Unusual Sensory Experiences in People on the Autism Spectrum

by

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A thesis submitted for the degree of Doctorate in Clinical Psychology

Chapter 1  The developmental pathway of sensory processing experiences in autism: A review

Abstract

1.1 Introduction

1.2 The autism diagnosis

1.2.1 Diagnostic criteria

1.3 Sensory processing

1.3.1 Diagnostic assessment of sensory processing

1.3.2 Assessment of sensory processing

1.3.2.1 Sensory processing assessment tools

1.4 Autism spectrum
diagnosis

1.4.1 Frequency

1.4.2 Age

1.4.3 Gender

1.4.4 Subtyping

1.4.5 Interventions in compensatory skills

1.5 Developmental delay

1.6 References

May 2008
Chapter 1  The developmental pathway of sensory processing experiences in autism: A review

1.1 Introduction 2

1.2 The autism spectrum 4

1.2.1 Diagnostic criteria 6

1.3 Sensory processing 6

1.3.1 Dunn’s model of sensory processing 8

1.3.2 Assessment of sensory processing 9

1.3.2.1 Sensory processing assessment tools 10

1.3.3 Typical and atypical development of sensory processing 12

1.4 Autism spectrum disorders and sensory processing 13

1.4.1 Prevalence rates across the lifespan 14

1.4.2 Profiles across the lifespan 16

1.4.3 Influencing factors 22

1.4.3.1 Increase in compensatory skills 22

1.4.3.2 Developmental delay 24

1.5 Summary and clinical implications 25

1.6 References 27


Chapter 2: An exploration in the sensory processing patterns of children on the autism spectrum  

Abstract 38  

2.1 Introduction 39  
2.1.1 The autism spectrum 39  
2.1.2 Sensory processing 39  
2.1.3 Assessment of sensory processing 40  
2.1.4 Sensory processing patterns in ASD 41  
2.1.5 Rationale for the study 42  

2.2 Methodology 43  
2.2.1 Participants 43  
2.2.2 Design and measures 44  
2.2.3 Recruitment and procedure 45  

2.3 Results 45  

2.4 Discussion 49  
2.4.1 Methodological concerns and future research 50  
2.4.2 Implications for clinical practice 51  
2.4.3 Summary 53  

2.5 References 54  

Chapter 3: Research in Clinical Training: Reflections 61  

3.1 Introduction 62  

3.2 Influences upon my research 62  
3.2.1 Clinical Experience: Getting started 63  
3.2.2 Personal life: Keeping going 64  

3.3 Research in sensory processing 64  
3.3.1 Empirical vs autobiographical accounts 66  
3.3.2 Methodological concerns 67  
3.3.3 Ethical issues 69  
3.3.4 Clinical implications 70  
3.3.5 Future research 70
3.4 My own sensory processing experiences 71
   3.4.1 Professional development 72
3.5 Summary 73
3.6 References 74

Appendices 77
Acknowledgements

I would like to thank Dr Sarah Kent and Mrs Jacky Knibbs for all their advice and support on this project. Both have been incredibly supportive during stressful times and their enthusiasm has helped to keep me going.

I am also grateful to all the services that were so helpful in the recruitment process. I would like to thank Karen Broderick and all of her team at Worcestershire Low Incidence Disability Service and also Sarah Carey and the staff team at Perdiswell Primary School. At Dudley Deaf Child and Family Service I would like to thank Kim Reeves, Dr Rob Walker, and the rest of the team. I would also like to thank the team at South Warwickshire Child and Adolescent Mental Health Service. Grateful thanks also go to all of the parents who participated in this project.

My friends have been an invaluable source of support throughout the duration this project. I would particularly like to thank Nat (whose faith in me and unfailing support always amazes me), and Sarah (a brilliant friend).

Finally, I would like to thank my parents - without whom I wouldn’t have had the courage to ever begin.
Declaration

This thesis has not been submitted for any other degree or to any other university. It is my own work except where it contains work based on collaborative research with Dr Sarah Kent and Mrs Jacky Knibbs.

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

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CAMHS</td>
<td>Child and Adolescent Mental Health Service</td>
</tr>
<tr>
<td>DISCO</td>
<td>Diagnostic Interview for Social and Communication Disorders</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition</td>
</tr>
<tr>
<td>SEQ</td>
<td>Sensory Experiences Questionnaire</td>
</tr>
</tbody>
</table>
Lists of Tables and Figures

List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1.1</td>
<td>Changes in sensory processing: key references</td>
<td>5</td>
</tr>
<tr>
<td>Table 1.2</td>
<td>The seven sensory systems</td>
<td>7</td>
</tr>
<tr>
<td>Table 2.1</td>
<td>Mean Total SEQ Scores for experimental and control groups</td>
<td>47</td>
</tr>
<tr>
<td>Table 2.2</td>
<td>Correlations for domains and age</td>
<td>49</td>
</tr>
</tbody>
</table>

List of Figures

| Figure 1.1 | Dunn’s Model of Sensory Processing                                         | 9    |
| Figure 2.1 | Hypo- and hyper-responsiveness across groups                               | 47   |
| Figure 2.2 | Subscale scores across groups                                              | 48   |
# List of Appendices

<table>
<thead>
<tr>
<th>Appendix 1.1</th>
<th>Publication criteria for <em>Autism Journal</em></th>
<th>77</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 2.1</td>
<td>Power analysis</td>
<td>78</td>
</tr>
<tr>
<td>Appendix 2.2</td>
<td>Criterion Cut-Off Points for Predecessor to SEQ</td>
<td>79</td>
</tr>
<tr>
<td>Appendix 2.3</td>
<td>National Research Ethics Committee approval documentation</td>
<td>80</td>
</tr>
<tr>
<td>Appendix 2.4</td>
<td>Information sheet for parents of experimental groups</td>
<td>83</td>
</tr>
<tr>
<td>Appendix 2.5</td>
<td>Consent form for parents of experimental groups</td>
<td>86</td>
</tr>
<tr>
<td>Appendix 2.6</td>
<td>Sensory Experiences Questionnaire - Short Form</td>
<td>88</td>
</tr>
<tr>
<td>Appendix 2.7</td>
<td>Introductory letter from specialist education service to parents</td>
<td>93</td>
</tr>
<tr>
<td>Appendix 2.8</td>
<td>Introductory letter from Child and Adolescent Mental Health Service to parents</td>
<td>94</td>
</tr>
<tr>
<td>Appendix 2.9</td>
<td>Introductory letter from school to parents</td>
<td>96</td>
</tr>
</tbody>
</table>
Summary

Past research has indicated that people diagnosed as being on the autism spectrum have unusual sensory experiences when compared with typically developing individuals (e.g., Tomchek & Dunn, 2007; Watling et al., 2001). However, an examination of the available evidence has revealed that little is known about either the nature or developmental course of these unusual sensory experiences (e.g., Leekam et al., 2007; O’Neill & Jones, 1997). The aim of this project is to investigate the patterns and developmental pathway of these unusual sensory experiences.

Chapter 1 reviews the published literature on the developmental pathway of unusual sensory experiences and highlights a need to identify patterns of sensory processing in people on the autism spectrum. Chapter 2 describes an empirical study that investigates patterns of these unusual sensory experiences. The results support previous research that indicates that children with ASD have co-existing patterns of hypo- and hyper-responsiveness. Chapter 3 presents a reflective account of the research process as a whole.

References


Chapter 1: The developmental pathway of sensory processing experiences in autism: A review

Evidence suggests that people on the autism spectrum have unusual sensory experiences when compared to people without autism. The existence of these sensory differences has been widely described, and it has been reported that these unusual sensory experiences may have the potential to improve over time. The evidence for this proposal is reviewed, and demonstrates that there is a need for standardised assessment tools in order to measure sensory processing experiences across the lifespan. Comparing sensory experiences of both children and adults is problematic due to limited assessment materials that can be used across age groups. This review highlights the difficulties of exploring the developmental trajectory of sensory experiences and identifies that more robust assessment methods for unusual sensory processing experiences across the lifespan are needed in order to be able to facilitate this.

KEYWORDS: Autism, Sensory Processing

Word Count: 6,142
1.1 Introduction

It is widely recognised that children diagnosed as being on the autism spectrum\(^1\) have unusual sensory experiences when compared with typically developing children (e.g., Kientz & Dunn, 1997; Liss et al., 2006; Minshew & Hobson, 2008; Rogers & Ozonoff, 2005, Tomchek & Dunn, 2007; Watling et al., 2001). Since the nature or the frequency of unusual sensory experiences is not included in the diagnostic criteria for autism, there has been a lack of research into sensory processing in people with ASD, and as a result, there is not a clear understanding of the nature of unusual sensory experiences, or their developmental course (Leekam et al., 2007; O'Neill & Jones, 1997). Consequently, there is a need for further research exploring unusual sensory experiences in order to understand the way they develop as children mature. It has been suggested that unusual sensory experiences may change over time (Baranek et al., 2006; Kern et al., 2006a, 2006b, 2007; Leekam et al., 2007). Potential explanations for this include development of compensatory skills by the child as s/he learns from experience (Baranek et al., 2006; Bodashina, 2003), or that the difference in sensory processing represents some form of developmental delay that may draw level with that of typically developing children as the child progresses into adulthood (e.g., Rogers & Ozonoff, 2005).

Unusual sensory processing experiences are suggested to have a significant impact upon the quality of life of a person with ASD. Researchers have indicated a link between the unusual sensory experiences of some people with ASD and difficulties in

\(^1\) The distinction is drawn between the terms 'children diagnosed as being on the autism spectrum' and 'children with autism'. Although the term 'children diagnosed as being on the autism spectrum' is preferred, the term 'children with an autism spectrum disorder' or 'children with ASD' has been adopted throughout the thesis in order to be more succinct.
Unusual Sensory Experiences

Coping with everyday life (Cook & Dunn, 1998; Dunn, 1997, 1999, 2001; Kern et al., 2006a). Autobiographical accounts written by people with ASD describe a range of unusual sensory processing experiences and have suggested that they can have an impact on the social interaction and communication difficulties that are consistent with autism spectrum conditions (Grandin, 1992; O'Neill & Jones 1997; Williams, 1994). Others have proposed that sensory processing difficulties may impact on the ability of children with ASD to participate in social, school and home activities (Anzalone & Williamson, 2000; DeGangi, 2000; Schaaf et al., 2002).

Therefore, in view of the significance of unusual sensory experiences in the lives of children with ASD and the potential for the distress caused by these experiences to be overlooked or misunderstood (Bogdashina, 2003), further research in this area is proposed to increase knowledge and understanding of the nature of sensory processing across the lifespan. There are implications for future research if unusual sensory experiences appear to change over time, which will be discussed further. The aim of this paper is to review the published literature regarding the possibility of developmental changes in unusual sensory experiences in people with ASD.

Literature review search strategies

The search for evidence concentrated on identifying peer reviewed studies written in English as well as a number of book chapters that made reference to the developmental nature of unusual sensory experiences. An Athens search was conducted during February 2008 using the following search terms: sensory, process*, experience*, abnormalities, impairment and autism*. Databases searched were Psycinfo, Medline and Academic Search Complete. The literature was then reviewed for
evidence relating to the notion that unusual sensory experiences have the potential to change over time. These sources were checked for references to other publications containing any of the search terms. The publications were then collated, and this process repeated until no new references could be gleaned. A total of thirty eight published articles about unusual sensory experiences in individuals with ASD were examined for this review. Of these, thirteen publications discussed sensory experiences over time, consisting of nine empirical papers and four theoretical or conceptual papers. Table 1.1 includes these thirteen papers, the age of participant involved, sample size and the tool used to assess sensory responses, and has been included in order to demonstrate the varied nature of assessment of sensory processing experiences reported in the literature.

