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Fear and Sensory Experiences in Children on the Autism Spectrum

by

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Declaration

This thesis has not been submitted for any other degree at any other university or institutions. The material in this thesis is my own, and had been completed under the supervision of Dr Sarah Kent and Mrs Jacky Knibbs.

The layout of this thesis follows the *Guide to Examinations for Higher Degrees by Research* handbook, provided by the University of Warwick.

Versions of Chapters 1 and 2 will be submitted to the journal *Autism* for publication, please see Appendix 1.1 for a copy of the submission criteria.

Word counts for the three chapters are as follows:

Chapter 1:	7979
Chapter 2:	6067
Chapter 3:	2123

Abbreviations

ANOVA	Analysis of Variance
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
DD	Developmental Delay
DSM-IV-TR	Diagnostic Statistical Manual, Fourth Edition, Text Revision
FSSC-R	Fear Survey Schedule for Children - Revised
HFA	High Functioning Autism
ICD-10	International Classification of Diseases, Tenth Edition
IQ	Intelligence Quotient
KFQ	Koala Fear Questionnaire
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder, Not Otherwise Specified
RCMAS	Revised Children's Manifest Anxiety Scale
SEQ	Sensory Experiences Questionnaire
S.D.	Standard Deviation
WISC	Wechsler Intelligence Scales for Children

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Abstract

Existing research indicates that typically developing children pass through predictable stages of fear development throughout their childhood. Evidence suggests that in general, children with disabilities experience more fears than typically developing children.

Children with disabilities share similar stages of fear development compared to typically developing children, but at a delayed rate, with a more protracted course. Children on the autism spectrum experience higher levels of anxiety, compared to other children. Limited fear research in children on the autism spectrum suggests that they exhibit a unique fear profile compared to their peers, however, little is known about why this may be.

Chapter 1 reviews published literature on fear development for typically developing children, children with physical and intellectual disabilities, and children on the autism spectrum. Chapter 2 presents an empirical study that investigates the relationship between sensory processing and fear profiles in children on the autism spectrum. The results support the notion that sensory experiences may account for a proportion of the unique fear pattern experienced by children on the autism spectrum. The thesis concludes with a reflective account that reviews the process of conducting internet-mediated research on children on the autism spectrum.

Chapter 1: An Overview of Fear Development in Typically Developing Children and Children with Disabilities

1.1 Abstract

Evidence suggests that typically developing children experience fears that appear regularly, disappear spontaneously, and follow a predictive course. This article reviews this pattern of fear development, along with associated etiological factors.

Evidence for fear development in atypically developing children is not as well established as that in the normative literature. Relevant studies in this area are reviewed; these generally suggest that children with disabilities follow a similar, albeit delayed pattern of fear development to their typically developing peers.

Limited fear research from children on the autism spectrum is then considered. This research indicates that children on the autism spectrum experience a different pattern of fear development to both typically developing children and children with other disabilities. The need for more research in this area is highlighted in order to adopt a developmental perspective of fear development for children on the autism spectrum, clinical implications for further research are outlined.

KEYWORDS: Autism, Fear, Children, Disabilities

Word Count: 7979

1.2 Introduction

The aim of this paper is to review existing literature on fear development in children. This will begin with a broad overview of fear development in typically developing children, the focus will then move towards children with disabilities. Particular attention is given to fear research on children on the autism spectrum.

Fear and anxiety problems account for the highest proportion of mental health difficulties in children on the autism spectrum (see Section 1.5.1). The National Autism Plan for Children (2003) outlined that there was a lack of research evidence investigating the needs of children on the autism spectrum, when compared to typically developing children.

Furthermore, the government is due to announce a 'New National Strategy for Autism' by the end of 2009 (Department of Health, 2009), which is thought to include guidance on clinical research pertaining to the mental health needs of children on the autism spectrum.

The latter part of the present paper will review existing literature relating to fear difficulties in children on the autism spectrum.

1.2.1 Literature Search Strategies

In order to identify publications relating to fear development in children with disabilities, two key search strategies were employed. First, three electronic databases were searched, ISI Web of Knowledge, CSA:PSYCH-INFO, and OVID:Medline. Searches were carried out periodically for two years until April 2009. The following search terms were inputted

for title and topic word searches: fear, autism*, phobia, pervasive developmental delay, and disability*. A combination of Boolean operators were used to identify the relevant publications. The second search strategy involved a manual check of reference lists from the publications previously identified, the same search terms were used. This process was then repeated for all of the newly identified literature.

Publications included were required to be case studies, cross-sectional, longitudinal, or control studies. Review papers were also included. Only peer-reviewed literature published in English language was integrated.

1.2.2 Epidemiology of Fear

Fear is a common childhood experience, in most cases this fear is short lived and quickly dissipates (see Craske, 2003). Research has established that high levels of childhood fear can often warrant a formal diagnosis amongst the anxiety disorder catalogue (MacNeil, Lopes, & Minnes, 2009). Epidemiological studies have demonstrated that anxiety disorders are the most prevalent form of psychopathology affecting children (Weems & Stickle, 2005).

Based on self-reports, children aged between 7 and 17 years, evince an average of 14 fears (Muris & Ollendick, 2002; Ollendick, King, & Frary, 1989). These results have been mirrored using a cross-cultural study by Ollendick, Yang, King, Dong, and Akande (1996) across non-western countries. Parent-reports typically underestimate children's fear frequency (see Gullone, 2000).

1.2.3 Assessment of Fear

The Fear Survey Schedule for Children (FSSC; Scherer & Nakamura, 1968) was the forerunner of standardised self-report fear scales. Prior to the FSSC, studies were typically neither methodologically sound nor comparable across studies (Burnham, 2009). The FSSC lists an extensive range of potentially fear-provoking stimuli and situations.

Modified versions of the FSSC, namely the FSSC-II (version 2; Burnham & Gullone, 1997) and the FSSC-R (revised version; Ollendick, 1983) are currently the most commonly used instrument for assessing fear in young people. The FSSC-R¹ is the most dominantly used in the literature.

Principal component analysis studies have found that the FSSC-R incorporates five factors which account for 41-77% of the variance (Ollendick, 1983). Typically, most childhood fears pertain to a factor categorised as 'Dangerous Situations and Physical Harm'. The remaining factors refer to fears of 'Failure and Criticism', the 'Unknown', 'Injury and Small Animals' and 'Medical Fears'. More recently, additional factor structures have been proposed² (see Mellon, Koliadis, & Paraskevopoulos, 2004; Shore & Rapport, 1998), however, they are not widely used in the literature.

According to numerous studies, employing the FSSC-R, the ten most prevalent fears among nonclinical young people are (1) not being able to breathe, (2) being hit by a car or truck, (3) bombing attacks/being invaded, (4) getting burned by fire, (5) falling from a high

¹ The FSSC-R requires young people to indicate on a 3-point scale ('none', 'some', and 'a lot') how much they fear 80 specific stimuli and situations.

² These alternative structures commonly include further subscales through splitting the original 'Failure and Criticism' factor, where the remaining original factors remain robustly the same.

place, (6) burglar breaking into the house, (7) earthquake, (8) death/dead people, (9) illness, and (10) snakes (e.g., Ollendick & King, 1994; Ollendick, Yule, & Ollier, 1991).

1.2.4 Distinctions between Fear, Phobia, and Anxiety

Over the past century, there has been considerable research attention that has explored the ontogeny of children's fears, phobias, and anxieties (see Gullone, 2000). Important distinctions are highlighted about appropriate terminology in this area.

i) Fear

Fear is considered to be a normal response to a wide variety of situations or objects. Simply, fear is the feeling or state of being afraid when exposed to real or imagined threatening stimuli. Importantly, fear has an adaptive function and “*makes for caution in the face of existing or reasonably anticipated danger*” (Kanner, 1972, p. 580). Fear, therefore, motivates us to behave in ways that promote our survival, and, thus, it has been dubbed one of our most significant emotions (Craske, 2003).

ii) Phobia

Fear responses can be problematic when they are excessive, persist over time, and produce considerable discomfort for the child (Essau, Conradt, & Petermann, 2000). Beyond what would be expected for the child's age, problematic fears are often referred to as *phobias* (Muris, Merckelbach, Mayer, & Prins, 2000). Ollendick and March (2004) calculated the mean prevalence rates of anxiety disorders in children using data from 14 epidemiological studies, and found that specific phobias were the most common of all anxiety disorders,

followed by social phobias. Such findings have added clinical credence to empirical fear research.

iii) Anxiety

Anxiety phenomena can be conceptualised in terms of manifestation, function, and biological foundations (Barlow, 2002). Autonomic arousal and fight-flight reactions are associated with fear, whereas tension, apprehension, and worry are defined as *anxiety*.

Worry is another idiom used within this area, and is in effect the prototypical example of anxiety.

More frequently, however, fear, and anxiety are defined in terms of the nosologic descriptions employed by both clinicians and researchers (Muris, 2007). In this respect, fear explicitly refers to *phobic* disorders that are characterised by a negative emotional response in relation to a specific stimulus or situation that is out of proportion to actual danger. *Anxiety*, in this frame, refers to anxiety disorders that are characterised by tension, apprehension, worry, and general distress that arise without any objective sources of danger (Pavuluri, Henry, & Allen, 2002).³

³ The present review primarily focuses on fear research, however, given the related nature of these phenomena, some anxiety research will also be considered.

1.3 Typical Fear Development

Children experience common patterns of normative fear throughout their development (Field & Davey, 2001). These fears regularly appear and disappear spontaneously and follow a predictive course. The following section will explore this normative fear development pathway explicitly in terms of children's development. Literature concerning the aetiology of fear development will then be reviewed.⁴

1.3.1 Developmental Patterns of Typical Fear

A developmental approach is particularly relevant to fear and anxiety disorders, since they are among the first psychological disorders to manifest (Leonardo & Hen, 2006). For example, while the mean age of onset for depression is 29 years, the mean age of onset for an anxiety disorder is 11 years (Kessler et al., 2005).

If it is the case that fear in children is strongly linked to development, one would expect to find a comprehensive developmental pattern in its manifestation. This appears to be the case (see Table 1.1, based on Warren & Sroufe, 2004).

i) Infancy

Fear research has established that, during infancy, children become more fearful of stimuli in their immediate environment. This includes fears of sudden loud noises or loss of

⁴ Although gender differences have been established in the normative literature, with females exhibiting higher levels of fearfulness than males (see Gullone, 2000), these shall not be focused upon in the present review.

support (Muris, 2007; Poulton, Waldie, Menzies, Craske, & Silva, 2001). Fears at such an early time in a child's life are thought to be largely biologically pre-programmed and occur in the absence of learning (Marks, 1987).

Towards the end of the first year of life, and continuing into the second, there is an increase in the fear of strange persons, strange objects, and separation from caregivers (Oosterman & Schuengel, 2007). Fears related to separation, peak between the ages of 9 to 18 months and typically decrease after two and a half years of age. At this time, in contrast to those fears experienced in earlier months, fears require cognitive maturation (Vasey, 1993).

ii) Pre-School

Around the pre-school years, prominent fears for children are associated with animals, followed by imaginary fears of the dark, monsters, and ghosts (Muris, 2003; Muris, Mayer, Huijding, & Konings, 2008). Most of these fears dissipate with school age, when more anticipatory fears emerge (Westenberg, Siebelink, & Treffers, 2001).

iii) School-Age

By school age, the developmental emergence of sense of industry and competence is accompanied by perceived dangers such as fire, burglars, harm and death (Gullone & King, 1992). At this age, children are thought to display fears that are more specific, contextual, and reflect experiential factors as opposed to previously biological or imaginary ones (Westenberg et al., 2001).

Table 1.1*Salient Developmental Issues in Common Fears and Anxiety Disorders*

Age	Developmental Issues	Hypothesised Common Fears and Concerns	Associations with Anxiety Disorders
0 – 6 months	<ul style="list-style-type: none"> ▪ Biological regulation 	<ul style="list-style-type: none"> ▪ Startle-like response to loud noises or loss of support 	<ul style="list-style-type: none"> ▪ High reactivity ▪ Low reactivity
6-18 months	<ul style="list-style-type: none"> ▪ Object permanence ▪ Formation of attachment relationship 	<ul style="list-style-type: none"> ▪ Fear of strange people and situations ▪ Separation anxiety 	<ul style="list-style-type: none"> ▪ Behavioural inhibition
2-3 years	<ul style="list-style-type: none"> ▪ Exploration of material object world ▪ Individuation and autonomy 	<ul style="list-style-type: none"> ▪ Fear of animals 	<ul style="list-style-type: none"> ▪ Animal phobia
3-6 years	<ul style="list-style-type: none"> ▪ Self-reliance ▪ Initiative ▪ Development of symbolic thought and representation 	<ul style="list-style-type: none"> ▪ Fears of dark, imaginary creatures, storms, and loss of caregivers 	<ul style="list-style-type: none"> ▪ Separation anxiety disorder ▪ Self-conscious shyness
6-10 years	<ul style="list-style-type: none"> ▪ Sense of industry or competence ▪ School adjustment 	<ul style="list-style-type: none"> ▪ Concerns about bodily injury, physical danger, and school 	<ul style="list-style-type: none"> ▪ Overanxious disorder ▪ Generalised anxiety disorder
10-12 years	<ul style="list-style-type: none"> ▪ Social understanding ▪ Same-sex friends 	<ul style="list-style-type: none"> ▪ Concerns about friendships 	<ul style="list-style-type: none"> ▪ Social phobia
13+ years	<ul style="list-style-type: none"> ▪ Flexible perspective taking ▪ Beginning heterosexual relationships ▪ Emancipation ▪ Identity 	<ul style="list-style-type: none"> ▪ Concerns about heterosexual relationships, independence, and life plans 	<ul style="list-style-type: none"> ▪ Agoraphobia ▪ Panic disorder

(adapted from Warren & Sroufe, 2004)

iv) Adolescence

The transitional nature of adolescence is characterised by an increased awareness of identity, both social and sexual in nature. Into adolescence and beyond, fears related to achievement and evaluative or social situations exist. A consistent finding is that the fear of danger and death that emerges in mid-adolescence, continues into late adolescence and continues throughout development into adulthood (Burnham & Gullone, 1997; Ollendick, 1983; Westenberg et al., 2001).

v) Summary

Fear development in typically developing children appears to occur in conjunction with corresponding normative developmental challenges. Altogether, empirical evidence suggests that typical fear can be considered as part of the “*ontogenetic parade*” (Marks, 1987, p. 109). Importantly, both innate biological mechanisms and children’s cognitive development appear to be crucial determinants in this parade.

1.3.2 Aetiology of Fear

While researchers have reached a considerable degree of consensus about the pattern of typical fear development, the aetiology of these fears remain a matter of debate (Poulton & Menzies, 2002). Some researchers hypothesise that fear reflects an innate, spontaneous reaction to evolutionary cues, others assume that the phenomena can be explained as a consequence of learning experiences, with more recent ideas focusing on parental and attachment styles (see Muris, 2007).

1.3.2.1 Genetic Influences

Behavioural-genetic research has consistently shown that approximately one-third of childhood fear variance can be attributed to genetic influences (Rutter, Silberg, O'Connor, & Simonoff, 1999). This has led some researchers to speculate about the innate temperament dispositions that make children prone to developing fear and anxiety problems (see Muris, 2007). Taylor (1998) distinguished two types of genetic influence that may contribute to fear and phobia aetiology. Taylor surmised that whereas a general genetic factor (i.e., behavioural inhibition⁵) would act as vulnerability factor to a wide range of fears, other specific genetic factors (e.g., disgust sensitivity⁶) would only predispose to certain types of fears. Biological processes involving the hyperarousability of the limbic brain structures have also been associated with other fear and phobic difficulties (LeDoux, 1998).

1.3.2.2 Environmental Influences

There has been an increase in self-reported fear in young people across recent decades. This shift has largely been explained by a decline in social connectedness (as indexed by divorce frequency) and an increase of threat (as indexed by crime rates) in society (Twenge, 2000). Therefore, even when indexed at a macro-level, environment plays a prominent role in the development of high fear and anxiety levels in youths.

⁵ Behavioural inhibition refers to a group of behaviours that are displayed when the child is confronted with a new situation or unfamiliar people. These behaviours include moving around, crying, and general irritability, followed by withdrawing, seeking comfort from a familiar person, and stopping what one is doing when one notices the new person or situation.

⁶ Disgust has been identified as a food-related basic emotion which has clear biological prewired antecedents (see McDonald, Hartman, & Vrana, 2008).

Where behavioural-genetic research has established that a substantial proportion of the variance in childhood fear and anxiety can be explained through genetic, heritable factors, it follows that the environment also has an attributable position. Two main environmental components are prominent in the literature, the three-pathways model and familial influence (Muris, 2007).

i) Three-Pathways Model (Rachman, 1977, 1991)

A valuable framework for considering the role of environmental learning experiences in the acquisition of fears and phobias was first provided by Rachman's seminal three-pathways theory (Rachman, 1977, 1991). In brief, Rachman implies that besides the direct route of (1) aversive classical conditioning, there are two other indirect ways along which fears can be learned, namely (2) modelling (i.e., vicarious learning), and (3) negative information transmission (i.e., exposure to negative information about the feared stimulus). Further to this, Rachman (1977) speculated that the severity of the fear is a function of the acquisition model. The theory also specifies that fears acquired through vicarious learning or exposure to negative information, would be less intense, whereas intense fears that result in clinical phobias would be more likely to have a direct conditioning aetiology.

Although numerous child studies have supported Rachman's pathway theory (e.g., Askew & Field, 2008; Field & Schorah, 2007; Gerull & Rapee, 2002), other authors acknowledge that these pathways may not be single routes to fear and that an anxious child will most likely endorse several of these routes as having contributed to their fear (e.g., Mineka & Zinbarg, 2006; Poulton & Menzies, 2002). Retrospective accounts, which have

methodological limitations, suggest multiple pathways. However, experimental research has focused on the effects of a single pathway in isolation in order to exert essential experimental control (Askew & Field, 2008). In reality, children have a variety of experiences across pathways, and learning through one pathway will impact upon learning through another (Field & Storksen-Coulson, 2007).

ii) Familial Influences

More recently, parental styles have been thought to have a role in the development of fearfulness (Bogels & Brechman-Toussaint, 2006). For example, Barrett, Rapee, Dadds, and Ryan (1996) reported that parents of anxious children often encourage their children to adopt avoidant coping strategies. Correspondingly, a study by Muris, Steerneman, Mercklebach, and Meesters (1996) found that specific fears reported by children are a function of the extent to which their mothers express their own fears in the presence of children. Research utilising questionnaires that assess children's perceptions of parental rearing behaviours suggest that anxious parenting, parental control, and rejection all account for a minor, but nontrivial proportion of children's fearfulness (see Wood, McLeod, Sigman, Hwang, & Chu, 2003).

Of all clusters of family variables associated with fear in children, the bond between parent and child, commonly known as attachment, has been the most extensively investigated (Thompson, 2001). One research hurdle has been to disentangle the role of attachment from a child's temperament in predicting fear and phobic difficulties. Nevertheless, insecure attachment in both parents and children seems to be associated with childhood

anxiety and phobic disorders, and this attachment style has been found to predict such difficulties (Barnett, Schaafsma, Guzman, & Parker, 1991; Crowell & Feldman, 1991).

Whether insecure attachment is indeed a moderator in the transmission of anxiety disorders from one generation to the next, rather than just a by-product of parent anxiety or child temperament, remains to be answered. Furthermore, there is an undefined yet undeniable intersection between systemic literature and associated aspects of Rachman's (1977, 1991) three-pathways model of fear acquisition.

1.3.3 Summary

Whilst a developmental model of fear development offers a useful framework in the consideration of typical fear development, genetic and environmental influences appear to play a significant role in the deviation from the typical fear pathway. Whilst the theoretical models discussed all account for significant proportions of variation in development, it is clear that a wide range of variables potentially predispose or protect children against the development of anxiety difficulties.

1.4 Fear Development in Children with Disabilities

Although considerable research attention has been paid to fearfulness across childhood, there is only a relatively small body of investigations that have explored the notion of normative fear in children with disabilities (see Gullone, 1996). Such research is usually classified in terms of physical and intellectual disabilities. The present review identified 24 studies investigating fear and fear development in children with disabilities. Accordingly, the following sections will be divided into physical disabilities (i.e., sensory impairments and health disabilities) and intellectual disabilities.

1.4.1 Physical Disabilities

It is accepted that children with physical disabilities appear to experience considerable psychological distress (King, Gullone, & Ollendick, 1990; Rutter, 1989). However, there has been little empirical investigation into the prevalence or nature of these psychosocial adjustment difficulties. The following sections will review fear literature in children with sensory impairments and health disabilities.

1.4.1.1 Sensory Impairments

Five studies have been identified that specifically assess fear in this special population, (King, Gullone, & Stafford, 1990; King, Mulhall, & Gullone, 1989; Matson, Manikam, Heinze, & Kapperman, 1986; Ollendick, Matson, & Helsel, 1985b; Wiemer & Kratochwill, 1991). These studies will be reviewed by considering children with visual impairments, followed by children with hearing impairments.

i) Visual Impairments

It has been suggested that increased fearfulness would be expected in children with visual impairments due to the presence of their disability, lack of social acceptance, and their reduced number of social contacts (Drotar, 1981). Ollendick et al. (1985b) administered the FSSC-R to visually impaired and typically sighted children aged between 10 and 18 years. Although the children with visual impairments were found to score significantly higher on total fear scores, the children only differed on one of the five factors (Death and Danger), whereby children with visually impairments scored highest. With regard to specific fear items, children with visual impairments were more likely to report fears associated with physically harmful situations (e.g., being hit by a car or truck), as opposed to normally sighted children who reported more fears of psychologically harmful situations (i.e., those items relating to failure and criticism).

