Sensory experiences of individuals with Autism Spectrum Disorder and autistic traits: a mixed methods approach

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For mum, dad, Cameron, Greig and Kyle

In memory of my papa, Frank

Abstract

There has been a recent increase in research into sensory sensitivity in Autism Spectrum Disorders (ASDs), which has prompted the inclusion of sensory issues as an explicit criterion in the impending revision of diagnostic guidelines (DSM-5: American Psychiatric Association, 2010). However, one of the most interesting aspects of research in this field is that a clear disparity exists between the results of self- or parent-report studies and behavioural studies. The former class of studies shows that those with ASD report clear, consistent differences in their sensory experiences (Baranek et al., 2006; Crane et al., 2009; Leekam et al., 2007), whereas the findings in the behavioural field are complex to interpret, with all but a few areas of sensory processing (e.g. visual search: Joliffe & Baron-Cohen, 1997; Shah & Frith, 1983, 1993) demonstrating consistent consensus (e.g. Dudova et al., 2011; Tavassoli et al., 2012a). The thesis presented here aims to explore the nature of sensory sensitivities in those with ASD and the broader autism phenotype (BAP) further using a combination of qualitative and quantitative research designs. In addition, an approach was developed (the Sensory Audit: Chapter 8) which can be used to objectively assess an environment for sensory stressors.

Chapters 2 and 3 report the development of a sensory questionnaire (GSQ: Robertson & Simmons, 2012), which was administered to those with varying AQ scores, as measured by the Autism Spectrum Quotient (AQ: Baron-Cohen et al., 2001). There were both quantitative (Chapter 2) and qualitative (Chapter 3) features of the questionnaire. In the quantitative component, seven modalities were assessed (vision, audition, gustation, olfaction, touch, vestibular processing and proprioception), taking into account both hyper- and hypo-sensitivity to stimuli. We found that there was a strong, positive relationship between sensory sensitivity and AQ score, with medium scorers (who would be unlikely to be diagnosed with ASD) reporting significantly more difficulties with sensory stimuli than low scorers. For Chapter 3, we found that those with high levels of autistic traits (i.e. may be likely to have a diagnosis of ASD) tended to report using different coping techniques from medium and low scorers (e.g. avoiding situations and using sensory soothing rather than non-sensory soothing). The results from these studies suggest that sensory issues may be prevalent throughout the population and that the differences observed in Chapter 2 are mirrored in the themes extracted for each group in Chapter 3.

The second set of studies (Chapters 4-6) report data from three focus groups (caregivers of those with autism, adults with ASD and an elderly control group), as well as from

interactive group interviews with children who have autism. Although similar themes (e.g. control, consequences of problematic stimuli and positive effects of sensory stimuli) arose in all four studies, there were different types of information gathered from the groups. For those with ASD (Chapter 4 and Chapter 5), the discussion mainly centred around how sensory stimuli made them feel, and the implications of this for them. For the caregivers (Chapter 4) and the elderly group (who mainly discussed their relatives' experiences) (Chapter 6), the themes reflected their own experiences, concentrating on the implications of adverse reactions to sensory stimuli (for both themselves and their loved ones). The data from these studies provide insight into living with someone who has sensory issues, for both those with a diagnosis of ASD and their caregivers, as well as the relatives of elderly individuals suffering from vision and hearing loss.

Chapter 7 reports a study into the relationship between olfactory processing and the broader autism phenotype (as measured by the AQ). Participants completed the AQ as well as the Sniffin' Sticks Extended Test. A subset of the sample (n=62) also completed the Glasgow Sensory Questionnaire (GSQ) that was developed as part of Chapter 2. As expected, there were no significant differences in the Threshold, Discrimination or Identification performance of those with high and low AQ scores. However, there was significantly greater intra-participant variability in the Threshold scores for the top 15% of scorers on the AQ. Furthermore, a similar relationship to that reported in Chapter 2 between sensory score and autistic traits was observed. These results indicate that there may be other differences in various aspects of performance in those with ASD that are not being targeted by current behavioural paradigms (which may explain the disparity between reported sensory differences and those observed using direct measurement).

Finally, the last study reported is that of the development of a pilot Sensory Audit. This was an effort to apply the information gained from our previous research in a practical, useful way for individuals with ASD. Details of the development of the Sensory Audit, as well as the results of the pilot study are reported in Chapter 8. By making this freely available, we hope to help companies ensure that their working environments do not contain any undue stressors that could increase stress for those with sensory issues in their workforce.

The results are discussed in light of three overarching themes of the thesis as a whole. Firstly, the potential mechanisms underlying sensory responsiveness in ASD, with the suggestion that emotional states may be an important avenue to consider in future research.

Secondly, the impact of atypical sensory processing on caregivers, with particular attention paid to the compensation of these issues by caregivers, and the social implications of challenging behaviour instigated by unpleasant sensory stimuli. Thirdly, the data are discussed in light of the relationship between sensory processing and the broader autism phenotype (as measured using the AQ). The greater levels of intra-participant variability in the olfactory task (Chapter 7) are highlighted, as is the elevated sensory responsiveness of those with moderate levels of autistic traits reported in Chapters 2 and 3. The final section of the discussion deals with the limitations of the thesis, potential practical applications of the research and future directions.

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Peer-reviewed journal articles

Robertson, A.E., & Simmons, D.R. (2012). The relationship between sensory sensitivity and autistic traits in the general population. *Journal of Autism and Developmental Disorders*, 1–9. doi:10.1007/s10803-012-1608-7 (**Chapter 2**)

Refereed abstracts

Simmons, D.R. & **Robertson, A.E**. (2012). Visual symptoms in children and adults with autism spectrum disorder. *Perception, (in press)*. (**Chapters 4 and 5**)

Simmons, D.R. & **Robertson, A.E**. (2012). Visual symptoms in adults with autism spectrum disorders. *iPerception, 3(6),* 397. (**Chapter 5**)

Conference presentations

Robertson, A.E. & Simmons, D.R. (2012). The Sensory Audit: Making the workplace safer for individuals on the autism spectrum. Poster presented at *International Meeting for Autism Research (IMFAR), Toronto, May 17-19. 2012*. (**Chapter 8**)

Robertson, A.E. & Simmons, D.R. (2012). The Sensory Audit: Making workplaces safer for those with ASD. Paper presented at *The Rank Prize Funds, Grasmere, Feb 2012* (**Chapter 8**)

Robertson, A.E. & Simmons, D.R. (2011). Sensory sensitivities in children with ASD: A qualitative analysis. Poster presented at *International Meeting for Autism Research (IMFAR), San Diego, May 12-14. 2011*. (**Chapter 4**)

Robertson, A.E. & Simmons, D.R. (2011). Sensory sensitivities and the Autism Spectrum Quotient. Poster presented at *Social Brain 3, Glasgow, March 2011*. (**Chapter 2**)

Robertson, A.E. & Simmons, D.R. (2010). Sensory Sensitivities in Autism Spectrum Disorders: a qualitative analysis. Poster presented at *Scottish Autism Research Group, Edinburgh, October 2010* (**Chapter 3**)

Robertson, A.E. & Simmons, D.R. (2010). Sensory sensitivities in Autism Spectrum Disorders: A qualitative analysis. Poster presented at *International Meeting for Autism Research (IMFAR), Philadelphia, May 20-22, 2010*. (**Chapter 3**)

Robertson, A.E. & Simmons, D.R. (2009). Sensory sensitivities and the Autism Spectrum Quotient. Poster presented at *International Meeting for Autism Research (IMFAR), Chicago, May 7-9, 2009* (**Chapter 2**)

Robertson, A. E. (2009). Sensory Sensitivities and the Autism Spectrum Quotient (AQ). Paper presented at *Scottish Vision Group, Isle of Mull, March 2009* (**Chapter 2**)

Robertson, A.E. (2008). Sensory Sensitivities and the Autism Spectrum Quotient (AQ). Paper presented at an *Autism workshop, Stirling University, October 2008* (**Chapters 2 and 3**)

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Finally, I'd like to thank all the participants who took part in my studies – I've learnt so much from each of you and I hope the research presented here does you justice.

Declaration

I declare that this thesis, submitted to the University of Glasgow for the degree of Doctor of Philosophy, is the result of my own research, except where otherwise acknowledged, and that this thesis has not been submitted for a higher degree to any other university or institution.

Signed: …………………………………………

(Ashley E. Robertson)

Date: ………………………………

List of Abbreviations

AD   Alzheimer's disease

ADHD   Attention Deficit Hyperactivity Disorder

ADI (-R)   Autism Diagnostic Interview (-Reviewed)

ADOS (-G)   Autism Diagnostic Observation Schedule (-General)

AFC   Alternate forced choice

AQ   Autism Spectrum Quotient

AS   Asperger syndrome

ASD   Autism Spectrum Disorders

BAP   Broader Autism Phenotype

BAPQ   Broader Autism Phenotype Questionnaire

BD   Block Design

BFI   Big Five Inventory

BOLD   Blood oxygenation level-dependent

CA   Chronological age

CARS   Childhood Autism Rating Scale

CAST   Childhood Asperger Syndrome Test

CBCL   Childhood Behaviour Checklist

CC   Central Coherence

CEBI   Children's Eating Behavior Inventory

CR   Chemosensory responsiveness

CS   Contrast sensitivity

CSF   Contrast sensitivity function

dB   Decibels

db(A)   A-weighted decibels

DISCO   Diagnostic Interview for Social and Communication Disorders

DSM-IV	Diagnostic and Statistical Manual (4th edition)
DSM-IV-TR	Diagnostic and Statistical Manual (4th edition, text revision)
DSM-5	Diagnostic and Statistic Manual (5th edition); N.B. currently in draft
EEG	Electroencephalography
EFT	Embedded Figures Test
EMB	Extreme Male Brain
EPF	Enhanced Perceptual Functioning
ERP	Event-related potentials
ESAT	Early Autism Screening Test
Eyes Test	Reading the Mind in the Eyes test
fMRI	Functional Magnetic Resonance Imaging
FMR-1	Fragile X mental retardation 1
FPI	Food Preference Inventory
FXS	Fragile X syndrome
GARS	Gilliam Autism Rating Scale
GSQ	Glasgow Sensory Questionnaire
HFA	High-functioning autism
HSPS	Highly Sensitive Person Scale
LD	Learning Difficulty
MA	Mental age
MABC-2	Movement Assessment Battery for Children – 2
MCS	Multiple Chemical Sensitivity
MMN	mismatch negativity
OCD	Obsessive Compulsive Disorder
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
PIQ	Performance IQ

PLD   Point light display

pSTS   Posterior Superior Temporal Sulcus

RP   Received Pronunciation

RT   Reaction time

SEQ   Sensory Experiences Questionnaire

SIPT   Sensory Integration Praxis Test

SP   Sensory Profile

SPSS   Statistical Package for Social Scientists

SRS   Social Responsiveness Scale

SSP   Short Sensory Profile

TI   Touch Inventory for Elementary-School-Aged-Children

TD   Typically developing

ToM   Theory of Mind

UPSIT   University of Pennsylvania Smell Identification Test

VIQ   Verbal IQ

VMA   Verbal mental age

V2v   ventral quadrant of V2

WAIS-III   Weschler Adult Intelligence Scale (3rd edition)

WCC   Weak Central Coherence

Chapter 1   General Introduction

This thesis focuses on the nature of sensory sensitivities in Autism Spectrum Disorders (ASDs) and the implications that these sensitivities have for these individuals. In this chapter, the predominant issues in ASD research will be presented and followed by a review of the literature on sensory processing in ASD (both 'general' processing and domain-specific). Thereafter, the presence of autistic traits in the general population and the primary theories in ASD will be discussed. Finally, the remaining chapters of the thesis will be outlined.

1.1   Issues in ASD research

Autism Spectrum Disorders (ASDs) are typically characterised by difficulties with communication and social relationships, as well as inflexibility of thought and action. These are known collectively as the triad of impairments, and are at the heart of the current diagnostic criteria (American Psychiatric Association, 2000) for ASD. In the most recent version of the DSM (DSM-IV-TR: American Psychiatric Association, 2000), autism and related disorders are collected under an umbrella term of 'Pervasive Developmental Disorders (PDD), consisting of five categorically defined disorders: Autistic Disorder (more commonly referred to as autism), Asperger's Disorder (more commonly referred to as Asperger's syndrome (AS)), Pervasive-Developmental Disorder – Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CD) and Rett's Disorder (more commonly referred to as Rett's syndrome (RS). However, the labels attributed to these disorders change depending on the diagnostic manual used. Although those in the US predominantly refer to the DSM (American Psychiatric Association, 2000), the 10th version of the International Classification of Diseases (ICD-10) (World Health Organization, 1992) is more commonly used throughout the rest of the world. In ICD-10 there are slight differences, with PDD instead consisting of seven disorders: childhood autism, atypical autism (which includes atypicality in age of onset and/or symptomatology), RS, other childhood disintegrative disorder, AS, other pervasive developmental disorders and pervasive developmental disorder, unspecified (World Health Organization, 1992). Within this thesis, the following labels will be used: autism (referring to those with Autistic Disorder or childhood autism), Asperger's syndrome (referring to those with Asperger's Disorder or Asperger's syndrome), PDD-NOS (referring to PDD-NOS and atypical autism) and Autism Spectrum Disorder (referring to those with either autism, Asperger's syndrome or PDD-NOS).

For a diagnosis of autism or AS to be made, an individual must meet criteria for all aspects of the triad of impairments. However, they must have exhibited functional language prior to 3 years of age to be diagnosed with AS; otherwise a diagnosis of autism is made. PDD-NOS, on the other hand, is the terminology used when the individual does not meet diagnostic criteria for all three domains. Diagnosis for ASD is based on wholly behavioural criteria and is typically based on a combination of parent interview (e.g. Autism Diagnostic Interview-Revised (ADI-R: Lord, Rutter, & Le Couteur, 1994)) and observation (e.g. Autism Diagnostic Observation Schedule – Generic (ADOS-G: Lord et al., 2000)) techniques, meaning that diagnosis is open to interpretation and can be dependent upon the experience and skill level of clinicians.

The proposed changes to the diagnostic criteria (American Psychiatric Association, 2010), which are due to be published in the fifth edition of the Diagnostic and Statistical Manual in 2013, is currently a 'hot topic' in the field of ASD (Ghaziuddin, 2010; Wing, Gould, & Gillberg, 2011). One of the most contentious changes involves the categorisation of ASD. ASD is often used as an unofficial umbrella term when discussing multiple subgroups and currently consists of three separately diagnosed disorders: autism, AS and PDD-NOS. However, the plans for DSM-V propose that Autistic Disorder, Asperger's Disorder, PDD-NOS and childhood disintegrative disorder are replaced by a single disorder called Autism Spectrum Disorder (American Psychiatric Association, 2010). This is perhaps the most controversial issue, as many people with AS see themselves as separate from those who have autism. Furthermore, many individuals with AS have expressed concern that removing the AS subgroup could affect recognition of their needs and access to services (Szatmari, 2011). On the other hand, this change may make clinical diagnosis easier, as the boundaries between the different disorders on the Autism Spectrum are often blurry (Wing et al., 2011). However, it should be noted that there have been concerns raised about the lack of objective, observable criteria listed, which would make diagnosis difficult for less experienced clinicians (Wing et al., 2011). The removal of subgroups would also have implications for research – some studies have shown differences between high-functioning autism (HFA) and AS groups (e.g. Bonnel et al., 2010) and the changes may make recruitment more complex. However, although Bertone, Bonnel, & Burack (2009) argue that greater care needs to be taken with participant subgrouping in research, this would not necessarily need to be based on diagnostic subgroups (it could be, for example, based on IQ level or communication level).

Another contemporary debate involves the observed increase of people with a diagnosis of ASD and whether this is the result of a true increase in prevalence or the effect of improvements in diagnosis. Genetics play an important role in ASD, as the concordance rates are higher for monozygotic than dizygotic twins (Bailey et al., 1995), indicating a strong genetic component. However, multiple genes have been implicated (Buxbaum, 2009) and the extent to which environmental factors are also involved is unclear. There is evidence that 54% of the increase in prevalence is a result of known factors, including changes in diagnosis, increased awareness and parental age, although this leaves 46% currently unaccounted for (Weintraub, 2011). A recent study found a startlingly high prevalence rate of ASD (1 in 38) in South Korea (Kim et al., 2011) and it has been reported that prevalence rates have been consistently rising (from 1 in 2500 in 1985 to 1 in 110 in 2009; Weintraub, 2011). However, a recent study has found that there are similar proportions of adults with ASD as there are children (which implies that autism prevalence is stable) (Brugha et al., 2011). Furthermore, Gillberg and colleagues have found relatively stable proportions of between 0.7:100 and 1:100 in their studies (Gillberg & Gillberg, 1983; Kadesjö, Gillberg, & Hagberg, 1999). In addition, there are suggestions that the current prevalence rates of those with ASD (1 in 110, in the US) are too low, as records do not take into account those on the milder end of the spectrum (Weintraub, 2011). At the moment, there is no consensus on the reasons behind the increase in the prevalence of ASD, or even whether a genuine increase exists. Therefore, it is only by uncovering both the genetic and environmental causes of ASD that we will be able to determine its true prevalence.

As well as the 'big issues' mentioned previously, there are certain things that researchers should take into consideration when working with this particular clinical group. The majority of research is carried out with individuals who are "high-functioning", i.e. typically have average or above-average IQs and do not have many of the difficulties facing those with "classic" autism (Boucher, Mayes, & Bigham, 2008). Logistically and ethically, there are inherent problems in working with those who have more severe forms of ASD, as they may be unable to communicate with the researcher, give informed consent, attend to the task or follow instructions. In addition, forming matched control groups can be difficult, especially as the same ethical and practical issues arise for many of those participants who could be matched on IQ or verbal ability. Furthermore, recruiting predominantly high-functioning individuals with ASD creates problems with generalising to the Autism Spectrum as a whole. Another consequence of solely using those with high-functioning variants of ASD is that performance differences are likely to be less than

would be observed in those with classic autism. This means that effects will be smaller, resulting in a need for a greater number of participants. Furthermore, researchers should account for the autistic traits of the control group, as those with higher-than-typical levels often have patterns of performance, and even brain structure, more similar to the clinical group than controls (Grinter, Maybery, Van Beek, Pellicano, Badcock, et al., 2009a; Grinter, Van Beek, Maybery, & Badcock, 2009b; Stewart, Watson, Allcock, & Yaqoob, 2009; Sutherland & Crewther, 2010, von dem Hagen et al., 2011).

1.2 General Sensory Processing in ASD

Although sensory issues are not yet a part of the diagnostic criteria for ASD (American Psychiatric Association, 2000), there are plans to include atypical sensory processing in the next version of the Diagnostic and Statistical Manual (American Psychiatric Association, 2010), due in 2013. There is compelling evidence that individuals with ASD often exhibit (and report) unusual responses to sensory stimuli (Ben-Sasson et al., 2009). These sensory disturbances can be broadly categorized as over (or hyper-) and under (or hypo-) sensitivity. Hyper-sensitivity occurs when the stimulus feels too intense, e.g. lights seem overly bright and sounds are too loud. There is evidence that this can cause individuals with ASD pain (see Chapters 4 and 5; Williams, 1998), increase levels of distress and discomfort (Bogdashina, 2003), affect concentration (see Chapter 5) and instigate challenging behaviour and self-stimulation (Bogdashina, 2003). On the other hand, hypo-sensitivities occur when the individual is under-responsive to a stimulus. This can cause those with ASD to become unresponsive to simulation (appearing to 'ignore' it). One example of this is that some children with ASD do not respond to auditory stimuli when they are young – leading them to being referred for hearing tests (Robertson & Simmons, 2008). Another consequence of hypo-sensitivity is that the person may actively seek out stimulation (which could manifest as self-injuring or self-stimulation behaviours) (Bogdashina, 2003).

1.2.1 – Self-report

There are few self-written accounts of the sensory sensitivities in ASD. Autobiographical accounts can provide insight into what it is like to live with an ASD, and the experiences described can be useful for researchers investigating the Autism Spectrum. However, there are certain drawbacks with only considering a single person's experiences. Although extremely detailed, researchers are often unable to generalize data to others with ASD, as a) the experiences described are subjective and b) the evidence is solely from one person's

perspective. Furthermore, the people who provide these accounts are often extremely high-functioning individuals. As a result, they will be likely to give insight into the experiences of only a small subgroup of people with ASD. Individuals with classic autism, perhaps with intellectual difficulties or problems communicating, are often unable to disclose their sensory experiences. Furthermore, these accounts are often written with a second person involved (e.g. Grandin & Scariano, 1996). In these situations, we are unable to determine whether the account has been influenced in any way by the second person's experiences.

There have been few qualitative studies of sensory issues in autism (see Dickie, Baranek, Schultz, Watson, & McComish (2009) and Jones, Quigney & Hews (2003) for examples). By examining the themes *common* to the participants, this type of research can often be useful in providing detailed descriptions about what it is like to live with ASD while also highlighting issues common to the majority of participants in the sample. Chamak, Bonniau, Jaunay, & Cohen (2008) recently brought attention to the need to take the experiences of those with ASD into account in our research. Indeed, Laurent Mottron (who works in Montréal, Canada) is an example of a researcher who consistently stresses the importance of integrating those with ASD throughout the whole research process (Mottron, 2011), a concept that has recently been garnering support (Pellicano & Stears, 2011).

Self-report questionnaires can also be a useful way to investigate the commonalities and differences in large groups of individuals, as well as being preferable to second-hand data. However, it should be cautioned that there are often limitations to self-report data, as participants can a) exhibit difficulties with recall and b) be influenced by social desirability effects (Crockett, Schulenberg, & Petersen, 1987). Crane, Goddard, & Pring (2009) assessed the sensory symptoms of adults with ASD and a group of age, sex- and IQ-matched TD controls. Atypical sensory responses were evident in 94% of the ASD group, and there was evidence that sensory issues continue well into adulthood. Furthermore, the data showed that sensory issues did not appear to diminish with age, suggesting that a) participants may develop compensatory strategies for coping with sensory issues and b) this could affect the judgement of sensory sensitivities in ASD by third parties (e.g. in studies using parent report rather than self-report).

1.2.2 – Parent Report

One of the most common methods of researching sensory issues in ASDs has been to utilize parent report data. This normally involves the administration of a questionnaire to parents of those with an ASD, with responses being compared to those of a matched control group. There have been striking differences in reported sensory behaviours in those with ASD and typically developing control groups (Baranek, David, Poe, Stone, & Watson, 2006; Ben-Sasson et al., 2008; Dunn, Myles, & Orr, 2002; Kientz & Dunn, 1997; Leekam, Nieto, Libby, Wing, & Gould, 2007; Ornitz, Guthrie, & Farley, 1977; Rogers, Hepburn, & Wehner, 2003; Talay-Ongan & Wood, 2000). Furthermore, different patterns have been observed between those with ASD and other clinical groups, including intellectual disability (Baranek et al., 2006; Dahlgren & Gillberg, 1989), PDD (Baranek et al., 2006; Lord, 1995), developmental delay (Baranek et al., 2006; Rogers et al., 2003; Wiggins, Robins, Bakeman, & Adamson, 2009), Down's Syndrome (Carter, Capone, Gray, Cox, & Kaufmann, 2006), sensory impairment (Wing & Gould, 1979) and Attention Deficit Hyperactivity Disorder (ADHD)/Attention Deficit Disorder (ADD) (Ermer & Dunn, 1998). However, one study did not find significant differences between the sensory issues of those with ASD and Fragile X syndrome (Rogers et al., 2003).

Within the parent report literature, there have been many different questionnaires used to investigate sensory issues in ASD. The most commonly used is probably the Sensory Profile (Dunn, 1999). Many studies have used these questionnaires as the basis for measuring sensory response in ASDs (Ben-Sasson et al., 2008; Dunn et al., 2002; Kientz & Dunn, 1997; Rogers et al., 2003; Wiggins et al., 2009), as well as in other clinical populations (Ermer & Dunn, 1998). One questionnaire specifically developed for use in research is the Sensory Experiences Questionnaire (SEQ: Baranek et al., 2006). Other studies extracted their questions from already-existing diagnostic tools (e.g. the Diagnostic Interview for Social and Communication Disorders (DISCO: Wing, Leekam, Libby, Gould, & Larcombe, 2002), and used it in their comparisons with typical groups (Leekam et al., 2007).

Parent report provides insight into the behaviours of participants that would be difficult to access using other methods, although it has many limitations. Methodological shortcomings (such as small sample sizes and uneven variability across groups) affect the degree to which results can be generalised. Also, second-hand data (i.e. from parents) will always be less useful than data obtained directly from the population itself. Indeed, when

self-report and parent-report measures are compared, there is often limited consistency between judgements made by children/adolescents and their parents (Achenbach, McConaughy, & Howell, 1987). One reason for this could be that parents may attribute their child's reaction to an incorrect precipitant (e.g. the parent may think that their child does not like the people in the supermarket when it is actually the flicker frequency of the lights that causes the problem). Although useful when working with children or individuals with classic autism (as it is very difficult to gain direct data from this population), data gained directly from participants themselves will always be preferable.

1.3 Domain-Specific Sensory Processing in ASD

1.3.1 – Vision

In this section of the thesis, studies which have investigated visual processing in ASD (see Simmons et al., 2009, for a review) will be examined. This overview will concentrate on studies addressing both low-level and higher-order visual processing, concentrating on spatial vision, colour vision, motion perception and visual search in ASDs.

1.3.1.1 – Spatial vision

Spatial vision is the ability to discriminate between, or resolve, features that are defined spatially. The two predominant measures of spatial vision are acuity and contrast sensitivity (CS). Acuity is the acuteness (or clearness) of vision. Ashwin, Ashwin, Tavassoli, Chakrabarti, & Baron-Cohen (2009) compared the acuity of those with ASD to a gender-matched TD group, finding that the former had superior levels to the latter. Results showed the ASD group had an acuity level of 20/7 (indicating the ability to see a distance of 20 feet as if it were 7 feet), whereas the control group had a mean acuity of 20/13. However, since these results were published, some methodological issues have been raised (Bach & Dakin, 2009; Crewther & Sutherland, 2009). It emerged that the spatial resolution of the screen was not able to support the acuity measurement based on the viewing distance used, rendering the results invalid. Indeed, subsequent studies (Bölte et al., 2011; Falkmer et al., 2011; Kéïta, Mottron, & Bertone, 2010; Koh, Milne, & Dobkins, 2010a; Tavassoli, Latham, Bach, Dakin, Baron-Cohen, 2011) have failed to find a significant difference in the acuity levels of those with ASD and TD individuals.

Static contrast sensitivity is the ability to discern different levels of luminance in a static image. Bertone, Mottron, Jelenic, & Faubert (2005) investigated the pathway-specific and complexity-specific hypotheses relating to visuo-spatial processing in autism. To do so,

they presented luminance-modulated (first-order) and texture-modulated (second-order) static gratings to participants with autism (and a control group) and asked them to determine their orientation. They found that the participants with autism performed better than a TD comparison group with the first-order stimuli (i.e. had lower thresholds), yet worse with the second-order (i.e. had higher thresholds), which supported the complexity-specific hypothesis (Bertone, Mottron, Jelenic, & Faubert, 2003) rather than the pathway-specific hypothesis for visuo-spatial processing in autism. However, this difference may be particularly subtle, as the authors have not been able to replicate these findings with another sample (Simard-Meilleur, Bertone & Mottron, 2012).

Sanchez-Marin & Padilla-Medina (2008) used a 2AFC (2-alternative-forced-choice) signal detection psychophysical experiment, with static stimuli added to Gaussian noise, to investigate the visual pathway of children with autism. Six participants with autism and six age- and gender-matched controls were recruited. Results showed that the children with autism performed significantly worse than the comparison group over a range of signal-to-noise ratios. However, it should be noted that, although the researchers matched for gender and age, they were not matched for IQ, and comorbidity was not controlled for (ability to follow instructions was the only inclusion criterion).

Koh, Milne, & Dobkins (2010a) carried out rigorous psychophysical testing in a group of adolescents with ASD (n=10) and a TD comparison group (n=25). To do this, they measured contrast sensitivity at seven spatial frequencies (0.5-20 cpd), fitting a contrast sensitivity function (CSF) to the data from each participant. Visual acuity, peak spatial frequency, peak contrast sensitivity, and contrast sensitivity at a low spatial frequency were obtained from the CSF. There were no significant differences in the differential spatial processing of the participants with ASD, compared to controls. Other studies have found similar results (Behrmann et al., 2006; de Jonge et al., 2007; Milne, Scope, Pascalis, Buckley, & Makeig, 2009).

There have also been studies investigating contrast sensitivity using dynamic stimuli. As well as using static gratings, Bertone et al. (2005) measured the contrast thresholds for a flickering grating. They found no difference between thresholds of participants with autism and a TD comparison group, showing that pre-cortical visual functioning appears to be unaffected in autism. Pellicano, Gibson, Maybery, Durkin, & Badcock (2005) found similar results, using a Gaussian blob stimulus.

Bertone et al. (2003) found no differences in contrast thresholds for first-order (luminance-defined) drifting grating stimuli between adolescents with HFA and typical controls matched for laterality, gender and chronological age. However, the participants with autism had higher thresholds with second-order (texture-defined) stimuli. A more recent study (McCleery, Allman, Carver, & Dobkins, 2007) lent limited support to these findings, by investigating contrast thresholds for drifting luminance gratings in 13-month old infants at risk from ASD (i.e. who had an older sibling with the disorder). In order to do this, they employed a preferential-looking technique. They found that the contrast thresholds were significantly lower for the 'at risk' group than for the comparison group (which consisted of two low-risk infants per high-risk baby, matched for age on the first day of testing, number of days that birth date was pre/post due date, and having an older sibling). There was no difference in performance with isoluminant red-green gratings.

Koh, Milne, & Dobkins (2010b) measured both luminance and chromatic contrast sensitivities in adolescents with ASD, 'unaffected' adolescent siblings of those with ASD and typical controls. Results showed that there was a group difference in relative sensitivity to chromatic stimuli compared to luminance. Siblings showed relatively higher chromatic vs. luminance CS than both the ASD and TD groups, which the authors suggest could be indicative of a protective factor against developing ASD.

To summarize, it appears that there is no evidence for increased acuity in ASD. However, the case is more convoluted for contrast sensitivity. For luminance-defined stimuli, most studies report no significant difference in the thresholds of those with ASD from typically developing controls (Bertone et al., 2003, 2005; Koh et al., 2010a), although some studies have found lower thresholds in those with ASD (Bertone et al., 2005) and high-risk infants (McCleery, et. al., 2007). However, when the stimuli are texture-modulated, the modulation thresholds appears to be significantly higher in ASD than for a TD comparison group (Bertone et al., 2003, 2005). Finally, there is evidence to suggest that siblings of those with ASD have higher chromatic contrast sensitivity thresholds than both those with ASD and controls.

1.3.1.2 – Colour vision

There have been multiple first-hand reports where people with autism discuss having unusual responses to certain colours (e.g. Williams, 1998; 1999). Ludlow, Wilkins, & Heaton (2006) studied the effect of self-selected colour overlays on reading efficacy in children with autism, compared to a comparison group (consisting of children with

moderate learning difficulties or typical development who were matched on a case-by-case basis for age, gender and verbal IQ). It should be noted that typically developing children also exhibit some improvement in visual tasks using coloured overlays (Wilkins & Lewis, 1999), with a variety in the level of benefit that people receive from coloured filters (Evans & Joseph, 2002). However, Ludlow et al. (2006) found that 79% of the autism group showed an improvement in reading speed, compared to 16% of the comparison group. In 2008, Ludlow, Wilkins, & Heaton replicated their previous study, finding that 74% of their autism group showed at least a 5% improvement in reading speed (compared to 23% of controls matched on age, gender and receptive vocabulary). They also did a matching-to-sample task with and without coloured overlays. They found that the children with autism in their sample showed an increase in speed, without compromising on accuracy. There was no improvement in accuracy with the overlays, although the authors suggest that this may have been a result of ceiling effects, due to the design of the task.

Recently, there have been some experimental studies investigating the nature of colour processing in autism. Heaton, Ludlow, & Roberson (2008b) investigated the performance of children with autism in colour discrimination and colour memory tasks. The experimenters found that the autism group was impaired at the colour discrimination task, relative to a typically developing control group. In contrast, they performed well in Phase 2 of the colour memory task (they were the only group to perform at a level above chance). The authors attributed this enhanced performance to an ability to ignore the name classification (thereby only attending to the perceptual qualities of the stimulus).

Franklin, Sowden, Burley, Notman, & Alder (2008) also used experimental techniques to investigate colour perception in autism. This study involved two separate experiments, one looking at colour memory and search with the other investigating chromatic discrimination and categorical perception. Results showed that the children with autism performed worse in the colour tasks, compared to a TD comparison group matched on gender, chronological age and non-verbal cognitive ability. However, there were no differences in the form task. Lastly, Franklin et al. (2010) investigated chromatic discrimination in children with autism, using the Farnsworth-Munsell 100 hue test (Farnsworth, 1957) as well as a psychophysical threshold discrimination task. As was found in the Franklin et al. (2008) study, the ASD group performed significantly worse on both colour experiments compared to matched TD controls, with no differences on the luminance tasks. It should be noted that the difficulties experienced by the ASD group were not confined to any particular axis of colour space. Conversely, Koh, Milne, &

Dobkins (2010b) found no significant differences in the chromatic contrast sensitivity of individuals with ASD and typically developing individuals. In fact, they found evidence that the siblings of those with ASD had superior chromatic colour sensitivity compared to those with ASD and a TD comparison group.

1.3.1.3 – Motion perception

The majority of studies investigating motion perception in ASD have concentrated on motion coherence and biological motion. A coherent motion task typically consists of a number of dots moving randomly on a screen, with a subset of the dots being programmed to move coherently in a certain direction. The participant is then asked to indicate the overall direction of the stimuli (normally running as a 2AFC task, with up/down or left/right being the choices). Spencer et al. (2000) investigated coherent motion perception in children with ASD, using a slightly different version (Wattam-Bell, 1994) of the coherence motion task. They found that their ASD group had significantly higher motion coherence thresholds than age-matched TD controls. Milne et al. (2002) also investigated motion coherence thresholds in ASD, finding that the range of performance was higher in the ASD groups. Furthermore, like Spencer et al. (2000), they found that the mean coherence thresholds were significantly higher for those with ASD than for the typical group. Lastly, a recent study by Koldewyn, Whitney & Rivera (2010) found higher thresholds for coherent motion in adolescents with autism, compared to TD controls matched in age and gender (but not IQ). The authors cautioned that there were significant correlations between IQ and task performance that impacted upon the observed group differences.

Although these studies reached a consensus by finding that motion coherence thresholds appear to be elevated in ASD (at least in children and adolescents), the results of other recent studies have made their interpretation more complex. Del Viva, Igliozzi, Tancredi, & Brizzolara (2006) found no significant differences between their ASD group and their two control groups (one matched on chronological age (CA) and the other on verbal mental age (VMA)). In addition, Jones et al. (2011) reported that they found no significant differences in a motion coherence task conducted with adolescents who had ASD and a control group (matched for age, verbal IQ, performance IQ and full-scale IQ). Conversely, Pellicano et al., (2005)'s results showed a highly significant difference in the global dot motion thresholds of their ASD and a TD control group matched in age, gender, nonverbal ability and handedness, with no overlap in the 95% confidence intervals computed for each group. Other contemporary studies have data which lies somewhere between these two

extremes, with some finding higher thresholds in children and adults with HFA but not AS (Spencer & O'Brien, 2006; Tsermentseli, O'Brien, & Spencer, 2008) and others only finding differences in a subset of the sample (Milne et al., 2006) (see reviews by Kaiser & Shiffrar (2009) and Simmons et al. (2009) for further discussion).

Biological motion refers to the ability to perceive object information from limited input and is typically depicted using point-light-displays (PLDs). Typically, actors are filmed performing various actions (e.g. running, throwing, jumping) and the movements of the joints are recorded and shown to participants as dots of light against a black background (Johansson, 1973). Moore, Hobson, & Lee (1997) were the first group to investigate biological motion processing in ASD. They presented PLDs of human walkers and the movement of various household objects (e.g. scissors opening and closing) and asked participants to verbally name the object they depicted. The number of points in the display (ranging from 5 to 10 points) and presentation times (ranging from 40 to 5000 ms) were varied in order to control the difficulty level of the stimuli. There were no significant differences in the ability of children with autism to detect biological motion, compared to controls with a learning disability, matched on chronological age and verbal ability. However, they did find that children with autism had significantly more difficulties with recognizing and describing emotion in PLDs. The authors thought this indicated that those with ASD experience difficulty with recognizing the internal states of others and concluded that children with ASD had intact biological motion processing.

Recent behavioural studies have also found no significant differences in the biological motion processing abilities of adults with ASD and controls (Atkinson, 2009; Kaiser, Demolino, Tannan & Shiffrar, 2010; McKay et al., 2012; Murphy, Brady, Fitzgerald, & Troje, 2009) – although Atkinson (2009) did find that, like Moore et al. (1997), their ASD group displayed more difficulty with emotion recognition compared to a TD comparison group. Blake, Turner, Smoski, Pozdol, & Stone (2003) used a more conventional psychophysical method than Moore et al. (1997), involving the use of "scrambled" versions of their PLD stimuli. They found that the children with autism were significantly worse at detecting biological motion than the TD group, in spite of comparable performance on a control task. Similarly, a recent study found that children with autism were significantly impaired in the perception of biological motion, compared to a TD group (Annaz et al., 2010).