1.2 The autism spectrum

Autism is a neurodevelopmental disorder that manifests itself in early childhood and persists throughout the individual’s life. It was first identified by Kanner in 1943. Since then our understanding and knowledge of autism has broadened and autism is perceived as one of a spectrum of disorders. This spectrum includes Asperger’s Syndrome, pervasive developmental disorder not otherwise specified (PDD NOS) and Rett Syndrome (Bishop & Lord, 2006). Wing (1996) introduced the term ‘autism spectrum disorder’.
Table 1.1: Changes in sensory processing: key references

<table>
<thead>
<tr>
<th>Paper (full reference can be found in Section 1.6)</th>
<th>Type of review</th>
<th>Sampling</th>
<th>Assessment tool used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baranek et al. (2006).</td>
<td>Empirical paper</td>
<td>258 children (5 - 80 months)</td>
<td>Sensory Experiences Questionnaire</td>
</tr>
<tr>
<td>Baranek et al. (2007).</td>
<td>Empirical paper</td>
<td>Children (sample size unknown)</td>
<td>Sensory Processing Assessment</td>
</tr>
<tr>
<td>Billstedt et al. (2007).</td>
<td>Empirical paper</td>
<td>105 (adults and children: age range unknown)</td>
<td>DISCO (child measures unknown)</td>
</tr>
<tr>
<td>Dunn (2001).</td>
<td>Literature review</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dunn et al. (2002b).</td>
<td>Conceptual paper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kern et al. (2006a).</td>
<td>Empirical paper</td>
<td>104 (3 - 56 years)</td>
<td>Sensory Profile</td>
</tr>
<tr>
<td>Kern et al. (2006b).</td>
<td>Empirical paper</td>
<td>103 (3 - 43 years)</td>
<td>Sensory Profile</td>
</tr>
<tr>
<td>Kern et al. (2007).</td>
<td>Empirical paper</td>
<td>104 (3 - 56 years)</td>
<td>Sensory Profile</td>
</tr>
<tr>
<td>Leekam et al. (2007).</td>
<td>Empirical paper</td>
<td>100 children, 100 adults (32 months - 38 years)</td>
<td>DISCO</td>
</tr>
<tr>
<td>Rogers &amp; Ozonoff (2005).</td>
<td>Literature review</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Williams et al. (2006).</td>
<td>Empirical paper</td>
<td>56 (child sample 8 - 15 years), 33 (adolescents and adult sample: 15 - 40 years)</td>
<td>Luria-Nebraska Tactile Scale</td>
</tr>
</tbody>
</table>

*References will also be made to the 25 remaining reviewed articles within the text.*
1.2.1 Diagnostic criteria

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR.; American Psychiatric Association, 2000) has provided diagnostic criteria for identifying autism which includes three essential features: difficulties in social interaction, difficulties in communication and a stereotyped or restricted repertoire of activities. These three features have been described as the 'Triad of Impairments' (Wing, 1992).

Unusual sensory responses were included as one of the diagnostic criteria for an assessment of autism in the Diagnostic and Statistical Manual of Mental Disorders (3rd edition) (DSM-III; American Psychiatric Association, 1980), although not included in later editions. Cases have been presented for its reintroduction as a core impairment in diagnostic manuals (Gillberg & Coleman, 1992). However, there has been some debate about this. It has been widely recognised that people with ASD have unusual sensory experiences when compared to people without ASD (e.g., Dunn et al., 2002a; Talay-Ongan & Wood, 2000; Watling et al., 2001). Dawson and Watling (2000) commented that although sensory processing differences are neither universal nor specific to autism, the prevalence of such differences in individuals with ASD is relatively high, and they have been considered as one of the core impairments in autism by some (Happé, 2005; Silva et al., 2007).

1.3 Sensory processing

The term sensory processing refers to the method the nervous system uses to receive, organise and understand sensory information that the brain has received (Miller & Lane, 2000). Seven sensory systems are present within the nervous system: sound, touch, vision, taste, smell, movement, and body position. Table 1.2 shows a summary of these sensory systems and their functions (Bogdashina, 2003).
### Table 1.2: The seven sensory systems (Bogdashina, 2003)

<table>
<thead>
<tr>
<th>Sensory System</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>The faculty of seeing</td>
</tr>
<tr>
<td>Hearing</td>
<td>The faculty of perceiving sounds</td>
</tr>
<tr>
<td>Vestibular system</td>
<td>Refers to structures within the inner ear that detect movement and changes in the position of the head</td>
</tr>
<tr>
<td>Olfaction (the sense of smell)</td>
<td>Perceiving odours or scents</td>
</tr>
<tr>
<td>Gustation (the sense of taste)</td>
<td>Perceiving the sensation of a soluble sensation caused in the mouth and throat by contact with that substance</td>
</tr>
<tr>
<td>Tactile system</td>
<td>Perceiving touch, pressure, pain, temperature</td>
</tr>
<tr>
<td>Proprioceptive system</td>
<td>Perceiving stimuli produced within an organism, especially relating to the position and movement to the body</td>
</tr>
</tbody>
</table>

The sensory systems act as a route via which the brain receives information. The brain must then derive meaning from this information and devise and implement a response. Generally, typically developing children and adults process sensory information without difficulties on a continual basis. Sensitivity to sensory stimuli occurs along a continuum, from hyper- to hypo-responsiveness. Hyper-responsiveness refers to the sensory channel being too ‘open’, and so there is too much stimulation for the brain to cope with, whereas hypo-responsiveness refers to the sensory channel not being open enough, therefore too little of the stimulation is able to get in and the brain is deprived of sensory input (Delacato, 1974).
1.3.1 Dunn's Model of Sensory Processing (1997)

Some of the literature on sensory processing and people with ASD has specifically drawn on Dunn's Model of Sensory Processing (see Figure 1.1). This model has been included because it provides a useful way of thinking about the context of sensory processing in autism spectrum disorders (Dunn, 1997). The principal concept of this model is that a person's way of responding to sensory events is a combination of their neurological threshold (high or low) and their responding strategy (passive or active). The neurological threshold takes the form of a continuum between a low threshold, when the nervous system responds quickly to sensory information; and a high threshold, when the nervous system responds more slowly than would be expected. The self regulation behavioural response continuum illustrates the strategies people use to manage the sensory information they receive, from active to passive. Passive self regulation means the person allows sensory events to take place around them. They may fail to notice sensory information, such as facial expressions, or feel overwhelmed by things happening around them. At the other end of this continuum are people with active self regulation strategies, who use behaviours to control their sensory experiences. These individuals may actively seek out or avoid sensory information, for example by putting their hands over their ears to block out sounds.

Using these concepts, Dunn (1997) described four basic patterns of responding to sensory events, shown in the four quadrants of the diagram. Each pattern shows a different combination of self regulation strategy and threshold for example, Sensation Seeking is the combination of a high neurological threshold and an active self regulation strategy.
1.3.2 Assessment of sensory processing

There are a number of assessment tools available for assessing sensory processing abilities. More specifically, there are assessment instruments for use with children (e.g., Baranek et al., 2006; Dunn, 1999; Morton & Woolford, 1994) and for use with adults (e.g., Brown & Dunn, 2002); tools that are designed specifically for measuring sensory processing per se (e.g., Baranek et al., 2006; Morton & Woolford, 1994), and those that are broad diagnostic tools used to assess for ASD but also highlight unusual sensory experiences (Lord et al., 1994; Schopler et al., 1994; Wing et al., 2002). There are assessment instruments that can be used for measuring sensory processing across the lifespan, although in some cases this is done by using different versions of the same tool (e.g., Infant/Toddler Sensory Profile, Dunn & Daniels, 2002; Sensory Profile, Dunn, 1999; Adolescent/Adult Sensory Profile, Brown & Dunn, 2002). Therefore, comparisons across age and instruments must be done with caution. Furthermore, assessment tools may vary according to the model on which they are
based. For example, some of the assessment instruments are based upon Dunn's Model of Sensory Processing (e.g., 1997; see Section 1.3.1), whereas others are influenced by a model based upon two thresholds of processing sensation, hyper- and hypo-responsiveness (Baranek et al., 2001), such as the Sensory Experiences Questionnaire (Baranek et al., 2006; see Section 1.3.2.1). Consequently, different assessment tools may contain different sensory items.

The assessment of unusual sensory experiences is typically by questionnaire, whether completed by caregiver or teacher (in the case of children) or self-report. Typically, additional factors are likely to also be taken into account and considered in conjunction with scores on the assessment tool used such as person's age, cognitive abilities, diagnosis and environment. The following sections will outline some of the key assessment instruments recurrent in the main empirical literature and used with children and adults with ASD.

1.3.2.1 Sensory processing assessment tools. The Sensory Profile (Dunn, 1999) is one of the assessment tools most often used and is based upon Dunn's Model of Sensory Processing (Dunn, 1997). It is a caregiver report instrument often used to measure sensory processing experiences in children aged 3-10 years of age. Caregiver report instruments usually ask the caregiver to check the box that most closely describes the frequency with which the child shows a particular behavioural response to everyday sensory events, such as having a bath or trying new foods. Responses are usually divided into categories of separate sensory modalities, such as visual, auditory, tactile, olfactory/gustatory and vestibular/proprioceptive. Further factors are likely to also be
taken into account and considered in conjunction with scores on this instrument such as the child’s age, cognitive abilities, diagnosis and environment.

There is also an Adolescent/Adult version of the Sensory Profile (Brown & Dunn, 2002) that can be used to measure sensory processing abilities in individuals aged from 11-65 years. However, comparing the Sensory Profile and Adolescent/Adult Sensory Profile would mean comparing caregiver-report with self-report responses. The ability of the caregiver to interpret the child’s behavioural response to sensory events is likely to vary from an adult’s ability to report on their own sensory experiences, as in the adolescent/adult version.

Further specific sensory tools include the Sensory Experiences Questionnaire (SEQ; Baranek et al., 2006). The Sensory Experiences Questionnaire evaluates behavioural responses to everyday sensory experiences in children. It was designed specifically to be able to identify sensory features in children aged 5 months – 6 years with ASD, developmental delay and typical development. The SEQ’s items were selected by comprehensively reviewing the literature on unusual sensory experiences in children with ASD. The theoretical background to the SEQ follows the model proposed by Baranek et al. (2001), in which two thresholds for processing sensation, a sensory orienting and sensory aversion threshold, may vary resulting in different degrees of hypo- and/or hyper-responsiveness. These are shown by the behaviours the child engages in. Therefore, SEQ items largely reflect the patterns of hypo- and hyper-responsiveness. The SEQ items are also devised to show whether the sensory experiences occur in a predominantly social context (such as tolerating physical contact with people) or a non-social context (such as response to sounds or objects).
Broader diagnostic tools that are also able to highlight unusual sensory experiences include the Autism Diagnostic Interview - Revised (ADI-R; Lord et al., 1994), the Childhood Autism Rating Scale (CARS; Schopler et al., 1994), and the Diagnostic Interview for Social and Communication disorders (DISCO; Wing et al., 2002). To the author's knowledge, few other assessment tools for measuring unusual sensory experiences in adults are available. Whilst there are a range of different assessment tools used to measure unusual sensory experiences, there is no single standardized assessment tool for sensory processing across the lifespan.

1.3.3 Typical and atypical development of sensory processing

The ability to interpret sensory information develops as the infant learns how to use their sensory organs and relate sensory images to meanings (Bogdashina, 2003). If the sensory and perceptual processes are functioning properly, the baby is able to 'make sense' of the sensory stimuli they absorb from their environment by deriving meaning from it and devising a response. However, if there are difficulties in making sense of these sensory stimuli, distorted sensory input becomes distorted information (Ornitz, 1983, 1985).

There are a number of conditions or disabilities that are reported to have sensory processing experiences that are different from the typically developing population, including genetic and developmental disorders, such as Fragile X syndrome and schizophrenia (Dunn et al., 2002b). This review focuses solely on the sensory processing experiences of people with ASD.
1.4 Autism spectrum disorders and sensory processing

Bogdashina (2003) argued that people with ASD do not respond to sensory events in the same way as people without ASD, because people with ASD have different systems of perception and communication. Bogdashina suggests that there is evidence that all people with ASD have unusual sensory and perceptual processing experiences.