Additional results from Ollendick et al. (1985b) indicated similarities in age and gender differences between the visually impaired and normally sighted children, however, this may be due to the age range of the sample which did not include very young children. Matson et al. (1986) assessed children from 9 to 22 years of age with visual impairments, and divided the sample into three age categories. Age differences between groups were as expected in normative samples (Wiemer & Kratochwill, 1991), however, no control group was used.

King et al. (1990) assessed 129 children from 8 to 16 years of age with visual impairments and also age and gender matched sighted controls. King et al. also omitted FSSC-R items

deemed irrelevant to this population, namely “the dark” and “shadows”. King et al. found no significant difference in the total number of fears reported across the two groups. These results contradict those found by Ollendick et al. (1985b), however, it must be noted that the children in King et al.’s study who were classified as ‘totally blind’ *did* report more fears than sighted children.

King et al. (1990) also found that psychologically distressing events were more disturbing to typically sighted children than children with visual impairments. However, their results indicated that sighted children evince a greater level of fear related to stimuli concerning danger and death, this is in direct contrast to previous findings (Ollendick et al., 1985b).

ii) Hearing Impairments

King et al. (1989) commented that due to sensory deficits and resulting difficulties in communication, children with hearing impairments may perceive the world as more frightening than hearing children. To date, only their study has specifically investigated fearfulness in hearing impaired children (King et al., 1989) and one other has included hearing impaired children as part of a mixed disability sample (King, Josephs, Gullone, Madden, & Ollendick, 1994).

King et al. (1989) used a sample of 138 prelingually deaf children aged between 8 and 16 years, along with a sample of 134 age-matched controls without a hearing impairment.

Interestingly, no differences in total fear score were found between the two groups of children. Some differences were found, however, on the five factors of the FSSC-R.

Generally, children without a hearing impairment were found to be more fearful of stimuli

related to the arousal of psychological distress such as “having my parents argue” and “getting poor grades”. Children with a hearing impairment though, were more fearful of stimuli that potentially created a threat to physical well-being such as “snakes” and “guns”.

King et al. (1994) included both children with hearing impairments ($n = 218$) and visual impairments ($n = 192$) in their total sample of children aged between 7 and 18 years.

Children with hearing impairments were found to report significantly more overall fearfulness than children with visual impairments. Both of these groups, however, reported significantly fewer fears than the children with intellectual disabilities ($n = 203$) in the sample, giving weight to the notion that the quantity and quality of self-reported fear is linked to cognitive development (see Section 1.4.2.4).

iii) Summary

Despite the variance of findings in overall fearfulness, the limited research in this area has yielded some consistencies. Children with sensory impairments report an equal or greater number fears than typically developing children. Children with sensory impairments are generally more concerned with stimuli associated with death, danger, harm, and the unknown, and less concerned with psychologically harmful stimuli compared to typically developing children.

1.4.1.2 Health Disabilities

The term 'health disabilities' encompasses individuals with physical disabilities and also individuals with chronic health conditions. King, Gullone, and Ollendick (1990) proposed that in children with health disabilities, several key factors may account for higher levels of psychological distress. These include poor physical health, lack of social acceptance, and consequent paucity of contacts outside of the home. Only one study investigating fear and fear development in children with health disabilities was found in the present literature search (King et al., 1990).

King et al. (1990) examined fears in 73 children with health disabilities ranging from 7 to 18 years in age, all of whom attended mainstream school. These children were control matched on age and gender with 73 typically developing children. Varying medical conditions were evident in the disabled group of children (including spina bifida and chronic asthma), and the FSSC-R was employed as the assessment measure. In accordance with King et al.'s hypothesis, children with health disabilities were found to report a significantly greater number of mean fears than their non-disabled counterparts. The disabled children in the sample also reported significantly more fears on two of the five factor structures, 'Fear of the Unknown', and 'Fear of Injury and Small Animals'.

King et al. (1990) found both gender and developmental differences within the experimental groups, concordant with normative fear development research. These findings are also broadly akin to those found in children with sensory impairments.

1.4.2 Intellectual Disabilities

Of all 'disabilities' under this terminology umbrella, intellectual disabilities has been the most focused upon with regard to childhood fear pattern research. Intellectual disability, also known as learning disability, affects approximately 2-3% of the population in England. This equates to around 189,000 people under 20 years of age, and it is estimated that around one third of these individuals has a moderate or severe intellectual disability. It has been reported that 40% of children and young people with an intellectual disability experience anxiety to a significant degree, this is compared to a rate of 10% in typically developing children (The Foundation for People with Learning Disabilities, n.d.).

Some authors (e.g., Hagopian & Jennett, 2008; King et al., 1994) have noted that clinicians frequently overlook anxiety difficulties when assessing children and adolescents with intellectual disabilities, a process most commonly referred to as 'diagnostic overshadowing'. In particular, Reiss and Szyszko (1983) discussed instances whereby the presence of an intellectual disability decreased the significance of an accompanying psychological disorder, such as a phobia. However, the existing body of literature largely supports the claim that children with intellectual disabilities are at heightened risk of experiencing emotional difficulties and manifesting higher levels of fear and anxiety than their typically developing peers (e.g., Al-Yagon & Mikulincer, 2004; Pearl & Bay, 1999).

1.4.2.1 Fear Development

Just as typically developing children display predictable fear profiles in relation to their age, it has been suggested that children with intellectual disabilities may also display such a profile in relation to other variables such as cognitive ability (Vandenberg, 1993). This section will review epidemiology of fear in this population, followed by patterns of fear development, and proposed fear models. All evidence will be considered in relation to fear development research in typically developing children.

1.4.2.2 Epidemiology of Fear

Gullone (1996) reviewed the empirical studies investigating fearfulness in individuals with an intellectual disability. In line with the wider anxiety literature, Gullone concluded that there was strong evidence to support the notion that children with intellectual disabilities consistently reported higher levels of fear than their chronological counterparts (e.g., Gullone, King, & Cummins, 1996).

1.4.2.3 Pattern of Fear Development

Section 1.3.1 outlined typical developmental patterns of fear in childhood. Given the difference in cognitive capacity in this population, investigations have sought to answer if children with intellectual disabilities share the same developmental pattern of fear as typically developing children (Gullone, 1996).

Table 1.2
Empirical Studies Investigating Fears in Children with Intellectual Disabilities

Reference	Sample	Methods	Outcomes and Limitations
Maurer (1965)	6-15 years old N = 18 intellectual disabilities N = 130 non-disabled	<ul style="list-style-type: none"> ▪ WISC ▪ Interview 	<ul style="list-style-type: none"> ▪ Similar developmental trends across groups ▪ Small disability sample size
Guarnaccia & Weiss (1974)	6-21 years old N = 102 non-disabled	<ul style="list-style-type: none"> ▪ Louisville Fear Survey for Children 	<ul style="list-style-type: none"> ▪ Factor structure similar to that of non-disabled children ▪ IQ and fearfulness positively correlated. No control group ▪ Non-standardised measure
Derevensky (1979)	7-18 years old N = 133 intellectual disabilities N = 106 non-disabled	<ul style="list-style-type: none"> ▪ Interview 	<ul style="list-style-type: none"> ▪ Similar fears between groups ▪ Disability group reported more animal and ghost fears ▪ Control group reported more people and machinery fears
Knapp, Barrett, Groden, & Groden (1992)	9-16 years old N = 28 intellectual disabilities	<ul style="list-style-type: none"> ▪ Spontaneous recall ▪ FSSC-R 	<ul style="list-style-type: none"> ▪ Total number of fears greater for children with intellectual disabilities, but intensity and factor profile similar to normative data ▪ No control group
Vandenberg (1993)	4-12 years old N = 42 intellectual disabilities N = 112 non-disabled	-	<ul style="list-style-type: none"> ▪ Generally, the disabled group reported more fears resembling those of younger, non-disabled children ▪ Non-disabled group reported more fears involving human agency
King, Josephs, Gullone, Madden, & Ollendick (1994)	7-18 years old N = 302 intellectual disabilities N = 192 visual disabilities N = 218 hearing disabilities N = 302 control group	<ul style="list-style-type: none"> ▪ FSSC-R 	<ul style="list-style-type: none"> ▪ Intellectually disabled children obtained the highest total fear scores ▪ Intellectually disabled children reported more fears of the unknown and more fears of injury and small animals compared to other groups
Gullone, King & Cummins (1996)	7-18 years old N = 187 intellectual disabilities N = 372 non-disabled	<ul style="list-style-type: none"> ▪ FSSC-II 	<ul style="list-style-type: none"> ▪ Disabled group reported more fears than non disabled group ▪ Disabled group showed no age-related decrease in fears ▪ Gender differences the same between the groups
Muris, Merckelbach, & Lujtjen (2002)	4-12 years old N = 105 intellectual disabilities N = 176 non-disabled	<ul style="list-style-type: none"> ▪ Interview ▪ KFQ 	<ul style="list-style-type: none"> ▪ Interview yielded no difference in fear content between groups, but cognitive ability was positively correlated with the experience of worry ▪ KFQ accessed more primitive fears, disability group reported more fears
Li & Morris (2007)	7-18 years old N = 131 intellectual disabilities N = 69 mild mental retardation	<ul style="list-style-type: none"> ▪ FSSC-R ▪ RCMAS 	<ul style="list-style-type: none"> ▪ Adolescent boys with mild mental retardation reported highest fears related to failure and criticism ▪ Younger children reported highest levels of non-specific general anxiety

An early study by Guarnaccia and Weiss (1974) asked parents of intellectually disabled and typically developing children to complete the Louisville Fear Survey for Children (Miller, Barrett, Hampe, & Noble, 1972). It was found that the two groups of children shared a similar factor structure profile and that IQ and fearfulness were positively correlated. This finding, however, has not been supported by any subsequent research to date and may be accounted for by the large age range of the sample employed (6-21 years) or the psychometric measure itself which was not standardised and has not been adopted since for any similar research (see Table 1.2).

More recently, the pattern that children with learning disabilities display a delayed typical fear trend has been demonstrated (e.g., Gullone, Cummins, & King, 1996; Knapp et al., 1992; Vandenberg, 1993), however, this trend is less prominent. Typically developing children experience an age-related decline in fears of animals, and imaginary creatures; and an increase in fears related to economic, social, political matters (Westenberg et al., 2001). The onset and dissipation of such fears are delayed in children with intellectual disabilities (King et al., 1994), giving a more protracted pattern of fear development and a more intense level of fear at a later age than their chronological counterparts.

1.4.2.4 Models of Fear Development

There are no formal models of fear development unique to children with intellectual disabilities. Since Gullone's (1996) review, only two studies have specifically investigating fearfulness in children with intellectual disabilities. Both of these studies

explored new ideas within the research domain with significant implications for developing models of fear development in this special population.

Muris, Mercklebach, and Luijten (2002) explored the relationship between fear and worry in 4-12 year olds. Muris et al. included 105 children with intellectual disabilities and 176 non-disabled children in their sample, who were subsequently assigned to three age categories. Two assessment methods were used in this study, a semi-structured anxiety interview and the Koala Fear Questionnaire (KFQ; Muris, Meesters, & Mayer, 2000). The interview results demonstrated no difference in fearfulness between the two groups. The interviews did, however, generate a pattern whereby cognitive experience was positively correlated with worry. The KFQ produced different results whereby the children with intellectual disabilities reported more fears than their non-disabled peers. The two measures used in this study tapped into quite different aspects of anxiety. The KFQ seemed to measure primitive fears that are likely to be prevalent amongst children with a limited cognitive capacity, whereas the anxiety interview appeared to assess more sophisticated anxiety phenomena that most likely depend on higher levels of cognitive functioning.

In a recent study, Li and Morris (2007) also investigated the variable of cognitive capacity. Li and Morris compared self-reported fears in children (7-18 years of age) who had 'mild mental retardation' with those who had a 'learning disability'⁷. The FSSC-R and the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1997) were used to explore whether there were any significant differences between these two groups of

⁷ 'Mild mental retardation' and 'learning disability' were defined by Li and Morris (2007) in terms of obtained Full Scale Intelligence Quotient Score, 1 or 2 standard deviations below the mean, respectively.

children who were both receiving special education services. There were in fact no significant differences found between the two disability groups in terms of fearfulness, i.e., total fear score. These findings suggest that variables other than IQ may play an important role in the development of fearfulness.

Innate biological theories, as discussed in Section 1.3.2.1, are as applicable to children with intellectual disabilities, as those without. Indeed, fears of death and danger appear to be strong for both children with and without intellectual disabilities (see Gullone, 2000).

Nonetheless, marked differences are apparent in reported fear factors. An interaction of relevant variables such as parenting style and cognitive capacity are likely to account for a proportion of this variance.

1.4.3 Summary

There is some evidence to support the notion that children with intellectual disabilities experience a similar, yet delayed pattern of fear development, in accordance with their typically developing counterparts. The fear pattern appears to be more drawn out, which may account for the higher levels, and wider ranging quality of fear experienced by children with intellectual disabilities.

Whilst individuals with intellectual disabilities are at greater general risk of experiencing significantly more fears than typically developing children, higher functioning children along the range of intellectual disabilities are more likely to experience worry associated with such fears.

Although there are no formal models of fear development in children with intellectual disabilities, much of the same literature can be applied from typically developing children. The roles of parenting style and cognitive capacity are emphasised.

1.5 Fear Development in Children on the Autism Spectrum

Anxiety was described in the initial account of autism by Kanner (1943). Some children on the autism spectrum⁸ are exceptionally afraid of everyday objects and situations, while other children on the autism spectrum display no fear at all in situations where there is real danger (e.g., Wing, 1996). In the DSM-IV-TR (American Psychiatric Association, 2000), this clinical impression is briefly cited: *“There may be a lack of fear in response to real dangers, and excessive fearfulness in response to harmless objects”* (p.68).

The following sections will review fear research in relation to diagnosis and autism spectrum symptomatology, and proceed to give an overview of research addressing fear epidemiology, development, and associated fear models for these children.

⁸ ‘Autism spectrum’ is a relatively new term that includes related subtypes of autism, including Autism Spectrum Disorder, Asperger Syndrome and Pervasive Developmental Disorder not Otherwise Specified (PDD-NOS). The umbrella term ‘Pervasive Developmental Disorders’ (PDDs) is used in both the DSM-IV-TR (American Psychiatric Association, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10; World Health Organisation, 1990) and includes the above listed disorders, along with Rett Disorder and Childhood Disintegrative Disorder. The present review will focus on the autism spectrum, unless otherwise stated.

1.5.1 Anxiety, Fear and Autism Spectrum Symptomatology

It was Kanner (1943) who first suggested that many of the core features of autism, were anxiety driven. Primarily these features were the insistence on sameness, and a repertoire of rigid behaviours, routines and obsessions. Therefore, researchers and clinicians have subsequently considered anxiety as both a possible consequence of, and possible cause of, aspects of behaviour in children on the autism spectrum (Davis, Saeed, & Antonacci, 2008).

Most of what is known about the occurrence of fear and anxiety disorders in children on the autism spectrum is derived from clinical samples⁹. Muris, Steerneman, Merckelbach, Holdrinet, and Meesters (1998) investigated co-morbidity of anxiety symptoms in children on the autism spectrum and found that 84% of children aged 2 to 18 years with PDD-NOS met diagnostic criteria for at least one anxiety disorder. PDD studies have found that anxiety ratings by parents and teachers are significantly higher for children with a PDD than children without a PDD (Weisbrot, Gadow, DeVincent, & Pomeroy, 2005).

Furthermore, anxiety ratings have been found to be positively correlated to cognitive ability in this population, with highest anxiety ratings given to children with Asperger syndrome (e.g., Gillott, Furniss, & Walter, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000).

Particular features of the autism spectrum have been viewed by some authors as mechanisms for coping with anxiety, induced by the significant and primary deficit in

⁹ 'Clinical samples' is a term used to describe samples which are comprised of individuals in receipt of mental health services.

understanding the environment (Gillott et al., 2001). Frequency of stereotypical behaviours, often displayed by children on the autism spectrum, such as echolalia, twirling, rocking, and hand flapping (Howlin, 1998), and more multi-faceted behaviours such as repetitive questioning (Thomas et al., 1998), often increase when these children are fearful or anxious. This is suggestive that such behaviours serve as self-soothing strategies for children on the autism spectrum in the face of fear or anxiety. Additional features such as obsessions and rituals are similarly thought to play a key role in keeping fear and anxiety under control (Howlin, 1998).

It is possible that anxiety may not play a fundamental role in the core difficulties of the autism spectrum, but instead, may represent a secondary phenomenon. Anxiety may actually result from children's self-awareness of their own difficulties when facing situations in which there exists, expectations to display age-appropriate social behaviour (Loveland et al., 1997). This is more likely to be the case for higher functioning children on the autism spectrum. According to the DSM-IV-TR (American Psychiatric Association, 2000), a diagnosis of social anxiety disorder should not be made if the symptoms co-occur in the context of a pervasive developmental disorder such as Asperger syndrome. This implies that symptoms of social anxiety disorder are part of these conditions, and may be an instance of diagnostic overshadowing, as outlined in Section 1.4.2.

Given the vague causal relationship between fear, anxiety, and autism spectrum symptomatology, some difficulties in the research domain exist. Numerous studies have measured symptoms of anxiety among children on the autism spectrum and found higher

than expected scores when compared with other groups (Vandergaag et al., 1995; Volkmar & Pauls, 2003). A significant difficulty with this literature is that it does not establish whether a particular symptom of anxiety (e.g., repetitive questioning) is indeed part of a co-morbid anxiety disorder, or a characteristic feature of the autism spectrum. A methodological flaw in this literature therefore is that it does not assess *changes* in behaviour nor include supplementary qualitative information. Given these methodological concerns, it follows that very little literature exists that examines the risk factors of anxiety and phobic disorders in children on the autism spectrum.

A key limitation in fear literature for children with all disabilities is that internalisation or externalisation of the emotion of fear is not investigated, qualitative comparisons can therefore not be drawn against other populations.

1.5.2 Fear Development

Just as there is a dearth of evidence concerning typical fear development in children with disabilities in general, fear research in children on the autism spectrum is also limited.

There are two studies that have specifically investigated fear in children on the autism spectrum, both of these used parental reports as the assessment measure (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005; Matson & Love, 1990).

1.5.3 Epidemiology of Fear

Matson and Love (1990) compared the fears of 14 children on the autism spectrum, aged 2-17 years, with typically developing age- and sex-matched controls. Parents of these

children were asked to complete the FSSC-R but were also given the added option of 'not applicable' due to the level of relevance of some of the items to children on the autism spectrum (e.g., "getting a report card" or "bombing attacks"). The mean total score for children on the autism spectrum was significantly lower compared to the typically developing children. Indeed, the difference between the groups is potentially greater since the mean total score for typically developing children in Matson and Love's study was substantially below previously reported results (e.g., Ollendick, 1983; Ollendick, Matson, & Helsel, 1985a). It is possible that these findings are the product of parental under-reporting, limited sample size, or the number of additional "not applicable" endorsements.

In a more recent study by Evans et al. (2005) the fears of children on the autism spectrum (n=25) were compared with those of children with Down Syndrome (n=43), and also mental age (n=45) and chronological age matched (n=37) controls. A 69-item fear inventory was compiled and adapted from other fear measures and completed by parents. The data suggested that whether children on the autism spectrum were more fearful or not, largely depended on the nature of the fears being assessed. These results are explored in Section 1.5.4.

While epidemiological studies have demonstrated that anxiety difficulties are among the most prevalent forms of psychopathology on the autism spectrum (Russell & Sofronoff, 2005), comparable statistics do not currently exist when considering fearfulness in the same population of children. It appears that unlike research conclusions formed from children with other disabilities, children on the autism spectrum cannot be broadly deemed as more

fearful than typically developing children. This is supported in PDD literature (MacNeil et al., 2009), and has been shown to be idiosyncratic to the fear quality being considered.

1.5.4 Pattern of Fear Development

Given that only two studies have investigated fearfulness in children on the autism spectrum and neither adopted a developmental perspective, it is unsurprising that there are no proposed fear development stages in children on the autism spectrum. Whereas there is strong research evidence to support the notion that children with other disabilities exhibit a delayed, but typical pattern of development (see Section 1.4.2.3), there is no such evidence to suggest this in children on the autism spectrum.

Table 1.3

Percentage of Endorsements of the Top Ten Fears of Children on the Autism Spectrum and Typically Developing Children

Rank	Children on the Autism Spectrum	Typically Developing Children
1.	Getting punished by mom (71%)	Getting a shot from the doctor (86%)
2.	Thunderstorms (71%)	Getting punished by mom (79%)
3.	Getting punished by father (71%)	Getting lost in a strange place (71%)
4.	Dark places (71%)	Looking foolish (64%)
5.	Getting a shot from a doctor (64%)	Ghosts and spooky things (64%)
6.	Being in a crowd (64%)	Snakes (64%)
7.	Dark rooms or closets (64%)	Sharp objects (64%)
8.	Going to bed in the dark (64%)	Dark rooms or closets (64%)
9.	Closed places (64%)	Strange or mean-looking dogs (64%)
10.	Going to the dentist (57%)	Deep water or the ocean (64%)

(Matson & Love, 1990)

Matson and Love (1990) tabulated the most common fears for both the children on the autism spectrum and typically developing children samples by combining ratings of “a lot” and “some”. These results, shown in Table 1.3, suggest that the fears and phobias of children on the autism spectrum are qualitatively different to those of typically developing children.

