention had finished. The school was also provided with copies of the intervention materials and offered training in the theory and content of the intervention.

It is acknowledged that the above modifications make the application of this intervention particular to Gradewood. However, in doing this, the intervention has ecological validity and is more likely to succeed, as it incorporates factors to be considered in the implementation of any school-based group intervention (Christner, Forrest, Morley, & Weinstein, 2007).

# 3.3.5. Qualifications and Experience of Intervention Leader

I have developed my theoretical understanding of autism through my year 1 DEdPsy Research Report (Edgington, 2012) and through lectures and assignments on the Masters in Psychology of Education and the DEdPsy at the IOE. I have worked with children with autism as a LSA in a primary school, play assistant in an afterschool stay-and-play centre and through LA casework as a TEP. I have developed my theoretical understanding of CBT through year 1 DEdPsy assignments and lectures and have practical experience in carrying out a course of CBT-based work with a typically developing 13 year-old boy. I have therefore developed a sound theoretical understanding and have had supervised practical experience in working with both individuals with autism and CBT approaches, making me suitable to carry out this intervention.

#### 3.4. Measures

Background measures were those quantitative measures chosen to describe participants in more detail than the 'participant demographics', described above. Outcomes measures were those that may be affected by the intervention and were further categorised into primary outcome measures, secondary quantitative measures, and qualitative measures.

# 3.4.1. Background Measures

Intellectual functioning and autism symptoms were chosen as background variables to contextualise findings and infer generalisability, as these have been associated with sensory reactivity (Crane et al., 2009; Donohue et al., 2012).

These data were collected once, at pre-intervention (see Table 3), using the instruments described below.

	<b>Pre-inte</b> Baselin	erventior e	I		Post Intervent ion	Follow- up	
	Jul-13			Sept – Oct 2013	Oct-13	Dec-13	Jan-Feb 2014
Expt N=7	WASI-II	AASP	Pre- intervention interviews	8 week CBT- based sensory intervention	AASP post- intervention focus groups	AASP	
Parents of Expt <i>N</i> =7	SRS-2	SP RBQ SCAS-P			SP post interviews	SP RBQ SCAS-P	
SaU N=5	WASI-II	AASP			AASP	AASP	Pre- intervention interviews + 8 week CBT- based sensory intervention
Parents of SaU <i>N</i> =5	SRS-2	SP RBQ SCAS-P			SP	SP RBQ SCAS-P	

Table 3. Participant groups, measures and intervention schedule

Expt: Experimental group, SaU: Services as usual group, WASI-II: Wescheler Abbreviated Scale of Intelligence, SRS-2: Social Responsiveness Scale, AASP: Adolescent/Adult Sensory Profile, SP: Sensory Profile, RBQ: Repetitive Behaviour Questionnaire, SCAS-P: Spence Children's Anxiety Scale - Parent version.

#### Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-

**II, Wechsler, 2011)**. The WASI-II is a brief measure of verbal, non-verbal and full-scale intellectual functioning, as measured through four subtests of vocabulary, block design, matrices and verbal similarities tasks. In 2010-11, the WASI-II was standardised on a nationally (United States) representative sample of individuals aged 6 to 90 years, to update the previous WASI and provide up-to-date norms, improving validity.

The 2-subtest IQ composite version of the WASI-II, the full scale IQ-2 (FSIQ-2), was carried out with in order to fit with Gradewood's timetable and limited participant availability. The FSIQ-2 takes 15 minutes to administer and consists of the Matricies and Vocabulary subtests. The test-retest coefficient for the FSIQ-2 for 12 to 16 years (r=.84) indicates good reliability. Evidence of convergent validity of the WASI-II is given by the pattern of subtest correlations and the corrected correlation coefficient of r=.85 for FSIQ-2 to FSIQ on the more comprehensive Weschler Intelligence Scale for Children – Fourth Edition WISC-IV (Wechsler, 2003).

#### Social Responsiveness Scale – Second Edition (SRS-2)

(Constantino, 2012). The SRS-2 was used to provide a consistent measure of current autism symptomatology across participants. The SRS-2 is a 65 item teacher or caregiver questionnaire which identifies social impairment in autism and quantifies its severity. The SRS-2 is standardised on a nationally representative sample of 1,906 individuals aged 2.5 to 99 years. It was chosen over the alternative measure of the Social Communication Questionnaire (SCQ, Rutter et al., 2003) as the SRS-2 provides a current, rather than retrospective

measure of autism symptomatology. In addition, the SRS-2 also provides two sub-scales of 'social communication and interaction' and 'restricted interests and repetitive behaviour' which are compatible with DSM-5 criteria for autism diagnosis (APA, 2013). Raw scores for the sub-scales and a total score are generated by scoring and summing individual items, these are then converted to T-scores using tables in the manual. Higher scores indicate more severe autistic symptoms with classifications of severity given in terms of number of SD above the mean score: 1*SD* above='mild', 2*SD* above='moderate', 3*SD* above='severe'. Caregivers, rather than teachers, were asked to complete the SRS-2, because teachers in a secondary school (unlike a primary school) may have limited exposure to individuals' behaviours.

## **3.4.2. Outcome Measures**

Outcomes were further categorised into quantitative primary and secondary measures, and qualitative measures. How measures were administered is described in 'General Procedures', below.

**Primary outcome measures.** Sensory reactivity was identified as the primary outcome measure, with measures taken at pre-intervention, post-intervention, and follow-up. Both an adolescent self-report measure and a parent report measure of sensory behaviours were used to triangulate data and improve reliability.

#### The Adolescent/Adult Sensory Profile (AASP) (Brown & Dunn,

**2002).** The AASP is a 60-item self-report questionnaire on sensory preferences and response to experiences. The AASP was standardised on a sample of 950

individuals with and without disabilities, aged 11 to 79 years (193 of whom were aged 11 to 17 years) (Brown & Dunn, 2002). Respondents rate the frequency of behaviours on a 5-point scale (e.g. "I only eat familiar foods": almost never=1, sometimes=2, often=3, frequently=4, almost always=5). An estimate of the measure's reliability was given by the internal consistency of these sub-scales, as measured by Cronbach's alpha, ranging from .65 (questionable) to .75 (acceptable) (Robson, 2002). While it is acknowledged that behaviour-based measures may capture a limited range of the sensory behaviours in autism and necessarily obscure the underlying sensory-perceptual experience, the AASP was chosen as it is the only known existing standardised measure for adolescents, as suggested by examination of the measures reviewed in Ben-Sasson et al.'s (2009) meta-analysis, together with a systematic search of the Web Of Science database<sup>6</sup>.

Raw scores were generated by scoring and summing individual items for 4 quadrant sub-scales, categorised according to Dunn's (1997) 4 quadrants of avoiding, sensitivity, seeking, and low registration. Normative data for children aged 11 to 17 years were used to determine whether subscale scores were atypical in terms of *SD* above and below the mean: 2*SD* below='much less than most people', 1*SD* below='less than most people', 1*SD* above='more than most people', 2*SD* above='much more than most people' (Brown & Dunn, 2002). In other words, both high scores (maximum 75) and low scores (minimum 15)

<sup>&</sup>lt;sup>6</sup> An 'all time' title search using these terms: [sensory OR multisensory OR sensitivity OR sensing] AND [adolescen\* OR school age OR teenage\* OR secondary age OR KS3 OR KS4] AND [measure OR questionnaire OR observation schedule OR tool] yielded 31 results in Web of Science

represent sensory atypicalities on sub-scales. As there is no total score for the AASP, total scores were generated in this study by summing scores from the 4 sub-scales, however, normative cut-offs were not calculated for total AASP score, as variance in the normative sample cannot be assumed to be independent between different sub-scales (e.g. individuals who score high on 'seeking' domain may score low on 'avoiding', which would affect the distribution of total scores). The questionnaire takes 10-15 minutes to complete and requires sufficient literacy for completion. Questionnaires were completed in the presence of the researcher, who clarified the meaning of items when asked (e.g. explaining that 'shades' refers to blinds' in item 18: 'I keep the shades down during the day...').

*The Short Sensory Profile (SSP) (Dunn, 1999).* The SSP is a 38-item caregiver completed version of the Sensory Profile (Dunn, 1999). Like the ASSP, the SSP measures frequency of observable sensory behaviours on a five-point scale (e.g. "withdraws from splashing water": never=1, seldom=2, occasionally=3, frequently=4, always=5). The SSP has good reliability (.90) and discriminant validity (above 95%) and is standardised for use with children aged 3 to 10 years. It is acknowledged that some items within the SSP may therefore have limited validity with adolescents. However, as the SSP was used as a repeated measure to capture change, standardised scores were of less importance and not referred to. As parents at Gradewood lived all over London and adolescents travelled in independently, the DISCO interview was not considered feasible. In the absence of any known caregiver questionnaire standardised to describe the sensory behaviours of adolescents, the SSP was

chosen for caregivers to complete rather than the AASP as it does not contain items written in the first person, yet is congruous with AASP. The SSP was chosen over the longer SP in order to minimise the demands on caregivers, and therefore increase the response rate of questionnaires. The SSP categorises behaviours according to 7 sensory modality subscales: tactile sensitivity, taste/smell sensitivity, movement sensitivity, under-responsive/seeks sensation, auditory filtering, low energy/weak, and visual/auditory sensitivity. Raw scores for the sub-scales and a total score were generated by scoring and summing individual items, giving a maximum score of 190. Lower scores reflect more atypical sensory behaviours.

**Secondary quantitative outcome measures.** The secondary outcome measures of repetitive behaviours and anxiety were taken at two time-points, during pre-intervention and follow-up, using the instruments below.

# Repetitive Behaviour Questionnaire (RBQ) (RBQ, Turner, 1999). The

RBQ is a 33-item caregiver questionnaire that rates severity or frequency of repetitive behaviours on a 3 or 4-point scale, dependent upon the behaviour (e.g. "Does he/she repeatedly fiddle with toys or other items?" 'never or rarely'=0, 'one'=1, '15 bouts daily'=2, or '30 bouts daily'=3). In an evaluation of its psychometric properties using a group of 180 children with autism (Honey, McConachie, Turner & Rodgers, 2012), the RBQ was reported to have good internal consistency reliability (ranging from .80 to .88). The RBQ scores correlate positively with repetitive behaviour scores on the 'gold standard' autism diagnostic measure of the ADI-R (ADI-R, Lord, Rutter & Le Couteur, 1994), suggesting good construct validity.

Total raw score was calculated by summing individual items, with higher scores indicating the presence of more atypical repetitive behaviours, up to a maximum score of 76 (Turner, 1999). In addition, raw scores for the sub-scales of insistence on sameness/circumscribed interests and sensory/motor behaviours were generated using Honey et al.'s method of scoring (2012). This enabled comparison with normative data from children aged 7 to 17 years in terms of *SD* above the typical mean range (Honey et al., 2012).

The RBQ was chosen as a commonly used, brief, caregiver questionnaire, suitable for use with adolescents which includes questions about stereotyped movements, rather than just 'unusual interests'. As the severity or frequency of behaviours is recorded and sub-categorised, this afforded it more sensitivity to detect any changes in repetitive behaviours. The Repetitive Behaviour Scale (Bodfish, Symons & Lewis, 1999) was another caregiver questionnaire which fit these criteria and has similar internal consistency (Lam & Aman, 2007). However, the RBQ was chosen over this measure as it was freely available for use and contains fewer items, thereby facilitating response rate.

#### Spence Children's Anxiety Scale – Parent (SCAS-P) (Spence, 1997).

The SCAS-P is a 38-item caregiver report questionnaire that rates anxiety related statements on a 4-point frequency scale (e.g. my child is scared of the dark: never=0, sometimes=1, often=2, always=3). There is an additional 'open' item where caregivers can name feared items, however this item was not used in the current study due to the variability between parent responses. The SCAS-P has been standardised on a community sample of 4916 individuals aged between 8 and 15 years and has been employed in studies measuring anxiety

in autism populations (Clarke, 2012; Sofronoff et al., 2005). The reliability of the scale is reported as high (.93). Correlations with the Revised Children's Manifest Anxiety Scale indicate a moderate (.75) convergent validity (Spence, 1997).

The SCAS-P categorises responses into 6 subscales (e.g. social phobia) (Spence, 1997). However, as anxiety was considered a secondary outcome, only total scores were used in analysis, generated by summing scores on individual items. Higher scores indicated the presence of more anxiety, with a maximum score of 114. Normative data for children aged 12 to 18 years were used to determine whether total scores were atypical in terms of *SD* above the mean (Nauta et al., 2004). The SCAS-P was chosen over the self-report version, (the SCAS-Child) as adolescents may have been influenced by a desire to appear 'brave' or by their expectations having taken part in the intervention if a self-report were used.

**Qualitative measures.** Qualitative data were collected from adolescents pre-intervention to understand their existing sensory experiences (Aim 1). Further qualitative data were collected from both adolescents in focus groups and parents individually post-intervention to gather participants' perspectives of the intervention (Aim 2iv and Aim 2v). A semi-structured interview format was chosen for all interviews as this allowed a natural discussion to flow around the main topics of interest to be covered, while also allowing for any contingent topics of interest to be discussed (Braun & Clarke, 2013; Robson, 2002).

Adolescent pre-intervention interviews. Expt adolescents were interviewed about their existing sensory experiences and coping strategies.

Individual, rather than group, interviews were chosen to exclude any social influences brought about by a new group set-up. To improve validity of responses, participants were asked about their responses to specific sensory experiences. Salient sensory experiences for interview were selected by asking adolescents to sort a pile of 25 beer-mat sized cards of sensory stimuli into 'like', 'ok' and 'dislike' piles (see Figure 7, Gaudion & Edgington, 2012). Then, adolescents chose the 2 'like' and 'dislike 'cards most relevant to them and were then asked questions about these experiences, using the semi-structured interview schedule (see Figure 8).

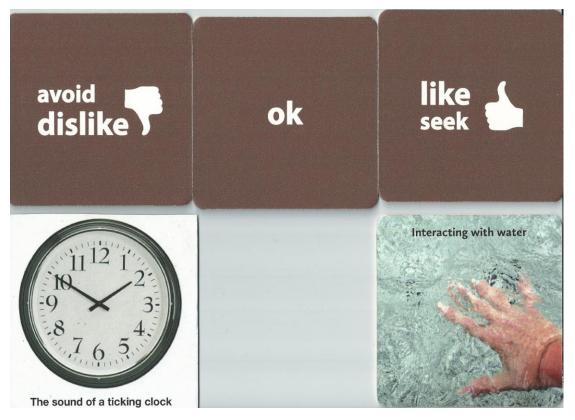


Figure 7. Image of Sensory School Cards, 'like', 'ok' and 'dislike' cards, with 2 example stimulus cards from the Sensory School Cards (Gaudion and Edgington, 2012).

The 25 cards were selected for being those most salient in pilot testing and in previous interviews with children with autism (Edgington, 2012). It is

acknowledged that the visual nature of the cards limited the power to evoke sensory feelings in other modalities (e.g. taste). However, as their purpose here was merely to stimulate discussion, the cards offered the most practical balance of allowing participants to consider different sensory experiences, whilst devoting the majority of interview time to discussion of their responses.

Broadly, the questions in the semi-structured interview (Figure 8) were designed to address the research sub-questions of Aim 1, to examine adolescents' conscious awareness of sensory processing experiences around the CBT framework of thoughts, feelings and behaviours and to elucidate existing conscious awareness of coping strategies and their sensory experiences being different to others'. Questions were designed to be open-ended (e.g. "what do you do when...?") and leading questions were avoided (e.g. "do you run away?"). Participants were also asked more generally about their desire to change and about any other sensory experiences, not covered by the cards. The pre-intervention interview was validated as a tool for inquiry by its use with a 12-year-old typically developing pupil, attending a different mainstream school. His responses indicated a conscious awareness of sensory experiences including the use of cognitive coping strategies, difference to others and a desired to change some sensory experiences.

#### Adolescent pre-intervention interviews

**Introduction** – reminder of previous meeting, what the term 'sensory' means and the format of the groups. Reminder of confidentiality and that taking part is voluntary. Introduce interview: look at cards & be asked about what preferences and experiences. Interested in what you think, no right or wrong answer.

Participants asked to look at all cards and arrange them along a scale of like ---- dislike Then ask them to pick out 2 cards of things they 'really like' and 2 they 'really dislike'.

#### For the 2 the 'like' cards or participants own examples:

- what is it that you like about \*\*\*\*
- what do you do when you see / hear / smell / touch \*\*\*\*
- what do you feel see / hear / smell / touch \*\*\*\*
  - emotions
  - feeling in your body?
- what do you think about when you see / hear / smell/ touch \*\*\*\*
- is there anything else (stimuli) that makes you think/ feel / do the same?
- does \*\*\*\* ever stop you from doing something else ?
- do you ever use \*\*\*\* to make yourself feel better? When?
- how else do you calm yourself down? When?
- how do other children respond to \*\*\*\* ?
- do you know anyone else that feels the same about \*\*\*\*

#### For the 2 'dislike' cards or participants own examples:

- what is it that you like about \*\*\*\*
- what do you do when you see / hear / smell / touch \*\*\*\*
- what do you feel see / hear / smell / touch \*\*\*\*
  - emotions
  - feeling in your body?
- what do you think about when you see / hear / smell/ touch \*\*\*\*
- is there anything else (stimuli) that makes you think/ feel / do the same?
- Is \*\*\*\* ever a problem ? when?
- what do you do to
  - avoid \*\*\*\*
  - change \*\*\*\*
  - make yourself feel better?
- how else do you cope with unpleasant things?
- how do other children respond to \*\*\*\* ?
- do you know anyone else that feels the same about \*\*\*\*

#### Finally:

Would you like to be able to manage some of your feelings of behaviours better?
 Are there any other sensory experiences you'd like to be able to change/ control or respond to better?

Figure 8. Adolescent pre-intervention semi-structured interview schedule.

To facilitate participant engagement and therefore improve validity of responses, the following additional steps were taken. Adolescents had previously met with the interviewer (for WASI-II and AASP initial data collection, see Table 3) and the same room as the intervention was used. Language used during interview was modified to suit the communication style and ability of the participant. Adolescents were reassured that there were no right or wrong answers and participation was voluntary.

#### Adolescent post-intervention focus groups. Adolescents in

Expt\_younger and Expt\_older groups were interviewed in focus groups postintervention, to determine adolescents' perceptions of the effectiveness of the intervention. Focus groups were chosen to facilitate a richer and wider discussion (Braun & Clarke, 2013), as adolescents had already demonstrated the ability to take turns in discussing sensory experiences with each other. Focus groups therefore represented the situation to which they were accustomed. Prior to the focus groups, adolescents were also offered the opportunity to meet the researcher individually to discuss anything in private.

In focus groups, adolescents were asked for their opinion on the intervention, whether coping tools were useful, and how far it met their needs. Questions were again designed to be 'open ended', however, participants were reminded of the types of 'coping tools' used in the groups, which served as a prompt for discussion (see Figure 9). In order to facilitate engagement and improve reliability, participants were encouraged not to talk over each other, and each was given the opportunity to answer the question and time for discussion to develop. Focus groups were conducted with the same group of individuals and

in the same room in which the groups took place.

# Adolescent post-intervention interviews

Introduction – going to ask questions about the groups, each person in turn to answer. Don't talk over each other. Can meet individually afterwards if you'd prefer. Ok to record?

- how did you find the group sessions
  - what was good?
  - what could have been better?
- which sensory picture are you most proud of?
- did you realise or learn anything new through the groups?
- are you using or going to use any of the tools?
  - behaviour turn something off move away ask someone to be quiet

body

pleasant sensory experience progressive muscle relaxation breathing exercises

thinking

focussing attention elsewhere positive self talk rationalising/ understanding

- do you have any sensory experiences you don't want to change?

- do you have any sensory experiences you do want to change, but haven't been considered in the groups?

Figure 9. Adolescent post-intervention focus group semi-structured interview schedule.

# Parent post-intervention interviews. Parents of adolescents in the

Expt group were interviewed over the telephone post-intervention, to determine

parents' perceptions of the effectiveness of the intervention (see Figure 10). A

similar set of questions were used to the ones for the adolescent post-

intervention interviews, with questions adapted to explore parents' perspectives.

It was emphasised to parents that adolescents had already been asked similar

questions and they were only expected to provide responses from their

perspective.

# Parent post-intervention interviews

Introduction – going to ask questions about the groups from your perspective (as far as you are aware). Have already asked your son himself. Ok to record?

- how did you find the groups ?

- what was good?
- what could have been better?

- did your son realise or learn anything new through the groups?

- have you noticed any change in your son's behavioural, physical (or cognitive) responses to sensory situations?

does your son have any sensory experiences you don't want them to change?
 does your son have any sensory experiences you do want to change, but which haven't been considered in the groups?

Would you like a copy of the children's sensory pictures – would you be happy for these to be shared with Learning Support Staff?

Figure 10. Parent post-intervention semi-structured interview schedule.

# 3.5. General Procedure

The steps indicated in Table 3 outline the procedures undertaken during data

collection. Time scales were chosen for convenience to fit around school terms

and research deadlines.

# 3.5.1. Step 1: Pre-Intervention, Baseline Data Collection

Parents of all adolescents were posted the SRS-2, SSP, RBQ, and the SCAS-P with an accompanying cover letter, which asked them to complete the questionnaires and return them in a self-addressed pre-paid envelope. All adolescents were seen initially at school for one session lasting approximately 45 minutes. In this session the objectives and the structure of the programme were explained to them both verbally and by providing written information (see Appendix C). Adolescents were informed of their ongoing right to withdraw, how the data would be stored and used, offered the opportunity to ask questions, then asked to sign the agreement form. At this stage, participants were assigned a number for identification.