There is information from different sources to indicate the significance of unusual sensory experiences in the lives of people with ASD including empirical, conceptual, and autobiographical information sources (Ermer & Dunn, 1998; Kientz & Dunn, 1997; Tomchek & Dunn, 2007; Watling et al., 2001). A wide range of published autobiographical accounts provide valuable insights into the subjective experience of unusual sensory experiences (Cesaroni & Garber, 1991; Grandin, 1992, 1995; Grandin & Scarino, 1986; Larrocci & McDonald, 2006; White & White, 1987). In fact, the initial appearance of these sensory processing findings often pre-dates diagnosis (Adrien et al., 1993; Baranek, 1999a; Dahlgreen & Gillberg, 1989). However, Tomcheck and Dunn (2007) highlighted the lack of consistency among these studies in the size and ages of their samples, methods of assessment, and there is also a lack of replication. Furthermore, it has been suggested that as a whole, sensory processing has received less attention in the literature than other developmental variables in autism (Baranek, 2002; National Research Council, 2001). Consequently, findings have lacked consistency and are likely to reflect the variability in research questions and methods used in the studies (Tomcheck & Dunn, 2007).

Research is needed to establish whether the developmental pathways for each group are similar or different, and if it is the latter, the underlying or contributing factors for this difference. The following sections review the prevalence rates and profiles of
sensory processing experiences of children and adults with ASD, and also potential influencing factors.

1.4.1 Prevalence rates across the lifespan

In a review, Dawson and Watling (2000) reported that based on their analysis of firsthand reports and clinical accounts, between 30% and 100% of children with ASD are believed to have unusual sensory experiences of some kind. Similarly, Tomcheck and Dunn (2007) stated that the incidence of unusual sensory experiences reported in children with ASD ranges from 42% to 88% (Baranek, 2002; Kientz & Dunn, 1997; Liss et al., 2006; Volkmar et al., 1986; Watling et al., 2001). The lack of consistency in terms of sampling and assessment procedures may be contributing factors to the range of prevalence rates reported in these reviews and highlights the need to address this by using standardised approaches and procedures. In order to explore the developmental course of unusual sensory processing experiences, the unusual sensory experiences of children and adults must be examined individually. This is so that they may be compared and any difference in sensory profiles can be identified.

An examination of the empirical evidence available demonstrates that evidence for unusual sensory processing may only be considered categorically (i.e., child versus adult), rather than continually (i.e., across the lifespan). Furthermore, although there are a wide range of studies documenting the prevalence rates of unusual sensory experiences in children (e.g., Kientz & Dunn, 1997; Rogers & Ozonoff, 2005; Tomcheck & Dunn, 2007; Watling et al., 2001), there are few empirical studies documenting the prevalence and range of unusual sensory experiences in adults with ASD (O'Neill & Jones, 1997). Studies reporting comparable prevalence rates for
children and adults would enable life span changes in sensory profile to be ascertained. If we make the assumption that in typically developing children and adults, sensory processing patterns remain stable throughout development, identifying changes that occur in sensory processing for people with ASD will contribute to our knowledge regarding the role of sensory processing in the lives of people with ASD. Therefore it is important to study the developmental perspective to highlight differences between people with ASD and those who are typically developing.

There are studies that have looked at sensory processing in children and adults and suggested that unusual sensory experiences appear to decrease over time (Baranek et al., 1997; Kern et al., 2006a, 2006b, 2007; Williams et al., 2006). However, the majority of these report specific prevalence rates in terms of quantitative rather than qualitative descriptions. Baranek et al. (1997) reported that 30% of children and 11% of adults demonstrated auditory sensory difficulties, 11% of children and 7% of adults had tactile sensory difficulties. However, if the assumption is stable sensory processing in typically developing children and adults, then this study’s generalisability is limited as it lacks a control group. There is a need to compare the prevalence rates for children and adults with ASD with those of people who are typically developing in order to explore a possible interaction between the sensory profiles of these two groups. These findings may indicate that sensory processing differences decrease over time. Unfortunately, the authors do not provide information regarding the assessment tools used. If different versions of the assessment tool were used, close comparison of the scores for the different age groups is difficult.
Overall, reported studies suggest that there are high prevalence rates of unusual sensory processing in children with ASD, and that these rates may be lower in adulthood. This indicates that unusual sensory experiences may decrease with maturation. However, there are few sources of evidence available comparing prevalence rates for adults and children that enable the developmental course of sensory processing experiences in people on the autism spectrum to be examined closely enough. Again the lack of a standardised assessment tool across age groups means that findings from these studies must be considered with caution. Consequently there is a need to develop common assessment tools that can be used across age groups, and also for further investigation into the developmental perspective of sensory processing experiences.

1.4.2 Profiles across the lifespan

It has been proposed that there is a need for better information concerning the nature, course and prevalence of unusual sensory experiences of people on the autism spectrum (Dawson & Watling, 2000); this will increase understanding about the developmental pathway of sensory processing for ASD. The discrepancies amongst prevalence rates of unusual sensory experiences of people with ASD suggest a closer analysis of sensory processing profiles is needed. The profiles refer to patterns of sensory processing, including hypo- and hyper-responsiveness, that may change or remain stable over time. However, as with the literature on prevalence rates, the main body of literature on sensory profiles focuses on children with ASD.

Sensory experiences are usually categorised into the different sensory modalities; visual, auditory, tactile, olfactory/gustatory and vestibular/propiroceptive. Individuals
with ASD may describe atypical reactions to sensory stimuli across the range of these modalities, and report both hyper- and hypo-responsiveness. Studies have reported significant differences in both high and low thresholds of sensory processing in people with ASD when compared to people without ASD (Baranek et al., 1997; Kern et al., 2006a; Rosenhall et al., 1999).

Evidence suggests that unusual sensory experiences in ASD are present from early on in a child’s life (Baranek, 1999a; Dawson et al., 2000). Dawson et al. (2000) in their case study report of an infant with autism, found that unusual sensory experiences were evident during the first year of life, and by 15 months responses indicating unusual levels of sensitivity to all sensory modalities were observed. However as this is a single case study, replication is needed to provide further evidence. Baranek (1999a) supported the notion that unusual sensory responses can be seen from a young age, and suggested that these sensory differences may eventually be useful in initial screenings for autism spectrum disorders.

Baranek et al. (2006) used the SEQ (see Section 1.3.2.1 for further information) to investigate the sensory experiences of 258 children aged 5-80 months, indicating significantly more unusual sensory experiences in the ASD group when compared to the typically developing group and the group with developmental delay. These experiences were found to be inversely correlated to mental age, so that less developmentally mature children showed the highest scores on the SEQ (Baranek et al., 2006), indicating a higher frequency of unusual responses to sensory events. This suggests that the developmental nature of unusual sensory experiences is influenced by an intellectual or cognitive maturational process rather than chronological age per
se. Baranek et al. (2006) reported that these findings give further support to the developmental nature of unusual sensory experiences in young children and the notion that unusual sensory experiences have the potential to decrease over time, as they indicate that as a child develops they may experience a lower frequency of unusual sensory processing. However, it also highlights that chronological age needs to be considered in relation to the children's developmental age.

Baranek et al. (2007) proceeded by investigating the nature of hyper-responsiveness to sensory stimuli in children with ASD using a new observational measure, the Sensory Processing Assessment (SPA; Baranek, 1999b). Groups with ASD, developmental delay and typically developing children were included. Again, mental age was a predictor of hyper-responsiveness, and aversion to multisensory toys decreased as mental age increased. Predictably, the participant groups with ASD and developmental delay showed greater sensory sensitivity than the group of typically developing children. These results support findings from the study by Baranek et al. (2006) and corroborate the notion that unusual sensory experiences are influenced by a developmental trend. However, although a similar trend was suggested by both studies, different sensory patterns were indicated. The initial study (Baranek et al., 2006) indicated a greater frequency of unusual sensory experiences as the child develops, whereas the second (Baranek et al., 2007) more specifically emphasised a decrease in hyper-responsiveness.

Similarly, Williams et al. (2006) assessed sensory-perceptual abilities in 56 high-functioning children with ASD and 56 age- and IQ-matched controls using the Luria-Nebraska Tactile Scale (Golden et al., 1986). These findings were compared with their previous study (Minshew et al., 1997) assessing the same abilities in adolescents
and adults with ASD. The adult study (Minshew et al., 1997) produced mixed results, showing some differences between the group with ASD and the group without ASD although these were not significant. In contrast to this, in the child study there were significant differences between the sensory processing abilities of the group with ASD and the group without. Although these results must be considered tentatively as the data is cross-sectional, these findings indicate that unusual sensory experiences are more pronounced during childhood in individuals with ASD, and provides support to the hypothesis that they may reduce over time (Williams et al., 2006).

Kern et al. (2006a) used the Sensory Profile (Dunn, 1999) with 104 children and adults (3 to 56 years) with ASD and compared scores to age- and gender- matched controls. Four sections from the Sensory Profile were examined: auditory processing, visual processing, oral sensory processing and touch processing. The group with ASD showed a significantly greater frequency of unusual sensory experiences than the group without ASD. Furthermore, there was a significant group by age effect, in that for the group with ASD there was an apparent decrease in unusual sensory experiences as age increased. This was not the case for the group without ASD. In the ASD group, the unusual auditory, visual and oral processing altered over the age groups, apparently becoming more similar to the control group data over time. The only sensory modality that did not appear to decrease over time for the ASD group was low threshold touch. Kern et al. reported that these findings were supported by parental qualitative accounts claiming sensory processing difficulties when the children were younger. Findings from the study by Kern et al. (2006a) provide evidence to support the notion that unusual sensory processing experiences decrease over time.
Further, Kern et al. (2006b) continued to investigate unusual sensory experiences across the lifespan by conducting a study with 103 individuals with ASD, from 3 to 43 years of age, compared to age- and gender-matched controls. This study differed from Kern et al. (2006a) in that it assessed sensory quadrants in autism (Low Registration, Sensation Seeking, Sensation Sensitivity, and Sensation Avoidance) based on Dunn's Model of Sensory Processing (Dunn, 1997) using the Sensory Profile and Adolescent/Adult Sensory Profile (Brown & Dunn, 2002; Dunn, 1999). Kern et al. found a group by age interaction within all four sensory quadrants, so that the older people with ASD showed scores closer to the control group than younger people with ASD. Results indicated that the older group with ASD experienced a lower frequency of unusual sensory experiences than the younger group. Kern et al. (2007) extended their research by conducting a further study assessing unusual sensory experiences across a range of age groups (groups consisted of 3 - 12 years, 13 - 25 years, 26+ years), again finding that there was an apparent decrease in unusual sensory processing with increasing age. This study did not include a control group, therefore it must be hypothesised that the pathway of sensory processing in typically developing children and adults remains stable over time. These findings provide further support for the idea that unusual sensory experiences in people with ASD decrease over time.

By contrast, as part of a long-term follow-up, Billstedt et al. (2007) investigated sensory processing abilities in 105 adults with ASD years after first diagnosis, and reported conflicting findings. Using the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002), Billstedt et al. found unusual sensory experiences were still extremely common at follow up. Therefore this study provides evidence to suggest that unusual sensory experiences persist into adulthood,
although as the measures used for children and adults were different, it is difficult to draw any conclusions regarding whether they fluctuate or remain stable over time.