Recent fMRI studies have provided further information about the brain regions involved in biological motion processing in ASD (Freitag et al., 2008; Herrington et al., 2007; McKay et al., 2012). These studies investigated biological motion processing in adults with AS (Herrington et al., 2007), adolescents with autism (Freitag et al., 2008) and adults with ASD (McKay et al., 2012). Herrington et al. (2007) and Freitag et al. (2008) found reduced activation in the superior-temporal-sulcus (STS) areas of the brain in the AS group, thought to be important to biological motion processing (Allison, Puce, & McCarthy, 2000). McKay et al. (2012) found that, despite comparable behavioural performance, the ASD group showed an atypical pattern of BOLD activation. The authors propose that the ASD group use two different networks to process biological motion, rather than the unitary network utilized by TD individuals. They hypothesise that this may be a result of dysfunctional neural connectivity in the brains of those with ASD.

1.3.1.4 – Visual search

Visual search tasks typically involve scanning an environment for a specific target among distractors. There are two types of visual search tasks: feature (where the target has a unique visual feature) and conjunctive (where the target has a unique combination of two or more features shared with the distractors) search. Plaisted, O'Riordan, Baron-Cohen, (1998a) used both types of search task in their experiment. They found that children with autism performed better than TD controls matched on age, verbal MA and spatial MA in the conjunctive visual search condition. Unlike the comparison group, the individuals with autism showed no deterioration of performance in conjunctive search compared to feature search. Other studies have found superior visual search performance in both children (Jarrold, Gilchrist, & Bender, 2005; O'Riordan, Plaisted, Driver, Baron-Cohen, 2001) and adults (O'Riordan, 2004) with autism. Furthermore, a recent brain imaging study (Keehn, Brenner, Palmer, Lincoln, & Müller, 2008) found greater activation in the ASD group's occipital and frontal regions when they were undertaking a visual search task, compared to a gender-, age-, handedness- and nonverbal IQ-matched TD comparison group. However, a recent study suggests that children with autism do not exhibit enhanced performance in true-to-life visual search tasks – with their findings suggesting that those with autism search less optimally and systematically than a typically developing matched control group (Pellicano et al., 2011).

Another type of visual search task, which has received considerable attention in ASD research, is the Embedded Figures Test (EFT: Witkin, Oltman, Raskin, & Karp, 1971).

This task involves participants finding a simple figure (e.g. a triangle) within a more complex pattern (e.g. a pram) (see Figure 1.1).

Figure 1.1 – Example from the Children's Embedded Figures Test (CEFT). Image taken from Happé (1999)

Shah & Frith (1983) compared the performance of children with autism and two groups matched in mental age (one TD group with a lower CA and one group with intellectual difficulties who matched on CA). They found that the autism group outperformed both control groups, exhibiting performance levels equal to, if not better than, what would be expected of children matching their CA. These results have been confirmed by a variety of researchers (de Jonge, Kemner, & van Engeland, 2006; Jarrold et al., 2005; Pellicano et al., 2005; Ropar & Mitchell, 2001), (de Jonge, Kemner, & van Engeland, 2006; Jarrold et al., 2005; Pellicano et al., 2005; Ropar & Mitchell, 2001), with one group finding that the advantage exhibited by those with ASD decreased with age (Edgin & Pennington, 2005). However, it should be noted that this difference might be the result of inherent sample differences rather than an age effect, as a recent longitudinal study in children with autism found no difference in EFT performance after a 3 year period (Pellicano, 2010).

Despite the results of Edgin & Pennington (2005), in which they found that the advantage exhibited by the autism group had disappeared by the age of 17, there is evidence to suggest that adults with autism also exhibit superior performance in the EFT. Jolliffe & Baron-Cohen (1997) used an adult version of the EFT and asked their participants to draw around the embedded object. They found that their ASD group was almost twice as fast at completing the task as typical controls matched on IQ (although they were not any more accurate, due to a ceiling effect). These results have been confirmed in both behavioural (Bölte, Holtmann, Poustka, Scheurich, & Schmidt, 2007) and fMRI studies (Lee et al., 2007; Manjaly et al., 2007; Ring et al., 1999). It should be noted that some studies have challenged the findings that individuals with autism are superior at performance in the EFT (Brian & Bryson, 1996; Kaland, Mortensen, & Smith, 2007; Ozonoff, Pennington, &

Rogers, 1991; Schlooz et al., 2006) although it has been suggested that none of these studies provide a sound argument against the original findings (Simmons et al., 2009).

Another visual search task commonly used in research is the Block Design (BD) test. It is often included in IQ tests (Wechsler, 1974; 1981) and involves the arranging of blocks with red, white and red/white sides to conform to a specific pattern (see Figure 1.2).

original

Types of block available for making the pattern
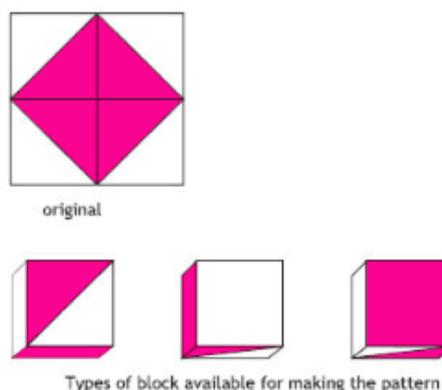
Figure 1.2 – Example from the Block Design Task. Image taken from Happé (1999)

Shah & Frith (1993) used five different groups in their study (high IQ autism, low IQ autism, TD older children, TD younger children, LD group). They presented the block design task as both "whole" and "segmented". They found that the autism groups had superior performance to all control groups, but only when the pattern was presented as whole. Shah & Frith (1993) hypothesised that superior performance in this task was caused by an increased ability to break the patterns down. These findings have been confirmed in many studies (Caron, Mottron, Berthiaume, & Dawson, 2006; Dennis et al., 1999; Ehlers et al., 1997; Happé, 1994; Ropar & Mitchell, 2001; Rühl, Werner, & Poustka, 1995; Siegel, Minshew, & Goldstein, 1996; Spek, Scholte, & Berckelaer-Onnes, 2008), although others have found no group differences in performance of the BD task (Bölte et al., 2007; Kaland et al., 2007). Bölte, Hubl, Dierks, Holtmann, & Poustka (2008) also found no difference in performance of the block design test in participants with ASD and TD controls (matched on gender, age, handedness and nonverbal IQ), although they did discover reduced activation in the right ventral quadrant of V2 (V2v). The differences between those with ASD and controls on the block design task are not as consistent as in other visual tasks; it may be that greater attention to the characteristics of both clinical and control groups are needed in order to determine whether inherent sub-group differences in the samples may be contributing to these mixed results.

1.3.1.5 – Summary of visual processing in ASD

The studies reported here show that there do appear to be some differences in visual processing in ASD (showing both enhanced and diminished performance in certain areas), although the evidence is often extremely inconsistent. Much of the difficulty in interpreting these data lies in the inherent variation between studies, including: methodological differences, disparities between experimental groups (including comorbidities, clinical diagnoses and age) across studies and differences in criteria for matching control groups. Disparities in one, or all, of these elements could affect the results from the studies. Furthermore, the evidence that those with ASD may exhibit greater inter- and intra-participant variability than TD individuals (Milne, 2011) could mean that studies may need much larger sample sizes in order to detect any real group differences. However, the literature shows that there are some consistent differences in the visual processing of individuals with ASD and typically developing controls, including certain types of search tasks (e.g. visual search, embedded figures). Furthermore, there appears to be a general trend that adults with ASD perform more similarly to age-matched TD individuals than their child counterparts, and that there are sometimes differences in the performances of those with different varieties of ASD (e.g. autism and Asperger Syndrome), although this may be connected to some other characteristic encapsulated by these diagnoses (e.g. language ability). Finally, it is important to highlight that there may be underlying differences that are not isolated by current behavioural paradigms (e.g. those with ASD using different brain pathways during a biological motion task) (McKay et al., 2012).

1.3.2 – Audition

In this section of the thesis, studies which have investigated auditory processing in ASD (see Haesen, Boets, & Wagemans, 2011, for a review) will be examined. This overview will concentrate on studies using both behavioural and electrophysiological techniques to investigate various types of auditory stimuli (namely pure tones, complex tones and speech perception) in ASD.

1.3.2.1 – Auditory processing: pure tones

The majority of auditory research in ASD has involved processing of certain sound properties, e.g. pitch, intensity or duration. Pitch is the process whereby tones are placed at certain places on a scale, depending primarily on their frequency content. Pitch discrimination has been frequently studied in autism, using both behavioural and

electrophysiological designs. O'Riordan & Passetti (2006) investigated pitch discrimination in children with HFA and a TD comparison group. They presented two tones in an ABA sequence, with one having a decrease in frequency (tone B) and the other staying at a constant frequency (tone A). Participants were asked to identify the point at which the tones sounded the same. The children with autism waited significantly longer to identify the tones, indicating greater accuracy. The authors suggest that these results indicate enhanced pitch discrimination in autism.

Bonnel, Mottron, Peretz, Trudel, & Gallun (2003) assessed both pitch discrimination and pitch categorisation abilities in ASD, using signal detection. Firstly, they utilized a "same-different" discrimination task, where pairs of tones were presented successively and participants judged if they were the same or different. The participants with ASD performed better than a TD control group in the 2% and 3% tasks but not the 1% tasks (the most difficult one). The authors suggest that this may be due to a floor effect. Secondly, the participants were asked to judge the pitch of pure tones in a pitch categorisation task. The authors found that the individuals with ASD outperformed the comparison group on all difficulties (1%, 2% and 3%). Furthermore, controls performed significantly worse in the categorisation than the discrimination task. Conversely, there was no significant difference in the performance levels of either task for the ASD group.

Jones et al. (2009) investigated frequency, intensity and duration discrimination in ASD. In order to assess the auditory discrimination abilities of their ASD sample (n=72) and age-matched controls (n=48), the authors presented two dinosaurs on a computer screen, each emitting a pure tone. Participants were asked to decide which dinosaur made the higher (frequency), louder (intensity) or longer (duration) sound. The authors found no group difference in the frequency discrimination abilities of participants. However, a subgroup of the ASD sample (19.7%) exhibited exceptional frequency discrimination, which may be representative of a specific phenotype in ASD.

Bonnel et al. (2010) performed an in-depth analysis of auditory processing in ASD. Both participants with autism (n=15) and AS (n=14) were recruited, as well as a TD comparison group (n=15). The authors used static and frequency-modulated pure tone and complex stimuli in their experiment. Pitch discrimination thresholds were established for participants, which were defined as the smallest detectable change in frequency. The results showed that the participants with autism displayed enhanced pitch discrimination

for pure tones, relative to controls. However, participants with AS did not show the same enhanced discrimination as the group with autism.

As well as behavioural experiments, there have been various electrophysiological studies investigating pitch perception in ASD. Gomot, Giard, Adrien, Barthélémy, & Bruneau, (2002) investigated the mechanisms involved in the detection of auditory frequency change in autism using an "oddball" paradigm (where a slightly different stimulus is presented among standard stimuli). Using EEG, they found that the autism group had an earlier Mismatch Negativity (MMN; brain response elicited by deviant stimuli) peak latency in response to changes in pitch. This is a measurement of the maximum negativity following deviant onset. The authors proposed that these results were indicative of superior pitch perception in autism. However, these findings are not wholly supported, with some researchers finding intact, but not enhanced, pitch discrimination (Čeponienė et al., 2003) and others discovering delayed MMN to changes in pitch, which is indicative of deficient auditory processing of pure tones in children with AS (Jansson-Verkasalo et al., 2003).

As well as pitch discrimination, studies have also investigated the perception of intensity (or the loudness) in ASD. Khalfa et al. (2004) examined the subjective perception of loudness in autism, measuring the auditory dynamic range of participants and administering a Categorical Loudness Scaling task. The authors found that children with autism had significantly smaller auditory dynamic ranges, although there were no differences in the absolute thresholds of the groups. Furthermore, the autism group perceived sounds to be louder than the control group. The differences between groups grew as intensity increased, which was indicative of hyperacusis (the experience of pain at relatively low levels of sound pressure; Jastreboff, 2000) in the autism group. However, Jones et al. (2009) also examined intensity discrimination. They found no significant group differences in the ability to discriminate between stimuli based on their intensity.

Bruneau, Roux, Adrien, & Barthélémy (1999) investigated auditory associative cortex dysfunction in children with autism. The evoked potentials of a group of children with autism and intellectual difficulties (n=16) to pure tones of various sound levels were compared to those of a typically developing control group (n=16) and a sample of children with intellectual difficulties, but without an autism diagnosis (n=16). Two negative peaks (N1b and N1c) were analysed according to stimulus intensity. The autism group exhibited diminished amplitude of N1b (fronto-central) across all intensities. However, unlike TD controls, the autism group only showed an intensity effect for the right hemisphere of N1c.

The authors suggested that this was evidence of right hemisphere dominance in the processing of auditory stimuli for the autism group. A replication study (Bruneau, Bonnet-Brilhault, Gomot, Adrien, & Barthélémy, 2003) found that participants with autism showed reduced N1c amplitudes and latencies across stimulus intensity levels in both the right and left hemispheres. However, the amplitudes were significantly higher in the right hemisphere in the autism group (the opposite, which did not reach significance, was observed in the TD comparison group). Furthermore, the amplitudes increased with intensity across both hemispheres for the controls; this effect was only detected in the right hemisphere for the autism sample.

More recently, Lepistö et al. (2009) investigated auditory stream segregation in AS using multiple intensities of stimuli. Their experiment consisted of three conditions: oddball (where a deviant tone of higher intensity was inserted into the repeated presentation of a standard tone), segregated (where two sounds with frequencies differing clearly from the oddball tones were included, creating two separate streams) and integrated (where tones with similar frequencies to the oddball tones were integrated into the oddball stream at four different intensities). The findings showed that the children with AS had difficulty with auditory segregation. However, in the conditions that did not require the segregation of auditory streams, intensity discrimination was intact.

Lastly, duration discrimination has also been investigated in people with ASD. In behavioural studies, this typically involves judging the longer stimulus from a pair presented simultaneously. As part of their extensive auditory processing study, Jones et al. (2009) assessed the duration discrimination abilities of adolescents with ASD and a comparison group matched on age and IQ. They found no significant difference between groups. This result has been corroborated by electrophysiological data. Kasai et al. (2005) assessed duration discrimination of both pure tones and speech sounds. They employed three conditions: tone-duration (standard = 100ms; deviant = 50ms), phoneme-duration (standard = /a/ for 150ms; deviant = /a/ for 100ms) and across-phoneme (standard = /a/ for 150ms; deviant = /o/ for 150ms). The results indicated that there were no significant differences in the duration discrimination abilities of the ASD and control groups.

1.3.2.2 – Auditory processing: complex tones

Järvinen-Pasley & Heaton (2007) investigated the domain-specificity of auditory processing in ASD. Children with an ASD diagnosis and a group of matched (for chronological age, non-verbal IQ and verbal IQ) controls participated. Auditory stimuli

consisted of frequently spoken words and complex tones (consisting of four pure tones) that shared the pitch and timing of the words. The conditions were speech-speech, speech-music and music-music. The authors found that there was no group difference for the processing of complex tones, indicating intact musical processing in ASD.

Heaton (2005) assessed perception of pitch and musical contours in those with ASD. Like Järvinen-Pasley & Heaton (2007), she found that overall pitch discrimination was intact in those with ASD. However, children with ASD displayed superior pitch discrimination for small pitch intervals compared to a non-ASD comparison group matched on age and IQ, although there was no group difference for medium and large intervals. In a second experiment, she found intact processing of musical contours. Järvinen-Pasley, Wallace, Ramus, Happé, & Heaton (2008b) also investigated auditory processing in ASD, using both speech and complex tone stimuli. Results indicated that there is superior pitch contour processing of complex tones in participants with autism. The authors suggest that the results are indicative of a different pattern of attentional focusing in autism.

Mottron, Peretz, & Ménard (2000) examined local and global music processing in participants with autism. Participants with ASD and a TD control group were recruited. Twelve basic melodies (consisting of nine tones) were created, as well as three versions for each: transposed melody, contour-violated and contour-preserved. Melodies were presented in pairs, and participants were asked to judge whether the stimuli were the same or different. The results showed that there was no deficit in global processing. Furthermore, the individuals with autism had superior performance in the non-transposed, contour-preserved melodies, which the authors suggest is indicative of superior absolute pitch performance in autism: something which has been observed elsewhere (e.g. Mottron, Peretz, Belleville, & Rouleau, 1999).

Gomot, Belmonte, Bullmore, Bernard, Baron-Cohen (2008) researched change detection in non-musical complex tones, using a variation of the oddball paradigm where the novel stimuli, rather than the deviant, were the targets. The findings showed that the children with ASD exhibited superior pitch processing compared to an age- and IQ-matched control group. Although the accuracy rates of both groups were similar, the children with ASD had significantly lower reaction times than controls. Furthermore, Bonnel et al. (2010) also investigated static and modulated complex tones, finding intact pitch discrimination. Timbre and loudness discrimination were also found to be intact for both types of complex tones.

Some studies have also used electrophysiological techniques to assess the processing of complex tones in ASD. Čeponienė et al. (2003) used ERPs to examine the sensory and attentional processes of different types of sounds in autism (compared to a TD control group). An oddball paradigm was employed, with stimuli including simple tones, complex tones and speech sounds (each with a standard and deviant version). The authors found that auditory processing and pitch discrimination was mostly intact for children with HFA. Moreover, the MMN of both groups for complex tones was not significantly different, indicating intact pitch discrimination in those with autism.

Lepistö et al. (2005) investigated how the different stages of auditory processing (e.g. sound encoding, discrimination and orienting) are affected in children with autism. They used speech (vowels) and non-speech stimuli, recording responses for pitch, duration and vowel changes recorded. Each block consisted of a standard stimulus (76%), pitch deviant stimulus (8%), duration deviant stimulus (8%) and vowel (or non-speech equivalent) (8%). Findings showed that children with autism exhibited an enhanced MMN for pitch changes in complex tones compared to age- and gender-matched TD controls, suggesting superior performance in pitch detection. However, the autism group also displayed poorer duration changes discrimination, which has also been replicated in children with AS (Lepistö et al., 2006).

1.3.2.3 – Auditory processing: speech

There have been several studies that have found evidence for either superior or intact performance of different aspects of speech processing in ASD. As mentioned previously, Järvinen-Pasley & Heaton (2007) measured pitch discrimination for both speech and complex tone stimuli. The ASD group showed similar sensitivity across all three conditions (music-music, music-speech and speech-speech). However, for the TD comparison group, performance was significantly worse in the conditions that contained speech stimuli. The authors suggested that this may have been due to controls being more distracted by the linguistic content, or that pitch information may be more salient for people with ASD.

Heaton, Hudry, Ludlow, & Hill (2008a) examined pitch contour discrimination in children with ASD and a group of matched controls (with either moderate learning difficulty or typical development). Stimuli consisted of 10 vowel sounds, with 5 monosyllabic real words and 5 monosyllabic non-words for each vowel sound. "Same" pairs and "different"

pairs with 2, 3 or 6 semitones of difference between sounds were used as stimuli. Results showed that the children with autism displayed superior contour discrimination, across all conditions, relative to controls. However, it should be noted that the same trend of performance was observed in both groups – that discrimination of pitch for speech stimuli was significantly worse than for non-speech stimuli. Two recent studies have also observed enhanced processing of speech processing contours in children with ASD (Järvinen-Pasley et al., 2008b; Järvinen-Pasley, Pasley, & Heaton, 2008a).

As mentioned previously, there is evidence that those with ASD may have poorer complex tone duration discrimination than typically developing individuals (Lepistö et al., 2005; 2006). Using a "same-different" behavioural task, Lepistö et al. (2006) investigated pitch and duration changes in speech stimuli for children with AS. The results indicated that the AS group had superior pitch perception and inferior duration discrimination compared to the control group. Lepistö, Nieminen-von Wendt, Wendt, Näätänen, & Kujala (2007) ran a similar study with adults who had AS. The adults with AS performed the task as accurately as controls, although they had significantly longer reaction times for the "speech-duration" pairs. The authors suggested that this indicated that adults with AS use a different response strategy compared to controls.

Electrophysiological data have also shown differences in the speech processing of individuals with ASD and TD controls. As mentioned previously, Čeponienė et al. (2003) examined the sensory and attentional processes of simple tones, complex tones and speech sounds in autism. The authors found that auditory processing and pitch discrimination was mostly intact for children with HFA, with an intact MMN response for vowels. However, subsequent studies with vowel stimuli have found significant differences in pitch and duration perception in children with AS (Lepistö et al., 2006) and in duration perception in adults with AS (Lepistö et al., 2007).

Furthermore, using an oddball paradigm (with both constant- and varying-feature conditions), Lepistö et al. (2008) assessed the effect that pitch discrimination abilities may have on speech perception. A group of children with autism (n=10) and a control group (n=16) participated in the study. Results showed that children with autism displayed enhanced MMN for both conditions with pitch deviants. However, for the phoneme deviants, the author only found a significant group difference for the constant-feature paradigm. The authors suggested that the children with autism lost their superior processing when the stimulus was speech-like and had varied input.

Kemner, Verbaten, Cuperus, Camfferman, & van Engeland (1995) examined MMN responses to syllable stimuli in children with autism, using an oddball paradigm. They found that there were no significant group differences for the MMN or N1 responses. The authors suggested that this indicated that discrimination of syllables is largely intact in autism. Conversely, Jansson-Verkasalo et al. (2003) recorded the MMN in response to syllable stimuli. They found that children with AS had shorter MMNs than TD controls individually matched for age and gender, although this was more apparent with pure tone stimuli than with syllables. Furthermore, Kuhl, Coffrey-Corina, Padden, & Dawson (2005) also found impaired syllable discrimination in toddlers with autism. Their results indicated that the children with autism a) preferred non-speech sounds to motherese and b) did not show an MMN response to syllable change, unlike comparison groups matched on either chronological or mental age.

As well as investigating isolated properties of speech, some researchers have studied integrated features of speech. One aspect of this is speech-in-noise perception, which is the discrimination of speech against a noisy background. Alcántara, Weisblatt, Moore, & Bolton (2004) examined the speech-in-noise perception of children with ASD and a group of TD controls. Stimuli consisted of spoken sentences (by a male with a received pronunciation (RP) accent) against one of five backgrounds: 1) steady speech-shaped noise, 2) a competing female talker, 3) temporal dips (points where the competing noise is lower, e.g. during pauses) 4) spectral dips (points when the frequencies of the competing speech and target noise are different) and 5) both spectral and temporal dips. The performance of the participants was determined by evaluating their speech reception thresholds (the point at which the speech-to-noise ratio gives 50% correct responses). The results showed that the participants with autism needed a significantly higher signal-to-noise ratio than controls. However, this was only found in the conditions that contained temporal dips. Furthermore, Groen et al. (2009) also found intact spectral but impaired temporal speech processing in children and adolescents with ASD. It has been suggested that this phenomenon may be indicative of an inability to take advantage of temporal dips in participants with ASD (Alcántara et al., 2004).

1.3.2.4 – Summary of auditory processing in ASD

The literature, on the whole, shows that there appear to be key differences in the way that those with ASD process auditory information. Firstly, behavioural data show that there seems to be a difference in pitch perception, as individuals with ASD demonstrate

enhanced ability in this task, across all types of stimulus (simple tones, complex tones and speech sounds). However, this is only partially demonstrated in the electrophysiological findings, with some studies finding MMN responses indicating impaired, comparable and enhanced perception for pitch. For intensity discrimination, results are inconsistent. Although there are no differences in absolute threshold, there are mixed results for atypical intensity perception at the suprathreshold level. Furthermore, the data show that there do not appear to be any significant differences in duration discrimination in ASD. Lastly, there appear to be some differences in the local and global processing of sounds, with evidence suggesting that those with ASD are better at detecting local features. However, the evidence suggesting that those with ASD have difficulties processing global auditory information is inconsistent. As in the visual domain, results are varied, and more stringent control over experimental and control participants, as well as replication of existing studies may be necessary in order to determine whether there are differences in the auditory processing of individuals with ASD (and if so, where they lie).

1.3.3 – Touch

Hyper-sensitivity to touch has been reported extensively, although mainly anecdotally, in individuals with ASD. Temple Grandin, a person with autism, has described the feeling of small scratches and itches as being tortuous (Grandin & Scarino, 1996). Recently, there has been an increase in the number of studies investigating tactile sensitivity in ASD. O'Riordan & Passetti (2006) assessed the tactile discrimination abilities of children with and without autism in two experiments, which involved the detection of string on the forearm and the discrimination of different types of sandpaper. They found that the two groups were comparable on the two tasks, indicating that children with autism were not hyper-sensitive to tactile stimulation.

Blakemore et al. (2006) assessed the tactile detection thresholds and performance at suprathreshold levels of adults with AS and a group of TD individuals. Firstly, they assessed the detection thresholds of low frequency (30Hz) and high frequency (200Hz) vibrotactile stimulation to the fingertip. The intensity of the stimulus was altered until threshold was determined. The authors found that the AS group had significantly lower thresholds for the high-frequency stimuli, but not for the low frequency. In a subsequent experiment, they assessed performance at suprathreshold levels by looking at whether tickly stimuli are perceived as a) more tickly or b) more intense in an ASD sample. They were also interested in whether these ratings changed depending on whether the

experimenter or participant controlled the stimulus. Typically, attenuation ensures that people with typical development only feel stimuli produced by others to be tickly (Weiskrantz, Elliott, & Darlington, 1971). Blakemore et al. (2006) found that people with AS rated light sensation to the palm as both ticklier and more intense than the TD control group. Furthermore, in the intensity condition, there was no difference in the type of touch (i.e. self- or experimenter-produced) for the AS sample. In the control group, self-produced touch was rated as significantly less intense. However, this difference in type of touch was not found in the tickly condition, suggesting that self-attenuation is intact in people with AS.

A subsequent study (Güçlü, Tanidir, Mukaddes, & Unal, 2007) also investigated low-frequency and high-frequency vibrotactile thresholds in children with autism by comparing performance to a TD group. They used stimuli of 40Hz and 250Hz, as well as administering the Childhood Autism Rating Scale (CARS: Schopler, Reichler, DeVellis, & Daly, 1980), the Childhood Behavior Checklist (CBCL: Achenbach, 1991), the Sensory Profile (SP: Dunn, 1999) and the Touch Inventory for Elementary-School-Aged Children (TI: Royeen & Fortune, 1990). In contrast to Blakemore et al. (2006), they found that there were no differences in either the masking mechanisms or the detection thresholds of the two groups. Furthermore, they did not find any significant correlations between the questionnaire data and the psychophysical thresholds. They did, however, find significant correlations between the tactile and emotional subsets of the questionnaires, which they perceived to be indicative of an emotional origin for tactile sensitivity. One possible explanation for these results, compared to those of Blakemore et al. (2006), is that the small sample used (n=6) may not have generated enough statistical power for any differences to be statistically significant.

In 2008, Cascio et al. published a comprehensive analysis of the tactile processing of adults with ASD, using a variety of experiments. They compared the contact detection thresholds, vibrotactile detection thresholds, vibrotactile adaptation, pleasantness ratings, thermal sensation detection and thermal pain perception of an ASD and TD group. The groups were not significantly different in their contact detection thresholds (which concurs with O'Riordan & Passetti, 2006) or in the vibrotactile detection thresholds at 33Hz on the palm (agreeing with Blakemore et al., 2006, and Güçlü et al., 2007). However, the participants with ASD in Cascio et al. (2008)'s study had significantly lower detection thresholds than TD controls when the stimulation was applied to the forearm. The authors also found there were no significant group differences in the vibrotactile adaptation,

pleasantness ratings and thermal detection experiments. However, there were differences for thermal pain perception, with the ASD group reporting significantly lower pain thresholds for both warm and cold stimuli. The results of this study suggest that there are atypicalities for some aspects of tactile processing.

In addition to behavioural and psychophysical experiments, there have been some recent studies of somatosensory processing in ASD, using neuroanatomical and neurophysiological measures. Tommerdahl, Tannan, Cascio, Baranek, & Whitsel (2007) investigated the spatial tactile acuity of individuals with ASD after adaptation to a vibrotactile stimulus. In 2006, Tannan, Whitsel, & Tommerdahl found that typical adults show an increased ability to detect the spatial location of a vibrotactile stimulus after long adaptation (5.0 sec) compared to short adaptation (0.5 sec). However, Tommerdahl et al. (2007) found that the participants with autism did not exhibit this increase in performance. Furthermore, the adults with autism significantly outperformed the TD adults in the short stimulus condition. This could suggest that the cortical inhibitory mechanisms may be functioning atypically in individuals with ASD (Cascio, 2010). There is further evidence for unusual cortical processing in ASD, including a difference in somatosensory evoked potentials compared to controls (Miyazaki et al., 2007) and atypical organisation of somatosensory cortex (Coskun et al., 2009).

Tannan, Holden, Zhang, Baranek, & Tommerdahl (2008) investigated a different aspect of tactile adaptation in ASD, by researching the effect of adaptation on amplitude discrimination. They found that tactile discrimination ability was not significantly different for the ASD group than for the TD participants. However, they did find that, similarly to Tommerdahl et al. (2007), the effects of adaptation were significantly different. While adaptation increased the amplitude discrimination performance of the controls, there was no such effect for the people with autism. A recent study (Francisco, Holden, Zhang, Favorov, & Tommerdahl, 2011) assessed the effect of adaptation on a vibrotactile amplitude matching task in those with autism and a TD comparison group. They discovered that a subset of the group (approximately half) outperformed the controls at the higher rate of modulation. The rest of the participants with autism performed at a level comparable to controls, with both groups performing equally well with the lower modulation stimuli.

1.3.3.1 – Summary of tactile processing in ASD

As with the data for visual and auditory perception, there appear to be some differences in how individuals with ASD process certain aspects of touch. The data show little difference in low-frequency vibrotactile threshold levels with stimulation to the palm or finger, yet there is some evidence to suggest lower detection thresholds in ASD when higher frequencies (Blakemore et al., 2006) or different placement of stimuli (Cascio et al., 2008) are used. Although there are no significant differences in the thermal detection abilities of those with ASD and TD individuals, there is evidence that pain thresholds for both hot and cold stimuli are consistently lower in individuals with ASD. This shows that, although detection thresholds are not lowered in the ASD group, those with ASD are significantly more susceptible to pain from thermal stimulation. Lastly, there are some differences in the adaptation of tactile stimulation. TD individuals tend to show increased improvement in both spatial acuity (Tommerdahl et al., 2007) and amplitude discrimination (Tannan et al., 2008) alongside an increase in length of adaptation. However, it appears that those with ASD do not show a similar increase in performance, instead outperforming the controls in the short-adaptation conditions but having comparable performance in the long-adaptation conditions (Tannan et al., 2008; Tommerdahl et al., 2007).

1.3.4 – Smell

Olfactory processing has recently begun to garner attention from autism researchers although, yet again, mixed results have been reported. Detection thresholds, identification abilities, preferences and adaptation to stimuli have all been investigated in autism. The concentration at which we are able to detect odours can be quantified by measuring odour detection thresholds. The first researchers to investigate the smell processing abilities of adults with autism were Suzuki, Critchley, Rowe, Howlin, & Murphy (2003). They assessed the odour detection thresholds of 12 males with AS and 12 TD controls, matched on gender, age, IQ and handedness. Odour detection thresholds were assessed using the two-bottle test (Cain, Gent, & Catalanotto, 1983). They found no significant differences between groups for olfactory detection thresholds. Two recent studies also assessed the odour detection thresholds of children (Dudova et al., 2011) and adults (Tavassoli & Baron-Cohen, 2012a) with a diagnosis of ASD. Both studies used Sniffin' Sticks (Burghart, Messetechnik) to assess thresholds and screened their TD comparison groups for autism traits/ASD. Similarly to Suzuki et al. (2003), Tavassoli & Baron-Cohen (2012a) found no group difference in the odour detection thresholds of their participants with ASD. Conversely, Dudova et al. (2011) did find a significant difference between

their samples, with the ASD group demonstrating diminished odour detection thresholds. Further research is needed, but it may be the case that there is an observable difference in detection thresholds in childhood that disappears by adulthood. Alternatively, it could be that there are methodological and/or sampling differences underlying these disparate results.

Unlike odour detection, odour identification tasks require the correct labelling of a variety of smells. Suzuki et al. (2003) assessed the odour identification abilities of their sample, using the University of Pennsylvania Smell Identification Test (UPSIT: Sensonics Inc., Haddon Heights, NJ). They reported that adults with AS were significantly impaired in odour identification, compared to TD matched controls. Similar results have been observed in children with HFA (Bennetto, Kuschner, & Hyman, 2007; May et al., 2011). However, May et al. (2011) did not find diminished olfactory identification in their AS group. They hypothesised that this may be a result of orbitofrontal compromise in those with autism, but not AS. However, some studies have found similar identification abilities in TD comparison groups and those with ASD. Brewer, Brereton, & Tonge (2008) reported comparable odour identification performance on an adapted version of the UPSIT. Notably, age and performance on the task were negatively correlated in the HFA group, whereas the results were positively correlated in the TD participants. Furthermore, Dudova et al. (2011) also found no significant differences in the smell identification skills of those with ASD. However, they did find that odour identification skills correlated with age in their TD control group, but not in their participants with ASD.

Hrdlicka et al. (2011) assessed the perceived pleasantness of odours in children with ASD, using the Identification part of the Sniffin' Sticks test (Burghart, Messetechnik). Participants (n=70) were asked to rate the pleasantness of each odour on a scale of 1-5. Those with ASD perceived the smell of cinnamon and pineapple as significantly less pleasant than controls. At the trend level (p<.1) they also found cloves less pleasant. Overall, participants with ASD assessed smells as less pleasant than controls, although this did not reach significance. Hrdlicka et al. (2011) suggested that pleasant scents (e.g. orange) could be used as a stimulant in autism training programs, as Wilder et al. (2008) found that access to high preference odours increased participation for three adults with autism in a sorting task.

Olfactory adaptation is the temporary reduction of sensitivity in response to exposure to a stimulus. It is a rapid process and the smell being adapted to will quickly become almost

imperceptible. However, after leaving the environment, sensitivity will return. Diminished adaptation has been found in the visual (Pellicano, Jeffery, Burr, & Rhodes, 2007) and tactile (Tommerdahl et al., 2007) sensory domains. Tavassoli & Baron-Cohen, 2012a) recently investigated basic olfactory adaptation in adults with ASD, by measuring the olfactory detection thresholds before and after adaptation to butanol and employing a forced-choice paradigm. They found no group differences between those with ASD and TD controls.

1.3.4.1 – Summary of olfactory processing in ASD

The studies reviewed in this section show that there may be differences in the olfactory performance of those with ASD, although the evidence for this is extremely variable. There has been relatively little research into olfactory processing in ASD, which means that it is more problematic to interpret these data due to inherent differences between the studies. However, although the olfactory thresholds of adults with ASD do not appear to be consistently lower than those of controls, there is limited evidence to suggest that children with ASD have significantly higher detection thresholds than TD children. Whether this difference in children but not adults is true, or whether it is a result of sampling and methodological dissimilarities, is something that should be clarified with further research. There is some evidence to suggest that there may be some differences in performance between the subgroups of ASD (e.g. autism and AS), with May et al. (2011) finding impaired olfactory identification in those with HFA but not AS. Overall, however, there is very little consistency in the results of studies assessing the olfactory identification skills of those with ASD and controls. It may be that this is indicative of inherent differences in the samples, and it may be useful for future studies to control for this by matching groups on verbal IQ (VIQ). Lastly, there appears to be no difference in the adaptation to olfactory stimuli between adults with ASD and controls (Tavassoli & Baron-Cohen, 2012a), which is perhaps surprising given recent findings in the visual and tactile domains (Pellicano et al., 2007; Tommerdahl et al., 2007)

1.3.5 – Taste

Taste and olfaction are strongly linked, with odour playing an important part in the experience of eating (de Araujo, Rolls, Kringelbach, McGlone, & Phillips, 2003). Few empirical studies have been reported on taste processing in ASD. In fact, only one has investigated taste detection thresholds (Bennetto et al., 2007) with two examining taste identification processing (Bennetto et al., 2007; Tavassoli & Baron-Cohen, 2012b) in

adolescents and adults with ASD. Bennetto et al. (2007) compared a sample of 21 children and adolescents with autism to a matched group of 27 TD controls. Taste detection thresholds were established using electrogustometry and taste identification was assessed with sweet, salty, sour and bitter solutions. They found that participants with autism were significantly worse than controls at distinguishing the sour taste (p=.03), and marginally worse (p=.07) for the bitter solution. There was no significant group difference in electrogustometry thresholds, suggesting that the differences observed in ASD are not due to impaired detection.

More recently, Tavassoli & Baron-Cohen (2012b) investigated taste identification in adults with ASD as well as a TD control group. They used 'Taste Strips' (Burghart, Messetechnik), a set of 16 strips infused with four concentrations of sweet, salty, bitter and sour tastes. Like Bennetto et al. (2007) , they found that the participants with ASD were significantly impaired at overall taste identification. The ASD group were significantly worse at identifying bitter, sour and sweet tastes, although there was no difference for salty tastes. The authors suggested that the intact performance of salty identification may be a result of a) the underlying mechanism for identification of salt being more similar to that of typicals or b) a different strategy used by the ASD group (i.e. the significantly increased likelihood of those with ASD labelling tastes as salty may have led to a non-significant result).

Although not strictly concerned with taste processing, some recent studies have concentrated on the issue of food selectivity and acceptance in ASD. In 2001, Ahearn, Castine, Nault, & Green investigated food acceptance in children with autism and PDD-NOS. In a sample of 30 children, they found that more than half of the children exhibited low levels of food acceptance. However, as control groups were not used, the results do not necessarily provide support for unusual patterns of food acceptance in ASD. Schreck, Williams, & Smith (2004) compared eating behaviours in children with autism to those of TD controls, using parent report. Parents were administered the Children's Eating Behavior Inventory (CEBI: Archer & Rosenbaum, 1991), the Food Preference Inventory (FPI: Schreck et al., 2004) and the Gilliam Autism Rating Scale (GARS: Gilliam, 1995). The autism group reportedly exhibited significantly higher feeding problems than controls. Furthermore, children with autism were more likely to refuse food, to eat a narrow range of foods, to require special utensils, to require specific presentation of food on the plate and to only accept foods of a lower texture. Following up this investigation, Schreck & Williams (2006) conducted a questionnaire-based study to determine factors influencing food

selectivity in autism. They found that children with autism preferred fewer types of items within each food groups than other members of their families. However, results indicated that family food preferences appeared to affect food selectivity in autism, rather than being symptomatic of autism itself.