The WASI-II was then administered to the adolescents. After a break, they completed the AASP in the researcher's presence. Following the first meeting, adolescents' diagnoses of autism were confirmed by visually inspecting the documentation held on the school's files. All 13 consenting participants met this inclusion criterion.

#### 3.5.2. Step 2: Randomisation

It was initially intended that Expt and SaU groups would matched on baseline and characterisation measures, collected in Step 1. However, due to difficulties in arranging a suitable start date with Gradewood, time constraints meant that both the initial data collection (Step 1), and the Expt group pre-intervention interviews (Step 3) had to be conducted on the same day. As this precluded the creation of matched Expt and SaU groups, participants were instead randomised into groups.

Participants were placed in stratified younger (academic years 7 to 9 in September 2013, *N*=6) and older groups (academic years 10 to 12 in September 2013, *N*=7) with balanced randomisation to Expt or SaU groups. Randomisation was achieved by generating a random number from 0 to 9 for each participant, using an online random number generator (Random.org, 2013). Within younger and older groups, participants were assigned to the Expt group if the random number was greater than or equal to 5 and assigned to the SaU group if the number was less than 5, until half of either condition had be

filled. This led to N=7 in the Expt group (Expt\_younger, n=3; Expt\_older, n=4) and 6 in the SaU group (SaU\_younger, n=3; SaU\_older, n=3). One participant in the SaU\_older group later dropped out of the study, bringing the final number of SaU participants to 5 (see Figure 1).

# 3.5.3. Step 3: Pre-Intervention Interviews

All 7 participants in the Expt group were seen on a separate occasion individually for 30-40 minutes for the pre-intervention interview (Figure 8). Participants were reminded of the previous meeting, the purpose of the groups, the meaning of the term sensory, and that they were free to leave. Permission was sought to record the interviews; recordings were carried out using a Sanyo digital voice recorder.

## 3.5.4. Step 4: Experimental Intervention

The 8 weekly sessions were delivered to both Expt\_younger and Expt\_older groups. After each session, parents of the Expt groups were emailed with details of the session and weekly Mission.

#### 3.5.5. Step 5: Post-Intervention

All adolescents in both Expt and SaU groups completed the AASP again in the Learning Support area of school in the presence of the researcher. Two focus group interviews were carried out with the Expt\_younger and Expt\_older groups, using the adolescent post-intervention interview schedule (Figure 9). Prior to starting the focus groups, permission was sought to record the interviews, all adolescents agreed, for which a Sanyo digital voice recorder was used. Both focus groups lasted approximately 15 minutes. During the focus groups, care was taken to ensure that each person had an opportunity to answer each question, without allowing any one person to dominate discussion. Timo in the Expt\_younger group was absent on the day of the focus group, meaning that 6 out of 7 Expt pupils took part in the focus groups.

All parents were asked to complete the SSP again, which was sent out by post with a self-addressed pre-paid envelope and accompanying cover letter. In addition, parents of adolescents in the Expt groups were interviewed individually over the telephone, using the parent post-intervention semi-structured interview schedule (Figure 10). All parents agreed for the call to be recorded which was done by turning on speaker-phone and using the Sanyo voice recorder.

#### 3.5.6. Step 6: Follow-Up

A further 8 weeks after the post-intervention data were collected, all children were again asked to complete the AASP. Parents of all adolescents were again sent the SSP, RBQ and SCAS-P with an accompanying cover letter; parents returned this in the self-addressed pre-paid envelope.

## 3.5.7. Step 7: SaU Intervention

Adolescents in the SaU group then received the pre-intervention interviews and the 8 weekly group sessions in Gradewood as an ethical measure. No data were gathered to assess the impact of this intervention. As the purpose of the pre-intervention interviews was to inform the content of the intervention (i.e. not to address Aim 1), pre-intervention interviews were not recorded and modified slightly from the schedule outlined above.

#### 3.7.1. Informed Consent

Several steps were taken to ensure that both parents and adolescent participants understood all aspects of the intervention and participated voluntarily. All parents signed a consent form (see Appendix A), which acknowledged that they were free to contact the researcher or withdraw their child from the study at any time, noting that this would not affect their child's education or access to services. Parents were asked to explain the research to adolescents and ask them if they were happy to participate. In addition, the study was explained to adolescents before participating, emphasising that information they provided was confidential and that they could leave at any time. Children signed an agreement form (Appendix C), to indicate that understood the project and agreed to participate. They were reminded throughout the sessions that they were free to leave at any time.

# 3.7.2. Sensitivity to Adolescents' Needs

Prior to the interview, steps were taken to ensure that the participants were comfortable with the researcher and interview and intervention setting, as described in 'engagement with the setting', above. The 'ice-breaker' and rule agreement activities in session 1 of the intervention were designed to facilitate the group dynamics. In addition, the engagement and well-being of each participant was monitored during each session. Breaks were offered if deemed necessary by the researcher or if requested by the participant. All adolescents were given positive reinforcement throughout the sessions. On the very rare occasion that a participant requested not take part, no further attempt was made to ensure their cooperation.

During the intervention itself, participants were encouraged to consider how they feel and behave when then encounter stimuli that they dislike. However, this did not induce any extra-ordinary distress, as these stimuli were those that adolescents would be expected to encounter in their daily lives. During the 'eating chilli' exercise of session 3, participation was emphasised as being totally voluntary. Aside from these 'example' sensory experiences the majority of sensory experiences considered by participants were self-chosen. This was an important aspect to the intervention, that adolescents must be motivated to take ownership for their behaviours in order to develop coping strategies.

#### 3.7.3. Anonymity and Data Protection

Participants were assigned anonymous ID numbers and these numbers were used on all test forms and computer records; pseudonyms were used in this thesis. In line with the UK's Data Protection Act, all data was kept in a secure location at the IOE and data was stored in a separate location from the one containing the name-ID number associations.

#### 3.7.4. Confidentiality

Although confidentiality could not be guaranteed within the group environment, participants signed an agreement not to discuss others' experiences outside of the group sessions. While efforts were taken to ensure confidentiality of the data, this was balanced by information sharing in that was felt to be in the interests of the participants. Adolescent and parental permission was sought to

share relevant information (such as elevated anxiety scores) with the SENCO. Participant sensory pictures were shared with parents and the SENCO after the interventions, so that reasonable adjustments to accommodate the adolescents' sensory preferences may be made.

#### 3.8. Data Analysis

To address Aim 1, examining adolescents' self-reported sensory experiences, pre-intervention interview recordings of the 7 Expt participants were transcribed promptly, and contextual or non-verbal factors noted within the transcripts. Recordings were transcribed verbatim, then checked for accuracy. Transcripts were re-read several times to ensure familiarity with the data. Thematic analysis was chosen as the research methodology for the qualitative analysis, being a flexible tool which allows for both inductive, data driven analysis associated with the constructivist research paradigms and for a more theoretical, 'top-down' analysis which fits with a more positivist paradigm (Braun & Clarke, 2006). Thematic analysis was therefore considered appropriate for the mixed methods design of the current study, which acknowledges the constructivist position inherent in individuals' subjective experiences of the world, but adopts a pragmatic approach, drawing on the more positivist, objective measures of behaviour to determine how far participants' experiences are consistent with expectations of society.

A thematic analysis was conducted on the entire data set of the 7 Expt participant pre-intervention interviews, using Nvivo10. A systematic approach to

the analysis was taken, following the steps described in Braun and Clarke (2006). First, initial thoughts around of points of interest were noted during transcription and familiarisation with the data. Next, the data were coded for initial potential themes of interest, largely at a descriptive level. It was permitted for one section of transcript to be coded with multiple codes. Then, these codes were reviewed, merged and distilled into interpretive 'candidate themes', arranged in hierarchies. The search for themes was guided by the pragmatic question of what about the sensory experience is most interesting and useful to those supporting the adolescents. At this stage, paper cuttings of the different excerpts were arranged by hand and mind-mapping was used to explore different candidate themes. Following this, the extracts within each candidate theme were re-read, to check whether the candidate themes formed a coherent pattern, each with internal homogeneity and external heterogeneity. Where necessary, themes were re-arranged. In acknowledgement of the potentially idiosyncratic nature of sensory experiences and coping, in some cases excerpts from one participant's experiences were deemed sufficient to form a code. The whole dataset was then re-read, and any additional data that was missed in previous stages was coded according to a theme. Finally, the names and descriptions of each theme were defined carefully in discussion with supervisors, to provide a meaningful and interpretive account of the sensory experiences described within. Throughout analysis, the themes were discussed in research supervision to improve validity of interpretations by reducing research bias and highlight additional areas of interpretation (Yardley, 2008).

To address the intervention effectiveness question of Aim 2, both quantitative and qualitative analyses were carried out. Prior to analysis, exploratory data analyses were carried out on all background and outcome measures at baseline, post-intervention and follow-up using SPSS 22. Distributions met the assumptions of normality in terms of skewness, kurtosis and the Shapiro-Wiki test of normality. Several outliers were included as they did not significantly affect the normality tests and were considered to represent valid individual differences. The only measures not to satisfy normality tests were several subscales of the SSP, total SSP score for SaU at baseline (p=.011) and total SSP score for SaU at post-intervention (having only n=2). As several SSP subscale scores were not normally distributed, total SSP scores only were used in subsequent analyses. Representativeness and variability of participant baseline data were examined by comparing individual total scores to typical norms. The degree to which group means were equivalent between Expt and SaU was examined by carrying out independent samples t-tests for the characterisation measures of the SRS-2 and WASI-II and the baseline outcome measures of the ASSP, SSP, RBQ and SCAS-P. Group mean comparisons with norms were also reported, to further describe the sample.

To address the group level analyses of change in primary (Aim 2i) and secondary (Aim 2ii) outcome measures, analyses were carried out separately for Expt and SaU, in light of limited success in the randomisation procedure producing matching groups (see results). Repeated measures analyses of Co-Variance (ANCOVA) were used, as this technique allowed for the effects of covariates as identified in the literature review to be accounted for (Kinnear &

Gray, 2009). Characterisation measures of age, intellectual functioning (WASI-II), and autism severity (SRS-2) score were placed as the covariates, with the different outcome measures of sensory reactivity (ASSP, SSP), repetitive behaviours (RBQ) and anxiety (SCAS-P) as the dependent variables for the different analyses at post-intervention (AASP only) and follow-up.

To address the individual level analyses of Aim 2)iii, the Reliable Change Index (RCI) was used to consider whether individual changes were significant and not attributable to measurement error (Bauer, Lambert & Nielsen, 2004), for all outcome measures. As the AASP and SP have differing internal reliability estimates (Cronbach's alpha), the more conservative, Gulliksen, Lord and Novick <sup>7</sup> (Hsu, 1999) algorithm was used, to account for each measure's reliability.

To address the qualitative analyses of participant perceptions of the efficacy of the intervention for adolescents (Aim 2iv) and parents (Aim 2v) the adolescent focus group and parent post-intervention interview data were transcribed promptly after the interviews. Dialogue considered extraneous to sensory topics was not transcribed. Transcripts were then checked for accuracy against the recordings and re-read several times to familiarise the researcher with the data.

7

 $\frac{(Xpost-Mpre)-Rxx(Xpre-Mpre)}{SDpre\sqrt{1-Rxx^2}}$ 

*Xpost/pre-* individual outcome scores *Mpre SDpre-* Means and SDs of pre-intervention scores *Rxx* - Cronbach  $\alpha$ Scores above 1.96 and below -1.96 suggest a high probability of clinically significant change Adolescents were easily identifiable by their voices in focus group recordings, so participant number was noted in the transcripts. Parent and adolescent focus group interviews were analysed separately, using the thematic analysis approach, outlined above (Braun & Clarke, 2006). The search for themes was guided by the overarching aim of determining the effects of the intervention, what aspects were useful and how it could be improved in future.

# 4. CHAPTER FOUR: RESULTS OF AIM 1) SELF-REPORTS OF SENSORY EXPERIENCES

Results from thematic analysis of adolescent pre-intervention interviews are presented below, to address Aim 1, adolescents' self-report sensory experiences. Transcripts from the pre-intervention semi-structured interviews with the 7 adolescents in Expt groups were analysed as outlined in the methodology (see Appendix D for an example transcript). Analysis revealed 5 themes (see Figure 11): 'need for control', 'resonance with stimulus affects reactivity', 'awareness of self in-relation-to others', 'barriers to coping relate to consciousness,' and 'features of adaptive coping strategies'. All subthemes contained extracts from at least 2 participants.

# 4.1. Theme 1: Need for Control

This first theme described how perceptions of control were closely related to emotions expressed in adolescents' sensory experience. Descriptions of several unpleasant sensory experiences referred to being subjected to something. Within the first of these 'subjection' subthemes, most adolescents indicated that they can frequently be subjected to a stimulus they find irritating or annoying, but can do little about. For example,

- Researcher: "so can you tell me about the loud, repetitive noise. When you hear it, what's going through your head, what do you think?"
- Milo: "cor I want to end it...I don't know...it's, ah that sound it's so annoying"

Researcher: "and how do you feel?"

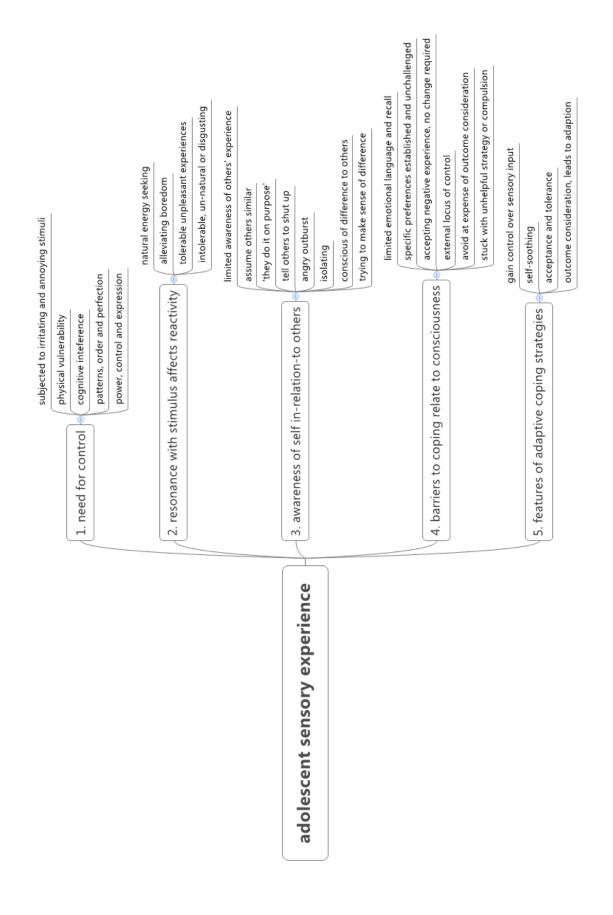


Figure 11. Summary of themes from analysis of adolescent pre-intervention interviews on their sensory experiences

Milo: "cornered, I don't know...some symbolism."

The second subtheme referred to feelings of physical vulnerability and fear at exposure to stimuli such as heights, open spaces and wobbling. For example,

"To be honest I feel as if I'm not concentrating on what's going on around me and I feel dizzy. So for example I feel as if somebody...could just come up from the back and just get me or something" Timo.

In the third theme, which again related to subjection to a stimulus, adolescents referred to their concentration being interrupted by thoughts about an unpleasant stimulus, including focusing on it and wishing it would disappear. For example,

"I used to have an alarm clock that used to tick. So I'd spend hours just lying still, just listening to the sound of the clock." Rupert.

Conversely, descriptions of pleasant sensory experiences were related to gaining control. The fourth subtheme described seeking behaviours for consistent patterns, creating order and perfection. These included both visual patterns and music being *"perfect and up to speed"* (Abel). There was the suggestion that this was an attempt to gain control over an annoying experience. For example,

"It's sort of, if it's not in order then it's annoying. I don't get something positive from doing it. I just don't get something negative." Frank

The fifth subtheme related to stimuli that brought the adolescent feelings of control, power and self-expression, which were reported as pleasant stimuli by

some adolescents. These ranged from preferring to control and plan activities to power fantasies. For example,

"I've only got to interact with a megaphone twice and I've loved it every time, cause like, everyone can hear me and I'm pretty sure that not a lot of people want to hear me. They're like...oh we have to cause like ... because you have to hear me you can't not hear me because it's like megaphone. I guess it's just like power, you know." Frank

Overall this theme indicates that being subjected to an unpleasant stimulus can provoke feelings of anger, irritation, fear, vulnerability and cognitive interference, while some sensory seeking behaviours may be motivated by a need to regain control or be heard. Throughout many of the adolescents' responses, phrases such as 'I don't know' or 'I guess' might suggest that adolescents were consciously considering these issues for the first time in the interview.

# 4.2. Theme 2: Resonance with Stimulus Affects Reactivity

This theme described how several adolescents were keen to convey a varying need to seek out a liked stimulus, or varying ability to tolerate an unpleasant one. Descriptions indicated that this was related to how far the sensory experience resonated with the natural state of being. At the most pleasant end of the scale described by this theme the subtheme of 'natural energy seeking' describes seeking exciting, calming or energising experiences. Responses suggest a sense that the stimulus 'fits' with or is in resonance with a natural energetic state of being. For example,

"Like if I'm in the darkness I'm just like: 'alright I'm free' and I can do more what I want and I'm more of a free person...Literally I feel more lively, stronger, fast and all that." Timo

Other pleasant sensory experiences are represented in the second subtheme of 'alleviating boredom', where adolescents may only engage in the sensory experience if bored and the opportunity presents itself. For example,

"Nah paint is alright. I actually sometimes just, when I'm bored I'll paint on my hand." Milo

Descriptions of experiences that are at odds with a natural state of being were more frequently reported by adolescents. The mildest of these were 'tolerable unpleasant experiences', where the adolescent expresses that they would prefer for the stimulus not to be present, but are able to tolerate its presence. For example,

"It's just something that I would prefer not to be there, but if it's there, I don't really care. It's not something that I can't resist." Timo (on bright light)

At the most unpleasant end of the scale, the subtheme 'intolerable, un-natural or disgusting' describes where adolescents reported a stimulus provoking an un-natural or disgusting feeling which could lead to avoidance, a compulsive behaviour (like having to wash hands) or unconscious instantaneous avoidant response. For example, "My sisters kiss my arm. I don't know why they do it but it really annoys me so I just jerk my arm back. So it's like second nature I just put my arm back. They don't get out the way in time, so...It's sort of like unnatural. Just, so I just instantly put my arm back." Abel

Overall adolescents' responses included within this theme suggest a need to react, or the ability to resist reacting to stimuli, is related to degree of 'fit' with the natural state. At the extreme ends of pleasant and unpleasant experiences, individuals may feel compelled to respond. The specificity and confidence implicit within adolescents' responses might suggest many were already aware of this aspect of sensory experiences, prior to the interviews.

# 4.3. Theme 3: Awareness of Self in-Relation-to Others

This theme combines aspects of the sensory experiences and consciousness, which relate how the adolescent sees themselves in-relation-to others and how they get on with others. Differences in sensory experiences may be both affected by and affect mentalising abilities. Subthemes were ordered to show the experiences that indicate an emerging awareness of a sensory 'difference' to others. The first subtheme (which included responses from all adolescents) indicated limited awareness of others' sensory experiences as responses suggested that this had not been previously considered, or that they did not know. For example,

Researcher: "how do other children feel when people bump or brush into them?" Freddie: "I don't really know, cause I'm not them"

Some adolescents assumed other people had a similar particular sensory preference, again indicating a limited awareness of difference. For example,

Researcher: "how do other boys react to gooey things like that (dough)?" Abel: "I think they're like me"

The subtheme of 'they do it on purpose', describes some adolescents' beliefs that others intentionally cause unpleasant sensory experiences to annoy them. For example,

"There's one song that I absolutely hate...and my dad plays it I instantly go to the device that's playing it and try to switch it off...my dad does it on purpose." Abel

This might indicate how a difficulty in understanding that others may have different sensory experiences may contribute to difficulties in relationships with others. Adolescents' own sensory reactivity may further exacerbate relationships. The subtheme, 'tell others to 'shut up'' describes adolescents' insensitive or rude responses, telling other people to stop the source of an unpleasant stimulus. For example,

"When my little sister starts singing, I tell her to be quiet. " Freddie

Adolescents showed no awareness that this may offend others, or be a potential source of conflict. Similarly, the subtheme 'angry outburst' describes how an uncontrollable anger response can lead to conflict. For example,

Researcher: "what do you think if someone just bumps into you, or brushes you?" Freddie: "um...then I don't really like that. Like if it was someone I knew and I didn't really like, then I could get like a bit like upset or angry."

Some adolescents acknowledged that their experiences of seeking or avoiding stimuli can be 'isolating' as they miss out on opportunities to interact with others. For example,

"I'm always keep away with people with curly hair...I just walk away. It looks really weird to me, I don't know why." Timo

When adolescents demonstrated a fledgling awareness that they have different sensory experiences, the responses within the theme 'conscious of difference to others' suggested some make attempts to down-play differences. For example,

"Yea, if I can, I'll go and wash my hands like that instant. I'm a bit weird cause...about my hygiene. I'm not sure about it cause...ah I don't mind" Milo

A few were 'trying to make sense of their difference'. Some responses indicated a level of confusion, while others formed an explanation. For example,

"I usually tend to fall over a lot. It's just something that I always do, I don't know why...I think I told you before, I was born on a cruise ship...so the water, it's so wavy, that's what I was thinking." Timo

In both this and the previous subtheme, there is a sense that the adolescent may feel discomfort at the realisation that they have a different sensory experience, so that the 'explanation' serves a normalising purpose. Overall this theme indicates that adolescents were at differing stages in the development of awareness of how their sensory experiences differ to others'. Responses also indicate that level of awareness may influence relationships with others via the mechanisms of misunderstanding intentions and inappropriate responses. As awareness develops, adolescents may feel some isolation and wish to normalise their responses.