Leekam et al. (2007) investigated the developmental pathway of unusual sensory experiences by comparing scores attained by different age groups, based on Kern et al.'s (2006a, 2006b) work. Findings showed that the younger group demonstrated a higher frequency of unusual sensory experiences than the older group (groups consisted of 1 year 7 months – 10 years and 10 years 3 months - 38 years). Leekam et al. suggested that it is difficult to draw definite conclusions about the sensory differences found between age groups in this study and that these findings may provide an understated view of the extent to which changes to sensory processing profiles take place, as the study included a wide range of ages. However, this study does present two main findings. Consistent with Billstedt et al. (2007), unusual sensory experiences appear to persist into adulthood in people with ASD, and secondly some sensory differences do appear to change with age. There are methodological restrictions of this study that inevitably limit the potential for firm conclusions, more specifically the small sample size, within-group variability, and the age groupings. Leekam et al. commented that the age groupings used may have prevented observation of changes that might be seen much earlier in development. The authors proposed that further research is required to clarify the developmental changes that occur from infancy to adulthood.

Overall, the literature outlined above highlights some problems with methodology within the studies that have researched the developmental pathway of unusual sensory experiences so far, but nonetheless some consistent themes. Certain methodological restrictions of the studies should be considered in order to balance the contribution of
the evidence, such as the heavy reliance upon parental/caregiver report, and, consequently, the potentially subjective nature of these findings. Therefore firm conclusions cannot be drawn regarding the profiles of unusual sensory experiences from childhood into adulthood. In addition, some of the studies (e.g., Kern et al., 2006a, 2006b) use assessments such as the Sensory Profile (Dunn, 1999) to measure sensory experiences across different age groups and determine the way that the profiles develop over time. In order to use this measure with both children and adults, different versions must be used as there is currently no standardised assessment tool available for children and adults.

1.4.3 Influencing factors

Assessment of prevalence rates and profiles indicate that there are differences between the sensory profiles of children and adults. However, in order to explore these differences further there is a need to establish the relevant factors that are associated with the development of sensory processing in people with ASD over time. Two principal influencing factors to be considered are the development of compensatory skills by individuals in order to cope with the complexities of their sensory world, and a possible delay in the development of sensory processing experienced by children with ASD.

1.4.3.1 Increase in compensatory skills. An increase or development in compensatory skills or coping strategies is often proposed as a possible reason for an apparent decrease in a person's unusual sensory experiences over time (Baranek et al., 2006). Bogdashina (2003) commented on the ability of individuals with ASD to adapt to their environment and proposed that these coping strategies used by people with ASD
are reflected in acquired perceptual styles. The more frequently reported are: monoprocessing (focusing on one sensory domain, such as vision), peripheral perception (avoidance of direct perception, such as eye contact), systems shutdowns, compensating for an unreliable sense by other senses, resonance (becoming fascinated and "losing oneself" in certain stimuli) and daydreaming. If a person with ASD has these perceptual styles, this may lead professionals or family members around them to view the person's responses to sensory stimuli as unusual. Factors that might enhance or restrict the person's ability to adapt to unusual sensory experiences by using these coping strategies include level of cognitive ability, co-morbid difficulties, and the responses of people around them.

There is some empirical work that has explained the increase in compensatory skills in people with ASD, however the evidence is fairly limited. One of the ways this can be investigated is by looking at autobiographical accounts written by people with ASD, which can provide a helpful insight into the subjective experience of unusual sensory experiences. Some of these accounts in which adults with ASD describe how they have developed ways of coping with unusual sensory processing experiences provides support for the idea that coping strategies develop with age. For example, Holliday Willey (1999 suggests:

"If washing your hair is a terrible issue for you, wear a very short hair cut that can be quickly washed in a few seconds.

"If you enjoy the sensation of deep pressure, you might put light weights (store bought or some you have made yourself from sacks of small coins, pebbles, marbles, etc.) in the pockets of your jackets, sweaters and vests, even if this means you have to sew pockets in your clothing." (Holliday Willey, 1999)."
Jones et al. (2003) analysed five autobiographical accounts of unusual sensory experiences written by people with ASD from web pages. Findings demonstrated that all five people used specific coping strategies in order to manage the discomfort caused by their unusual sensory experiences, such as employing repetitive behaviours.

Baranek et al. (2006) suggested that children improve their repertoire of coping strategies and ability to adapt as they grow older and gain life experiences, which may enable the child to deal more easily with stressful situations. For example, Kinnealey et al. (1995) found that adults with ASD had developed individual coping strategies, such as talking themselves through difficulties, or counteracting uncomfortable situations. Therefore, evidence indicates that people with ASD develop ways of coping with unusual sensory experiences, which may create the impression that there is a decrease in these experiences over time.

1.4.3.2 Developmental delay. A further hypothesis for a decrease in unusual sensory processing experiences over time, is that it is due to a form of developmental delay specific to people with ASD (e.g., Rogers & Ozonoff, 2005). Williams et al. (2006) questioned whether findings demonstrating higher levels of unusual sensory experiences in children than adults may indicate developmental maturation, for example increased integration within the sensory system at the cortical level, as appears to happen with other abilities.

It is possible that the sensory processing experiences of people with ASD follow a particular developmental course and that over time these sensory processing experiences are naturally brought closer to that of the typically developing population.
However, as the aetiological basis for the development of autism spectrum disorders is unclear, to investigate causes of sensory processing changes over time, there must be a great deal of reliance on the observation of behavioural responses (Baranek, 1998), which means that it is difficult to attribute cause and effect.

1.5 Summary and clinical implications

This review highlights a need for further investigation into the developmental pathway of unusual sensory experiences. An examination of the literature has indicated a difference between the sensory profiles experienced by children and adults (Baranek et al., 2006; Kern et al., 2006a, 2006b; Leekam et al., 2007), which suggests that unusual sensory experiences may have the potential to decrease over time (Baranek et al., 2006, 2007; Kern et al., 2006a, 2006b; Leekam et al., 2007; Williams et al., 2006). However, there is high variation between the reported prevalence rates in both children and adults (Tomchek & Dunn, 2007), which is partly due to a lack of standardised assessment procedures and tools across age groups. Consequently, there is a need for the development of standardised assessment tools that can be used across age groups in order to measure sensory processing experiences across the lifespan.

The potential contribution of increasing our knowledge regarding the nature and developmental course of these unusual sensory experiences towards intervention planning has been noted (Baranek et al., 2006; Dunn, 2001; Kern et al., 2006a; Rogers & Ozonoff, 2005). According to Dawson and Watling (2000), in spite of the high frequency of unusual sensory experiences in people with ASD, there is a lack of research into the effectiveness of interventions devised to address them.
Whilst there have been some promising attempts at intervention e.g. use of massage (e.g., Silva et al., 2007), sensory integration training (e.g., Ayres, 1972, 1979, 1989; Cook & Dunn 1998; Schaaf & Miller, 2005), the evidence base is insufficiently robust for these to be widely available. It has been suggested that parents of children with ASD may underestimate the sensory processing differences experienced by their children (Baranek et al., 2006). It is likely that if these differences are being underestimated for verbal children, then for children and adults with ASD who are less verbally competent or have greater communication needs, the possibility of underestimating unusual sensory experiences may be increased. Adaptive behaviours or coping strategies for managing sensory experiences may be misunderstood by carers (Bogdashina, 2003). Increasing knowledge regarding the developmental course of unusual sensory experiences will facilitate understanding of the atypical responses sometimes shown by people with ASD and the unusual sensory experiences underlying them.

More information is needed in order to achieve a deeper understanding of these unusual sensory experiences, the way that they develop, and the factors that influence sensory processing experiences. Identifying specific profiles or patterns of these unusual sensory experiences will facilitate exploration and understanding of the way that these unusual sensory experiences tend to develop over time.
1.6 References


Chapter II: An exploration into the sensory processing patterns of children on the autism spectrum

Research suggests that children with ASD have unusual sensory experiences when compared with age-matched typically developing children. However, there is a dearth of research focusing on the nature of these sensory differences. The existence of sensory patterns of hyper- and hypo-responsiveness has been suggested. Sensory processing patterns of children with ASD (n = 53, aged 7-10 years) were investigated using the Sensory Experiences Questionnaire (Baranek et al., 2006). Overall results indicated that children with ASD demonstrated higher levels of sensory experiences compared to typically developing children, including hypo- and hyper-responsiveness, but that the sensory patterns were the same. Clinical and research implications, and directions for future research are discussed.

Word Count: 3,416
2.1 Introduction

This paper explores the sensory processing patterns of children with autism spectrum disorder (ASD). There is wide acknowledgement that sensory processing differences exist between children with ASD and typically developing children (e.g., Kientz & Dunn, 1997; Rogers & Ozonoff, 2005; Tomchek & Dunn, 2007; Watling et al., 2001). However, there is little research investigating the nature or patterns of these sensory differences. It has been suggested that people with ASD may have distinctive sensory patterns (e.g., Baranek et al., 2006; Dawson & Watling, 2000; Greenspan & Wieder, 1997; Hirstein et al., 2001; McAlonan et al., 2002; Miller et al., 2001).

2.1.1 The autism spectrum

The term autism spectrum disorder was introduced by Wing (1996) and refers to a spectrum of conditions including autism and Asperger's Syndrome (Bishop & Lord, 2006). Three main diagnostic criteria are used to identify autism; these include difficulties in social interaction, difficulties in communication and a stereotyped or restricted repertoire of activities (American Psychiatric Association, 2000). Despite wide recognition that people with ASD also have unusual sensory experiences when compared with those without ASD (e.g., Dunn et al., 2002a; Talay-Ongan & Wood, 2000; Watling et al., 2001), they are not included as part of the core diagnostic criteria.

2.1.2 Sensory processing

The sensory systems provide the pathway via which the brain receives information. The seven sensory systems are: sound, touch, vision, taste, smell, movement, and

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1 The distinction is drawn between the terms 'children diagnosed as being on the autism spectrum' and 'children with autism'. Although the term 'children diagnosed as being on the autism spectrum' is preferred, the term 'children with an autism spectrum disorder' or 'children with ASD' has been adopted throughout the thesis in order to be more succinct.
Sensory processing experiences in children are often measured using caregiver report instruments, such as the Sensory Profile (Dunn, 1999; see Henshall, 2008a, for further information), which is one of the most commonly used. The caregiver is asked to indicate the frequency with which the child shows a particular behavioural response to everyday sensory events, such as having a bath or trying new foods. Responses are usually divided into categories of separate sensory domains, such as visual, auditory, tactile, olfactory/gustatory and vestibular/proprioceptive (for further details on the assessment of sensory processing abilities and the different assessment tools that can be used, see Henshall, 2008a).

The Sensory Experiences Questionnaire (SEQ; Baranek et al., 2006) has been designed to identify patterns of sensory processing in children aged 5 months to 6 years, who have ASD, are typically developing, or who have a developmental delay. This measure provides information regarding the different sensory domains (i.e., visual, auditory, tactile, gustatory/olfactory, vestibular/proprioceptive) and in addition
Responsivity to sensory stimuli refers to the level of response the individual gives to particular sensory stimuli. Responsivity has been suggested to exist along a continuum, with the two most common sensory patterns being hypo- and hyper-responsivity. Hyper-responsivity refers to an exaggerated behavioural response to sensory stimuli (Baranek et al., 2006), such as covering the ears to block out sounds. Hypo-responsivity refers to a diminished response to sensory stimuli (Baranek et al., 2006), such as a lack of response to pain. Assessment of sensory processing can reveal the extent to which a child is hypo- or hyper-sensitive to each of the different sensory domains. A child may demonstrate particular patterns of hypo- and hyper-responsiveness to different types of sensory stimuli which can be observed in different settings, such that children may be hypo- and hyper-responsive to different sensory stimuli at the same time.

2.1.4 Sensory processing patterns in ASD

Since Kanner (1943) first acknowledged sensory processing differences in ASD, a number of studies have provided further evidence of the unusual sensory experiences of children with ASD compared to typically developing children (e.g., Ermer & Dunn, 1998; Kientz & Dunn, 1997; Watling et al., 2001). For example, Watling, Dietz, and White (2001) reported that children with ASD scored significantly higher than typically developing children on the Sensory Profile (Dunn, 1999). Further, Ermer and Dunn (1998) compared children with ASD, children with Attention Deficit
Hyperactivity Disorder (ADHD) and children without disabilities on Sensory Profile scores. Ermer and Dunn were able to identify children's group membership based on their Sensory Profile scores with 89% accuracy.