1.3.5.1 – Summary of taste processing in ASD

As in the other sensory modalities, these data show that there do not appear to be any significant differences in detection thresholds – suggesting that this aspect of taste processing is unlikely to play a role in the unusual eating behaviours often observed in ASD. However, this assertion is based on a single study investigating taste processing in children and adolescents with ASD (Bennetto et al., 2007). As such, further research should be conducted to determine a) whether this is also the case in adults with ASD and b) whether there may be differences in some of the ASD subgroups. Taste identification does appear to be impaired in individuals with ASD (Bennetto et al., 2007; Tavassoli & Baron-Cohen, 2012a), although whether this is due to a difference in the underlying mechanisms of taste, or due to a strategic error in the task, cannot be determined at this point. Food acceptance appears to be very low in ASD, and hopefully further research into taste processing (as well as oral tactile processing) will provide insight into the reasons behind such difficulties with food.

1.3.6 – Vestibular

The vestibular system contributes to our sense of balance and spatial orientation. Dysfunction in the vestibular system of children with autism has been reported for many years (see Maurer & Damasio, 1979, for a review). Despite this awareness, few have investigated the vestibular processing of those with autism. Kern et al. (2007a) isolated the vestibular sections of the Sensory Profile (Dunn, 1999) and compared the parent/caregiver report data from 103 children and adults with autism to a group of age- and gender-matched community controls (ranging from 3 to 43 years old). They found that those with autism engaged more frequently in "vestibular processing behaviours", compared to the comparison group. Furthermore, individuals with autism displayed more sensory avoidant responses (indicating a low threshold), although there was no age effect. Lastly, individuals with autism displayed a higher number of sensory seeking behaviours (indicating a high threshold) – these behaviours tended to decrease with age. Kern et al. (2007a)'s findings support the results of the early studies – suggesting that there does

indeed seem to be a difference (e.g Ornitz, 1970; 1974) in the vestibular processing of individuals with ASD and controls.

This view has been supported in a recent experimental study. Siaperas et al. (2011) investigated the motor abilities and sensorimotor processing abilities of children with AS and a group of age-matched TD controls. The participants were asked to undertake a battery of tests assessing their movement (Movement Assessment Battery for Children – 2 (MABC-2: Henderson, Sugden, & Barnett, 2007) and sensory integration (Sensory Integration Praxis Test (SIPT: Ayres, 1989)). The children with autism displayed significant vestibular processing deficits (along with proprioceptive and movement dysfunction).

Vestibular processing is heavily involved in postural control (Cullen & Sadeghi, 2008). Recent studies investigating the postural control of those with autism have attempted to isolate the subsystems of this process. Kohen-Raz, Volkmar, & Cohen (1992) compared the postural patterns exhibited by children with autism to TD children, children with intellectual difficulties and adults with vestibular dysfunction. The postural patterns of the autism group differed from all control groups. Children with autism displayed more variable and less stable postural performance than the TD controls. However, the children with autism actually displayed greater stability in some of the more "stressful" poses. The authors propose that the differences observed in postural stability in autism appear to be consistent with dysfunction in the cerebellum, rather than in the vestibular system itself.

Molloy, Dietrich, & Bhattacharya (2003) investigated the various contributions made by the vestibular, visual and somatosensory systems in maintaining upright posture in ASD. They found that, when eyes were occluded, children with ASD had a significantly greater sway area than typical controls, regardless of presence or absence of somatosensory input. Furthermore, children with ASD found it more difficult to stand upright in the condition where visual cues were removed and somatosensory ones were changed. The authors suggested that the results indicated dysfunction in the integration of the different systems involved in postural control, rather than a deficit in a single system. Greffou et al. (2012) assessed the visual and vestibular components involved in postural control reactivity in autism, using a fully immersive virtual environment. They found that 12-15 year old children with autism displayed less instability than their TD counterparts (although this was only apparent in the highest oscillation frequency of the dynamic condition). The authors suggested that their results showed no deficit in the vestibular subsystem, instead

indicating that the differences observed in posture in autism are a result of both visual environment and development. Likewise, Minshew, Sung, Jones, & Furman (2004) found no vestibular dysfunction in their postural control study. They hypothesised that issues with postural control in autism may be a result of multimodal sensory integration.

1.3.6.1 – Summary of vestibular processing in ASD

Few experimental studies have investigated the vestibular processing of individuals with ASD. However, a recent study by Siaperas et al. (2011) found that children with ASD exhibited significant vestibular processing difficulties compared to TD controls. Much of the difficulty with researching vestibular processing is that it can be extremely difficult to isolate a specific subsystem in order to test it. For example, the vestibular system is important in postural control, which appears to be reduced in those with ASD. However, there are also other senses that are important in this process, including vision and proprioception. Indeed, findings seem to indicate that poor postural control is a result of dysfunction in the cerebellum, rather than in the vestibular system. Therefore, it is perhaps more important, in this case, to first determine the higher-level movement processes affected in ASD before then isolating the role that vestibular processing may play in these.

1.3.7 – Proprioception

Proprioception is the sense of the position, location and orientation of one's body and body parts. This sense is interoceptive, meaning it does not rely on external signals. Weimer, Schatz, Lincoln, Ballantyne, & Trauner (2001) investigated the issue of motor impairment in children and young adults with AS. They recruited an AS sample (n=10) and a TD case-control group matched to age, gender, socioeconomic status and verbal IQ. A comprehensive language assessment and motor battery were administered. They found that participants with AS performed more poorly than a TD comparison group on a variety of measures (including apraxia, one-leg balance with eyes closed, tandem gait and repetitive finger-thumb apposition), with no significant group differences in other tasks (finger-tapping, grooved pegboard, trail-making and visual-spatial integration). Results indicated that the greatest discrepancy in performance occurred when proprioceptive processing was central to the task. Furthermore, as discussed previously (section 1.3.6), Siaperas et al. (2011) also reported proprioceptive impairments in their group of children with AS.

However, Fuentes, Mostofsky, & Bastian (2010) studied proprioception in adolescents with autism and a matched group of TD controls, using a variety of proprioceptive tasks (using the KINARM™; BKIN Technologies). These included a passive elbow angle task, a passive fingertip-matching task and an active elbow matching task, as well as control tasks (where participants could see their arm). The authors found no significant group differences in accuracy or precision, in either active or passive tasks. Despite the autism group reporting lower movement processing thresholds in the AASP (Brown & Dunn, 2002), this was not reflected in the results of the proprioceptive tasks.

Lastly, Haswell, Izawa, Dowell, Mostofsky, & Shadmehr (2009) investigated the link between internal models of action and their contributions to difficulties in motor control, imitation and social function in ASD. Using a group of children with ASD and TD controls, they found a positive correlation between the severity of general motor functioning (as assessed by the ADOS-G and the SRS) and proprioceptive-driven generalisation in the tasks. The authors suggested that their findings indicated an over-reliance on areas of the brain where movements are related intrinsically, and an under-reliance on areas where movements are related extrinsically.

1.3.7.1 – Summary of proprioception in ASD

Like vestibular processing, few studies have attempted to assess whether proprioception is different in those with ASD, compared to typically developing individuals. Furthermore, results are mixed as to whether this process is impaired in ASD. For example, Fuentes et al. (2010) found no significant differences in the accuracy or precision of a proprioceptive matching task, using a robot-arm device. Conversely, some studies (Siaperas et al., 2011; Weimer et al., 2001) have found that children with ASD exhibit impairment in tasks where proprioception is essential to performance. However, it should be noted that, like the vestibular system, it is difficult to isolate the proprioceptive system and assess it experimentally. Therefore, as with the vestibular system, it is perhaps more important to first isolate the movement processes affected in ASD before attempting to assess whether proprioception processing is different in ASDs.

1.3.8 – Summary of sensory processing

Overall, the evidence of the differences in sensory processing of those with ASD is inconsistent, throughout all the sensory modalities detailed in this section. For visual processing, there is strong evidence that individuals with ASD perform significantly faster

in visual search tasks than typically developing controls (Shah & Frith, 1983; 1993), although there are not such consistent differences for other aspects of visual processing (e.g. motion coherence thresholds: Del Viva et al., 2006; Spencer et al., 2000). However, there appears to be a slightly more coherent story of the auditory processing of those with ASD, with individuals on the Autism Spectrum demonstrating significantly superior pitch processing for pure tones, complex tones and speech sounds (Bonnel et al., 2003; Heaton, 2005; Järvinen-Pasley & Heaton, 2007). However, this is only partly reflected in the electrophysiological data (Čeponienė et al., 2003; Gomot et al., 2002; Jansson-Verkasalo et al., 2003). For touch, there are differences in vibrotactile threshold levels, although this evidence is mixed (Blakemore et al., 2006; Cascio et al., 2008). There is, however, evidence that those with ASD perform better than TD individuals in a tactile spatial acuity task (Tommerdahl et al., 2007), as well as demonstrating differences with adaptation to stimuli (Tannan et al., 2008; Tommerdahl et al., 2007). For olfactory processing, there is little consistency in the findings, particularly when determining whether there are differences in the thresholds (Dudova et al., 2011; Suzuki et al., 2003; Tavassoli et al., 2012a) or identification skills (Bennetto et al., 2007; Brewer et al., 2008; Dudova et al., 2011; May et al., 2011; Suzuki et al., 2003). Few studies have investigated gustation (Bennetto et al., 2007; Tavassoli et al., 2012b), vestibular processing (Siaperas et al., 2011) and proprioception (Fuentes et al., 2010; Siaperas et al., 2011; Weimer et al., 2001), so it is important that future research investigates these modalities (and multi-sensory processing) further in order to determine if there are consistent differences between those with ASD and controls.

1.4 The Broader Autism Phenotype

1.4.1 – General

Evidence that relatives of those with ASD often exhibit characteristics of autism, albeit to a lesser degree (Constantino et al., 2006; Piven et al., 1994) has prompted the concept of a 'broader phenotype' of autism. Typically, this term is used to describe a person who exhibits subclinical traits of autism, e.g. obsessional tendencies or difficulties in forming social relationships. Furthermore, there is evidence that these characteristics are not only prevalent in the general population (Constantino & Todd, 2003), but that they are continuously distributed (Hoekstra, Bartels, Verweij, & Boomsma, 2007). There have been a variety of questionnaires developed to assess the level of "autistic traits" that a person may possess, including the Broader Autism Phenotype Questionnaire (BAPQ; (Hurley, Losh, Parlier, Reznick, & Piven, 2007), the Autism Spectrum Quotient (AQ:

Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and the Social Responsiveness Scale (SRS: Constantino & Gruber, 2005). These scales have been used to reliably discriminate between individuals with a diagnosis of ASD and typically developing individuals (e.g. Baron-Cohen et al., 2001), although it should be noted that these questionnaires are not designed to be diagnostic tools.

Bolton et al. (1994) investigated the prevalence of a) autism, b) PDD and c) the broader phenotype in siblings of children with autism and Down's syndrome. They discovered that there was a greater increase in autism (2.9% vs. 0%) and PDD (2.9% vs. 0%) prevalence rates in the children with autism's siblings than those with Down's Syndrome relatives. Furthermore, there was a marked increase in the percentage of siblings that exhibited ASD-like traits in the autism group (12.4% to 20.4%, depending on strictness of criteria) compared to the control group (between 1.6% and 3.2%). The authors suggested that this pattern was indicative of a) a broader phenotype which extends beyond clinically diagnosed autism and b) that the aetiology of autism involves several genes.

It is well established that individuals with a diagnosis of ASD have difficulties with social interaction (Wing & Gould, 1979), language impairments (Wing & Gould, 1979) and executive processing (Ozonoff et al., 1991). Briskman, Happé, & Frith (2001) investigated the social and non-social preferences of first-degree relatives of those with autism. They found no significant difference in the parent-rated social (or non-social) preferences of the siblings of those with autism compared to the other sibling groups (dyslexia and typically developing). However, parents of those with autism were significantly more likely to report social preferences typically associated with autism compared to the control parent groups. Fathers were also significantly more likely to describe having non-social preferences similar to those with autism. However, Constantino & Todd (2003) found higher rates of impaired social responsiveness, measured by the Social Responsiveness Scale (SRS: Constantino & Gruber, 2005), in the siblings of children with autism and, to a lesser extent, PDD. These scores were continuously distributed and supported the notion that a continuum of 'autistic' traits related to categorical ASD diagnoses could be pervasive throughout the general population. Lastly, a recent study by Elsabbagh et al. (2011) studied social perception in babies with an older sibling diagnosed with autism. They found that, at the age of 9 months, the at-risk group (those with a sibling who had autism) had significantly impaired social perception compared to a group of low-risk controls. Furthermore, the authors also found a clear association between social processing at 9 months old and level of autistic traits at 3 years.

Difficulty with communication is one of the core criteria for autism spectrum disorders (American Psychiatric Association, 2000). Early studies investigated the language abilities of first-degree relatives of those with autism, finding evidence that parents (Folstein et al., 1999; Piven et al., 1997) and twin siblings (Le Couteur et al., 1996) both experienced language difficulties. More recently, Ronald, Happé, Price, Baron-Cohen, & Plomin (2006) investigated the phenotypic and genetic traits of those with extreme levels of autistic traits (highest 5%) with those without extreme levels of autistic traits. They found that those with extreme levels of autistic traits (in any single domain of the Childhood Asperger Syndrome Test (CAST: Scott, Baron-Cohen, Bolton, & Brayne, 2002) as well as in multiple domains) had significantly more communication difficulties than those without any extreme levels of autistic traits. This difference was not only found in those with extreme scores in the 'Communication' domain, but in the 'Social' and 'Restricted and Repetitive Behaviours' ones too. Furthermore, Möricke, Swinkels, Beuker, & Buitelaar (2010) assessed the autistic traits of a group of children at 14-15 months of age, and determined their behavioural and cognitive problems at the ages of 3-5 years. They split their sample into 3 subgroups: high, moderate and low scorers on the Early Autism Screening Test (ESAT). They found that the high-ESAT scorers scored significantly lower on language tests at age 4-5 years than both moderate and low scorers. It should be noted that none of the children met diagnostic criteria for ASD at follow-up

Executive function is a term used to describe the cognitive system that oversees and manages other cognitive processes, such as working memory, attention and planning. There is evidence that executive functioning is impaired in (although not restricted to) autism (Hughes & Russell, 1993; Ozonoff et al., 1991) and AS (Nydén, Gillberg, Hjelmquist, & Heiman, 1999). Recently, there has been interest in whether difficulties with executive function extend to those with subclinical levels of autistic traits. Hughes, Plumet, & Leboyer (1999) researched executive function in the siblings of those with autism using a set-shifting task, a planning task and a spatial working memory task. The siblings of those with autism performed more poorly on the set-shifting and planning tasks than either control group (siblings of those with a developmental disability and children from 'unaffected' families), although there were no group differences in the spatial working memory task. Executive dysfunction has also been observed in the parents of those with autism (Hughes, Leboyer, & Bouvard, 1997), with results indicating poorer attentional flexibility and planning skills and relatively good working memory. However, others have not found differences in the executive function of parents of individuals with

ASD (Bölte & Poustka, 2006) or those with high levels of autistic traits in the general population (Kunihira et al., 2006).

There has been evidence to suggest that autistic traits manifest as personality characteristics (Austin, 2005), and may actually be an independent personality dimension (Wakabayashi, Baron-Cohen, & Wheelwright, 2006). Many studies have assessed the personality characteristics of relatives of those with autism and compared them to control groups (both clinical and typically developing). There is evidence to suggest that close relatives of those with autism can be more aloof (Losh, Childress, Lam, & Piven, 2008; Murphy et al., 2000; Piven et al., 1994; 1997), tactless (Losh et al., 2008; Piven et al., 1994), rigid (Losh et al., 2008; Piven et al., 1997), impulsive (Murphy et al., 2000) shy (Murphy et al., 2000) and anxious (Losh et al., 2008; Murphy et al., 2000; Piven et al., 1997) than comparison groups consisting of those unrelated to individuals with ASD. Furthermore, data suggest that relatives of those with ASD are more sensitive to criticism (Losh et al., 2008; Murphy et al., 2000; Piven et al., 1997) and have more limited friendships (Piven et al., 1997) than controls. However, it should be noted that some studies have not found differences in the social, cognitive or language functioning of siblings (Szatmari et al., 1993) and parents (Szatmari et al., 1995) of individuals with PDDs.

However, there is also evidence that autistic traits are related to various personality characteristics within the general population. People with higher levels of autistic traits tend to be more neurotic (Austin, 2005), obsessional (Kunihira, Senju, Dairoku, Wakabayashi, & Hasegawa, 2006) and anxious (Bejerot, Nylander, & Lindström, 2001). Furthermore, they are more likely to reach diagnostic criteria of various personality disorders (Bejerot et al., 2001) and suffer from difficulties with socialisation (Bejerot et al., 2001). Lastly, there are also data to suggest that people with OCD are more likely to have high levels of autistic traits (Bejerot et al., 2001; Ivarsson & Melin, 2008), which may not be surprising, given that those with autism can be obsessional in nature.

Some researchers have hypothesised that an increase in foetal testosterone is associated with autistic traits (Auyeung et al., 2009) which provides the basis for one of the main cognitive theories of ASD – the Extreme Male Brain Theory (EMB: Baron-Cohen, 2002; 2003). Although the role that increased foetal testosterone plays in ASD is not clear-cut, studies have found clear biological differences between those with high and low levels of autistic traits. As suggested by the EMB theory, there is evidence that there is a positive

relationship between foetal testosterone levels and autistic traits in toddlers (Auyeung, Taylor, Hackett, Baron-Cohen, 2010) and children (Auyeung et al., 2009). In addition, Whitehouse, Maybery, Hickey, & Sloboda (2011) assessed the autistic traits of a group of 2 year old girls and later compared age of menarche (first menstrual period) using self-report questionnaires at age 8, 10, 14 and 17. They found that the girls with 'high' levels of autistic traits were significantly older at menarche than both 'typical' and 'low' scorers. Furthermore, elevated autistic traits have been found in female-to-male transsexuals (transmen) (Jones et al., 2012), compared to women, men and male-to-female transsexuals (transwomen). Conversely, there was no significant difference in the level of autistic traits of transwomen compared to men.

Recently, there has been evidence to suggest that there are differences in the cortical brain structure and function of those with high and low levels of autistic traits. In a large sample (n=91), von dem Hagen et al. (2011) found a correlation between white matter volume and score on the AQ. Furthermore, an increase in AQ was associated with BOLD response in posterior superior temporal sulcus (pSTS), which appears to play an important role in social functioning (Redcay, 2008). Although they did not specifically record autistic traits in their study, Dalton, Nacewicz, Alexander, & Davidson (2007) used fMRI to study face processing in participants with autism, siblings of those with autism and TD controls. They found that the brain activation patterns of the siblings were more similar to the autism group than to the controls. Moreover, mean amygdala volume for the sibling group was significantly decreased compared to controls. Lastly, Belmonte, Gomot & Baron-Cohen (2010) found atypical frontal-cerebral activation in siblings of those with autism, compared to TD controls. The degree of this atypical activation related positively to level of autistic traits, as measured by the AQ.

1.4.2 – Sensory

There is evidence that, in the general population, sensitivity to sensory stimuli is highly variable (Thomas & Chess, 1977), with evidence that introverts are more sensitive to certain sound frequencies (Stelmack & Campbell, 1974), pain (Barnes, 1975) and olfactory stimuli (Herberner, Kagan, & Cohen, 1989). As discussed previously (in section 1.2), sensory sensitivities are commonly reported in ASD. As such, it would stand to reason that sensitivity to sensory stimuli might be associated with autistic traits. In order to assess this, we looked at the naturally varying sensitivity to sensory stimuli, using both quantitative (Chapter 2; Chapter 7) and qualitative (Chapter 3) analysis techniques.

1.4.2.1 – First-degree relatives

There has been a recent increase in studies assessing the relationship between different aspects of sensory processing and autistic traits. Many individuals with ASD show superior performance in a variety of visual tasks (Jolliffe & Baron-Cohen, 1997; Shah & Frith, 1983; 1993). More recently, various studies have attempted to discover whether such differences are also observed in a) first-degree relatives of those with ASD, and b) those with elevated levels of autistic traits in the general population. In 1997, Baron-Cohen & Hammer examined the performance of parents of individuals with AS on two visual tasks: the EFT (Witkin et al., 1971), which assesses the detection of a target shape in a holistic pattern, and the Reading the Mind in the Eyes Test (Eyes Test: Baron-Cohen, Wheelwright, & Jolliffe, 1997), which determines Theory of Mind ability. In the latter task, the AS-parent group performed significantly worse than controls (parents of those without AS or autism), with the difference holding for both mothers and fathers. Conversely, the AS-parent group was significantly faster in the EFT, which was also significant for both genders.

There is evidence for superior performance in the EFT for parents (particularly fathers) of those with ASD. Happé, Briskman, & Frith (2001) found that fathers of boys with autism were significantly faster and more accurate than individuals in the comparison groups (fathers of boys with dyslexia and fathers of TD boys) when asked to complete the EFT. This difference was not replicated in either mothers or siblings of those with autism. Moreover, Bölte & Poustka (2006) found that parents of those with ASD performed significantly better on the EFT than parents of those with early-onset schizophrenia and of those with intellectual difficulty. However, although de Jonge et al. (2006) found no significant differences in RT between parents of those with ASD and the comparison group (parents of TD individuals), fathers did perform significantly more accurately than control fathers.

The Block Design task measures visuospatial and motor abilities, and is often used as a subset in many intelligence tests (Wechsler, 1981). Happé et al. (2001) used both segmented and unsegmented versions of the task, in order to test the hypothesis that superior performance in ASD is the result of an increased ability to perceive local stimuli over global. The authors found that fathers in the ASD group performed significantly better than both control groups (fathers of boys with dyslexia and fathers of TD boys), although only in the unsegmented condition. There were no group differences for mothers or siblings in either condition. Conversely, many studies have failed to find group

differences on the block design task, in either parents (Bölte & Poustka, 2006; Fombonne, Bolton, Prior, Jordan, & Rutter, 1997; Fuentes et al., 2010; Piven & Palmer, 1997; Scheeren & Stauder, 2008; Smalley & Asarnow, 1990; Szatmari et al., 1993) or siblings (Fombonne et al., 1997; Smalley & Asarnow, 1990; Szatmari et al., 1993) of those with ASD. It should be noted that Scheeren & Stauder (2008) administered the AQ as well as the Block Design Task, finding no group differences in either, which may explain their results.

Atypical chromatic contrast sensitivity and luminance motion processing have been found in siblings of those with ASD. As reported in section 1.3.1.1, Koh, Milne, & Dobkins (2010b) compared the performance of individuals with ASD and siblings of those with ASD to that of a TD control group. The authors found a significant group difference in relative sensitivity to chromatic stimuli compared to luminance, with siblings showing higher chromatic contrast sensitivity compared to both the ASD and control groups, which the authors suggested could be evidence for a protective factor in siblings of those with ASD. In addition, there appear to be fundamental differences in certain aspects of visual processing in very young children with an older sibling who has ASD (known as 'high-risk' infants). McCleery et al. (2007) presented faces and objects to infants and measured their event-related potentials (ERPs) elicited by the stimuli and found that the responses of high-risk infants to faces were atypical. The authors suggest that these findings demonstrate two specific endophenotypes (measurable, heritable characteristics normally associated with, but not symptomatic of, a disorder) present in ASD – a lack of hemisphere asymmetry and atypical face/object processing, which could be important for better understanding the mechanisms underlying ASD.

Finally, a recent study investigated the face processing abilities of parents and siblings of those with ASD, as well as those with an ASD diagnosis and typically developing controls (Wallace, Sebastian, Pellicano, Parr, & Bailey, 2010). Participants were examined for unfamiliar face and object discrimination, facial expression recognition and discrimination of directional cues. In the first task, the relatives group performed significantly worse than controls in perceiving slight differences for faces, but not objects. Those in the relatives group also performed significantly worse than controls in the facial expression task, especially in their judgement of 'fear' and 'disgust'. In the final task, the relatives of those with ASD failed to show an advantage for direct versus averted eye-gaze. However, it should be noted that the sibling and parent group, like controls, did exhibit a whole to part-face advantage for judging eye direction, which indicates holistic processing strategies not

observed in the ASD participants. Therefore, the performance of relatives on a variety of face processing tasks was significantly impaired compared to controls, yet superior to those with a diagnosis of ASD. The authors suggest that these results are indicative of a cognitive endophenotype in ASD.

1.4.2.2 – General population

Although there is evidence that siblings and parents exhibit similar, albeit less obvious, performance patterns to those with ASD, there are also many studies which have not found differences between perception and cognition of ASD relatives and controls unrelated to those with ASD. One study has estimated that the prevalence of those with significant levels of autistic traits (which they separate into the broader, medium and narrow phenotype) is 25-35% in ASD parents and 10-25% of TD controls (Wheelwright, Auyeung, Allison, Baron-Cohen, 2010). It could be argued that the non-significant results or partial support could be a consequence of insufficient screening of controls for autistic traits.

However, in the last 3-4 years, there has been an increase in the number of studies comparing the performance (in a variety of tasks) of individuals with high and low levels of autistic traits in the general population. Grinter et al (2009a) examined the global visual processing of adults with high and low levels of autistic traits. Firstly, performance on the EFT and on a global motion task was assessed. Secondly, the question of whether performance was linked to enhanced local processing or reduced global processing was assessed. Results indicated that those with high levels of autistic traits were more accurate, as well as faster, in the EFT. Furthermore, the participants in the high-AQ group had significantly elevated global dot motion thresholds, indicating impaired performance. Performance in psychophysical tasks showed that reduced performance for global dot motion could not be attributed to poorer performance in psychophysical tasks in general. Instead, the pattern of performance suggests that the higher thresholds for global dot motion point to a difficulty in integrating local signals into a global percept.

Grinter et al. (2009b) investigated the visuospatial performance in high and low scorers on the AQ. They administered the EFT and the Block Design subset of the WAIS-III, as well as the AQ, to a group of university students. The results of this study indicated that those with higher AQ scores were more accurate and faster at both tasks than those with low AQ scores. Kunihira et al. (2006) also assessed EFT in a group of people with a variety of autistic traits, finding no significant difference between groups. Grinter et al. (2009b)

questioned the results of Kunihira et al. (2006), highlighting that their low AQ group had significantly higher AQ scores than in their own study. In order to determine whether faster performance could be a result of IQ, instead of autistic traits, the experiment was replicated, with participants also being administered the verbal and performance subscales of the WAIS-III. There was no group difference for verbal IQ, although the high-AQ group exhibited significantly higher performance IQ scores. However, performance on the EFT was found to be unaffected by IQ. Stewart et al. (2009) also investigated the relationship between performance on the Block Design task and autistic traits. Like Happé et al. (2001), they included both whole and segmented versions of the task in their study. As would be expected, the high AQ scorers completed the 'whole' trials significantly faster than the low AQ group. However, there was no difference between groups in the segmented trials, indicating that the faster performance in those with higher levels of autistic traits could lie in superior disembedding skills.

Sutherland & Crewther (2010) evaluated performance on visual tasks assessing local/global processing, motion processing and visual pathway integrity and compared it to AQ score. Local and global processing was examined using Navon figures, which are global figures that consist of multiple local figures. A simple example of this would be a large 'S' consisting of small 'H's. The authors found that high AQ scorers had significantly more difficulty in identifying the global features of a stimulus. The finding that people with higher AQ scores exhibit superior local performance in Navon figures has recently been replicated (Reed, Lowe, & Everett, 2011).

Bayliss & Kritikos (2011) assessed the relationship between perceptual load (amount of information which is potentially relevant to the task) and subclinical autistic traits by varying the perceptual load of a flanker task. Previous research has indicated that those with ASD show stronger interference effects at high versus low perceptual loads compared to typically developing individuals without ASD (Remington, Swettenham, Campbell, & Coleman, 2009). The purpose of Bayliss & Kritikos (2011)'s study was to determine whether the same performance pattern differences were observed in those with high and low levels of autistic traits. As hypothesised, they found that the interference effect was much greater for the high-AQ group when trials consisted of a set size of 4 (high load) whereas there was no significant difference between groups in trials with a set size of 2 (low load). This provides further evidence that subclinical autistic traits, which are often considered to be pervasive throughout the general population, may reflect a specific cognitive style.

Although the majority of studies have investigated the relationship between autistic traits and different aspects of visual processing, there is evidence that autistic traits can also affect speech processing. Stewart & Ota (2008) evaluated auditory speech perception in individuals with varied AQ scores using an identification task, a discrimination task and a lexical decision task. Participants were presented with stimuli from a 7-point word – non-word continuum (e.g. ranging from "gift" to "kift" or "giss" to "kiss"). Participants were asked to respond with whether the word began with a g or a k. The results indicated that participants tended to be biased toward the real word in their response. However, the effect was negatively correlated with AQ score, indicating that as level of autistic traits increased, participants were not as biased by the linguistic features of the stimuli.

1.4.2.3 – Summary of the Broader Autism Phenotype

Overall, consistent differences between individuals with high and low levels of autistic traits have been elicited in a range of studies targeting the biological, perceptual and cognitive domains. These increased levels of autistic traits appear to be continuously distributed within the general population (Hoekstra et al., 2007), although there is also evidence that first-degree relatives of those with ASD often demonstrate elevated levels of autistic traits compared to individuals who do not have relatives with ASD (Constantino et al., 2006; Piven et al., 1994). The siblings of those with ASD have been shown to exhibit significantly higher social impairment compared to TD individuals (Constantino & Todd, 2003; Elsabbagh et al., 2011), although evidence for social difficulties in parents of those with ASD is mixed (Briskman, Happé, & Frith, 2001). Studies have found that both parents (Folstein et al., 1999; Piven et al., 1997) and twin siblings (Le Couteur et al., 1996) of those with autism often experience language difficulties, and that this trend is also observed in the general population (i.e. those with high levels of autistic traits are more likely to exhibit language difficulties than those with low levels of traits) (Möricke et al., 2010; Ronald et al., 2006). Studies investigating the executive functioning performance of those with high levels of autistic traits have found mixed results. Although some studies have found poorer executive function in siblings (Hughes et al., 1999) and parents of those with ASD (Hughes et al., 1997), other studies have found no significant group differences in either the parents of those with ASD (Bölte & Poustka, 2006) or in those with high levels of autistic traits in the general population (Kunihira et al., 2006).

Furthermore, there is evidence to suggest that personality traits are expressed differently in those with high levels of autistic traits. This has been observed in both the relatives of

those with ASD (Losh et al., 2008; Murphy et al., 2000; Piven et al., 1994; 1997) and in the general population (Austin, 2005, Bejerot et al., 2001; Kunihira et al., 2006). In terms of the biological basis of ASD, some researchers have posited that an increase in foetal testosterone is associated with an increase in autistic traits (Auyeung et al., 2009), and there is evidence to suggest that higher levels of autistic traits may be related to age at menarche (Whitehouse et al., 2010) and gender identity (Jones et al., 2012). Moreover, there is evidence that differences can be observed in the cortical brain structure and function of those with high and low levels of autistic traits (von dem Hagen et al., 2011), and this should be investigated further in the future in order to determine whether a) these results are replicable and b) what the implications of different brain structure and function in those with high levels of autistic traits could be.

There is also evidence that the sensory processing of a) first-degree relatives of those with ASD and b) those with high levels of autistic traits in the general population is different to those with low levels of autistic traits. However, as results are extremely variable for the majority of the sensory processing literature in ASD, it is unsurprising that studies into the broader phenotype have concentrated on areas where there are consistent differences in the performance of individuals with ASD (e.g. visual search tasks). Results have shown that both relatives of those with ASD and those with high levels of autistic traits in the general population perform significantly better than TD controls, although not as well as individuals with an ASD diagnosis, on visual search tasks (Baron-Cohen & Hammer, 1997; Bölte & Poustka 2006; Grinter et al., 2009a, 2009b; Happé et al., 2001; Stewart et al., 2009; Sutherland & Crewther (2010). However, it should be noted that results have been less consistent for the block design task (Bölte & Poustka, 2006; Fombonne et al., 1997; Fuentes et al., 2010; Happé et al., 2001; Piven & Palmer, 1997; Scheeren & Stauder, 2008; Smalley & Asarnow, 1990; Stewart et al., 2009; Szatmari et al., 1993). Finally, there is also evidence that those with high levels of autistic traits perform differently to those with low levels of autistic traits in auditory tasks, with results showing that, as AQ scores increased, participants were less biased by the linguistic features of a word (instead, relying on the perceptual features) (Stewart & Ota, 2008).

1.5 Theories of ASD

Here, the predominant theories relevant to sensory processing in ASD will be reviewed. This will include both cognitive (such as Weak Central Coherence and Executive Dysfunction Theory) and neural theories (such as the Enhanced Perceptual Functioning

and neural noise theories) of autism (see Rajendran & Mitchell (2007) for a review of the cognitive theories).

1.5.1 – Cognitive

1.5.1.1 – Theory of Mind/Extreme Male Brain theory

The Theory of Mind (ToM) hypothesis (Baron-Cohen, Leslie, & Frith, 1985) has been one of the most influential theories of autism in the last 25 years (Simmons et al., 2009). This theory posits that individuals with autism have difficulty inferring the mental states of others. Most commonly, the False Belief task (Wimmer & Perner, 1983) is used to assess ToM. This task typically involves the playing out of a 'scene' in front of participants, using dolls, and is commonly known as the 'Sally-Anne task'. As the scene develops, one doll holds a false belief about the placement of an object (e.g. that a marble is in the box when it is actually in the basket). The child is asked to consider where the doll considers the object to be, thereby inferring the mental state of the doll. Baron-Cohen et al. (1985) found that 80% of children with autism failed the task. However, criticism of this theory has included concerns about the lack of universality (i.e. that a subset of the group did manage to complete the task) (Happé, 1994) and that atypical behaviour can often be observed in children with autism before typically developing children develop the capacity for "theory of mind" (around 3-4 years old: Klin, Volkmar, & Sparrow, 1992; Wimmer & Perner, 1983). In order to address these concerns, the theory was updated 10 years later (Baron-Cohen, 1995). Using evidence from second-order false belief tasks (where the participant attempts to understand what one person's mental state is about a third person), Baron-Cohen (1989) found that 90% of typically developing children (mean CA = 7.5 years) could complete the task. However, none of the children with autism passed (mean MA = 12.2 years). Baron-Cohen (1995) concluded that individuals with autism did not have a fully representational theory of mind, as even the subset who were able to pass the first-order task were unable to complete the second order task (Rajendran & Mitchell, 2007).

The ToM hypothesis has been recently transformed into the Extreme Male Brain (EMB) theory of autism (Baron-Cohen, 2002), which argues that individuals with ASD are excellent "systemizers" and poor "empathizers". The concept of the theory comes from the finding that males are generally better systemizers than females, with women instead displaying superiority for empathizing (Manson & Winterbottom, 2012). Empathizing is related to theory of mind, as it involves being able to interpret the emotions of others –

although it also requires the observer to have an emotional response to the affective state of another (e.g. to feel upset when another person displays sadness). Systemizing involves the analysis, exploration and construction of rule-based systems and is associated with technical professions (e.g. mathematics, engineering). The EMB theory has hypothesised that the extreme 'maleness' of the brains of those with autism are a result of increased foetal testosterone in the womb (Knickmeyer & Baron-Cohen, 2006).

One of the main problems with the EMB theory is that it fails to account for the sensory sensitivities experienced by individuals on the Autism Spectrum. Another criticism levelled at the EMB theory is that the high levels of systemizing observed in ASD are not evident in a real-world context (Pellicano et al., 2011). Twenty children with autism and matched TD controls took part in a large-scale searching task. Contrary to the E-S hypothesis, the children with autism were much less systematic in their searching. In fact, those with autism had difficulty navigating and exploring the large space. Furthermore, Francesca Happé and Uta Frith have recently cautioned against taking self-perceptions at face value, proposing that studies should assess the systematic abilities of those with ASD and compare to comparison groups rather than relying solely on questionnaire data (Buchen, 2011). In addition, there have also been criticisms that EMB theory is based predominantly on findings from high-functioning individuals with ASD (Buchen, 2011), although Baron-Cohen suggests that his systemizing theory is applicable throughout the Autism Spectrum, including those with classic autism. Lastly, there is a lack of objective evidence to support the EMB theory, with some researchers failing to find support for the concept that those with ASD are 'hyper-male' (although this is restricted to visuo-spatial processing performance) (Falter, Plaisted, & Davis, 2008).

1.5.1.2 – (Weak) Central Coherence Theory

The Central Coherence (CC) theory (originally known as Weak Central Coherence (WCC)) proposes that individuals with ASD have a specific cognitive style causing those with ASD to think about things in the smallest possible parts, rather than seeing the "big picture" (Frith, 1989; Happé & Frith, 2006). One of the main strengths of this theory is that it provides an explanation for the non-social aspects of autism, particularly the patterns observed in some visual and auditory tasks. The discovery that individuals with ASD exhibit superior performance in tasks involving embedded figures (Jolliffe & Baron-Cohen, 1997; Shah & Frith, 1983) and other visual tasks (Shah & Frith, 1993) has recently been extended to include those with high levels of autistic traits (Grinter et al., 2009a; 2009b; Stewart et al., 2009; Sutherland & Crewther, 2010). There is further support for

CC from the observation that an unusually high proportion of individuals with ASD display extraordinary skills in certain areas (sometimes known as 'savantism') (Howlin, Goode, Hutton, & Rutter, 2009). However, although CC theory accounts for some of the sensory atypicalities observed in autism (e.g. enhanced local processing), this theory provides little explanation of the hyper-sensitivity and hypo-sensitivity to sensory stimuli experienced by many individuals with ASD.