# 4.4. Theme 4: Barriers to Coping Relate to Consciousness

Throughout adolescents' reports there was a sense that many responses to sensory experiences were unconscious. Subthemes suggest that a certain cognitive inflexibility may be acting as a barrier to them developing coping strategies on their own. The first subtheme relates to a limited emotional language and recall (e.g. *"yea, it just makes me feel like…like…um I er…yea like different, like…it just makes me like wake up. When I wake up I just feel different than like just wake."* Freddie, talking about bright colours). Within some quotes there was a sense that adolescents had difficulty recalling or considering moments in the past. For example,

Researcher: "How do you feel when you're in the bus?"

Abel: "I'm happy, I think, well I take the bus anyway"

The subtheme of 'specific preferences established and accepted and unchallenged' conveyed the sense that adolescents were well aware of some established sensory preferences, but appeared to have just accepted them and them to guide their behaviour. For example, "Like, if there was a really hard rock or something, like a really rough rock. I'd like to, let's say touch it or punch it, or do something to it, I dunno why it's just something like that." Timo

The extension of this unquestioning acceptance was evident in the subtheme of 'accepting negative experiences', where adolescents resisted helpful changes. For example,

- Frank: "I think I used up about 10 minutes of my exam time once when I was just replacing all the crossed out words with just rectangles so then it'll be like in place."
- Researcher: "aahh. So are you happy with doing that, or would you like to not do that?"

Frank: "er...I wish I could do it quicker"

One subtheme which may partially explain this resistance to change was an 'external locus of control', with participants believing they cannot affect experiences. For example,

Researcher: "would you like to be able to manage that a bit better?" Freddie: "um I might not be able to but, um I sometimes get annoyed and I sometimes don't."

Another explanation for a resistance to change is the next subtheme of 'avoid at expense of outcome consideration', where adolescents described avoidant behaviours with a negative secondary consequence that they had either devalued or not considered. For example,

"I'd just put that away <demonstrates hand behind back> and start doing things with one hand" Milo on accidently touching gum

Perhaps as a result of the inflexibility described above, some adolescents described the use of an ineffective coping strategy, which more resembled a habitual response or compulsion. For example,

"I think I'd just sort of wobble to stay stable, in a way. Like, it wouldn't work, I know it wouldn't work". Frank

Two participants reported different compulsions, including having to wash hands if sticky (Milo) and wiping all around screens to clear condensation (Frank).

Overall, this theme describes how many adolescents found it difficult to engage in the meta-cognitive steps of reflecting on experiences and outcomes, and taking ownership for change, resulting in some participants being stuck in repeated patterns of unhelpful responses.

## 4.5. Theme 5: Features of Adaptive Coping Strategies

Of the coping strategies that appeared to be adaptive, or helpful, the first two subthemes alluded to a somewhat unconscious response that tried to control the input or make the individual feel better. Gaining control over sensory input included: avoiding, putting hands over ears, controlling the stimulus at its source and controlling visual attention (e.g. *"I went to Tower of London before and I just didn't look down at the river below"* Rupert). One participant referred to planning and preparation as a means of avoiding piano mistakes: *"um…Just, basically I memorised the music, so I know what's going to happen"* (Abel). When prompted, some adolescents identified self-soothing activities (e.g. tapping a pen) forming the second subtheme. For example,

"Umm, I don't really think about it, I just...well it kind of just helps me think. I just use it, break it in half and rub it" Angus (on 'science putty')

In all examples from the previous 2 subthemes, adolescents were able to say what they did, but did not recognise these as a means of coping per se. Only 4 of the adolescents' responses suggested that they engaged in conscious consideration of coping strategies prior to the interview (Milo, Rupert, Frank and Abel in Expt\_older) forming the other 2 subthemes. The first was of 'acceptance and tolerance' in the face of uncontrollable stimuli, indicating a level of conscious cognitive control. For example,

"Well I can't do anything basically so I just get on with it. That helps so...if you accept it." Abel (on a ticking clock)

Three adolescents' responses made up the next subtheme of conscious coping, indicating that considering the outcomes of sensory experiences has led to behavioural adaptation, including overcoming unhelpful avoidance strategies. For example,

"I don't do it all the time because like I don't want to fence myself off, like...fence myself off from everybody else. So I do it sometimes and then sometimes I'll, like, stay downstairs with the rest of my family, like watch TV or something." Rupert (on listening to music)

Another was motivated to adapt his behaviour to "keep everyone else happy", adding: "If someone doesn't give you a glare or tuts at me, you just say 'I'm alright'." (Abel).

Overall, this theme suggests that the majority of adaptive coping strategies were somewhat unconscious reactions (e.g. covering ears). Only the older adolescents' responses indicated an emergent conscious deployment of coping strategies. Together with reports in other themes from pre-intervention interviews, adolescents would appear to have an emergent awareness of their sensory experiences.

# 5. CHAPTER FIVE: RESULTS OF AIM 2) EFFECTIVENESS OF CBT-BASED SENSORY INTERVENTION

In this chapter, the effectiveness of the intervention is evaluated using quantitative and qualitative analyses. In initial data analysis, baseline characteristics of the sample are described by comparing individual total scores on background and outcome baseline measures to typical norms. Next, the randomisation of participants is described, reporting the comparisons between Expt and SaU group means on background and outcome baseline measures, using t-tests and comparisons with norms. Then, group level analyses of change are reported in primary (Aim 2i) and secondary (Aim 2ii) outcome measures. This is followed by analyses of change on the individual level (Aim 2iii). Fidelity to the programme and attendance are also considered. Finally the qualitative thematic analyses from adolescent post-intervention focus groups (Aim 2iv) and parent post-intervention interviews (Aim 2v) are reported.

#### 5.1. Initial Data Analysis

The standardised norms of background and outcome measures are displayed in Table 4, along with means, *SD* and ranges of these measures for Expt and SaU groups, calculated as reported in section 3.4. Below, comparisons between standardised norms and individual total scores on background and outcome baseline measures are reported to describe characteristics of the sample.

# 5.1.1. Characteristics of Sample

**WASI-II.** Analysis of the individual FSIQ-2 scores indicated the following distribution of IQ scores. For the 7 Expt participants, one was in the average

range (within 1*SD* from normative mean), 4 scored above 1*SD* above the mean and 2 scored above 2*SD* above the mean. For the 5 SaU participants, 4 were in the average range and one scored more than 2*SD* above 100. All participants comfortably met inclusion criterion of IQs greater than 70. Visual inspection of participants' scores indicated that all but 3 participants had comparable verbal and non-verbal subscale scores (within 1*SD*), which suggests that both groups had an IQ profile in the above average range, with largely similar verbal and non-verbal abilities.

SRS-2. Analysis of the individual total SRS-2 T-scores indicated the following distribution of autism severity scores. For the 7 Expt participants: 'within normal limits', n=1; mild (>1*SD* from mean), n=1; moderate (>2*SD*), n=3; severe (>3*SD*), n=2. For the 5 SaU participants: 'within normal limits', n=1; mild, n=0; moderate, n=1; severe, n=3. Both groups showed a wide range of autism severity scores. One participant in each group scored 'within normal limits', but as per inclusion criteria had a diagnosis of autism. However both of these adolescents did report some sensory and autism-related difficulties in the intervention groups.

**AASP.** Individual participant scores on the 4 subscales of the AASP are shown in Figure 12. All but one participant in each of the Expt and SaU groups scored more than 1*SD* above or below the 'typical' range in at least one of the 4 subscale domains on the AASP, indicating the presence of 'probable' atypical sensory reactivity. The two participants whose self-ratings fell within 'typical' ranges in all domains did however report some atypical sensory sensitivities in

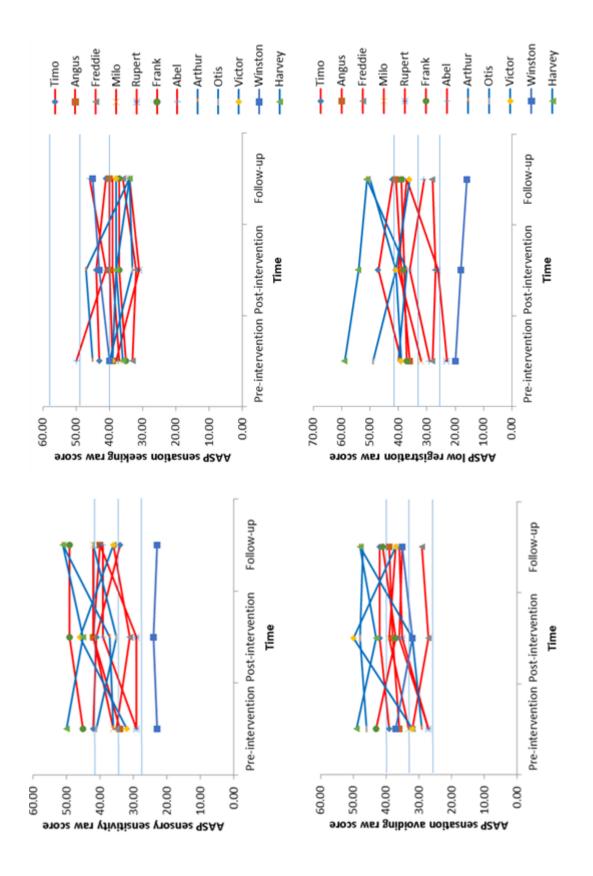


Figure 12. Individual scores on AASP subscales, normative means and SDs (Brown & Dunn, 2002). Expt:Timo-Abel, SaU:Arthur-Harvey.

the intervention groups. Norms were not available for the total AASP scores generated by summing subscale scores (see Figure 13).

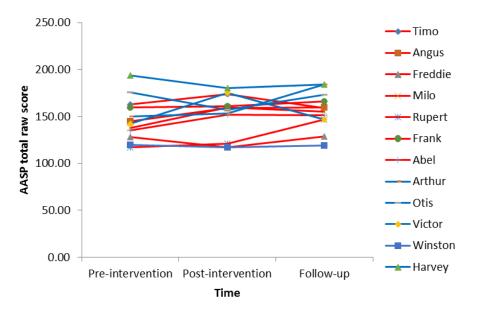


Figure 13. Individual scores on AASP total. Expt:Timo-Abel, SaU:Arthur-Harvey

**SSP.** SSP baseline subscale scores are included in Table 4 for information, however, as reported above, several SSP subscale scores were not normally distributed, subsequent analysis focussed on total SSP score (Figure 14). As the SSP is not standardised for use with adolescents, normative data were unavailable.

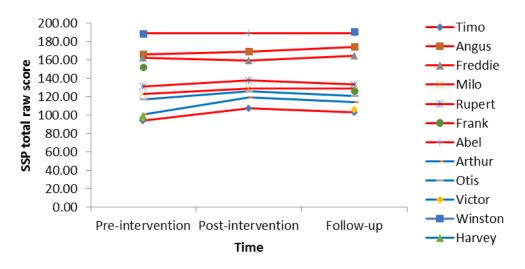


Figure 14. Individual scores on SSP total. Expt:Timo-Abel, SaU:Arthur-Harvey

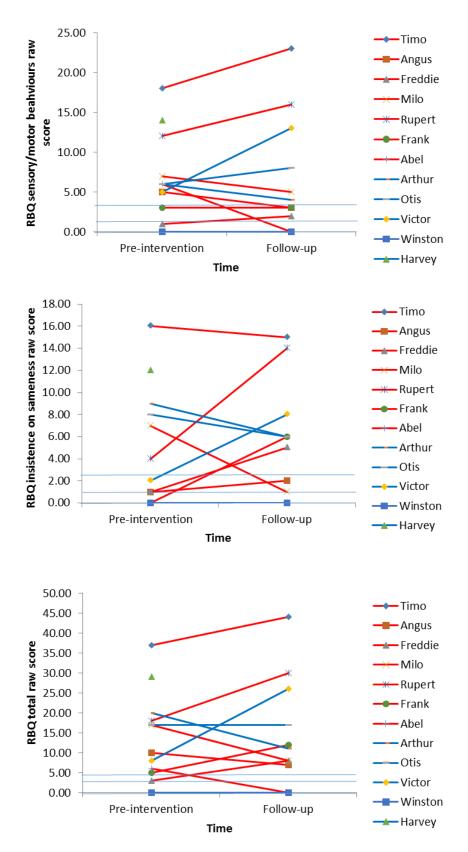


Figure 15. Individual RBQ subscale and total scores, normative means and SDs (Honey et al. 2012). Expt:Timo-Abel, SaU:Arthur-Harvey

**RBQ.** All but one participant in each of the Expt and SaU groups had a total RBQ pre-intervention score 1*SD* above the 'typical' mean as reported in Honey et al. (2012) (see Figure 15), consistent with repetivite behaviours being part of the diagnosit criteria for autism (APA, 2013). Looking specifically at the sensory/ motor subscale of the RBQ, 2 participants in the Expt group and one in the SaU group scored in the typical range, indicating a presence of sensory/ motor and total repetitive behaviours in the majority of participants.

**SCAS-P.** Individual analysis indicated that 3 adolescents in each of the Expt and SaU groups had pre-intervention parent-reported anxiety scores within the elevated range, as indicated by scores 1*SD* above the typical mean in Nauta et al. (2004) (see Figure 16).

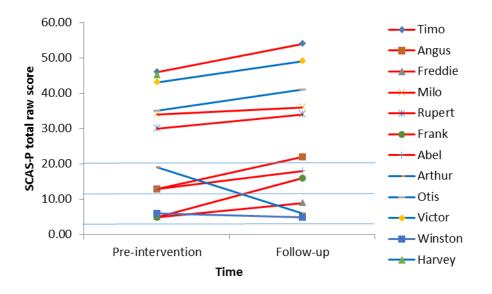


Figure 16. Individual SCAS-P total scores, normative means and SDs (Nauta et al. 2004). Expt:Timo-Abel, SaU:Arthur-Harvey

# 5.1.2. Randomisation and Comparison of Group Means

To determine whether Expt and SaU groups differed on baseline measures

independent samples t-tests (2-tailed) were carried out on the characterisation

measures of the SRS-2 and WASI-II and the baseline outcome measures of the ASSP, SSP, RBQ, and SCAS-P. Group mean comparisons with norms were also made, to further describe the sample.

All t-tests were non-significant at p=.05 level, except for WASI-II verbal T-score, where adolescents in the Expt group (M=64.43, SD=6.78) scored higher than the SaU group (M=49.20, SD=5.54), t(10,4.12) p=.002. Although these analyses suggest no difference between groups on the overall measures of intellectual functioning, self-reported sensory reactivity (AASP), parent-reported sensory total reactivity (SSP), repetitive behaviours (RBQ) and anxiety (SCAS-P), visual inspection of the group means (Table 4) suggested that the groups were in fact not matched on these measures.

In addition to the Expt group being significantly higher on verbal IQ, Expt group means on non-verbal abilities (M=60.00, SD=15.99) and FSIQ-2 (M=121.14, SD=13.96) were in the above average range, higher than that for SaU (non-verbal M=46.20, SD=14.41; FSIQ-2 M=108.40, SD=16.50), which were in the average range. Although not significant, Expt means for SRS-2 autism severity symptoms were also different to SaU. Expt scores for repetitive behaviours (M=69.14, SD=12.85) and social communication (M=68.57, SD=11.46) were in the mild range (1SD above average norms) and total SRS-2 was just above (M=70.57, SD=12.09), while SaU autism severity scores were all higher and in the moderate range (repetitive behaviours M=72.60, SD=21.28; social communication M=76.80, SD=15.48; total SRS-2 M=76.60, SD=17.17).

Measure	Subscale	Ш	Expt (N=7)	6	S	SaU (N=5)	(	Norm	Normative Sample	umple	SaU (n=4)	(n=4)
	I	М	SD	Range	Μ	SD	Range	Μ	SD	Range	Ν	SD
	Verbal (Vocabulary T-score)	64.43	6.78	53-73	49.20	5.54	43-58	50.00	10.00	40-60	49.50	6.35
WASI-II	Non-verbal (Matricies T-score)	60.00	15.99	30-80	46.20	14.41	25-64	50.00	10.00	40-60	41.75	12.04
	FSIQ-2 (standard score)	121.14	13.96	95-139	108.40	16.50	92-135	100.00	15.00	85-115	108.00	19.03
	Restricted Interests and Repetitive Behaviour	69.14	12.85	46-89	72.60	21.28	45-97	50.00	10.00	40-60	66.50	18.86
SRS-2 (T-score)	Social Communication and Interaction	68.57	11.46	46-82	76.80	15.48	52-94	50.00	10.00	40-60	72.50	14.01
	Total	70.57	12.09	47-85	76.60	17.17	50-96	50.00	10.00	40-60	71.75	15.37
	Low registration	32.00	5.72	23-39	41.40	14.43	20-59	33.57	7.66	26-41	37.00	12.19
	Sensation seeking	39.29	5.68	33-50	40.00	3.24	36-45	49.42	8.98	40-58	41.00	2.71
AASP (IAW	Sensory sensitivity	35.71	6.05	29-45	36.40	10.06	23-50	33.98	7.39	27-41	33.00	7.62
200163	Sensation avoiding	33.86	5.96	27-40	38.60	8.68	29-49	33.02	7.06	26-40	36.00	7.44
	Total	140.86	16.59	117-163	156.40	29.03	120-294	not availa	ble for to	not available for total scores	147.00	23.12
	Tactile	28.00	5.94	20-35	25.00	6.60	17-35				25.75	7.37
	Taste/smell	12.71	6.78	5-20	8.40	6.69	4-20				9.50	7.19
	Movement	12.86	3.13	7-15	13.00	2.92	8-15				12.50	3.11
SSP (raw score)	Underresponsive/seeks sensation	25.57	8.79	8-34	24.60	6.35	19-35	not avail	not available for ages 11-16 years	ges 11-16	24.75	7.32
	Auditory	20.57	6.60	11-30	14.20	8.93	9-30				15.00	10.10
	Low energy/weak	24.29	3.95	21-30	15.60	8.88	8-30				17.50	9.00
	Visual/auditory	21.29	5.44	12-25	19.60	5.27	14-25				20.75	5.32
	Total	145.29	31.61	94-189	120.40	38.61	97-188				125.75	42.39
RBQ (raw score)	Insistence on Sameness/ Circumscribed Interests	4.14	5.81	0-16	6.20	5.02	0-12	1.05	1.34	0-2.39	4.75	4.43
norms from Honey et	Sensory/Motor Behaviours	7.43	5.80	1-18	6.20	5.02	0-14	1.38	2.00	0-3.38	4.25	2.87
aı. (zu ız)	Total	13.71	11.80	3-37	14.80	11.17	0-29	2.22	2.56	0-4.78	11.25	9.07
SCAS-P (raw score) noms from Nauta et al. (2004)	Total	20.86	15.89	4-46	29.60	16.70	6-45	11.80	8.30	3.50- 20.10	25.75	16.52
1:												

Table 4. Expt, SaU group, and normative means, SD and ranges on baseline measures. Means for SaU (n=4) are included for comparisons to inform analyses on parent-report measures.

Groups were slightly better matched on AASP scores and also more typical, with 'sensory sensitivity' scores for Expt (M=35.71, SD=6.05) and SaU (M=36.40, SD=10.06), and 'sensation avoiding' scores for Expt (M=33.86, SD=5.96) and SaU (M=38.60, SD=8.68), all in the typical range. 'Sensation seeking' scores for Expt (M=39.29, SD=5.68) and SaU (M=40.00, SD=3.24) were both slightly below the typical range. 'Low registration' was within the typical range for Expt (M=32.00, SD=5.27) and slightly above typical range for SaU (M=41.40, SD=14.43).

For the parent-reported outcome measures of SSP, RBQ and SCAS-P, preliminary analyses of changes following the intervention were only carried out using 4 participants from the SaU group, as one parent did not return questionnaires for post-intervention and follow-up (see Figure 1). For the purposes of group comparisons at baseline for these analyses, SaU group means excluding this participant (n=4) are also presented in Table 4. Further independent t-tests indicated no significant differences (p>.05) between Expt (N=7) and SaU (n=4) on any measures, except again for verbal IQ, t(9,3.59)p=.006, with adolescents in the Expt group (M=64.43, SD=6.78) again scoring higher than those in the SaU group (n=4, M=49.50, SD=6.53). Visual comparison of FSIQ-2 again indicated that adolescents in the Expt group (*M*=121.14, *SD*=13.96) had higher overall intellectual functioning than those in the SaU group (n=4, M=108.00, SD=19.03), although visual comparisons between SRS-2 scores suggest that the 'reduced' SaU group (n=4, M=71.75, SD=15.37) was more similar to the Expt group on this measure (M=70.57, SD=12.09).

Visual inspection of the remaining parent-report total scale scores, suggest that on total SSP scores, Expt groups (M=145.29, SD=31.61) appeared more 'typical' than SaU (n=4, M=125.75, SD=42.39). Although normative SSP data were not available for adolescents, it is noteworthy that both groups' scores were in the typical range for 3 to 10 year-old norms. Mean SCAS-P scores for Expt (M=20.86, SD=15.89) and SaU (n=4, M=25.75, SD=16.52) were similar, with both indicating slightly elevated anxiety. Likewise, Expt (M=13.71, SD=11.80) and SaU (n=4, M=11.25, SD=9.07) mean RBQ scores were similar and both higher than the typical population range.

Overall, for both sets of comparisons between Expt and SaU groups, visual inspection of means would indicate that adolescents in the Expt group had higher overall intellectual functioning and were more typical on several other baseline measures. In effect, this means that the randomisation of participants into Expt and SaU groups failed to produce adequately matched groups, which was most likely due to the small sample size. Analyses were therefore not carried out using the SaU as a control group. Instead, differences within groups and individuals were analysed.