Matson and Love’s (1990) results were further analysed using Ollendick’s (1983) 5-factor solution for the FSSC-R; it can be seen that six of the top ten endorsed fears for children on the autism spectrum in Matson and Love’s study are loaded onto Factor 2 (Fear of the Unknown). This Factor was the most significant for children on the autism spectrum, accounting for 36% of the group’s endorsements compared to 23% of the typically developing group’s. Fear items on this factor are more concrete, more likely to be encountered, and more situationally-specific than items on other Factors which may account for the group difference. By contrast, Matson and Love (1990) found that the most prevalent Factors for the typically developing group were Factor 1 (Fear of Failure or Criticism) and Factor 3 (Fear of Injury and Small Animals). It is difficult to compare these results with other typical fear research due to the limited sample size and wide age-range used. However, it is expected that typically developing children exhibit more fears associated with social evaluation than children on the autism spectrum who may have a poorer understanding of the concepts of “failure” and “criticism”. The finding relating to injury and small animals is in direct contrast to previous research that has found that children with disabilities are *more* likely to exhibit fears loaded onto this item than children without disabilities (Gullone, Cummins et al., 1996). The previously discussed

methodological issues could account for this discrepancy, or it could be viewed as evidence that children on the autism spectrum display a distinct fear profile to both children with other disabilities and typically developing children.

Research has shown that parents tend to under-report the frequency and severity of fears experienced by their children (see Section 1.2.2). Whilst this issue is relevant to children both with and without disabilities, caution should be exercised when considering the fear assessment results in Matson and Love's (1990) study. Many of the children belonging to the autism spectrum group in this study were non-verbal. Therefore, parents will have received little in the way of direct feedback pertaining to which stimuli are in fact fear-producing, and what the causes are for this fear.

It appears from the endorsements in Matson and Love's (1990) study, that the stimuli to which children on the autism spectrum had no contact with, or no conceptual understanding of, were not considered to be fear-producing. Matson and Love suggest that this would be the same for typically developing children, however, the opportunities of children on the autism spectrum to experience or learn about the range of objects and situations listed in the FSSC-R are more likely to be limited by virtue of their disability. This hypothesis, though, does not explain the fear difference when compared to children with other disabilities.

Evans et al. (2005) did not populate a fear rankings table, however, results indicated that children on the autism spectrum exhibited more situational and medical fears than the other groups. Evans et al. also found that children on the autism spectrum were least fearful of

harm. These findings are all supportive of (although not directly comparable with) Matson and Love's (1990) findings.

Unlike previous fear research in children with disabilities, Evans et al. (2005) investigated the relationship between fear and behaviour difficulties. Evans et al. found that it was not only anxiety symptoms that correlated with fears. Rather, in children on the autism spectrum, externalising problems including conduct, impulsivity, and hyperactivity, were associated with situational fears, fears of harm, and medical and environmental fears. Somatic complaints were negatively associated with fearfulness of animals and social anxiety. Some correlations did emerge between fears and behaviour symptoms in the other groups of children, but these were not nearly as widespread. These findings suggest that while each group of children may exhibit a characteristic profile of fear, fears in children on the autism spectrum are more symptomatic.

A major limitation in the study by Evans et al. arises when diagnostic issues are considered. Children comprising the autism spectrum group were classified by their parents as 'autistic'. This placed them in the more inclusive participant group of autism spectrum disorders (ASD) without further subdivision on diagnosis or IQ. Further to this limitation, the same shortcomings of using parental reports, previously discussed, apply.

The results from the two studies discussed suggest a distinct fear profile in children on the autism spectrum, whereby concrete situational specific fears and fears of the unknown are more readily experienced. These findings are consistent with case reports addressing the

treatment of specific phobias in children on the autism spectrum (Rapp, Vollmer, & Hovanetz, 2005; Ricciardi, Luiselli, & Camare, 2006). Evidence with regard to fear of social situations is mixed as to whether children on the autism spectrum are less fearful or the same as typically developing children. However, there is no evidence to suggest whether or not these fears change with children's age, therefore, developmental comparisons cannot be drawn.

1.5.5 Models of Fear Development

No formal models of fear development exist for children on the autism spectrum, however, several hypotheses have been postulated in the literature.

Concordant with a developmental perspective, cognitive ability has been recognised as an important variable when considering fear development in children with and without disabilities (Muris et al., 2002). Evans et al. (2005) found that IQ is an important determinant in predicting fear profiles in children on the autism spectrum. However, it is difficult to conclude the role of chronological age and IQ in fears of children on the autism spectrum given the present paucity of evidence.

Pathological features of the amygdala, which is the brain structure involved in both social and emotional processing (LeDoux, 1998), have been documented as significant in the autism spectrum (Nacewicz et al., 2006; Schultz, 2005) and implicated in co-existing autism spectrum features and anxiety (Amaral, Bauman, & Schumann, 2003). An additional suggestion is that abnormalities in serotonin neurotransmission could represent a

shared causal factor in the autism spectrum, anxiety and fear development (Chandana et al., 2005).

A more prevalent hypothesis related to fear and anxiety in the autism spectrum literature, is associated with the disturbance of perceptual-cognitive style, known as Weak Central Coherence (WCC; Burnette et al., 2005). The WCC theory suggests that certain deficits in the autism spectrum are due to a failure to integrate local details into a global entity (Frith, 1989). It is therefore possible that children on the autism spectrum have difficulties in relating to diverse sources of information and that this could lead them to experience commonplace situations as chaotic and therefore become fearful of them. This argument is given weight from the discussed studies in this area, both of which found that children on the autism spectrum were more likely to display situational-specific fears compared to typically developing children, and children with other disabilities. However, a recent study by Burnette et al. (2005) failed to establish an association between WCC and anxiety in 20 children at the 'high functioning' end of the autism spectrum.

It is also possible that an important link exists between fear patterns on the autism spectrum, and their sensory profiles. Despite decades of phenomenological reports documenting the presence of special sensory features in autism (Baranek, David, Poe, Stone, & Watson, 2006), no research exists that links the unique nature of these features to the experience of fear. The two most common sensory patterns reported among the myriad

of terms are hyper- and hypo-responsiveness¹⁰ (Delacato, 1974; O'Neill & Jones, 1997). It must be noted that unusual sensory experiences are not thought to be universal in the autism spectrum (Baranek, 2002; Dawson & Watling, 2000). Indeed, it has been demonstrated that children can show hyper- and hypo-responsivity across the seven sensory domains¹¹ (Baranek et al., 2006; Harrison & Hare, 2004). It is plausible that such a special sensory pattern could account for the unique fear profile of children on the autism spectrum. For example, it would correspond that a child who has auditory hypersensitivity may endorse high fear ratings for "loud sirens". Similarly, a child who has a hyposensitive visual system may endorse high fear ratings for "dark places". Investigation into the relationship between sensory and fear patterns in children on the autism spectrum could produce a number of significant clinical benefits (McGowan, 2009b).

1.5.6 Summary

Fear studies investigating children on the autism spectrum have shown that they do not necessarily evince greater fear levels than other children. Rather, the degree of fear greatly depends on the nature of the fear being considered. Generally, children on the autism spectrum have greater fears in relation to the unknown, and fewer fears associated with failure, criticism, harm, and danger than other children.

The relationship between fear and autism spectrum symptomatology is both vague and complex. It remains unclear whether fears in these children are primary or secondary

¹⁰ *Hyper-responsiveness* refers to the sensory channel being too 'open', and therefore the brain can easily become stimulated. *Hypo-responsiveness* refers to the sensory channel not being receptive enough, and therefore the brain can easily be deprived of that particular sensory input.

¹¹ There are seven sensory processing systems present within the central nervous system: vision, hearing, vestibular system, olfaction (smell), gustation (taste), tactile system, and proprioceptive system

impairments. Relevant hypotheses in the literature can be applied to fear research, including WCC and sensory processing.

1.6 Summary and Clinical Implications

This paper has shown that there is an established evidence base pertaining to fear development in typically developing children. It has also demonstrated that there are many consistencies within the literature to suggest that children with disabilities in general exhibit a similar, albeit delayed, pattern of fear development. Section 1.5, however, highlights the need for further investigation into the nature of fear development in children on the autism spectrum. More research in this area could potentially establish a unique fear profile for this population, and also clarify significant variables associated with all or parts of this fear profile.

Strengthening the knowledge-base in this area could potentially contribute to more sophisticated psychological interventions for fear and phobia difficulties, and also enhance the assessment procedure for such difficulties in children on the autism spectrum. It would also serve to develop practical strategies for children on the autism spectrum in home and educational environments. Professionals working with children on the autism spectrum would have an enhanced knowledge of their needs and difficulties leading to a decrease in psychological distress for these children. Inter-professional alliances may also be

strengthened by a more robust research-base, leading to more effective care-pathways for children on the autism spectrum.

Future research may include differentiating between co-morbid anxiety symptoms and characteristics of the autism spectrum. An increased awareness in this area may lead to a decrease in diagnostic overshadowing and enhance psychological assessment and interventions for phobia and anxiety difficulties in children on the autism spectrum.

Research would also benefit from comparing sensory and fear relationships *within* the autism spectrum disorders, and also *between* groups with other clinical populations (e.g., attention deficit hyperactivity disorder, obsessive-compulsive disorder). This would establish how unique the relationship is between fear and sensory profiles for children on the autism spectrum.

In summary, whilst there is an established fear development pattern in typically developing children which informs parenting style, teaching strategies, and psychological interventions, no such pattern has been established in children on the autism spectrum.

Differentiation between the primary and secondary nature of fear phenomena in children on the autism spectrum, has numerous potential benefits which would potentially lead to a decrease in distress and increase in quality of life.

1.7 References

Al-Yagon, M., & Mikulincer, M. (2004). Socioemotional and academic adjustment among children with learning disorders: The mediational role of attachment-based factors. *Journal of Special Education, 38*(2), 111-123.

Amaral, D. G., Bauman, M. D., & Schumann, C. M. (2003). The amygdala and autism: implications from non-human primate studies. *Genes Brain and Behavior, 2*(5), 295-302.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, fourth edition-text revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association.

Askew, C., & Field, A. P. (2008). The vicarious learning pathway to fear 40 years on. *Clinical Psychology Review, 28*(7), 1249-1265.

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., 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.

- Barlow, D. H. (2002). *Anxiety and its disorders. The nature and treatment of anxiety and panic*. (2nd ed.). New York: Guilford.
- Barnett, B., Schaafsma, M. F., Guzman, A. M., & Parker, G. B. (1991). Maternal anxiety - A 5-year review of an intervention study. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 32(3), 423-438.
- Barrett, P. M., Rapee, R. M., Dadds, M. M., & Ryan, S. M. (1996). Family enhancement of cognitive style in anxious and aggressive children. *Journal of Abnormal Child Psychology*, 24(2), 187-203.
- Bogels, S. M., & Brechman-Toussaint, M. L. (2006). Family issues in child anxiety: Attachment, family functioning, parental rearing and beliefs. *Clinical Psychology Review*, 26(7), 834-856.
- Burnette, C. P., Mundy, P. C., Meyer, J. A., Sutton, S. K., Vaughan, A. E., & Charak, D. (2005). Weak central coherence and its relations to theory of mind and anxiety in autism. *Journal of Autism and Developmental Disorders*, 35(1), 63-73.
- Burnham, J. J. (2009). Contemporary fears of children and adolescents: Coping and resiliency in the 21st century. *Journal of Counseling and Development*, 87(1), 28-35.
- Burnham, J. J., & Gullone, E. (1997). The fear survey schedule for children .2. A psychometric investigation with American data. *Behaviour Research and Therapy*, 35(2), 165-173.

- Chandana, S. R., Behen, M. E., Juhasz, C., Muzik, O., Rothermel, R. D., Mangner, T. J., et al. (2005). Significance of abnormalities in developmental trajectory and asymmetry of cortical serotonin synthesis in autism. *International Journal of Developmental Neuroscience*, 23(2-3), 171-182.
- Craske, M. G. (2003). *Origins of phobias and anxiety disorders. Why more women than men?* . Oxford: Elsevier.
- Crowell, J. A., & Feldman, S. S. (1991). Mothers working models of attachment relationships and mother and child-behavior during separation and reunion. *Developmental Psychology*, 27(4), 597-605.
- Davis, E., Saeed, S. A., & Antonacci, D. J. (2008). Anxiety disorders in persons with developmental disabilities: Empirically informed diagnosis and treatment - Reviews literature on anxiety disorders in DD population with practical take-home messages for the clinician. *Psychiatric Quarterly*, 79(3), 249-263.
- 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.
- Delacato, C. (1974). *The ultimate stranger: The autistic child*. Novato, CA: Academic Therapy Publications.
- Department of Health. (2009). Government support to improve services for services for people with autism and their families. Retrieved 30 April, 2009, from http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/DH_095172

- Derevensky, J. L. (1979). Childrens fears- - Developmental comparison of normal and exceptional-children. *Journal of Genetic Psychology, 135*(1), 11-21.
- Drotor, D. (1981). Psychological perspectives in childhood illness. *Journal of Pediatric Psychology, 6*, 211-228.
- Essau, C. A., Conradt, J., & Petermann, F. (2000). Frequency, comorbidity, and psychosocial impairment of depressive disorders in adolescents. *Journal of Adolescent Research, 15*(4), 470-481.
- Evans, D. W., Canavera, K., Kleinpeter, F. L., Maccubbin, E., & Taga, K. (2005). The fears, phobias and anxieties of children with Autism Spectrum Disorders and Down Syndrome: Comparisons with developmentally and chronologically age matched children. *Child Psychiatry & Human Development, 36*(1), 3-26.
- Field, A. P., & Davey, G. C. L. (2001). Conditioning models of childhood anxiety. In W. K. Silverman & P. A. Treffers (Eds.), *Anxiety disorders in children and adolescents: Research assessment and intervention*. Cambridge: Cambridge University Press.
- Field, A. P., & Schorah, H. (2007). The verbal information pathway to fear and heart rate changes in children. *Journal of Child Psychology and Psychiatry, 48*(11), 1088-1093.
- Field, A. P., & Storksen-Coulson, H. (2007). The interaction of pathways to fear in childhood anxiety: A preliminary study. *Behaviour Research and Therapy, 45*(12), 3051-3059.

Frith, U. (1989). *Autism: Explaining the enigma*. Oxford: Basil Blackwell.

Gerull, F. C., & Rapee, R. M. (2002). Mother knows best: effects of maternal modelling on the acquisition of fear and avoidance behaviour in toddlers. *Behaviour Research and Therapy, 40*(3), 279-287.

Gillott, A., Furniss, F., & Walter, A. (2001). Anxiety in high-functioning children with autism. *Autism, 5*(3), 277-286.

Guarnaccia, V. J., & Weiss, R. L. (1974). Factor structure of fears in mentally-retarded. *Journal of Clinical Psychology, 30*(4), 540-544.

Gullone, E. (1996). Normal fear in people with a physical or intellectual disability. *Clinical Psychology Review, 16*(8), 689-706.

Gullone, E. (2000). The development of normal fear: A century of research. *Clinical Psychology Review, 20*(4), 429-451.

Gullone, E., Cummins, R. A., & King, N. J. (1996). Self-reported fears: A comparison study of youths with and without an intellectual disability. *Journal of Intellectual Disability Research, 40*, 227-240.

Gullone, E., & King, N. J. (1992). Psychometric evaluation of a revised fear survey schedule for children and adolescents. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 33*(6), 987-998.

- Gullone, E., King, N. J., & Cummins, R. A. (1996). Fears of youth with mental retardation: Psychometric evaluation of the fear survey schedule for children-II (FSSC-II). *Research in Developmental Disabilities, 17*(4), 269-284.
- Hagopian, L. P., & Jennett, H. K. (2008). Behavioral assessment and treatment of anxiety in individuals with intellectual disabilities and autism. *Journal of Developmental and Physical Disabilities, 20*(5), 467-483.
- Harrison, J., & Hare, D. J. (2004). Brief report: Assessment of sensory abnormalities in people with autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 34*(6), 727-730.
- Howlin, P. (1998). Handbook of autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 39*(5), 790-790.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.
- Kanner, L. (1972). *Child Psychiatry* (4th ed.). Springfield, Illinois: Charles C. Thomas.
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication.(vol 62, pg 593, 2005). *Archives of General Psychiatry, 62*(7), 768-768.
- Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism, 4*(2), 117-132.

- King, N. J., Gullone, E., & Ollendick, T. H. (1990). Fears in children and adolescents with chronic medical conditions. *Journal of Clinical Child Psychology, 19*(2), 173-177.
- King, N. J., Gullone, E., & Stafford, C. (1990). Fears in visually-impaired and normally sighted children and adolescents. *Journal of School Psychology, 28*(3), 225-231.
- King, N. J., Josephs, A., Gullone, E., Madden, C., & Ollendick, T. H. (1994). Assessing the fears of children with disability using the Revised Fear Survey Schedule for Children - A comparative study. *British Journal of Medical Psychology, 67*, 377-386.
- King, N. J., Mulhall, J., & Gullone, E. (1989). Fears in hearing-impaired and normally hearing children and adolescents. *Behaviour Research and Therapy, 27*(5), 577-580.
- Knapp, L. G., Barrett, R. P., Groden, G. G., & Groden, J. (1992). The nature and prevalence of fears in developmentally disabled children and adolescents: A preliminary investigation. *Journal of Developmental and Physical Disabilities, 4*(3), 195-203.
- LeDoux, J. (1998). The neural circuits underlying anxiety and fear. Fear and the brain: Where have we been, and where are we going? *Biological Psychiatry, 44*, 1229-1238.
- Leonardo, E. D., & Hen, R. (2006). Genetics of affective and anxiety disorders. *Annual Review of Psychology, 57*, 117-137.

- Li, H. J., & Morris, R. J. (2007). Assessing fears and related anxieties in children and adolescents with learning disabilities or mild mental retardation. *Research in Developmental Disabilities, 28*(5), 445-457.
- Loveland, K. A., TunaliKotoski, B., Chen, Y. R., Ortegon, J., Pearson, D. A., Brelsford, K. A., et al. (1997). Emotion recognition in autism: Verbal and nonverbal information. *Development and Psychopathology, 9*(3), 579-593.
- MacNeil, B. M., Lopes, V. A., & Minnes, P. M. (2009). Anxiety in children and adolescents with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 3*(1), 1-21.
- Marks, I. (1987). The development of normal fear - A review. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 28*(5), 667-697.
- Matson, J. L., & Love, S. R. (1990). A comparison of parent-reported fear for autistic and nonhandicapped age-matched children and youth. *Australia and New Zealand Journal of Developmental Disabilities, 16*(4), 349-357.
- Matson, J. L., Manikam, R., Heinze, A., & Kapperman, G. (1986). Anxiety in visually-handicapped children and youth. *Journal of Clinical Child Psychology, 15*(4), 356-359.
- Maurer, A. (1965). What children fear. *The Journal of Genetic Psychology, 106*, 265-277.

- McDonald, S. D., Hartman, N. S., & Vrana, S. R. (2008). Trait anxiety, disgust sensitivity, and the hierarchic structure of fears. *Journal of Anxiety Disorders, 22*(6), 1059-1074.
- McGowan, L. S. (2009b). Sensory processing and the fears of children on the autism spectrum. Unpublished doctoral dissertation. University of Warwick & Coventry University.
- Mellon, R., Koliadis, E. A., & Paraskevopoulos, T. D. (2004). Normative development of fears in Greece: Self-reports on the Hellenic Fear Survey Schedule for Children. *Journal of Anxiety Disorders, 18*(3), 233-254.
- Miller, L. C., Barrett, C. L., Hampe, E., & Noble, H. (1972). Factor structure of childhood fears. *Journal of Consulting and Clinical Psychology, 39*(2), 264.
- Mineka, S., & Zinbarg, R. (2006). A contemporary learning theory perspective on the etiology of anxiety disorders - It's not what you thought it was. *American Psychologist, 61*(1), 10-26.
- Muris, P. (2003). The "anti-monster letter" as a simple therapeutic tool for reducing night-time fears in young children. *Behaviour Change, 20*(4), 200-207.
- Muris, P. (2007). *Normal and abnormal fear and anxiety in children and adolescents*. New York: Elsevier.

- Muris, P., Mayer, B., Huijding, J., & Konings, T. (2008). A dirty animal is a scary animal! Effects of disgust-related information on fear beliefs in children. *Behaviour Research and Therapy*, 46(1), 137-144.
- Muris, P., Meesters, C., & Mayer, B. (2000). *The Koala Fear Questionnaire: A standardized, pictorial scale for measuring fears in young children*. Maastricht: Maastricht University.
- Muris, P., Merckelbach, H., & Luijten, M. (2002). The connection between cognitive development and specific fears and worries in normal children and children with below-average intellectual abilities: a preliminary study. *Behaviour Research and Therapy*, 40(1), 37-56.
- Muris, P., Merckelbach, H., Mayer, B., & Prins, E. (2000). How serious are common childhood fears? *Behaviour Research and Therapy*, 38(3), 217-228.
- Muris, P., & Ollendick, T. H. (2002). The assessment of contemporary fears in adolescents using a modified version of the Fear Survey Schedule for Children-Revised. *Journal of Anxiety Disorders*, 16(6), 567-584.
- Muris, P., Steerneman, P., Merckelbach, H., Holdrinet, I., & Meesters, C. (1998). Comorbid anxiety symptoms in children with pervasive developmental disorders. *Journal of Anxiety Disorders*, 12(4), 387-393.
- Muris, P., Steerneman, P., Merckelbach, H., & Meesters, C. (1996). The role of parental fearfulness and modeling in children's fear. *Behaviour Research and Therapy*, 34(3), 265-268.