The original theory suggested that impairment in global processing caused the superior local processing observed in ASD (Frith, 1989). However, subsequent studies showed that people with ASD either exhibited intact global perception (Heaton, 2005; Mottron et al., 1999; Mottron, Burack, Iarocci, Belleville, & Enns, 2003) or could be primed to process globally, under certain circumstances (López, Donnelly, Hadwin, & Leekam, 2004). In order to address these findings, an updated theory was published (Happé & Frith, 2006), which consisted of a number of differences: 1) that CC is a result of superior local processing, rather than poorer global processing, 2) CC is considered to be a cognitive style, rather than a deficit, 3) it is now considered to partially account for cognition in autism, rather than the disorder as a whole and 4) the processing style can be overcome in certain circumstances.

1.5.1.3 – Executive Dysfunction Theory

The Executive Dysfunction theory proposes that the core cognitive symptoms observed in ASD are a result of improper performance by the executive function system, which mediates tasks such as working memory, planning and attention (Hill, 2004; Ozonoff et al., 1991; Russell, 1997). One strength of the executive dysfunction theory is that it explains some of the non-social symptoms not covered by ToM and WCC, including attention-switching problems, dislike of change and reduced impulse inhibition (Rajendran & Mitchell, 2007). Furthermore, there is evidence that executive dysfunction and ToM are related (Hughes, 1998) and that performance in ToM tasks can be partially attributed to the level of executive control dysfunction exhibited (Hill, 2008). The theory falls short in its explanation of sensory sensitivities, although it does address the restricted and repetitive behaviours of those with autism by hypothesising that these may be the result of an inability to shift attention from a stimulus (thereby repeating it over and over) (Turner, 1999). However, it should be noted that recent work in the area has not found a strong relationship between executive dysfunction and repetitive behaviours (Lopez, Lincoln, Ozonoff, & Lai, 2005; Rogers & Ozonoff, 2005).

1.5.2 – Neural

1.5.2.1 – Enhanced Perceptual Functioning Theory

Like Central Coherence theory, Enhanced Perceptual Functioning (EPF) theory is based on the premise that individuals with ASD exhibit superior local processing abilities (Shah & Frith, 1983; 1993). The original theory proposes that ASD stems from a superiority of low-level perception (such as discrimination and pattern perception), resulting in increased attention to lower-order cognitive processes, at the expense of higher-order ones (e.g. social interaction) (Mottron & Burack, 2001). Possible mechanisms proposed for EPF included a) unusual growth and connection of neurons, b) rededication of cortical areas, c) irregular inhibition, d) deficit compensation and e) atypical "functional persistence", which refers to increased refinement of low-level processes at the expense of higher order processes (Mottron, Dawson, Soulières, Hubert, & Burack, 2006).

In an update to the theory, Mottron et al. (2006) proposed eight principles of perception in ASD, which are:

1. The default setting of perception in individuals with autism is more locally oriented than that of typical individuals

2. Increased gradient of neural complexity is inversely related to level of performance in low-level tasks

3. Early atypical behaviours have a regulatory function toward perceptual input

4. Perceptual primary and associative brain regions are atypically activated during social and non-social tasks

5. Higher-order processing is optional in autism and mandatory in typicals

6. Perceptual expertise underlies savant syndrome

7. Savant syndrome provides a model for subtyping Pervasive Developmental Disorders

8. Enhanced functioning of primary perceptual brain regions may account for the perceptual atypicalities in autism

One interesting change between the original and updated versions of the EPF involves the concept that individuals with ASD are not biased toward either local or global processing – the superior local processing observed in ASD is actually a result of mandatory global bias in the TD individual, even when it is detrimental to task performance.

Currently, the EPF model is mostly consistent with the literature, although it should be noted that a recent study into colour discrimination in autism did not show superior performance that would be expected according to EPF theory (Franklin et al., 2010). EPF

theory is able to explain a number of features of autism using a low-level causal mechanism, although the neuropathology behind it is, as yet, undefined. However, it has been recently suggested that there are similarities in the minicolumn theory of autism (there is evidence that those with autism have shorter minicolumns, often in greater number due to the larger size of brains of those with ASD: Casanova, Buxhoeveden, Switala, & Roy, 2002) and the EPF theory (Simard-Meilleur et al., 2012), and further investigation into this link is warranted. A particular strength of the theory is that it accounts for some of the sensory atypicalities reported in ASD, unlike many of the cognitive accounts of autism (e.g. EMB). As well as providing an explanation for improved local performance in certain perceptual tasks in those with ASD (e.g. EFT, block design and visual search), EPF theory also explains hyper-sensitivity by suggesting that this process could be the result of atypical inhibitory and excitatory local network connectivity in sensory regions. However, this theory does not fully account for sensory sensitivities as reported in the literature. In particular, the theory provides little explanation of the hypo-sensitivities often described by individuals with ASD.

1.5.2.2 – Neural noise hypothesis

As mentioned previously (section 1.2), individuals with ASD experience hyper- and hypo-sensitivities to sensory stimuli, often within the same modality. One explanation for the patterns observed in ASD could be the increase of noisy signals in the perceptual system decreasing the signal-to-noise ratio, which would result in hypo-sensitivities. Although it seems counter-intuitive, hyper-sensitivity can be explained using the concept of "stochastic resonance", which is where the signal-to-noise ratio is amplified under certain circumstances (i.e. in a non-linear system with a fixed threshold: Wiesenfeld & Moss, 1995). The neural noise theory can also attempt to explain the results obtained by Bertone et al. (2005), who found superior performance for those with ASD (compared to a TD comparison group) in first-order luminance gratings, but poorer performance in second-order gratings. Stochastic resonance would mean that those with ASD perform better than typically developing individuals in detection tasks with first-order luminance-defined gratings in noise (as the signal may be amplified slightly, giving an advantage to the ASD participants). However, as the second-order grating task requires combining information across additional visual filters, the increased neural noise would not be able to help in the detection task and would instead mask the signal (leading to poorer performance).

The concept of a "noisy system" has been proposed in multiple studies (Belmonte & Yurgelun-Todd, 2003; Dakin & Frith, 2005; Franklin et al., 2010; Rubenstein &

Merzenich, 2003; Sanchez-Marin & Padilla-Medina, 2008; Simmons et al., 2009; Thornton, 2006) as explaining the performance of those with ASD. When combined with the evidence of increased heterogeneity in ASD, particularly that of intra-participant variability (Milne, 2011), it was proposed that neural noise could account for the strengths and impairments observed in ASD (Simmons et al., 2007; 2008). The theory would predict that participants with ASD would exhibit superior performance in tasks involving first-order luminance-gratings in noise and worse in those involving second-order, which was observed in an experiment with adults who had a diagnosis of autism (Bertone et al., 2005). One of the strengths of the neural noise theory is its ability to explain both the over- and under-sensitivities reported and demonstrated by individuals on the Autistic Spectrum. However, the main drawback to this hypothesis is a lack of empirical data – although it has been suggested as a possible explanation for the patterns observed in ASD, only a single study has thus far experimentally assessed neural noise levels (using EEG) in individuals with ASD and TD age-, IQ-, and gender-matched controls (Milne, 2011).

1.6 Aims and outline of the thesis

The overall aim of the thesis is to examine the sensory issues present in those with a diagnosis of ASD, as well as in individuals who exhibit higher-than-typical levels of autistic traits. The direct measurement data for sensory sensitivities in ASD are extremely variable, across all the sensory domains. As a result of the hyper-sensitive responses exhibited by many individuals with ASD, experimenters have concentrated on measuring absolute detection thresholds in a variety of sensory domains, with the majority of studies finding no differences (Bennetto et al., 2007; Bertone et al., 2005; Güçlü et al., 2007; Jones et al., 2009; Pellicano et al., 2005; Tavassoli & Baron-Cohen, 2012a). It would appear that the sensory issues experienced by many with ASD could be far more complex than lowered thresholds; it may be the way that the brain *deals* with the stimuli that is of greater importance. Therefore, the work presented in this thesis concentrates on the sensory *experiences* that those with ASD (and the broader phenotype) have. It is hoped that by elucidating the common triggers, coping mechanisms and impact of sensory stimuli, that a) improved experimental paradigms for assessing sensory atypicalities in ASD and b) an environmental intervention to help increase accessibility could be developed. As there is increasing evidence for the role of an endophenotype in ASD, the sensory issues of those with elevated autistic traits will also be reported. Overviews of the other chapters in the thesis are provided below.

In Chapter 2, I report the results of a questionnaire-based study assessing atypical sensory experiences in those with varying levels of autistic traits. The sensory questionnaire was constructed and developed by us, and used alongside a standard questionnaire for determining autistic traits (Baron-Cohen et al., 2001). The purpose of the study was to determine whether there was a relationship between number of autistic traits (measured by the AQ; Baron-Cohen et al., 2001) and sensory sensitivities (measured by the GSQ; Robertson & Simmons, 2012). Both hyper- and hypo-sensitivities were assessed over seven modalities (vision, audition, gustation, olfaction, touch, vestibular processing and proprioception). After the preliminary data analysis, a principal components analysis was performed in order to reduce the number of questions in GSQ. Data from the development of the GSQ, as well as from the experiment proper are presented in Chapter 2. The results are discussed in relation to the literature on self- and parent-report data on sensory sensitivities in ASD.

In Chapter 3, I report the results of responses to four open questions about sensory issues from a broad population, with participants (n=212) also completing the AQ. These data were analysed using mixed methods. Two themes were drawn from these data using thematic analysis and frequency comparisons were made across sub-groups. Data are presented in Chapter 3 and the results are critiqued in comparison to relevant studies.

The aim of the research described in Chapter 4 was to investigate the sensory experiences of children with a diagnosis of autism. This involved conducting two separate studies: a focus group with caregivers of those with autism and small group interactive interviews with children who had autism. Nine participants took part in the caregiver focus group. Caregivers provided negative and positive examples of interaction with sensory stimuli and described the impact that this could have on their child, as well as themselves. Furthermore, children with a diagnosis of autism (n=10) participated in one of three group interviews, where they were asked questions in a short semi-structured interview format. They also took part in interactive 'experiments' designed to elicit descriptions of tactile, auditory and olfactory stimuli. The data from these studies are discussed, in relation to both self-report and direct measurement literature, in Chapter 4.

The purpose of the study described in Chapter 5 was to elucidate information about the nature and impact of sensory issues directly from those with a diagnosis of ASD. This involved conducting a focus group study with a group of adults working for a local company that employs those with a diagnosis of ASD. Thematic analysis showed that there

were four main themes, and that negative affect could impact on the response to sensory stimuli. Both positive and negative interactions with sensory stimuli were reported.

In Chapter 6, the results from a group discussion of older adults are reported. The purpose of this study was to determine the effect that naturally-occurring sensory changes in older adults could have, on both the individuals themselves and their relatives. Three themes were drawn from these data, showing that sensory issues were a problem concomitant with normal ageing. Data are presented in Chapter 6 and the results are critiqued in comparison to our findings from the ASD population as well as relevant studies.

The aim of the study reported in Chapter 7 was to determine whether there were any significant differences in the olfactory thresholds, discrimination abilities and identification skills of those with high and low levels of autistic traits. Participants in the general population were administered the AQ and the Sniffin' Sticks Extended Test (n=106), with a sub-group also being given the GSQ developed in Chapter 2 (n=62). These data are presented in Chapter 7, with results discussed in light of recent evidence of increased intra-participant variability in ASD (Gowen & Hamilton, 2012; Milne, 2011; Simmons et al., 2009).

The purpose of the pilot study described in Chapter 8 was to develop a freely available and systematic method of assessing an environment, highlighting any difficulties, and ameliorating associated problems. In order to do this, we worked in conjunction with a local company employing those with ASD, as well as determining the most problematic causes of sensory discomfort from the studies described in Chapters 3-5. Data of a) how the sensory audit was developed and b) the results of the pilot sensory audit are reported in Chapter 8, along with potential practical applications of the Sensory Audit and ideas for future development.

In Chapter 9, the results of all the studies are summarised and compared to each other and the literature. In addition, the data are discussed in relation to a) the potential mechanisms underlying sensory issues, b) the implications of atypical sensory processing for caregivers and c) the relationship between atypical sensory processing and the broader phenotype. In addition, the practical applications of the work discussed in this thesis and the potential future directions of research in this field are discussed.

Chapter 2   The Relationship between sensory issues and autistic traits

2.1 Introduction

Our senses provide us with key information about ourselves and our environment, such as the identities and locations of objects, the speed of our own movement within the environment and the safety of substances that we ingest (Goldstein, 2002). However, as with all sensory systems, our senses have a finite dynamic range. Considering the auditory system, for example, humans are typically able to hear sounds between 12Hz and 20kHz (Goldstein, 2002), although this frequency range reduces with age (Willott, 1991). Moreover, we cannot hear sounds of very low sound pressure level [0 dB SPL] and sounds above certain amplitudes [120 -140 dB SPL] will cause us pain and also potentially damage the auditory system (Nave, 2006). It is obvious that this "comfort range" for hearing will vary between individuals. Those with sensorineural hearing loss will need higher amplitudes in order to detect a sound and those with other conditions, such as tinnitus (i.e. the perception of sound within the ear in the absence of external sounds), may experience auditory pain at relatively low sound amplitudes (sometimes called "hyperacusis": Jastreboff, 2000). This type of reduced comfort range is a particular issue for individuals on the autism spectrum (Khalfa et al., 2004).

As discussed in Chapter 1, individuals with ASD often report atypical experiences with a variety of sensory stimuli (Ben-Sasson et al., 2009; Bogdashina, 2003) and a number of experimental studies have discovered differences between ASD and control groups in a variety of sensory modalities (Bennetto et al., 2007; Cascio et al., 2008; Haesen et al., 2011; Simmons et al., 2009; Tavassoli & Baron-Cohen, 2012b). As a result, it is anticipated that sensory atypicalities will now be included in the impending revision of diagnostic criteria for ASD (American Psychiatric Association, 2010).

There are a number of informative first-hand accounts of the sensory experiences of individuals with ASD. Many "high-functioning" individuals with ASD (i.e. those with a typical-to-high IQ) describe responding to sensory stimulation in unusual ways (Jones et al., 2003; Williams, 1998). More formal evidence for atypical sensory responses in ASD comes from parent/carer report data (Baranek et al., 2006; Leekam et al., 2007) and self-report data from questionnaires (Crane et al., 2009). It is thus reasonably well established

that a diagnosis of ASD is likely to be associated with atypical sensory functioning, although there is considerable debate about precisely what these atypicalities are, and what causes them.

It should be noted that existing standard clinical tests (e.g. visual acuity) will not necessarily detect these sensory processing difficulties (Chapter 1; Simmons et al., 2009). As reported in section 1.3, many studies have found that there is little difference in baseline sensory performance (as measured by determining sensory thresholds) between those with ASD and TD matched controls (Bertone et al., 2005; Khalfa et al., 2004; Jones et al., 2009). This general result indicates that it may not be that those with ASD are more sensitive to sensory stimuli per se, but rather that there may be differences in the way these stimuli are processed by the brain, especially in "real-life", as opposed to laboratory or clinical environments. As a precursor to developing more relevant sensory tests for adults with ASD we constructed a self-report sensory questionnaire[1].

Evidence that relatives of those with ASD exhibit some characteristics of autism, although to a lesser degree (Piven et al., 1994), has recently prompted the development of the concept of the 'broader autism phenotype' (BAP). There is evidence that these characteristics are prevalent in the general population (Constantino & Todd, 2003) and a variety of questionnaires (Baron-Cohen et al., 2001; Constantino & Gruber, 2005; Hurley et al., 2007) have been developed to assess the level of "autistic traits" that a person may have (see section 1.4.1 for further details). Although not designed to be used for diagnostic purposes, these questionnaires can offer reliable discrimination between TD individuals and those with an ASD (e.g. Baron-Cohen et al., 2001).

Several studies have related autistic traits to other factors such as personality (Austin, 2005), biological processes (e.g. delayed menarche onset) (Whitehouse et al., 2011) and social functioning (Elsabbagh et al., 2011). Furthermore, there is evidence that there are some differences in brain structure and function of those with high and low autistic trait

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[1] Note that a self-report sensory questionnaire (The Adult/Adolescent Sensory Profile: AASP) has previously been published by Brown & Dunn (2002). However, this instrument was not specifically designed to target the sensory issues associated with ASD populations, and contains some questions that overlap with those on autism diagnostic instruments, making it unsuitable for our purposes. In addition, our questionnaire assessed reported sensitivity separately in the proprioceptive, vestibular, taste and smell modalities (these modalities are combined into 'taste/smell' and 'movement' in the AASP), as well as including items for visual, auditory and touch sensitivity. Furthermore, we did not include items on 'activity level', which is assessed in the AASP.

levels. This has been observed in the posterior superior temporal sulcus (pSTS), with high scorers on the AQ demonstrating reduced white matter volume (von dem Hagen et al., 2011). The STS is implicated in social cognition, and there is evidence that differences in this brain region could underlie the differences observed in those with ASD and typically developing controls (Redcay, 2008). In terms of sensory processing, it has been recently demonstrated that high- and low-scorers on the AQ perform differently on a variety of visual processing tasks (see section 1.4.2).

Parent report and autobiographical accounts provide evidence that atypical responses to sensory stimuli can affect quality of social interaction and the ability to tolerate certain environments amongst individuals with ASD (Baranek et al., 2006; Leekam et al., 2007; Williams, 1998). Decreased social interaction is often observed in individuals with ASD (Sigman et al., 1999). Systematic avoidance of people and places as a result of sensory intolerances could easily lead to social isolation (Cosbey, Johnston, & Dunn, 2010), perhaps resulting in phobias of people, places or certain types of environmental stimuli.

In order to relate the sensory data to personality and social skills, we presented our sensory questionnaire together with the Autism Spectrum Quotient (AQ: Baron-Cohen et al., 2001). The AQ is a short, self-administered tool which determines the degree to which someone has traits similar to those of individuals on the autism spectrum. It has been shown to be a reliable and valid measurement (Baron-Cohen et al., 2001; Hurley et al., 2007; Woodbury-Smith, Robinson, Wheelwright, Baron-Cohen, 2005), able to differentiate between those with either autism (Baron-Cohen et al., 2001) or Asperger's Syndrome (Woodbury-Smith et al., 2005) and those without an ASD diagnosis.

Our hypothesis was that individuals with "high" AQ scores who, according to the original study, have an 80% chance of being diagnosed with ASD, would have high scores on our sensory questionnaire, indicating higher frequencies of sensory difficulties, but that those with low and medium AQ scores would show relatively low sensory scores. A higher total sensory score is generally indicative of experiencing both hyper- and hypo-sensitivity to sensory stimuli more frequently, although modality subscales and a breakdown of hyper- or hypo-scores can also be obtained.

2.2 Methods

2.2.1 – Participants and recruitment

English-speaking individuals (n = 212 (n=270, before exclusion criteria were applied); 142 females, 70 males; mean age = 26.75 years, S.D. = 9.84 years, range = 16 - 66 years) were recruited from the general population. Ethical permission from the Faculty sub-committee of the University of Glasgow ethics committee was granted prior to recruitment commencing. Students and colleagues from the University of Glasgow were invited to participate by email, and encouraged to forward the email on to others who might be interested. In order to recruit those with high AQ scores, an advert was also placed on an online forum for those with a diagnosis of AS. The majority of participants were based in the UK (n=180). Potential participants were provided with a paragraph explaining the study and a hyperlink taking them to a survey website (Survey Monkey: www.surveymonkey.com). Note that the experiment was carried out entirely online with no face-to-face contact between participants and experimenter. Although the AQ was developed as a 'pen-and-paper' questionnaire, it has been administered online previously to a large sample, with no differences reported (Wheelwright et al., 2006). Furthermore, there is evidence that there is little variation in responses when 'pen-and-paper' questionnaires are presented online (Van De Looij-Jansen & De Wilde, 2008; Wu et al., 2009). Individuals were advised that completion of the study would take approximately 25 minutes in total. Participants from the UK were offered the chance to enter into a prize draw for one of three £15 vouchers.

Each participant completed the AQ and the GSQ and was assigned to a group based on their AQ score. Although some participants disclosed that they had a diagnosis of ASD (n=2), we collected data based purely on AQ score, as recent evidence suggests that autistic traits lie on a continuum in the general population (Constantino & Todd, 2003). Neither IQ nor comprehension skills were formally assessed, but participants were encouraged to provide feedback on any difficulties they experienced with the questionnaires and were excluded from analysis if they indicated comprehension problems on multiple items (n=1). Group 1 (n=79) consisted of those who scored less than 19 on the AQ, Group 2 was composed of those who scored between 19 and 31 (n=94) and Group 3 (n=39) contained 'high-scorers' (i.e. had a score of 32 or more). The value of 32 was chosen for the 'High' scoring group because this was the reported minimum score in Baron-Cohen et al. (2001)'s original paper at which 80% of those with autism score. In addition, we decided to set the lowest value for the 'Medium' group at 19. This was chosen in order to ensure that we were targeting those with a 'higher-than-average' AQ score in the 'Medium' group (the mean AQ score for controls in the original AQ study was 16.4).

2.2.2 – Materials

The study made use of two questionnaires: the GSQ (which we developed as part of the study) and the AQ (Baron-Cohen et al., 2001). The GSQ was initially constructed based on a) reports in the literature of sensory signs and symptoms commonly associated with ASD (Baranek et al., 2006) and b) signs and symptoms reported by parents of children with autism (Robertson & Simmons, 2008). Two ASD researchers and a consultant psychiatrist who specializes in ASD revised the original questionnaire (Appendix A). Changes to the phrasing were made and the response scale was altered before piloting with a small group (n=5) of people with varying AQ scores. One of the participants in the pilot group had a confirmed diagnosis of HFA, and we worked with him on an individual basis to ensure that the questions were clear and understandable. After further revisions, the questionnaire, consisting of 70 quantitative and 4 qualitative items, was administered online to our participants. Only the results from the quantitative items are reported here – the qualitative results are reported in Chapter 3. The qualitative questions were open, rather than forced-choice, and asked participants to detail sensory events that were most problematic and soothing for them.

The Kaiser-Meyer-Olkin measure of sampling adequacy and the Bartlett test for sphericity indicated that the data were suitable for factor analysis. Principal Components Analysis (PCA) was performed in order to reduce the number of items in the sensory questionnaire, as well as to determine whether the questions grouped into underlying factors. The majority of items had their highest loading on a single factor. The output from the PCA (see Appendix B) was used to reduce the number of questionnaire items from 70 to 42 for the purposes of analysis (but note that all data were collected with the original 70-item questionnaire). The reduction affected all modalities equally (the number of items for each modality was reduced from 10 to 6, with an even split between questions targeting hyper-sensitivity and hypo-sensitivity). 22% of the variance was accounted for in the 70 item questionnaire with this increasing to 28% in the 42 item version. Further PCA analysis confirmed that the single-factor model was appropriate, as did a Scree Plot (see Appendix C and Figure 2.1, respectively).
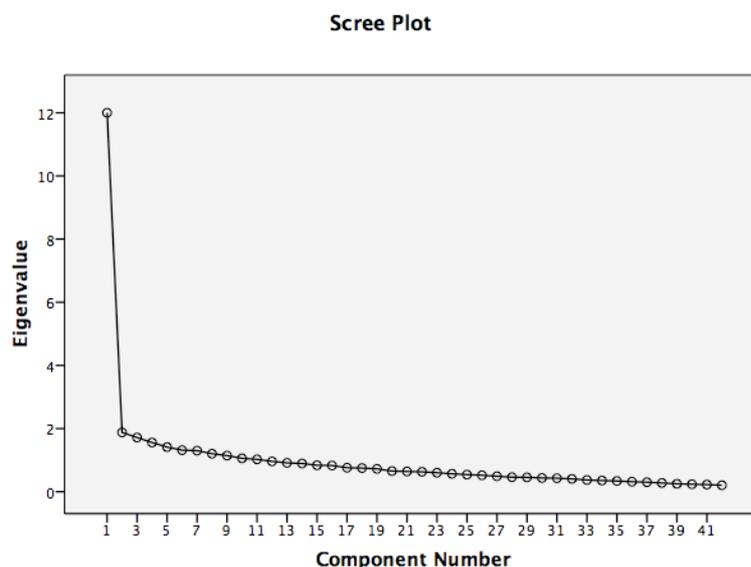
Scree Plot

Figure 2.1 – The scree plot for the 42-item data supports the conclusion that a single-factor model fits these data best (the point of inflexion is at factor 2).

Reliability analysis for the 42 key items of the questionnaire utilized Cronbach's Alpha (r=.935) and Guttman's Split-Half technique (r=.929). These scores indicated acceptable levels of reliability (Field, 2005). The questionnaire appears to have reasonable face validity, as all items ask questions about sensory experiences. In addition, there is reasonable content validity, as a) all items were checked by five independent observers and deemed appropriate for inclusion within the questionnaire and b) the number of sensory experiences discussed in the qualitative questions, reported elsewhere (Chapter 3), increase alongside total sensory score (Greco, Walop & McCarthy, 1987).

All results from the original data were reanalysed using the shortened version of the sensory questionnaire (Appendix D). This version (on which the results reported in this chapter are based) has 42 items and investigates both hyper- and hypo-sensitivities in seven modalities: visual; auditory; gustatory; olfactory; tactile; vestibular and proprioceptive. Items were equally distributed among sensory modalities, with three questions assessing reported hyper-sensitivity and three hypo-sensitivity. All questions asked how frequently certain sensory events were experienced, with participants responding using the scale: "Never – Rarely – Sometimes – Often – Always". Responses were coded on a scale from 0 to 4, with possible scores ranging from 0 to 168. A breakdown of each item and how it is coded is included in Appendix E.

2.2.3 – Missing data and comprehension difficulties

If more than 10% of the responses were left blank for the AQ (5 items) or the Glasgow Sensory Questionnaire (4 items), the data were excluded from analysis (n=57). In order to compensate for missing data, total scores were corrected by using the following calculation: total score + (mean item score x number of missing items) (Auyeung, Baron-Coehn, Wheelwright, & Allison, 2008; Hoekstra et al., 2007). Furthermore, those who indicated they did not understand multiple questions (n=1) were excluded from analysis. When participants indicated they had comprehension difficulties with a single question (n=1), their response for that particular question was dealt with in the same way as the missing response data.

2.2.4 – Data Analysis

Statistical analysis was performed using IBM Statistical Package for Social Sciences (IBM SPSS, version 19.0). Group differences in age were analysed using a one-way ANOVA, with gender differences assessed using Independent Samples t-tests. The relationship between total sensory score and AQ score was analysed using Pearson Correlation analysis, as were the relationships between the AQ subgroups and sensory score. Differences in the sensory scores of the AQ subgroups (Low = 0-18; Medium = 19-31; High = 32-50) were analysed using Independent Samples t-tests, compensating for multiple comparisons using Bonferroni Corrections. Effect sizes (which measure the strength of a relationship between variables) were also included for all inferential statistics.

2.3 **Results**

2.3.1 – Descriptive statistics

Although the distributions of the AQ score and total sensory score appeared to be slightly positively skewed, they were both found to be normally distributed using the Kolmogorov-Smirnov test statistic (p>.05). There were almost twice as many female participants as males (33% males) in the whole dataset, although these ratios differed throughout the subgroups. Males were more likely to have high or medium AQ scores, with females more spread out across the continuum (Low = 19.0% males; Medium = 43.6% males; High = 36.0% males). There was no significant difference in the mean sensory scores [t(210) = 1.578, p<.116] of males and females. However, there was a significant difference in the AQ scores of males and females, as would be expected [t(210) = 2.92, p<.01] (Baron-

Cohen et al., 2001). Furthermore, there was no effect of age on either sensory scores [$F_{(3, 209)}$ = .857, p=.465] or AQ scores [$F_{(3, 209)}$ = 1.41, p=.241]. Descriptive statistics for both AQ and the GSQ are provided in Table 2.1.

Table 2.1 – Descriptive statistics for AQ and GSQ scores

	Min	Max	Mean	Standard Deviation
AQ *(0-50)*	4	49	22.48	10.57
GSQ *(0-168)*	11	137	56.65	23.60

2.3.2 – Relationship between sensory score and AQ score

Pearson correlation analysis indicated that AQ score had a positive, linear relationship with total sensory score [r(210)= 775, p<.0001, R^2=.600]. This indicates that individuals with high AQ scores report having more frequent and extreme reactions (both hyper- and hypo-) to sensory stimuli than individuals with lower AQ scores (see Figure 2.2).
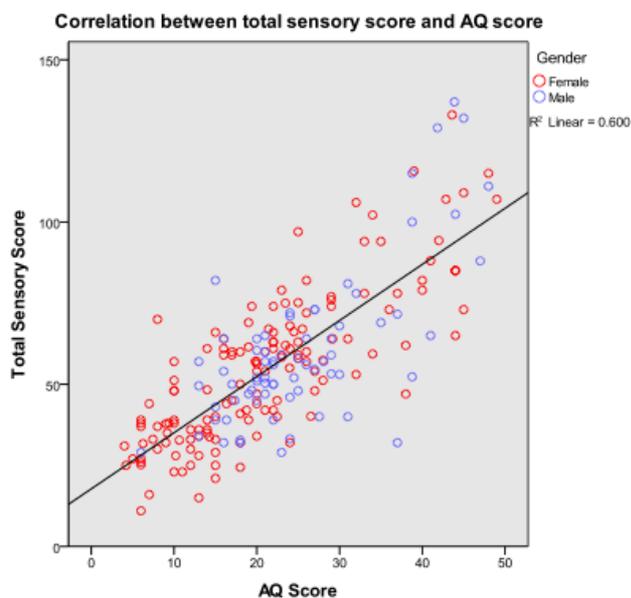
Figure 2.2 – Correlation between total sensory score (measured by the Sensory Questionnaire) and AQ score (measured by the Autism Spectrum Quotient). Pearson correlation was positive (r(210)= .775).

In order to determine whether any AQ sub-scales were driving the correlation observed in Figure 1, separate Pearson correlations were calculated for each sub-scale of the AQ. All of the sub-scales indicated a significant, positive correlation with total sensory score and are displayed in Table 2.2.

Table 2.2 – Correlations of AQ subscales with total sensory score

AQ sub-scale	Correlation with total sensory score
Social	.631**
Attention Switching	.612**
Attention to detail	.532**
Communication	.687**
Imagination	.631**

*Significance levels: * p<.05; **p<.01*

A regression analysis was computed in order to determine the effect, if any, that gender would have on the relationship observed between total sensory score and autistic traits. As can be observed (Table 2.3), the contribution of gender within the regression model was not significant.

Table 2.3 – Regression analysis of GSQ score, AQ score and gender

Variables	B	SE(B)	β	t	Sig. (p)
Constant	18.081	2.437		7.420	.000
Gender	-2.318	2.228	-.046	-1.040	.299
AQ Score	1.749	.099	.784	17.609	.000
R^2= .602					

2.3.3 – Group Differences

As previously mentioned, participants were split into three distinct groups based on AQ score, in order to ascertain whether a particular range of AQ scorers (Low = 0-18; Medium = 19-31; High = 32-50) were driving the correlation. There were significant differences

between the sensory scores of all three of these groups (see Figure 2.3). Medium scorers on the AQ had a significantly higher sensory score than Low [$t(171) = 20.4$, $p<.0001$, r=.839], while also being significantly lower than High [$t(131) = 22.0$, $p<.0001$, r=.888]. Furthermore, the mean sensory scores of the Low and High AQ groups were also found to be different [$t(116) = 32.05$, $p<.0001$, r=0.950].
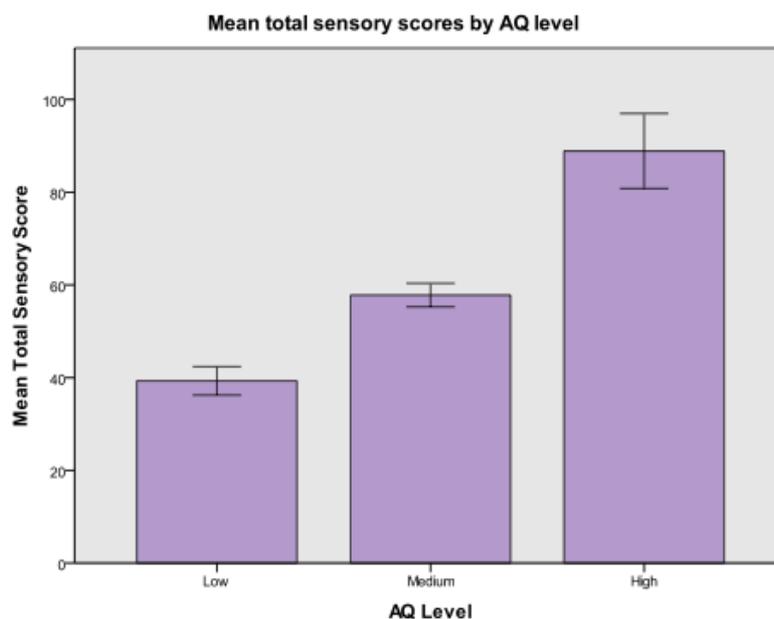
Figure 2.3 – Comparison of total sensory score for low, medium and high scorers on the AQ. Error bars represent +/- 2 standard errors

In order to determine whether the group trend was driven by particular modalities, we calculated the mean sensory scores within each modality for the three groups (Figure 2.4).
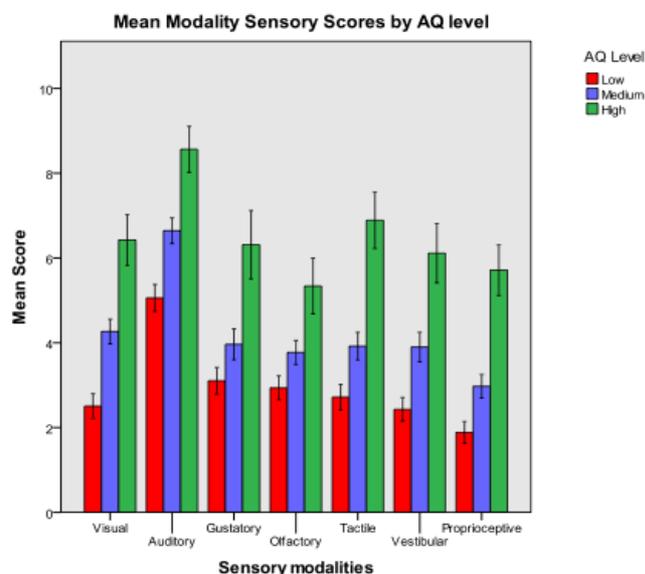
Figure 2.4 – Comparison of sensory scores in each modality for low, medium and high scorers on the AQ. Error bars represent +/- 2 standard errors

Figure 2.4 shows a trend pervasive throughout all seven modalities tested. The mean sensory score increases with AQ level for each sensory modality, with the mean scores being similar across all modalities except auditory. A two-way analysis of variance yielded a main effect for the level of autistic traits, $F(2,2947) = 470.61$, $p<.0001$, and a significant main effect for modality, $F(6,2947) = 80.71$, $p<.0001$. However, the interaction effect was also significant, $F(12,2947) = 2,743$, $p < .001$, indicating that differences between scores for each AQ level differed depending on the sensory modality being tested.

2.3.4 – Analysis of AQ scores <28

In order to analyse a full range of AQ scores, we advertised for participants with a diagnosis of AS as well as recruiting participants in the general population. As a result, we had a number of participants with scores of 28 (n=54) and 32 (n=39) or higher, which may be indicative of AS (Woodbury-Smith et al., 2005) or autism (Baron-Cohen et al., 2001) respectively. In order to ensure that the results observed are applicable to the general population, and are not solely driven by the inclusion of participants who may have a diagnosis of ASD, we performed additional statistical analyses on all participants with AQ scores less than 28 (n=158). Although the high-scorers' group consists of those with an AQ score greater than 32, we felt that it was prudent to exclude those who scored between 28 and 31 from the medium scoring group too, in order to exclude as many with a potential diagnosis of ASD as possible. This resulted in two new subgroups being formed (Low-2, n=79; Medium-2, n=79).

A Pearson's correlational analysis showed that a significant positive relationship was still found between AQ score and total sensory score [r(156)=.602, $p<.001$, $R^2=.362$]. Although the observed correlations between the AQ subscales were smaller than with the complete sample, they were significant in all cases: Social [r(156)=.273, $p<.001$, $R^2=.075$], Attention Switching [r(156)=.375, $p < .001$, $R^2=.141$], Attention to Detail [r(156)=·494, $p<.001$, $R^2=.244$], Communication [r(156)=.404, $p < .001$, $R^2=.163$] and Imagination [r(156)=.342, $p<.001$, $R^2=.117$]. Furthermore, even with the removal of all scores above 28, an Independent Samples t-test showed that the mean sensory score for low (0-18) and medium (19-27) scorers was still significantly different [t(156) = 8.39, $p<.0001$, r = .555].

2.4 Discussion

This study investigated whether the sensory difficulties experienced by those with ASD (Baranek et al., 2006; Grandin & Scarino, 1996; Leekam et al., 2007; Williams, 1998)

might extend to those with high levels of autistic traits in the general population. Results showed that atypical sensory responsiveness (including both hyper- and hypo-sensitivity), as measured by the GSQ (Robertson & Simmons, 2012), was much more common in individuals with higher levels of autistic traits, as measured by the AQ (Baron-Cohen et al., 2001). In particular, individuals with medium AQ scores (19-31) reported moderate levels of sensory difficulties, significantly different from those with either low (0-18) or high (32-50) scores on the AQ. This result is not confined to a specific sensory modality and does not seem to favour a particular sub-scale of the AQ.