# 5.2. Group Analysis of Intervention Effectiveness

Analysis of changes over time in primary (Aim 2i) and secondary (Aim 2ii) outcome measures are reported below. Repeated measures ANCOVA were carried out for Expt and SaU groups separately for each of the primary outcome measures (AASP and SSP) and secondary outcome measures (RBQ and SCAS-P) as dependent variables. For each analysis, age and the

characterisation measures of intellectual functioning (WASI-II), autism symptom severity (SRS-2) were entered as covariates.

## 5.2.1. Primary Outcome Measures

The means of AASP and SSP primary outcomes at pre-intervention, postintervention and follow-up are presented in Table 5

**AASP.** For the AASP, total and subscale scores were entered as the dependent variable at pre-intervention, post-intervention and follow-up. The repeated measures ANCOVA revealed no significant intervention effect for the changes in Expt group ASSP total scores [pre-intervention: M=140.86, SD=16.59; post-intervention: M=149.14, SD=21.63; follow-up: M=152.43, SD=12.05; F(1.14,3.42)=2.46, p=.21]. Similarly, there was no significant intervention effect for the SaU group total AASP scores [pre-intervention: M=156.40, SD=29.03; post-intervention: M=156.40, SD=24.84; follow-up, M=161.40, SD=28.11; F(1,1)=.24, p=.71].

The repeated measures ANCOVA analyses also revealed no significant changes between for AASP subscale scores (represented in Table 5), neither for the Expt group (N=7) [AASP low registration: F(1.03,3.07)=2.41, p=.22; AASP sensation seeking: F(1.51,4.52)=4.64, p=.09; AASP sensory sensitivity: F(1.65,4.96)=3.07, p=.14; AASP sensation avoiding: F(1.08,3.23)=1.67, p=.29], nor for SaU (N =5) [ AASP low registration: F(1,1)=.033, p=.97; AASP sensation seeking: F(1,1)=3.78, p=.30; AASP sensory sensitivity: F(1,1)=.43, p=.70; AASP sensation avoiding: F(1,1)=1.46, p=.44] (Greenhouse-Geisser corrected). Table 5. Means of Expt and SaU primary outcome measures at pre-intervention, postintervention and follow-up

			Expt (N=7)		SaU	SaU (AASP: N=5, SSP: n=4)	)=4)
	1	pre-intervention	post-intervention	follow-up	pre-intervention	post-intervention	follow-up
Measure	Measure Subscale	M SD	M SD	M SD	M SD	M SD	M SD
	Low registration	32.00 (5.71)	36.14 (7.43)	36.43 (5.16)	41.40 (14.43)	38.20 (12.99)	40.80 (15.25)
AASP	Sensation seeking	39.29 (5.67)	37.71 (4.75)	39.00 (3.92)	40.00 (3.24)	39.80 (5.36)	37.00 (4.80)
(raw scores)	Sensory sensitivity	35.71 (6.05)	39.00 (6.90)	40.00 (4.80)	36.40 (10.06)	37.40 (8.91)	40.60 (11.72)
	Sensation avoiding	33.86 (5.96)	36.29 (4.68)	37.00 (4.36)	38.60 (8.68)	41.00 (8.60)	43.00 (6.44)
	Total	140.86 (16.59)	149.14 (21.63)	152.43 (12.05)	156.40 (29.03)	156.40 (24.84)	161.40 (28.11)
SSP (raw score)	Total	Total 145.29 (31.61)	missing data, not calculated	145.43 (30.72)	120.40 (38.61)	missing data, not calculated	132.75 (38.66)

**SSP.** For the parent measure of total SSP score, missing postintervention data meant that total scores were entered at pre-intervention and follow-up only. The repeated measures ANCOVA revealed no significant intervention effect for the Expt group SSP total scores between pre-intervention (M=145.29, SD=12.05) and follow-up (M=145.43, SD=30.79), F(1,3)=.60, p=.50.The small sample size for the SaU group (n=4 parents returning questionnaires at both pre-intervention and follow-up) meant that no analyses could be performed.

# 5.2.2. Secondary Outcome Measures

RBQ total and subscale scores, and SCAS-P secondary outcomes were entered as the dependent variable for the repeated measures ANCOVA at preintervention and follow-up (see means in Table 6). As with the SSP, SaU group size meant that no analyses could be performed.

Table 6. Means of Expt and SaU secondary outcome measures at pre-intervention and followup

	_	Expt (	N=7)	SaU (n=4)	
	_	pre- intervention	follow-up	pre- intervention	follow-up
Measure	Subscale	M SD	M SD	M SD	M SD
RBQ	Insistence on Sameness/ Circumscribed Interests	4.14 (5.81)	6.14 (6.09)	6.20 (5.02)	5.00 (3.46)
(raw score) _	Sensory/Motor Behaviours	7.43 (5.80)	7.43 (8.62)	6.20 (5.02)	6.25 (5.56)
	Total	13.71 (11.80)	15.57 (15.60)	14.80 (11.17)	13.50 (10.91)
SCAS-P (raw score)	Total	20.86 (15.89)	27.00 (15.33)	25.75 (16.52)	25.25 (23.04)

**RBQ.** Analyses confirmed no significant intervention effect for Expt RBQ scores [RBQ total: F(1,3)=.003, p=.96; RBQ insistence on sameness: F(1,3)=.84, p=.43; RBQ sensory motor: F(1,3)=.68, p=.47].

**SCAS-P.** Analyses confirmed no significant intervention effect for Expt SCAS-P scores, F(1,3)=.40, p=.57.

Overall, group analyses indicated no significant changes in Expt or SaU group scores over time, on any measures.

# 5.3. Individual Analysis of Intervention Effectiveness

Analysis of changes over time on the individual level (Aim 2iii) is reported below. Individual scores on the outcome measures of AASP (total and 4 subscales), SSP total, RBQ (total and 2 subscales) and SCAS-P total are presented in Figure 12 to Figure 16, (above), for pre-intervention, postintervention (AASP and SSP only) and follow-up.

The 'reliable change index' RCI<sup>8</sup> (Hsu, 1999) was calculated for these measures and all individuals (see Table 7 and Table 8). The RCI accounts for regression to the mean due to the different measures' internal consistency reliability (Cronbach's alpha). Positive index values indicate a reliable increase,

 $\frac{(Xpost-Mpre)-Rxx(Xpre-Mpre)}{SDpre\sqrt{1-Rxx^2}}$ 

Xpost/pre- individual outcome scores Mpre SDpre- Means and SDs of pre-intervention scores Rxx - Cronbach  $\alpha$ Scores above 1.96 and below -1.96 suggest a high probability of clinically significant change accounting for regression to the mean, while negative values indicate a reliable decrease (note that an apparent 'increase' in raw score may not necessarily yield a positive RCI value and vice-versa). RCI values indicating a reliable change towards the typical mean (i.e. change in the 'expected direction') were identified using the normative means (given in Table 4 and represented visually in Figure 12 to Figure 16). These expected changes are shaded in Table 7 and Table 8, below. Although normative means were not available for AASP and SSP total scores, the calculated mean of the normative AASP subscale scores (M=141.5, SD=28.5) and the mean SSP total score for 3-10 year olds (M=172.50, SD=17.50) were used to infer the 'expected direction' of change. RCI with absolute values greater than 1.96 indicate a 'high probability of a clinically significant change', being 1SD above or below the mean, and are indicated in bold in Table 7 and Table 8.

Visual inspection of the pattern of changes indicated that certain participants (Angus, Milo and Abel) in the Expt group showed some changes in the expected direction for the AASP subscales and SSP total score postintervention, which were maintained at follow-up, along with a reduction in repetitive behaviours. However, similar beneficial changes were evident in the SaU group. In fact, the pattern of changes in the desired direction appeared to be the same across groups, with approximately half of participants in both groups showing a beneficial change for any one outcome.

		AASF	P RCI (pre-in	itervention to	AASP RCI (pre-intervention to post-intervention)	tion)	AA	<b>VSP RCI</b> (p	AASP RCI (pre-intervention to follow-up)	n to follow-up	~
	Participant							2			
	pseudo-	Low	Sensation	Sensory	Sensation		Low	Sensation	Sensory	Sensation	
	nym	registration	seeking	sensitivity	avoiding	Total	registration	seeking	sensitivity	avoiding	Total
	Timo	0.51	0.91	0.20	0.75	0.96	1.17	-0.06	-1.02	0.75	0.05
Expt_younger Angus	Angus	0.66	0.58	1.27	0.38	0.81	0.40	0.58	0.92	0.57	0.87
	Freddie	-0.30	-0.56	-0.76	-1.17	-1.03	-0.43	0.74	0.11	-0.79	-0.30
	Milo	0.51	0.75	1.04	0.95	1.17	06.0	0.75	1.04	0.58	0.86
Evnt older	Rupert	1.35	-2.10	-0.43	0.97	-0.32	-0.09	-1.12	1.48	1.15	1.27
L API_DIGG	Frank	0.30	0.58	1.25	-0.69	0.30	0.17	0.58	1.25	0.06	0.60
	Abel	0.00	-1.76	1.31	1.15	0.81	0.66	-0.14	1.31	0.97	0.75
	Arthur	1.60	1.40	0.17	0.15	0.23	-0.24	-2.82	2.60	3.15	2.12
SaU_younger	Otis	0.63	-1.93	-0.73	0.99	-0.63	-0.56	-1.61	0.48	0.80	0.35
	Victor	-0.28	-0.07	2.19	3.14	1.92	0.38	-0.07	0.45	0.71	0.21
Sall older	Winston	-1.13	1.32	-0.63	-0.87	-0.69	-0.87	1.96	-0.80	-0.30	-0.57
000_0106	Harvey	-0.18	0.66	-0.01	-0.33	0.01	0.22	-0.64	1.03	0.61	0.26

Table 7. RCI coefficients for AASP subscale and total scores, for changes pre-intervention to follow-up and pre-intervention to post-intervention. Reliable changes in the desired direction are shaded, clinically significant changes in bold.

	SCAS-P	RCI (pre-	intervention	to follow-up)	1.61	1.38	0.45	0.45	0.74	1.63	0.71	-2.26	1.14	1.23	-0.39		
(dn-w				Total	1.85	-0.66	0.68	-1.63	2.35	1.11	-1.32	-1.56	0.07	3.25	-0.33		
RBQ RCI (pre-intervention to follow-up)		Sensory/	Motor	Behaviours	2.27	-0.75	-0.06	-0.62	1.58	-0.25	-1.94	-0.69	0.57	2.39	-0.44		
R (pre-interv	Insistence on	Sameness/	Circumscribed	Interests	0.20	0.16	1.25	-2.08	3.58	1.92	-0.26	-0.88	-0.57	2.02	-0.26		
	DAP RCI (pre-	intervention	to post-	intervention)	-0.18	0.22	0.16	-0.04	0.02		0.35	-0.10	-0.06				
	SSP RCI	(pre-	intervention	to follow-up) intervention)	0.32	0.72	0.31	0.31	0.10	-1.58	0.35	0.62	0.14	0.34	0.47		
		Participant	pseudo-	nym	Timo	Angus	Freddie	Milo	Rupert		Abel	Arthur	Otis	Victor	Winston	Harvey	
y significant change				in t	a Expt_younger		sire			tion	vas	SaU_younger	lica	ted			

Table 8. RCI coefficients for SSP, RBQ (inc. subscale) and SCAS-P total scores, for changes pre-intervention to follow-up and pre-intervention to post-intervention (AASP only). Reliable changes in the desired direction are shaded, clinically significant changes in bold.

Clinically significant change in the desired direction was indicated for one participant in the Expt group (insistence on sameness reduced) and for 2 participants in the SaU group (showing reductions in sensation avoiding, sensory sensitivity and anxiety). There were 2 participants in both groups who showed clinically significant deterioration in behaviours in AASP and RBQ scores.

The pattern of individual improvement therefore appears inconsistent, with both positive and negative changes occurring for both groups throughout the 16-week period, which might be related to extraneous factors. The only two reliable, but not-clinically significant, patterns observed were that (1) parent-rated sensory behaviours (SSP scores) at follow-up increased for all but one participant, and (2) unlike the SaU group, all Expt participants showed an *increase* in parent-rated anxiety following the intervention.

### 5.4. Fidelity and Attendance

Fidelity to the programme was considered to be good. Sessions were carried out as per the descriptions in section 3.5, with the adaptations to engage in the Gradewood setting. All adolescents completed between 10 to 25 sensory pictures in total (see Figure 17 for one adolescent's example). Being optional, 'Mission' completion rates were not recorded, though an estimated half of participants did complete the Mission following each session.

The total attendance rate of the Expt sessions was 92.8%, representing 4 individual pupil absences over the 8 week Expt intervention period, which were due to school absence. Total attendance at the SaU sessions was 54%, excluding the two SaU participants who did not complete the intervention in the spring of 2014 (see Figure 1). Poor SaU group attendance was attributed to a move of intervention room due to building works.

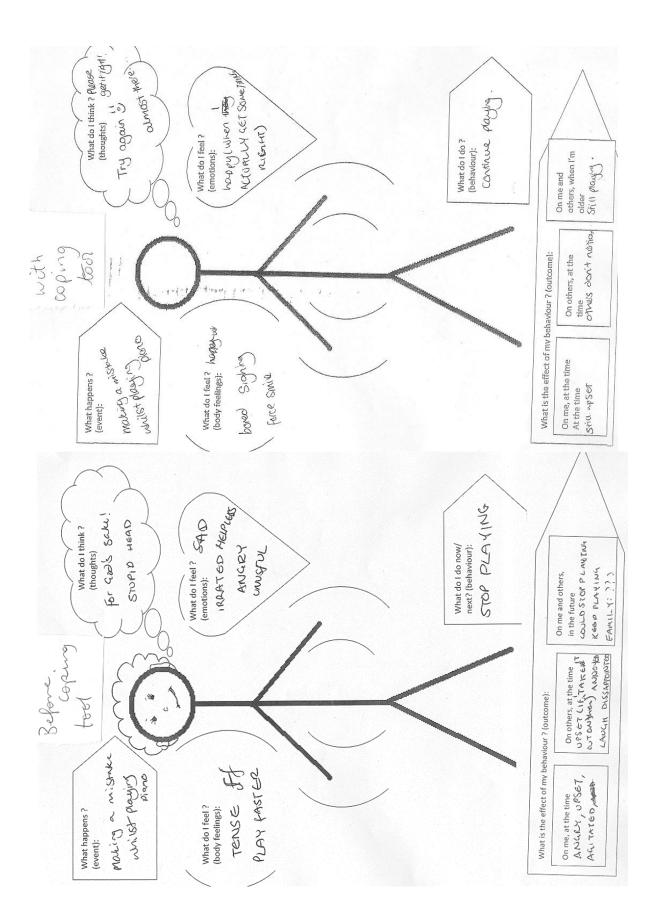


Figure 17. Exemplar adolescent Sensory pictures, before and after application of coping tool 49

#### 5.1. Participant Perceptions of the Effectiveness of the Intervention

Transcripts from the 2 adolescent focus groups (n=6) and 7 parent interviews post-intervention for Expt groups were analysed as outlined in the methodology to determine adolescent (Aim 2iv) and parent (Aim 2v) perspectives of the effectiveness of the intervention (see Appendix E and Appendix F for transcript examples). A summary of the themes from each analysis is presented in *Figure 18* and Figure 19 and discussed in more detail below.

## 5.1.1. Adolescent's Perceptions of the Intervention

Adolescents' comments were uniformly positive. Analysis of their responses in the focus groups revealed 5 main themes: 'raised awareness of sensory experiences', 'new found self-expression', 'motivation for using coping strategies', 'generalising learning' and 'improvements to programme' (see *Figure 18*). The first two themes referred to post-intervention changes implicit in their responses while themes 3 and 4 contain self-reported changes or use of coping tools. The final theme refers to suggested improvements to the programme.

Theme 1: Raised awareness of sensory experiences. Several

adolescents' contributions indicated a level of consciousness of sensory experiences that was not evident in pre-intervention interviews. This related to their consideration of three areas directly addressed in the intervention. The first was evaluation of the outcome of experiences (e.g. *"yea, like if the outcome's bad then I have to obviously change it, if I can."* Freddie).

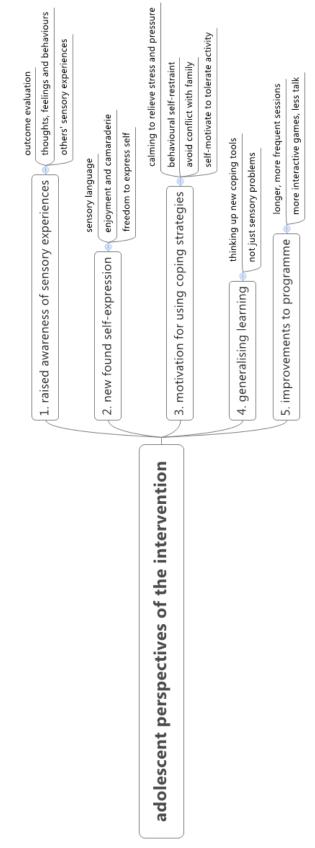


Figure 18. Themes from analysis of adolescent post-intervention interviews

The second was around an increased awareness of the interplay between thoughts, feelings and behaviours (e.g. *"I've learnt that my thoughts are…what do you call it? Have an impact on my body and when I'm angry I get tense and my emotions go everywhere."* Abel). The third subtheme related to an increased awareness of how their own sensory experiences relate to others'. For example,

"I also learnt that...anyone has sensory problems, not really just people with like autism, anyone really can have sensory problems...and autism might be to do with it, but it might not." Angus

Theme 2: New-found self-expression. In addition to an increased awareness, three aspects of the intervention were indicated to facilitate adolescents' ability to express their experiences. In the first subtheme, responses appeared more fluent than pre-intervention, drawing on language of the intervention. For example,

"I found them very useful because I learnt some body and thinking coping tools and when I use them it's really helped me to do better." Freddie

In the Expt\_older group, some contributions referred to a fun and collaborative team spirit, where adolescents valued each other's contributions. For example,

"Yea, I found it good. It was fun, you know we got together, we went through sensory experiences and we sort of helped each other." Frank

The third subtheme contained contributions that alluded to a feeling of being given an opportunity or the freedom to express themselves. For example,

"I don't normally tell people about how I'm feeling usually but then...I think I actually encouraged to tell people about it and then that's like a good thing." Angus

# Theme 3: Motivation for using coping strategies. The coping

strategies that were valued by adolescents were those that sought to ameliorate an unpleasant situation, falling into 4 subthemes. The first was of self-soothing and calming strategies. For example,

"Yea, well I think coping tools like touching stuff's quite a good coping tool and sometimes lying down and not really thinking about anything, that's a good coping tool and science putty stuff, that's a good coping tool." Angus

"Probably the breathing one...when, I'm stressed or something. Like you feel all over the place, like I don't want to get like that, make my heart speed up and stuff". Rupert

"Well, the one I'm most proud of is the one where the guy's pestering me and I counted to relieve pressure on me." Abel

Equally as common were comments which referred to a new-found ability to exercise restraint towards an unhelpful behaviour which was previously out of their control. For example,

"People are telling me that I have to do stuff better and I'm trying to but I don't really...I didn't really know how. Like when people are telling me that I have to behave myself more I didn't really know how to but now I found a way how to....Like if there's a fight or if there's like a physical action that I want to go into then I could walk away." Freddie

"I won't flip out on someone now." Rupert

In a less common subtheme, communicating sensory experiences with family was seen as a means of avoiding conflict or not causing them distress. For example,

"Like if they were cooking the bad, like fish or something, I wouldn't like shout at them or be like 'Ah, take that out the oven!' Like I'll just walk out or just tell em' what it is." Rupert

One adolescent referred to a cognitive coping strategy to help him 'selfmotivate' to tolerate daily compulsory activities:

> "Like at home, for doing homework I'm probably going to be doing thinking tools, like to get me into the frame of mind and like, when I do rugby and all those things, to get me into the frame of mind for what I'm going to be doing. Whatever I have to do but don't want to do." Freddie

Theme 4: Generalising learning. There was some evidence that

adolescents had or were planning on applying the principle of 'coping tools' to new situations (e.g. "*I could learn a coping tool that I talk to people I know and I just talk and not...play rough.*" Freddie). This same adolescent also expressed a degree of confidence in his ability to deal with future problematic situations:

"If there are any then I think I can change them using the coping tools I've learnt." Freddie

Some adolescents also indicated that they have or would use the framework of sensory pictures to cope with problems additional to sensory situations. For example,

"I didn't understand it at first, I thought it was more about sensory stuff then I realised it was more about problems and solving them, then that was new so that was good." Angus

This may indicate that for adolescents of this profile or intellectual functioning, purely 'sensory' issues may not necessarily be the most salient.

Theme 5: Improvements to programme. Adolescents generally reported that the groups were 'good' and better than they imagined. In fact, their responses indicated that they wanted longer, or more frequent sessions (e.g. *"Have more sessions…have more frequent sessions"* Rupert). One adolescent indicated that he would have liked *"more interactive game, like instead of keep talking and do all the sensory pictures, you could have more game involved"*. (Abel). This may have been alluding to the interactive elements of the initial three sessions.

Overall, analysis of focus group responses indicated that the intervention acted as a supportive space for adolescents to express their sensory experiences and learn from others' experiences, thereby developing their meta-awareness of the relationship between thoughts, feelings, behaviours, and outcomes. There was evidence that some adolescents had learned to self-soothe and modify their behaviours to avoid conflict, and some evidence that the 'coping tool' strategy may be applied in new situations. When responses are compared to adolescents' pre-intervention interview responses, there is a striking difference in the quality of their responses. The intervention appeared to have facilitated their meta-cognitive and linguistic skills on this topic.