More recently, Baranek et al. (2006) examined sensory patterns in children with ASD aged 5 months to 6 years. Baranek et al. found significantly higher levels of sensory experiences in the ASD group when compared to the typically developing group. Research into hyper- and hypo-responsiveness to sensory input in children with ASD has led to the suggestion of two types of sensory responders, children who are predominantly hypo-responsive to sensory stimuli and children who are predominantly hyper-responsive (Dawson & Watling, 2000; Hirstein et al., 2001).

Overall, research has indicated that children with ASD experience unusual sensory experiences compared to typically developing children. However, Tomcheck and Dunn (2007) commented that there remains a lack of consistency among these studies in the size and ages of their samples, methods of measurement, and lack of replication. Further, Baranek et al. (2006) suggested that a crucial contributing factor to this gap in the research is the lack of valid and reliable assessment tools, as well as appropriate instruments that can be used across the lifespan (Henshall, 2008a). Baranek et al. commented that using the Sensory Experiences Questionnaire in longitudinal studies will contribute to our understanding of the developmental perspective of unusual sensory experiences.

2.1.5 Rationale for the study

The aim of this study is to broaden the knowledge base so far, by taking a developmental perspective and extending the age range used by Baranek et al. (5
months to 6 years 8 months) to an age range of 7 to 10 years. Sensory processing will be investigated in children with ASD compared to typically developing children for sensory domains (i.e., visual, auditory, tactile, gustatory/olfactory and vestibular/proprioceptive) and responsivity (hypo- and hyper-responsiveness). In addition, the patterns of sensory processing will be examined specifically for children with ASD.

2.2 METHODOLOGY

2.2.1 Participants

Experimental group 1 consisted of 29 children with ASD (3 female and 26 male, aged 7 years 5 months to 10 years 7 months). Participants for this group were recruited through a specialist educational service. Experimental group 2 consisted of 24 children with ASD (3 female and 21 male, aged 7 years to 10 years 5 months). Participants were recruited by clinicians working in local Child and Adolescent Mental Health Services. The purpose of selecting participants via sources from both health and educational services was to ensure there were no specific sensory processing differences in relation to the recruitment pathway. Children recruited through health services were being seen in relation to their diagnosis, rather than due to the presence of any other mental health issues. The control group consisted of 17 typically developing children (11 female and 6 male, aged 7 years 8 months to 10 years 3 months). Participants for the control group were recruited via mainstream primary schools.

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3 Power calculations were performed in order to establish the sample size required to produce findings that would be deemed generalisable to the target population, see Appendix 2.1.

4 The authors acknowledge the possible impact of recruiting from Education and Health. This will be addressed in the Results Section, see Section 2.3.
Children who were deaf/blind were not included in the research, as these children already experience sensory impairments which may also be indicative of unusual patterns in other sensory domains. Children with special needs, other syndromes or psychiatric diagnoses were also excluded to limit possible confounding variables regarding the link between sensory processing and ASD.

An independent sample t-test was carried out and there was no significant difference between the two groups for age \( t(51) = 2.284, p > .05, \text{SEM} = 1.806 \). A Chi-Square test was carried out to examine the data for gender differences and a significant difference was found, \( \chi^2 (1, N = 70) = 19.950, p = .000 \); boys demonstrated significantly higher levels of sensory experiences.

2.2.2 Design and Measures

This study used a survey design. Data was collected from parents about children's behavioural responses to everyday sensory events via the Sensory Experiences Questionnaire-Short Form\(^5\) (SEQ; Baranek et al., 2006, for more information see Henshall, 2008a). The overall internal consistency of the SEQ (21-item version) is .80 (Cronbach's alpha) and the test-retest reliability is .80 (Intraclass correlation coefficient). A validity study with 258 caregivers of children aged 5-80 months found that the SEQ discriminated well between children with ASD, typically developing children and those with developmental delay (Baranek et al., 2006). The short form of the SEQ was used in this study with children aged 7-10 years. The author of the SEQ was contacted prior to the study to request permission to use the measure. Although the SEQ was piloted with younger children with ASD, it has also been used with individuals with Angelman Syndrome aged 3-22 years (Baranek & Walz, 2006). The SEQ is based upon a model reflecting thresholds of sensory orienting and sensory

\(^5\) A copy of the SEQ-Short Form can be found in the appendices.
aversion and therefore specifically identifies patterns of hypo- and hyper-
responsiveness. As these patterns are the focus of this study, there was a clear
rationale for using the SEQ in this project. Cut-off scores are provided for the
predecessor to the SEQ, the Sensory Supplement Questionnaire, and are indicative of
cut-off points that can be used with the SEQ. They are divided into cut-off’s for the
*Typical* range, cut-off’s for the *At Risk* range and cut-off’s for the *Deficient* range
(see Appendix 2.2).

### 2.2.3 Recruitment and Procedure

Parents of all participants completed the SEQ. Parents were provided with research
packs containing an information sheet about the research, consent form, questionnaire
and stamped addressed envelope to return the questionnaire directly to the researcher.
Written consent was sought from all parents/caregivers. All participants were
offered a debriefing session afterwards.

### 2.3 RESULTS

The data was analysed in two parts. The first part investigated differences between the
control and experimental groups. The data was analysed for patterns of hypo- and
hyper-responsiveness and relationships within the different sensory domains across
experimental and control groups, to identify sensory processing patterns. Scores were
converted into proportions to allow for comparison across the subscales. The second
part explored the experimental data more extensively, and investigated the
relationship between the sensory domains and age to explore patterns across time.

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6 The labels used for the cut-off scores are those used by Baranek et al. These labels are not the authors' preferred terms.

7 Further details regarding consent and ethical approval can be found in the appendices.
An independent sample $t$-test was carried out to compare total SEQ scores from the two experimental groups (child and adolescent mental health services sample compared with the specialist education sample). There was no significant difference between these groups, $t(51) = -0.420, p > .05, SEM = 4.506$, therefore, data was pooled for the groups and now will be referred to as the experimental group. Throughout this thesis where homogeneity of variance is violated, Levene's procedure is used. An independent sample $t$-test was then carried out to investigate whether the total scores of the experimental and control groups of the SEQ differed from one another. There was a significant difference, $t(68) = 3.556, p < .05, SEM = 4.525$; the experimental group showed significantly higher scores than the control group. Higher scores on the SEQ represent a higher frequency of sensory experiences. Generally children with ASD were in the Deficient range and typically developing children were in the Typical and At Risk ranges (see Table 2.1). Two of the typically developing children had high SEQ total scores, resulting in a higher mean score that is not strictly representative of this group. Hypotheses for the presence of these high scores include the possibility that these children are experiencing some neurodevelopmental difficulties that have not been identified as yet, such as Attention Deficit Hyperactivity Disorder (ADHD), of which unusual sensory experiences can be a characteristic. Table 2.1 shows mean scores including and excluding the two outlier scores.

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8 Recruitment was through Health and Education. This analysis allowed for ensuring there were no specific sensory processing differences in relation to the recruitment pathway, see also Section 2.2.1.
Table 2.1 Mean Total SEQ Scores for experimental and control groups

<table>
<thead>
<tr>
<th></th>
<th>Mean SEQ scores (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with ASD</td>
<td>69.6 (15.7)</td>
</tr>
<tr>
<td>Typically developing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Including outliers</td>
</tr>
<tr>
<td></td>
<td>53.5 (17.6)</td>
</tr>
<tr>
<td></td>
<td>Excluding outliers</td>
</tr>
<tr>
<td></td>
<td>49.7 (14.8)</td>
</tr>
</tbody>
</table>

Note: Typical range = 21-44, At Risk range = 45-51, Deficient range = 52-105.

A Repeated Measures ANOVA was carried out to investigate differences between hypo-responsiveness and hyper-responsiveness (condition) across the two groups. There was a significant group effect, $F(1,68) = 10.2, p < .005$; the control group showed a significantly lower frequency of unusual sensory experiences than the experimental group (refer to Figure 2.1). There was no significant condition effect, $F(1,68) = .338, p > .05$. The group-condition interaction was not significant, $F(1,68) = 2.882, p > .05$.

Figure 2.1: Hypo- and hyper-responsiveness across groups
A repeated measures ANOVA was carried out to investigate differences between the five sensory domain subscales (i.e., visual, auditory, tactile, gustatory/olfactory, vestibular/proprioceptive) across the two groups. There was a significant group effect, \( F(1,68) = 10.779, p < .002 \), see Figure 2.2. There was also a significant subscale effect, \( F(1,68) = 12.008, p < .000 \); there was no significant group-subscale interaction, \( F(1,68) = 2.35, p > .05 \).

**Figure 2.2: Subscale scores across groups**

![Graph showing subscale scores across groups](attachment:image.png)

The data was then analysed for patterns of sensory processing across time for children with ASD. A correlation was performed to investigate whether age would correlate with the total score, which did not produce a significant difference, \( r = -.002, p > .05 \). In addition, age was explored for correlations with each of the sub-scales and hypo- and hyper-responsiveness. There were no significant differences between age and the sensory domains or patterns, see Table 2.2.
Table 2.2: Correlations for domains and age

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Patterns</th>
<th>Tactile</th>
<th>Auditory</th>
<th>Visual</th>
<th>Gustatory</th>
<th>Vestibular</th>
<th>Hypo-responsiveness</th>
<th>Hyper-responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td>.061*</td>
<td>-.045</td>
<td>.181</td>
<td>.010</td>
<td>-.080</td>
<td>.086</td>
<td>.078</td>
</tr>
</tbody>
</table>

* All p-values are larger than .05.

2.4 DISCUSSION

The aim of this study was to explore sensory processing patterns in children with ASD compared to typically developing children. Overall, children with ASD had significantly higher levels of sensory experiences than typically developing children, which included sensory domains and responsivity. The higher frequency of sensory experiences can be seen by the higher mean total SEQ scores obtained by the children with ASD (see Table 2.1 in Section 2.3). Children with ASD were largely in the Deficient range and typically developing children were in the Typical and At Risk ranges. However, the patterns remained the same for the sensory domains and responsivity. Results for children with ASD were examined for patterns within the sensory domains according to age, to examine sensory patterns across time. There were no significant differences found, however.

Overall, this study has confirmed that there are differences between the two groups, although not in the sensory patterns. More specifically, findings support previous research that patterns of hypo- and hyper-responsiveness can be observed in children with ASD (Baranek et al., 2006; Greenspan & Wieder, 1997; Hirstein et al, 2001).
Some studies have suggested that people with ASD fall into two distinct groups of sensory responders (e.g., Dawson & Watling, 2000), suggesting sensory patterns exist along a continuum. In the current study, hypo- and hyper-responsiveness are found to exist simultaneously, in both experimental and control groups. This supports other findings (Baranek et al., 2006; Greenspan & Wieder, 1997), and indicates that children can show hypo- and hyper-responsivity within a single sensory domain or also across sensory domains, thereby demonstrating a mixed sensory pattern. It has been suggested that at times, children with ASD can fluctuate between hypo- and hyper-responsivity (e.g., Harrison & Hare, 2004). Waterhouse et al. (1996) have proposed a model that accounts for the simultaneous presentation of hypo- and hyper-responsiveness. This model explains that concurrent patterns of hypo- and hyper-responsiveness could be caused by overlapping neurofunctional impairments that interact and disrupt complex human behaviours. This is a useful model because it attempts to explain the co-existence of these two sensory patterns.