- Nacewicz, B. M., Dalton, K. M., Johnstone, T., Long, M. T., McAuliff, E. M., Oakes, T. R., et al. (2006). Amygdala volume and nonverbal social impairment in adolescent and adult males with autism. *Archives of General Psychiatry*, 63(12), 1417-1428.
- National Initiative for Autism: Screening and Assessment. (2003). *National autism plan for children* Retrieved 30 April from <http://www.nas.org.uk/content/1/c4/34/54/NIASAREp.pdf>
- O'Neill, M., & Jones, R. S. P. (1997). Sensory-perceptual abnormalities in autism: A case for more research? *Journal of Autism and Developmental Disorders*, 27(3), 283-293.
- Ollendick, T. H. (1983). Reliability and validity of the Revised Fear Survey Schedule for Children (FSSC-R). *Behaviour Research and Therapy*, 21, 685-692.
- Ollendick, T. H., & King, N. J. (1994). Fears and their level of interference in adolescents. *Behaviour Research and Therapy*, 32(6), 635-638.
- Ollendick, T. H., King, N. J., & Frary, R. B. (1989). Fears in children and adolescents - Reliability and generalizability across gender, age and nationality. *Behaviour Research and Therapy*, 27(1), 19-26.
- Ollendick, T. H., & March, J. S. (2004). *Phobic and anxiety disorders in children and adolescents: A clinician's guide to effective psychosocial and pharmacological interventions*. New York: Oxford University Press.

- Ollendick, T. H., Matson, J. L., & Helsel, W. J. (1985a). Fears in children and adolescents - Normative data. *Behaviour Research and Therapy*, 23(4), 465-467.
- Ollendick, T. H., Matson, J. L., & Helsel, W. J. (1985b). Fears in visually-impaired and normally-sighted youths. *Behaviour Research and Therapy*, 23(3), 375-378.
- Ollendick, T. H., Yang, B., King, N. J., Dong, Q., & Akande, A. (1996). Fears in American, Australian, Chinese, and Nigerian children and adolescents: A cross-cultural study. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 37(2), 213-220.
- Ollendick, T. H., Yule, W., & Ollier, K. (1991). Fears in British children and their relationship to manifest anxiety and depression. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 32(2), 321-331.
- Oosterman, M., & Schuengel, C. (2007). Physiological effects of separation and reunion in relation to attachment and temperament in young children. *Developmental Psychobiology*, 49(2), 119-128.
- Pavuluri, M. N., Henry, D., & Allen, K. (2002). Anxiety and fear - Discriminant validity in the child and adolescent practitioner's perspective. *European Child & Adolescent Psychiatry*, 11(6), 273-280.
- Pearl, R., & Bay, M. (1999). Psychosocial correlates of learning disabilities. In V. L. Schwaen & D. H. Saklofske (Eds.), *Handbook of psychosocial characteristics of exceptional children* (pp. 443-470). New York: Kluwer Academic/Plenum.

- Poulton, R., & Menzies, R. G. (2002). Fears born and bred: toward a more inclusive theory of fear acquisition. *Behaviour Research and Therapy*, 40(2), 197-208.
- Poulton, R., Waldie, K. E., Menzies, R. G., Craske, M. G., & Silva, P. A. (2001). Failure to overcome 'innate' fear: a developmental test of the non-associative model of fear acquisition. *Behaviour Research and Therapy*, 39(1), 29-43.
- Rachman, S. (1977). Conditioning theory of fear-acquisition - Critical examination. *Behaviour Research and Therapy*, 15(5), 375-387.
- Rachman, S. (1991). Neo-conditioning and the classical theory of fear acquisition. *Clinical Psychology Review*, 11(2), 155-173.
- Rapp, J. T., Vollmer, T. R., & Hovanetz, A. N. (2005). Evaluation and treatment of swimming pool avoidance exhibited by an adolescent girl with autism. *Behavior Therapy*, 36(1), 101-105.
- Reiss, S., & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally-retarded persons. *American Journal of Mental Deficiency*, 87(4), 396-402.
- Reynolds, C. R., & Richmond, B. O. (1997). What I think and feel: A revised measure of children's manifest anxiety (Reprinted from *Journal of Abnormal Child Psychology*, vol 6, pg 271-280, 1978). *Journal of Abnormal Child Psychology*, 25(1), 15-20.

- Ricciardi, J. N., Luiselli, J. K., & Camare, M. (2006). Shaping approach responses as intervention for specific phobia in a child with autism. *Journal of Applied Behavior Analysis, 39*(4), 445-448.
- Russell, E., & Sofronoff, K. (2005). Anxiety and social worries in children with Asperger syndrome. *Australian and New Zealand Journal of Psychiatry, 39*(7), 633-638.
- Rutter, M. (1989). Isle of Wight revisited - 25 years of child psychiatric epidemiology. *Journal of the American Academy of Child and Adolescent Psychiatry, 28*(5), 633-653.
- Rutter, M., Silberg, J., O'Connor, T., & Simonoff, E. (1999). Genetics and child psychiatry: II - Empirical research findings. *Journal of Child Psychology and Psychiatry, 40*(1), 19-55.
- Scherer, M. W., & Nakamura, C. Y. (1968). A Fear Survey for Children (FSS-FC): A factor analytic comparison with manifest anxiety (CMAS). *Behaviour Research and Therapy, 6*, 173-182.
- Schultz, R. T. (2005). Developmental deficits in social perception in autism: the role of the amygdala and fusiform face area. *International Journal of Developmental Neuroscience, 23*(2-3), 125-141.
- Shore, G. N., & Rapport, M. D. (1998). The Fear Survey Schedule for Children-Revised (FSSC-HI): Ethnocultural variations in children's fearfulness. *Journal of Anxiety Disorders, 12*(5), 437-461.

- Taylor, S. (1998). The hierarchic structure of fears. *Behaviour Research and Therapy*, 36(2), 205-214.
- The Foundation for People with Learning Disabilities. (n.d.). Statistics about people with learning disabilities. Retrieved 15 April, 2009, from <http://www.learningdisabilities.org.uk/information/learning-disabilities-statistics/>
- Thomas, G., Barratt, P., Clewley, H., Joy, H., Potter, M., & Whittaker, P. (1998). *Asperger syndrome: Practical strategies for the classroom*. London: The National Autistic Society.
- Thompson, R. A. (2001). Childhood anxiety disorders from the perspective of emotional regulation and attachment. In M. W. Vasey & M. R. Dadds (Eds.), *The developmental psychopathology of anxiety* (pp. 160-182). New York: Oxford University Press.
- Twenge, J. M. (2000). The age of anxiety? Birth cohort changes in anxiety and neuroticism. *Journal of Personality and Social Psychology*, 79, 1007-1021.
- Vandenberg, B. (1993). Fears of normal and retarded-children. *Psychological Reports*, 72(2), 473-474.
- Vandergaag, R. J., Buitelaar, J., Vandenban, E., Bezemer, M., Njio, L., & Vanengeland, H. (1995). A Controlled Multivariate Chart Review of Multiple Complex Developmental Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34(8), 1096-1106.

- Vasey, M. W. (1993). Development and cognition in childhood anxiety - the example of worry. *Advances in Clinical Child Psychology*, 15, 1-39.
- Volkmar, F. R., & Pauls, D. (2003). Autism. *Lancet*, 362(9390), 1133-1141.
- Warren, S. L., & Sroufe, L. A. (2004). Developmental issues. In T. H. Ollendick & J. S. March (Eds.), *Phobic and anxiety disorders in children and adolescents. A clinician's guide to effective psychosocial and pharmacological interventions* (pp. 92-115). New York: Oxford University Press.
- Weems, C. F., & Stickle, T. R. (2005). Anxiety disorders in childhood: Casting a nomological net. *Clinical Child and Family Psychology Review*, 8(2), 107-134.
- Weisbrot, D. M., Gadow, K. D., DeVincent, C. J., & Pomeroy, J. (2005). The presentation of anxiety in children with pervasive developmental disorders. *Journal of Child and Adolescent Psychopharmacology*, 15(3), 477-496.
- Westenberg, P. M., Siebelink, B. M., & Treffers, P. D. A. (2001). Psychosocial developmental theory in relation to anxiety and its disorders. In W. K. Silverman & P. D. A. Treffers (Eds.), *Anxiety disorders in children and adolescents: Research assessment and intervention* (pp. 72-89). Cambridge: Cambridge University Press.
- Wiemer, S. A., & Kratochwill, T. R. (1991). Fears of visually-impaired children. *Journal of Visual Impairment & Blindness*, 85(3), 118-124.
- Wing, L. (1996). *The autism spectrum*. London: Constable.

Wood, J. J., McLeod, B. D., Sigman, M., Hwang, W. C., & Chu, B. C. (2003). Parenting and childhood anxiety: theory, empirical findings, and future directions. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 44(1), 134-151.

World Health Organisation. (1990). *ICD-10 : The ICD-10 classification of mental and behavioural disorders : Clinical descriptions and diagnostic guidelines*: World Health Organisation.

Chapter 2: Sensory Processing and the Fears of Children on the Autism Spectrum

2.1 Abstract

This paper explores the relationship between fear and sensory processing in children on the autism spectrum. A sample of 89 parents of children aged 7-12 years on the autism spectrum completed questionnaires pertaining to their child's sensory processing and fear patterns. Quantitative methodology was used to analyse the data. Results were consistent with previous findings and indicated that children on the autism spectrum display a unique fear profile. A significant relationship was found between sensory difficulty and fear difficulty totals. Furthermore, hyper-responsiveness patterns were found to largely account for the strong sensory relationship with fear.

The relationship between sensory profiles and fearfulness has important clinical implications in the assessment and intervention of phobias for children on the autism spectrum. Further research is needed in this area in order to investigate other relevant variables in fearfulness, and also to advance understanding in the nature of the relationship between sensory processing and fear patterns.

Word Count: 6067

2.2 Introduction

This paper explores the nature of the relationship between fear patterns of children on the autism spectrum and their sensory profiles. There is acknowledgement in the literature that children on the autism spectrum do not follow the same fear development pattern as typically developing children (Matson & Love, 1990). However, there has been no research investigating the *nature* of the fear profile in children on the autism spectrum, furthermore, hypotheses pertaining to the cause of this fear profile have been speculative. There has, however, been considerable research investigating the distinctive sensory processing patterns of children on the autism spectrum (Kern et al., 2007).

2.2.1 The Autism Spectrum

Autism spectrum disorder (ASD¹²) is a term that was introduced by Wing (1996) and refers to a spectrum of conditions including the different subtypes of autism. ASD is characterised by three primary areas of development: communication (verbal and nonverbal), social interaction, and behaviour (repetitive patterns, interests and activities). Classically, these three areas are referred to as the ‘triad of impairments’; and form the core diagnostic criteria for ASD (DSM-IV-TR; American Psychiatric Association, 2000).

Although sensory processing differences between typically developing individuals and individuals on the autism spectrum are widely acknowledged (e.g., Rogers & Ozonoff, 2005; Tomchek & Dunn, 2007), sensory processing patterns are seen as an associated, and

¹² The term ‘ASD’ shall be used in the present paper with reference to diagnosis. The term ‘autism spectrum’ shall be used as the preferred general term.

not essential, feature of diagnostic criteria. Atypical fear profiles, however, do not form part of any ASD nosologic classification. Sensory processing models cannot be seen as all-encompassing solution to ASD symptomatology, however, they provide a useful framework when considering the 'behaviour' component within the triad of impairments.

2.2.2 Fear Development in Children on the Autism Spectrum

Although there is sparse research in the area of typical fear and fear development of children on the autism spectrum, studies have shown that children with a diagnosis of ASD display a different fear profile when compared with chronologically age-matched children (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005; Matson & Love, 1990). The administration of fear survey schedules to groups of children and carers has been the most commonly used method of assessing these fears in both children on the autism spectrum and typically developing children. The Fear Survey Schedule for Children - Revised, (FSSC-R; Ollendick, 1983) is the most frequently used questionnaire for assessing fear quantity and quality in both typical and atypical child populations (see McGowan, 2009a, for a review of fear assessment in children).

Fear research has demonstrated that typically developing children progress through different types and stages of fear as they develop (see McGowan, 2009a, for a review of typical fear development). Infancy sees children becoming fearful of stimuli within their immediate environment (e.g., loud noises; Westenberg, Siebelink, & Treffers, 2001). Separation anxiety is apparent at the end of the first year of life as the child is able to discriminate between familiar and unfamiliar stimuli (Warren & Sroufe, 2004). Preschool

children are most likely to be fearful of animals and this is followed by fears of imaginary phenomena (e.g., ghosts) and the unknown (e.g., the dark; Muris, 2007). By school age children have typically developed fears of harm and danger, these are thought to reflect contextual and experiential factors rather than the biologically determined fears that are exhibited in early life (Bokhorst, Westenberg, Oosterlaan, & Heyne, 2008).

To date, only two empirical studies have specifically investigated fear patterns in children on the autism spectrum (Evans et al., 2005; Matson & Love, 1990). The limited research base that does exist in this area has shown that children on the autism spectrum display a different pattern of fear to that outlined above of typically developing children (McGowan, 2009a). When research data has been analysed using the five-factor solution for the FSSC-R, fear categories that typically developing children endorse more than children on the autism spectrum are fear of failure or criticism, along with fear of harm, danger, and death. Matson and Love (1990) have argued that this trend may be due to the fact that children on the autism spectrum have inadequate knowledge or comprehension of abstract concepts such as 'criticism', 'danger', and 'death' and therefore would not fear them. Furthermore, research in this area, even when broadened to studies of children with pervasive developmental delay (PDD), relies primarily on parent-report data, compared to similar research in typically developing children (Gullone, 2000). Given that many children on the autism spectrum may have limited or no verbal communication, parents possibly receive diminutive feedback pertaining to fear producing stimuli, consequently, the responses being given by the parents may lack validity.

Children on the autism spectrum, typically show more fears associated with the unknown and medical fears (Evans et al., 2005). Fear of the unknown may be linked with characteristics of the autism spectrum such as a general desire for sameness or aversion to certain stimuli. Greater fears for medical situations may well be indicative of the situation-specific fears often presented by children on the autism spectrum (Matson & Love, 1990).

When the items on the FSSC-R are analysed, it is apparent that there are many situations and objects that can be clearly related to sensory processing. Such items include “riding on a train”, “thunderstorms”, “dark places”, and “loud noises”. It is plausible that the special sensory patterns experienced by children on the autism spectrum (see Section 2.2.3) could account for the unique fear profile they appear to exhibit (see McGowan, 2009a, for a review of fear development literature in children on the autism spectrum). Investigations into sensory and fear profile relationships may help to explain the possibly higher fear prevalence in children on the autism spectrum (see Muris, Steerneman, Merckelbach, Holdrinet, & Meesters, 1998, for a discussion on fear and anxiety co-morbidity in children on the autism spectrum). More specifically, such research may help to draw out specific fear patterns in relation to the special sensory profiles of children on the autism spectrum.

2.2.3 Sensory Processing in Children on the Autism Spectrum

Sensory processing refers to the method by which the central nervous system (CNS) receives, organises, and understands sensory information (Miller, Anzalone, Lane, Cermak, & Osten, 2007). There are seven sensory processing systems present within the CNS:

vision, hearing, the vestibular system, olfaction (smell), gustation (taste), the tactile, and proprioceptive systems (see Bogdashina, 2003, for further detail).

Typically developing individuals generally process sensory information without difficulties on a continual basis. Delacato (1974), classified sensitivities in responsiveness to the above sensory systems: '*hyper-responsiveness*' refers to the sensory channel being too 'open', and the brain can easily become stimulated; '*hypo-responsiveness*' refers to the sensory channel not being receptive enough and therefore the brain can easily be deprived of that particular sensory input. It is now believed that sensitivity to sensory stimuli received by the above systems occurs along a continuum from hyper- to hypo-responsiveness (O'Neill & Jones, 1997).

The autism spectrum is considered by some researchers to be a sensory dysfunction as opposed to a social one (e.g., Delacato, 1974; Hatch-Rasmussen, 1995). Originally, research into hyper- and hypo-responsivity in children on the autism spectrum suggested that there were two types of sensory responders. Children were thought to be either predominantly hypo-responsive or hyper-responsive (Dawson & Watling, 2000; Hirstein, Iversen, & Ramachandran, 2001). More recently however, it has been shown that children can fluctuate between the two responsivities (Baranek, Reinhartsen, & Wannamaker, 2001).

2.2.4 Sensory Experiences Questionnaire (Baranek, 1999)

The Sensory Profile (Dunn, 1999) is one of the most widely used sensory processing assessment tools in the literature, and is based upon Dunn's Model of Sensory processing

(Dunn, 1997). A more recently developed tool for caregivers is the Sensory Experiences Questionnaire (SEQ; Baranek, 1999). The SEQ evaluates behavioural responses to everyday sensory experiences in children. It was initially designed to discriminate between sensory features in children with ASD, developmental delay, and typically developing children (aged between 5 months and 6 years). More recently, however, the SEQ has been used in older child populations (see Henshall, 2008).

The theoretical underpinnings of the SEQ follows the model proposed by Baranek, Reinhartsen, and Wannamaker (2001), in which two thresholds for processing sensation – a sensory *orienting* threshold and a sensory *aversion* threshold – result in varying degrees of hypo- and/or hyper-responsiveness. Unlike in the Sensory Profile measure, SEQ items are further devised to show whether the sensory experiences occur in a predominantly social context (e.g., tolerating physical contact with people) or non-social context (e.g., responding to loud noises or textured objects).

Baranek et al. (2006) utilised the SEQ with caregivers of 258 children, aged 5-80 months, in different diagnostic groups (including children with ASD, PDD, developmental delay (DD) and typically developing children). Sensory symptoms were found to be highest in the ASD group, followed by the PDD group, and lowest in the typical group. Furthermore, the SEQ was able to distinguish specific sensory patterns between groups. A unique pattern of hypo-responsiveness was found in the ASD group in both social and non-social contexts. Interestingly, hypo-responsiveness to sensory stimuli was exacerbated under social contexts for children with ASD. A similarity in hyper-responsiveness was found

between the ASD and DD group, this was significantly greater compared to the typically developing group. In summary, children with ASD were found to have deficiencies in both hypo- and hyper-responsivity, similar findings have also been found in more recent research (e.g., Henshall, 2008).

2.2.5 Sensory Profiles, Fear Development and the Autism Spectrum

Despite decades of phenomenological reports documenting the presence of special sensory features in autism (Jones, Quigney, & Huws, 2003), no research exists that links the unique nature of these features to the experience of fear. It is plausible that a special sensory pattern could account for a proportion of the unique fear profile of children on the autism spectrum. For example, it would correspond that a child who has auditory hypersensitivity may endorse high fear ratings for “loud sirens”. Similarly, a child who has a hyposensitive visual system may endorse high fear ratings for “dark places”.

Matson and Love (1990) found that children on the autism spectrum were more fearful of Factor 2 items on the FSSC-R (‘Fear of the Unknown’). Items loaded onto this factor include “going to bed in the dark”, “loud sirens”, and “being in a big crowd”. Factor 2 items of the FSSC-R are largely non-social, concrete and situation-specific fears, there is also a clear sensory component to many of these same items.

Table 2.1

The Seven Sensory Systems in Relation to Hypo- and Hyper-Responsiveness Patterns

	Description	Hypo-Responsive	Hyper-Responsive
Vision	The faculty of seeing	<ul style="list-style-type: none"> May see things darker or lose features or lines May concentrate on peripheral vision because their central vision is blurred (or converse) Poor depth perception – problems with throwing and catching: clumsiness 	<ul style="list-style-type: none"> Distorted vision occurs Small objects and bright lights can jump around Focusing on particular details such as sand grains may be more pleasurable than looking at something as a whole
Hearing	The faculty of perceiving sounds	<ul style="list-style-type: none"> The individual may not acknowledge particular sounds May enjoy crowded noisy places, kitchens, bangs doors and objects 	<ul style="list-style-type: none"> Volume of noise can be magnified and surrounding sounds distorted and muddled Inability to cut out particular sounds, leading to difficulties concentrating May have a lower hearing threshold, sensitivity to auditory stimuli
Vestibular	Refers to the structures within the inner ear that detect movement and changes	<ul style="list-style-type: none"> The need for rocking, swinging, spinning 	<ul style="list-style-type: none"> Difficulties in activities which include movement – sport Difficulties in stopping quickly or during an activity
Olfaction	The faculty of perceiving odours or scents	<ul style="list-style-type: none"> Some individuals have no sense of smell and fail to notice extreme odours Individuals may lick objects 	<ul style="list-style-type: none"> Smells can be intensified and become overpowering Toileting problems Dislike of individuals with distinctive perfumes
Gustation	The faculty of perceiving the sensation of soluble substance caused by contact with that substance	<ul style="list-style-type: none"> Likes very spicy foods Pica: eats non-nutritious substances e.g., soil, grass 	<ul style="list-style-type: none"> Some flavours and foods are experienced as too strong and over-powering Certain textures may cause discomfort. Some children will only eat smooth foods such as mashed potato or ice-cream
Tactile	The faculty of perceiving touch, pressure, pain, temperature	<ul style="list-style-type: none"> Holds others tightly Has high pain or temperature threshold Self-harming May enjoy heavy objects on top of them 	<ul style="list-style-type: none"> Touch can be painful and uncomfortable and may often withdraw from aspects of touch, which can have a grave effect on relationships with others Difficulties in brushing and washing hair Only likes certain types of clothing, textures
Proprioceptive	The faculty of perceiving stimuli produced within an organism, especially relating to the position of the body	<ul style="list-style-type: none"> Proximity – standing too close to others Lack of awareness of personal body space Difficulties in navigating rooms – avoiding obstructions, bumping into people 	<ul style="list-style-type: none"> Difficulties with fine motor skills Manipulating small objects (buttons, tying shoes laces) Movement of the whole body to look at something

(Based on Bogdashina, 2003; Smith-Myles, Tapscott-Cook, Miller, Rinner, & Robbins, 2000)

2.2.6 Aim

Research into the relationship between fear and sensory processing in children on the autism spectrum has several potential benefits. It is possible that sensory profiles become a predictor of fear development, thus, contributing to a new model of fear development in children on the autism spectrum. There are also several clinical implications for the current study. Interventions and treatment plans for helping children to cope with fears would be drawn from an evidence-base and therefore be more efficacious.