# 5.1.2. Parents' Perceptions of the Intervention

Parents' perceptions were largely limited to what they could gather from the weekly emails, or from observing their child's behaviours. Aspects of the intervention that addressed barriers to 'knowing' were identified as helpful. Analysis of their responses in post-intervention interviews revealed 5 main themes: 'challenges to parental involvement', 'importance of communication with parents', 'parental perspectives of change post-intervention', 'importance of group dynamics', and 'improvements in future support and delivery' (see Figure 19).

Theme 1: Challenges to parental involvement. Several parents indicated that adolescents typically do not involve or allow their parents to be involved in understanding or supporting their difficulties, including parental attempts to support the current sensory intervention. The most common barrier to parental involvement was the evasiveness of adolescents. For example,

"Basically he wasn't interested in telling us much about it, other than he was enjoying it and he liked being in the groups." Abel's mother

In the absence of adolescents reporting their sensory experiences, parents were largely required to infer them from behaviours, which parents noted were increasingly hidden as the adolescent becomes more independent or the family changes its habits. For example,

"He used to be really scared of dogs. But I don't walk with Rupert as much as I used to so I don't really see his reaction anymore, so a lot of things I don't really know if he don't tell me...we haven't got an animal at home." Rupert's mother

Some parents' direct attempts to intervene were met with resistance:

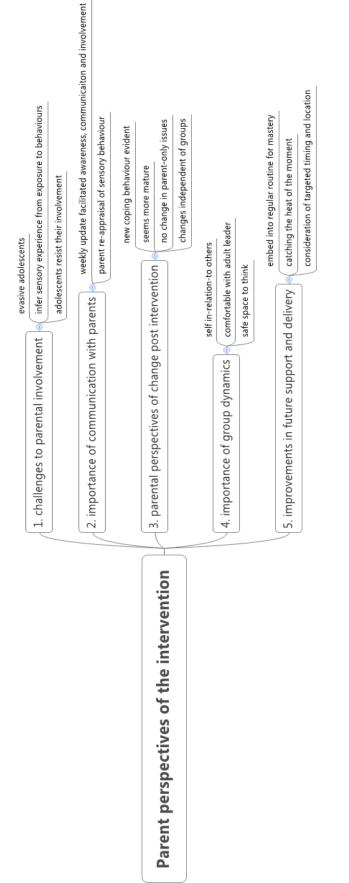


Figure 19. Themes from analysis of parent post-intervention interviews

"He feels this really irrational anger and I say to him, this is the time when you should do your sensory exercises and he says 'no they don't work', but obviously he hasn't tried. As soon as you tell him something, it's always 'no' and then when he starts doing it, he enjoys it." Timo's mother

### Theme 2: Importance of communication with parents. Responses

indicated that communicating information and aspects of the intervention addressed some of the aforementioned challenges to involvement. The weekly emails equipped several parents with information they would not otherwise have:

"I liked very much, the fact that you were sending us, every week the update. That was really nice in terms of being able to talk with Freddie what he was doing. Because sometimes it's difficult to know without knowing because you can't ask most silly questions so you have to guess the answer." Freddie's mother

Information also led to one parent's re-appraisal of her child's difficult behaviours as being sensory in nature:

Oh yea! He comes home and you know 'nothing can be cooked', and you know 'what's the smell?' I used to be like that as a child, so I didn't think anything of it, but now you mention it, he has to run upstairs and he gets quite annoyed." Rupert's mother

Theme 3: Parents' perspectives of change post intervention. The most common parent-identified changes occurring over the course of the intervention were observable, new behaviours attributed to the intervention. For example,

"He was sitting down and doing these amazing drawings, very intricate, some of them quite weird...he gets quite a lot of satisfaction from it cause it's quite a visual thing for him to do and very calming so I was wondering if maybe, that was mentioned in the course, about doing things, drawing something when you feel tense, because on that occasion that really worked." Rupert's mother

Two parents identified a change in adolescents' maturity and sense of self:

"He seems in himself, calmer again. He was going through a stage of being quite unsettled and almost fighting with his conscience all the time it was...Since he's being doing the groups he's actually now, seems to kind of got out of that and seems to have kind of grown up, almost, if that makes sense." Abel's mother

However, parents also noted some sensory behaviours which were unchanged. As none of these were raised by the adolescents themselves in interview or groups, this would suggest that change may not occur in issues which affect parents only. For example,

"Still he's not changing food habits. He dislike vegetables, even worse than before, he seems more fussy." Milo's mother

Other changes perceived to be independent from the intervention, such as naturally overcoming a fear of heights over several years were also noted.

Theme 4: Importance of group dynamics. Several parents also commented on the group dynamics as a therapeutic factor itself. Within the first subtheme of 'self in-relation-to others' were feelings that adolescents benefitted from feeling included and understood by peers in a similar situation. For example, "It was giving him this buddy situation. The sort of situation where he was understood, not judged." Freddie's mother

However, within this subtheme, differences between group members were also acknowledged to be helpful. For example,

"I think it's been good for him to think about how he finds some things more difficult than other people." Angus' mother

For some adolescents, positive group dynamics were a necessary condition for their engagement, with some parents referring to the importance of feeling comfortable with the adult leader (e.g. *"For some reason you're one of the people he likes."* Mother of Timo). Nevertheless, within the context of understanding and trusting relationships, the final subtheme contained responses that considered the groups a 'safe space to think'. For example,

"So I think, probably he did benefit, just you the fact that fact you were there and concentrate and listen and probably took stock of things." Rupert's mother

Theme 5: Improvements in future support and delivery. In the first of 3 subthemes of parent-suggested improvements, parents emphasised the need to embed learning into the adolescents' everyday routine. For example,

"If he had even just a few months of it, every day, regularly, then it would become a routine for him and he would implement them at the right time and use the when he needs. I really think it's very beneficial and a lot of

things I read on your email, I really like those and I really wish he could do them on a regular basis". Timo's mother Similarly another subtheme suggested that adolescents really need the support 'in the heat of the moment', when they are overwhelmed with stress (e.g. *"he's only thinking of it when she's doing it* (sister playing a song) *and then he can't think straight to think it through"* Angus' mother). The parent of the only pupil in year 7 noted that the timing and school setting of the intervention worked well in supporting his transition from the junior school:

"It did come also at a very good time, when you doing, because I think it was quite stressful, the change for him." Freddie's mother

While adolescents' resistance and evasiveness may act as a barrier to parental involvement, the groups appeared to offer a supportive space to help them think about themselves in-relation-to others. Equipping parents with knowledge from the intervention facilitated their communication and understanding, which was often otherwise limited to inferring their child's sensory experience from behaviours. Accordingly, some noticed new observable 'coping' behaviours in adolescents, and some a newfound sense of maturity. However, this change was not evident for behaviours that were an issue to the parent only.

### 6. CHAPTER SIX: DISCUSSION

The inclusion of sensory reactivity in the diagnostic criteria for autism in DSM-5 (APA, 2013) reflects a growing recognition of the impact, and potentially central role, of sensory processing atypicalities in autism. Limited 'top-down' conscious interpretation of sensory input is theorised to underlie the development of autistic symptoms (Frith, 2003; Pellicano & Burr, 2012) and supported by self-reports of individuals with autism (e.g. Williams, 1998). However, the traditional sensory measures (e.g. Dunn, 1999) and sensory integration therapies are based on theories that are not empirically validated and, with their focus on behaviour, have limited power to represent or change the root cause of the issues (American Academy of Pediatrics. 2012; Case-Smith et al., 2014; Schoen et al., 2009).

This study has called for the need for the understanding and management of sensory difficulties to take an entirely different approach. It embraces both theory and the autistic experience, through its focus on bringing the cognitions, emotions, and responses involved in sensory experiences to consciousness. This was accomplished through two main aims. The first aim expanded the growing evidence base of self-reports of sensory experiences in autism by eliciting these from adolescents with autism. The second aim assessed the effectiveness of a CBT-based intervention to manage sensory experiences, reporting the design, delivery and evaluation of the intervention, using a mixed methods design. Although methodological limitations (discussed below) may have contributed to the lack of significant quantitative intervention effects, there were nevertheless striking differences in the quality of adolescents responses

post-intervention suggesting that the intervention was successful in raising adolescents' conscious awareness and coping strategies for sensory experiences.

In this discussion section, I discuss the findings and implications for each aim, followed by the study's strengths and limitations, including the impact of more general methodological limitations. Finally, I discuss the study's implications for professional EP practice and potential future directions.

#### 6.1. Self-Reports of Sensory Experiences

This study has built on the few existing self-report studies with adolescents. Rather than focussing on sensory preferences (Robertson, 2012), *how* the experience is shared (Kirby et al., 2014) or using predefined codes in analysis (Ashburner et al., 2013), analysis of self-reports in the current study sought to be inductive, yet influenced by theories of sensory processing in autism (Frith, 2003; Mottron et al., 2006; Pellicano & Burr, 2012). Specifically, this study examined the extent to which adolescents with autism have conscious awareness of their own sensory coping strategies, or of their experience being 'atypical', all of which was considered important in understanding experiences in relation to variation in age, autism severity, and intellectual functioning.

## 6.1.1. Awareness of Behavioural, Physical and Emotional Response

The interviews with adolescents clearly illustrated that they have conscious awareness of how some sensory experiences relate to their emotions, thoughts and behaviours. This is consistent with previous self-report studies with even younger and less intellectually-able children with autism (Edgington, 2012). Analysis suggests that the salient experiences to adolescents were those that were either resonant (fit) with the natural state or those that felt unnatural, affecting the way that they respond to sensory input. Unnatural feelings reflect Kirby et al.'s (2014) subtheme of 'uncontrollable physical responses' of nausea and pain, however this is the first self-report study to extend this theme to encompass pleasant sensations, which can be energising or soothing. The suggestion that responses may be determined by perceived control or feelings of 'fit' with the current natural state may offer one explanation as to why sensory reactivity can vary from day to day in autism.

The 'need for control' was also expressed more implicitly by several adolescents, a factor that potentially underlies some of the physical, emotional and behavioural responses. Previous research has related control to coping behaviours and suggested adolescents with autism prefer controllable stimuli (Ashburner et al., 2013). However, the current analysis goes further in suggesting that perceived control influences these adolescents' full sensory experience, including emotional responses. In the current study, adolescents' responses about emotions and control indicated a nascent understanding of this aspect of sensory experiences.

## 6.1.2. Awareness of Sensory Difference

Analysis indicated that adolescents had differing levels of awareness of their sensory experiences, in-relation-to others'. For those with a lack of awareness, misunderstanding intentions and inappropriate responses influenced their social relationships in a negative way, bringing to mind the social features of autism. This is consistent with consistent with previous examples of self-reports, which

illustrate how social difficulties may arise from sensory atypicalities (e.g. Williams, 1998). Those with a developing awareness of having a sensory difference reported some feelings of isolation or sought to normalise their experience. This is consistent with adult self-reports of isolation in Smith and Sharp (2012) and adolescent attempts to 'normalise' their experiences (Kirby et al., 2014). Only a small number of adolescents in the current study demonstrated an emergent awareness of their sensory processing being different. This finding builds on the work of previous self-report studies in adolescents, where level of conscious awareness of a sensory processing difference is either not considered or is assumed (Kirby et al., 2014). One implication is that adolescents who might be becoming more aware of their 'sensory differences' may benefit from support to identify which experiences are atypical, without creating further feelings of isolation – a feature that was key to the 'supportive group' design of the current intervention.

### 6.1.3. Awareness of Coping Strategies

Analysis revealed that only the older adolescents had consciously employed a coping strategy to deal with their sensory difficulties. Of these, the strategy of 'acceptance' reflects previous adolescent reports that 'getting used to it' helps alleviate discomfort (Ashburner et al., 2013), consistent with the role of 'priors' in sensory interpretation (Pellicano & Burr, 2012). Relatively few adolescents in the current study reported conscious consideration of the impact of their behaviour for guiding decision making, again consistent with theories of limited 'top-down' conscious sensory processing in autism (e.g. Frith, 2003).

The majority of adaptive coping strategies reported were unconscious reactions (e.g. covering ears). A difficulty with meta-cognitive reflection and taking ownership for change was linked to some participants being stuck in repeated patterns of unhelpful responding. This finding chimes with previous self-report studies, where a only a few meta-cognitive conscious coping strategies (e.g. self-talk) were used by adolescents (Ashburner et al., 2013) and adults (Elwin et al., 2012; Smith & Sharp, 2012), whilst unhelpful patterns of coping behaviours remained evident (e.g. staying indoors). Adolescents' responses in the current study indicated a high level of attachment to these rigid behaviours or compulsions within the 'barriers to coping' theme, bringing to mind the nonsocial features of autism (Bogdashina, 2003). Likewise, these 'rigid behaviours' were not raised as potential areas for change by adolescents within group sessions. This could add support to the argument that parents' or teachers' concerns should be targeted in the intervention sessions and that adolescents should not have 'free-rein' over which experiences to work on. However, it is argued here that giving adolescents control over issues to focus on is a more ethical and effective approach, which allows them to build up feelings of metacognitive control and self-efficacy for change through consideration of selfchosen examples, thereby targeting some of the 'barriers' which may be maintaining rigid behaviours.

Overall, findings from current adolescent self-reports of sensory experiences support theories of sensory processing in autism (Frith, 2003; Mottron et al., 2006; Pellicano & Burr, 2012). The limited quality of language and awareness indicated in participants' responses suggests that a degree of unconscious

processing may underlie the social and non-social features of autism. How far this is different to typical sensory experiences is unclear. While some metacognitive ability and coping strategies may emerge with age in individual, this was not applied uniformly to all sensory experiences. How intellectual functioning is related to sensory experiences and coping is not yet clear, although current findings would indicate that having average or above average intellectual functioning, like the adolescents in the current study, is not sufficient to develop sensory coping strategies, as these were evident in only a handful of responses.

### 6.2. Effectiveness of CBT-Based Intervention

This study is the first to present the design, delivery and evaluation of a CBTbased intervention to manage sensory experiences. The intervention was unique, being the first sensory self-regulatory intervention programme for adolescents with autism. It built on the sensory-based coping strategies of selfcalming and mental preparation in the Alert Program (Williams & Shellenberger, 1994) and Sensory Stories (Therapro Inc., 2011) for young children, combining these approaches with the psycho-educational approach of CBT, theories of sensory processing in autism and self-reports of coping strategies already used by some individuals with autism (e.g. Ashburner et al., 2013). The intervention was considered to be child-centred, as unlike previous sensory interventions, adolescents determined which issues to consider themselves. Below, the effectiveness of the intervention is discussed by referring to findings from the background, quantitative and qualitative analyses in this mixed methods study.

### 6.2.1. Participant Characteristics and Randomisation

It was unfortunate that the sample size in the current study was too small for randomisation to work, especially given the variability evident in baseline measures in the adolescent. While there was no significant statistical difference between Expt and SaU group means on baseline measures, except for verbal IQ, visual inspection indicated that the Expt group had higher overall intellectual functioning and was more typical on several other measures, meaning the groups were not matched on these variables.

This limitation might have been avoided with the sample originally intended and discussed with the Gradewood SENCO. As indicated in Figure 1, 15 of the potential participants were excluded on the grounds that they did not have a diagnosis of autism; this revelation came towards the end of the participant recruitment phase, which unfortunately precluded any further recruitment of participants. This has implications for future recruitment of participants and intervention, as the population of individuals whom schools consider to benefit from autism interventions may be larger than those with formal diagnoses.

The questionnaire response rates and participant retention rates were further limited by personal, medical and family factors over the course of the study, which also limited the sample size for comparison on baseline measures. In addition to affecting participant retention rates (as indicated in Figure 1), informal conversations with approximately half of the parents also indicated that personal, medical, and family factors affected parental time and stress, meaning they had limited time to complete questionnaires; some received up to 5 'reminder' phone calls. This, together with short timescales for data collection meant that of the 12 final participants, one parent did not complete any measures at post-intervention or follow up, 3 additional parents did not complete the SSP post-intervention. Previous research has suggested that families of individuals with autism might be expected to experience more stress (e.g. Rao & Beidel, 2009; Sivberg, 2002), which may impact on the questionnaire response rates of parents. This suggestion is supported by a reported parent response-rate of under 50% after one year in a larger study with parents of primary-age children with autism (Charman, Howlin, Berry, & Prince, 2004). However, the expected 8-week response rates from parents of individuals comparable to that in the current sample is unclear.

In addition to sample size, the broad range of participants' baseline intellectual functioning, autism severity scores, sensory reactivity, repetitive behaviours, and anxiety may have also limited the success of the randomisation procedure in producing matched groups. This might imply that inclusion criteria were too broad in the current study, being limited to a confirmed diagnosis of autism and IQ above 70, thereby including participants with any score on baseline measures. However, all participants included in the study *did* report atypical sensory experiences in interviews and intervention groups. This supports the rationale for including all participants with a diagnosis of autism; atypical sensory experiences are implicated in all autistic individuals. Furthermore, as the presentation of autistic (and associated) symptoms is known to be highly heterogeneous (APA, 2013; Happé & Ronald, 2008), limiting the profile of included participants may have reduced the ecological validity of the study.

### 6.2.2. Group and Individual Analyses of Intervention Effectiveness

Group analyses of changes over time in primary (Aim 2i) and secondary (Aim 2ii) outcome measures were carried out separately for Expt and SaU groups, controlling for intellectual functioning, autism symptom severity, and age. There were no significant changes in Expt or SaU group primary outcome measures (AASP and SSP) or secondary outcome measures (RBQ and SCAS-P). This is perhaps not surprising, given the small sample sizes and variability in participants' baseline scores, as discussed above.

The possibility that idiosyncratic individual changes were masked within the whole group analyses was explored using the RCI to account for the reliability of measures and identify patterns of reliable change on individuals' scores on primary and secondary outcome measures (Aim 2iii). Individual analysis revealed a largely random pattern of improvement and deterioration on different measures, spread across Expt and SaU groups, which would suggest no consistent pattern of intervention effect at the individual level. The changes noted in this analysis were instead likely to be attributable to naturally occurring changes related to other personal, medical and familial factors, discussed above.

Together, the lack of significant group and individual intervention effects might indicate that the intervention yielded no effect on the outcomes of sensory reactivity, repetitive behaviours, and anxiety. However, this interpretation would be inconsistent with both parents' and adolescents' qualitative post-intervention data, which provides strong evidence of adolescents' enhanced cognitive awareness and coping behaviours. Rather, it is highly likely that lack of

significant findings are attributable to the reduced power of the study's small sample size and additional factors, discussed below.

It is acknowledged that the inclusion of participants with baseline scores already in the 'typical' range may have made it harder to detect changes postintervention. However, as reported in 'characteristics of sample' 2 participants' scores were within typical norms for each of autism severity, sensory reactivity and repetitive behaviours measures and 6 were typical for anxiety. This represented 7 out of the 12 participants with 'typical' baseline characteristics, despite reporting sensory and autism-related difficulties in interview and interventions. Excluding participants on the grounds of typical functioning on outcome measures would therefore have reduced the sample size even further and misrepresented the heterogeneity characteristic of autistic populations.

The 8-week timescale between the data collection points of pre-intervention, post-intervention, and follow-up may be another limitation to the current study. As questionnaires were collected by post, some parents completed two sets of questionnaires in close succession, or missed the post-intervention round altogether. One way to overcome this might have been to gather parents together to complete questionnaires, however, this would not have been feasible at Gradewood, as parents live all over London. The timescale may also have been too short to detect change post-intervention. It seems likely that there may be a delay between changes to adolescents' internal cognitions (as evidenced in adolescent self-reports and parent reports of 'maturity' postintervention) becoming evident in patterns of behaviours. However, longer timescales were precluded by time constraints in the current study.

One additional limitation lay with the stability and validity of sensory reactivity measures themselves, which limited the sensitivity of these measures to detect change. The ASSP's reported internal consistency (.65 -.75, Brown and Dunn, 2002), together with visual inspection of SaU group scores on the AASP over time (see Figure 12), indicate that it is an unstable measure. While it could be argued that this reflects the natural variability in sensory experiences, the AASP might lack sensitivity to detect changes beyond the 'noise' of natural variability. However, this is perhaps not surprising as the measure is not designed for repeated use. The SSP appears to be a more stable measure (see Figure 14) and has a higher reported internal consistency reliability (.90, Dunn, 1999). However, this measure is also not designed for repeated use, which might underlie the uniform drop in sensory reactivities across the whole sample, found in the individual analysis.

Moreover, as discussed throughout this study, the AASP and SSP have limited validity to represent the sensory experience, being based on unfounded assumptions of 'neurological thresholds' and compiled from clinical observations of sensory behaviours from different clinical populations. Visual comparison of the items on the AASP and SSP with the self-report sensory experiences of adolescents in the current study (Figure 11) suggest that the measures do not adequately represent the experience as reported by adolescents in the current study. Indeed, during administration to adolescents, several were confused by items that asked; 'I don't seem to notice when...(e.g. someone touches my arm or back)' asking 'how would I know?' This further illustrates how questions structured from the point of view of the observer may

misrepresent the underlying experience. The validity of the SSP is also limited in the current study, being designed and standardised for use with children aged 3 to 11 years. This may suggest that the SSP, as well as the AASP has limited power to capture the sensory experiences that are relevant to adolescents of this profile. The qualitative measures of the semi-structured interviews appear to better-suited to capture the sensory experience at the cognitive and emotional level than the questionnaires. However, as discussed in the methodology, these questionnaires were the most suitable from the ones available. The AASP was chosen for being the only adolescent measure of sensory reactivity and in the absence of a parent-report questionnaire of sensory reactivity in adolescents, the SSP chosen for being a congruent, short scale for parents.