The finding that those with high levels of autistic traits also experience sensory disturbances is consistent with a growing number of studies, which have found differences in visual processing (Bayliss & Kritikos, 2011; Grinter et al., 2009a; 2009b; Stewart et al., 2009; Sutherland & Crewther, 2010) and speech perception (Stewart & Ota, 2008; Yu, 2010) in those with high and low levels of autistic traits. Our results indicate that these differences may be present in multiple sensory domains, and it would be interesting to determine whether the differences observed in touch (Cascio et al., 2008) and taste (Tavassoli & Baron-Cohen, 2012b) for those with ASD are replicated in low/high AQ scorers within the general population.

In this study, we found a positive correlational relationship between number of autistic traits and the frequency of atypical responses to sensory stimuli. This is in line with the results of Yu (2010), who found a significant correlation between normalization for phonetic context and AQ score. However, our results somewhat contrast with Kern et al. (2007b), who found that severity of autism was related to scores on the Sensory Profile (Dunn, 1999) in children, but not in adolescents or adults. Furthermore, they found that sensory sensitivities reduced with age (which was also observed in certain sensory domains for Leekam et al., 2007). However, like Crane et al. (2009), we found no age effect in our sample. This contrast could be a result of methodological differences, as both this study and Crane et al. (2009) used a self-report questionnaire, whereas Kern et al. (2007b) utilized a parent report design. Alternatively, it may be that sensory issues are more severe in children and stabilize once reaching adulthood. A final possibility, linked with the methodological differences, is that sensory processing difficulties are apparent to individual adults on the autism spectrum, or with high autistic trait levels, but have less obvious effects than in childhood: in other words these adults are able to cope but they are still bothered by sensory stressors more than those with low autistic trait levels.

This result has important implications for society. First, and least controversially, our data support findings that autistic traits are continuously distributed in the general population (Constantino & Todd, 2003). The key novel finding is the high correlation between AQ score and the frequency of experiencing problematic sensory responses. To our knowledge, this is the first report of a significant correlation between sensory ability and autistic traits in a broad population. Our results suggest that the sensory differences experienced by those with a diagnosis of ASD can also be extended into the general population and could be indicative of a sensory phenotype.

It could be argued that recruiting individuals from an online forum for those with AS could be a limitation of the study, as they would be likely to be aware of the relationship between ASD and sensory issues. However, the number recruited from that particular source was small (n=31) and it is arguably a strength of our study that we have investigated all aspects of the 'Autistic Spectrum', recently highlighted as a direction for future research (von dem Hagen et al., 2011). Furthermore, by reanalyzing the data of all participants who scored less than 28 on the AQ, we found that the pattern observed in the whole sample could also be observed in this sub-sample (therefore the high scorers in the 'medium' group and those in the 'high' group are not overly-influencing the data). It should be noted that the strength of the correlational relationship lowers considerably when those with high scores on the AQ are removed. However, it is likely that this is a by-product of restricting the range of data on one variable (Bland & Altman, 2011).

A further limitation of the study is that the content or construct validity of the questionnaire has not been rigorously assessed, nor has test-retest reliability been determined. We do have plans to administer the GSQ alongside established measures of sensory responsiveness, in order to better determine content validity. Moreover, it should be noted that the frequency of sensory experiences detailed by our participants in the qualitative questions (which were administered alongside the questionnaires, reported in Chapter 3) correlated with both sensory scores and AQ scores, indicating reasonable validity.

Another limitation with our study is that, due to time constraints, we were unable to assess IQ. A previous study has found a modest negative correlation between autistic traits and IQ ($r = -.27$), which was mainly explained by communication problems (Hoekstra, Happé, Baron-Cohen, & Ronald, 2010). However, the authors stress that autistic traits and IQ are mostly independent. It should be noted that we asked participants to disclose any

difficulties that they had with understanding the questionnaire, with very few indicating comprehension difficulties with any of the questions (n=2). Finally, whilst the unequal age and gender distribution is another limitation of the study, statistical analysis showed that age effects for both the sensory questionnaire and the AQ were non-significant and that, although males had higher AQ scores than females, a regression analysis showed that this had no significant effect on the relationship between AQ and GSQ scores. Gender has been identified in previous studies as having an effect on likelihood of response to questionnaires (e.g. Oremus & Wolfson, 2004). This could have implications for the development of the GSQ, as it is important that it is as suitable and applicable to men and women equally. In addition, it is a particular concern when using our questionnaire alongside the AQ (in which men score consistently higher than women; Baron-Cohen et al., 2001). Therefore, it is important that the increased likelihood of women responding to such a questionnaire is accounted for in future versions of the GSQ.

In this chapter the relationship between sensory processing and autistic traits in adults was investigated. One interesting direction for future research would be an investigation into the sensory processing of children with varying levels of autistic traits. Furthermore, it would be interesting to investigate whether the differences observed in those with high and low levels of autistic traits in behavioural studies (Grinter et al., 2009a; 2009b; Stewart & Ota, 2008) and fMRI (von dem Hagen et al., 2011) would also be found in children. In addition, it would be an important next step to determine whether self-reported sensory sensitivity actually corresponds to differences in threshold. Although it is possible to assess modalities and hyper-/hypo-sensitivity separately with the GSQ, it is not currently possible to disentangle frequency and intensity within this questionnaire. This would be an interesting development for future versions of the GSQ. According to our results, it would appear that a significant proportion of the population is affected by hyper- and/or hypo-sensory sensitivity in some way and that consideration should be given to modifying the environment to counter at least the most severe sensory stressors (see Chapter 8 for details of the development of a sensory audit). It would also be interesting to replicate the study with a larger group, including those with explicit diagnoses of ASD, in order to further validate the sensory questionnaire.

Chapter 3: The relationship between self-reported sensory experiences and autistic traits: a mixed methods analysis

3.1 Introduction

There are many contrasts between qualitative and quantitative research, with each having its own merits. On the whole, there are three main differences between these two approaches to research (Brotherson, 1994). Firstly, the qualitative approach tends to suggest that there are multiple realities, and that by elucidating the details of a person's perception of various events, experiences and relationships, an understanding as to how these events are connected can be reached. In contrast, the quantitative methodology presupposes that there is a singular reality, and that we can determine cause and effect by using tightly controlled experiments. Secondly, within qualitative analysis, the researcher is seen as part of the research process, whereas for studies using quantitative methods, the experimenter is external to the experimental process. Lastly, the qualitative ethos believes that developing a deep understanding of the issues, based in context, is important (Patton, 2007). This contrasts with quantitative studies, which aim to develop generalizable theories.

The main merit of qualitative research, in the context of this thesis, is that we can begin to develop a deeper understanding of the day-to-day experience of living with sensory issues, which in turn may give ideas for the construction of new experimental paradigms. Primarily, rather than determining cause and effect, qualitative research investigates the *why* and *how* of a particular phenomenon. While there have been qualitative studies investigating various aspects of social functioning (Müller et al., 2008; Sperry & Mesibov, 2005), family routines (DeGrace, 2004) and schooling (Carrington & Graham, 2001; Humphreys & Lewis, 2008) in those with ASD, few have looked at sensory processing issues.

As has been discussed in previous chapters (see section 1.4 and Chapter 2), there is much evidence to suggest that autistic traits are prevalent throughout the general population (Constantino & Todd, 2003). There has been a recent surge in publications showing that those with high (yet non-clinical) levels of autistic traits exhibit many differences to those with low autistic traits, including brain structure and function (von dem Hagen et al.,

2011), biological processes (e.g. menarche: Whitehouse et al., 2011), visual search tasks (Grinter et al., 2009a; 2009b; Stewart et al., 2009; Sutherland & Crewther, 2010), face perception (Wilson, Freeman, Brock, Burton, & Palermo, 2010), speech perception (Stewart & Ota, 2008; Yu, 2010) and reported sensory sensitivity (see Chapter 2). The similarities in performance of those with high levels of autistic traits to those with ASD could be indicative of an endophenotype, and is a potentially profitable line of enquiry.

Although there have been qualitative studies conducted which investigate the sensory processing of those with varying levels of autistic traits, there has been no attempt (as far as I am aware) at a similar study using a qualitative methodology. Therefore, we felt that it would be interesting to include four open questions with the questionnaire described in Chapter 2, which we would analyse inductively using a thematic approach (Thomas, 2006). In addition to performing qualitative analyses of these data, we also employed quantitative techniques in order to determine whether there were group differences in the types or frequency of examples given by participants.

3.2 Methods

3.2.1 – Participants and recruitment

See section 2.2.1 for details of participants and recruitment

3.2.2 – Materials

Participants were asked to respond to 4 open questions designed to elicit details about problematic stimuli or environments. The 4 questions were:

1. Can you describe which environments/situations, if any, cause you difficulty or cause you to panic?
2. Do you ever find yourself reaching "meltdown" due to too much sensory input – for example feeling like too much noise/lights/smells cause an 'overload'?
3. How do you calm yourself down if you start to panic?
4. Do you find going to leisure centres/supermarkets difficult? If so, what makes it difficult?

See section 2.2.2 for further details of materials used.

3.2.3 – Procedure

This was a part of a larger study (reported in Chapter 2) that investigated sensory sensitivities in individuals with autistic traits and was conducted online using a survey

website (Survey Monkey: www.surveymonkey.com). Participants were asked questions about environments and stimuli that they found difficult to cope with. They were also given the opportunity to divulge any extra information that they felt we would be interested in. The qualitative questionnaire was presented after the quantitative questions, for all respondents.

3.2.4 – Increasing rigour

3.2.4.1 – Inter-rater reliability

The author was the sole coder for these data. However, in an effort to establish reliability, certain steps were carried out. Firstly, codes were developed and discussed with a supervisor (DS) as coding developed. Secondly, DS was asked to code 20% of the transcript. A Kappa Coefficient of .916 was obtained for AR and DS's attribution of codes for this section, showing a high level of agreement. In addition, intra-rater reliability was obtained (.952) for 20% of the transcript (where AR coded the transcript twice, one month apart).

3.2.4.2 – Verbatim accounts

In an effort to increase the rigour of these findings, data are presented verbatim from the accounts that we received. This is a recognized method of increasing rigour of qualitative analysis (Whittemore, Chase, & Mandle, 2001).

3.2.5 – Data Analysis

Qualitative research can be either inductive (exploratory) or deductive (testing prior assumptions). We decided that, as our aim was to learn more about sensory issues in ASD from those with a diagnosis and their families, an inductive approach was most appropriate. We decided to analyse the data using a general inductive qualitative approach (Thomas, 2006). This involves the generation of over-arching themes of the data, perhaps the most frequent or significant. Thomas (2006) describes the procedure for this approach as:

1. Preparing the raw files for analysis (e.g. transcribing)
2. Close reading of the transcript
3. Identifying categories in the data (both lower- and higher-level)
   a. More than one code can be assigned to a section
   b. Many areas of the transcript can be left uncoded
4. Refining the categories

The outcome of the data analysis process is the generation of key themes (which encapsulate the main categories identified in the coding process). This method of data analysis is most similar to Grounded Theory (Corbin & Strauss, 2008), although there are some differences in the coding procedures. For example, Grounded Theory separates the coding process into open coding (defining concepts and categories) and axial coding (relating codes/categories to each other). Furthermore, there are differences in the outcome (e.g. a theory is constructed from Grounded Theory analysis, whereas overarching themes are produced in a general inductive approach). As this was a mixed methods analysis, we were also interested in determining whether there were any group differences in the themes arising for each question. Finally, the percentage of respondents per group to each question was also analysed.

3.3 Results

Two categories emerged from the data. The core category was 'problematic sensory experiences', with 'calming sensory experiences' also being of interest. Although the categories were developed from the full range of data, it should be noted that the majority of the examples were from participants with a high or medium AQ score. Analysis showed that some people in our sample routinely experienced difficulties with sensory stimuli, often resulting in strong physiological and emotional reactions (for example, experiencing pain or a surge of hostility towards others). Lastly, it was found that sensory stimuli could have a calming effect on a person's behaviour.

3.3.1 – Qualitative analysis of all data

3.3.1.1 – Problematic sensory experiences

Participants were much more likely to describe hyper-sensitivity to sensory stimuli than hypo-sensitivity, with issues involving noise being most commonly reported. A large variety of sounds were problematic to our sample, including 'road/building works or loud traffic', 'the constant squeeking [sic] on the floor from shoes' and 'the noise from tvs [sic] (not just volume, the buzzing from them as well…)'. However, when investigating *why* auditory stimuli were sometimes difficult to cope with, we were able to extract particular qualities that made sounds more unbearable than others.

The loudness of a sound was described as being the main cause of distress when it comes to auditory stimuli. One person found it very hard to cope with 'overwhelmingly noisey [sic] environments', with another describing feeling 'this way [panicked] due to too much

noise'. An elevated noise level appeared to be the most severe problem for the individuals in the sample. Some of the participants reported adverse effects when faced with too much noise ('sounds … are just head ache [sic] inducing') and others reported having to withdraw from situations when they experienced high noise levels ('Other members in the group made more noise than I could cope with and I had to stop because I felt too uncomfortable').

Also, the pitch of the noise was often an issue. Both high-frequency sounds ('screeching sounds … can be a problem', 'high-pitched noises [are an issue]') and certain low-frequency sounds ('persistent low-frequency noises') were described as being difficult to cope with. Participants reported feeling strong negative physiological reactions to both high- ('very high sounds make me feel sick') and low-pitched sounds ('painful sounds – motorcycles').

Furthermore, the sudden onset of a noise was often described as causing anxiety or making a loud noise particularly difficult to deal with effectively. Examples included sudden noises ('a sudden bang of sound') and those that were unexpected ('loud unexpected noises'). Typically, participants reported that the unexpected nature of noises made loud sounds harder to cope with (i.e. that the sudden nature made them worse, but it was the loudness of them that was hard to deal with in the first instance).

Some participants also reported that repetitive noises or those that fluctuated in amplitude ('repetitive sounds, such as beeping [can be a problem]') could be difficult to endure. To some people, sounds like this can increase discomfort and feelings of annoyance ('if there is alot [sic] of repeataive [sic] noises I can often get very irritated and uncomfortable'). A few participants also mentioned that experiencing a multitude of different sounds at the same time could be unpleasant ('discordant noise' was mentioned as being irritating, as well as 'excess mixed noise').

Stimuli related to four of the other sensory domains (vision, touch, taste and smell) were also described as being difficult to deal with at times. The main complaints in the visual domain involved strong stimuli ('bright lights') and certain types of lighting ('Bright, humming fluorescent lights'). Some participants described certain types of lighting as 'artificial' and 'horrible'. One individual also described the flickering associated with particular types of lights as 'unpleasant'. Several participants in our sample mentioned flickering lights as being problematic for them. As with auditory stimuli, some people

reported ill effects with visual stimuli. One person disclosed that they felt unwell when they went to the supermarket ('the lights in the big supermarkets give me [a] headache and I feel sick'), with another disclosing that some colours had the effect of making them feel physically unusual ('Some bright, fluorescent colours make me feel really weird, like time is disjointed!').

Within the tactile domain, the main complaints involved the feeling of certain textures against the skin. One person told us that 'some clothing textures…really irritate me'. They did not mention the particular types of fabric that caused most issues. Other participants mentioned smooth stimuli (specifically paper) as feeling strange at times ('hand on writing paper – felt too smooth somehow'). One other individual also mentioned negative reactions to paper. In their case, extended exposure to it causes feelings of discomfort ('touching too much paper makes me feel uncomfortable').

Some participants reported that particular food could be problematic. Typically, the texture of the food was an issue ('slippery, slimy things, especially foods'), sometimes even invoking an individual's gag reflex ('some food textures make me gag: avacado [sic], tomato, onion, any overcooked, mushy vegetable'), or in one case, vomiting ('With the food issues, I just throw up'). In addition, one participant noted the tastes that they found to be repellent ('certain tastes…spearmint, liquorice, aniseed, citrus').

Finally, some participants also reported finding unwanted smells difficult to deal with in their everyday lives. People were most bothered by particularly intense smells ('overpowering smells … give me headaches'), certain types of smell ('musky smells [are horrible]') or a mixing of scents ('I find perfume shops quite unpleasant even though I like sibgle [sic] fragrances on their own – even when their [sic] quite strong'). As in the other modalities, participants mentioned experiencing strong reactions when faced with noxious olfactory stimuli ('Smells induce a feeling of being unable to breath [sic]' and 'I can't smell more than 2-3 different kinds of perfume. If I do, I feel dizzy and sick').

3.3.1.2 – Enjoyable and calming sensory experiences

The second category that was identified was that sensory stimuli could be enjoyable, even sometimes helping people to cope with certain situations/stimuli. Within the sample, the amount of sensory-based examples given for calming down increased as AQ score rose. Some participants showed an awareness that using certain techniques when under stress is not socially typical. One participant liked the feeling of certain fabrics, but mentioned that

she would only touch them when she felt it would not be observed or judged by others ('Other textures (satins, twills, ravon [sic] wovens) I really like, and will rub between my fingers if I think noone [sic] would notice or care'). This example highlights the dichotomy between the desire to engage in enjoyable sensory behaviours while also being aware that it can be perceived as unusual or inappropriate.

In terms of specifically using sensory techniques to calm down when under stress, there was a lot of variety within the sample. Typically, participants would mention some kind of tactile or proprioceptive-based input. Examples included 'rock[ing]', 'rub[bing] the outside of my ear with my fingers' and 'jump[ing] on a trampoline'. These techniques were all described as bringing relief from anxiety and distress to the individual and helping them to cope with uncomfortable situations.

3.3.2 – Analysis of individual questions

As well as picking out the most important categories in the data, we looked at the response patterns for each group (as defined in Chapter 2) (Figure 3.1).
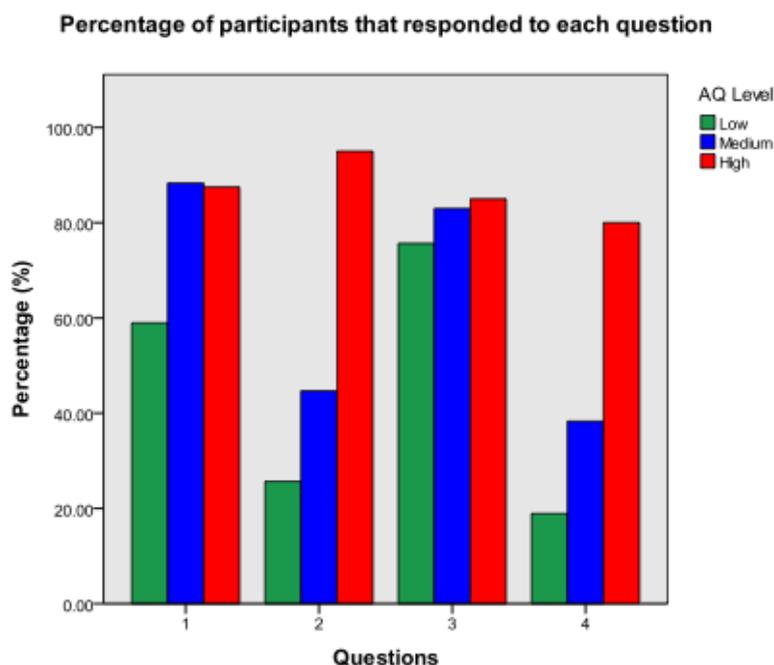
Figure 3.1 – The response rates of the three subgroups for each question. Questions 1 and 3 were answered by the majority of participants in each group. In contrast, Questions 2 and 4 were more likely to be answered by people with a higher AQ score than by those with a lower AQ score.

There was no group difference in the likelihood of responding to Q3, χ^2 (2, N=212) = 4.34, p=.12. However, there were significant differences in the response frequencies of Q1 (χ^2 (2, N=212) = 23.89, p<.001), Q2 (χ^2 (2, N=212) = 53.28, p<.001) and Q4 (χ^2 (2, N=212) =

42.93, $p<.001$). All of these remained significant with the application of Bonferroni Corrections.

It emerged that the high-AQ scorers, in particular, described both problematic and enjoyable experiences with sensory stimuli. In order to look more closely at this within our sample, it was decided to separate the categories identified within the responses to two of the questions: 'Can you describe which environments/situations, if any, cause you difficulty or cause you to panic?' and 'How do you calm yourself down if you start to panic?'. The reasons for investigating these two questions in depth are a) the response rate was much more similar across groups than in questions 2 and 4; and b) responses were more general (i.e. less sensory-exclusive) across all groups than in the other questions.

The codes identified and the percentages of responses are shown in Figure 3.2.
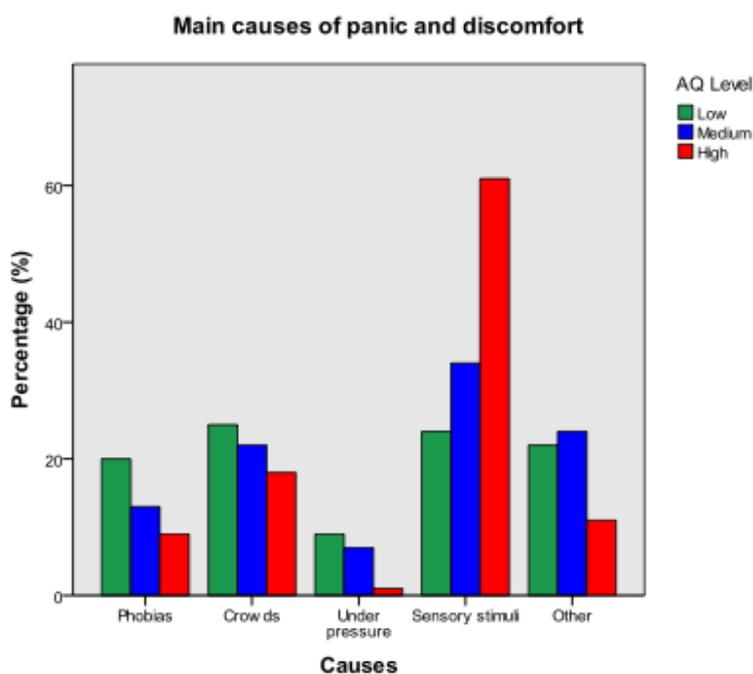
Figure 3.2 – The main causes of panic and discomfort reported by participants. Responses are grouped by level of AQ score (high, medium and low).

Responses to this question fell into one of five categories: phobias, crowds, being put under pressure (e.g. by a deadline), sensory stimuli and other (which included triggers only mentioned once or twice by the sample).

Chi-squared analysis showed that there was a significant group difference in the frequency distribution of the examples ((χ^2 (8, N=265) = 27.16, $p<.001$). The percentage of

examples related to sensory stimuli was higher in the medium-AQ group than in the low group (and higher still in the high-AQ group). Furthermore, the causes of panic and discomfort were more equally distributed for the low AQ-group than the other two (who had been most likely to give sensory examples). It seems that sensory stimuli are more likely to present problems for participants in the high-AQ group (and the medium, to a lesser extent). This, in turn, meant that the percentage of examples given for other causes of discomfort was reduced in comparison.

The third question asked for details of the types of things people did to try to deal with uncomfortable situations. The responses to this question were coded into 5 different categories: distraction, avoidance, sensory self-soothing, non-sensory self-soothing and seeking support from others (Figure 3.3).
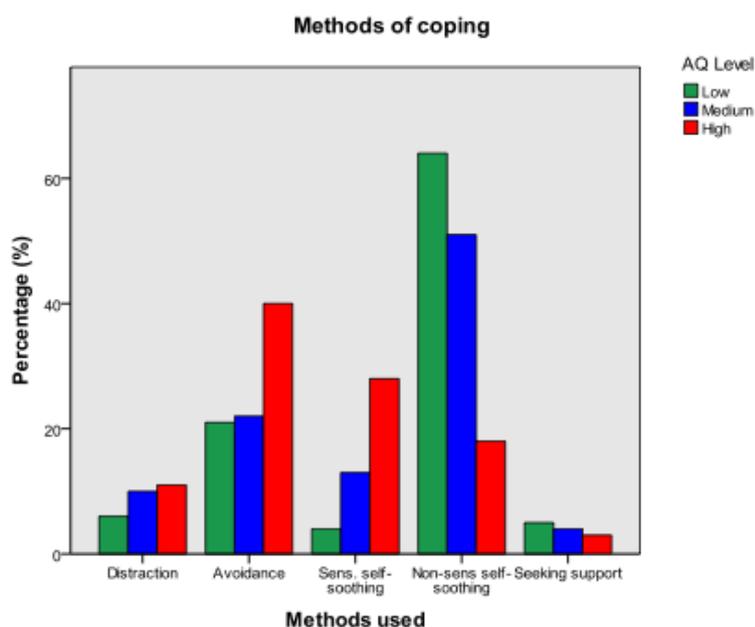
Figure 3.3 – The main techniques that people in the sample use to cope with stressful situations. Responses are grouped by level of AQ score (high, medium and low).

Chi-squared analysis showed that there was a significant group difference in the frequency distribution of the examples (χ^2 (8, N=250) = 40.43, *p<.001*). Even though Q3 was likely to be answered by all three groups equally (Figure 3.1), there was still a difference in the examples given by respondents. The low and medium groups were most likely to self-soothe using non-sensory techniques (e.g. deep breathing and 'centering' oneself). More than half of the examples given by participants in the low and medium groups fell into these categories. In contrast, the most common example given by the high-AQ group was avoidance. 40% of the examples given by those with a high level of autism traits involved

the leaving of a situation, compared to around 20% in the low and medium groups. Furthermore, if the high-AQ scorers stayed in a difficult situation, they were much more likely to use sensory-based self-soothing techniques (e.g. rocking and humming) than those in the other groups (who would use other types of self-soothing methods).

3.4 Discussion

This mixed methods analysis reports the sensory experiences of individuals with varying levels of autistic traits. By extracting common themes, we were able to elucidate details of the different sources of discomfort and coping strategies employed across a large sample. Furthermore, by separating participants into groups based on AQ score, we could observe whether the response patterns changed according to group.

When looking at the response rates of the sample (Figure 3.1), some interesting patterns can be observed. The three questions asking specifically about sensory issues (Q1 and Q2) and avoidance of certain environments (Q4) seemed to elicit examples more readily from those with a high or medium AQ score. Analysis of whether a participant responded to each question yielded significant group differences in each of these questions. In contrast, there was no significant difference in the response groups for Q3, arguably the most general question asked of the participants. Although the design of the study means we are unable to suggest causality, it is interesting to note that the general trend across all four questions was an increase in the percentage of responses as AQ level rose.

The participants in our sample reported a number of issues with visual, auditory, tactile, olfactory, gustatory and proprioceptive stimuli. Although high and (to a lesser extent) medium scorers on the AQ provided the majority of examples, there were still some people with low AQ scores who reported having issues with certain stimuli. Unpleasant noises were, by far, the most common complaint within the entire sample. As such, we were able to determine some of the particular properties that caused some noises to be perceived as more bothersome than others. Reflecting discoveries in the acoustic properties literature (Rasmussen, 1979), loudness appeared to be the most important aspect. Participants complained that loud noises could cause headaches, migraines or nausea, and even make them feel so uncomfortable that they had to leave certain environments. In addition, the frequency content and modulation of sounds appears to play an important role. Again, these noise properties are known to affect how annoying a person perceives a sound to be (Bradley, 1994; Gray, 2000). However, it is important to consider the person's own

sensitivity to auditory stimuli as well as the acoustic properties of a noise. If people with higher AQ scores (80% of whom would be likely to receive a diagnosis of ASD (Baron-Cohen et al., 2001) are more sensitive to sounds, then it stands to reason that they may be increasingly disturbed by noises known to annoy the general population. However, there is evidence that there are no differences in the absolute auditory thresholds of those with ASD (Jones et al., 2009; Khalfa et al., 2004).

Within the other sensory domains, the intensity of the stimulus was regularly cited as the main reason that it was uncomfortable. As well as the auditory domain, this was observed in the visual (brightness) and olfactory (odour strength) domains. The other reasons cited for how uncomfortable a stimulus could be were duration (e.g. prolonged exposure), some issue with the nature of the stimulus (e.g. flickering lights), whether the onset of the stimulus was sudden or unexpected in some way and the mixing of different stimuli within the same domain (e.g. competing noise or the mixing of scents). In contrast, the quality of the stimulus was the most important factor in the tactile and gustatory domains. This seems intuitive, as these are the two domains which require direct contact, meaning that they are more easily avoidable.

One interesting theme that arose from the data was that some people described feeling overwhelming negative emotions towards people, as a result of some kind of sensory stressor. One participant gave an example of how being 'prodded/poked' was likely to make them 'unreasonably angry'. From the example given, we are unable to discern whether it is the feeling of being poked, or the interaction with other people that causes this participant's anger level to rise. This difficulty in parsing out the social and the sensory is also evident in the account given by another participant, who detailed that 'I hate strangers brushing against me or standing so close they are touching me'. They go on to say that when this type of incident occurs, they say that it 'makes me stressed and give[s] me feelings of hostility towards others'. It may be likely that the difficulties interacting with people and some of the sensory issues that people experience are linked. It could be argued that if someone consistently feels hostility and anger towards another as a result of circumstances beyond their control, the person may develop negative reactions to people in general (rather than just under the stressful circumstances). This, in turn, could manifest into a limitation on the ability or desire to interact socially.

Although sample size is generally not as important in qualitative research, we argue that it is a particular strength of this study. By accessing over 200 participants, we were able to

ascertain the general difficulties people have in difficult/uncomfortable situations, while also being able to compare, in depth, the types of responses by AQ group. Furthermore, we were able to delve into the particular stimulus properties that people find most difficult to cope with, as well as looking at the methods that people use to deal with difficult stimuli and problematic situations. In addition, our study suggests that while some types of stimuli are often difficult for participants (regardless of AQ score), there are certain issues which seem to be more problematic for medium and high scorers. These include the negative reactions experienced from sensory stimuli, social difficulties (often independent of, but sometimes appearing to be exacerbated or caused by, sensory stimuli) and the differing coping mechanisms (e.g. an increase in avoidance and sensory-based self-soothing in high AQ scorers, compared to medium and low). It could be argued that some of the higher AQ scorers may have a diagnosis of ASD (this question was not asked, although a few participants disclosed it independently) and therefore would be far more aware of the propensity for sensory issues in ASD (potentially leading to a reporting bias). However, this argument does not explain the differences identified between low and medium scorers, neither of whom would be likely to be overly-aware of the link between sensory issues and ASDs.

The qualitative data show that people with higher levels of autism traits are more likely to avoid difficult situations. A systematic avoidance of people and places as a result of sensory intolerances could to lead to social isolation, even resulting in phobias of people, places or certain types of environmental stimuli. An increase in negative emotions towards others as a result of sensory issues could also affect ability to integrate socially with others. This observation highlights the idea that signs and symptoms related to social behaviour could actually be the consequence of sensory atypicality. Previous studies have made a similar link, in children with visual impairment (Celeste, 2006), as well as those with autism (Hilton et al., 2010). In our study, it appears that a significant proportion of the population is affected by sensory hyper-sensitivity in some way. As such, consideration should be given to modifying the environment to counter at least the most severe sensory causes, for example strong-smelling environments, high-pitched loud noises and flicker in lighting. These themes will be further analysed and considered in subsequent chapters of this thesis.

Chapter 4 Sensory experiences of children with ASD: a dual perspective

4.1 Introduction

A recent review demonstrated that sensory issues are common in ASDs, albeit heterogeneous in their nature (Ben-Sasson et al., 2009). This review substantiated accounts that have been written by people with ASD (e.g. Grandin & Scariano, 1996; Williams, 1998), in which the authors describe overwhelming responses to certain stimuli. Furthermore, studies using parent report techniques have consistently found evidence that there are significant differences between the sensory signs exhibited by those with ASD and both typically developing (Baranek et al., 2006; Leekam et al., 2007) and certain clinical control groups (Dahlgren & Gillberg, 1989; Rogers et al., 2003; Wiggins et al., 2009). Although there have been few examples of qualitative research into sensory issues in ASD reported in the literature, an overview has been given previously, in sections 1.2 and 3.1.

Dickie et al. (2009) investigated sensory responses in preschoolers by holding interviews with parents of children with autism and comparing the emergent data to a control group of parents of typically developing children. The study used the Critical Incident Technique, which involved parents describing one situation in which their child had a "good" sensory experience and another in which they'd had a "bad" sensory experience. Children with autism were reported to have more extreme or unusual sensory experiences, as well as more negative food-related experiences, than typically developing peers. Parents of children with autism were more likely to recognize their children's experiences as being sensory and to attribute those responses to different aspects of autism.

Qualitative research has enjoyed increasing popularity in domains that were previously only inhabited by quantitative designs (Rowan & Huston, 1997). As described in Chapter 1, there appears to be dichotomy between the prevalence of sensory experiences described using self- or parent-report techniques and the findings of many direct measurement studies. Although there are studies showing differences between those with ASD and TD controls in various aspects of sensory processing, researchers have tended to concentrate their efforts in determining whether there are differences in absolute thresholds. There is little consistent evidence that this is the case, which indicates that other mechanisms must

be playing a role. Qualitative analysis, therefore, is a useful approach to understanding sensory experiences from the view of those with ASD and their family members. Results are extremely variable in this field, and it is anticipated that by gaining a better understanding of what it is like to live with these sensory issues, we can design experiments that may be more likely to elucidate the true differences in sensory processing between those with ASD and typically developing individuals.

In order to gain insight about the nature of sensory experiences of children with ASD, we designed a qualitative study that investigated this from multiple points of view. We held small, interactive group interviews with children who had diagnoses of ASD, as well as a focus group with caregivers of individuals with autism and other complex needs (note that the caregivers were not related to the children in our sample). We decided that it was important to talk to children themselves, rather than solely interacting with caregivers, for reasons discussed in section 1.2.2. Recent studies have discussed the importance of including those with ASD in the research process themselves (Chamak et al., 2008; Pellicano & Stears, 2011). For the parent study, as well as the adults with ASD (Chapter 5) and the elderly control group (Chapter 6) studies, we used focus groups (see section 3.2.5) in order to increase the interaction between participants. However, we felt that this approach would not be appropriate for the children's group, especially when considering the communication difficulties facing those with ASD. Punch (2002) argues that conducting research with children should be task-based (i.e. interactive and oriented towards children) within the confines of a traditional 'adult' based research methodology, in order to a) make the child feel more comfortable interacting with an unknown adult researcher and b) help sustain interest and maintain attention. Thus, we designed a session (in conjunction with a lecturer in primary education), which consisted of traditional research methods (e.g. group interview and semi-structured interviews) as well as interactive tasks (e.g. worksheets, listening to sounds, feeling objects hidden in a box and guessing smells).

The aim of the study was to identify themes in the data, which would give an 'insider' view of living with the sensory sensitivities present in many people with ASD. In addition, we were particularly interested in the effect that these sensory sensitivities can have (on both the individual with ASD and their family) and the methods that were employed to cope with them. Although there is evidence that sensory issues are an important part of ASD, few studies have explored directly the effect that they can have on a person's life, especially by taking multiple viewpoints into consideration.

4.2 Methods

4.2.1 – ASD perspective 1: Children's Group Interviews

4.2.1.1 – Participants

Participants were recruited from two schools in East Dunbartonshire, a district to the north-west of Glasgow (two groups were from one school (total n=5) and one group from the other school (n=5)). Twelve parents were sent an information letter, a copy of the Social and Communication Questionnaire (SCQ: Rutter, Bailey, & Lord, 2003) and a consent form. Parents were asked to give informed consent for their children, as all of the participants were deemed vulnerable as well as being under the age of 16. Ten parents agreed for their child (male, n=8) to participate in the study. SCQ scores were calculated for six of the ten participants (questionnaires were not returned for the other four participants). Participant data (including ages and available SCQ scores) are displayed in Table 4.1.

Table 4.1 – Participant characteristics		
	Age	**SCQ**
Range	9.61 – 14.22 years	12 - 25
Mean	11.89	18.17
Standard Deviation	1.80	4.81

4.2.1.2 – Stimuli

SCQ

The SCQ is a parent report questionnaire that identifies individuals who may have autism. In our study, parents were given the 'Lifetime' form, which focuses on the entire developmental history of the child. The reported cut-off for ASD is 15, although scores slightly below this can also be indicative of ASD. On average, typically developing children score 5.2 in this questionnaire.

Other materials

As part of the study, each participant took part in 3 interactive tasks. The purpose of these interactive tasks was to provide an enjoyable experience for the children, and to encourage them to discuss their sensory experiences. Tasks were identified for the auditory (listening to sounds), tactile (feeling items hidden in a box) and olfactory (smelling odours in unmarked bottles) domains, with worksheets being used to target the visual (their favourite and least favourite colours) and gustatory (their favourite and least favourite foods)

modalities. This ensured that all five senses were covered in the tasks, as well as during the 'semi-structured interview' portion of the study. The stimuli for each of the interactive activities are displayed in Table 4.2. Stimuli that parents of those with ASD had reported as being problematic and potentially neutral or enjoyable were chosen for all three tasks (Robertson & Simmons, 2008). In addition, it was important to target a range of stimuli (e.g. soft, rough and sticky textures within the tactile task). The reason for this variety was to encourage the children to discuss problematic stimuli and the effect it had on them, while hopefully also capturing positive interactions with sensory stimuli.

Table 4.2 – Auditory stimuli used in children's group sessions

	Auditory stimuli	Tactile stimuli	Olfactory stimuli
1	Dog barking	Teddy bear	Perfume
2	School bell	Sandpaper	Garlic
3	Supermarket till	Sellotape	Coffee
4	Baby crying	Apple	Lemon
5	Train	Lentils	Vanilla
6	Fire engine siren	Plasticine	Vinegar
7	Fireworks banging		
8	Birds tweeting		

Each child also answered questions in either small groups (n=5) or individually (n=5). The questions were designed to elicit descriptions of the sensory issues that the children experienced daily and covered all five senses, as well as general sensory issues (see Appendix F for questions and prompts used during this study).