The current research utilises a survey design methodology, two main aims will be investigated:

1. To investigate the profile of fear and sensory experience questionnaire scores in relation to demographic variables (i.e., age, gender, and diagnosis).
2. To investigate the relationship between sensory experiences and fear by analysing questionnaire variables with particular reference to hyper- and hypo-responsiveness patterns across social and non-social domains.

2.3 Methodology

2.3.1 Participants

The participants in the present study were parents of children aged between 7 and 12 years of age (inclusive) with a diagnosis on the autism spectrum.

i) Experimental Group 1

Experimental group 1 consisted of 47 parents¹³ of children on the autism spectrum, and were a website-only sample. Of the index children in this group, 3 were female and 44 were male; their ages ranged from 7 to 12 years, with a mean age of 8 years and 10 months. This group comprised of 38 children with ASD, 6 children with Asperger Syndrome (AS), and 3 children with high functioning autism (HFA)¹⁴. They were largely recruited through regional and national autism charities, however, some participants¹⁵ were recruited from clinical sources (as per Section 2.3.5) and chose to complete the study through the website.

ii) Experimental Group 2

Experimental group 2 consisted of 42 parents of children on the autism spectrum, 40 mothers and 2 fathers. Participants in this sample completed postal questionnaires and

¹³ Information was not available pertaining to the ratio of mothers to fathers in this sample. The website section asked participants to provide information on the 'person completing the form', options parent/guardian/carer. All participants in experimental group 1 were parents.

¹⁴ HFA is a form of autism, with similar diagnostic criteria to Asperger syndrome. Typically children with a diagnosis of HFA will have experienced a significant language delay (see Carpenter, Soorya, & Halpern, 2009).

¹⁵ Due to the anonymised method of data collection through the website, the exact proportion of participants that were clinically recruited is through this method is unknown.

were all recruited through local NHS services¹⁶. The age of the index children ranged from 7 to 12 years, with a mean age of 8 years and 10 months; 11 children were female and 31 were male. 26 children in the group were classified by their parents as having ASD, and 16 with AS.

The purpose of selecting participants via both NHS and non-NHS routes was to ensure that no specific mental health or sensory integration difficulties were determined by a particular recruitment pathway. Children with known co-morbid psychiatric diagnoses, and other syndromes were excluded from the research in order to minimise possible confounding variables regarding the relationship between sensory processing and fears in children on the autism spectrum. Similarly, children who were deaf/blind were not included in the research, since these children already experience sensory impairments, and possibly fears, that are largely related to their sensory impairments rather than autism spectrum traits.

2.3.2 Design

The present study operated a survey design whereby all participants completed the same measures.

2.3.3 Measures

Three measures were completed by participants, the demographic questionnaire, the Sensory Experiences Questionnaire (SEQ; Baranek, 1999), and the Fear Survey Schedule

¹⁶ Child and Adolescent Mental Health services (CAMHS) from two NHS Trusts were used for recruitment in the present study.

for Children – Revised (FSSC-R; Ollendick, 1983). Copies of these measures can be found in Appendix 2.1, 2.2, and 2.3 respectively.

i) Demographic Questionnaire

The participants were asked to complete a general information questionnaire outlining demographics of their child such as gender, age, and diagnoses.

ii) Sensory Experiences Questionnaire (Baranek, 1999)

The short-form of the SEQ (Baranek, 1999) was used to collect data about children's behavioural responses to everyday sensory events. Cronbach's alpha coefficient for the overall consistency of the SEQ (21-item version) has been found at .80, with a test-retest reliability also at .80 (intraclass correlation coefficient; Baranek et al., 2005). A validity study with 258 caregivers of children aged 5 to 80 months found that the SEQ discriminated well between children with ASD, those with developmental delay, and with typically developing children (Baranek et al. 2006). The short-form of this measure was employed in the present study, with children aged 7-12 years (inclusive). The author of the SEQ was contacted prior to the study commencement to request permission and advise suitability of the measure, both of these were granted favourable opinion.

iii) Fear Survey Schedule for Children – Revised (Ollendick, 1983)

Fear construct data was collected by using the FSSC-R (Ollendick, 1983). Norms for children and adolescents between 7 and 16 years of age are available for this measure (Ollendick et al., 1989). The FSSC-R possesses a relatively robust 5 factor structure that

has been replicated across age, sex, and nationalities¹⁷ (e.g., Fonseca, Yule, & Erol, 1994; Ollendick, Yang, King, Dong, & Akande, 1996). The reliability of the FSSC-R has been examined in two principal ways: internal consistency coefficients and test-retest reliabilities. Cronbach's alpha coefficients for the total fearfulness score have consistently been reported to be above .90, with the factor subscale scores ranging from .57 to .89 (Friedman, Campbell, & Okifuji, 1991; King, Tonge, & Ollendick, 1992). The test-retest reliability for overall fearfulness has been estimated to be .82 for one week, .85 for two weeks, and .62 for three months (King, Gullone, & Ollendick, 1992; Ollendick, 1983). This measure also has been found to possess good convergent and divergent validity (Weems, Silverman, Saavedra, Pina, & Lumpkin, 1999). The author of the FSSC-R was contacted prior to the study to request permission to use the measure and also to assess its suitability in the present research, the author responded positively on both counts.

2.3.4 Questionnaire Scoring

i) Demographic Questionnaire

The data gathered from this questionnaire was not quantitatively scored, rather used to verify inclusion eligibility and also to provide further information for the analysis by way of categorical variables (i.e., gender, age, and diagnoses).

ii) Sensory Experiences Questionnaire (Baranek, 1999)

The conceptual model of the SEQ follows the framework depicted by Baranek, Reinhartsen, and Wannamaker (2001), whereby two thresholds for processing sensation – a

¹⁷ The FSSC-R version used in the present study has UK spelling and language amendments

sensory orienting threshold and a sensory aversion threshold – shift to result in varying degrees of hypo- and/or hyper-responsiveness seen behaviourally. Therefore, the SEQ items largely reflect hyper- and hypo-responsiveness patterns.

Hypo-responsive difficulties would be indicated by high scores on items such as “Does your child stare at lights or objects that spin and move?”. Hyper-responsive difficulties would be indicated by high scores on items such as “Does your child dislike cuddling or being held?”. In addition to this, the SEQ items are devised to show whether the sensory experiences occur in a predominantly social context. An example of a *hypo-responsive social* question would be “Does your child ignore you when you tap him/her on the shoulder for attention?”. An example of a *hyper-responsive non-social* question would be “Does your child refuse to try new foods or avoid certain tastes, smells, or textures of food?”.

In order to investigate the nature of the relationship between sensory processing and fear patterns, the total level of sensory processing difficulties was used and the overall sensory processing patterns of hyper- and hypo-responsiveness were also calculated. More specifically, the hyper- and hypo-responsiveness to social and non-social stimuli subscales were determined, as were the sensory system category scores (i.e. auditory, tactile, visual, tactile, gustatory/olfactory, and vestibular/proprioceptive)¹⁸. Cut-off scores are provided by the author pertaining to the predecessor to the SEQ, the Sensory Experiences Supplement

¹⁸ Sensory system category scores are not a primary part of the data analysis, however, the data is available to view in Appendix 2.12.

Questionnaire, these are divided into cut-offs for the *Typical Range*, *At Risk Range*, and the *Deficient*¹⁹ *Range*.

iii) Fear Survey Schedule for Children – Revised (Ollendick, 1983)

The FSSC-R requires a rating of fear for different situations and stimuli at three levels (“none”, “some”, or “a lot”). There are 80 items in total that are presented in no particular order. The final item asks the participant to include any fears that have not already been presented. In order to investigate possible relationship variables with sensory processing data, the data from the FSSC-R was scored in terms of general fearfulness and the five factor structure: Failure and Criticism, The Unknown, Minor Injury and Small Animals, Danger and Death, and Medical Fears.

2.3.5 Procedure

i) Experimental Group 1

Experimental group 1 participants were largely self-selected through regional and national autism charity advertisements on relevant newsletter and recruitment web-pages. A proportion of this group were also recruited through clinical samples and chose to complete the study online. Participants were directed to the research webpage and asked to read the participant information section, complete the demographic information and consent to taking part in the study. Participants who completed this form were then automatically sent

¹⁹ The labels provided for the cut-off scores are those chosen by Baranek et al. (2001), and are not the author’s preferred terms. These labels were derived from a different research version of the SEQ and therefore will not be applied to the present data.

a link to their email address which enabled them to access the remaining two questionnaires online. Additional contact information for the researcher was provided during each stage.

ii) Experimental Group 2

Experimental group 2 participants were identified through different local NHS CAMHS services²⁰. Parents were sent a cover letter and information sheet about the research from the relative head of service or lead clinician. Parents were asked to return the ‘consent to be contacted form’ in a prepaid envelope if they wished to be contacted directly by the researcher regarding the study. Participants were then sent a consent form and the three questionnaires in the post with a prepaid addressed envelope for return. Parents were provided with additional contact details for the researcher in the event of a query. Copies of relevant recruitment documentation sent to participants can be located in Appendix 2.7, 2.8, 2.9 and 2.10.

²⁰ Ethical details regarding consent and ethical approval can be found in Appendix 2.4, 2.5 and 2.6.

2.4 Results

The data was analysed in four parts in relation to the aims of the study²¹. The first part investigated independence of the two recruitment sources, i.e., website and CAMHS service recruitment. The second and third part analysed SEQ and FSSC-R scores, respectively, in relation to demographic variables. The final part of the analysis investigated relationships between the subscales of the two questionnaires.

2.4.1 Differences between Recruitment Groups

In order to establish differences between the two groups in terms of categorical variables²², chi-square tests were administered²³. No significant difference was found between age category and recruitment source ($p > .05$)²⁴. A significant difference was established between gender and recruitment source, $\chi^2(1) = 5.16, p < .05$, with higher than expected numbers of females existing in the CAMHS paper-based questionnaire group.

Two independent sample t-tests²⁵ were carried out to investigate differences between the recruitment source and the total questionnaire scores. No significant differences were found for the SEQ ($p > .05$) or FSSC-R ($p > .05$) totals, see table 2.2 below.

²¹ Power calculations were carried out and are located in Appendix 2.11.

²² The categorical variables in this analysis were age category (7-9 years, 10-12 years) and gender (male, female).

²³ Where the categorical data sets both have 2 levels (i.e., a contingency table of 2x2), Yates' continuity correction has been applied.

²⁴ Significance is calculated at the .05 level throughout the results unless otherwise stated.

²⁵ Where between group parametric statistics are referred to in this study, homogeneity of variance has been established.

Table 2.2

Mean Scores and Standard Deviations for total SEQ and FSSC-R scores by recruitment group

	Experimental Group 1 (N=47)	Experimental Group 2 (N=42)
SEQ Total	72.79 (17.28)	75.17 (14.17)
FSSC-R Total	138.32 (26.76)	147.69 (30.24)

As stated, there was no significant difference between age category and experimental group. There was a significant difference between gender and experimental group, however, the proceeding part of the analysis demonstrates that there is no difference between gender and questionnaire totals (see Sections 2.4.2 and 2.4.3). Importantly, there was no significant difference between questionnaire totals for recruitment source. For these reasons, from this point onwards, the data from the two groups is pooled (n=89).

2.4.2 Sensory Experiences Questionnaire (Baranek, 1999)

i) Descriptives

Table 2.2 shows a fairly even profile of sensory difficulties in the present sample, with children scoring highest on hyper-responsivity to social items, and lowest on hypo-responsivity to non-social items. No normative data from this SEQ version is available to provide comparisons with the present SEQ data.

Table 2.3

Mean Scores for the SEQ in Relation to Hypo- and Hyper-Responsiveness Subscales

	Total	Hypo-responsive			Hyper-responsive		
	SEQ	Total	Social	Non-Social	Total	Social	Non-Social
Mean (standard deviation; s.d.)	73.83 (15.92)	34.66 (9.07)	13.91 (3.91)	20.75 (6.11)	39.17 (8.66)	18.50 (4.72)	20.67 (4.99)
Mean of the proportion ²⁶	.57	.53	.56	.52	.60	.62	.59

ii) Age

Pearson's product-moment correlation coefficient²⁷ was used to investigate the relationship between age and SEQ totals. No significant relationship was found between age and total SEQ score ($p > .05$).

iii) Gender

An independent sample t-test was administered in order to investigate the difference between gender and SEQ totals. No significant difference in scores was found for the SEQ ($p > .05$) between the gender groups.

iv) Diagnosis

A one-way analysis of variance (ANOVA) was used to investigate the difference in total SEQ scores between diagnostic groups²⁸. No significant difference was found between diagnostic group and SEQ totals ($p > .05$).

²⁶ Means of the proportion are calculated since there are an unequal number of items in each factor.

²⁷ Where correlations are referred to in this study, preliminary analyses were performed to ensure to violations of the normality, linearity, and homoscedasticity

²⁸ Diagnostic groups in the pooled sample were ASD (n=64), AS (n=22), and HFA (n=3). Due to low numbers of children in the HFA category, separate results will not be described. The data from the HFA category is still used as part of the pooled sample.

2.4.3 Fear Survey Schedule for Children – Revised (Ollendick, 1983)

i) Descriptives

The means and standard deviations (s.d.) from factors on the FSSC-R can be considered against British normative data (Ollendick, Yule, & Ollier, 1991), see Table 2.3. All of the scores in the present sample fall within one standard deviation of the normative data, with the exception of ‘Fear of Danger and Death’ which falls within two standard deviations below the normative mean. Rankings for fear factors are different across the two groups, with children in the present sample having most items associated with ‘Medical Fears’ and the normative sample having most fears associated with ‘Danger and Death’. Fears associated with injury and death are ranked lowest for the children on the autism spectrum (5th and 4th respectively).

Table 2.4
Ranked²⁹ Mean Subscale Scores for the FSSC-R

FSSC-R Factor	Present Autism Spectrum Sample n = 89		Typically Developing Children n = 327	
	Mean (s.d.)	Rank	Mean (s.d.)	Rank
Total Fear	142.74 (28.68)	-	138.33 (25.87)	-
Fear of Failure and Criticism	44.65 (12.69)	2	40.03 (7.52)	2
Fear of the Unknown	33.06 (7.61)	3	29.20 (6.70)	3
Fear of Animals and Minor Injuries	27.13 (7.53)	5	27.25 (4.86)	5
Fear of Danger and Death	19.58 (6.07)	4	27.35 (4.86)	1
Medical Fears	8.16 (2.53)	1	6.47 (1.76)	4

(Normative data from Ollendick et al., 1991)³⁰

²⁹ Rankings are calculated by proportions of the mean due to unequal item numbers across factors.

³⁰ The author acknowledges the age of this normative data. The author also acknowledges the different age category used in the Ollendick et al. (1991) sample, 8-10 years compared to 7-12 years in the present sample. However, in the present data, age has not been found to be related to FSSC-R scores.

ii) Age

Pearson's product-moment correlation coefficient was used to investigate the relationship between age and FSSC-R totals. No significant relationship was found between age and total FSSC-R score ($p > .05$).

iii) Gender

An independent sample t-test was administered in order to investigate the difference between gender and FSSC-R totals. No significant difference in scores was found for the FSSC-R with gender ($p > .05$).

iv) Diagnosis

An ANOVA³¹ was used to investigate the difference in total FSSC-R scores between diagnostic groups. A significant difference was found between the three diagnostic groups, $F(2, 86) = 6.94, p < .05$. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for children with a diagnosis of AS ($M = 160.00, SD = 27.06$) was significantly different to the mean score for children with a diagnosis of ASD ($M = 138.05, SD = 27.20$), $p < .01$.

³¹ An ANOVA was carried out since the diagnostic category variable had three levels. Results for children with HFA however will not be reported. Please refer to footnote 18 and also Section 2.5.2.

2.4.4 Relationships between the SEQ and FSSC-R

Pearson product-moment correlation coefficients were used to investigate relationships between questionnaire totals, and also relationships between hypo- and hyper-responsiveness subscales in the social and non-social domain with FSSC-R factors.³²

i) Total FSSC-R Scores with Total SEQ Scores

A significant positive relationship was found between the SEQ total and FSSC-R total scores ($r = .33, p < 0.05$).

ii) Hypo- and Hyper-Responsiveness on the SEQ and FSSC-R Factors

The hypo-responsiveness scale on the SEQ was found to have a significant positive relationship with 'Fear of the Unknown' ($r = .23, p < .05$), and also a significant positive relationship with 'Medical Fears' ($r = .25, p < .05$).

A significant positive relationship was found between the hyper-responsiveness subscale and the total fear score ($r = .45, p < .001$). Hyper-responsiveness was also found to have significant relationships with most of the FSSC-R subscales. Significant positive relationships were found with 'Fear of Failure and Criticism' ($r = .38, p < .001$), 'Fear of the Unknown' ($r = .48, p < .001$), 'Fear of Minor Injury and Small Animals' ($r = .27, p < .05$), and 'Medical Fears' ($r = .40, p < .001$). The only subscale not found to have a significant association with hyper-sensitivity was 'Fear of Danger and Death' ($p > .05$).

³² SEQ sensory system subscale and FSSC-R factor correlations are not directly related to the aims of the present study. These results, however, are located in Appendix 2.12.

iii) *Social and Non-Social Domains*³³ on the SEQ and FSSC-R Factors

There are seven significant correlations with fear subscales for both the social and non-social domains (see Table 2.5). The hyper-responsiveness scale was found to have several significant relationships with fear factors across both social and non-social domains. All of the factors on the FSSC-R had a significant relationship with hyper-responsiveness in the social domain. Only two factors on the FSSC-R were found to have a non-significant relationship with hyper-responsiveness in the non-social domain: 'Fear of Animals and Minor Injury' ($p > .05$) and 'Fear of Danger and Death' ($p > .05$). These two fear factors were ranked lowest for children in the present sample (see Table 2.4).

Table 2.5

Correlations (Pearson product-moment coefficient r values) for the Social and Non-Social Variables of the SEQ with the FSSC-R Subscales

FSSC-R Subscale	Hypo-Responsive		Hyper-Responsive	
	Social	Non-Social	Social	Non-Social
Total Fear	.212 *	.093	.379**	.240**
Fear of Failure and Criticism	.131	.109	.359**	.284**
Fear of the Unknown	.276**	.171	.373**	.322**
Fear of Animals and Minor Injuries	.089	.039	.203	.296**
Fear of Danger and Death	.169	.001	.130	.104*
Medical fears	.248*	.214**	.394**	.072**

N.B. * denotes a significant relationship at the .05 significance level; ** denotes a significant relationship at the .01 significance level.

³³ To clarify for the reader, *hypo-responsive* items are those that children are not easily stimulated by, a *social* difficulty may be ignoring someone when they are tapped on the shoulder for attention, a *non-social* difficulty may be smelling objects during activities. *Hyper-responsive* items are those that children are easily stimulated by, a *social* difficulty may be a dislike of being tickled, a *non-social* difficulty may be a strong reaction to unexpected or loud noises.

2.5 Discussion

2.5.1 Summary of Findings

To summarise the results of study, children in the present autism spectrum sample were found to display relatively equal levels of fear to their typically developing peers. The types of feared stimuli however for the present sample were different to existing normative data. Furthermore, sensory processing experiences, hyper-responsivity in particular, were found to share significant positive relationships with the said unique fear profile.

The present study had several aims, before these aims could be investigated, differences between the recruitment sources were established. Gender categories were not equally expected between the recruitment sources. Age levels, however, were as expected.

Importantly, no difference in total SEQ and FSSC-R scores was found between the two recruitment sources. The data set was therefore pooled for all further analysis. The first investigational aim was to establish differences between the demographic variables for both the SEQ and FSSC-R data. The second aim was to investigate relationships between the SEQ and FSSC-R subscales.

In terms of descriptive outcomes for the SEQ, children in the present sample represented a fairly even profile across hypo- and hyper-responsiveness subscales and also a relatively even profile when further divided into social and non-social domains. According to the parent-reports, children on the autism spectrum in the present study experienced most of their difficulties in hyper-responsive social situations. In terms of demographic variables

for the SEQ, no significant relationship was found between age and total score. Existing research investigating sensory experiences and age is limited (e.g., Kern et al., 2007), so it is difficult to draw conclusions based on past research. Similarly, no significant difference was found between gender and total SEQ score or diagnostic group and total SEQ score.