Other aspects of the programme may also explain the lack of significant quantitative findings. Over the course of the intervention, participants each considered between 5 and 12 sensory scenarios each (with 2 sensory pictures for each scenario). While some adolescents reported they were transferring coping tools to other scenarios, other adolescents may only have experienced actual change in their handful of specific scenarios, which were unlikely to have been detected by the measures. Another aspect of the programme, was that adolescents were given control over *which* sensory issues were considered in the groups. Qualitative data indicated that adolescents were generally motivated to change experiences that were unpleasant for them (rather than disapproved of by others) and were 'stuck' with some habitual and unhelpful responses, experiencing cognitive barriers to change in these areas. These

behaviours, which resemble repetitive behaviours or the non-social symptoms of autism may therefore have been under-addressed in the groups, resulting in no significant changes on RBQ measures. However, as argued above, this child-centred approach is believed to be more ethical and effective, as it addresses some of the 'barriers to change including meta-cognitive control and self-efficacy for change, identified in the self-report analysis.

### 6.2.3. Participant Perceptions of Intervention Efficacy

Comparison of adolescent interview responses pre to post-intervention, revealed striking differences in their awareness of the relationship between thoughts, feelings, behaviours and outcomes, and their capacity to reflect upon and express their sensory experiences, suggesting that the intervention was successful in bringing sensory issues to consciousness. Three adolescents, Timo, Milo and Frank, appeared to be less engaged with the intervention and reported less impact in post-intervention interviews than other Expt participants, yet these adolescents were also the most self-aware and articulate in preintervention interviews. The relation between existing awareness and engagement in the meta-cognitive intervention was not directly explored in the current study, but has implications for screening participants who may most benefit from the intervention; those who present as more self-aware and articulate may have less to gain from the intervention.

Analysis of both adolescent (Aim 2iv) and parent (Aim 2v) reports postintervention indicated that the focus on building up awareness and introducing coping tools had brought about positive changes in three ways.

First, several adolescents had learned to self-soothe and modify their behaviours to avoid conflict, with some adolescents applying the 'coping tool' strategy in new contexts or to broader situations such as homework. At home, several parents noticed some new observable 'coping' behaviours in adolescents and also a newfound sense of maturity. However, this change was not evident for behaviours that were an issue to the parent alone (e.g. fussy eating), which would be consistent with the adolescents' motivation for using coping strategies. While a few adolescents were motivated to avoid conflict with family, most were motivated to change in order to ameliorate an unpleasant experience, consistent with reports from Kirby et al. (2014). This finding may indicate that even if the intervention had stipulated sensory issues on which to focus, adolescents may not necessarily have been motivated to implement change in their everyday lives.

Second, the supportive group atmosphere of the intervention was also identified as a therapeutic element itself. Both parents' and adolescents' responses indicated that the intervention acted as a supportive space for adolescents to express their sensory experiences and learn from others' experiences. Some parents noted that their children are selective about which adults they work with, which may have implications for future intervention. This finding is consistent with that of Clarke (2012), who also identified group dynamics as an important factor in CBT with children with autism.

Third, one additional effective element of the intervention was that equipping parents with knowledge from the groups facilitated their communication and understanding, in some cases overcoming adolescents' evasiveness which can

act as a barrier to parental involvement. Parents acknowledged that they often otherwise infer their child's sensory experience from their behaviours, as it is rarely communicated by the adolescent.

In general, both adolescent and parent suggestions for improvement indicated that the groups were considered useful, and may have been even more effective if they were embedded into the routine or curriculum and with support being more readily available at times of increased stress.

#### 6.3. Further Limitations and Strengths of the Study

Further to the limitations in outcome measures, discussed above, the qualitative measures of semi-structured interviews were also limited in their ability to elicit the full range of salient sensory experiences in the adolescents interviewed. Unlike the use of multi-sensory stimuli in Robertson (2012) or personalised video clips in Kirby et al. (2014), the semi-structured interviews in the current study only employed visual stimuli, which may not have evoked the required experience. However, the use of the 'feely-box', video clips, participants' 'missions' (to bring in items), and the eating chilli and chocolate exercises during the intervention were well received by participants and believed to help bring the sensory experiences to life.

However, it is acknowledged that the self-reports of adolescents are also limited to that of the Expt group, as the SaU group's interviews were not recorded and included in the thematic analysis due to time constraints. It cannot be assumed that adolescents reported the whole range of their sensory experience in interviews. It is likely that sensory experiences in autism are far more complex

than that represented in Figure 11. However, this might represent those experiences which are the most immediately accessible to consciousness, thereby addressing the underlying purpose of Aim 1. How far this level of conscious awareness is evident in typical populations is unclear as the study is limited by the lack of a typically developing group for comparison of self-reports.

The generalisability of the current study is limited by sample characteristics, focussing on adolescent boys with autism, with average or above average intellectual functioning, already well-adapted into mainstream education. The participants were all sampled from one school, which itself may have limited representativeness to other secondary mainstream schools in the country, being high attaining and selective on the grounds of religious faith. The sample was largely homogenous with respect to gender, culture and ethnicity, as such the findings may not be generalised to other populations. Within Gradewood, convenience sampling may have meant that individuals who agreed to participate were those more inclined to engage. Similarly, it is unclear how far the behavioural and work expectations of the setting contributed to the success of the intervention; in other settings, adolescents might be more reluctant to engage or require longer sessions.

However, in carrying out the intervention at Gradewood and implementing modifications to the programme to adapt it to this setting, the study has good ecological validity (Christner, Forrest, Morley, & Weinstein, 2007). In addition to factors identified by participants, additional factors, believed to have contributed to the success of the intervention included, small group sizes (facilitating participation), familiarity of the intervention room, and having one researcher

throughout design, implementation and analysis meaning that an overarching understanding was brought to the study. The success in the implementation of the intervention is further evidenced by all adolescents engaging in activities and the high (92.8%) attendance rate in the Expt group. As reported by all participants, they also enjoyed the programme.

# 6.4. Relevance to Professional EP Practice

The child-centred approach adopted throughout the current study is well suited to the emphasis on the views and participatory role of children and young people in the Department for Education's new (draft) SEN Code of Practice (CoP) (DfE, 2014). Both the 'understanding' and intervention elements addressed in Aims 1 and 2 of the current study have implications for the role of the EP in supporting individuals with autism.

## 6.4.1. Facilitating Understanding in Teaching and Learning

One of the widely recognised roles of EPs, which will continue to be important under the new legislative context of the Children and Families Act (2014), underpinning the SEN CoP (2014), is to elicit and represent pupil views (Allen & Hardy, 2013). The current findings of adolescent self-reports of sensory experiences emphasise the need to represent the views of autistic adolescents in particular. Both adolescent and parent reports indicated that individuals with autism may not be inclined or able to communicate aspects of their sensory experience to others, or may not even be aware that their experience is different. As merely having the space to talk and consider sensory issues itself was identified as a helpful aspect of the groups in post-intervention interviews, adolescents may simply benefit from EPs asking them about their sensory preferences and experiences, for this information to be shared with those around them, and incorporated into pupil Individual Education Plans (IEPs).

Developing staff understanding may be particularly important under the SEN CoP's (2014) focus on high quality, personalised and differentiated teaching, where teachers have a strengthened responsibility for meeting the needs of pupils with SEN in their classes. Rather than relying on LSAs to support the pupil, teachers would benefit from developing their understanding of sensory experiences in autism. Professionals should be mindful of the potentially strong feelings of control, vulnerability or degree of fit with the natural state of being that may underlie sensory experiences. Forcing an individual to endure an unpleasant or unnatural stimulus may lead to further anxiety around that experience (Kirby et al., 2014) or to the generation of further barriers to adaptive coping (e.g. avoidance), compulsions or repetitive behaviours, as per adolescent self-reports in the current study. There is a role for EPs to share these psychological insights with staff, and through consultation, identify ways for the teacher to allow the individual to feel in control of their sensory environment, thereby minimising the impact on learning.

### 6.4.2. Application of CBT-Based Sensory Intervention

The strong qualitative evidence from parents and adolescents supports the effectiveness of the CBT-based sensory intervention as a psycho-educational therapeutic intervention in schools. Given their position within school and community settings, EPs are well placed to engage in therapeutic work in schools, which Hill (2013) argues is a potential area of growth for EP work.

Even if time constraints limit the opportunities for EPs to engage in therapeutic work directly, EPs may use knowledge of therapeutic interventions to guide thinking in consultations around the best approach to intervention (Hill, 2013).

There is a role for EPs working with schools to select the pupils that may benefit most from a CBT-based sensory approach to intervention. Findings from the current study tentatively suggest which pupils may benefit most from the intervention: pupils experiencing transition, or times of increased stress, and those with limited existing awareness of how their behaviours are influenced by a sensory processing difference. In view of the SEN CoP's (2014) focus on preparing pupils for adulthood and independence, there may also be a role for EPs in adopting the CBT-based sensory approach to working with pupils in further education settings.

If not carrying out the intervention themselves, EPs may also advise schools on how to implement the intervention successfully. For example, working with schools to ensure adolescents feel comfortable with the room, the intervention leader and each other, and ensuring that adolescents are allowed to focus on self-chosen issues, so that they develop self-efficacy for change and selfregulatory behaviours. This approach to intervention is again in line with the SEN CoP principles of involving children in the design and delivery of intervention approaches (DfE, 2014).

There may also be risks associated with bringing sensory experiences to consciousness in the current intervention. This may include an increased 'awareness of being different', which the current study would indicate may be linked with feelings of isolation. However, both parent and adolescent reports

indicated that the supportive group environment may help to reduce this impact. Nevertheless, EPs may need to work with schools to be vigilant for any signs of increased anxiety or feelings of isolation, and work with staff and families to put support in place to manage this. With adolescent permission, sharing information arising from the intervention with parents and other professionals would allow them to support the adolescents to embed coping tools into their everyday lives. Parents or LSAs, who spend more time with the adolescents, may be well-placed to anticipate and respond to unhelpful sensory experiences (e.g. passing them a calming object or suggesting how to ask someone to stop doing something). Such an approach again fits with the SEN CoP (DfE, 2014) emphasis on involving families and working collaboratively with other professionals.

#### 6.5. Future Directions

The current findings indicate that changes would be needed to design an RCT to assess fully its effectiveness using quantitative measures. Larger sample sizes would be needed to increase the likelihood that Expt and SaU groups were matched, to increase the power of the RCT and to mitigate the effects of participant drop-out rates. Longer timescales between data collection points may allow for any intervention effects to embed or manifest as observable behaviours. In addition, further study with longer-term follow-up would be able to determine whether the short-term rise in Expt participants' parent-rated anxiety diminished with time.

Further study is also needed to determine how the intervention would be received in other settings or with other populations. While it is unclear how far the intervention may be suitable for younger or less cognitively able children, the programme may be adapted by increasing the duration or sessions and incorporating more interactive sensory elements. The inclusion criteria was considered appropriate in the current study, being representative of the variability in autistic populations. However, one potential area of future study is to carry out the intervention with groups clustered together on baseline characteristics, including autistic symptoms, sensory reactivity age, and intellectual function. Such an approach has the potential to both increase understanding of sensory experiences in autism and to indicate which groups may benefit most from the intervention. How participants' pre-existing levels of sensory awareness affect their response to intervention would be a particularly interesting area of study, however, a quantitative measure of 'sensory experience awareness' would need to first be developed.

While larger sample sizes in future studies may mitigate the variability inherent in some of the measures in the current sample, the feasibility of the AASP and SSP as sensory reactivity measures is questionable. More work is needed to develop a measure of sensory experiences that captures the experiences relevant to the individual with autism, rather than relying on observable behaviours. Such a measure would build on Bogdashina's SPC-R (2003), which draws on the self-reports of autistic authors, but also on that of other individuals with autism, including those in the current study.

#### 6.6. Conclusion

In the current educational and legislative national context of services moving towards evidence-based and child-centred interventions (DfE, 2014), there is inadequate understanding and ineffective support for sensory issues in autism, despite growing recognition of their importance (DSM-5; APA, 2013). This study has addressed the need for the understanding and management of autistic sensory difficulties to embrace both theory and the autistic experience. It is the first to report the design, implementation and evaluation of a CBT-based framework for sensory intervention, designed around theories of sensory processing in autism and previous self-reports of coping strategies. Its focus on bringing the cognitions, emotions, and responses involved in sensory experiences to consciousness is unique.

The qualitative analysis of adolescents' self-reports pre-intervention provides a valuable contribution to our understanding of sensory experiences, being the first to suggest that intensity and reactivity to sensory experiences relate to degree of perceived control and 'fit' with the natural state. Analysis also uniquely suggests that adolescents may only have an emergent meta-awareness of their own and others' sensory experiences. It highlights mechanisms through which this may contribute to difficulties in social interactions and the development of unhelpful coping strategies, or repetitive behaviours. As indicated by some parents in the current study, adolescents rarely communicate their experiences, which can be difficult to infer from behaviour. Eliciting and explaining the sensory experiences of autistic individuals to those supporting them is a key implication for the role of the EP.

The intervention was implemented successfully in the school and well received by parent and adolescent participants. No significant change was found in measures of sensory reactivity, repetitive behaviours or anxiety at the group or individual level. The lack of significant intervention effect is likely to be attributable to the small sample size, homogeneity of the sample and reliability of the sensory reactivity measures. However, there may also be a more fundamental mismatch between these traditional measures of sensory reactivity and the actual sensory experience of those with autism. Existing measures focus on behaviours that are an issue to outside observers, so are therefore unlikely to be suitable in the evaluation of an intervention which adopts a childcentred approach and allowed adolescents to choose their own issues to consider. There is a need for measures of sensory experiences to better represent the autistic experience.

Post-intervention cognitive and emotional changes were instead captured in qualitative data. Qualitative evaluations provided evidence for the effectiveness of the intervention and also highlight the importance of factors including: the importance of group dynamics, allowing adolescents choice, embedding the strategies into everyday life, ongoing communication with parents, and identifying which adolescents may benefit most. Both parents' and adolescents' reports indicated striking developments in meta-awareness, expression and use of language, sense of self in-relation-to others, use of new coping behaviours and for some, an increased sense of maturity. The implication is that this programme is an effective intervention for EPs and other professionals to implement in schools to support the management of sensory difficulties.

- Allen, A. & Hardy, J. (2013). 'The future of educational psycholgy'. In C. Arnold and J. Hardy (Eds), *British educational psychology: The first hundred years.* Leicester: The British Psychological Society
- American Academy of Pediatrics. (2012). 'Policy Statement: Sensory integration therapies for children with developmental and behavioral disorders'. *Pediatrics, 129* (6), 1186.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders (4th Edition)*. Washington D.C.:
   American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (5th Ed.) (DSM-5)*. Washington DC:
   American Psychiatric Association.
- Ames, C. S., & White, S. J. (2011). 'Brief report: Are ADHD traits dissociable from the autistic profile? Links between cognition and behaviour'. *Journal of Autism and Developmental* Disorders, 41 (3), 357-363.

Ashburner, J., Bennett, L., Rodger, S., & Ziviani, J. (2013).

'Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation'. *Australian Occupational Therapy Journal, 60* (3), 171-80.

- Ashburner, J., Ziviani, J., & Rodger, S. (2008). 'Sensory processing and classroom emotional, behavioral, and educational outcomes in children with autism spectrum disorder'. *The American Journal of Occupational Therapy*, *62* (5), 564-573.
- Ashburner, J. K., Rodger, S. A., Ziviani, J. M., & Hinder, E. A. (2014).
  'Optimizing participation of children with autism spectrum disorder experiencing sensory challenges: A clinical reasoning framework: Optimiser la participation des enfants atteints d'un trouble du spectre autistique ayant des troubles sensoriels : Un cadre pour le raisonnement clinique'. *Canadian Journal of Occupational Therapy, 81* (1), 29-38.
- Attwood, T. (2004). Exploring feelings: Cognitive behaviour therapy to manage anxiety. Arlington, Texas: Future Horizons.
- Ayres, A. J. (1972). Sensory integration and learning disabilities. Los Angeles: Western Psychological Services.
- Baker, A. E. Z., Lane, A., Angley, M. T., & Young, R. L. (2008). 'The relationship between sensory processing patterns and behavioural responsiveness in autistic disorder: A pilot study'. *Journal of Autism and Developmental Disorders, 38* (5), 867-875.
- Baranek, G. T. (2002). 'Efficacy of sensory and motor interventions for children with autism'. *Journal of Autism and Developmental Disorders, 32* (5), 397-422.

Baranek, G. T., Boyd, B. A., Poe, M. D., David, F. J., & Watson, L. R. (2007). 'Hyperresponsive sensory patterns in young children with autism, developmental delay, and typical development'. *Journal on Mental Retardation, 112* (4), 233-245.

- Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2005). 'Sensory Experiences Questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development'. *Journal of Child Psychology and Psychiatry, 47* (6), 591-601.
- Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2006). 'Sensory Experiences Questionnaire: discriminating sensory features in young children with autism, developmental delays, and typical development'. *Journal of Child Psychology and Psychiatry, 47* (6), 591-601.
- Baranek, G. T., Foster, L. G., & Berkson, G. (1997). 'Tactile defensiveness and stereotyped behaviors'. *The American Journal* of Occupational Therapy, 51 (2), 91-95.
- Baranek, G. T., Watson, L. R., Boyd, B. A., Poe, M. D., David, F. J., &
  McGuire, L. (2013). 'Hyporesponsiveness to social and nonsocial sensory stimuli in children with autism, children with developmental delays, and typically developing children'.
  Development and Psychopathology, 25 (2), 307-320.

- Barnes, K. J., Vogel, K. A., Beck, A. J., Schoenfeld, H. B., & Owen, S. V. (2008). 'Self-regulation strategies of children with emotional disturbance'. *Physical and Occupational Therapy in Pediatrics, 28* (4), 369-387.
- Baron-Cohen, S., Ashwin, E., Ashwin, C., Tavassoli, T., & Chakrabarti,
  B. (2009). 'Talent in autism: hyper-systemizing, hyper-attention to detail and sensory hypersensitivity'. *Philosophical Transactions of the Royal Society: Biological Sciences*, *364* (1522), 1377-1383.
- Baron-Cohen, S., Leslie, A., & Frith, U. (1985). 'Does the autistic child have a "theory of mind"?'. *Cognition, 21* (1), 37-46.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J. and Clubley, E.
  (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* (1), 5-17.
- Barrett, P. (2004). *FRIENDS for life: Group leader's manual for children*. Brisbane, Australia: Australian Academic Press.

Bates, J. (1997). *Retracking*. Torquay: Devon Education Authority.

Bauer, S., Lambert, M. J., & Nielsen, S. L. (2004). 'Clinical significance methods: A comparison of statistical techniques'. *Journal of Personality Assessment, 82* (1), 60-70.

- Ben-Sasson, A., Hen, L., Fluss, R., Cermak, S. A., Engel-Yeger, B., &
  Gal, E. (2009). 'A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders'. *Journal of Autism and Developmental Disorders, 39* (1), 1-11.
- Bernstein, D. (2010). *Essentials of psychology*. Belmont, CA.: Wadsworth.
- Bodfish, J., Symons, F., & Lewis, M. (1999). *The Repetitive Behavior Scales (RBS)*: Western Carolina Center Research Reports.
- Bogdashina, O. (2003). Sensory perceptual issues in autism and asperger syndrome: Different sensory experiences--different perceptual worlds. London: Jessica Kingsley Publishers.
- Brandwein, A. B., Foxe, J. J., Butler, J. S., Russo, N. N., Altschuler, T.
  S., Gomes, H., & Molholm, S. (2013). 'The development of multisensory integration in high-functioning autism: High-density electrical mapping and psychophysical measures reveal impairments in the processing of audiovisual inputs'. *Cerebral Cortex*, 23 (6), 1329-1341.
- Braun, V., & Clarke, V. (2006). 'Using thematic analysis in psychology'. *Qualitative Research in Psychology, 3* (2), 77-101.
- Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. London: Sage.

- Bremner, A. J., Lewkowicz, D. J., & Spence, C. (2012). *Multisensory development*. Oxford: Oxford University Press.
- Brown, C., & Dunn, W. (2002). *Adult/Adolescent Sensory Profile: User's manual.* San Antonio, TX: Psychological Corporation.

Burr, V. (2003). Social constructionism. Hove, Sussex: Routledge.

- Case-Smith, J., Weaver, L. L., & Fristad, M. A. (2014). 'A systematic review of sensory processing interventions for children with autism spectrum disorders'. *autism,* [epublication ahead of print].
- Chalfant, A. M., Rapee, R., & Carroll, L. (2007). 'Treating anxiety disorders in children with high functioning autism spectrum disorders: A controlled trial'. *Journal of Autism and Developmental Disorders*, 37 (10), 1842-1857.
- Chen, Y., Rodgers, J., & McConachie, H. (2009). 'Restricted and repetitive behaviours, sensory processing and cognitive style in children with autism spectrum disorders'. *Journal of Autism and Developmental Disorders, 39* (4), 635-642.
- Cheung, P. P., & Siu, A. M. (2009). 'A comparison of patterns of sensory processing in children with and without developmental disabilities'. *Research in Developmental Disabilities, 30* (6), 1468-1480.

Children and Families Act, 2014. London: HMSO [Online]. Available at: http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted [Last accessed 19.05.2014].