2.4.1 Methodological concerns and future research

The aim of this study was to explore patterns of sensory processing in children with ASD compared with a control group, rather than predictors of sensory processing patterns to consider possible influencing factors. The difficulty with such an approach is that it is possible to establish differences, but not to address possible underlying factors. For example, age may be an influencing factor as children’s unusual sensory experiences may decrease with maturation. Gender and cognitive ability may also be influencing factors.

Baranek et al. (2006) found no significant differences for IQ and unusual sensory experiences, and in addition, Leekam et al. (2007) found that unusual sensory experiences persisted across age and cognitive ability in children and adults with
ASD. Leekam et al. commented, however, that age and IQ differences may be found with a larger sample. In terms of gender, it is known that more boys are diagnosed with ASD (Goin-Kochel et al., 2007), which may have contributed to the female/male ratio discrepancy across these samples. The significant gender imbalance between experimental and control groups within this study may have been an influencing factor upon differences in sensory processing between the groups. Further research is needed to determine whether gender is a predictive factor in sensory processing generally, and specifically for ASD.

This study investigated children with ASD and typically developing children for differences in sensory processing and then explored differences within the sensory domains across a specific age range. Although there was no significant variability across time, the age range of this study was limited. Further research would allow for a broader age range to be included, which could extend up to secondary school, or longitudinal research as previously suggested by Baranek et al. (2006).

Overall, additional research investigating the sensory domains across a wider range of ages is suggested. A clearer understanding of the way the sensory domains interact with one another and change across time will give us insight into children's responses and behaviours and contribute to future interventions. Further research is needed to determine the cause of this difference in levels of responsiveness and to identify influencing factors that facilitate or inhibit sensory processing in people with ASD.

### 2.4.2 Implications for clinical practice

If the sensory patterns of children with ASD involve both hypo- and hyper-responsiveness within each sensory domain, this has implications for the ability to
predict children's sensory responses, and emphasises the need for intervention plans
tailored to the child and his/her unique sensory pattern. It means that there is a need to
be tentative when predicting children's sensory patterns. Assumptions cannot be made
that a particular child has a sensory pattern of either hypo-responsiveness, hyper-
responsiveness, or both, as sensory patterns could consist of any combination of these.
Intervention programs that are helpful for some children may be unsuitable for others
(Grandin, 2000), as there may not be common sensory patterns between children with
ASD and other typically developing and developmental groups. More information
about the way in which sensory patterns co-exist is needed, and the influence of other
factors upon the child's sensory response.

There is a growing evidence base to establish the effectiveness of therapeutic
interventions to address unusual sensory experiences. One such intervention is
sensory integration training (e.g., Ayres, 1972, 1979, 1989; Schaaf & Miller, 2005).
Sensory integration is the ability to take in information through the senses and to
combine the resulting perceptions with prior information, memories, and knowledge,
in order to make sense of the stimuli. Smith et al. (2005) compared the effectiveness
of a sensory integration approach with a control intervention of table top activities
with children with developmental delay. Using a sensory integration approach, self-
stimulating behaviours were reduced by 11% after one hour of intervention compared
to the tabletop activity. These results suggest that the sensory integration approach is
effective in addressing self-stimulating behaviours that prevent an individual with
ASD from taking part in other activities.

Overall, whilst there is preliminary evidence to suggest the effectiveness of
interventions such as sensory integration training, more research is needed to establish
a firm evidence-base, particularly given that tailored interventions may be required for
different children with unique sensory patterns.
2.4.3 Summary

This study found that children with ASD had higher levels of sensory experiences compared to typically developing children. Patterns for the sensory domains and for hypo- and hyper-responsivity remained the same. The patterns of hypo- and hyper-responsiveness were found to co-exist in children with ASD, meaning that children may be simultaneously hypo- and hyper-responsive to particular sensory stimuli. Further research is needed into the factors that influence sensory processing and the interactions between sensory patterns. There were no correlations between age and the sensory domains, which highlights the need for studies to investigate unusual sensory experiences across a broader age range to explore the developmental perspective of unusual sensory experiences. These findings emphasise that intervention plans devised to address sensory needs may need to be specific to individual children and their unique sensory patterns.
2.5 References


3.1 Introduction

The aim of this paper is to provide personal reflections on the research process undertaken during clinical training. It is divided into three main sections; influences upon my research, research into sensory processing, and personal experiences of sensory processing. Within the first section I aim to cover personal factors that may have contributed or influenced the research topic and design of the study, such as previous clinical experiences that may have had an impact upon my expectations or perspective. The second section will discuss research in sensory processing, including a consideration of methodological concerns, ethical issues and suggestions for future research. The third section describes my own experiences of sensory processing, and also covers impact of the research upon professional development.

3.2 Influences upon my research

This section is divided into two parts, the first part will explain the influences my previous clinical work had upon the choice of research topic, and the second will describe reflections on the impact events in my personal life had upon the project.

During my clinical work with people with ASD I had become aware of the link between unusual sensory experiences and ASD and the distress that they could sometimes cause (Bogdashina, 2003). It seemed that unusual sensory experiences are highly significant in the lives of people with ASD. Furthermore, it appeared that sometimes these unusual sensory experiences could be neglected or overlooked by others, such as family members or professionals working with the individual. This train of thought led to the decision to explore the nature of these sensory processing experiences. A preliminary examination of relevant literature revealed a need for
further research into this area (e.g., Leekam, Nieto, Libby, Wing, & Gould, 2007; O’Neill & Jones, 1997).

3.2.1 Clinical experience: Getting started

This was my starting point: having identified the need to extend the research into sensory processing in people with ASD, I linked this with my own experiences of the importance of addressing unusual sensory experiences clinically. This theory-practice link was the trigger for the research topic of this project.

I recognised that my experiences of working with children and adults with ASD and their caregivers would influence the project to some extent. Whilst working with people with ASD I had become aware of the impact that unusual sensory experiences can have upon individuals’ day-to-day functioning. The majority of my clinical work with people with ASD has been whilst working in learning disability services. During my clinical work I found that people with ASD and communication difficulties would struggle to let staff members know when they were distressed by sensory difficulties. Consequently, at times, individuals’ sensory needs were overlooked, which can be a common occurrence within services (Bogdashina, 2003). Bogdashina (2003) commented that when children’s unusual sensory experiences are neglected and they struggle to cope with sensory challenges, they are more likely to engage in behaviours that are difficult to manage, such as self-stimulation or self-injury. This highlights the importance of addressing people’s sensory needs.

I found that my clinical work had highlighted the challenges of helping people with unusual sensory experiences to let us know how to decrease their sensory distress. I found it difficult to imagine how life would be if I had unusual sensory experiences to contend with. I found that my experiences of working clinically led to my having a
strong expectation that my research would demonstrate a significant difference between the sensory experiences of those with ASD and those without. I had to remind myself not to become too wedded to the idea that all people with ASD have these unusual sensory experiences, and to approach doing the project with an open mind.

3.2.2 Personal life: Keeping going

Whilst the project was underway, events in my personal life inevitably had an impact upon me, and therefore the research process, at times. Retaining levels of motivation and enthusiasm for the project was more difficult when life outside the course was turbulent. Whilst writing this paper I considered my need for routine and order within the research process, how easily this became chaotic at times, and my distress when this happened. I could see a potential parallel process with people with ASD, in the way that people also tend to feel distressed by change to the routine and order that may give them a sense of safety. Although this feature of people with ASD is seen as a ‘difference’ from people without ASD, perhaps we are not always as different as we think, as most people find routine and order reassuring and safe at times. Thinking about this parallel process facilitated my attempts to try and take on the perspective of someone with ASD, another way of attempting to gain insight into people with ASD’s lives.

3.3 Research in sensory processing

The aim of this project was to investigate unusual sensory experiences. The first chapter reviews the literature on the developmental pathway of unusual sensory experiences. I found this a thought-provoking paper to write and found that I was curious about what people with ASD would say if asked themselves – how had they
found living with unusual sensory experiences? I wondered about whether adults with ASD would feel that their unusual sensory experiences had decreased as they had got older, and what might have influenced these changes. Many autobiographical accounts are written by adults recounting their experiences as children (O’Neill & Jones, 1997), and it would be interesting to find out what people would say about their experiences as adults.

The second chapter is the empirical paper, in which patterns of unusual sensory experiences were investigated. I found that I was fascinated to find out more about these sensory experiences, particularly the way that they affected families’ lives. Many parents wrote comments at the end of the questionnaire, often descriptions of how their child behaved in response to particular sensory stimuli. I was touched by the parents’ keenness to contribute (some parents included their phone number in case I needed more information), and this made me think about what other outlets, if any, some of these parents might have for sharing worries and concerns in relation to their child’s sensory difficulties. I also found that I felt very sympathetic towards the parents of children with ASD who participated in the research. Reading highly personal comments gave me an insight into people’s lives and the difficulties they were facing on a daily basis. Two examples of these comments are given below:

"Never still. Seeks out extreme movements. Spins but never dizzy. Jumps off high things with no fear. Loves fairground rides. Rubs his feet on us when sitting near us. Hangs off us. Falls of chairs for no reason.” (written by the mother of an eight year old boy with ASD)

"Fine in bath but petrified of showers. Dislikes getting rained on or having a wet object to hold. Scared of loud traffic noise e.g. lorries and motorbikes."
Dislikes sudden movement, uneven surfaces to walk on. Likes his feet firmly on the ground.

Has severe eating problems. Only eats certain foods. Will not eat anything broken e.g. breadstick, or anything that looks slightly different. The sight, texture or smell of certain foods will cause him to be physically sick.” (written by the mother of a 7 year old boy with ASD)

The difference between these two accounts is striking and emphasises the importance of ensuring intervention plans are tailored to the individual child. I hoped that doing this piece of research would add to the knowledge base regarding sensory patterns, and so help other professionals to support these parents.

3.3.1 Empirical vs autobiographical accounts

Whilst researching the topic, I read a wide variety of published material about unusual sensory experiences in people with ASD. Reading this material prompted reflection on the differences between using empirical studies and autobiographical accounts as sources of information about unusual sensory experiences, as there are advantages and disadvantages of relying upon each as a source of evidence. Autobiographical accounts tend to produce rich, detailed information, and give helpful insight into people’s subjective experiences. For example, autobiographical accounts by people with ASD have revealed that although some unusual sensory experiences, such as extreme sensory overload, can lead to distress and discomfort (e.g., Bogdashina, 2003; Jones, Quigney, & Huws, 2003), they have also shown that enjoyment can result from sensory experiences (e.g., Bogdashina, 2003; Jones et al., 2003).
These accounts are generally written by a single individual however, and so the generalisability of the descriptions of unusual sensory experiences to the population of people with ASD as a whole is questionable. Furthermore, these accounts are often drawn from a “higher functioning” group of individuals (O’Neill & Jones, 1997) as many individuals with ASD may not have the cognitive skills to write descriptive autobiographical accounts, which further restricts the generalisability of these accounts. Consequently, the insight gained from these accounts may only have applicability to some people with ASD (Jones et al., 2003). Findings from empirical studies involving high numbers of participants may be considered more reflective of other children with ASD. However, both sources of evidence have merits, and even if the autobiographical accounts are generally not able to be extended to others they can sometimes provide a valuable window into the complexity of the sensory world of someone with ASD. For example:

“I had always known that the world was fragmented. My mother was a smell and a texture, my father was a tone, and my older brother was something, which was moving about.” (Williams, 1992)

“Occasionally I lost all sense of perspective. Something would seem monstrously large if coming towards me at speed, or if I was unprepared. Someone suddenly leaning over me could frighten me enormously. I felt something was falling onto me and that I’d be crushed underneath it.” (Gerland, 1997)

3.3.2 Methodological concerns

This section aims to report some of the methodological concerns that should be considered when undertaking research in sensory processing. As highlighted above,
the extent to which research in sensory processing may be considered to be reflective of children with ASD as a whole is a concern within this area of research generally. There are various factors that might influence the generalisability of findings, such as small sample sizes or method of sampling. Different assessment tools are used within different studies to measure unusual sensory processing (see Henshall, 2008a), which further impacts upon the validity of using the current evidence base in sensory processing and people with ASD to build a true picture of the frequency or prevalence of these experiences.