Descriptive statistics from the FSSC-R (see Table 2.4) show that there is a similar overall level of fearfulness for children in the present study compared to typically developing children. The factor fear rankings between the children, however, are different. In the present study, children on the autism spectrum had most endorsements for situationally-specific fears i.e., 'Medical Fears' (rank 1) and 'Fear of the Unknown' (rank 3). This finding supports previous fear research in children on the autism spectrum (Evans et al., 2005; Matson & Love, 1990). It has been established that typically developing children experience fears mostly associated with 'Danger and Death' (Ollendick et al., 1991), however this factor was ranked at position 4 for children on the autism spectrum in the present study. It has also been shown that children with intellectual disabilities are largely afraid of 'Minor Injury and Small Animals' (Gullone, 1996), this fear factor was ranked last (position 5) in the present study. Interestingly, 'Fear of Failure and Criticism' was prevalent in the present sample and ranked 2nd, which is comparable with fear rankings in typically developing children (Ollendick et al., 1991). A quarter of the present sample consisted of children with Asperger syndrome, with possibly more included under the umbrella 'ASD' category. Children with higher IQs are more likely to understand abstract concepts such as 'failure' and criticism, and it is possible that higher endorsements would have been from these children.

In terms of the FSSC-R and demographic variables, no significant relationship was found between age and total score. This is in direct contrast to results for typically developing children and children with intellectual disabilities, where FSSC-R scores are found to decrease with age (see McGowan, 2009a). No significant difference was found between gender groups and FSSC-R totals. Again, this is in contrast to research which suggests that females consistently report higher fear scores than males (e.g., Gullone, 2000; Li & Morris, 2007). The results did, however, demonstrate a significant difference between diagnostic groups for FSSC-R totals. The analysis indicated that children categorised as having Asperger syndrome were significantly more fearful than children categorised as having ASD. The principal diagnostic differentials between these two groups are IQ and language development. It has been shown in the PDD literature that IQ has a positive relationship with levels of anxiety (Gillott, Furniss, & Walter, 2001). This relationship has also been demonstrated in levels of fearfulness in children with intellectual disabilities (Muris, Merckelbach, & Luijten, 2002). However, it could be hypothesised in the present study, children with Asperger syndrome are likely to be more verbally expressive than other children on the autism spectrum. Parents' responses are therefore more likely to be accurate pertaining to fearful stimuli.

The final and principal aim of the study was to investigate the relationship between FSSC-R and SEQ scores. It was primarily established that there was a strong positive relationship between SEQ and FSSC-R totals. Since higher scores on both measures indicated higher difficulties, this suggests that the more sensory difficulties that are experienced, the more fearful children are.

Hypo-responsiveness was found to have a significant positive relationship with situational factor subscales on the FSSC-R, i.e., 'Medical Fears' and 'Fear of the Unknown'. *Hyper*-responsiveness was found to have significant positive relationships with all of the factors on the FSSC-R, apart from 'Fear of Danger and Death'. It could be concluded therefore that hyper-responsiveness difficulties are strongly related to fearfulness.

The social and non-social domains of the SEQ were also considered (see Table 2.2). Both social and non-social sensory difficulties shared significant positive relationships with FSSC-R factors. These relationships however were most prevalent in patterns of hyper-responsiveness.

2.5.2 Methodological Concerns and Future Research

In the present study, only parents of children on the autism spectrum were included in the sample. This was due to the exploratory nature of the investigation, and also the time constraints of the study. However, where some of the data has been compared to existing normative data, the current experimental design would have been more robust if a control group, consisting of typically developing children, was used for the same age range.

The age range in the present study was 7-12 years inclusive in order to build upon the original SEQ studies which used younger children (Baranek et al., 2006). The age range in the sample was also divided into two three-year age brackets for comparisons. However, it may have been more useful to adopt an age range that was directly related to either developmental stages or school-age. Furthermore, some studies have considered both

chronological-age and mental-age (i.e., cognitive capacity) in their comparisons (e.g., Evans et al., 2005); no IQ data was available in the present study. These are all important considerations for further research in this area.

Regarding the factor structure used to analyse the FSSC-R, this structure has not been extensively researched in children on the autism spectrum. Similar caution should also be applied when considering the representativeness of the present sample. Whereas the present results can be broadly compared to existing fear research in children on the autism spectrum, they cannot be *robustly* generalised to children on the autism spectrum as a whole (heterogeneous) population.

Significant differences between diagnostic groups were reported in relation to FSSC-R totals. However, several problems exist relating to how these diagnostic categories were established. Website participants were asked if their child had received a formal diagnosis, this was not verified for paper-based participants since they were all identified for this study by CAMHS professionals. Differences exist in how professionals make diagnoses on the autism spectrum and also how these diagnoses are perceived by parents (Klin, Lang, Cicchetti, & Volkmar, 2000). For example, children with Asperger syndrome may have been included in the ASD category due to the way a diagnosis was delivered or perceived. This idiosyncratic diagnosis process means that present results relating to diagnostic category should be interpreted with caution. Further research in this area may wish to clarify the diagnosis of the participants, and even include diagnostic categories outside of

the autism spectrum, e.g., attention deficit hyperactivity disorder and obsessive-compulsive disorder.

A further limitation of the present study is in the fact that it utilised parent-reports for data collection. Research in children with disabilities has shown that parents tend to under-report the fears of their children in terms of frequency and severity (e.g., Knapp, Barrett, Groden, & Groden, 1992). Due to the nature of the disability in the present sample, parents may have found it difficult to rate which stimuli are indeed fear-producing in their children, especially where verbal language is impaired. Further to this, a number of the participants in the present study endorsed a fear rating of “0 = not at all” for items in the FSSC-R that their children had not encountered or would not understand e.g., “Russia”. It is an important consideration for future research that measures are suitably adapted so they are relevant to the population being investigated.

2.5.3 Clinical Implications

Where it cannot be assumed that children on the autism spectrum share a similar sensory profile, it can be assumed that they experience increased sensory difficulties compared to other children (Baranek et al., 2006). The present study has shown that hyper-sensitivity difficulties are strongly related to overall fearfulness. It may be possible that clinical psychology and occupational therapy professionals work in alliance in tailoring intervention packages for children on the autism spectrum. This would be highly relevant in the case of phobias, where, traditionally, a behavioural approach of graded-exposure is adopted (e.g., Ricciardi, Luiselli, & Camare, 2006). Assessments of sensory experiences

could be incorporated into the assessment of phobic difficulties in children on the autism spectrum, such assessments would inform formulation and lead to effective clinical interventions.

Although it was not a principal aim of the investigation, results from the present study supported the notion that the fear profile for children on the autism spectrum is different from that of children with disabilities and typically developing children. Awareness of 'typical' fears in children on the autism spectrum should be raised given the relevance in home, social, educational, and health environments. It has been demonstrated that children on the autism spectrum evince high levels of fear in medical situations. It follows therefore, that in order to reduce the levels of distress in these children, medical professionals, such as general practitioners and dentists, have enhanced training relevant to the needs of children on the autism spectrum.

2.5.4 Summary

Overall, the findings from the present study suggest that children on the autism spectrum have a unique fear profile pertaining to the nature of these fears when compared with other children. This is concordant with existing fear research in children on the autism spectrum. The results demonstrate that there is a strong positive relationship between sensory difficulties and fearfulness. Difficulties in hyper-sensitivity have been found to account for much of the relationship with fear. Further research is required in this area to investigate alternative hypotheses and also establish clarity in the relationship between sensory experiences and fearfulness.

2.6 References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, fourth edition-text revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association.
- Baranek, G. T. (1999). *Sensory Experiences Questionnaire manual (SEQ)*. Unpublished manuscript. University of North Carolina at Chapel Hill.
- 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., Reinhartsen, D., & Wannamaker, S. (2001). Play: Engaging children with autism. In R. Huebner (Ed.), *Sensorimotor interventions in autism*. Philadelphia: F. A. Davis.
- Bogdashina, O. (2003). *Sensory perceptual issues in autism and Asperger Syndrome*. London: Jessica Kingsley.
- Bokhorst, C. L., Westenberg, P. M., Oosterlaan, J., & Heyne, D. A. (2008). Changes in social fears across childhood and adolescence: Age-related differences in the factor structure of the Fear Survey Schedule for Children-Revised. *Journal of Anxiety Disorders*, 22(1), 135-142.

Carpenter, L. A., Soorya, L., & Halpern, D. (2009). Asperger's Syndrome and High-Functioning Autism. *Pediatric Annals*, 38(1), 30-35.

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.

Delacato, C. (1974). *The ultimate stranger: The autistic child*. Novato, CA: Academic Therapy Publications.

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(4), 23-35.

Dunn, W. (1999). *The sensory profile manual*. San Antonio: The Psychological Corporation.

Evans, D. W., Canavera, K., Kleinpeter, F. L., Maccubbin, E., & Taga, K. (2005). The fears, phobias and anxieties of children with Autism Spectrum Disorders and Down Syndrome: Comparisons with developmentally and chronologically age matched children. *Child Psychiatry & Human Development*, 36(1), 3-26.

Fonseca, A. C., Yule, W., & Erol, N. (1994). Cross-cultural issues. In T. Ollendick, N. King & W. Yule (Eds.), *International handbook of phobic and anxiety disorders in children and adolescents. Issues in clinical child psychology* (pp. 67-84). New York: Plenum Press.

- Friedman, A. G., Campbell, T., & Okifuji, A. (1991). Specific fears as predictors of generalised anxiety in children *Journal of Psychopathology and Behavioral Assessment*, 13(1), 45-52.
- Gillott, A., Furniss, F., & Walter, A. (2001). Anxiety in high-functioning children with autism. *Autism*, 5(3), 277-286.
- Gullone, E. (1996). Normal fear in people with a physical or intellectual disability. *Clinical Psychology Review*, 16(8), 689-706.
- Gullone, E. (2000). The development of normal fear: A century of research. *Clinical Psychology Review*, 20(4), 429-451.
- Hatch-Rasmussen, C. (1995). Sensory integration. Retrieved 14 April, 2009, from <http://www.autism.com/families/therapy/si.htm>
- Henshall, C. (2008). An exploration into the sensory processing patterns of children on the autism spectrum. Unpublished doctoral dissertation. University of Warwick & Coventry University.
- Hirstein, W., Iversen, P., & Ramachandran, V. S. (2001). Autonomic responses of autistic children to people and objects. *Proceedings of the Royal Society of London Series B-Biological Sciences*, 268(1479), 1883-1888.
- Jones, R. S. P., Quigney, C., & Huws, J. C. (2003). First-hand accounts of sensory perceptual experiences in autism: a qualitative analysis. *Journal of Intellectual & Developmental Disability*, 28(2), 112-121.

- Kern, J. K., Trivedi, M. H., Grannemann, B. D., Garver, C. R., Johnson, D. G., Andrews, A. A., et al. (2007). Sensory correlations in autism. *Autism, 11*(2), 123-134.
- King, N. J., Gullone, E., & Ollendick, T. H. (1992). Manifest anxiety and fearfulness in children and adolescents *Journal of Genetic Psychology, 153*(1), 63-73.
- King, N. J., Tonge, B. J., & Ollendick, T. H. (1992). Nighttime fears in children. *Journal of Paediatrics and Child Health, 28*(5), 347-350.
- Klin, A., Lang, J., Cicchetti, D. V., & Volkmar, F. R. (2000). Brief report: Interrater reliability of clinical diagnosis and DSM-IV criteria for autistic disorder: Results of the DSM-IV autism field trial. *Journal of Autism and Developmental Disorders, 30*(2), 163-167.
- Knapp, L. G., Barrett, R. P., Groden, G. G., & Groden, J. (1992). The nature and prevalence of fears in developmentally disabled children and adolescents: A preliminary investigation. *Journal of Developmental and Physical Disabilities, 4*(3), 195-203.
- Li, H. J., & Morris, R. J. (2007). Assessing fears and related anxieties in children and adolescents with learning disabilities or mild mental retardation. *Research in Developmental Disabilities, 28*(5), 445-457.
- Matson, J. L., & Love, S. R. (1990). A comparison of parent-reported fear for autistic and nonhandicapped age-matched children and youth. *Australia and New Zealand Journal of Developmental Disabilities, 16*(4), 349-357.

- McGowan, L. S. (2009a). An overview of fear development in typically developing children and children with disabilities. Unpublished doctoral dissertation. University of Warwick & Coventry University.
- Miller, L. J., Anzalone, M. E., Lane, S. J., Cermak, S. A., & Osten, E. T. (2007). Concept evolution in sensory integration: A proposed nosology for diagnosis. *American Journal of Occupational Therapy, 61*(2), 135-140.
- Muris, P. (2007). *Normal and abnormal fear and anxiety in children and adolescents*. New York: Elsevier.
- Muris, P., Merckelbach, H., & Luijten, M. (2002). The connection between cognitive development and specific fears and worries in normal children and children with below-average intellectual abilities: a preliminary study. *Behaviour Research and Therapy, 40*(1), 37-56.
- Muris, P., Steerneman, P., Merckelbach, H., Holdrinet, I., & Meesters, C. (1998). Comorbid anxiety symptoms in children with pervasive developmental disorders. *Journal of Anxiety Disorders, 12*(4), 387-393.
- O'Neill, M., & Jones, R. S. P. (1997). Sensory-perceptual abnormalities in autism: A case for more research? *Journal of Autism and Developmental Disorders, 27*(3), 283-293.
- Ollendick, T. H. (1983). Reliability and validity of the Revised Fear Survey Schedule for Children (FSSC-R). *Behaviour Research and Therapy, 21*, 685-692.

- Ollendick, T. H., Yang, B., King, N. J., Dong, Q., & Akande, A. (1996). Fears in American, Australian, Chinese, and Nigerian children and adolescents: A cross-cultural study. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 37(2), 213-220.
- Ollendick, T. H., Yule, W., & Ollier, K. (1991). Fears in British children and their relationship to manifest anxiety and depression. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 32(2), 321-331.
- Ricciardi, J. N., Luiselli, J. K., & Camare, M. (2006). Shaping approach responses as intervention for specific phobia in a child with autism. *Journal of Applied Behavior Analysis*, 39(4), 445-448.
- 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*, 46(12), 1255-1268.
- Smith-Myles, B., Tapscott-Cook, K., Miller, N. E., Rinner, L., & Robbins, L. A. (2000). *Asperger Syndrome and sensory issues - practical solutions for making sense of the world*. Shawnee Mission, Kansas: Autism Asperger Publishing Co.
- Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy*, 61(2), 190-200.
- Warren, S. L., & Sroufe, L. A. (2004). Developmental issues. In T. H. Ollendick & J. S. March (Eds.), *Phobic and anxiety disorders in children and adolescents*. A

clinician's guide to effective psychosocial and pharmacological interventions (pp. 92-115). New York: Oxford University Press.

Weems, C. F., Silverman, W. K., Saavedra, L. M., Pina, A. A., & Lumpkin, P. W. (1999). The discrimination of children's phobias using the revised fear survey schedule for children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40(6), 941-952.

Westenberg, P. M., Siebelink, B. M., & Treffers, P. D. A. (2001). Psychosocial developmental theory in relation to anxiety and its disorders. In W. K. Silverman & P. D. A. Treffers (Eds.), *Anxiety disorders in children and adolescents: Research assessment and intervention* (pp. 72-89). Cambridge: Cambridge University Press.

Wing, L. (1996). *The autism spectrum*. London: Constable.

Chapter 3: Internet Mediated Research in Autism Spectrum Disorders: Personal, Professional and Research Reflections

3.1 Introduction

Reflection is a notion, which, on surface level, does not sit harmoniously with quantitative research. Qualitative research methods such as grounded theory and interpretive phenomenological analysis, imbue reflection and personal stance in their research process; quantitative methodologies do not necessitate this level of self-awareness (Madill & Gough, 2008). For this reason, I have chosen to focus the majority of this reflective paper on the internet mediated research (IMR) component of my empirical paper. I shall consider IMR within the context of my research journey, offering personal and professional reflections along the way.

3.2 Development of Research Ideas

Upon reflection of the contributing factors to my research ideas, I considered the stable interests I have held across my life. If I were to tabulate the top three topics that have sustained my appeal, it would be (in no particular order): human behaviour, animal behaviour and modern technology. It is now clear for me to see how these interests have pervaded decisions in both my personal and professional life.

My interest in human behaviour is most evident in my academic and vocational choices. Upon completion of my undergraduate psychology degree, I took a post in a residential home as a support worker for individuals with mental health difficulties and learning disabilities. Despite the long hours, low wages, and intense shifts, I thought then, and still do now, that it was one of the most rewarding jobs that I could have wished for. I was able to indulge my fascination of human behaviour and apply it in a practical and meaningful way. It was also in this post that I first met someone on the autism spectrum. It was this gentleman, for whom I was keyworker, and who to this day has a profound influence on my continued interest in the autism spectrum.

My enthusiasm for animal behaviour and modern technology was observable from a younger age. Some may argue that the nature-nurture debate would enter neatly here, since one of my parents was/is a biology teacher, and the other was/is involved in the field of 'gadgetary'. Indeed, my partner has an amusing expression which he regularly uses along the lines of "I know my place... firmly below the pets and the laptop".

I have many pets, the ones most demanding of my time are my two Samoyed dogs. I got the second dog as my thesis writing block began, thinking this would provide a welcome distraction for me and human company for the new puppy. Was I right? Well, the destructive behaviour, barking and toileting mishaps may sway my answer, however, it is hard to put into words the profound joy that the company of pets can bring. Indeed, so much so is my interest in four-legged creatures that one of my initial research ideas was to investigate the relationship between pets/animal therapy and children with ASD.

Ultimately, this idea was dismissed as it ventured more into the realm of occupational therapy than clinical psychology. I was disappointed, I had been advised prior to beginning my clinical training by a newly qualified clinical psychologist, that I should be genuinely interested in whatever topic I chose for my thesis, given the consuming and enduring nature of the process.

My actual empirical paper investigated the relationship between fear and sensory processing in children with ASD. My animal interest had been omitted but, it had been substituted for another one, that of modern technology – more specifically, the internet. IMR was a realm in which I had no previous experience before conducting my present empirical study. In the past, I have set-up and maintained a website, however, this had little relevance for my research. I was fortunate in that a contact of one my supervisory team, had set up a web-based survey previously, it was he who completed all the back of house administration needed to make my research web pages go live.

3.3 Internet Mediated Research in Autism Spectrum Disorders

Although neither my literature review nor my empirical paper investigated the implications of the internet for individuals with ASD, when writing this reflective piece, I could not help but have clinical and anecdotal intrusions about its relevance. Given the high genetic incidence of ASD (Losh, Childress, Lam, & Piven, 2008), some of the considerations in this issue could be highly relevant to some of the parents that took part in my study.

Popular periodicals and mainstream media report regularly on the conspicuous 'autistic presence' online (Biever, 2007). It has also been argued that there is an emergence of a 'distinctive autistic culture' on the internet (Dekker, 2006). There has even been the proclamation that "the impact of the internet on autistics may one day be compared to the spread of sign language among the deaf" (Singer, 1999, p. 67). Communications through chat rooms, email lists and forums are commonplace within this special population. There has also been utilisation of websites such as 'Second Life' (home of the autism island 'Brigadoon') which provide a private virtual world which are thought to allow individuals with ASD to enhance and practice their socialisation skills in a preferred non-face to face habitat (Lester, 2005).

If indeed, as suggested by some (Baron-Cohen, 2002), that everyone lies somewhere along the autism spectrum, this applies most to me through this online communication phenomenon. I do not solely conduct relationships over the internet, nor am I particularly accustomed with 'Second Life' websites, however, I do recognise the appeal and opportunity that these all offer to individuals that struggle within the social domain. Personally, I would much rather send somebody an email than talk to that person on the phone. This may be to do with convenience, laziness, or grumpiness, I am not entirely sure, however, I believe that much of this lies with my own adjudged social competence. It is because of such elements in my personality that I resonate in part with individuals with ASD.

3.4 Methodological Considerations

On reflection, there have been several methodological advantages and disadvantages to the IMR component of my empirical work. Before commencing data collection, I was blinded with the benefits of using the internet to both recruit and conduct my research. These anticipated benefits were indeed realised, however, I had not given such attention to potential methodological drawbacks of using IMR.

3.4.1 Advantages

Both time and financial resource constraints are apparent when planning a Clinical Psychology Doctorate thesis. Since a technician set-up my research web pages following my brief at no charge, the costings were minimal on both counts. The website was fairly self-sufficient in that participants read the information on the initial web page, gave consent and contact information, and then were automatically sent a link to their email address whereby they could complete the fear and sensory questionnaires. Once the questionnaires were submitted, data was automatically captured on a spreadsheet, meaning that conversion into subscales and meaningful scaled scores took minutes, if not seconds. When I compare the above process to the time involved at each stage for the paper-based group, the difference is considerable. From personal experience, I also feel that there is an increased convenience in completing online- as opposed to paper-based surveys, a novelty factor may also have helped to reduce drop-out rates. However, due to lack of detailed information across the two groups, it is impossible to compare the uptake or drop-out rates of my research.

3.4.2 Disadvantages

A member of my supervisory team was very wise in reminding me throughout the early stages of the research that the IMR component of my study was an ‘unknown quantity’. Potentially, I could have had thousands of visitors to my website, equally I could have had very little interest. As part of my recruitment protocol, I contacted local and national ASD charities who in turn endorsed my research through their website and electronic newsletters. Given those links, I felt underwhelmed at the number of ‘hits’ on my website and subsequently the number of completed questionnaires. I had not appreciated that, just like an e-commerce store, my website needed marketing. My research budget would not have stretched to a sufficient Google ‘adwords’ campaign, however, If I were to do similar research in the future I would be more strategic about my marketing by submitting the website to search engines earlier on, and even posting on relevant psychological research and ASD parent forums.