- Clarke, C. (2012). An evaluation of a brief school-based cognitive behavioural therapy programme for children with ASD. Unpublished Thesis, Institute of Education London.
- Constantino, J. (2012). Social Responsiveness Scale, Second Edition (SRS-2). Los Angeles: Western Psychological Services.
- Crane, L., Goddard, L., & Pring, L. (2009). 'Sensory processing in adults with autism spectrum disorders'. *Autism, 13* (3), 215-228.
- Crick, F., & Koch, C. (2003). 'A framework for consciousness'. *Nature Neuroscience, 6 (2),* 119-126.
- Chang, M., Parham, L., Blanche, E., Schell, A., Chou, C., Dawson, M., & Clark, F. (2012). Autonomic and behavioral responses of children with autism to auditory stimuli. *American Journal of Occupational Therapy*, 66 (5), 567-576.
- Charman, T., Howlin, P., Berry, B. and Prince, E. (2004). 'Measuring developmental progress of children with autism spectrum disorder on school entry using parent report'. *Autism, 8* (1), 89-100.
- Christner, R. W., Forrest, E., Morley, J. and Weinstein, E. (2007). 'Taking cognitive-behavior therapy to school: A school-based mental health approach'. *Journal of Contemporary Psychotherapy*, 37 (3), 175-183.

- Dawson, G., & Watling, R. (2000). 'Interventions to facilitate auditory, visual, and motor integration in autism: A review of the evidence'.
   *Journal of Autism and Developmental Disorders, 30* (5), 415-421.
- De la Marche, W., Steyaert, J., & Noens, I. (2012). 'Atypical sensory processing in adolescents with an autism spectrum disorder and their non-affected siblings'. *Research in Autism Spectrum Disorders, 6* (2), 639-645.
- Department for Education. (2014). Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years. London.
- Department for Education. (2014). School performance tables. [Online]. Available at: http://www.education.gov.uk/cgibin/schools/performance/. [Last accessed 14.01.2014].
- Donoghue, K., Stallard, P., & Kucia, J. (2011). The clinical practice of Cognitive Behavioural Therapy for children and young people with a diagnosis of Asperger's Syndrome. *Clinical Child Psychology and Psychiatry*, *16* (1), 89-102.
- Dunn, W. (1997). 'The impact of sensory processing abilities on the daily lives of young children and their families: A conceptual model'.
   Infants and Young Children, 9, 23-35.
- Dunn, W. (1999). *Sensory Profile*. San Antonio, TX: Psychological Corporation

- Dunn, W. (2006). *Sensory Profile School Companion*. San Antonio, TX: Psychological Corporation.
- Dunn, W., & Daniels, D. B. (2002). 'Initial development of the
  Infant/Toddler Sensory Profile'. *Journal of Early Intervention*, 25 (1), 27-41.
- Edgington, L. (2012). Self-reports of sensory expereinces of young people with an autistic spectrum condition (ASC), and comparision to parent or caregiver and teacher reports. Unpublished DEdPsy Year 1 Research Report, Institute of Education, London.
- Education Adviser. (2014). *School profile*. [Online]. Available at: http://www.educationadviser.co.uk/school/\_[Last accessed 14.01.2014].
- Elwin, M., Ek, L., Kjellin, L., & Schroder, A. (2013). 'Too much or too little: Hyper- and hypo-reactivity in high-functioning autism spectrum conditions'. *Journal of Intellectual and Developmental Disability,* 38 (3), 232-241.
- Elwin, M., Ek, L., Schroder, A., & Kjellin, L. (2012). 'Autobiographical accounts of sensing in asperger syndrome and high-functioning autism'. *Archives of Psychiatric Nursing*, *26* (5), 420-429.
- Emmons, P. G., & Anderson, L. M. K. (2005). Understanding sensory dysfunction: learning, development and sensory dysfunction in autism spectrum disorders, ADHD, learning disabilities and bipolar disorder. London: Jessica Kingsley

- Fallon, K., Woods, K., & Rooney, S. (2010). 'A discussion of the developing role of educational psychologists within Children's Services'. *Educational Psychology in Practice*, 26 (1), 1-23.
- Fein, D., Barton, M., Eigsti, I. M., Kelley, E., Naigles, L., Schultz, R. T.,
  Stevens, M., Helt, M., Orinstein, A. & Rosenthal, M. (2013).
  'Optimal outcome in individuals with a history of autism'. *Journal of Child Psychology and Psychiatry, 54* (2), 195-205.
- Frith, U. (2003). Autism: Explaining the enigma. London: Wiley-Blackwell.
- Frith, U., & Happé, F. (1994). 'Autism: Beyond " theory of mind"'. *Cognition, 50,* 115-132.
- Gabriels, R. L., Agnew, J. A., Miller, L. J., Gralla, J., Pan, Z., Goldson, E., Ledbetter, J. C., Dinkins, J. P., & Hooks, E. (2008). 'Is there a relationship between restricted, repetitive, stereotyped behaviors and interests and abnormal sensory response in children with autism spectrum disorders?'. *Research in Autism Spectrum Disorders, 2* (4), 660-670.
- Gal, E., Cermak, S. A., & Ben-Sasson, A. (2007). 'Sensory processing disorders in children with autism: Nature assessement and intervention '. In R. L. Gabriels and D. E. Hill (Eds), *Growing up with autism: Working with school age children and adolescents*. New York: Guilford Press.

- Gaudion, K., & Brand, A. (2011). Sensory preferences: Housing design for adults with autism. Unpublished project, Royal College of Art, London.
- Gaudion, K., & Edgington, L. (2012). Sensory School Cards. Unpublished project, Royal College of Art London.
- Gearhart, C. C., & Bodie, G. D. (2012). 'Sensory-processing sensitivity and communication apprehension: Dual influences on selfreported stress in a college student sample'. *Communication Reports, 25* (1), 27-39.

Gordon, M. (2012). 'Finding the senses'. The Psychologist, 25.

- Gotham, K., Pickles, A., & Lord, C. (2009). 'Standardizing ADOS scores for a measure of severity in autism spectrum disorders'. *Journal of Autism and Developmental Disorders*, *39* (5), 693-705.
- Graham, P. (2005). 'Jack Tizard lecture: Cognitive behaviour therapies for children: Passing fashion or here to stay?'. *Child and Adolescent Mental Health*, 10 (2), 57-62.
- Grandin, T. (2006). *Thinking in pictures: And other reports from my life with autism.* London: Bloomsbury.
- Grandin, T., & Scariano, M. M. (1986). *Emergence: Labeled autistic*. New York: Warner Books

- Graziano, M. S. A., & Kastner, S. (2011). 'Human consciousness and its relationship to social neuroscience: A novel hypothesis'. *Cognitive Neuroscience*, 2 (2), 98-113.
- Green, S. A., Ben-Sasson, A., Soto, T. W., & Carter, A. S. (2012).
  'Anxiety and sensory over-responsivity in toddlers with autism spectrum disorders: Bidirectional effects across time'. *Journal of Autism and Developmental Disorders, 42* (6), 1112-1119.
- Happé, F., & Ronald, A. (2008). 'The 'fractionable autism triad': A review of evidence from behavioural, genetic, cognitive and neural research'. *Neuropsychology Review*, 18 (4), 287-304.
- Henry, M. (2013). *Emotions/Sentiments*. [Online]. Available at: http://www.henry4school.fr/Vocabulary/emotion.htm. [Last accessed 1.7.13].
- Higashida, N. (2013). *The reason I jump: The inner voice of a thirteenyear-old boy with autism.* London: Random House LLC.
- Hill, V. (2013). 'Working across diverse contexts with wider populations: The developing role of the educational psychologist'. In C. Arnold and J. Hardy (Eds), *British educational psychology: The first hundred years*. Leicester: The British Psychological Society.
- Hilton, C. L., Harper, J. D., Kueker, R. H., Lang, A. R., Abbacchi, A. M.,Todorov, A., & LaVesser, P. D. (2010). 'Sensory responsiveness as a predictor of social severity in children with high functioning

autism spectrum disorders'. *Journal of Autism and Developmental Disorders, 40* (8), 937-945.

- Hochhauser, M., & Engel-Yeger, B. (2010). 'Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder (HFASD)'. *Research in Autism Spectrum Disorders, 4* (4), 746-754.
- Hofmann, S. G. (2011). An introduction to modern CBT: Psychological solutions to mental health problems. London: Wiley.
- Hollocks, M. J., Ozsivadjian, A., Matthews, C. E., Howlin, P., & Simonoff,
  E. (2013). 'The relationship between attentional bias andanxiety in children and adolescents with autism spectrum disorders'. *Autism Research*, 6 (4), 237-247.
- Honey, E., McConachie, H., Turner, M., & Rodgers, J. (2012). 'Validation of the Repetitive Behaviour Questionnaire for use with children with autism spectrum disorder'. *Research in Autism Spectrum Disorders, 6* (1), 355-364.
- Hsu, L. (1999). 'A comparision of three methods of identifying reliable and clinically significant changes: Commentary on Hageman and Arrindell'. *Behaviour Research and Therapy, 37* (12), 1195-1202.
- Iarocci, G., & McDonald, J. (2006). 'Sensory integration and the perceptual experience of persons with autism'. *Journal of Autism and Developmental Disorders, 36* (1), 77-90.

- Jaarsma, P., & Welin, S. (2012). 'Autism as a natural human variation: Reflections on the claims of the neurodiversity movement'. *Health Care Analysis, 20* (1), 20-30.
- James, W. (1890). The Principles of Psychology. London: Macmillan.
- Jaynes, J. (1976). *The origin of consciousness in the breakdown of the bicameral mind.* Boston: Houghton-Mifflin.
- Jones, R., Quigney, C., & Huws, J. (2003). 'First-hand accounts of sensory perceptual experiences in autism: A qualitative analysis'. *Journal of Intellectual and Developmental Disability, 28* (2), 112-121.
- Kanner, L. (1943). 'Autistic disturbances of affective contact'. *Nervous Child, 2* (2), 217-230.
- Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews,
  A. A., Savla, J. S., Johnson, D. G., Mehta, J. A., & Schroeder, J.
  L. (2006). 'The pattern of sensory processing abnormalities in autism'. *Autism, 10* (5), 480-494.
- Kern, J. K., Trivedi, M. H., Grannemann, B. D., Garver, C. R., Johnson,
  D. G., Andrews, A. A., Savla, J. S., Mehta, J. A., & Schroeder, J.
  L. (2007). 'Sensory correlations in autism'. *Autism, 11* (2), 123-134.
- Kinnear, P. R., & Gray, C. D. (2009). SPSS 16 made simple. East Sussex: Psychology Press.

- Kirby, A. V., Dickie, V. A., & Baranek, G. T. (2014). 'Sensory experiences of children with autism spectrum disorder: In their own words'. *autism*, [epublication ahead of print].
- Lai, J., Parham, D., & Johnson-Ecker, C. (1999). 'Sensory dormancy and sensory defensiveness: Two sides of the same coin'. Sensory Integration Special Interest Section Quarterly, 22 (4), 1-4.
- Lam, K. S. L., & Aman, M. G. (2007). 'The Repetitive Behavior Scale-Revised: Independent validation in individuals with autism spectrum disorders'. *Journal of Autism and Developmental Disorders, 37* (5), 855-866.
- Leekam, S. R., Nieto, C., Libby, S. J., Wing, L., & Gould, J. (2007).
  'Describing the sensory abnormalities of children and adults with autism'. *Journal of autism and Developmental Disorders, 37* (5), 894-910.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). 'Autism Diagnostic
  Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders'. *Journal of Autism and Developmental Disorders, 24* (5), 659-685.
- Marr, D., Mika, H., Miraglia, J., Roerig, M., & Sinnott, R. (2007). 'The effect of sensory stories on targeted behaviors in preschool children with autism'. *Physical and Occupational Therapy in Pediatrics, 27* (1), 63-79.

- Mazurek, M., Vasa, R., Kalb, L., Kanne, S., Rosenberg, D., Keefer, A., Murray, D., Freedman, B., & Lowery, L. (2013). 'Anxiety, sensory over-responsivity, and gastrointestinal problems in children with autism spectrum disorders'. *Journal of Abnormal Child Psychology, 41* (1), 165-176.
- Milton, D., Mills, R., & Pellicano, E. (2012). 'Ethics and autism: Where is the autistic voice? Commentary on Post et al.'. *Journal of Autism* and Developmental Disorders, [epublicaion].
- Mindfulness in Schools Project. (2013). *.be*. [Online]. Available at: http://mindfulnessinschools.org/. [Last accessed 5.2.14].
- Mottron, L., Dawson, M., Soulieres, I., Hubert, B., & Burack, J. (2006).
  'Enhanced perceptual functioning in autism: An update, and eight principles of autistic perception'. *Journal of Autism and Developmental Disorders, 36* (1), 27-43.
- Nauta, M. H., Scholing, A., Rapee, R. M., Abbott, M., Spence, S. H., & Waters, A. (2004). 'A parent-report measure of children's anxiety: Psychometric properties and comparison with child-report in a clinic and normal sample'. *Behaviour Research and Therapy, 42* (7), 813-839.
- O'Donnell, S., Deitz, J., Kartin, D., Nalty, T., & Dawson, G. (2012). 'Sensory processing, problem behavior, adaptive behavior, and cognition in preschool children with autism spectrum disorders'. *The American Journal of Occupational Therapy, 66* (5), 586-594.

- Papauasiliou, A. S., Nikaina, I., Rizou, J., & Alexandrou, S. (2011). 'The effect of a psycho-educational programme on CARS scores and short sensory profile in autistic children'. *European Journal of Paediatric Neurology*, 15 (4), 338-344.
- Patten, E., Ausderau, K. K., Watson, L. R., & Baranek, G. T. (2013).
  'Sensory response patterns in nonverbal children with ASD'. *Autism Research and Treatment,* ID 436286.
- Pellicano, E. (2013). 'Sensory symptoms in autism: A blooming, buzzing confusion?'. *Child Development Perspectives,* 7 (3), 143-148.
- Pellicano, E., & Burr, D. (2012). 'When the world becomes 'too real': a Bayesian explanation of autistic perception'. *Trends in Cognitive Sciences, 16* (10), 504-510.
- Pellicano, E., Dinsmore, A. & Charman, T. (2014). 'What should autism research focus upon? Community views and priorities from the United Kingdom'. *Autism*.
- Pellicano, E., Jeffery, L., Burr, D., & Rhodes, G. (2007). 'Abnormal adaptive face-coding mechanisms in children with autism spectrum disorder'. *Current Biology, 17* (17), 1508-1512.
- Pennington, B., & Ozonoff, S. (1996). 'Executive functions and developmental psychopathology'. *Journal of Child Psychology and Psychiatry*, 37 (1), 51-87.

- Pfeiffer, B., Kinnealey, M., Reed, C., & Herzberg, G. (2005). 'Sensory modulation and affective disorders in children and adolescents with Asperger's disorder'. *The American Journal of Occupational Therapy*, *59* (3), 335-345.
- Random.org. (2013). *True random number generator*. [Online]. Available at: http://www.random.org/. [Last accessed 24.6.13].
- Rao, P. A., & Beidel, D. C. (2009). 'The impact of children with highfunctioning autism on parental stress, sibling adjustment, and family functioning'. *Behavior Modification*, 33 (4), 437-451.
- Reaven, J., Blakeley-Smith, A., Culhane-Shelburne, K., & Hepburn, S.
  (2012). Group cognitive behavior therapy for children with high-functioning autism spectrum disorders and anxiety: A randomized trial. *Journal of Child Psychology and Psychiatry*, 53
  (4), 410-419.
- Reebye, P., & Stalker, A. (2008). Understanding regulation disorders of sensory processing in children: Management strategies for parents and professionals. London: Jessica Kingsley Publishers.
- Reid, H. and Westergaard, J. (2011). Effective counselling with young people. Exeter: Learning Matters.Robertson, A. (2012). Sensory experiences of individuals with autism spectrum disorder and autistic traits: A mixed methods approach. Unpublished Thesis, Glasgow University, Glasgow.

- Robertson, A., & Simmons, D. (2012). 'The relationship between sensory sensitivity and autistic traits in the general population'. *Journal of Autism and Developmental Disorders, 43* (4), 1-10.
- Robinson, L. D. (2010). Towards standardisation of the Sensory Profile Checklist Revisited: Perceptual and sensory sensitivities in autism spectrum conditions. Unpublished Thesis, Edinburgh University, Edinburgh.
- Robson, C. (2002). *Real world research: A resource for social scientists* and practitioner-researchers. London: Blackwell
- Rogers, S. J., Hepburn, S., & Wehner, E. (2003). 'Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders'. *Journal of Autism and Developmental Disorders*, 33 (6), 631-642.
- Rogers, S. J., & Ozonoff, S. (2005). 'Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence'. *Journal of Child Psychology and Psychiatry, 4*6 (12), 1255-1268.
- Rutter, M., Bailey, A., & Lord, C. (2003). SCQ: The Social
   Communication Questionnaire Manual. Los Angeles, CA:
   Western Psychological Services.
- Schoen, S. A., Miller, L. J., Brett-Green, B. A., & Nielsen, D. M. (2009). 'Physiological and behavioral differences in sensory processing: A

comparison of children with autism spectrum disorder and sensory modulation disorder'. *Frontiers in Integrative Neuroscience, 3.* 

- Schopler, E., Reichler, R. J. & Renner, B. R. (1994). The Childhood Autism Rating Scale (CARS). Los Angeles, CA: Western Psychological Services.
- Schulz, K. F., Altman, D. G., & Moher, D. (2010). 'CONSORT 2010 statement: Updated guidelines for reporting parallel group randomised trials'. *BMC medicine*, 8 (1), 18.
- Sherick, J. R. (2004). *The effects of sensory stories on behaviors in children with autism*. Unpublished Thesis, Ohio State University.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T. & Baird,
  G. (2008). 'Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample'. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47 (8), 921-929.
- Sinclair J (1999). *Why I dislike 'person first' language*. [Online]. Available at: http://autismmythbusters.com/general-public/autistic-vs-people-with-autism/jim-sinclair-why-i-dislike-person-first-language /. [Last accessed 22.5.14].
- Sivberg, B. (2002). 'Family System and Coping Behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children'. *Autism, 6* (4), 397-409.

- Smith, R., & Sharp, J. (2012). 'Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with asperger syndrome'. *Journal of Autism and Developmental Disorders, 43* (4), 891-910.
- Sofronoff, K., Attwood, T., & Hinton, S. (2005). 'A randomised controlled trial of a CBT intervention for anxiety in children with Asperger syndrome'. *Journal of Child Psychology and Psychiatry, 46* (11), 1152-1160.
- Spence, S. H. (1997). 'Structure of anxiety symptoms among children: A confirmatory factor-analytic study'. *Journal of Abnormal Psychology*, *106* (2), 280-297.
- Suarez, M. A. (2012). 'Sensory processing in children with autism spectrum disorders and impact on functioning'. *The Pediatric Clinics of North America, 59* (1).
- Sung, M., Ooi, Y. P., Goh, T. J., Pathy, P., Fung, D. S., Ang, R. P., & Lam, C. M. (2011). Effects of cognitive-behavioral therapy on anxiety in children with autism spectrum disorders: a randomized controlled trial. *Child Psychiatry & Human Development*, *42* (6), 634-649.
- Teddlie, C., & Tashakkori, A. (2009). Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioural sciences. Thousand Oaks: SAGE Publications.

Therapro Inc. (2011). Sensory Stories. [Online]. Available at: http://www.sensorystories.com/. [Last accessed 28.3.14].

- Tseng, M.-H., Fu, C.-P., Cermak, S. A., Lu, L., & Shieh, J.-Y. (2011).
  'Emotional and behavioral problems in preschool children with autism: Relationship with sensory processing dysfunction'. *Research in Autism Spectrum Disorders*, 5 (4), 1441-1450.
- Turner, M. (1999). 'Annotation: Repetitive behaviour in autism: A review of psychological research'. The Journal of Child Psychology and Psychiatry and Allied Disciplines, 40 (6), 839-849.
- Wechsler, D. (2003). Wechsler Intelligence Scale for Children Fourth Edition. San Antonio, TX: PsychCorp.
- Wechsler, D. (2011). Wechsler Abbreviated Scale of Intelligence Second Edition (WASI-II). San Antonio, TX: PsychCorp.
- Westbrook, D., Kennerley, H., & Kirk, J. (2007). *An introduction to cognitive behaviour therapy skills and applications*. London: Sage.
- Williams, D. (1998). *Autism and sensing: The unlost instinct*: London: Jessica Kingsley.
- Williams, M. S., & Shellenberger, S. (1994). How does your engine run?:
   Leader's guide to the alert programme for self-regulation.
   TherapyWorks, Inc.
- Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). 'The diagnostic interview for social and communication disorders:

Background, inter-rater reliability and clinical use'. *Journal of Child Psychology and Psychiatry, 43* (3), 307-325.

- Wood, J. J., Drahota, A., Sze, K., Har, K., Chiu, A., & Langer, D. A.
  (2009). 'Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: A randomized, controlled trial'. *Journal* of Child Psychology and Psychiatry, 50 (3), 224-234.
- Yardley, L. (Ed.) (2008), *Demonstrating validity in qualitative psychology*. (Vol. 2). London: Sage.

## 8. APPENDICES

Appendix A. Information sheet and consent form for parents

Louise Edgington, Dr Liz Pellicano & Vivian Hill Department of Psychology & Human Development London WC1H 0BR



#### Leading education and social research Institute of Education University of London

# Helping young people with autism manage their sensory experiences

Dear Parent and Guardians,

We are conducting an intervention to help young people with an autism spectrum condition manage their sensory experiences and associated behaviours. We would like to invite you and your child to be involved in the project. We very much hope you would like to take part.

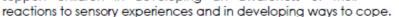
#### Who is conducting this project?

Louise Edgington will be conducting the project as part of her Doctorate in Educational Psychology at the Institute of Education, supervised by Vivian Hill and Dr Liz Pellicano.

#### Why is this work being done?

We interpret the world by what we see, hear, touch, taste, and smell. Many individuals on the autism spectrum seem to process or interpret sensory information differently, which often lead to unpleasant or unhelpful emotional and behavioural reactions, which can have a negative effect on their everyday lives.