A further methodological concern within sensory processing research is the method of data collection. The majority of the research within this topic area uses parental report questionnaires to collect information about children’s sensory responses. There are several difficulties with this method of data collection: it is highly subjective, language used within the questionnaire may be interpreted differently, and parents’ responses may be influenced by expectations about changes to service provision. In addition, one parent’s perception of scale items, such as, *Once in a While*, or *Sometimes* to denote the level of frequency a particular behavioural response occurs, may be different from that of another.

The use of questionnaires to measure unusual sensory experiences is also problematic in that the assumption as been made that a child’s sensory experiences can be measured by observing their behavioural responses. It may be the case that some experiences can be tapped into by noting the child’s response to a sensory event, but that other forms of sensory experience are expressed in a less covert manner. Also, it is possible that the child’s response may be misinterpreted by the caregiver or in fact
by the questionnaire. A further point to be considered is that the study assumes that parent or caregivers’ responses reflect the true picture of their child’s behavioural responses. The responses may be specific to a particular place and time, for example the participant responses may reflect the last time they can remember the child being presented with that particular stimuli (such as a new type of food) rather than the way the child usually or most often responds, which could be influenced by other factors, such as environment, other people present, how the child is feeling and so on. The child may also behave differently within different environments, depending upon the responses they are given, for example parental response may be very different from a teacher’s response.

3.3.3 Ethical issues

This section will cover some of the ethical issues that may arise when researching unusual sensory experiences. One particular issue associated with researching children’s sensory experiences is that asking parents about their child’s behaviour may raise parents’ expectations that there would be some changes to service provision based upon their responses. Often it may be the case that findings do influence the practitioners involved and possibly, to some extent the way services are run, however there can usually be no direct promise of service development as a result.

A further ethical issue that may occur when using questionnaires as the method of data collection is that some parents might struggle to understand the questionnaire. Given that there may be familial patterns within autism spectrum disorders and many parents may be on the autism spectrum themselves, they may struggle with communication and understanding.
It is also worth considering that asking parents to complete a questionnaire about their child's responses to sensory events may invite parents to worry that there is something wrong with their child. Whilst completing the study that is part of this thesis, it was hoped that the effect of completing the questionnaire would in fact be the opposite for parents: that participation would help to normalise parents' experiences and allow them to feel reassured that other parents may be coping with similar kinds of difficulties.

3.3.4 Clinical implications

Findings from this study indicated that children with ASD demonstrate higher levels of sensory experiences compared to typically developing children, which supports previous research (Tomchek & Dunn, 2007; Watling et al., 2001). Given the potential impact of these unusual sensory experiences upon aspects of children's lives (e.g., Dunn, 1997; Kern et al., 2006), it is important that these sensory needs are addressed. Difficulties with sensory processing have been suggested to be linked to the development of social and communication difficulties (Leekam et al., 2007), anxiety-related behaviours (O'Neill & Jones, 1997), and high levels of stereotypic, repetitive behaviours (e.g., Baranek et al., 1997). Furthermore, the development of effective interventions to address children's sensory needs may have the potential to facilitate children's responses to social and communication interventions.

3.3.5 Future research

There is still a great deal to investigate regarding the unusual sensory experiences of children on the autism spectrum. Expansions of this project in particular could include a qualitative research project exploring children and adults with ASD's views
regarding the experience of unusual sensory processing from the inside. This may help us to understand influencing factors upon levels of hypo- and hyper-responsiveness. I would be curious about whether people with ASD tend to consider themselves to have unusual sensory experiences and/or responses. If they do, when did it first become apparent to them that their senses were behaving in a different manner to their typically developing peers, and what did they notice about the way these unusual sensory experiences changed as they matured into adulthood? This may tell us more about the developmental pathway of unusual sensory experiences. It could also be interesting to use a self-report measure asking children to report upon their own sensory experiences, and comparing these with parents’ responses to reveal how accurate parents’ perceptions of their child’s sensory experiences are.

3.4 My own sensory processing experiences

Reading parents’ comments about their children’s sensory experiences led to reflection upon my own sensory processing experiences. I noticed that when I am tired or under stress, my awareness of sensory stimuli around me invariably increases. I recalled a recent visit to a supermarket one late evening after work. Tiredness and pressure to pick up what I needed and get home enhanced my sensory awareness. I found that particular forms of sensory input, such as a child screaming nearby, were almost unbearable. It seemed that the more tired and stressed I became the more intolerable the situation became. I noticed that my responses became more extreme as sensory information grew more difficult to process. For example, I was irritated by somebody brushing past me, and felt frustrated when I tried to scan the numerous product labels for something I wanted buy could not seem to see. My first urge was to leave the shop and remove myself from the situation. However, I had a basket full of
items I wished to buy. I managed to locate a quiet aisle and looked back at the shopping list to decide what I really needed. This helped me to calm down and think more clearly. I asked a member of staff to help me locate the last few items and then went to the checkout.

I could imagine that if a person with ASD was struggling to cope with sensory overload, that the longer they remained in the difficult situation, the more difficult the sensory information would become to manage, as this is how it had felt in the supermarket. It was a useful experience to help me make sense of how it might feel for someone with ASD having difficulty managing the sensory input flooding in, particularly since my first thought about how to cope involved escaping from the difficult situation. Although I found it helpful to go somewhere quieter and to ask for help, ways of coping are likely to vary for different people, depending upon factors such as age, cognitive ability, and the particular environment the person is in.

3.4.1 Professional development

Whilst in the final stages of the project I was offered a position as a clinical psychologist in a service for people with learning disabilities, which I accepted. The interviewers expressed a great deal of interest and enthusiasm in the project, which helped to fuel my enthusiasm and motivation for the project. Given that my prospective employers are so keen on the research topic, it is likely that I will have further opportunities to explore unusual sensory experiences in the future. I feel that within my future clinical practice, I will be more aware of the potential distress people could be experiencing through unusual sensory experiences. Completing this project has led to reflection upon the ways we work with people with sensory difficulties, and
thoughts about how to be creative in adapting environments in order to make people more comfortable.

3.5 Summary

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR; American Psychiatric Association, 2000) provides specific criteria for identifying autism yet does not include unusual sensory experiences to date. It is hoped that as more research is conducted within this field, the importance of unusual sensory experiences is recognised and the impact that they can have upon individual’s and their families’ daily lives.
3.6 References


Autism Journal

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. Length of paper. 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.

4. The maximum text length, therefore, should be 1000 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.

5. When submitting papers for consideration, please supply four paper copies. If the paper is accepted for publication, then a copy of the final version will be required on disk. The author is responsible for formatting the final hard copy and diskette versions of the manuscript as final.

6. 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.

7. The Editors welcome contributions to the Letters to the editors section of the journal. In the interests of saving space, or to expedite their review, we welcome contributions to the Letters to the Editor section.

8. 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.

9. Manuscripts will not be returned to authors if rejected.

10. Read per 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.

11. 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.

12. Articles submitted for publication must be typed (or word processed) in double spacing (eg. all sub-headings and main headings, on one side only of white A4 or US standard paper, with generous left- and right-hand margin but without justification).

13. Pages should be stapled. Titles and section headings should be neat and brief with a maximum of three orders of heading

14. Quotations. Lengthy quotations (exceeding 40 words) should be displayed and indented in the text.

15. 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’.

16. Articles. Authors should retain one copy of their typescript and send four copies, each fully numbered and legible, together with all figures and tables and a covering letter. Authors from outside the Americas should send their typescripts to Vicky Ellam, City University, Northampton Square, London EC1V 0HN, UK. Email: vellam@city.ac.uk. Authors from the Americas should send their typescripts in the first instance to: Mohammad Ghaziuddin, Division of Child Psychiatry, L507, University of Michigan Medical Center, 1500 East Medical Center Drive, Ann Arbor, MI 48109-2777, USA. Fax +1-[734]-615 9003; email: mghaziud@umich.edu

17. Books and suggestions should be sent to the Reviews Editor: Tony Cherman, The Behavioural Sciences Unit, Institute of Child Health, 30 Guilford Street, London WC1N 1EH. Email: t.berman@ch.uel.ac.uk
Appendix 2.1  Power Analysis

A power calculation was carried out to inform the sample size estimation for this study. Predicting a large effect size (Cohen, 1992) by drawing on past research of sensory processing difficulties in children on the autism spectrum compared with typically developing children, the aim was to achieve a power of .8 for this study. To achieve a power of .8, with a significance level of .5, a minimum of 26 participants is required for each group. Therefore, the aim was to recruit 52 participants in total for this study in order to be able to compare sensory processing differences between typically developing children and those on the autism spectrum.

Following on from this, the study aimed to explore the sensory processing profiles of children on the autism spectrum. In order to do this, a larger sample of parents of children on the autism spectrum was required. As a survey design is to be used the appropriate sample size was estimated using confidence intervals, in order to provide a range within which the population mean could be predicted to fall. With a confidence interval of 10%, and a probability level of 0.05, the sample size required to provide data that can be assumed to be reflective of the population of children on the autism spectrum as a whole was calculated to be 98 participants. Therefore the target sample size was 100 participants, who were parents/caregivers of children with diagnosis of an autistic spectrum disorder.
Appendix 2.2 Criterion Cut-Off Points for Predecessor to SEQ

These are the criterion reference for the predecessor to the SEQ, based on the norms for the typical sample in the Baranek et al. (2006) study.

To determine level of sensory processing difficulties, compare the child’s raw score sums to the criterion scores presented in this table. The child can be categorized in the typical range, at-risk range, or deficient range for total Sensory Supplement Questionnaire (SSP), and/or for each of the mutually exclusive subscales. Total scores are most internally consistent and are recommended for screening purposes. Any child receiving an at-risk or deficient score may be in need of further evaluation.

<table>
<thead>
<tr>
<th>Former SSQ-Original 21 items</th>
<th>Reference norms for typical children Means (standard deviations)</th>
<th>Cut-offs for Typical Range Scores between 0 and -1 SD</th>
<th>Cut-offs for At Risk Range Scores between -1 and -2 SD</th>
<th>Cut-offs for Deficient Range Scores greater than -2 SD</th>
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<tr>
<td>TOTAL RAW SCORE (21 items)</td>
<td>37.48 (7.16)</td>
<td>21 - 44</td>
<td>45 - 51</td>
<td>52 - 105</td>
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<td>SUBSCALES</td>
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<td>Hypo-social (3 items)</td>
<td>5.78 (1.85)</td>
<td>3 - 7</td>
<td>8 - 9</td>
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<tr>
<td>Hypo-nonsocial (8 items)</td>
<td>15.00 (4.48)</td>
<td>8 - 19</td>
<td>20 - 23</td>
<td>24 - 40</td>
</tr>
<tr>
<td>Hyper-social (5 items)</td>
<td>8.46 (2.50)</td>
<td>5 - 10</td>
<td>11 - 12</td>
<td>13 - 25</td>
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<tr>
<td>Hyper-nonsocial (5 items)</td>
<td>8.35 (2.31)</td>
<td>5 - 10</td>
<td>11 - 12</td>
<td>13 - 25</td>
</tr>
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</table>
29 November 2007

Miss Carolyn Henshall
Clinical Psychologist in Training
Universities of Coventry and Warwick
Doctorate in Clinical Psychology, Health
and Social Sciences,
Coventry University, Priory Street,
Coventry
CV1 5FB

Dear Miss Henshall

Full title of study: An exploration into the sensory processing patterns of children on the autism spectrum.

REC reference number: 07/H1211/112

Thank you for your letter of 21 November 2007, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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 approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

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<tr>
<th>Document</th>
<th>Version</th>
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<td>5.4</td>
<td>13 August 2007</td>
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<td>Peer Review</td>
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<tr>
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<td>15 August 2007</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
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<td>06 October 2007</td>
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R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.