4.2.1.3 – Ethical considerations

The Faculty of Information and Mathematical Sciences at the University of Glasgow granted ethical permission prior to recruitment commencing. The head teachers of two local schools were approached and asked if it would be possible to recruit children to take part in the study. A gate-keeper was identified for each of the schools, and they handled the recruitment of suitable pupils directly. Parents were sent a letter, the SCQ and a consent form asking them if their children could take part in the study. Five pupils from each school were able to participate in the study. The children were reminded that they were able to leave the study at any time.

4.2.1.4 – Procedure

Three groups were held, with each being run in the same way. Prior to commencing each session, participants were informed that they could leave at any time and were taken through an itinerary for the session. The children were informed that the group would be recorded using an audio recorder. Each session consisted of the following: a group discussion in which eight sounds were played out and rated; a tactile task; an olfactory task; a worksheet questioning their favourite/least favourite foods; a worksheet questioning colours they liked/disliked; and a small group/individual interview. Each group took around 40 minutes in total to complete. At the end, the children were thanked for their participation and given a small gift (this was a small stationary set) as thanks.

4.2.1.5 – Increasing rigour

Inter-rater reliability

The author was the sole coder for these data. However, in an effort to establish reliability, certain steps were carried out. Firstly, codes were developed and discussed with a supervisor (DS) as coding developed. Secondly, DS was asked to code 20% of the transcript. A Kappa Coefficient of .806 was obtained for AR and DS's attribution of codes for this section, showing a high level of agreement. In addition, intra-rater reliability was obtained (.943) for 20% of the transcript (where AR coded the transcript twice, one month apart).

Verbatim accounts

As in section 3.2.4.2, data are presented verbatim

4.2.1.6 – Data Analysis

Data were analysed using a general inductive approach (similar to 'thematic analysis') (Thomas, 2006), as described in section 3.2.5. It should be noted that all participants are referred to using two initials unrelated to their names.

4.2.2 – ASD Perspective 2: Caregiver Focus Group

4.2.2.1 – Participants

Nine women related to children (or young adults) with a diagnosis of ASD and other complex needs were recruited (mother: n=7; grandmother: n=1; great-aunt: n=1). The participants were recruited through a gate-keeper at Sense Scotland, a charity supporting those with sensory impairment and their families. Two of the members were related to

each other (ST and UV) but the other participants did not know each other prior to the focus group. Participants were aged between 41 years 1.8 months and 68 years 2.8 months on the day of the focus group (mean = 51 years 5.9 months; SD = 10 years 9.9 months). They were not related to the children described in section 4.2.1. Table 4.3 shows the diagnoses of the children (as disclosed by the participants).

Table 4.3 – Frequency table of diagnoses	
Main diagnoses	**Frequency**
Autism only	2
Autism and Down's Syndrome	3
Autism and blindness	1
Autism and cortical dysplasia	1
Autism and Angelman's Syndrome	1

4.2.2.2 – Ethical considerations

The Faculty Ethical sub-committee of the University of Glasgow granted ethical permission for the study prior to recruitment commencing. Initially, contact was made with management at a local charity that supports individuals with sensory impairment and their families. We were invited to run our focus group at one of the monthly relative support group meetings. The gate-keeper advertised the focus group through their email list. All participants were informed that the topic of the focus group would be sensory issues and it was stressed that they would be free to leave the study at any time. Nine individuals turned up to the focus group on the chosen day, with one leaving half way through after receiving a phone call. They were also told that, although the data may be used for publication in journal articles or at conferences they would not be identifiable, as the transcript would be anonymized prior to analysis. All participants were happy to take part in the study and signed consent forms.

4.2.2.3 – Procedure

A focus group is a group discussion that centres on a certain topic. Rather than being of a question and answer format, participants are encouraged to interact with each other on a focused topic. The experimenter's role is to moderate the group, ensuring that people are given ample opportunity to speak and are keeping the discussion on-topic. The study was organised through a gate-keeper, who scheduled the focus group at a time convenient to everyone involved (within working hours). The focus group took 1 hour 33 minutes to

complete. All participants were fully informed about the study prior to recruitment, although the experimenter re-iterated the most important points and answered any questions prior to starting the group. All participants also signed consent forms and filled out a brief demographics questionnaire. The topic of the focus group was sensory issues in autism spectrum disorders. After the focus group was completed, a feedback session was scheduled for autumn 2012.

4.2.2.4 – Increasing rigour

Inter-rater reliability

The author was the sole coder for these data. However, in an effort to establish reliability, certain steps were carried out. Firstly, codes were developed and discussed with a supervisor (DS) as coding developed. Secondly, DS was asked to code 20% of the transcript. A Kappa Coefficient of .813 was obtained for AR and DS's attribution of codes for this section, showing a high level of agreement. In addition, intra-rater reliability was obtained (.932) for 20% of the transcript (where AR coded the transcript twice, one month apart).

Verbatim accounts

As in section 3.2.4.2, data are presented verbatim

4.2.2.5 – Data Analysis

Data were analysed using a general inductive approach (similar to 'thematic analysis') (Thomas, 2006), as described in section 3.2.5. As in Chapters 5 and 6, all participants are referred to using two initials unrelated to their names.

4.3 Results

4.3.1 – Children's Group Interview

Three core categories emerged from these data: negative sensory experiences, positive sensory experiences and extremely strong reactions to stimuli. The children in the sample described problematic responses to sensory stimuli. They disclosed experiencing negative reactions to certain types of sensory stimuli (most commonly describing hyper-sensitivity). Specific features that were more problematic for the sample included a) an aversive quality (this would depend on what each person found aversive), b) high intensity (i.e. loud noise/bright light) and c) if the stimulus was unexpected. If the negative sensory experience was particularly bad, it could sometimes result in pain, nausea, discomfort, fear

or annoyance. Participants also described participating in pleasurable sensory events. Typically, enjoyable sensory experiences were typified by a) having some quality that the person found enjoyable and b) the stimulus being under their own control.

4.3.1.1 – Negative sensory experiences

All of the children in our sample described (or exhibited negative reactions to) certain types of sensory stimuli. The accounts that the participants gave were much more likely to include examples of hyper- rather than hypo-sensitivities. Hyper-sensitivity to sensory stimuli often resulted in unpleasant experiences. Difficulties with all five senses (vision, audition, gustation, olfaction and touch) were disclosed.

Auditory stimuli were reported most frequently, with every child in the sample mentioning at least one example of negative noises or sounds. When presented with the auditory stimuli during the group discussion part of the session, many children expressed dislike for certain sounds. The most problematic for our sample were the baby crying, the fire engine siren, dogs barking and fireworks.

The sample disclosed that listening to certain sounds caused them pain, e.g. 'the school bell hurts my ears' and 'I know something that's even more sore … the emergency bell!'. In the second example, CC says that he finds the sound of an emergency bell more painful than that of a fire engine siren. This shows that, depending on the nature of the stimulus, there are varying levels of discomfort experienced. Specific reasons given for why these particular sounds caused discomfort included the amplitude of the noise, e.g. 'it's really noisy that sound', whether a noise was unexpected or not, e.g. 'I just don't like it when [the bell] goes off unexpectedly' and the nature of the noise (II mentioned disliking sounds that were high-pitched), e.g. 'I really like die of hearing and have a heart attack sometimes…when your hand goes down a blackboard'.

Although auditory examples were most commonly cited, other modalities were also discussed. The texture of a stimulus was the main issue in the tactile domain, with the prospect of touching certain materials provoking a variety of emotions. AA displayed disgust at the prospect of the 'feeling boxes' containing liquid: 'I hope it's not something wet because…I'd be disgusted!'. Many of the children said that texture was an important reason for not liking specific types of foods. BB disclosed that he did not like rice, as it was 'stringy', while CC felt the reason he disliked eating pasta was because it was 'slippery'. Discomfort with touch also appeared to be a problem when it came to personal

grooming activities. II said 'I feel physically sick when I have to get a haircut - I don't know why'. By stressing that she was not sure of the reasons behind her physical reaction to this activity, II shows that she is unaware as to which particular aspects are most unpleasant for her. Furthermore, some of the children also said they disliked particular items of clothing because of the way they feel. CC disliked a particular jumper because of the texture and colour: 'It was a hairy j-, wooly jumper … I just didn't like the colour or the feeling'.

When it came to the visual domain, the main problems seemed to be related to specific colours. CC and DD disclosed that they did not like to wear certain clothes because of the colours: 'I just didn't like the colour or the feeling [of the jumper]' and 'I don't like one top – a pink top'. II also mentioned experiencing pain when she looked at certain colours: 'I like [bright colours] as colours but they hurt my eyes'. She also mentioned 'super hot orange' as being particularly painful. This example again demonstrates the degrees of discomfort that are experienced – II finds some colours are more painful than others – with bright orange being the worst. JJ disclosed that his eyes sometimes hurt from different visual stimuli. Examples included bright lights and television screens: 'Em, the sun, the lights, my TV 'n' lots of other stuff [hurt my eyes]'. Finally, BB mentioned that he does not like eating certain foods if they are a certain shape or colour, e.g. chocolate because it is 'rectangular' and plums because they are 'red'.

The element that elicited the strongest negative reactions during each session was the olfactory task. One child (EE) refused to participate after smelling the garlic, as he disliked it so much. AA displayed strong reactions to many of the odours, citing the ones he particularly disliked as "smelling like vomit". AA related a few scents to vomit – he seemed to generalize this descriptor to all the ones he particularly disliked. The garlic, vinegar and coffee smells were most disliked by all groups, with some of the adjectives used to describe them being 'nasty', 'bad', 'horrible' and 'annoying'. As well as discussing particular smells, the children also disliked odours that were particularly strong. AA disclosed that, in his experience, 'places [in] which they sell make up is smelly!'. GG said that he liked the smell of perfumes, but not when they were particularly pungent: 'I like [perfumes], but not strong ones'. JJ disclosed that smelling lots of perfume made him feel 'uncomfortable'. These are both examples of the strength of the stimulus playing a role in whether it evokes a negative reaction or ambivalence.

As part of the sessions, children were asked a) what their favourite and least favourite foods were and b) why. Our sample typically mentioned texture as the reason motivating their dislike of a food. However, some children did mention specifically that they disliked the taste of certain foods. II displayed a potential hypo-sensitivity in the gustatory modality, as she mentioned that she liked strong-tasting foods in particular. She found that certain foods (e.g. carrots and apples) had 'no flavour'. Conversely, JJ mentioned that he was very aware of the taste of salt when he was eating '[My gran's new soup] tastes horrible and [has] too much salt' and '[My mum's mince] is too salty – [it is] disgusting in [my] mouth'. JJ stresses that he can taste the salt strongly in his family's cooking – this may either be because the dishes contain more salt than JJ likes or that he is hyper-sensitive to it.

4.3.1.2 – Positive sensory experiences

The children in the group also discussed pleasant sensory experiences. The events that were described could be separated into three types of interaction. Firstly, some children sought out stimuli as they enjoyed the sensations, e.g. II liked the click of the light switch – 'I like the sound of lights going on and off…it's quite weird but I like it'. Secondly, some children sought out certain sensations as it helped to calm them down when they were under stress, e.g. GG felt that "squeezing something" helped him. Finally, they associated the stimuli with something positive, e.g. II said that the colour purple made her 'think of bright, colourful lands'. Typically, the sample described enjoying things that they had autonomy over. Examples of this included jumping on a trampoline, listening to music, kneading or squeezing things and letting water run through their hands.

In one of the schools we visited, the school bell consisted of pop songs, rather than a standard ringing noise. Different songs were played to indicate interval, lunchtime and changing classes, as well as to signify the beginning and ending of the school day. The bell rang during our session and the children in the group (n=5) all displayed pleasure when the bell played: HH said, 'I like hearing the bell', while EE agreed: 'I like – listening to the sound of the [musical] bell'. This is in contrast to the other school (n=5), where the children mentioned that they really disliked their school bell: 'the school bell hurts my ears' and 'it gives you a fright when … the bell goes'. It is worth noting that the first school caters only to those with Additional Support Needs while the second school is a mainstream establishment with a language support unit.

Many of the positive examples cited involve touch. GG owned his own 'feeling box' that he kept in school, full of textures that he enjoyed to touch. JJ described taking pleasure in the sensation of things flowing through his hands: 'I like to feel water, I like to feel the air blowing through my hands'. In addition, the textures and temperatures of food were often one of the reasons that certain foods were found to be enjoyable. AA described that he liked really cold food, whereas CC preferred food that was hot. BB specifically mentioned that he liked food that was 'crunchy' or 'soft'. II liked the really strong taste of vinegar and also particularly enjoyed the sensation of foods that melted in her mouth: 'like [food which is] melting in mouth'.

When asked about methods they used to calm themselves when they were upset, the majority of the sample described avoidance or distraction techniques. However, one child specifically mentioned using sensory stimuli to help calm himself when he felt upset or angry. GG mentioned that he had his own 'feeling box' and that he used it when he felt overwhelmed. When asked how he calmed himself down, he replied, 'squeezing something'. Furthermore, he also mentioned splashing water on his face: 'water – you know water ((mimed splashing water on face)) sssshhhh'.

4.3.1.3 – Particularly strong reactions to certain stimuli

When discussing the negative sensory experiences, one of the most common reasons reported for disliking a certain stimulus was that it caused them physical pain. Typically, the children described unpleasant stimuli as hurting them in some way. There were many examples of this for the auditory stimuli. AA mentioned that 'the school bell hurts my ears', whereas CC mentioned something similar 'I know something that's even more sore – the emergency bell!'. When JJ was asked what hurt her ears, she mentioned the 'fire alarm'. These are all loud, high-pitched sounds that are somewhat unexpected in their onset. BB also mentioned that the sound of a baby's cry was painful: 'Since babies cry so loud I just cover my ears'. JJ mentioned having to cover his ears (when he was younger) when he heard the same stimulus: 'When I was about five my … brother was about two and he always used to cry all the time'. DD also mentioned that 'balloon[s] burst[ing]' caused her to have to cover her ears. Covering their ears seemed to be a common coping strategy for many of our sample when coming into contact with unpleasant noises. Although the majority of examples of painful stimuli involved auditory stimuli, there were descriptions of other modalities, e.g. vision. JJ mentioned that bright lights and other visual stimuli hurt his eyes: 'the sun, the lights, my TV 'n' lots of other stuff [hurt my eyes]'. Physical reactions were not restricted to pain – II discussed how she feels nauseous

whenever she has to have her hair cut: '[I] absolutely hate it … I feel physically sick when I have to have a haircut'.

Many of the children disclosed that certain stimuli could affect their mood or emotions. AA sounded fearful when listening to the firework stimulus: 'That's just the sound of … bangin' fireworks – and I <u>hate them</u> because they can …explode in your face, you can lose sight … and it's <u>really noisy</u> that sound!'. In this instance, it seemed that AA was fearful of the potential dangers of fireworks (e.g. that they could damage eyesight, as well as discomfort about the loud noise that they make).

FF displayed anxiety during the session, after the fireworks sound had been played. He became fixated on it, becoming concerned that it would be played again and verbally stressing on three different occasions that he did not want to hear it: 'You're not going back to the fireworks?', 'Do not go back to the fireworks' and 'Yeah – never ever again … understand'. However, once reassured that we were moving on to a different sound, he seemed to settle down. Later on, FF refused to participate once had smelled the garlic (this was near the end of the session). At both points, he was given the opportunity to leave, doing so after the latter.

II disclosed that she experienced strong reactions whenever she heard certain sounds (typically high-pitched, squeaky ones). She described this as feeling like her heart was racing: 'this is one that I … like die of hearing and have like a heart attack sometimes … when plates scratch on the – or when your hand goes down a blackboard'. Here II describes having a very strong physical reaction to hearing certain auditory stimuli. Describing it as akin to having a 'heart attack' suggests that she experiences great anxiety as a result of hearing these types of sounds. JJ also described having a powerful negative reaction when he had to have his hair cut as a child 'one of my caretakers came over and cut it for me and I was greetin''. It should be noted that, in this context, the final word in this excerpt ('greetin') is a Scottish slang word for crying. Although it seems to be no longer the case, JJ describes receiving haircuts in the past as being a traumatic experience.

4.3.2. – Caregiver Focus Group

The discussion generated by the group detailed the sensory experiences of children with autism and other complex needs. As caregivers are only able to report on their child's behaviour from a second-hand perspective, the themes drawn from the data were notably

different in their nature from those from children with autism themselves (see Section 4.2.1). Two main themes emerged from these data: the impact of negative sensory experiences (for both the carer and the child) and techniques used to deal with problematic behaviour stemming from sensory sensitivities.

4.3.2.1 – The impact of negative sensory experiences

The impact of negative sensory experiences in autism was the most pervasive theme throughout the focus group discussion. The participants discussed, at length, the negative effect that sensory issues could have on their child. This typically resulted in challenging behaviour, which could lead to three types of consequences for both caregiver and child: physical, emotional and social.

Emotional consequences of negative sensory experiences

The participants in the group disclosed that there were negative emotional consequences to their child's unpleasant sensory experiences. For the child themselves, this appeared to be a result of interacting with problematic sensory stimuli; for the caregiver it was due to observing the distress that these experiences caused their child. OP mentioned that her son became incredibly upset when he had to have his hair cut:

> 'The biggest thing with my son is getting his hair cut – it's absolutely
> horrific – we went into the hairdressers and suddenly he was so upset
> by it he was sick, so we decided that we were never going to the
> hairdressers again'

This participant continued by clarifying that it did not matter which methods the hairdressers used ('it doesn't matter if it's clippers, scissors…') and that she attributed this aversion to tactile hyper-sensitivity: ('he doesn't even want you washing his hair'). For this child, the experience of having his hair cut could upset him so much that he became physically sick.

KL described how her child became upset when transitioning between two differently coloured floor tiles at a local activity centre:

> 'The problem my daughter has as well – see if you've got different
> coloured tiles, like if you go into Xscape … I'd never noticed, I just
> thought it was all tiles on the floor and you walk in, but … when you
> took her in you saw it slightly differently – she was hysterical … they
> had a border round it and something on the inside … I don't know, I can't
> even remember, but she was absolutely terrified'

KL believed that this reaction was due to the change in visual stimuli, and discussed her suspicions that it may be some kind of difficulty with depth perception ('I don't know if maybe the lights were hitting off something and it was maybe creating, I don't know, a problem with depth or something'). The problem that KL's daughter had in transitioning from one surface to another was not specific to that environment:

> EF   'Could that have been the noise as well, because it's a very
>
> noisy place?'
>
> KL   'No, no, no – 'cos even with the aeroplane … it was going
>
> from one point to that – she has huge problems transitioning
>
> but not to everything … it seems to be if it's changing from a
>
> different colour or different texture'

The participants disclosed that interaction with unpleasant sensory stimuli could result in their child exhibiting challenging behaviour. This challenging behaviour often had a profound effect on the emotional well-being of the relatives as well. After a lengthy discussion about the difficulty of treating their child medically (due to their sensory sensitivities as well as other aspects of their disability), the caregivers disclosed how emotionally taxing taking care of their child could be at times.

> UV 'I find that when, after all that carry on, I come home and cry'
>
> EF   'Oh I've lost count of the times I've cried … you feel sorry for them, but you
>
> feel sorry for yourself as well'

At the start of the discussion, the caregivers did not openly discuss how difficult it can be to care for a child with autism and other complex needs (although there were a few inferences). However, as they became more comfortable with each other and realised that other people were having similar experiences to themselves, they began to disclose their feelings more as discussion progressed.

Indeed, the caregivers reported being put in uncomfortable positions due to the challenging behaviour of their child. EF went on to describe how traumatic it was to have to physically pin down her child because she refused to drink a barium meal (a medical procedure involving the ingestion of a radio-opaque material and subsequent imaging of the gut):

> 'She was getting her barium meal…she wouldn't drink it so they had
>
> to put a tube through her nose and it took four of us to hold her down …
>
> she was about fourteen at the time, and I was crying all through that
>
> because it was terrible'

It is difficult to determine whether this example is a result of sensory processing (e.g. hyper-sensitive to gustatory) or is the reaction of a child who is scared and doesn't know what is happening to them. As with many other examples, it is probably a combination of both, therefore it is treated as relevant information. This example highlights some of the difficulties that both caregivers and medical professionals may have when treating a child with disabilities, and the effect that going through these difficult experiences can have for both the child and their relatives.

The majority of the time, the caregiver will be able to predict whether sensory stimuli (or specific environments) will be problematic, which will have been developed through years of observing the behaviour of their child in response to certain situations and stimulation. However, when they are not expecting a negative reaction, it can be particularly frightening. KL found the experience of her child becoming upset at the flooring in a local entertainment complex as very frightening and unpleasant: 'she always has to rock, or flap, so you'll always have something but, you know, it absolutely terrified me'.

Physical consequences of negative sensory experiences
Another category drawn from these data was that there could be physical consequences due to atypical interaction with sensory stimuli. This was further broken down into health implications (for both the child and the caregiver) and also prevention of harm to the child (safety).

Many of the participants reported that they had difficulty with getting their child to put on accessories that would keep them warm during the cold weather. UV and OP had an exchange about this struggle:

> UV 'The kids in the cold weather – my grandson won't wear a hat,
>   scarf or gloves'
>
> OP 'I've only got one hat that he'll wear'
>
> UV 'No – nothing he'll wear – frozen cold outside'
>
> OP 'He won't wear gloves'
>
> UV 'All ripped off – thrown away – hat off'

Both UV's grandson and OP's son refused to wear these items, regardless of the weather outside. This could have health implications, especially for individuals with additional support needs. This does not seem to be restricted to an apparent inability to feel – GH mentioned that her daughter always wore a thick dressing gown, even during hot weather ('you'll say to her – it's a beautiful day take the housecoat off, you're too warm and she'll

say 'cold' and she's absolutely sweating!'). OP discussed that there was one particular hat that her son would wear, and that she worried about the impression she gave the school when insisting that they return it ('I'll go ooh where's that hat – I think they think I'm being really mean … but it's because it's the only one he'll wear'), which is reflected in the theme of social implications reported in the next section.

As well as having an emotional impact on the caregiver, challenging behaviour instigated by sensory issues could have a physical impact as well. UV (who is the sole carer for her grandson) described how he would physically lash out at her and she had to hold him down: 'You know you've got kicks, you've got black and blue marks, your arms are sore holding them down'. She also described how this could impact others, and recounted an incident where her grandson had hit her mother (his great-grandmother) on her ear. Although the description in this example was not necessarily instigated by sensory stimuli, it is included here in order to highlight the potential repercussions of challenging behaviour for other vulnerable groups:

> 'My mother's 94 … and she wears a hearing aid and I used to go over
>
> to see my mum but one day he went up and … clapped her ear with the
>
> hearing [aid] and she got a fright and said don't bring him back, just come
>
> alone – so, to me, it's – it's not worth my while going over'

This extract highlights two things in particular: a) that there can be health implications for those around the child with autism, rather than just the child themselves and b) that this can lead to social isolation and the breakdown of relationships (explored further in the following section).

Lastly, sensory sensitivities can have a profound effect on safety. GH described how her daughter would avoid certain noises at all costs – even running in front of cars in her desperation to evade the auditory stimuli:

> 'I would say my daughter's the same – noise seems to be the issue … you
>
> can come out Central Station and she can hear the guy playing the bagpipes
>
> streets away and she will not go in that direction, and she will do anything
>
> to get away from it – run in front of cars – the lot'

This poses great danger for the child herself, and places primary responsibility on the carer to be constantly aware of the sensory environment. This is particularly difficult when GH's daughter appears to notice the sounds before the person accompanying her: 'you've to stop and listen to hear what's she listening to'.

Social consequences of negative sensory experiences

As described in the previous sections, one of the consequences of challenging behaviour stemming from interaction with problematic stimuli was isolation and restriction, particularly in relation to social events. Once their child had become distressed in a particular situation, the participants found themselves unable to return. OP disclosed that after her son had become upset at the hairdressers, she refused to take him again: 'he was so upset by it he was sick – so we decided that we were never going to the hairdressers again'

In addition, difficult experiences can mean that this has an impact on family activities. After a traumatic experience in an airport with her daughter, EF mentioned that she hadn't felt able to attempt going on a holiday by plane again: 'my daughter's … biggest problem's been loud noises … we were in Prestwick Airport and she just freaked out … I haven't risked an airport since then'.

The challenging behaviour exhibited in response to negative sensory experiences not only affects the child's well-being, but their carers' as well. Although some of the caregivers felt that, with repetition, their child may be able to get used to these types of events, there is a real difficulty with being able to 'practice' infrequent events, like holidays, parties and going to the hairdresser:

> 'We find that if you do a thing often enough {EF's daughter} does get
>
> over the hurdle and she will eventually accept it … if there was a party
>
> on every week in the same hall with the same people and the same music
>
> she would eventually go in, but these things are kind of intermittant'

Indeed, as can be seen in the previous sections, the emotional and physical price of repeatedly taking their child to problematic environments would be high, for both the child and their carer. Therefore, the potential for habituation to an environment as a result of increased exposure would have to be assessed on a case-by-case basis, as it may be too traumatic for the child and their caregivers.

UV discussed how caring for her grandson, particularly as she lives on her own, could mean that she is unable to meet up with friends: 'Does anyone feel isolated – times come up when you've to go to a night out – do you feel isolated? I feel very isolated'. UV went on to highlight that, because she has to look after her grandson, she relies on people visiting her. She mentioned that some people had stopped visiting her, because of the demands her grandson places on her: '– a lot of people don't come because they're fed up,

you know you know, interfering with the kid, and … the TV has to be on blaring all the time'. Another aspect of this was mentioned by KL, who described how her daughter's additional support needs meant that she was unable to have nights out alone with her partner: 'We don't tend to go out at night, or if we do we tend to split up – like either I'll go out or my partner'll go out, but it's not usually together'. Being unable to spend time alone as a couple may affect relationships and was mentioned by a few participants as a difficulty they had experienced.

A lack of understanding from others was a common discussion point throughout the focus group. EF discussed that people just did not understand the ramifications of putting her daughter in uncomfortable situations:

> 'my cousin's 40th is in a couple of weeks and I don't think we'll have
> somebody to watch her so my husband probably won't go, but you know
> the relatives don't always understand – they'll say, just bring her, but we
> can't bring her because she won't come in, or she'll get stressed out'

This shows that, even within their extended families, there can be a fundamental lack of understanding about the realities of caring for a child who has disabilities.

4.3.2.2 – Dealing with negative sensory interaction and its consequences

The second major theme of the discussion surrounded how to deal with a) challenging behaviour arising from interaction with unpleasant stimuli and b) how to minimise the effect of problematic stimuli. Many examples included using enjoyable sensory stimulation and so this will be covered in depth alongside other methods employed by caregivers.

Purposefully exposing child to positive sensory experiences
The participants discussed how their children often enjoyed interacting with certain sensory stimuli, and they would encourage this in order to calm them down when they were upset or to distract them from negative sensory experiences. The most common positive sensory stimuli, as with the children (see section 4.3.1) and adults with autism (see Chapter 5) were related to touch.

Many participants gave examples of positive tactile sensory experiences. QR ('My wee girl loves just, you know you could rub her all day … she just loves it') and UV ('When {UV's grandson} goes to sleep at night he's got to have his back rubbed') described how their relatives with autism loved being rubbed. This appeared to have a calming effect for

UV's grandson (helping him to sleep) and was extremely pleasureable for QR's daughter. EF had also found that her daughter thoroughly enjoyed tactile sensory input ('Another positive one is massage – my daughter loves massage'), and ensured that her daughter was able to experience full body massages on a regular basis ('we have somebody that comes into the house once a month to give her a full body massage'). Furthermore, she mentioned that she had taken a course in massage in an effort to provide positive tactile input for her daughter ('I've done a wee course in massage as well so I can do bits and pieces').

There were also many examples of positive visual stimuli in the examples given by the participants. It should be noted that the majority of the examples appear to be related to motion or colour. KL described how her daughter became fascinated by looking at light streaming through trees, particularly if it was a windy day and they were moving:

> 'she likes looking at the trees, but it seems it's not the trees she's liking
> –   it's actually the light coming through the leaves and how they're moving
> … she'll stand there for thirty minutes – {KL's daughter} never stands
> <u>anywhere</u> for any length of time but she'll just … stand and stare at the trees
> if the wind's blowing'

She went on to describe how this was providing pleasure for her daughter ('it's a great thing') and that her daughter would be so fixated on the trees, it was like she was in a trance ('you can't interrupt her … you just have to wait until she comes out of that'). OP also found that motion was enjoyable for her son – she described how bubble tubes (a plastic tube filled with water, through which air bubbles are passed) provide enjoyment for her son ('{OP's son}'ll sit and watch a bubble tube for hours on end. He loves things like that').

Colour was also an aspect of visual stimuli that seemed to be particularly enjoyable for the children. KL described how her daughter loves watching her star projector, which slowly changes colour:

> 'the stars on the sky … I got one for {KL's daughter} to try and get her to
> calm down. Sometimes she'll tell you when she wants it on – she'll just say
> stars, and you put it on, and it's quite calming … it very gently changes
> colour … it's just a little projector type thing it covers the whole room'

As with the motion example provided previously, this seemed to have the effect of calming KL's daughter down when she was upset or stressed. By asking for it directly, it shows that KL's daughter is gaining something positive from being able to watch the output from

the projector.   OP also described how, on a family holiday to Disneyworld, her son thoroughly enjoyed the visual stimuli (particularly the bright colours):

> 'The bright colours … we went to Disney on holiday and he absolutely loved
> it … I mean he doesn't like lights in certain shops but he loved the light shows
> and the fireworks … he loved all that and I think it's because it's so colourful,
> it's so so colourful – he loves bright things'

It should be noted that OP wasn't sure whether it was the bright colours that he particularly enjoyed ('I think it's because it's so colourful') – this highlights the difficulty in truly determining the cause of a behaviour observed by a third party.

Vestibular stimulation was also reported to be particularly enjoyable for the children in the sample. KL described how her daughter often swung herself in a garden swing: 'My daughter loves swinging … if you've got a garden swing or something she's quite happy and she's very relaxed'. In addition, MN and EF had a short exchange where they discussed their children jumping on their beds:

> MN 'I've got a trampoline for his bedroom because he was bouncing on the
> bed so much – now he bounces on the bed <u>and</u> the trampoline!'
> EF 'Well we've moved on to a rocking chair because {EF's daughter}
> broke about three beds – so we got a rocking chair out of Ikea which
> she always sits in now – she doesn't jump on the bed anymore'

Avoidance

As well as providing positive sensory experiences, there were other methods used (by both the children themselves and their caregivers) to try to avoid unpleasant sensory interaction. As mentioned in the previous section, the participants tended to avoid situations which had unpleasant sensory stimuli when they were with their children. This can have social consequences for both the adult and the child, although it can be an effective method of reducing the exposure to problematic stimuli.

Moreover, the children themselves tended to use avoidance techniques if they were faced with unpleasant sensory stimuli. EF mentioned that, when her daughter became overwhelmed by the noise, she asked to go to the toilet and then refused to get off the floor:

> 'the airport itself – that was worse than getting on the plane … she lay on
> the floor and when there was an announcement … her way of getting out
> of something is to ask to go to the toilet, so of course you're never sure if

she wants to go to the toilet or not – but we gave her the benefit of the

doubt – took her to the toilet – she lay on the floor of the toilet and wouldn't

get up'

This child had developed a consistent way of avoiding problematic sensory stimuli (or something else unpleasant), which was to ask to go to the toilet. Her mother assumes that the cause of her discomfort, in this case, was the loud noise of the PA system. Her reaction to sit (or lie) down when she hears something she does not like is common to other situations as well, e.g. when going to the supermarket: '[she would] hear the trollies outside ASDA and she would lie down on the ground and she wouldn't go in'.

Distraction

Another coping mechanism used by both the adults and their children was distraction. KL's daughter carries a bag with her everywhere and she fixates on it when her surroundings become overwhelming:

'she had to focus on her bag – she dangles – everything has to dangle.

She constantly has to dangle, and the more stressed she gets, you'll

see the faster the bag will go – and so you can usually pick up how

stressed she is from the speed'

This is also an example of instigating positive sensory experiences (visual motion) in order to distract herself from the things in her surroundings that are overwhelming for her.

In addition, GH described how it was important to distract her daughter when she was on public transport.

'we take her wee iTouch [sic] with her everywhere, and as long as she's got

this one video, on buses and things, if you put it on … it's as if it sort

of distracts her slightly from everything else'

She went on to mention that the headphones were particularly important ('You keep the headphones on – it'll distract her'), even though her daughter never has them directly on her ears ('she sort of has them at the back of her ears – she doesn't actually have them on … but it obviously is enough').

Compensation

The final example of coping with negative sensory stimulation is that the caregivers try to compensate in some way. They tended to try to get their child to do what they needed to (e.g. have a haircut) by compensating for some of their child's sensitivities and finding another way to do this (e.g. having a hairdresser come to the house/cutting hair in the

bath). OP discussed how, after her son had been sick at the hairdressers, she was going to try to get someone to come to the house and cut his hair (i.e. which should be less stressful for her child):

> 'we went into the hairdressers and suddenly he was so upset by it he was sick,
>
> so we decided that we were never going to the hairdressers again – I'm going
>
> to try and get somebody to come to the house'

GH also mentioned that her daughter had problems getting her hair cut – she managed to circumvent this problem by ensuring that her daughter only goes when there is nobody else there:

> 'in the hairdressers we used to get it as well, but now we … go when it's
>
> really quiet and [it's fine] as long as there's nobody else in – but if there's
>
> somebody else in or she heard that buzzing noise, we'd leave with half a
>
> haircut!'

EF also mentioned how her daughter had gone through a phase of taking her clothes off in public, and had to make sure that she wore specific clothes that were difficult to remove:

> 'we went through a phase where she was taking all her clothes off, quite
>
> regularly and … for about three years … she had to wear dungarees and
>
> she had to get all-in-one pyjamas'

These examples show that the caregiver will often manage to find a way to help their child cope with the sensory issues they are experiencing, without having to restrict their activities too much.

4.4. Discussion

In this chapter, we used interactive tasks, group work and interview techniques to investigate sensory issues experienced by children with a diagnosis of ASD. By interviewing children with ASD themselves, we were able to receive unique insight into their sensory experiences. In addition, it was useful to analyse detailed examples from the caregivers of children and young adults with ASD, in order to better understand the impact that these sensory issues can have on the child (and the rest of the family).

4.4.1 – Children's Group Interview

Three main themes emerged from the analysis. These were negative sensory experiences, positive sensory experiences and extremely strong reactions. The children in our sample reported experiencing negative reactions to a variety of sensory stimuli across all five main modalities. The nature of the stimuli appeared to play a role in whether the experience was

negative or not. Typically, the strength of the stimuli was an issue, with hyper-sensitivity leading to discomfort and hypo-sensitivity causing sensation seeking. The strength of stimuli was expressed as a particular issue in the auditory domain, as many children described covering their ears when they heard something that they felt was particularly loud. Furthermore, another issue within the auditory domain was unexpected onset – being warned that a stimulus is about to begin allows the child to take evasive action or compensate for it in some way. The finding that auditory stimuli appeared to be most problematic for those with ASD concurs with the findings of the caregiver focus group, as well as previous studies (Dickie et al., 2009).

The participants also discussed sensations that they liked. Our sample mentioned stimuli that possessed specific qualities, e.g. being able to flow through the fingers, feeling smooth or being very strong tasting. Also, they seemed to prefer stimuli that were more likely to be under their control (i.e. they were able to initiate contact themselves). Lastly, there were often semantic associations for liking something (i.e. JJ liked the colour purple because she associated it with 'bright, colourful lands'). In turn, it may be the case that some negative experiences with stimuli could be from long-held negative associations; almost like a phobia. Indeed, there is evidence that sensory hyper-sensitivity is associated with anxiety (Green & Ben-Sasson, 2010), another study showing that sensory hyper-sensitivity may cause increased anxiety in individuals with ASD (Green, Ben-Sasson, Soto, & Carter, 2012). Although these papers do not directly investigate phobias in those with ASD, phobias are considered to be sub-types of anxiety disorder (American Psychiatric Association, 2000). Therefore, if sensory sensitivities have an impact on anxiety, it could be argued that they may also be responsible for some phobias, which often last into adulthood - even if the hyper-sensitivity causing the initial aversion has since subsided.

The third category to be extracted from these data was the strong reactions to sensory stimuli by many of the children. In this instance, these were mostly negative reactions. Experiencing pain from stimuli was common among the sample, particularly for the auditory and visual domains. Although the sample mentioned negative reactions to stimuli in other modalities, they did not specifically mention pain. It could be argued that it is much harder to control for visual and auditory stimuli outwith the child's home and school environments. This is because these would be likely to be a) more common and b) harder to avoid. Taking the second point, if strong smells are an issue for children with autism, their parents would most likely pick up on this and begin to avoid these environments. In

turn, both tactile and gustatory stimuli need direct contact to be problematic. However, strong visual stimuli and loud noises could be present in many different environments.

Children also described certain stimuli as being 'annoying', 'uncomfortable' and as making them feel 'physically sick'. This shows that pain is not the only reaction experienced by the children in our sample. Interacting with specific stimuli invoked fear, disgust, annoyance and even nausea in participants taking part in the study. We reported similar reactions in Chapter 3.

The ability of the children to draw on their own experiences and communicate these effectively was a factor in this study. In the interactions with the children, it appeared that some participants were more highly functioning than others (e.g. in one particular group, the children exhibited lower language skills and found it harder to stay focused on the task at hand). When coding the groups, we found that this meant there was a large difference in the volume and quality of the data produced. However, it should be noted that, despite this disparity, similar concepts emerged from all three groups. This is important as it suggests that the types of issues experienced by children with ASD are similar in their nature despite differing levels of communication ability.