We are interested in helping reduce the impact of these negative experiences. We have designed a group intervention, based on cognitive-behavioural therapy, to support children in developing an awareness of their



#### What will happen if my child and I take part?

Step 1 (Summer term): your child would be seen in school by Louise Edgington. S/he would hear about the project, fill in a short questionnaire about their sensory sensitivities and would also carry out a short test of their language and nonverbal reasoning ability.

Step 2: Your child would then take part in an initial interview followed by 8 weekly group sessions at school either in the Autumn term (beg. Sept 2013) or in the Spring term (beg. Jan 2013). Groups would consist of 4-6 children with an autism diagnosis in the same school. Each session would last for one hour. During these sessions, children would take part in activities to develop better awareness of their reactions to sensory information and to encourage them to consider other ways of coping. The sessions are designed to be engaging and fun, although children will be reminded that they are free to leave the sessions at any time. The details of each session in the intervention will be shared with you so that you may also support your child to apply what they are learning at home.



Step 3: Children would be seen again on two separate occasions for a short (15-20 minute) session to complete the sensory questionnaire.

As the child's parent, you would be asked to complete several questionnaires on your child's social and communication behaviours and others on behaviours more generally, once at the start of the Summer term and again at the end of the Autumn term. The questionnaires should each take about 10 minutes to complete.

#### What will happen to the results of the project?

At the completion of the study, we will send the school a brief report regarding the findings of the study. Your child's sensory preferences will be fed back to you and, if you wish, your child's teacher, as it is hoped that you might find this information useful. All other information we collect is kept strictly confidential. Your child will be identified by a code number only and all information and results are kept on a password protected computer and in a locked filing cabinet at the Institute of Education.

#### Do we have to take part?

It is up to you and your child whether or not you want to take part. At the end of this information sheet there is a form for you to sign if you and your child decide that you wish to take part. Anyone who signs a form is still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your child's education or access to services in any way.

#### What should I do next?

If appropriate, please explain the project to your child and discuss whether they want to take part. It is important that he or she knows that they do not have to take part, and if they do agree, that they are free to withdraw at any time. We will also ask the children during sessions and make it clear that they can stop whenever they wish.

If you and your child would like to take part in this study, please fill in the enclosed consent form and return it using the freepost envelope provided (no stamp necessary!). If you would like to discuss the research with someone beforehand (or if you have questions at any time), please do not hesitate to contact:

Louise Edgington ledgington@ioe.ac.uk 07919022153 DEdPsy student Dr Liz Pellicano <u>I.pellicano@ioe.ac.uk</u> 0207 331 5140 Supervisor Vivian Hill v.hill@ioe.ac.uk 020 7612 6296 Supervisor

This study has been reviewed and approved by the Faculty's Research Ethics Committee, Institute of Education, London. Thank you for your interest in our research.

#### Louise Edgington, Dr Liz Pellicano & Vivian Hill Department of Psychology & Human Development London WC1H OBR



Leading education and social research Institute of Education University of London

#### Consent form

Parent/guardian copy - Please keep this copy for your records.

I have read the information sheet about the research and discussed the project with my child (if appropriate).	Yes No
I understand that participation is voluntary and that my child and I are free to withdraw at any time, without giving any reason and without my child's education being affected in any way.	Yes No
I understand that I can contact Louise Edgington by email (ledgington@ioe.ac.uk) or by telephone on 07919 022153 to discuss this study at any time	Yes No
My child has good hearing and vision or wears glasses/hearing aid to correct his/her vision/hearing	Yes No
My child has a diagnosis of Autism or Asperger's. Please note any additional diagnoses below:	Yes No
Name of child:	(Male) 🗌 (Female)
Name of child:(Surname)	
Date of Birth: School:	
Contact email:	
Contact phone:	
Name of parent/guardian (please print):	
Signature: Today's	date

Appendix B. Weekly intervention session outlines

# session 1: introduction

#### Introduction to purpose of the groups [10 mins]

- a weekly group of 45 minutes, 8 weeks long, every Friday until half term
- remember sensory questionnaire and sensory interview?
  - 'sensory': sights, smells, sounds, taste, touch, balance, movement. Nice things→relaxing/ in your own world
    - Not nice things  $\rightarrow$  annoying/ scary
- aim to help be aware of how we feel, what we do and what we think in response to sensory things and to help you manage this.
- will be given things to do ('Mission') between each session. Great if you
  do it, don't worry if you don't.
- outline of today's session

#### introduction to group members [20 mins]

following the demo everyone to say their name & something from the list below. Stand up if you like it too

- favourite food
- something you like doing
- favourite TV program
- favourite computer game

following the demo on the 'Sensory Picture' everyone try to say an emotion feeling and a body feeling for a chosen 'favourite' example above. You can use the example sheets to help you.

#### establish ground rules [10 mins]

- reminder of 'agreement form': group confidential, can stop at any time, ask questions !
- stickers awarded for participation, listening to others, completing a 'sensory picture' or a *Mission*

brainstorming ground rules on a A3 piece of paper. This could include personal rules for you. Suggestions:

- · there are no right or wrong answers
- respect others and their ideas
- only one person speaks at a time
- all group members encouraged to participate
- · everything discussed is confidential

everyone then sign the rules sheet

#### reflect and summarise [5 mins]

- see if you can remember one thing about others in the group.
- Mission: bring something you like to the next session

## session 2: positive experiences

## good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
- outline of session

### introduction to Sensory Pictures [10 mins]

- Sensory Picture template: Events, thoughts, feelings (body and emotional) and behaviours are linked
- demo of how to fill in a Sensory Picture (refer to emotion and body feeling e.g. sheets)
  - roller coaster
  - o bath
  - o eating chocolate try it together !
  - o listening to music try it together !
- no right/ wrong answers, don't worry if you can't put something in every box

## Sensory Pictures activity [20 mins]

- last week's Mission: bring something you like
- pick things you like from:
  - o the feely box
  - o find a video or picture of it on the computer, or
  - think of something you like from the interviews e.g. the dark
- try with your own positive sensory experiences, write out as many situations as they can (use emotion and body feeling e.g. sheets as prompts)

### reflect and summarise what learnt [10 mins]

- share pictures with group who is different / the same?
- Mission: notice a new positive sensory experience over the next week (and make a sensory picture)

# session 3: difficult experiences

## good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
  - Last week's *Mission*: notice a positive sensory experience (and make a sensory picture)
- outline of session

## introduction to difficult Sensory Pictures [10 mins]

- demo of how to fill in a difficult Sensory Picture (refer to emotion and body feeling e.g. sheets)
  - o filing my nails
  - o people talking when I'm trying to work
  - eating raw chilli try it together ! (optional)
- no right/ wrong answers, don't worry if you can't put something in every box

## difficult sensory experiences [5 mins]

- pick things you dislike like from:
  - o the feely box
  - o find a video or picture of it on the computer, or
  - think of something you like from the interviews e.g. heights

## Sensory Pictures activity [15 mins]

 try with your own difficult sensory experiences, write out as many situations as they can(use emotion and body feeling e.g. sheets)

### reflect and summarise what learnt [10 mins]

- share pictures with group who is different / the same?
- Mission: notice a new difficult sensory experience over the next week (and make a sensory picture)

# session 4: outcomes or effect of sensory experiences: helpful or unhelpful?

## good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
  - Last week's *Mission*: notice a difficult sensory experience (and make a sensory picture)
- outline of session

## introduction to outcomes of sensory experiences [10 mins]

- sometimes our behaviours or responses can affect:
  - o us, at the time
  - o someone else, at the time
  - o us, or someone else in the future
- demo of how to fill in a difficult Sensory Picture with outcomes:
  - roller coasters
  - eating chocolate
  - o other people chewing gum
  - having a bath
  - o people talking when I'm trying to work
- no right/ wrong answers, don't worry if you can't put something in every box

## outcomes of sensory pictures [15 mins]

 look back at your sensory pictures from session 2 & 3 and stick outcomes onto the pictures. If necessary, you may wish to complete new sensory pictures, with outcomes.

### helpful/ unhelpful outcomes [10 mins]

- separate your sensory pictures into helpful, unhelpful and neutral outcomes.
- Have a look at the helpful outcomes with group: these are coping tools

## reflect and summarise what learnt [5 mins]

Mission: try out someone else's coping tool. What is the outcome?

# session 5: behaviour coping tools

#### good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
  - last week's *Mission*: try out someone else's coping tool. What was the outcome?
- outline of session

#### introduction to changing the sensory experience [15 mins]

- remember, last time we saw that when our behaviour means the outcome is good: this is a coping tool. Today we're going to think of other coping tools we could use for our 'unhelpful outcomes' sensory pictures.
- behaviour coping tools means we can change our behaviour in response to something. How?
  - turn something off
  - move away
  - o ask someone to be quiet
- demo of <u>controlling or changing</u> some sensory experiences make new sensory picture for different behaviour
  - people talking when I'm trying to work listen to headphones/ ask them to be quiet
- sometimes people get offended when you ask them to be quiet / stop doing something. That's why it doesn't always work! Role play nice ways of doing it e.g.

'sorry... I'm finding it hard to concentrate, would you mind being a bit quieter?'

### changing the sensory picture [20 mins]

- look back your 'unhelpful outcome' sensory pictures divide them into things you can and can't control
- things you can control: think of things to do to control the sensory experience (e.g. ask teacher to turn off fan).
- make a new sensory picture to see what would happen with your new behaviour coping tool

### reflect and summarise what learnt [5 mins]

 Mission: try out a new behaviour coping tool and make a sensory picture of what happens

# session 6: body coping tools

## good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
  - last week's *Mission*: try out a new behaviour coping tool and make a sensory picture of what happens
- outline of session

### introduction to body coping tools [5 mins]

- remember, last time we saw that changing some behaviours can lead to helpful outcomes – these are behaviour coping tools
- body coping tools means we can change our body or our emotion feelings in response to something. How?
  - Use a pleasant sensory experience (e.g. bath/ listening to music)
  - o progressive muscle relaxation
  - breathing exercises
  - o mindfulness paying attention to the body.
- demo using a body coping tool to change an uncontrollable, bad outcome sensory experience

## trying out body coping tools [15 mins]

- try the following out together how do you feel now and which is your favourite?
  - progressive muscle relaxation
  - o breathing exercises
  - o mindfulness paying attention to the body.
- What pleasant sensory experiences could you use to make yourself feel better?

### changing the sensory picture [15 mins]

 Select uncontrollable, bad outcome sensory pictures. Draw out new sensory pictures and think what might happen if you use your body coping tool. Is the outcome better?

### reflect and summarise what learnt [5 mins]

 Mission: try out a body coping tool and make a new sensory picture. How was the outcome different?

# session 7: thinking tools

#### good news sharing [5 mins]

- how has your week been?
- have you noticed any sensory experiences?
  - last week's *Mission*: try out a new body coping tool and make a new sensory picture. How was the outcome different?
- outline of session

### introduction to thinking coping tools [10 mins]

- remember, last time we saw that changing the way the body feels can lead to helpful outcomes – these are body coping tools
- thinking coping tools means we can try and change our thoughts in response to something. How?
  - focus your attention on something else (e.g. imagine pleasant sensory experience)
  - o positive self talk be a friend to yourself!
  - understand / rationalise what's going on (e.g. what is this object for?, how is it made?, are there different kinds of this thing?)
- demo using a thinking coping tool to change an uncontrollable, bad outcome sensory experience

#### trying out thinking coping tools [5 mins]

- try the following out together how do you feel now ?
  - focus your attention on something else (e.g. imagine pleasant sensory experience)

### changing the sensory picture [15 mins]

- select uncontrollable, bad outcome sensory pictures. Draw out new sensory pictures and think what might happen if you use you're a thinking coping tool. Is the outcome better?
- rehearse using the thinking tool in your head or start to research you disliked object now!
  - o what is it for?
  - o how does it work?
  - o examples of different types of this item

### reflect and summarise what learnt [10 mins]

• *Mission*: try out a thinking coping tool and make a new sensory picture. How was the outcome different?

# session 8: review and celebration

#### good news sharing [5 mins]

- how has your week been?
- · have you noticed any sensory experiences?
  - last week's *Mission*: try out a new thinking coping tool and make a new sensory picture. How was the outcome different?
- outline of session

#### review and effect of tools [20 mins]

- reminder of tools used:
  - o behaviour e.g.
    - turn something off
    - move away
    - ask someone to be quiet
  - o body
    - pleasant sensory experience
    - progressive muscle relaxation
    - breathing exercises
  - o thinking
    - focussing attention elsewhere
    - positive self talk
    - rationalising/ understanding
- spend time looking at your sensory pictures, adding on changes, or possible changes and drawing new sensory pictures
- share and celebrate good examples with the group

#### Putting into practice [10 mins]

have a go at putting your strategies into practice!

#### reflect and summarise what learnt [10 mins]

Mission: keep trying out your tools and finding new ones!

"Managing our senses" Department of Psychology & Human Development London WC1H 0BR



Leading education and social research Institute of Education University of London

#### Hello!



My name is Louise.

I am running a project which is hopes to help young people manage how they feel about and respond to difficult sights, sounds, smells and touch sensations.

I have spoken to your parents and they have given their permission for you to join in. Now I want to know if you would be interested too.

If you decide to join in, you will carry out some exercises with me today, like working out the meaning of words and patterns. I want you to try your best, but it's ok if you're not always right; I just want to know what you can do. I will also ask you about what different senses (sights, sounds, smells and touch sensations) are like for you.

All the answers you give today will be kept between you and me. I will give you a number so that when I look at your answers I won't know they came from you. So your name will not appear on any papers or lists.

After today, there will be and interview plus 8 weekly sessions with 3-5 other young people where we will do more fun activities and talk about our senses, either this term or the next. It's important to know that it's ok if you don't have anything to say, but that you can say whatever you like in these groups.

It is ok if you don't want to take part. If you do decide to take part, I will ask you to write your name on a piece of paper which says that:

1) You understand what the project is about

2) You agree to join in with the project

I hope that working with me would be fun for you but if at any time you decide you don't want to join in anymore then please tell me or your parents and it will stop.

Your parents have my telephone number so if there are things you want to ask they can call me or my colleague, Liz.



Hope to see you soon!

Louise

"Managing our senses" Project Department of Psychology & Human Development London WC1H 0BR



Leading education and social research Institute of Education University of London

#### AGREEMENT FORM



I have chatted with Louise about her project and decided that I want to join in.

Please circle your answer: YES / NO

I understand that I can stop joining in with the project at any time. I know that I don't have to give a reason if I don't want to join in.

Please circle your answer: YES / NO

I understand that anything I tell Louise will be between me and her. No-one else will know my answers and my name will not be written on any papers or lists.

Please circle your answer: YES / NO

I understand that I can ask Louise anything I want to about the project and that my parents have her phone number and email address.

Please circle your answer: YES / NO

Your Name: ..... Date: ..... Researcher's Signature:..... Appendix D. Pre-intervention adolescent interview transcript exemplar

Participant Number: 5

C – I feel like I'm going to be really modest and put them all here (OK) C – Active touch, I sort of dislike, when people touch me for no reason. Tidiness and order, I don't know if it's sort of self-evident, by the fact that I'm trying to arrange these sort of

R - <laughs>

C - just there, no I'm joking I'll put it so that ...

R - right, well thank you, j.

C - I sort of want to move this one here so it's a square ...

R – well do that if you like

C - no, cause then it's not right

R – there's no right answer

C - but it's not, not, what I actually think, I just want it to be. ...

R – I know.. that's this, the tidiness and order. So what I want to do now is to pick 2 that you know. like and ask you some questions about that, and 3 you don't like. So which one of these ones you like shall we talk about. This one? The tidiness one.. yea ok

C - and probably and <inaudible>

R - ok, well let's start with that one.. big echoey rooms, what is it you like about that? C – cause then I can just make like a big sound.. it feels.. an echo always sort of feels nice. When you have an echo sort of ah.. echo!

R – feels nice> like how?

C - like as in for.. I fink I hear it goes echo. Ah ... yea I sound so loud!

R - so what do you think when you make and echo noise?

C - like power? I feel powerful cause I have a giant voice.

R – that's cool, I'm liking that. How do you feel when you.. I know you say you feel powerful, but you do you feel either in your body, or emotions?

C - I feel important just continue echoing <inaudible>

R - that's cool. So when do you have the opportunity to be in a big echoey room?

C – there's hardly any places. Cause there's 2 types of echo for me. And the one that I like is the one where you shout and then you hear it and hear it. And there's another one which repeats as you say it and it sounds good.

R – ok

C – but like, when you're in a tunnel, if you're in a tunnel, its like, you can hear it lots of times, it's reflecting off the walls.

R – so how about in here?

C – in here, so this is all the echo I don't' really mind, but it's not really something I like. It just repeats as you're saying it. I more like the stereotypical echoes, like 'echo'! echo!

R - <laughs> cool. Do you know anyone else that likes echoes, doing that kind of thing?

C - um.. I don't really know. It's not really a conversation topic, is it?

R - <laughs> well have you noticed if other boys might do it

C - some other boys might do it for a joke, like

R – but do you think they feel the same as you about it?

C - maybe. I know younger kids like .. < inaudible>

Appendix E. Adolescent focus group post-intervention transcript exemplar

Post intervention interview: Expt< participants 6(J) & 7(M) (not participant 2- absent)

R - ok, so, how did you find the group sessions, M?

7 – um, I found them very useful because I learnt some body and thinking coping tools and when I use them it's really helped me to do better

R – that's nice and I'm gonna ask you more about that in a second. How about you, J, how did you find the groups?

6 – I liked it. Yea I leant lots of em.. yea like sensory things and then about um how like. . um about sensory stuff.

R – good. Cause you don't normally get to think about that do you? So what was good about the groups?

7 – um I think what was good about the groups was that I learnt how to stop..like when I do something.. like I don't' need to do, or I should do. I learnt how to think or act how to not do it and to learn not to do it and to stop me from doing that

R - that's good, what specifically was it useful for?

7 – um so like when someone's doing something that I don't want to do .. that I don't want them to do, or when I'm doing something I don't really want to do, I learnt how to cope with it and like to how stop or make it better in the future.

R – that's nice. Thank you. I'm going to ask you again more specifically about that. But thank you. How about you, J, what was good about the groups in general?

6 – well I general. .um getting to miss classes was ok and also, um learning about like sensory tools and then cause I don't really normally think about that and um those sensory um those pictures that I can um.. also I don't normally tell people about how I'm feeling usually but then I and I think I actually encouraged to tell people about it and then that's like a good thing.

R – good ! I think that's definitely important for you to know it's ok to do that. And what could have been better about the groups, what would you change?

7 – um I think a thing that would have made the groups better would have been if I, if it could help me like not muck around so like how to help like when people are expecting me to do something how I could have learnt to show them that I don't want to do that and if.. because if people are like if I got myself in a position where everyone's expecting me to do something like play a joke on someone, that would have got me into trouble and I don't want to do it, but everyone's expecting me to. Stuff like that

R - right, so that's something you'd still like to know how to cope with?

7 – yea. I could try thinking of a coping tool for that. I could tell them that I really don't want to do it and get into trouble because I would get into trouble if I do it.

R – yea. That sounds like a good coping tool. What do you think, J. do you think that sounds...?

6 – yea, well I think coping tools like touching stuff's quite a good coping tool and sometimes lying down and not really thinking about anything, that's a good coping tool and science putty stuff.. that's a good coping tool.

R – yea, so you're talking about those body relaxation coping tools?

#### Appendix F. Parent post-intervention interview transcript exemplar

Mother of participant 8

n.b. interviews are not transcribed verbatim – introductions and extraneous chat not related to sensory groups is omitted

P: what do you think was good about the groups, or what could have been better?

R: J always seemed to be happy with what's going on. He didn't really talk more about it. I said 'how do you feel about it?' and he said 'no I'm enjoying them' but he never said specifically what he didn't like about it. Obviously one of the very good things about it was that we were continually kept in the loop, being told what was going on. Basically he wasn't interested in telling us much about it, other than he was enjoying it and he liked being in the groups.

R: good, well I'm pleased to hear he was enjoying it. .. so did you get a sense that J learnt or realised anything from the groups at all?

P: well as I say, he never really said. He seems, in himself, calmer again. He was going through a stage of being quite unsettled and almost fighting with his conscience all the time it was. You just got a sense of him being unsettled. Since he's being doing the groups he's actually now, seems to kind of got out of that and seems to have kind of grown up, almost, if that makes sense.

R: that's lovely. Have you noticed a change in his response to specific situations, perhaps?

P: er not really.

R: ok things we talked about were piano playing or if his sisters touch his arm, is that still an issue?

P: the playing the piano, he seems to want to do more, now. Whether that's because errm... and his eldest brother will hear a pop song and say I really like the piano music in that, down load it on youtube and learn to play it, which isn't something he was doing before.

R: that's nice, we specifically talked about how to not get frustrated if he gets a note wrong

P: yea, before, I used to sit down and show him how the song sounded because he wasn't interested because he'd play the wrong notes, or he could play the wrong notes so he wouldn't just go and listen to the music. On youtube they show you how to play the song. He doesn't seem to mind that he might have played the wrong note, whereas before he'd sort of slam the keys and start again from the beginning. So whether that was something to do with it. But also he's got an exam coming up in December so is that's the thing that he's suddenly realised.

R: well that's something we specifically talked about, so it's nice to hear that there's been an improvement, whatever it's due to. Are there any sensory experiences that you feel haven't been covered in the groups that are still an issue?

P: I didn't notice too many with him. He prefers soft clothes to hard clothes, but he'd still wear it. He'll do as he's asked to do.

R: and does J have any sensory experiences that you wouldn't want him to change?

P: no I don't' think there's anything we'd change about him.