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

Here you will find links to the following

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

b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

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@nationalres.org.uk.
With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

Paul Hamilton
Chair

Enclosures: Standard approval conditions

Copy to: Professor Ian Marshall
R&D office
Appendix 2.4  Information sheet for parents of experimental groups

Fax 024 7688 8702

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

Title of Project:
An exploration into the sensory processing patterns of children on the autism spectrum

Parent / Guardian 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 am inviting you to take part in this project. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the research?
The purpose of the research is to explore the sensory processing difficulties some children on the autism spectrum experience. A child experiencing sensory processing difficulties might be distressed by certain things, such as certain colours, lights, noises or smells. Sometimes these children behave in certain ways to avoid, or sometimes seek, particular sensory events, such as wanting to touch a particular type of material. Although it is known that some children experience sensory processing difficulties, there is little research about the patterns these difficulties take. This research project is exploring patterns of sensory processing difficulties to find out more about how we can help children on the autism spectrum who experience these difficulties.

Why have I been chosen?
This project involves approaching parents whose child has been diagnosed as being on the autistic spectrum.

Do I have to take part?
It is up to you to decide whether you would like to take part. If you decide that you...
would like to take part, I would ask you to sign one of the attached consent forms and return it with the completed questionnaire in the envelope provided. However, signing the consent form does not mean that you have to participate. You can withdraw from the project at any time during the process. You do not have to give a reason for this and it will not affect any services your child receives.

If you do not wish to take part, please do not return the questionnaire and this will be taken as a wish not to participate and I will not contact you again.

If you would like to take part, I would ask you to complete the attached questionnaire about your child's behaviour during everyday experiences, and return it via the stamped addressed envelope enclosed. The questionnaire takes about five to ten minutes to complete.

All participants are offered an optional debriefing session after taking part. During the debriefing session you would be able to discuss any issues that had arisen during completing the questionnaire if you wished to.

What are the possible disadvantages in taking part?
The questionnaire takes about five to ten minutes of your time. I do not anticipate that participants will find the questionnaire difficult to complete as it is about their child's reactions to everyday sensory experiences. If you experience difficulties completing the questionnaire, please feel free to contact me by telephone or email for support.

What are the possible benefits in taking part?
The information gained from this research will help provide information about patterns of children's sensory processing difficulties. Results will be communicated to the services involved and it is hoped that if possible this will help to inform ways of working with children on the autism spectrum for these services.

What will happen when the project is finished?
After all of the data has been collected, this data will be analysed and written up for
scientific journals. All participants are offered a summary report after the project is completed. You are welcome to contact me if you require any further information.

Will the information be confidential?
All personally identifying information gained during the research will be kept strictly confidential. None of the results of this research will include any identifying details of any of the parents who have participated or their children. Only the researcher and her two supervisors will have access to the data.

Who has looked at the research and agreed it can go ahead?
The project has been reviewed by Coventry University Ethics Committee and also the local Research Ethics Committee.
If you have any complaints about the way you have been treated during the study please contact Mrs Jacky Knibbs or Dr Sarah Kent on 02476 328 888 and these will be addressed.

Who can I contact for further information?
If you would like to find out more about what is involved in participation or any other part of the study please contact Carolyn Henshall or her supervisors Mrs Jacky Knibbs or Dr Sarah Kent:

Clinical Psychology Doctorate
School of Health and Social Sciences
James Starley Building
Coventry University
Priory Street
Coventry CV1 5FB
Email: carolyn.henshall@nhs.net
Tel: 02476 328 888

Many thanks for taking the time to read this information sheet and considering participation in this study. I hope that you feel happy to take part.
CONSENT FORM

Title of Project:
An exploration into the sensory processing patterns of children on the autism spectrum

Name of Researcher: Carolyn Henshall

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, and contact the researcher with any questions I might have. Questions I have asked have been answered satisfactorily.

Please tick this box if you agree with the statement above (1.). ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

Please tick this box if you agree with the statement above (2.). ☐

3. I understand that relevant sections of the data collected during the study may be looked at by the researcher and two supervisors where it is relevant to my taking part in this research. I give permission for these individuals only to have access to this information.

Please tick this box if you agree with the statement above (3.). ☐

4. I agree to take part in the above study.

Please tick this box if you agree with the statement above (4.). ☐

Name __________________ Date ______ Signature __________________

Address (only if copy of summary report required):

________________________________________

Researcher__________________ Date______ Signature__________________

Version 2: 4.10.07
Please return one of these consent forms in the stamped addressed envelope with the completed questionnaire if you wish to take part and retain the other for your own records. Please return this envelope to:

Carolyn Henshall  
Doctorate of Clinical Psychology  
James Starley Building  
Coventry University  
Priory Street  
Coventry  
CV1 5FB
Appendix 2.6  Sensory Experiences Questionnaire – Short Form

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)
### Experiences with Sound:

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Once in a While</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.)</td>
<td></td>
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<tr>
<td>Does your child enjoy listening to music?</td>
<td></td>
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<tr>
<td>Does your child ignore you when you call his/her name?</td>
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</tr>
<tr>
<td>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.)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Does your child notice sounds in the environment (such as planes, trains, faucets dripping, lights buzzing, etc.) before other people do?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your child show distress (startles, covers ears, etc.) during loud conversations or singing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Experiences with Sight:

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Once in a While</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your child enjoy looking at picture books?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Is your child disturbed by too much light inside or brightness outside?</td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Does your child stare at lights or objects that spin or move?</td>
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</tr>
<tr>
<td>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?</td>
<td></td>
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</tr>
<tr>
<td>Does your child avoid looking at your face during social games/play?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Does your child seem to ignore (doesn't notice) when someone new or different enters the room?</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Does your child enjoy watching children's videos or TV programs?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>ID #:</td>
<td>Date:</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Experiences with Touch:

<table>
<thead>
<tr>
<th>Does your child dislike cuddling or being held?</th>
<th>Almost Never</th>
<th>Once in a While</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

| Does your child show distress during grooming? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
| (For example: cries or fusses during face washing, hair combing, fingernail cutting, or teeth brushing)? |              |                |           |            |               |
|                                                 |              |                |           |            |               |

| Does your child avoid touching certain textures (such as fuzzy or squishy toys) or playing with messy materials (such as sand, lotion)? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child react negatively or pull away when touched by a person? (For example: pulls away when head is patted.) | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child have trouble adjusting to the water temperature during bath time or does he/she dislike being in water? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child seem slow to react to pain? (For example: he/she isn't bothered by bumps, scrapes, cuts, or falls.) | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child dislike being tickled? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child ignore you (doesn't notice) when you tap him/her on the shoulder for attention? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

### Experiences with Taste or Smell:

| Does your child refuse to try new foods or avoid certain tastes, smells, or textures (consistencies) of food? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child smell objects or toys during play or other activities? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child seem interested in the way people smell? (For example: smells hair, breath.) | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |

| Does your child put objects, toys or other non-food items in his/her mouth to lick, suck, or explore? | Almost Never | Once in a While | Sometimes | Frequently | Almost Always |
|                                                                 |              |                |           |            |               |
**Experiences with Movement:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Almost Never</th>
<th>Once in a While</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your child enjoy riding in a car?</td>
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<tr>
<td>Does your child like to jump up/down, rock back/forth, or spin in circles?</td>
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<td></td>
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<td></td>
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<tr>
<td>Does your child seek out physical rough-housing play?</td>
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<tr>
<td>(For example: craves being tossed in the air or spun around.)</td>
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<tr>
<td>Does your child seem uneasy or become dizzy when moving on a swing or rocking chair, for example?</td>
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</tr>
<tr>
<td>Does your child flap his/her arms or hands repeatedly, particularly when excited?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.

---

**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.**
SEQ Addendum for Fascinations:

How often is your child extremely fascinated with:

<table>
<thead>
<tr>
<th></th>
<th>A. Sounds</th>
<th>B. Lights</th>
<th>C. Smells</th>
<th>D. Tastes</th>
<th>E. Textures</th>
<th>F. Touch</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Almost Never</td>
<td>Once in a While</td>
<td>Sometimes</td>
<td>Frequently</td>
<td>Almost Always</td>
<td></td>
</tr>
<tr>
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<td>☐</td>
</tr>
</tbody>
</table>

Does your child “seek” or “crave” particular sensory experiences? If so please describe all fascinations/cravings.

_________________________________________________________________________________
_________________________________________________________________________________

Dear Parent or Guardian,

I am contacting you to introduce you to Carolyn Henshall, who is currently involved in a research project that is supported by the Worcestershire Low Incidence Disability (LID/MET) Service. Carolyn has been checked by the Criminal Records Bureau as part of her employment contract.

Carolyn 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 the sensory processing profiles of children who are on the autism spectrum.

Carolyn is currently recruiting parents of children on the autism spectrum within Worcestershire to take part in this study. Her research involves asking parents to spend five to ten minutes completing a brief questionnaire about their child's responses to everyday sensory events, such as having a bath or trying new foods.

All details that would identify your child are confidential. No personally identifiable information or contact details of parents will be retained by the researcher once the questionnaire has been sent out. No child will be identified by name in the results of the survey.

I enclose with this letter an information sheet outlining Carolyn's research and the procedure of collecting the data. Should you have any further questions please do not hesitate to contact Carolyn at Coventry University on 02476 328 888. If you would like to take part in this project, please complete the attached questionnaire and consent form and return directly to Carolyn:

Carolyn Henshall  
Doctorate of Clinical Psychology  
James Starley Building  
Coventry University  
Priory Street  
Coventry  
CV1 5FB

Please contact Carolyn by phone or email if you would prefer to complete and return the questionnaire electronically.

Many thanks for your time and interest.

Yours sincerely,

Karen Broderick  
Principal Teacher – Autism.
Appendix 2.8 Introductory letter from Child and Adult Mental Health Service to parents

10th March 2008

Dear Parent or Guardian,

I am contacting you to introduce you to Carolyn Henshall, who is currently involved in a research project that is supported by the Coventry & Warwickshire Partnership Trust. Carolyn 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 the sensory processing profiles of children who are on the autism spectrum. 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.

Carolyn 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 five to ten minutes completing a new brief questionnaire about their child's responses to everyday sensory events, such as having a bath or trying new foods.

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 Carolyn's research and the procedure of collecting the data. Should you have any further questions please do not hesitate to contact Carolyn at Coventry University on 02476 328 888. If you would like to take part in this project, please complete the attached questionnaire and consent form and return directly to Carolyn:

Carolyn Henshall
Doctorate of Clinical Psychology
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

Please contact Carolyn by phone or email if you would prefer to complete and return the questionnaire electronically. Carolyn 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, Consultant Clinical Psychologist
Appendix 2.9 Introductory letter from school to parents

Dear Parent or Guardian,

I am contacting you to introduce you to Carolyn Henshall, who is currently involved in a research project that is supported by Perdiswell Primary School. Carolyn has been checked by the Criminal Records Bureau as part of her employment contract.

Carolyn 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 comparing the sensory processing profiles of typically developing children with those of children who are on the autism spectrum.

Carolyn is currently recruiting parents within Worcestershire to take part in this study. Her research involves asking parents to spend five to ten minutes completing a brief questionnaire about their child's responses to everyday sensory events, such as having a bath or trying new foods.

All details that would identify your child are confidential. No personally identifiable information or contact details of parents will be released to researchers. No child will be identified by name.

I enclose with this letter an information sheet outlining Carolyn's research and the procedure of collecting the data. Should you have any further questions please do not hesitate to contact Carolyn at Coventry University on 02476 328 888. If you would like to take part in this project, please complete the attached questionnaire and consent form and return them in the pre-paid envelope to Carolyn. Please contact Carolyn by phone or email if you would prefer to complete and return the questionnaire electronically.

Many thanks for your time and interest.

Yours sincerely,

To be signed by the headteacher/SENCO