I recognise that I was fortunate to have a very competent and generous technician to create my website, I appreciate that not all researchers are this lucky. There were a couple of hitches on the questionnaire webpage that prevented participants from submitting their data under certain circumstances. With thanks to participant email contact, these anomalies were swiftly identified and corrected by myself.

Individuals who participate in online surveys such as mine are self-selected, and are by no means random representatives of the population under investigation. Broadly speaking, internet users are younger in age, and skewed towards the higher end of the socio-economic and educational spectrum (Riva, Teruzzi, & Anolli, 2003). Having said that, the study

adopted a traditional research route alongside IMR. Statistical analysis, as you would carry out with other participant variables, generally demonstrated homogeneity across the two samples.

3.5 Ethical Considerations

I was aware at the time of writing my research proposal that the British Psychological Society (BPS) had published guidelines for ethical practices on psychological research online (BPS, 2007). Many of the ethical considerations in conducting IMR are similar to the core ethical issues associated with more traditional methods (BPS, 2006). Some ethical matters in IMR, however, are very different.

3.5.1 Advantages

I addressed the ethical issue of informed consent in the same manner for the web-sample, as I did for the paper-sample. That is to say, participants read through the participant information, were given the opportunity to ask questions to the researcher, and indicated their consent before proceeding to the next stage of the research. Similarly, the right to withdraw was made explicit at every stage of the study. If participants did have any questions, the online sample would email these, which allowed minimal turnaround times in terms of receiving and responding to such queries, in comparison to writing or telephoning the research office.

A topical ethical advantage (not covered by the BPS) that occurred to me when reflecting upon this subject was of an environmental nature. Although there are some energy consumption implications in using a computer to conduct research, these are minimal compared to the printing, photocopying, and petrol resources consumed by more traditional research options.

3.5.2 Disadvantages

Verifying the identity of the participants is an area of difficulty in IMR. In my research, parents were identified through their email address. This helped to prevent multiple submissions, and also enabled the correspondence of demographic and questionnaire data submission. Email addresses, however, were removed from complete data sets to preserve anonymity and confidentiality. In IMR it is impossible to verify the identity of participants who are self-selecting through the internet. There is therefore an increased risk of attracting non-eligible participants and subsequently invalid data sets. My online recruitment protocol of advertising only on ASD websites was my way of constraining audience range.

Data protection legislation (Data Protection Act, 1998) has an equally important impact on IMR as it does on traditional research methods. Although identifiable information was removed from the stored data spreadsheet in my research, it is acknowledged that, in IMR, data can be inadvertently disclosed when it is being collected live *or* when it is stored. The nature of the openness of the computer networks and possibility of 'sniffing' programmes

which eavesdrop on data in transit (another topical governmental issue) meant that the data for the present study was stored in an encrypted file on a restricted directory.

3.6 Conclusions

There were some clear personal interests that directed me firstly to conduct my research in the domain of ASD, and secondly, to conduct a portion of that research online. Whilst prior to conducting my research I may have been naively blinded by the rapidness and efficiency of IMR, I am now aware of the host of methodological and ethical concerns unique to this method of psychological recruitment and data collection. IMR has, however, helped to enhance my technical and research skill repertoire.

Completing this reflective review has highlighted for me, the importance of the internet in the future of clinical psychology as a profession. I also believe that there will be a prospective growth in research investigating the relationship between ASD and the internet. This thesis has led me to feel that I would like to continue to be a part of, and contribute towards, this important advancement in our understanding.

3.7 References

- Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences*, 6(6), 248-254.
- Biever, E. (2007). Let's meet tomorrow in second Life. *New Scientist*, 194(2610), 26-27.
- British Psychological Society. (2006). *Code of ethics and conduct*. Leicester: British Psychological Society.
- British Psychological Society. (2007). *Guidelines for ethical practice in psychological research online*. Leicester: British Psychological Society.
- Data Protection Act. (1998). London: The Stationery Office, HMSO.
- Dekker, M. (2006). On our own terms:emerging autistic culture [Electronic Version]. *Autistic Culture*. Retrieved 14 April, 2009, from <http://autisticculture.com/index.php?page=articles>
- Lester, J. (2005). About Brigadoon. Retrieved 14 April, 2009, from http://braintalk.blogs.com/brigadoon/2005/01about_brigadoon.html
- Losh, M., Childress, D., Lam, K., & Piven, J. (2008). Defining key features of the broad autism phenotype: A comparison across parents of multiple- and single-incidence autism families. *American Journal of Medical Genetics Part B-Neuropsychiatric Genetics*, 147B(4), 424-433.

Madill, A., & Gough, B. (2008). Qualitative research and its place in psychological science. *Psychological Methods, 13*(3), 254-271.

Riva, G., Teruzzi, T., & Anolli, L. (2003). The use of the internet in psychological research: Comparison of online and offline questionnaires. *Cyberpsychology & Behavior, 6*(1), 73-80.

Singer, J. (1999). 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 59-67). Buckingham: Open University Press.

Appendices



Appendix 1.1 Publication Criteria for *Autism Journal*

NOTES FOR CONTRIBUTORS

1. The aim of the journal is to publish original research or original contributions to the existing literature on autism. Papers should not previously have been published or be under consideration elsewhere.
2. Each paper submitted will be refereed by at least two anonymous referees.
3. The number of high quality submissions to the Journal has increased significantly over the last few years and in order to facilitate more rapid publication of important papers it has become necessary to limit the size of manuscripts accepted. The maximum text length, therefore, should be 5000 words and the total number of end references should not exceed 30 entries. In exceptional circumstances we may be able to accept manuscripts that exceed this length, but this should be discussed with one of the editors before submission.
4. In order to protect the identity of clients or participants, authors should use pseudonyms and remove any information leading to identification of any of the individuals described in the study.
5. The Editors welcome contributions to the Letters to the editors section of the journal. In the interests of saving space, or to protect confidentiality, for example, the Editors may edit letters for publication.
6. Unsolicited manuscripts will not be returned to authors if rejected.
7. Blind peer review. Authors should provide two title pages, one containing names, affiliations, full mailing address plus telephone, fax, email address, and one containing the title only.
9. Please number all pages except the title pages, in the following order: abstract (100-150 words), keywords (up to five), address for correspondence; main text; appendices; acknowledgements; notes; references; tables; figure captions; figures. Each of the above sections should start on a fresh page.
10. Articles submitted for publication must be set in double spacing throughout (especially all notes and references), with generous left- and right-hand margins but without justification. Titles and section headings should be clear and brief with a maximum of three orders of heading.
11. Quotations. Lengthy quotations (exceeding 40 words) should be indented in the text.
12. American or UK spelling may be used, to the author's preference. Indicate italics by underlining and use single quotation marks. Dates should be in the form '9 May 1995'. Delete points from 'USA' and other such abbreviations.

Coventry University

Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Version 2.1 ©1999 Grace T. Barwick, PhD, OBE

GENERAL INFORMATION

1. Your relationship to the child

2. Your child's birthday/...../.....

3. Your child's gender: Female/Male

4. Has your child received a formal diagnosis of any of the following (tick as appropriate):

Autism Spectrum Disorder (ASD)

Autism

Asperger Syndrome

Pervasive Developmental Disorder (PDD)

5. Has your child received any other formal diagnosis not listed above:

Yes, please detail

No

Unsure

6. Are you or any other family member afraid of certain objects or situations?
e.g. spiders, heights, busy places

Yes, please detail

No

Thank you for completing this questionnaire

SENSORY EXPERIENCES QUESTIONNAIRE (SEQ) Short Form

(Note: formerly known as the Sensory Supplement Questionnaire - SSQ)

Version 2.1 ©1999 Grace T. Baranek, Ph.D., OTR/L



Child's ID #: _____ Date: _____ Child's Birthdate: _____ Gender: F M

Person completing form (check one):

Mother Father Both Parents Teacher Other (describe: _____)

Directions

The following are some brief questions about how your child uses his/her senses (for example hearing, vision, touch, etc.) to experience the world. No two children are alike. This questionnaire asks about behaviors that make your child unique. Consider your child's usual responses to these situations or activities. The questions ask **how often your child responds or behaves in a certain way**. Check the box that fits best (almost never, once in a while, sometimes, frequently, almost always). Answer all questions completely.

For more information about the SEQ contact:
Grace Baranek, Ph.D., OTR/L
Division of Occupational Science CB # 7120
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7120
Email: gbaranek@med.unc.edu

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(Research version: 04/23/06)

ID #: _____ Date: _____

Experiences with Sound:

Does your child react sensitively or startle easily to unexpected or loud sounds? (For example: covers ears when hearing a vacuum, baby cry, door close, etc.)	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	1-A-R-N
Does your child enjoy listening to music?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	2-D-Y
Does your child ignore you when you call his/her name?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	3-A-O-S
Does your child seem to ignore or tune-out loud noises? (For example: no reaction when alarms go off, vacuum turns on or object falls to the floor.)	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	4-A-O-N
Does your child notice sounds in the environment (such as planes, trains, faucets dripping, lights buzzing, etc.) before other people do?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	5-A-R-N
Does your child show distress (startles, covers ears, etc.) during loud conversations or singing?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	6-A-R-S

Experiences with Sight:

Does your child enjoy looking at picture books?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	7-D-Y
Is your child disturbed by too much light inside or brightness outside?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	8-V-R-N
Does your child stare at lights or objects that spin or move?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	9-V-O-N
Is your child slow to notice new objects or toys in the room, or slow to look at objects that are placed or held near him/her?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	10-V-O-N
Does your child avoid looking at your face during social games/play?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	11-V-R-S
Does your child seem to ignore (doesn't notice) when someone new or different enters the room?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	12-V-O-S
Does your child enjoy watching children's videos or TV programs?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	13-D-Y

ID #: _____ Date: _____

Experiences with Touch:

Does your child dislike cuddling or being held? <i>(Does your child enjoy riding in a car?)</i>	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	14-T-R-S
Does your child show distress during grooming? (For example: cries or fusses during face washing, hair combing, fingernail cutting, or teeth brushing)?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	15-T-R-S
Does your child avoid touching certain textures (such as fuzzy or squishy toys) or playing with messy materials (such as sand, lotion)?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	16-T-R-N
Does your child react negatively or pull away when touched by a person? (For example: pulls away when head is patted.)	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	17-T-R-S
Does your child have trouble adjusting to the water temperature during bath time or does he/she dislike being in water?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	18-T-R-N
Does your child seem slow to react to pain? (For example: he/she isn't bothered by bumps scrapes, cuts, or falls.)	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	19-T-O-N
Does your child dislike being tickled?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	20-T-R-S
Does your child ignore you (doesn't notice) when you tap him/her on the shoulder for attention?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	21-T-O-S

Experiences with Taste or Smell:

Does your child refuse to try new foods or avoid certain tastes, smells, or textures (consistencies) of food?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	22-G-R-N
Does your child smell objects or toys during play or other activities?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	23-G-O-N
Does your child seem interested in the way people smell? (For example: smells hair, breath.)	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	24-G-O-S
Does your child put objects, toys or other non-food items in his/her mouth to lick, suck, or explore?	<i>Almost Never</i> <input type="checkbox"/>	<i>Once in a While</i> <input type="checkbox"/>	<i>Sometimes</i> <input type="checkbox"/>	<i>Frequently</i> <input type="checkbox"/>	<i>Almost Always</i> <input type="checkbox"/>	25-G-O-N

ID #: _____

Date: _____

FEAR-RATING QUESTIONNAIRE (FSSC-R)
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Experiences with Movement:

	<i>Almost Never</i>	<i>Once in a While</i>	<i>Sometimes</i>	<i>Frequently</i>	<i>Almost Always</i>	
Does your child enjoy riding in a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	26-D-Y
Does your child like to jump up/down, rock back/forth, or spin in circles?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	27-P-O-N
Does your child seek out physical roughhousing play? (For example: craves being tossed in the air or spun around.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	28-P-O-S
Does your child seem uneasy or become dizzy when moving on a swing or rocking chair, for example?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	29-P-R-N
Does your child flap his/her arms or hands repeatedly, particularly when excited?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	30-P-O-N

List other comments you would like to make about your child's preferred experiences or avoidances/sensitivities to sound, sight, touch, smell, taste, or movement.

SELF-RATING QUESTIONNAIRE (FSSC-R)

© Thomas H. Ollendick

DIRECTIONS:


A number of statements which boys and girls use to describe the fears they have are given below. Tick the box in front of the words that best describes the rating of your child's fear. There are no right or wrong answers, please try to put a rating for all items.

	None	Some	A lot
38. Having to eat something they don't like			
39. Cats			
40. Failing a test			
41. Being hit by a car or lorry			
42. Having to go to school			
43. Playing rough games during playtime			
44. Hearing parents argue			
1. Having to talk to the class			
2. Going in the car or bus			
3. Getting punished by mother			
4. Lizards			
5. Looking foolish			
6. Ghosts or spooky things			
7. Sharp objects			
8. Having to go to hospital			
9. Death or dead people			
10. Getting lost in a strange place			
11. Snakes			
12. Talking on the telephone			
13. Roller coaster or carnival rides			
14. Getting sick at school			
15. Being sent to the head-teacher			
16. Riding on the train			
17. Being left at home with a baby-sitter			
18. Bears or wolves			
19. Meeting someone for the first time			
20. Bombing attacks—being invaded			
21. Getting an injection from the nurse or doctor			
22. Going to the dentist			
23. High places like mountains			
24. Being teased			
25. Spiders			
26. A burglar breaking into the house			
27. Flying in a plane			
28. Being called on unexpectedly by the teacher			
29. Getting poor marks for school work			
30. Bats or birds			
31. Being criticised by parents			
32. Guns			
33. Being in a fight			
34. Fire—getting burned			

	None	Some	A lot
79. Rats or mice			
80. Taking a test			
35. Getting a cut or injury			
36. Being in a big crowd			
37. Thunderstorms			
38. Having to eat some food they don't like			
39. Cats			
40. Failing a test			
41. Being hit by a car or lorry			
42. Having to go to school			
43. Playing rough games during playtime			
44. Hearing parents argue			
45. Dark rooms or closets			
46. Having to perform in front of others			
47. Ants or beetles			
48. Being criticised by others			
49. Strange looking people			
50. The sight of blood			
51. Going to the doctor			
52. Nasty looking dogs			
53. Cemeteries			
54. Getting a school report			
55. Getting a haircut			
56. Deep water or the ocean			
57. Nightmares			
58. Falling from high places			
59. Getting a shock from electricity			
60. Going to bed in the dark			
61. Getting car sick			
62. Being alone			
63. Having to wear clothes different from others.....			
64. Getting punished by my father			
65. Having to stay after school			
66. Making mistakes			
67. Detective movies			
68. Loud sirens			
69. Doing something new			
70. Germs or getting a serious illness			
71. enclosed spaces			
72. Earthquakes			
73. Russia			
74. Lifts or elevators			
75. Dark places			
76. Not being able to breathe			
77. Getting a bee sting			
78. Worms or snails			


- 79. Rats or mice
- 80. Taking a test



POSTGRADUATE STUDENT & STAFF APPLICATION FOR ETHICAL APPROVAL

Name	E-mail	
Laura McGowan	L.MCGOWAN@UNIVERSITY.WARWICK	
Designation / Subject & Faculty	Trainee Clinical Psychologist, Doctorate in Clinical Psychology, Health & Life Sciences	
Title of Study	An exploration into the relationship between sensory processing and the fears of children on the autism spectrum	
1. Summary of proposal	<p>The current study wishes to explore the relationship between the sensory experiences and the fears of children aged 7-12 years, on the autism spectrum. Participants in the study will be parents or main carers of the children. Three questionnaires will be completed by participants concerning demographics, fears and sensory experiences. Some participants will be recruited via a local NHS Child and Adolescent Mental Health Service, these participants will complete the survey through the post. Other participants will be recruited via an established autism charity website, these participants will complete the survey using email exchanges. The results will be analysed in such a way to gain a greater understanding into the sensory needs of children on the autism spectrum. The results will also add to the existing research base into why these children may experience different types of fear compared to normal developing children of the same age.</p>	
2. Sample of participants	<p>The current study aims to recruit 100 parents or main carers of children with a diagnosis on the autism spectrum who are aged between 7 and 12 years (inclusive)</p>	
3. Sites location	<p>The current project will be using postal survey methods. The researcher's academic base will be between Coventry University and the University of Warwick.</p>	
Tick / Cross, 'Where answered NO', please give reasons on separate page	Yes	No
4. Scientific background, design, method and conduct of the study		
a) Have you given a justification for the research?	✓	
b) Have you justified on the appropriateness of the design, the perceived benefits, risks and inconveniences to participants?	✓	
5. Recruitment of participants	✓	
Have you provided a comprehensive account of the characteristics of the population including the process for obtaining houses as well as the inclusion and exclusion criteria?		
6. Care and protection of research participants and researcher	✓	
Have you given an account of any interventions, situations and risks which have the potential to cause harm to the participants and researchers?		
7. Access, storage, security and protection of participants' confidentiality	✓	
Have you identified who will have access to the data and what measures have been taken to ensure confidentiality and compliance with the Data Protection Act?		
8. Informed Consent	✓	
Have you given a full description of the process for requesting and obtaining informed consent?		
9. Community considerations	✓	
Have you considered how this study will benefit the participants or the community from which they have been drawn?		
10. Participant Information Sheet and consent form	✓	
Are these attached?		
11. Source of External Funding if any		
N/A		
Signature of student / staff	Address	Date
		25.01.08

COVENTRY UNIVERSITY ETHICS COMMITTEE (CU Ethics Form 1)

POSTGRADUATE STUDENT & STAFF APPLICATION FOR ETHICAL APPROVAL

Name	E-mail	
Laura McGowan	mcgowanl@coventry.ac.uk	
Designation / Subject & Faculty		
Trainee Clinical Psychologist, Doctorate in Clinical Psychology, Health & Life Sciences		
Title of Study		
An exploration into the relationship between sensory processing and the fears of children on the autism spectrum		
1. Summary of proposal		
The current study wishes to explore the relationship between the sensory experiences and the fears of children, aged 7-12 years, on the autism spectrum. Participants in the study will be parents or main carers of the children. Three questionnaires will be completed by participants concerning demographics, fears and sensory experiences. Some participants will be recruited via a local NHS Child and Adolescent Mental Health Service, these participants will complete the survey through the post. Other participants will be recruited via an established autism charity website, these participants will complete the survey using email exchanges. The results will be analysed in such a way to gain a greater understanding into the sensory needs of children on the autism spectrum. The results will also add to the existing research base into why these children may experience different types of fear compared to normal developing children of the same age.		
2. Sample of participants		
The current study aims to recruit 100 parents or main carers of children with a diagnosis on the autism spectrum who are aged between 7 and 12 years (inclusive)		
3. Site/s location		
The current project will be using postal survey methods. The researcher's academic base will be between Coventry University and the University of Warwick.		
<i>Tick / Cross. *Where answered 'NO', please give reasons on separate page.</i>		
4. Scientific background, design, method and conduct of the study.		Yes
a) Have you given a justification for the research?		<input checked="" type="checkbox"/>
b) Have you commented on the appropriateness of the design, the perceived benefits, risks and inconveniences to participants?		<input checked="" type="checkbox"/>
5. Recruitment of participants.		No*
Have you provided a comprehensive account of the characteristics of the population including the process for obtaining access as well as the inclusion and exclusion criteria?		<input checked="" type="checkbox"/>
6. Care and protection of research participants and researcher.		<input checked="" type="checkbox"/>
Have you given an account of any interventions, situations and risks which have the potential to cause harm to the participants and researchers?		<input checked="" type="checkbox"/>
7. Access, storage, security and protection of participants' confidentiality.		<input checked="" type="checkbox"/>
Have you identified who will have access to the data and what measures have been taken to ensure confidentiality and compliance with the Data Protection Act?		<input checked="" type="checkbox"/>
8. Informed Consent.		<input checked="" type="checkbox"/>
Have you given a full description of the process for requesting and obtaining informed consent?		<input checked="" type="checkbox"/>
9. Community considerations.		<input checked="" type="checkbox"/>
Have you considered how this study will benefit the participants or the community from which they have been drawn?		<input checked="" type="checkbox"/>
10. Participant Information Sheet and consent form.		<input checked="" type="checkbox"/>
Are these attached?		<input checked="" type="checkbox"/>
11. Source of External Funding if any		
N/A		
Signature of student / staff	Address:	Date
		25 01 08

Signature of Supervisor 	Print Name: Dr Sarah Kent SARAH KENT Internal Address: Clinical Psychology Doctorate Office JSG24	Date 25.01.08
Signature of Chair 	<input checked="" type="checkbox"/> Approved. <input type="checkbox"/> Approved with the conditions below:	Date 29/02/08
Conditions / Comments:		

Please complete in full and return to: Research Manager, CU Ethics Committee, Richard Crossman RCG 17, Coventry University.

This form should be accompanied by the full research study proposal, or the COREC form if applicable. Further help & information can be found on W / HLS / Student / Ethics or call Satwant Sandhu on 024 7679 5813, or e-mail s.sandhu@coventry.ac.uk.