One important thing to note is the importance of interaction between the children. One problem with qualitative research is that the data are wholly dependent upon the person disclosing their experiences and being honest with the researcher. For the most part, the children seemed to be honest when answering questions and disclosing their experiences, particularly in the one-to-one interactions with the interviewer. However, there were a few instances of note. Firstly, during the auditory discussion session, BB initially seemed to copy AA's responses for the noises. At this point in the session, the noises were played and each person had to hold up a colour corresponding to how they felt about the noise (i.e. whether they liked it, disliked it or had no strong feelings toward it). However, for the first 3 noises, BB chose a colour and moved to respond before checking what AA had raised, then changing his option to reflect AA's choice. However, this copying behaviour stopped after BB spoke at length about his experiences after the third noise, as he seemed to grow in confidence.

Another problem was that some of the children were more reticent to talk than others, meaning that they would only respond with a yes or no to direct questions. This brings up the issue of whether there was a similar experience they could have discussed but the

question did not directly address it. However, in these instances, the author tried whenever possible to encourage them to disclose a little more about why they felt that way. Finally, in one group, there were two children who disliked each other. In this particular group, one child would say that he disliked all the noises that the other child had mentioned that she liked. During the session, this was obvious as II repeated verbatim all the sounds that JJ had previously said she enjoyed listening to. However, this seemed to be an isolated incident, as these types of interaction were not repeated throughout the session.

This study provides insight into the sensory experiences of some children with a diagnosis of ASD. The descriptions of pain felt, and enjoyment received, from certain stimuli would be particularly useful for parents to hear, as the unusual behaviours of children with ASD can be bewildering and it may provide caregivers with insight as to why their child exhibits unusual behaviour at times. Furthermore, the groups showed that small adaptations make a large difference to the lives of some individuals with ASD. The main difference we saw was the response to the school bell. The children at School 2 enjoyed hearing the pop song that was played, whereas almost all of the children at School 1 said that the school bell hurt their ears.

To the best of our knowledge, this is the first study to qualitatively explore the views of children with autism and their experiences with sensory stimuli. The main advantage of this study is that the data are directly from the children with autism, rather than from another person's viewpoint. It could be argued that one disadvantage of this study was the lack of control group – however this is not an integral part of a qualitative research design and our aim was to explore the nature and consequences of atypical sensory experiences, rather than compare group differences. Every member of our sample disclosed some sort of hyper- or hypo-sensitivity to sensory stimuli. By extrapolating the most problematic stimuli, ways to change or adapt environments (e.g. changing the school bell) can be developed and would most likely make a huge difference to the lives of many children with sensory issues.

4.4.2 – Caregiver Group Interview

Two main findings emerged from these data. Firstly, the participants described the profound impact that negative sensory experiences can have. This applied to both the child with autism and the participants themselves. These could be further separated into emotional, physical and social consequences of interaction with unpleasant sensory

stimuli. Examples included descriptions of challenging behaviour, negative emotional reactions and avoidance of specific environments. Although these accounts are from a third-party viewpoint, and therefore subject to observer bias, it was extremely valuable to gain insight into the effect that sensory issues (and other aspects of autism) can have for the primary carers. Secondly, methods of dealing with sensory issues (or the reaction that they can elicit) were discussed. Participants tended to either initiate a) positive sensory interaction or b) non-sensory methods of coping (e.g. avoidance, distraction). In addition, they made a conscious effort to circumvent the problem at hand while helping their child integrate as fully as possible into society (i.e. by employing compensation techniques).

The dominant theme extracted from the data was that negative sensory experiences could have a profound impact on many aspects of daily life. Firstly, there were emotional ramifications of interaction with negative sensory stimuli. For the child, this involved extreme levels of distress, which the caregivers found very difficult to observe (resulting in them also becoming anxious and upset). The participants were more reticent to disclose the effect that looking after a child with autism could have at the beginning of the discussion. This may be because they would not want to appear to be 'complaining' about their child. However, it was apparent that they really valued the group discussion and became much more likely to 'admit' to finding it difficult to cope at times as the session wore on.

Secondly, when a child exhibited challenging behaviour in response to unpleasant sensory input, this could have health and safety ramifications for both the child and those around them. Primarily, the sensory issues could lead them to lash out at their caregivers ('You know you've got kicks, you've got black and blue marks') – this is particularly problematic when the recipient is not physically fit. Moreover, there is evidence that the well-being of the principal carer is related to the level of challenging behaviour exhibited by the child (Hastings, 2003), which was an issue for those in our sample.

Furthermore, there are health implications for the children themselves, especially if they refuse to wear winter accessories during the colder seasons, or eat non-food substances (also known as pica). The latter, in particular, is a major concern as there can be severe consequences (McLoughlin, 1988), including surgery or even death. It is a disorder which is much more common in individuals with intellectual disabilities than in the general population (González et al., 2009), and individuals with autism are deemed to be particularly at risk (Matson & Shoemaker, 2009). Some of the participants in the sample

described that their child would eat non-food substances ('My daughter has just recently started licking the top of her deodorant'), which was concerning. In addition, there were anxieties about the safety of the child, as they would often try to avoid negative stimuli in desperation, without taking into account hazards around them (e.g. cars, other pedestrians). This could become more of a problem as the child grows older, as they will become far harder to physically control.

Lastly, there were often social implications, for both the child with autism and their caregivers, of interacting with problematic sensory stimuli. The participants often found that they had to avoid certain places as a result of the sensory environment. Sometimes, this had an effect on family life, e.g. whether they were able to go on a foreign holiday or attend a family gathering. This concurs with the literature, and there is evidence that the challenging behaviours often exhibited by those with autism can result in feelings of social isolation (Gray, 2002).

The second main theme of the data was that caregivers used certain coping methods to deal with negative sensory issues and the challenging behaviour arising from them. Firstly, there was a discussion around the positive impact of certain sensory experiences, and that these could help to calm the child when they were under distress. Typically, the positive stimuli were related to tactile or vestibular input, as well as certain aspects of visual stimuli (namely movement and colour). These modalities (particularly touch) have been consistently reported as bringing pleasure and enjoyment throughout all the qualitative studies (see Chapter 3, Chapter 4.3.1 and Chapter 5) and could be useful information for relatives and those working with people who have ASD. Caregivers also tended to avoid certain situations that had proved problematic in the past, as well as use distraction techniques and attempt to compensate in some way for their child's sensitivities.

The majority of children in this group had other complex needs (see Table 4.3), which makes it difficult to generalize the experiences of the participants (and their children) to others in a similar position. However, the majority of participants described both pleasant and unpleasant sensory experiences. Indeed, the most interesting finding from this focus group was not that sensory issues were pervasive, but that they could have such an extensive impact on the well-being of the individual with ASD and their families. Furthermore, one thing highlighted through the data was the importance of peer support. Many of the caregivers felt incredibly isolated and repeatedly discussed how they felt a

lack of understanding from others, even their own families. They appeared to value hearing similar experiences from others in a similar situation.

These data show that the children with ASD reported by our sample often experience strong positive and negative responses to sensory stimulation. Exposure to negative sensory stimuli can result in challenging behaviour and social isolation. In comparison, exposure to enjoyable sensory experiences could help to calm the child when they were upset. As many of the children in this study have limited or no language abilities, the caregivers describe the difficulty of being 'caught unaware' by the problems in the sensory environment. These data show the (often traumatic) effect that problematic sensory stimuli can cause, and this is one group that would benefit from being able to modify their environment in some way. As such, taking measures to assess an environment before taking the child in (and perhaps modifying it) could make accessibility easier for individuals with autism, and could minimise distress in uncomfortable situations (see Chapter 8).

One potential limitation of the research reported in this chapter is that the children in the caregiver focus group had other comorbidities. Indeed, it may be that the sensory difficulties reported by the parents could be concomitant of their comorbidities, rather than the ASD itself. This means that the results of this group have limited generalizability to ASD as a whole. However, as mentioned in Chapter 1, it is a limitation of much of the research today that focus is placed predominantly on 'higher-functioning individuals', and I would argue that it is important to consider the experiences of those with ASD and co-occurring disorders, albeit through second-hand sources. Indeed, the purpose of the research was to investigate the implications of sensory issues themselves, rather than to determine whether their origin was a result of their autism diagnoses, although repeating the study in a group of parents of those with only autism diagnoses would be an interesting avenue to pursue in the future.

4.4.3 – General discussion

By considering both the views of children and parents in this study, we were able to gain different insight into the sensory issues of those with ASD, and the implications of this for a) the child themselves and b) their family. The children's experiences centred on descriptions of what it <u>feels</u> like to be sensitive to sensory stimuli. By giving the children a way to express their experiences in a fun, enjoyable setting, we were able to gain a deeper

understanding of what it can be like to experience hyper- and hypo-sensitivity to sensory stimuli. In contrast, the parents' accounts were more likely to consist of descriptions of the social, physical and emotional implications of sensory issues (for both the child and themselves). Again, this was fascinating, as we were able to extract more information about the impact of sensory issues, on the child as well as those closest to them. Interestingly, similar themes arose from both the children's groups and the parent's focus group, including the recognition that interacting with sensory stimuli could be painful, that interaction with sensory stimuli could be enjoyable (under the right circumstances) and that auditory stimuli seemed to cause children with ASD the most difficulty. We would argue that it is important to find ways of including clinical groups (and their families) into the research process as a precursor for developing new experimental paradigms (Chamak et al., 2008; Pellicano & Stears, 2011), and that it could be best to approach different groups for information, rather than relying solely on a single viewpoint.

Chapter 5   Sensory experiences of adults with ASD: a focus group study

5.1 Introduction

Although the first accounts of autism were published in the 1940s (Asperger, 1944; Kanner, 1943), there have been huge advances in the understanding of ASD in recent years, with a corresponding increase in support and services. However, the development of services for adults with ASD has been gradual, with equivalent services in place for children far earlier (Morgan, 1996). Furthermore, many individuals with ASD can find life difficult after they leave school (Hendricks & Wehman, 2009; Taylor & Seltzer, 2011), as they are often unable to find employment and may not have structured day activities to attend. This can have a subsequent effect on mental health, with Taylor & Seltzer (2011) finding that 86% of their ASD sample with no daytime activities also had comorbid psychiatric diagnoses. Therefore it is important to consider the viewpoints of adults with ASD as well as children, and we felt that a focus group with this population would be a beneficial addition to the work reported in Chapter 4.

As reported in Chapter 1, the Autism Spectrum is an informal umbrella term used to encapsulate several separate diagnoses, although this will change in the next version of the DSM (American Psychiatric Association, 2010). As such, ASD is often used to refer to a heterogeneous group of individuals with huge variability in various aspects of their functioning. Baird et al. (2006) estimates a UK prevalence rate of approximately 116.1 per 10,000 people (equivalent to 1.16%) for ASD. On average, each person with autism will cost the economy between £0.80 million and £1.23 million over their lifetime, both due to the direct cost of services and indirect costs of lost productivity (Knapp, Romeo, & Beecham, 2009). However, many individuals with ASD want to work, and studies show that with the right level of support in adulthood, this is often achievable (Hurlbutt & Chalmers, 2004). It is therefore particularly important that, for adults with ASD, services are tailored to the individual and provided based on need (Hendricks & Wehman, 2009).

 Jones et al. (2003) examined five autobiographical accounts, by studying a sample of personal websites written by people with self-disclosed HFA. They explored the accounts, identifying and categorizing the unusual sensory perceptual experiences described. The authors used Grounded Theory to analyse the data (Corbin & Strauss, 2008). Four core

categories emerged from these data: turbulent sensory experiences, enjoyable sensory experiences, coping strategies and an awareness of being different. They concluded that it is important to note that sensory experiences can sometimes be positive as well as debilitating. Furthermore, they suggested that providing parents of those with ASD with a greater understanding of the manner in which unusual behaviours are a manifestation of sensory-perceptual problems may lead to a decrease in parental stress levels.

As mentioned in section 4.1, it is important to take the views of those with ASD into account when conducting research, and I would argue that it is imperative that researchers conducting qualitative studies find ways to engage clinical groups wherever possible. This chapter reports, as far as we are aware, the first focus group discussion of sensory issues in a group of high-functioning participants with a confirmed diagnosis of ASD. The aim of the study was to gain first-hand insight into the sensory experiences of individuals with ASD, in their own words.

5.2 Methods

5.2.1 – Participants and recruitment

6 individuals (1 female; 5 males) with a diagnosis of ASD were recruited as part of this study. All participants worked for a local company that employs those with a diagnosis of ASD. All participants knew each other prior to the focus group, although some had only recently joined the company. Participants were aged between 24 years 2.5 months and 51 years 6.3 months at the time of the focus group (mean = 32 years 1.3 months; SD = 10 years 3.1 months).

5.2.2 – Stimuli

The group was asked the following questions throughout the course of the discussion:

1. Do you feel more/less sensitive to your environment than other people seem to?
2. Do you ever have physical reactions to sensory stimuli?
3. Are there particular aspects of stimuli that make it particularly difficult or enjoyable for you?
4. We're planning on developing a toolkit that we can use to assess an environment. What would you say are the most problematic a) visual, b) auditory and c) olfactory aspects of an environment? Can you describe why?

5.2.3 – Ethical considerations

The Faculty Ethical sub-committee of the University of Glasgow granted ethical permission for the study prior to recruitment commencing. Initially, contact was made with management at a local company that employs individuals with confirmed diagnoses of ASD. Thereafter, the author and her supervisor (DS) met with two members of staff, where the possibility of running a focus group was discussed. It was decided that the staff at the company would be invited to participate (through a gate-keeper) and that they would be informed about the nature of the study. The decision was made to use a gate-keeper to ensure that potential recruits felt no undue pressure to participate. All participants were informed that the topic of the focus group would be sensory issues and it was stressed that they would be free to leave the study at any time. Seven individuals agreed to participate, although one was not able to take part on the day chosen.

On the day of the study, it was reinforced that the participants were able to leave the study at any time, without having to give justification. They were also told that, although the data may be used for publication in journal articles or at conferences, they would never be identifiable as the transcript would be anonymized prior to analysis. As with the other focus groups (Chapter 4; Chapter 6) initials were assigned to each participant. All participants were happy to take part in the study and signed consent forms. One participant asked for clarification that data could be redacted from the transcript if necessary, which was given. However, none of the participants contacted the experimenter after the study to ask for this.

5.2.4 – Procedure

This study was organised through a gate-keeper, who scheduled the focus group at a time convenient for everyone involved (within working hours). The focus group took 1 hour 20 mins to complete, excluding a 20 minute break at a convenient point in the discussion. All participants were fully informed about the study prior to recruitment, although the experimenter re-iterated the most important points and answered any questions prior to starting the group. All participants also signed consent forms and filled out a brief demographics questionnaire. The topic of the focus group was sensory issues in autism spectrum disorders. After the focus group was completed, all participants were keen to learn of the results, and gave the experimenter their email addresses to be contacted at a later date. A summary was emailed to participants 3 months after the focus group was held.

5.2.5 – Increasing rigour

5.2.5.1 – Inter-rater reliability

The author was the sole coder for these data. However, in an effort to establish reliability, certain steps were carried out. Firstly, codes were developed and discussed with a supervisor (DS) as coding developed. Secondly, DS was asked to code 20% of the transcript. A Kappa Coefficient of .800 was obtained for AR and DS's attribution of codes for this section, showing a high level of agreement. In addition, intra-rater reliability was obtained (.969) for 20% of the transcript (where AR coded the transcript twice, one month apart).

5.2.5.2 – Verbatim accounts

As in section 3.2.4.2, data are presented verbatim

5.2.6 – Data analysis

Data were analysed using a general inductive approach (similar to 'thematic analysis') (Thomas, 2006), as described in section 3.2.5. As in Chapters 4 and 6, all participants are referred to using two initials unrelated to their names.

5.3 Results

The discussion generated by the group detailed the sensory experiences of individuals with a diagnosis of ASD. There were four main themes that emerged from these data: particular aspects of stimuli, control over stimuli, emotions and physical responses to stimuli. These are reported separately for positive and negative sensory experiences. Analysis of the data showed that all of the participants in the focus group consistently experienced atypical sensory perception with certain stimuli, which often resulted in strong physical or emotional reactions. This could either be a difficult experience (resulting in negative emotions and physical reactions) or a positive experience (resulting in enjoyment or comfort). The coping mechanisms for dealing with problematic stimuli were also discussed, with avoidance, concentration on 'good' sensory stimuli and compensation being the main forms of relieving the discomfort caused.

5.3.1 – Negative experiences with sensory stimuli

The discussion of negative sensory experiences mainly focused on visual, auditory and olfactory stimuli, although there were also descriptions of certain tactile and gustatory stimuli that were unpleasant to interact with. This is understandable, as tactile and

gustatory stimuli would require direct skin contact in order to be perceived, whereas this is not necessary for visual, auditory and olfactory stimuli. The participants engaged in discussion about the control of a stimulus, and came to the conclusion that an inability to control something could affect whether the perception of it is positive or negative. Furthermore, emotions appeared to have an interesting role in perception of stimuli – like negative physical responses, uncomfortable emotional states were often a consequence of interacting with problematic stimuli. However, unlike physical responses, emotions also seemed to play a role in shaping *how* a stimulus is perceived. An illustration of the way in which each of the main categories influenced the others (in the negative sensory experiences) is depicted in Figure 5.1.
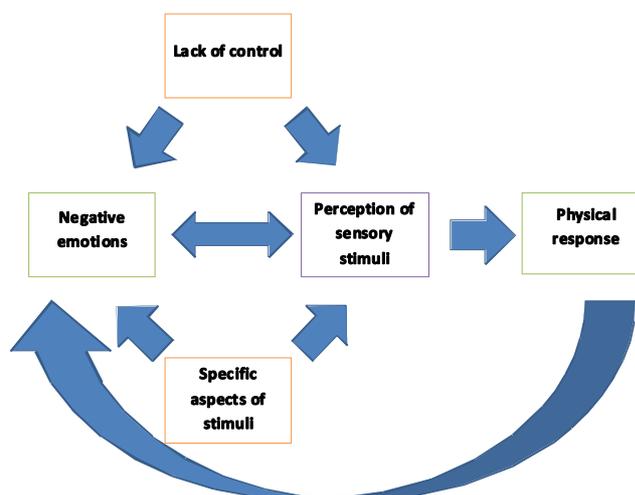
Figure 5.1 – This figure shows the aspects of a stimulus that reportedly impacted on perception (orange boxes) and the consequences of interacting with sensory stimuli (purple boxes). It should be noted that uncomfortable emotions were also reported to sometimes have an effect on the perception of a stimulus

The pattern that emerged from the data was that the perception of difficult sensory stimuli was dependent upon three things: emotional state, specific aspects of a stimulus and lack of control. In turn, negative response to the stimuli could either be emotional or physical in nature, with the latter occasionally causing emotional distress. Specific qualities to the stimuli (e.g. intensity), as well as lack of control, appeared to impact on emotions.

5.3.1.1 – Specific aspects of stimuli

For visual stimuli, the intensity of a light often had a discernable impact on whether response was uncomfortable. Bright lights were often cited as problematic, with participants stressing that they preferred 'dullness or darkness' and that 'bright light becomes very uncomfortable'. Moreover, the type of lighting used in environments was

deemed very important, with natural lighting being preferred over fluorescent light ('my eyes have struggled in sort of like fluorescent light or unnatural light … that sort of stimulus becomes painful after a while'). YY also mentioned low flicker rates in lights, specifying that once he had noticed flicker, he found it hard to divert his attention ('I do notice flicker … in things and I tend to have a focus on it').

Furthermore, strong colours appeared to be an issue with certain members of the focus group, even affecting the colours used in the signs of the working environment: 'I remember the issue we had with the signage in here and … certain colours would hurt s- so red was a no-no in here'. Patterns were also difficult for some members of staff, with YY recalling an incident where he was unable to process the repeated pattern of items in a shop ('I have the experience still to this day of standing in the shop staring at things for about five minutes … it's the kind of structure of the shelves and repeated things, it becomes too much and I just stop being able to process any of it'). XX also mentioned having difficulty with certain patterns ('[I have problems with] maybe one of those mats … with zillions of these metal strips like the station – it's like an optical illusion'). Lastly, rapid change of either intensity ('when I come out of this building, I've got to put my head down for a minute for my eyes to adjust to the light') or type of lighting ('if you go from here into natural light – that's another [problem] too') caused issues for the participants in our sample.

Certain sounds were also an issue with the group, with particularly loud ones often causing pain ('loud noise can bother me quite a lot and it can feel painful'). However, it should be noted that noises with low intensity could also cause discomfort. WW mentioned that certain noises annoyed him ('Small noises annoy me, like breathing, crunching food or … someone whistling … it makes me ratty'), whereas XX felt that noise was often a distraction, particularly when working ('what anyone else might … consider minor or trivial … like someone's music, like quite quietly … any noise can be a distraction for me if I'm trying to concentrate').

There was also a suggestion that a mixture of competing sounds could be an issue. AB recalled a period where she worked in a call centre, which was particularly difficult:

> 'the job I had before this one … was [in] an open plan office where they played five different radios in the same office … and then you would have people coming in and out … by the end of each day … I was literally sitting with my head on my desk'.

The frequency of noises was also an issue; with particularly high and low frequency sounds deemed the most uncomfortable. CD described the whirring of the computer fan and the sound of a vacuum as being uncomfortable for him: 'the fan whirring in a computer … that particular frequency can be annoying, or a hoover … I couldn't stand the noise of that'.

For olfactory stimuli, the intensity of a smell appeared to be the most likely factor to affect whether perception was uncomfortable. WW and YY described their reactions to a change in disinfectant gel made available in the bathrooms: 'they've got a new hand gel in the loo … and I just couldn't use it because it was just so overpowering' and 'the same hand gel – I was noticing it for two days afterwards … I've stopped using it as well'. Moreover, the ability to adapt to olfactory stimuli was reportedly diminished in our sample ('the smell of food … I don't get used to it while I'm around it'). Lastly, XX indicated certain smells could have an impact socially, as his aversion to cigarette smoke was so overwhelming that he was unable to visit certain relatives unless it was a very special occasion (e.g. Christmas): 'my biggest issue … is smoking – I've got one relative in particular … I won't even visit her unless there's a really good reason for it'.

YY mentioned that people lightly brushing past him could cause an adverse reaction ('people brushing past me … it's like pain mixed with panic … and I can become quite aggravated because of it'). AB also mentioned that being hugged caused her physical pain ('[with] light hugs … it gets to the point where my body tenses to the point of being painful'). However, the majority of tactile discomfort related to the texture of food. Both ZZ ('I can't eat whelks and mussels … because, like, they burst in your mouth') and AB ('I've got to sort of burst [peas and grapes] a little before I eat them because anything bursting … I feel like anything … pop[ping] … in my mouth will make me feel physically sick') disclosed that the sensation of popping in the mouth was uncomfortable. Lastly, the mixture of textures was an issue for many in the group, with one common method to compensate being to eat one type of food at a time ('about mixing your textures, you find you have to eat one, you know, after another'). Furthermore, participants reported that they often experienced nausea whenever they ate food with multiple textures ('there are other textures that, if they were mixed … the sensation makes me want to feel physically sick').

5.3.1.2 – Lack of control

One pervasive point throughout the discussion was that of control over sensory input or the sensory aspects of the environment. The participants stressed that a lack of control altered the effect that a sensory stimulus could have. For example, CD discussed his experiences with control over tactile stimuli:

> 'one of the themes I've noticed come up quite a lot is control, for people, and that seems to matter. If they have control over the sensory input then it's much less distressing, and I find that's quite true with touch. If it's a surprise, or if I don't feel control over it, for example if somebody's bigger and stronger, then the touch … [is] more unsettling than if we've got a feeling of control'

In this example, CD highlights that the discomfort he feels from the sensation of being touched is much less when he has control over it (i.e. being the stronger person in a hug, or being aware that someone is going to touch him).

The concept of control over sensory stimuli was important to other members of the focus group. AB discussed the need to be self-aware and to take precautions when interacting with potentially uncomfortable stimuli: 'I'm going to see Scrillex on Saturday night, and that's really loud dubstep with really high frequencies and really low frequencies, but I have earplugs which take out the high and the low frequencies, so I can stand it'. It is only by exerting control over her sensory environment, by wearing specific earplugs (acting as a type of band-pass filter) that AB would be able to attend the concert.

YY mentioned that he enjoyed working in an environment where staff were encouraged to discuss their sensory needs with management: 'I find it very reassuring, even if it's not complete control … that it's OK to say to people, or to even discuss [changing the environment]'. He also mentioned the relief at being allowed to alter the environment in the designated 'chill out room':

> 'in the chill out room … I find it quite comforting … that in there it's OK to touch the lights and stuff, because in another situation, it would make me more stressed out – the fact that I was doing something I wasn't supposed to be'

The data from the focus group showed that the participants really valued the opportunity to adapt their surroundings and that this ethos had positive effects, both personally ('the idea that it's OK in this environment … to talk about [your sensory needs] … is very comforting') and professionally ('with that kind of provision I actually got a lot more work done than I would have imagined was possible').

5.3.1.3 – Negative emotions

The discussion from the group showed that negative feelings could both alter perception and be a consequence of interaction with negative sensory stimuli. AB disclosed that anxiety could affect whether she was able to enter a busy environment: 'if I was very anxious before going into that gig, and you know, if I was already having a pretty bad … sensory day, then I wouldn't be able to walk into the place', as it made her more sensitive to the sensory stimuli in the environment. Conversely, YY described how being anxious or upset meant he became unable to process sensory stimuli at all: 'I've had the experience of being in bad situations where I was … distraught … [and I] actually accidentally hurt myself, like standing on … glass and not noting for at least twenty minutes that I was bleeding'.

Moreover, some participants disclosed experiences where the sensory stimuli themselves caused a strong emotional reaction. YY discussed how the temperature of an environment was important for him: 'if an environment's too warm, that would … be like the worst thing – I lose all ability to focus [and] become very very agitated'. Moreover, AB discussed the strong reaction she had to the odour of a certain brand of tobacco ('a friend of my grandfather … smoked Golden Virginia and it would frighten me – I would run away screaming') and the effect that smells could have on her perception of a person ('I associated a person by their smell … they could be the nicest person in the world but if I didn't like how they smelled, they were evil to me').

5.3.1.4 – Physical responses

All participants in the focus group described experiencing some sort of physical discomfort from sensory stimuli at some point in their lives. The majority of examples were related to pain in the visual, auditory and olfactory domains. YY described feeling pain when he smelled certain scents ('bad smells feel quite painful as well … I always just assumed that's just how they are'). Headaches and migraines were commonly reported for specific types of lighting ('I actually get severe migraines because of light' and 'strip lighting … that can immediately … hurt a lot'). Moreover, loud noise ('loud noise can bother me quite a lot and it can feel painful') and certain frequencies ('high-frequency noises and low-frequency noises tend to really hurt me') were reported to cause physical discomfort. In addition, some participants mentioned that a sensory stimulus could elicit nausea, although this reaction seemed restricted to interaction with foodstuffs: 'if … [there's] a

strong kind of sensory smell of a food … I couldn't even think about eating it' and '[if] textures … were mixed … the sensation makes me want to feel physically sick'.

5.3.2 – Positive experiences with sensory stimuli

The discussion around positive sensory experiences mainly focused on the auditory and tactile domains, with a particular focus on music. The theme of control was again evident, with participants reporting that the most enjoyable sensations were those initiated by the participants themselves. As was observed for the negative experiences, emotions appeared to have an interesting role in perception of stimuli – positive physical responses (e.g. relaxation) as well as enjoyable emotional states were often a result of interacting with pleasurable stimuli. However, unlike in the perception of distressing stimuli, emotions did not appear to have the same role in shaping *how* a stimulus is perceived. Despite this, certain members of the focus group mentioned how they were able to manipulate their emotions at will by using specific sensory stimuli (e.g. music). An illustration of the way in which each of the main categories influenced the others (for the positive sensory experiences) is depicted in Figure 5.2.
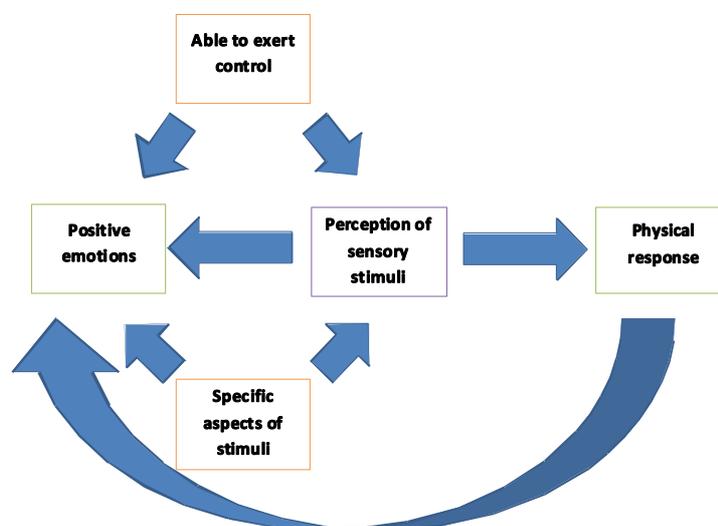
Figure 5.2 – This figure shows the aspects of a stimulus that reportedly impacted on perception (orange boxes) and the consequences of interacting with sensory stimuli (green boxes).

The pattern observed for positive sensory stimuli was similar to that for problematic sensory experiences (see Figure 5.1). However, the main difference was that there was no suggestion that positive emotions affected the perception (or response) to sensory stimuli. As mentioned previously, participants indicated that interaction with enjoyable stimuli increased positive affect. Although many participants reported 'using', or manipulating

stimuli to change their emotions, there was no suggestion that being in a positive emotional state enhanced the positive sensory experiences.

5.3.2.1 – Specific aspects of stimuli

The majority of positive sensory experiences described by the group involved the auditory and tactile domains, with intensity and texture being particularly important. ZZ discussed the positive impact of playing loud music ('I like loud music and stuff like that really helps calm me down'), while XX specified that he enjoys loud music of his choosing ('I like loud music, if it's my choice of music … whether it's Mozart or … something more rock or pop-py – if I've chosen it then I like it loud and if it's not my choice then I want rid').

In terms of the tactility of a surface, cold smooth surfaces seemed to be the most pleasurable among the participants. YY described how he sought out cool wooden or metal surfaces: 'Especially as a young child [but] still now as well … I used to put my hand underneath chairs and stroke the metal bits on benches'. AB depicted how she loved the smooth, cool sensation of tiles from a young age and that touching them could even help her fall asleep: 'the basement had these sort of slate tiles … [which] were always cool and always very smooth and if I was having trouble sleeping [my parents] would take me to the basement … because I'd go out like a light'.

5.3.2.2 – Able to exert control

The ability to control the environment, or at least aspects of it, was deemed very important by the focus group. AB discussed a previous job working in a call centre: 'the job I had before this one was an open plan office where they played five different radios in the same office at varying volumes and varying styles of music'. She continued by discussing that one method she used to cope with this aversive environment was to play her own music and try and concentrate specifically on it: 'I used to have an iPod deck … and I tried to listen to music on that … I would try and physically concentrate on my music … it made everything a little bit bearable'. AB found that having control over some of the noise made the situation less distressing. In additon, YY found that being free to listen to music in the workplace (using earphones) has reduced the sensory stress that he experiences from the environment: 'the provision to be able to listen to music in the environment … has a huge ability to kind of remove stress from the environment'.

5.3.2.3 – Positive emotions

The participants in the focus group described the pleasure they received from interacting with certain sensory stimuli. AB mentioned that she enjoyed the whole process of eating a particular type of chocolate biscuit, primarily because of the wrapper: 'I liked the sensation of pressing the tinfoil into the KitKat … and… tearing the paper open … it was a very tactile pleasure'. Predominantly, participants reported a sense of comfort when interacting with enjoyable sensory stimuli. YY and AB both described deriving comfort from small sections of songs or certain sounds, and even reported using software to loop the sections in order to be able to listen again and again ('I would just keep repeating … the same 10 seconds of a song … it is something to comfort me' and 'I would use … music software … to isolate that sound – just have that looping constantly and that would bring great comfort').

As mentioned previously, the pattern observed for negative stimuli (that mood and emotions can, at times, shape sensory perception) did not emerge in the discussion of positive sensory experiences. However, the ability to manipulate emotions, particularly by using music, was discussed at length. WW reported that a certain piece was able to calm him down when stressed: 'I'll listen to classical music if I want to be calm or I want to be peaceful … other music, you'll learn if you want to be happy … playing Vivaldi's Four Seasons … is the only way [for me] to sort of calm down in certain situations'. In addition, ZZ discussed how he uses music playlists to alter his emotional state: 'I can almost manipulate my responses to the sound … and sort of, you know, program that'.

5.3.2.4 – Physical responses

The majority of positive physical experiences with sensory stimuli involved relaxation. AB mentioned that her eyes feel as if they noticeably relax when she goes into a room with natural lighting: 'I can physically feel my eyeballs straining right now, because of the light in this room – but as soon as I go into my office, you know, I can feel them almost sort of … relaxing'. XX discussed that the sound of a detuned radio would help him to sleep ('A radio not tuned to anything is a very send asleep noise for me'), whereas YY described the sound of a vacuum cleaner as being soothing ('When I was a child my mum said the only way I could sleep was if she put the hoover on').

5.3.3 – Other notable themes

5.3.3.1 – Adaptation

One of the other themes that arose during the focus group concerned adaptation. Participants reported that they did not habituate as readily to stimuli as others appeared to. YY described noticing that other people seemed to be more able to adapt to stimuli: 'I don't get used to a smell very quickly – I notice other people … if they mention a bad smell they seem to forget about it – it doesn't seem to die down in the same way [for me]'. He also described that it took him weeks to get used to the smells in a new environment: 'It would have to be weeks … before I would get used to the smell of a place'.

5.3.3.2 – Single-channel processing

Many of the participants described experiencing single-channel processing, where the sensory channels appear to stop processing information to the exclusion of one modality. XX reported that small noises could 'shut off' his other senses in a discussion with AB:

> AB: 'small noises annoy me, like breathing or crunching food or, you
>
> Know, someone whistling (…) it makes me ratty as well because –'
>
> XX: 'it shuts off your other senses, in a certain respect'

He indicated that when his attention is diverted to an annoying stimulus (like hearing small, irritating noises), he is less likely to notice the sensations from his other senses as much.

YY reported that this often happened to him, and he would often use it to deal with difficult sensory situations. He found that he found it much easier to cope with crowds at a gig than in other situations, because he was able to concentrate on the music being played:

> '… it's the same with gigs, I haven't been in a while, but I used to do that. In any other crowded environment I'd have been extremely anxious, but that kind of – the fact I'm engaging one sense kind of dulls everything else out. [The crowd] stops being an issue entirely'.

This shows that YY attributes his problems with crowds to be, at least in part, a result of his sensory sensitivities. By engaging in single-channel processing, he feels better able to cope with large numbers of people. He also said using headphones in a busy street could be helpful: 'its like tunnel vision with one sense at a time … I have to listen to music on my headphones when I'm in busy streets … and it has to be loud'.

5.3.3.3 – Compensation

The participants also indicated that, when sensory problems arose, they often made certain adaptations in order to be able to interact with them. Both WW and AB described having to eat food serially, so that the textures (or the tastes) of the food would not mix in the mouth: 'when I used to be smaller … you'd work your way around the plate, you'd never mix textures or anything like that. It's not until, what, about five, six years ago that I'll actually put meat with a veg with potato'. AB mentioned something similar: 'going on from what WW was saying… you find you have to eat one, you know, one after the other so that your … mouth isn't basically fighting to process the tastes at the same time'. Eating foods one at a time appears to be a strategy used by some individuals with ASD to deal with the myriad of textures and tastes that can be present during meals.

There were other examples which highlighted that the participants in the focus group readily made changes to compensate for their strong sensory aversions. AB described how she disliked the smell of her mother-in-law, because of the deodorant she wore, and the steps she was taking to overcome this: 'I don't like how my mother-in-law smells … I've tried to make myself associate with her … she uses a certain type of deodorant and I'm trying to force myself to accept that smell by trying to use the deodorant myself'. In addition, CD mentioned that he found certain frequencies of noise to be particularly irritating, and he would shut the door to try and block them out: 'it used to be I'd always shut the door when the hoover was going. I couldn't stand the … noise of that'. AB described finding high and low frequencies particularly distressing, and had to resort to using certain earplugs at times: 'I'm going to see Scrillex…which is really loud dubstep with really high frequencies and really low frequencies, but I have earplugs which take out the high and the low [frequencies]'.

5.4 Discussion

This chapter reports the sensory experiences of a group of adults with a diagnosis of ASD. By extracting the most common themes within the data, we were able to build a picture of the sensory experiences that are most problematic (and most enjoyable) for our participants, as well as the factors that affect them. Although both hyper- and hypo-sensitivity was reported, the majority of examples given were related to over-reactivity to stimuli (or sensory-seeking behaviour), rather than under-reactivity. This tendency to report hyper-sensitivity rather than hypo-sensitivity was also reflected in the qualitative data from those with varying levels of autistic traits (Chapter 3), the children's groups

(Chapter 4) and the parent's groups (Chapter 4). It should be noted that, on occasion, the participants did disclose that they experienced hyper- and hypo-sensitivity in the same modality (e.g. auditory), but that this may be a result of focused attention on another sense (e.g. vision).

Three main findings emerged from these data. Firstly, the participants described the extremely debilitating effect that negative sensory experiences can have. These varied from nausea ('[if there's a] strong kind of sensory smell of a food … it makes me feel physically sick') and physical pain ('[with] light hugs … it gets to the point where my body tenses to the point of being painful') to immobility ('[with] high-frequency and low-frequency noises … I'll just become like a statue'). The description of sensory stimuli as being painful was also found in the qualitative studies mentioned previously (Dickie et al., 2009; Jones et al., 2003), as well as elsewhere in the thesis (Chapter 3; Chapter 4). It appeared that particularly intense stimuli or stimuli with a particular quality (e.g. certain frequency content or texture) were most problematic.