Coventry University ETHICS Committee

Form 4 – Ethics Peer Review

1.	Reference No:	PG12/08
2.	Title of Study:	An exploration into the relationship between sensory processing and the fears of children on the autism spectrum
3.	Scientific Background, Design and conduct of the study: Demonstration of a breadth of reading from a good range of resources. Relevant appraisal has been completed on the literature that has been identified. Good linkage is made between those studies which relate to different clinical diagnoses and the fears experienced by the children in each category. The research question is adequately defined and addressed. The design is appropriate and is evidenced by work completed by previous researchers.	
4.	Recruitment of participants: The recruitment of parents of autistic children via the NAS site and through the local CAMHs team is feasible and no intrusive. However as this is reliant on goodwill it is debateable whether the target number of 100 respondents will be achieved. Has the author considered any other motivational factors that will attract parents to the study. Also is there any inclusion/exclusion criteria being enforced – for example what will happen to those individuals who have multiple diagnoses (ie autistic and dyslexic, autistic and ocd?)	
5.	Care of researcher and participants and protection of research participants' confidentiality: Confidential material is to be handled with appropriate levels of discretion and due diligence is applied to the safe keeping of the data collected.	
6.	Informed consent An appropriate participant information sheet and an informed consent sheet have been provided with the study. These are clearly written and advise the respondent that participation is of a voluntary nature and that withdrawal from the study can be made at any stage without detriment to the individual.	
7.	Community considerations: The NAS and CAMHs team will be sent details of the findings of the project. Participant parents will be sent a summarised report.	
8.	Information sheet: This has been provided. It is logically written in a format that should be understood by the chief participants (parents of children with a diagnosis of autism)	
9.	Consent form: Consent will be obtained from both respondent groups. Online respondents will tick a check list and give permission by returning a completed online questionnaire. The parents contacted via the CAMHs team will be given a pre paid and addressed envelope for signature and return to the chief investigator.	
10.	Comments on the ethical aspects of the proposal: No specific ethical concerns are raised by this proposal. It is noted in the data analysis that variables such as group difference, age and gender will be analysed via t tests and ANOVA. Are the variables of IQ and position on the autistic spectrum also going to be considered as these may have an impact on the child's reaction to feared situations and their exposure to fear experiences	

11.	Recommendations	Please circle:
	Approved with no amendments	YES / NO
	Approved subject to specified conditions.	YES / NO
	Reject	YES - NO
12.	Completed by: S.Heeney OT Department HLS	Date: 25.02.08

Please return this form electronically to s.sandhu@coventry.ac.uk and please **DO NOT CONTACT THE APPLICANT DIRECTLY.**



National Research Ethics Service

Coventry Research Ethics Committee

2nd floor West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

Telephone: 024 7696 7529
Facsimile: 024 7696 5033

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	A&S	14 April 2008
Investigator CV	L McGowan	16 April 2008
26 June 2008	Version 2.1	01 February 2008
Covering Letter	L McGowan	18 April 2008
Miss Laura McGowan Trainee Clinical Psychologist Clinical Psychology Doctorate Course JSG24 Coventry University Coventry CV1 5FB	Group 1 Participation Pathway Flowchart version 1.1	16 April 2008
	Group 2 Participation Pathway Flowchart Version 2.2	23 June 2008
	Coventry University	03 March 2008
Consentment Arrangements	Coventry University	16 April 2008
Dear Laura McGowan	Version 2.1	17 March 2008
Full title of study:	An exploration into the relationship between sensory processing and the fears of children on the autism spectrum	
REC reference number:	08/H1210/59	
	version 2.1	23 June 2008
	Version 1.1	16 April 2008
Thank you for your letter of 23 June 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.	Version 2.1	16 November 2007
The further information has been considered on behalf of the Committee by the Chairman.	McGowan	
Confirmation of ethical opinion	S Kent	16 April 2008

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

08/H1210/59

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	A&B	14 April 2008
Investigator CV	L McGowan	16 April 2008
Protocol	Version 2.1	01 February 2008
Covering Letter	L McGowan	18 April 2008
Summary/Synopsis	Group 1 Participation Pathway Flowchart version 1.1	16 April 2008
Summary/Synopsis	Group 2 Participation Pathway Flowchart Version 2.2	23 June 2008
Peer Review	Coventry University	03 March 2008
Compensation Arrangements	Coventry University	16 April 2008
Questionnaire: General Information	Version 2.1	17 March 2008
Questionnaire: Fear Survey Schedule Revised		
Questionnaire: Sensory Experiences Questionnaire Short Form	Version 2.1	01 January 1999
Questionnaire: Self Rating Questionnaire	version 2.1	23 June 2008
Letter of invitation to participant	Version 1.1	16 April 2008
Participant Information Sheet	Version 2.2	26 June 2007
Participant Consent Form: Consent to be Contacted	Version 3.1	24 January 2008
Participant Consent Form	Version 2.1	18 November 2007
Response to Request for Further Information	Clarification letter from Laura McGowan	23 June 2008
CV Academic Supervisor	S Kent	16 April 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study



08/H1210/59

National Research Ethics Service Page 3

Coventry Research Ethics Committee

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

Tel: 024 7696 7529
Fax: 024 7696 5025

08/H1210/59

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Stephen Keay
Chairman

Email: pauline.pittaway@uhcw.nhs.uk

Enclosures: "After ethical review – guidance for researchers SL- AR2"

Copy to: Prof Ian Marshall, Coventry University

R&D office for Coventry & Warwickshire NHS Partnership Trust

Document	Version	Date
Notice of Subordinate Amendment (non-CTMPs)	Version 1	25 January 2009
Amendment	Version 1.1	25 January 2009

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.



National Research Ethics Service

Coventry Research Ethics Committee

2nd floor West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

0871121059

Please quote this number on all correspondence

21 January 2009

Tel: 024 7696 7529

Fax: 024 7696 5033

Miss Laura McGowan
Trainee Clinical Psychologist
Clinical Psychology Doctorate Course JSG24
Coventry University
Coventry
CV1 5FB
l.mcgowan@uhow.nhs.uk

Dear Miss McGowan

Study title: An exploration into the relationship between sensory processing and the fears of children on the autism spectrum

REC reference: 08/H1210/59

Amendment number: Version 1

Amendment date: 05 January 2009

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 20 January 2009.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Version 1	05 January 2009
Advertisement	Version 1.1	05 January 2009

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H1210/59 **Please quote this number on all correspondence**

Yours sincerely

Ms Pauline Pittaway
Committee Co-ordinator

E-mail: pauline.pittaway@uhcw.nhs.uk

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: *Mr Ian Marshall, Coventry University*
R&D office for Coventry & Warwickshire Partnership Trust

Coventry & Warwickshire Partnership Trust has renewed your research approval for The Relationship Between Sensory Processing and The and give approval for you to conduct the study on the condition that the Trust suffers no costs as a result of the study being undertaken. Your research has been entered into the Trust's research register.

Please reply to this letter by completing the enclosed Study Update Sheet. As part of the Research Governance Framework it is important that the PCT is notified as to the progress of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Should you require any further information regarding the research project or researcher change, you should be advised.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

Pauline Pittaway

Page
numbering as
original



NHS
**National Institute for
Health Research**

West Midlands (South) Comprehensive Local Research Network (CLRN)
Fourth Floor Rotunda (ADA40017)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

01 August 2008

Ms Laura Mc Gowan
Trainee Clinical Psychologist
Clinical Psychology Doctorate Course JSG24
Coventry University
Coventry
CV1 5FB

R&D Ref: WAR300608
REC Ref: 08/H1210/59

Dear Miss McGowan


I am pleased to confirm that **Warwickshire Primary Care Trust** has reviewed your research study entitled 'An Exploration into The Relationship Between Sensory Processing and The Fears of Children on The Autism Spectrum', and give approval for you to conduct this research within the Trust on the condition that the Trust suffers no costs as a result of this study being undertaken. Your research has been entered into the Trust's research database.

Please reply to this letter by completing the enclosed Study Update Sheet. As part of the Research Governance Framework it is important that the PCT is notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Similarly, if at anytime details relating to the research project or researcher change, WM (South) CLRN must be informed.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

Luke Chaplin

Wolverhampton City 

Primary Care Trust

Project No: **251** (Please quote on all correspondence)

Research and Development
 The Beeches
 Penn Hospital
 Penn Road
 Wolverhampton
 WV4 5HN
 01902-444609

Ms Laura McGowan
 Trainee Clinical Psychologist
 Coventry University
 Clinical Psychology Doctorate Course
 Priory Street
 Coventry
 CV1 5FB

ivan.burchess@wolvespct.nhs.uk
<http://www.wolverhamptonhealth.nhs.uk>

Dear Ms McGowan

Re: An Exploration into the relationship between sensory processing and the fears of children on the autism spectrum

REC: 08/H1210/59

Thank you for supplying the Research and Development Department with the requested documentation. We are pleased to inform you that from a research point of view we are happy for you to undertake the research in line with the protocol you have submitted.

This permission covers the following Trust:

Wolverhampton City PCT

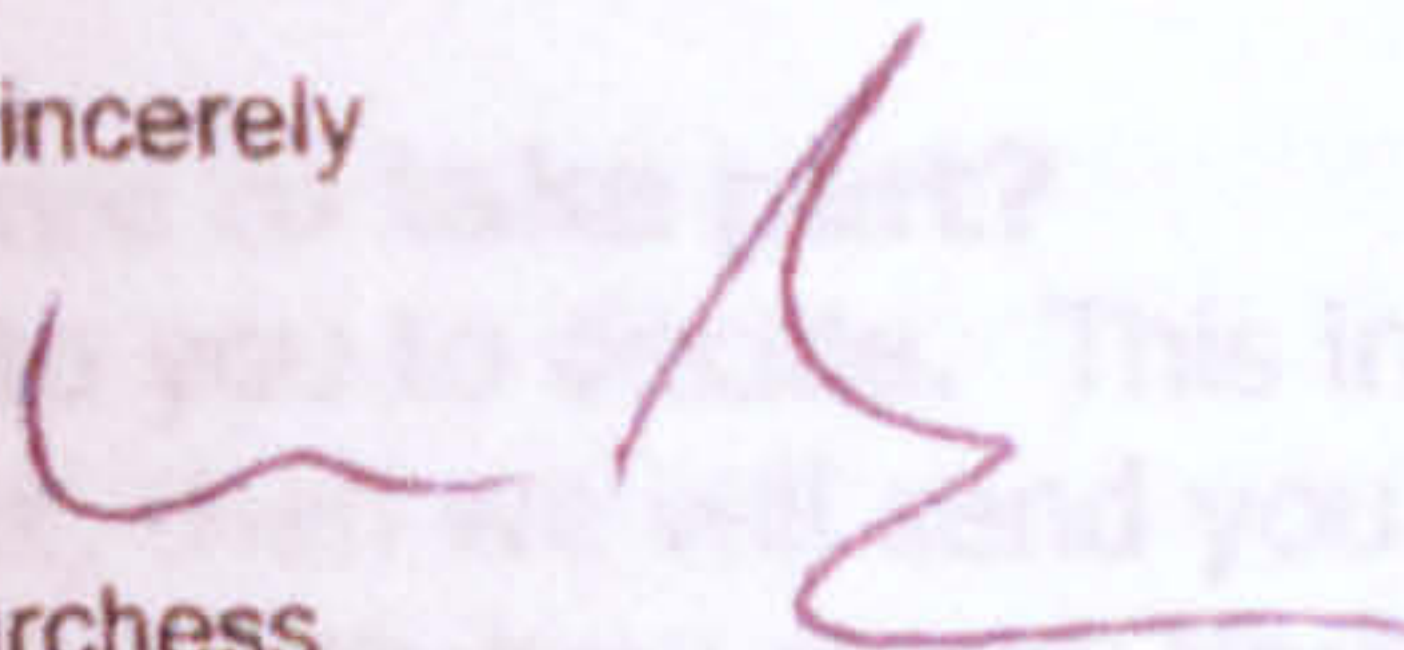
We must remind you that the *National Research Governance Framework for Health and Social Care* governs research in all NHS Trusts. As the Chief Investigator of the research, you are responsible for the conduct of the project in accordance with these guidelines, particularly in terms of ensuring that participants are properly treated, that data is protected and that adverse events are reported to us and the ethics committee who originally gave approval for the research.

At some point we are likely to audit your paperwork for this project and it is important that you keep everything secure, especially that relating to informed consent from participants in your research.

If there are any changes to your research, any difficult incidents or if you have queries about conducting the research, please inform R&D office immediately on 01902 444609.

We look forward to hearing the outcomes of your research and receiving a copy of the final report. Good luck with the project.

Yours sincerely


 Ivan Burchess
 Chair, Black Country Research Governance Network

Enc Research Governance Information Sheet
 Copy to: Catherine Dexter, Wolverhampton City PCT

Coventry University

Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

THE UNIVERSITY OF
WARWICK



Programme Director

Doctorate Course in Clinical Psychology

Professor Delia Cushway

BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

An exploration into the relationship between sensory processing and the fears of children on the autism spectrum

Participant Information Sheet

I am a Clinical Psychologist in Training working in the NHS and completing a Clinical Psychology Doctorate at the Universities of Coventry and Warwick. As part of my doctorate I am carrying out a research project.

I would like to invite you to take part in this research project. Before you decide you need to understand why the research is being done and what it would involve. Ask us if there is anything that is not clear for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of this research?

The purpose of this research is to explore the relationship between the sensory experiences and the fears of children on the autism spectrum.

It is possible that children on the autism spectrum experience different types of fears to children of a similar age. It is also possible that children on the autism spectrum experience fears that are related to their sensory experiences. However, there has been very little research conducted in this area.

We are interested in exploring the relationship between sensory processing and fears of children on the autism spectrum because it may provide us with greater understanding of *why* some children on the autism spectrum become distressed when they do. It could give us greater understanding into the sensory needs of children on the autism spectrum and enable us to develop appropriate environments and responses to children on the autism spectrum when they are experiencing fear.

Why have I been invited?

You have been identified as fitting the criteria for this study. We are looking for parents and carers of children who have an existing diagnosis on the autism spectrum, and who are aged between 7 to 12 years (inclusive). We hope to include a minimum of 100 parents and carers in this study.

Do I have to take part?

It is up to you to decide. This information sheet will describe the study for you. If you decide to take part, then we will send you a consent form to sign to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This will not affect any services that you or your child receives.

What will happen to me if I take part?

If you decide to participate in this project, you will be posted three forms to complete about you and your child.

What will I have to do?

- 1) You will receive a general information sheet that you will be asked to complete about your child, this will ask for information about your child's age, sex, diagnoses, and will also ask briefly about any fears that you or members of your close family have.
- 2) You will be asked to complete a short questionnaire about the types of objects and situations that your child may fear
- 3) You will be asked to complete a brief questionnaire relating to your child's sensory experiences
- 4) You will be asked to return the general information sheet and the questionnaires to the researcher in the stamped and addressed envelope that you will be provided with.

What should I do if I want to take part?

If, when you have finished reading this participant information sheet, you feel happy to take part in the study, please complete the attached consent to be contacted form. You will then be sent the research pack outlined above containing the appropriate questionnaires and consent form.

What are the possible disadvantages of taking part?

We do not anticipate there to be any risks of taking part in this study. However, the questionnaires are related to your child's sensory experiences and fears, which *may* bring up some uncomfortable issues for some parents and carers. Although we anticipate that the study will not cause you any distress, should you feel the need to contact the researcher about this, full contact details will be provided for you.

The general information sheet and questionnaires should take about 30 minutes to complete in total, plus the time needed to post them back to the researcher.

What are the possible benefits of taking part?

We do not anticipate that there will be any specific personal benefits in taking part. However, the information that we obtain from this research will help us to gain a better understanding of children's fears and why these fears may develop. This information will be used to inform services who work with children who are on the autism spectrum.

What happens when the study is finished?

After we have finished collecting all of the data, this data will be analysed and written up for specific journals and presentations.

You will receive a summary report of the results. We will not contact you again after this. However, you will be provided with contact details of the researcher if you wish to discuss anything about the study or your participation in further detail.

Will the information I provide be kept confidential?

All information which is collected about you and your child is kept strictly confidential. At no point in the study will you be asked for your child's name. Any identifiable information you provide about yourself will be for correspondence purposes only. Only authorised persons involved in the research will be granted access to the data. During the data analysis, your information will be assigned a numerical code to ensure anonymity. All data will be held securely for five years, after which time it will be disposed of safely.

Who has reviewed this research?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Coventry Research Ethics Committee. Furthermore, this project has been reviewed by the Ethics Committee at Coventry University.

Who can I contact for further information?

If you have any further questions or concerns, please do not hesitate to contact the main researcher, Laura McGowan or her supervisor, Dr Sarah Kent:

Clinical Psychology Doctorate
School of Health and Life Sciences
JSG24
Coventry University
Priory Street
Coventry
CV1 5FB

E-mail: mcgowanl@coventry.ac.uk (Ms Laura McGowan)
aa2691@coventry.ac.uk (Dr Sarah Kent)

Tel: 02476 888 328
Fax: 02476 888 300

Who is responsible for the complaint's procedure?

If you have any complaints and would like to contact someone who is independent of the research team, you can contact:

Eve Knight, Course Director
Clinical Psychology Doctorate
School of Health and Life Sciences
JSG24, Coventry University
Priory Street, Coventry
CV1 5FB

Tel: 02476 888 328

Many thanks for taking the time to read this information sheet. We hope you feel happy to participate in this project

Coventry and Warwickshire



Partnership Trust

CAMHS
Orchard House
83 Radford Road
Leamington Spa
Warwickshire
CV31 1JQ

22 September 2008

Dear Parent or Guardian,

I am contacting you to introduce you to Laura McGowan, who is currently involved in a research project that is supported by the Coventry & Warwickshire Partnership Trust. Laura is a Clinical Psychologist in Training working in the NHS and completing a Clinical Psychology Doctorate at the Universities of Coventry and Warwick. As part of her doctorate she is carrying out a research project. She is interested in how the sensory processing profiles of children who are on the autism spectrum relate to the objects and situations they are afraid of. We, as a Team and Service, will have access to the conclusions of this research and hope to use this to develop further strategies to help the young people and families that we work with.

Laura is currently recruiting parents of children on the autism spectrum within South Warwickshire to take part in this study. Her research involves asking parents to spend about half an hour completing three brief questionnaires about their child's responses to everyday sensory events and the things they are fearful of. All details that would identify your child are confidential. No personally identifiable information or contact details of parents have been released to the researcher. **No child will be identified by name.**

I enclose with this letter an information sheet outlining Laura's research and the procedure of collecting the data. Should you have any further questions please do not hesitate to contact Laura at Coventry University on 02476 888 328 or mcgowanl@coventry.ac.uk. If you would like to take part in this project, please complete the attached **consent to be contacted form** and return directly to Laura in the prepaid envelope enclosed.

Please contact Laura by phone or email if you would prefer to complete and return the questionnaires electronically. Laura has been checked by the Criminal Records Bureau as part of her employment contract.

Many thanks for your time and interest.

Yours sincerely,

Jacky Knibbs

Jacky Knibbs, Consultant Clinical Psychologist

Version 3.1 dated 29.02.2008
Karamjit Singh - Chairman
Sandy Taylor - Chief Executive

www.covwarkpt.nhs.uk



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Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)



CONSENT TO BE CONTACTED

CONSENT FORM

Title of research project: An exploration into the relationship between sensory processing and the fears of children on the autism spectrum

Name of researcher: Laura McGowan

I agree to be contacted by Laura McGowan to receive further information about this research project (please tick)

Name of child (this is used for initial identification only) _____

Please contact me initially by (delete as appropriate)

POST _____

EMAIL _____

By consenting to be contacted you ARE NOT consenting to participate, but only to be contacted by Laura McGowan, researcher.

.....
Name of Parent or Carer

.....
Date

.....
Signature

Version 3.1 dated 24.01.2008

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

.....c PhD University of Warwick, Coventry CV4 7AL Tel 024 7652 3096

Coventry University

Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director

Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)



CONSENT FORM

Title of research project: An exploration into the relationship between sensory processing and the fears of children on the autism spectrum

Name of researcher: Laura McGowan

- 1. I confirm that I have read and understood the information sheet 26 June 2007 (version 2.2) for the above study. I have also had the opportunity to ask questions and raise concerns.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.
- 3. I agree to participate

.....
Name of Parent or Carer

.....
Date

.....
Signature

.....
Name of Researcher

.....
Date

.....
Signature

Version 2.1 dated 18.11.2007

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

.....c PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

Appendix 2.11 Power Analysis

Power calculations (see Cohen, 1992) were carried out to inform the sample size estimation for this study. The first stage of the data analysis involved administering chi-square and t-test calculations.

In order to predict a large effect size (.5) for the chi-square test, with a significance level of .05, a minimum of 80 participants was required in the total sample. The current study recruited 89 participants in general.

In order to predict a large effect size (.8) for the t-tests, with a significance level of .05, and a two-tailed hypothesis, a minimum of 42 participants were required in each experimental group. The present study had 47 participants in experimental group 1, and 42 participants in experimental group 2.

Reference

Cohen, J. (1992). A Power Primer. *Psychological Bulletin*, 112(1), 155-159.

Appendix 2.12 Correlations: Sensory System Subscales of the SEQ with FSSC-R Subscales

Table 2.6

Correlations (Pearson product-moment coefficient r values) for the Sensory System Subscales of the SEQ with the FSSC-R Subscales

	Tactile	Auditory	Visual	Olfactory	Vestibular
Total Fear	.284**	.367**	.181	.120	.256*
Fear of Failure and Criticism	.322**	.294**	.103	.121	.125
Fear of the Unknown	.296**	.383**	.273**	.158	.328**
Fear of Animals and Minor Injuries	.104	.229*	.053	.064	.255*
Fear of Danger and Death	.072	.274**	.036	.030	.198
Medical fears	.296**	.306**	.320**	.171	.193

N.B. * denotes a significant relationship at the .05 level; ** denotes a significant relationship at the .01 significance level.