In addition, the participants also described experiencing emotional discomfort when interacting with certain stimuli ('if an environment's too warm … I become very very agitated'). It should be noted that, for the sample, negative emotional states (e.g. anxiety and distress) reportedly affected perception in some way, either decreasing tolerance for sensory stimulation ('if I was very anxious before going into that gig, and if, you know, I was already … having a bad sensory day, then I wouldn't be able to walk in') or diminishing the ability to perceive sensory stimuli that causes pain ('when I'm particularly anxious, I don't feel pain at all'). These descriptions concur with the literature – for example there is evidence that threat and anxiety can affect some aspects of visual perception (Laretzaki, Plainis, Argyropoulos, Pallikaris, & Bitsios, 2010). Furthermore, it has been established that emotions can affect pain perception (Malow, 2003) – as participants became more anxious, they became less likely to *report* the pain, although there is no difference in pain threshold. This concurs with YY's experience, as once his injury was pointed out to him, he became aware of the sensation of pain ('I've actually accidentally hurt myself, standing on … glass, and not noting for at least 20 minutes that I was bleeding, until somebody pointed it out … I didn't register the pain at all').

The second finding was that positive sensory experiences were highly enjoyable for the sample. The participants described manipulating their emotional and physical states with certain sensory stimuli, often using it as a way to calm down. The most common method

of doing this was to play music (not necessarily calming music). The use of music being a useful tool to soothe agitated individuals has been observed in those with dementia (Ragneskog & Kihlgren, 1997) as well as in university students with test anxiety (Stanton, 1973). In addition, (Stoudenmire, 1975) found that music could have a significant effect on situational (rather than dispositional) anxiety.

The participants also described being fascinated by certain stimuli and taking great pleasure in interacting with them (i.e. rather than using them only as a tool to manage stress). Again, this was also found in both Dickie et al. (2009) and Jones et al. (2003)'s studies. In the former, one parent described how their child derived pleasure from movement "'he likes to jump. So he jumps a lot, and he seems to get pleasure out of that'". In our sample, the majority of pleasurable experiences were involved with touch. AB described how she felt when touching cool metal: 'I like touching metal a lot … I love smooth metal – like cold smooth metal is like, just amazing'. One of the major themes to emerge from Jones et al. (2003)'s research was that sensory experiences could be highly enjoyable. One of their participants, Jane, described how enjoyable sensory experiences appeared to be heightened for her, in comparison to those without autism: "'All things are heightened for me, so what a regular person would be tickled with pleasure over, I'll be totally ecstatic'". The concept that both negative and positive responses to sensory stimuli are heightened in ASD was also discussed in our group, with the consensus being that the ASD experience of sensory stimuli is different from typically developed individuals: 'the main things that have bothered me throughout my … life … make more sense now (with) the diagnosis, but [I already knew] that [the sensory issues] were different from other people … they were more problematic for me'.

The last main finding was that control over a stimulus was extremely important to the participants, and affected their responses to it. In addition, certain emotional states (e.g. anxiety) appeared to heighten the negative perception of certain sensory stimuli. The participants were all in agreement that control was extremely important, and it was a theme which was discussed openly within the group: 'one of the themes I've noticed come up a lot is control … if they've got control over the sensory stimulus then it's much less distressing'. Dickie et al. (2009) found that uncontrollable stimuli were more distressing for children with ASD (as well as controls) than sensory stimuli that could be induced and terminated by the children themselves. It should be noted that Blakemore et al. (2006) found that those with Asperger's Syndrome (AS) rated self-controlled touch as just as intense as experimenter-controlled touch, compared to TD controls, who rated self-

controlled touch as less intense. However, the nature of the touch was not in itself distressing, so it may be that control is most important with negative sensory experiences.

In addition, there were other notable themes which emerged from these data. Firstly, there was discussion of adaptation to sensory stimuli, with some of the participants reporting that they did not feel they habituated to stimuli as quickly as others appeared to. This was particularly evident when discussing smells, with one participant mentioning that he can still smell alcohol disinfectant gel for days after he uses it. However, Tavassoli & Baron-Cohen (2012a) found no difference in the adaptation of individuals with ASD and TD controls to olfactory stimuli. Despite this, findings for olfactory processing in ASD have been mixed (Bennetto et al., 2007; Dudova et al., 2011; May et al., 2011; Suzuki et al., 2003; Tavassoli & Baron-Cohen, 2012a), so further investigation is warranted (perhaps in other ASD sub-groups), particularly as unusual adaptation to stimuli has been observed in the visual (Pellicano et al., 2007) and tactile (Tommerdahl et al., 2007) domains.

Secondly, some participants described a phenomenon where, once fixated on a strong stimulus, they became unable to consciously process information in the other sensory domains. This phenomenon was also discussed in Jones et al. (2003)'s paper. One of their participants, James, had developed this skill in order to cope with lots of stimuli in class. He was able to filter out all non-auditory information, which enhanced his ability to maintain concentration. In addition this skill was tremendously enjoyable, as he was able to replay enjoyable experiences verbatim. The main difference between the experiences of our participants and James is that the latter appears to have developed the ability to turn it on and off at will, whereas for XX and YY it seems to be (for the moment) uncontrollable.

Lastly, the participants described using compensation strategies to cope with aversive sensory stimuli. These included eating foods a certain way (e.g. one after the other), wearing earplugs which filter out high and low frequencies, having to pop the skins of certain foods before eating and wearing deodorant in order to try and become habituated to the smell. This shows that the adults in our focus group have developed strategies for certain issues, and may go some way towards explaining some of the unusual behaviours exhibited by those with ASD. Difficulties with food appear to be a real issue for individuals with ASD (Ahearn et al., 2001; Schreck et al., 2004), and it may be that similar issues underlie unusual eating behaviours in younger children. Our participants relayed that some of them still ate food sequentially, even as adults. In fact, the oldest participant in the group (WW), disclosed that he had only started to eat foods together 5-6 years

previously. It is well known that the senses of taste and smell diminish as we age (Schiffman, 1997), so one explanation for WW being able to mix foods now may have been that his hyper-sensitivity to food has reduced as he has aged.

This chapter reports a focus group discussion on the topic of sensory sensitivities between adults with a diagnosis of ASD. The main strength of these data is that we are able to gain vivid descriptions of the consequences of sensory sensitivities directly from those with ASD. One potential limitation of the study is that all the participants knew each other. There is often an expectation (which appears to stem from their market research origins) that focus groups should consist of strangers (Morgan, 1998), although the value of using pre-existing groups is highlighted in the literature (e.g. Kitzinger, 1994; 1995). We argue that prior relationships were beneficial to the study, as it meant that participants were comfortable with each other and enthustiastic about participating. Another possible limitation was that we used a sample in which all participants were extremely high-functioning individuals. However, it is much more difficult to employ a qualitative design with participants who have difficulties communicating. Moreover, it it not our aim to generalise these results to all others with ASD, but to use the data to better understand the sensory issues inherent within the Autism Spectrum and in future experimental design.

The data show that the individuals with ASD in our sample often experience strong positive and negative responses to sensory stimulation. The negative experiences can be extremely distressing and often painful. There were particular aspects of a stimulus that made processing more difficult, including the intensity, texture or frequency. Lastly, whether the participant had control over the stimulus was very important. Although there has been some research in control over sensory stimuli in AS (Blakemore et al., 2006), future research could address whether having control (i.e. over onset/length of stimulation/termination, rather than just onset) affects ratings of intensity in perception of sensory stimuli. The data from the focus group show that modification of the environment can make a huge difference to the productivity and well-being of individuals with autism, and this is something that workplaces should take into account. As such, taking measures to modify the environment (or even to be open to discussion about it) could make accessibility easier for individuals with autism, and could minimise distress in uncomfortable situations. This idea is taken further in Chapter 8.

Chapter 6 Experiences of others with sensory issues (elderly control group)

6.1 Introduction

Although sensory issues appear to be an integral part of ASD (Ben-Sasson et al., 2009), they are not exclusive to the autism spectrum. For example, individuals with Fragile X Syndrome (FXS) (a genetic condition which causes intellectual disability and physical/behavioural atypicalities) often display over-responsiveness to sensory stimulation (Scharfenaker, O'Connor, Stackhouse, Braden, & Gray, 2002). In addition, Miller et al. (1999) found that, for those with FXS, electrodermal responses to sensory stimulation were significantly different from those of TD controls, including being significantly larger, more frequent and demonstrating poorer adaptation to stimuli. This result suggests that individuals with FXS experience a physiologically elevated response to sensory stimuli. Moreover, there has been evidence that mice with Fragile X (instigated by knocking out their *FMR-1* gene) develop auditory hyper-responsiveness (Chen & Toth, 2001). As well as those with FXS (Baranek, 2002; Rogers et al., 2003), there is evidence that those with ADHD display unusual responses to sensory stimuli. Using the Sensory Profile (SP: Dunn, 1999) and the Short Sensory Profile (SSP: McIntosh, Miller, & Shyu, 1999) researchers found that those with ADHD demonstrate different sensory responsiveness compared to typically developing children (Dunn & Bennett, 2002; Mangeot et al., 2001; Yochman, Parush, & Ornoy, 2004).

Some researchers have developed the idea that the sensory sensitivity exhibited by some individuals is related to the concept of a 'highly sensitive person'. The Highly Sensitive Person Scale (HSPS: Aron & Aron, 1997) measures the 'sensitivity' of a person and includes items targeting emotional as well as physiological sensitivity. Smolewska, McCabe, & Woody (2006) found that the HSPS appeared to have three separate factors (ease of excitation, aesthetic sensitivity and low sensitivity threshold), rather than the single dimensional scale suggested by Aron & Aron (1997). These factors correspond to a) how easily excited someone is (with more sensitive people being aroused more easily), b) an appreciation of aesthetic attractiveness (e.g. art) and c) lower perceptual thresholds. However, one drawback with this scale is that reports of greater sensitivity do not necessarily correspond with lower thresholds, at least in the olfactory (Caccappolo et al., 2000; Doty, Deems, Frye, Pelberg, & Shapiro, 1988; Nordin, Martinkauppi, & Olofsson,

2005) and auditory (Khalfa et al., 2004) domains. However, there have been some interesting results using the HSP Scale. Jagiellowicz et al. (2011) recently found that people with higher sensitivity exhibited greater neural activation in areas implicated in higher order visual processing (e.g. right claustrum, left occipitotemporal, bilateral temporal and medial and posterior parietal regions), despite no difference in the accuracy of the change detection behavioural task. Liss, Mailloux, & Erchull (2008) also found that two aspects of the HSPS (EOE and LST) were related to autism symptoms (measured by the AQ), and that these aspects were conceptually different from aesthetic sensitivity (AES). Thus, it would have been interesting if Jagiellowicz et al. (2011) had controlled for AQ score in their study, in order to see whether there was a relationship between the HSPS and level of autistic traits.

However, it is not only increased sensitivity to stimuli that can be difficult for people to cope with. Those with diminished sensory sensitivity also experience difficulties in their everyday lives. This is particularly relevant to ASD as individuals on the spectrum experience both over- and under-responsiveness to sensory stimuli (Baranek et al., 2006; Leekam et al., 2007). There is evidence that hearing loss can reduce independence and increase the need to rely upon familial or community support (Schneider et al., 2010). In addition, Wauters & Knoors (2007) reported that children with hearing impairments have lower levels of social competence than their peers (despite similar levels of peer acceptance and friendship relations). Specifically, they had lower levels of prosocial behaviour (i.e. voluntary behaviour which helps others) and higher levels of socially withdrawn behaviour. In a study investigating the experiences of deaf adolescents, results indicated that those with hearing difficulties reported more symptoms of depression than their hearing counterparts (Watt & Davis, 1991). Furthermore, hearing loss is common as we age, particularly the ability to hear higher frequencies (Willott, 1991). There is evidence that hearing loss has implications for communication (Heine, Erber, Osborn, & Browning, 2002), as well as an impact upon the quality of social relationships (Nunes, Pretzlik, & Olsson, 2001).

However, audition is not the only sense in which a loss of sensitivity can cause difficulties. Vision often changes dramatically as we age, with acuity, contrast sensitivity and light sensitivity diminishing in older age (Fozard, 1990). In addition, various ocular diseases (e.g. cataracts, glaucoma and age-related macular degeneration) can cause visual occlusion, or even vision loss. Clark, Bond, & Sanchez (1999) investigated hearing and vision loss in aging adults. They found that visual impairment (rather than auditory) was

associated with a reduction in ability to carry out basic domestic chores. In males, there was also a reduction in frequency of social and leisure activities. However, the authors stress that it is important to take into account that these changes may be age-related, rather than purely a result of vision loss. Furthermore, Legault, Gagné, Rhoualem, & Anderson-Gosselin (2010) assessed the effect that blurred vision could have on auditory-visual perception in both younger and older adults. Results showed that loss of visual cues was associated with compromised speech understanding. In turn, this would mean that vision problems might make it harder to communicate when someone has hearing loss (because they would be less able to lip-read/use other visual cues etc.). Lastly, there is also evidence that there is a high prevalence of olfactory impairment in elderly people, and that sensitivity decreases with age (Murphy, 2002). While a loss of olfactory functioning is often an indicator of dementia (McCaffrey, Duff, & Solomon, 2000; Murphy et al., 1990), elderly people without dementia also experience diminished olfactory ability (Murphy, 2002). There are safety concerns associated with loss of olfactory ability, including problems smelling gas leaks or smoke – this becomes especially important if the older adult lives alone.

Elderly individuals are often described as being at risk of increased isolation as they age (Golden et al., 2009). We were interested in determining how sensory loss in elderly adults was related to social interaction and, as such, whether the link between atypical sensory processing and social functioning observed in previous chapters (Chapters 3-5) was also apparent in a non-ASD sample. An important aim was to determine whether there were any commonalities between the experiences of those with diminished sensory ability and both children (see Chapter 4) and adults (see Chapter 5) with ASD. In order to better understand the sensory experiences of elderly people (we defined this as over the age of 60 as the United Nations use 60 years as a cut off to refer to the older population) (World Health Organization, 2012), a group discussion with carers of those with dementia was carried out. Both first-hand and second-hand data were collected in this group discussion, and they will be reported separately in section 6.3.

6.2 Methods

6.2.1 – Participants

A convenience sample of those caring for individuals with dementia was used (consisting of a support group). The purpose of the meeting is to provide peer support in a friendly environment. At the time of the study, the support group had been in existence for

approximately 8 months and consisted of members who attended on a monthly basis. Staff (n=1) and volunteers from local care (n=1) and dementia (n=1) charities were also on hand to provide support. As they were interested in the topic, they were invited to participate in the discussion. 12/16 participants were over the age of 60 years (which is the age deemed 'elderly' by the UN).

6.2.2 – Stimuli

The group was asked three questions throughout the course of the discussion:

1. It is well known that we become less able to sense things as we age … is this something that you've noticed and, if so, what impact has it had on your life?

2. Some people say that if their senses change it can affect their relationships in some way … is this something that you've ever experienced?

3. Are there any places that you visit, or normal daily activities that you now find problematic because of sensory issues, and if so, what is it that makes them problematic?

6.2.3 – Ethical considerations

The Faculty Ethical sub-committee of the University of Glasgow granted ethical permission for the study prior to recruitment commencing. Management at Carers Link East Dunbartonshire, a charity that provides support for carers, suggested running the group discussion with one of their support groups. Participants were informed that there would be a group discussion during the August 2010 meeting. On the day of the study, all participants were informed that they were able to leave the study at any time, without having to give a reason. They were also told that, although the data may be used for publication in journal articles or at conferences, they would not be identifiable, as the transcript would be anonymized prior to analysis. All participants were happy to take part in the study and signed consent forms.

6.2.4 – Procedure

On the day, the group was informed that a discussion would take place. Everyone was free to participate in the discussion (if they wished) and informed consent was obtained for all participants. The session consisted of 3 main topics which were discussed by the group. The author was the moderator and her role was to prompt discussion if needed, but to mainly let the discussion grow organically from the participants. The group discussion

took approximately 35 mins to complete and 12 of the 16 participants joined in at various points.

6.2.5 – Increasing rigour

6.2.5.1 – Inter-rater reliability

The author was the sole coder for these data. In an effort to establish reliability, certain steps were carried out. Firstly, codes were developed and discussed with a supervisor (DS) as coding developed. Secondly, DS was asked to code 20% of the transcript. A Kappa Coefficient of .810 was obtained for AR and DS's attribution of codes for this section, showing a high level of agreement. In addition, intra-rater reliability was obtained (.948) for 20% of the transcript (where AR coded the transcript twice, one month apart).

6.2.5.2 – Verbatim accounts

As in section 3.2.4.2, data are presented verbatim

6.2.6 – Data analysis

Data were analysed using a general inductive approach (similar to 'thematic analysis') (Thomas, 2006), as described in section 3.2.5. As in Chapters 4 and 5, all participants are referred to using two initials unrelated to their names.

6.3 Results

There were three over-arching categories formed from these data: a) that the diminishment of sensory ability impacted on an individual's ability to participate in their daily routines, b) that the impairment of senses can negatively affect a person's desire and ability to participate socially with others and c) that people often attempt to compensate for loss of sensation. This compensation was either for the sense itself (e.g. using a hearing aid) or for the effect that it has (e.g. having to give bank details to another person as they are unable to see the numbers on the ATM).

6.3.1 – First-hand data

6.3.1.1 – Sensory issues can affect daily functioning

There was evidence that sensory issues could affect daily routine in some way. KK disclosed that she had lost the hearing in one of her ears, and that this had a substantial negative effect on her life: 'Well I've lost hearing in one of my ears and it's terribly

detrimental on my life'. She elaborated by describing the impact that her hearing loss has, in addition to her visual difficulties:

'I find it <u>awful</u> being deaf in one ear – I also wear glasses and I

was just saying I wear tri-focal glasses – I can't see to read, I can't

see to watch the television and I can't see to drive without my glasses'

She also highlighted that she relied heavily on her glasses and found noisy environments intolerable:

'so take my glasses away, put me in a room with noisy people and I can

neither see nor can I hear … but I find that very detrimental'

For this individual, the loss of her vision and hearing hugely affects her ability to participate fully in her daily routine. Indeed, her ability to do so depends on several factors (e.g. access to her glasses/being in quiet environments).

The participants reported visual difficulties that were the result of aging. LL found that she now needed to have a brighter environment in order to complete visual tasks: 'as I got older I found that I need more light, to read and do things'. In addition, she noted that new energy saving lightbulbs appeared to emit less light than the older incandescent bulbs: 'I feel the house is awfully dim at night [with] all these new wattage bulbs that you get'. QQ described how he was now unable to read the prices in supermarkets: 'I'm having to use my specs in the- the supermarket … I used to be able to just go in and … be able to distinguish prices – now I just can't'. However, he later suggested this may be a result of smaller font sizes, as his visual acuity had changed very little: 'I don't really understand it because I had my eyes tested just a few weeks ago and there's been virtually no change in the last twenty years – [then] I could make out the prices – now, today, I can't'. RR coped with being unable to see prices in a supermarket by using a small magnifying glass: 'I got a necklace and at- at the end of it- it looks like a necklace but it's a magnifying glass – it was great in the supermarkets but now I've lost it and I can't find it!'.

In addition to descriptions about visual and hearing impairment with age, one participant mentioned noticing her taste ability had diminished with age: 'I don't know about any of you but I find my sense of taste is not as good, because <u>food</u> doesn't taste as good as it did thirty- [or] forty years ago'. It should be noted that this may actually be a result of smell sensitivity lessening, rather than taste, as the two senses are strongly linked. However, there was no further discussion of taste or smell, so we were unable to explore this further.

Moreover, participants indicated that they tended to avoid things (perhaps subconsciously) when they started to find them difficult. When AR asked a question about eating out in restaurants, the immediate response was that they avoided these types of activities:

AR   'what about going out to restaurants and reading menus and things?'

LL   'you don't!'

MM   'Yeah – you- you make the choice!'

UU   'Not often!'

The responses of the group indicated that they felt unable to eat out as often, due to small font sizes used on menus. Although this would be easily remedied by using reading glasses, it could be difficult for someone to become used to carrying them everywhere, in case they ever need to read small print. In addition, it may be annoying to ensure they are accessible at a moment's notice.

Lastly, there was evidence that sensory issues could cause pain and discomfort. KK described how loud sounds could be physically painful:

'loud sounds are very painful – if I'm out and there's a band playing

and they play loud, it actually hurts my deaf ear – you know you think

I'd be happy because it was loud but no- – it actually hurts me'.

She also discussed how high-frequency sounds were particularly painful: 'it's high-pitched, high-pitched, it's- it's painful'. In addition, LL and NN discussed how certain sound frequencies and types of lighting gave them migraines: 'the thump thump thump of the background music and it actually gets on your nerves and gets into your head somehow and- it can almost trigger a migraine' and 'I find, like, fluorescents very difficult to deal with, as I'm getting older I get more migraines with them'.

6.3.1.2 – Sensory issues can affect communication and relationships

Primarily, the discussion that sensory issues could impact upon relationships was related with how they affected the participants' relationships with others (e.g. how their father's difficulty hearing affected his relationships with others) (see section 6.3.2.2). However, examples were given which suggested that it could affect relationships in other ways. LL described finding her son harder to understand, as she got older:

LL   'I find it very difficult when I'm with my son and his friends – they

all seem to mumble somehow … I don't know whether they mumble

or whether I'm getting deaf! But probably I am but I- I mean I'm

aware that there's speaking but I can no longer make out the ind- individual

words somehow'

    MM   'The young ones speak very quietly'

LL described the problem to be a lack of clarity, rather than the volume of the speech, whereas MM felt that the problem was that younger people were speaking more quietly. Although not necessarily detrimental to a relationship, difficulty communicating with each other would certainly have an effect.

Other people in the group indicated that having poor hearing meant that interacting with people on a daily basis became far more of a challenge. KK described how being deaf in one ear can be extremely discouraging:

> 'Everywhere – everywhere I go – there's a glass barrier at the bank – there's a reception desk between you and the receptionist and every single time you have to say sorry but I don't hear very well – can you speak a wee bit louder – everywhere I go'

The example shows that KK feels frustrated by the difficulty she has understanding people – she knows it is a result of her being hard of hearing, but the fact it is so pervasive means she has to constantly ask people to repeat what they are saying. As shown in section 6.3.2.2, this can cause tensions and difficulties in social relationships with others. In addition, QQ also mentioned that he had to ask people to repeat what they were saying when he spoke to them on the phone, which seemed to be common for older adults (see section 6.3.2.2): 'I have, I have difficulty on the phone – the telephones these days, they seem to crackle a bit more and I'm having to ask people to repeat quite frequently'. Like MM, QQ attributed his difficulty to hearing to extrinsic factors (the additional crackle on the phones) rather than difficulty hearing as he gets older.

6.3.1.3 – Compensation for impact of sensory issues

This section details the compensatory strategies that the participants make for their own sensory issues. Details of compensatory strategies used for their loved one's sensory issues, or by others (observed by the participants) are described in section 6.3.2.3. NN described that she had a naturally low voice and that sometimes people struggled to hear her properly. In order to combat this, she tended to raise the pitch when speaking in certain circumstances: 'when I'm doing talks, in fact I'm doing it now, I'm lifting the tone of my voice 'cos I'm actually down here – I'm very very low as well'.

KK described that she always tried to sit as close to a speaker as possible, in order to hear them as well as she could: 'You're [referring to AR] quite soft spoken and I was obviously

struggling there as well … but I always try and sit as close as I can to the person that's speaking rather than in a bit that I can't hear'. KK, knowing that she has difficulties hearing, always attempts to maximize her chances of hearing what is being said, by choosing a place in close proximity to the speaker.

It is quite possible to compensate for diminishing sensitivity without realizing. One example of this is gradually increasing the volume on the television over a long period of time. MM described that her grandchildren complained that the television was turned up too high: 'I notice that, with the television, when the young ones are in, you know, when the grandchildren are in they say oh it's far too loud granny, you know, they turn it down'. It was only her grandchildren's complaints about the volume of the television that alerted her to the fact that she needs the volume to be particularly high in order to hear it properly. In contrast, LL was very aware that she needed much more lighting as she aged. She compensated for this by increasing the number of lights in her home: 'you've got lights on everywhere to try and- [compensate] – yes, I'm very conscious that years ago I wouldn't have needed half the lighting that I need now'. This is an example where there was an active attempt to offset her change in vision by increasing the luminance levels in her home.

6.3.2 – Second-hand data

6.3.2.1 – Sensory issues can affect daily functioning

The second-hand examples given by participants about their relatives also showed that sensory issues could affect day-to-day activities and the ability to participate fully in society. A discussion between three members of the group (and AR) showed, as well as visual problems, vestibular issues could also affect being able to walk safely:

> PP   'I was thinking about people who trip a lot [as they] get older – y- you don't feel the ground as mu[ch] as-, ups and downs like that'
>
> RR   'not so good on rough roads'
>
> AR   'it would obviously affect you being able to get out and about …'
>
> NN   ' 'Cos if you don't feel confident walking about you're not going to – it's simple'

This excerpt highlights that being less sure-footed could affect a person's confidence to walk about. As well as affecting mobility, this could have a negative impact on mental health (or indeed, physical health).

As previously mentioned (section 6.3.2.1), something as simple as talking to other people can be affected by hearing loss (whether age-related or not). RR described how her husband passes the phone over to her, as he was unable to hear what people on the other end were saying:

'well my husband will come on the phone and say oh here, you take it,

I don't know what she's saying, and my daughter says you'd be as well

answering the phone in the first place mum 'cos it just gets passed over'

Hearing loss may mean that older adults might a) not be able to hear the phone ring or b) be able to hear what is being said. In turn, this could limit a lot of older adults to face-to-face communication (where they can pick up on visual cues). Furthermore, it places pressure on family or friends, as they may have to be responsible for speaking to all callers and perhaps have to place phonecalls on their behalf.

Lastly, PP described her father, who became incredibly isolated when he developed problems seeing and hearing:

'Yes that's why dad … had to go in- into care – he was isolated, he didn't

benefit from what was available because he couldn't. They thought he

was deaf and he was stupid as a result, but he wasn't – he couldn't see them –

his eyesight and his hearing [were poor] and that was him excluded really'

She highlighted the isolation that a loss of sensitivity to the senses can cause – in this man's case, he had to go into a home as he was unable to cope independently. PP also brings up the assumptions that others may make about those who are unable to communicate effectively (i.e. that they are stupid) and that this resulted in her father's exclusion.

6.3.2.2 – Sensory issues can affect communication and relationships

The most prevalent issue that emerged from the data was that sensory issues could affect the quality of social interaction. The data written about in this section details examples of sensory issues observed in others and how they affect social relationships (these may be the participant's relationships or the relationship with another person).

OO mentioned how she has noticed that her parents have problems communicating, as her father finds it difficult to hear his wife speaking. This has caused tension in their relationship:

'my mum and I both have … a quite low voice for a woman … so my

> dad just can't hear my mum and that has definite-, not fundamentally
> changed their relationship, but there is so much friction and argument and
> miscommunication, you know with – my dad'll say things like the cat got
> stuck in a hole in the tree? and my mum'll say why would I say the cat
> got stuck in a hole?'

This example clearly shows that diminishing sensory ability can place pressure on relationships, causing tension that would not be there otherwise. The person who is unable to hear properly becomes irritated, as they can't hear what is being said properly despite their best efforts. The person they are speaking to also becomes frustrated, as they have to repeat what they are saying, over and over again, in order to maximize the chances of the other person what is being said.

The concept of exclusion also arose here, with the participants observing exclusion as a direct result of communication difficulties. QQ became emotive as he described how certain individuals can be ostracized if they have difficulties understanding or communicating with others:

> 'if people, an individual starts to show signs of, of an impairment of- of
> any description, they get bypassed…especially in- in a group situation
> because the group will bypass that one per- person, and this is not an age
> thing – it happens regardless of- of people's age …Oh aye, just shut them
> out – just like that. They used to talk ab-, say it was children that did that
> sort of thing but it's, it's every age group – twenties, thirties – right
> through. They will shut an individual out, just like that, because they
> don't respond instantly'

This is a real difficulty facing those with any kind of disability, but it has particular relevance for those who have difficulty communicating in some way.

NN had found something similar with her family – in group situations involving her father-in-law, she noticed that people were less likely to interact with him than they had been previously: 'People don't talk to my father-in-law as much because, especially in a group, they tend to talk past him 'cos they know he's not picking up on what's being said to him'. Rather than exclusion from a group, OO summarised that there could be some kind of self-exclusion in certain group situations, because of the greater amount of effort it takes to stay 'tuned in' to the conversation:

> 'I see my dad struggling very much with that – he wears two digital hearing
> aids and he- he really struggles with that. He struggles with the family all

there together and there's quite often, you'll see my dad just sits back in his

chair and he just kind of opts out of the conversation … because he just

can't follow everything that's going on'

PP had found something similar with one of her relatives too: '[He] had trouble as well … if it was person to person – no problem – but as soon as he was in company, he just used to switch off'. This highlights that it is not a simple situation and that there are at least two ways in which exclusion could occur alongside differences in sensory sensitivity. It may be that as people grow older, they run the risk of becoming more excluded a) by others, as it's harder for them to interact with the individual and b) by the individual themselves, as they may find it exhausting.

These findings resonated with two of the participants, who had previously worked as teachers of the deaf. TT described how there seems to be far more awareness now about the importance of integrating those with hearing impairments into society:

'[WW] and I, we were both teachers of the deaf, and it's something –

that exclusion thing that, you know, now when you're a teacher of the deaf

you really work hard to try and remove these barriers from the younger people who

are are deaf now – kids in school, you know? It's an ongoing battle, heh.

But it's something, you know, awareness-raising [has] come up a lot, maybe,

since we were young! heh'

This is an important point, as it shows that, although things can be difficult, there is far more awareness now, regarding how to interact with people who have different sensory needs. Furthermore, it highlights how important it is to try and find ways to communicate with those who find it more difficult.

Lastly, RR mentioned how important it is to explain to relatives why their loved ones do not seem to understand them and why they need to repeat what they are saying.

RR 'I discovered that – I thought – he's just not paying attention, he's

just not concentrating, 'til I discovered, when we went to a dementia

night at [name removed] – they said that sometimes it's not that

he's not listening, but it takes that bit to get through'

Murmurs of agreement from whole group

TT 'you realise, well don't moan about saying everything twice because

he's not getting it'

NN 'that's right, spot on'

RR 'it helped me that'

This extract really highlights the importance of support for those in the life of individuals with additional support needs. Even an explanation of *why* someone behaves in a certain way can, as indicated above, provide great comfort, reduce frustration and increase understanding.

6.3.2.3 – Compensation for impact of sensory issues

One important theme which emerged from the data was that it was sometimes necessary to compensate for others' sensory issues, and that this often occured subconsciously. NN described going for a walk with her father-in-law and having to ensure that he was on side furthest from the kerb:

> NN   '[sensory issues] can affect your mobility because I know that if I'm out with my father-in-law we've now got to make sure that we walk to the edge of the kerb, and he's got to be on our right-hand side because otherwise he will just walk off the kerb, 'cos his visual ability's not as good…'.
>
> QQ   'What happens if there is no kerb?'
>
> NN   'He's totally lost – he actually gets to the point where he doesn't know … he likes to walk across grass, because if you're walking along a path it's very narrow and he doesn't see it properly … he'll walk on the grass because he's much comfier'

This shows that a loss in vision can affect mobility – making even a simple task like going for a walk exceptionally difficult without help.

When the participants discussed having to compensate for the diminished sensory sensitivity of those close to them, it was obvious that they were willing to make many sacrifices in order to help their loved ones integrate as much as possible. However, this takes a toll on people who look after those individuals who find it difficult to communicate. OO described how everything had to be planned, in order to take her father's needs into consideration:

> 'I think that's true – I think that's what you do and I haven't actually thought about it, but I think you probably do just plan. You can't go anywhere spontaneously – everywhere you go you're planning ahead, or if you're going somewhere new you're thinking will there be this'

She described the need to consciously plan every activity – which despite being stressful in itself, is another example of family members automatically compensating for the difficulties that sensory problems bring.

Lastly, OO described how she and her sister have had to take on greater responsibility with their father's money, as he is unable to see the digits on the number pads.

> 'The other thing … is that my dad's visually impaired too and like
>
> using autotellers and ATM's … he's had to tell my sister and I what his PIN
>
> numbers are so, you know, so that we can … get his card out his wallet and
>
> then it just gets passed to us and, you know we- we have to do the- ((mimes
>
> typing on a keypad)) and then when he has to go and sign anything is a problem'

This would be stressful for the family members as well as the person with visual problems, as the individual would be reliant upon them for access to their money. This is especially relevant in today's society, where the majority of salaries are paid directly into an individual's bank account. In addition, it could open up potential avenues for fraudulent behaviour, as some individuals may take advantage of the position of trust that they find themselves in.

6.4 Discussion

This chapter reports the issues facing older adults as a consequence of losing their sensitivity to certain sensory input. Discussion between the participants was coded and combined into overall concepts. The concepts extracted from these data were a) diminished sensory ability could affect daily functioning, b) diminished sensory ability could affect social relationships and communication and c) compensation for these sensory issues were often made by both individuals themselves or their loved ones. The discussion yielded examples of both the participants' own experiences with unusual sensory perception as well as relevant examples that they had found in their interactions with relatives.

Firstly, the data showed that problems with hearing and seeing, in particular, caused many difficulties for older adults. The participants indicated that, in their experience, loss of visual acuity and hearing ability was related to loss of independence and ability to carry out typical daily routines. This was highlighted by OO's example with her father, where he became unable to take money out of the ATM on his own. This meant he became reliant on his daughters for access to his finances. Also, PP mentioned how her father had to go into care, because he became unable to look after himself in his home. She attributed this to his vision and hearing difficulties, and highlighted that he had become excluded as a result.

It has been well established that there is a relationship between aging and diminishing functional ability (Skelton, Greig, Davies, & Young, 1994), which links into the ability to carry out daily living tasks. Raina, Wong, & Massfeller (2004) investigated the relationship between sensory impairment and functional independence in the elderly in a large-scale study. They found that those who reported both hearing and vision difficulties disclosed that they had the most difficulties with daily routines and functional independence, compared to those with either a hearing or vision impairment. Those with particularly severe impairments indicated that they were less happy and reported being less independent. In addition, there is evidence to suggest that single domain impairments, particularly visual (Dargent-Molina, Hays, & Bréart, 1996; Reuben, Mui, Damesyn, Moore, & Greendaleand, 1999) and hearing impairment (Carabellese et al., 1993; Dalton et al., 2003) can decrease independence and ability to carry out daily activities.

Secondly, the group described situations where reducing sensory sensitivity had a real effect on ability to communicate effectively with others, and thereby on social relationships. LL described finding it harder to understand what younger people were saying, mentioning that clarity, rather than volume, was an issue for her. This may indicate that LL has developed mild hearing loss with age, as even small changes in absolute threshold can affect the ability to perceive certain speech sounds (Bakke, Bernstein, Bally, & Pray, 2008), especially in background noise. Hearing loss appears to have a real effect on the ability to communicate with others (Dalton et al., 2003; Heine et al., 2002). Visual cues have a discernable impact on typical communication (Arnold & Hill, 2001), and therefore become even more important when hearing loss is present, as many people will rely on visual cues to help them communicate (e.g. lip reading, reading facial expressions).

There was also in-depth discussion of the effect that sensory impairment can have on quality of relationships. OO mentioned that her parents' relationship had become more difficult over the years, predominantly due to her father's hearing loss, resulting in miscommunication between her father and mother. In 2004, Wallhagen, Strawbridge, Shema, & Kaplan examined the relationship between hearing loss and health and well-being of 418 married older couples over a 5-year period. They found that the partners of those with hearing loss were more likely to suffer from physical, psychological and social difficulties. In addition, Carabellese et al. (1993) found that visual impairment was also significantly associated with social relationship difficulty.

Furthermore, there was also evidence that people who have difficulty communicating (including those with age-related sensory impairment) can be at risk of exclusion. QQ expressed his belief that individuals with impairment were more likely to be excluded from society, and that this was not necessarily restricted to a specific age group. TT discussed how she felt that there were more measures in place nowadays to help integrate those with hearing impairments into the community, thereby 'removing barriers'. OO and PP mentioned that self-exclusion is also possible – that those with hearing loss or visual impairment find large groups and communicating with others to be exhausting at times. There is indeed evidence that older people, as well as those with disabilities, are more at risk from social exclusion and it is important that efforts are made to limit this.

Lastly, both the individuals with sensory impairments and their relatives made compensations for the effect that the vision or hearing loss had. Participants described situations where they made active efforts to compensate for their own sensory impairment or that of their loved ones (or recounted examples where their relatives had made compensations for their own sensory loss). Examples included repeating everything that was being said multiple times, using more lighting, taking over some of the daily tasks (e.g. withdrawing money from the ATM) and consciously planning every activity. Research has shown that support systems are extremely important for those with hearing loss (Cummings, Sproull, & Kiesler, 2002), and that those with sensory impairments are aware that communication can be difficult for their family and friends (Heine et al., 2002). Indeed, the communication partners of those with visual and hearing impairment made conscious efforts to control for these factors, using techniques such as repetition.

The main strength of this study was that we were able to gain insight on how sensory loss can affect both those with visual and hearing impairment, as well as their family members. This provided us with detailed information on the joys, frustrations and idiosyncrasies involved in caring for an individual with sensory impairment. One limitation of this study is that the focus was on a group of elderly adults without ASD. However, the purpose of this study was to explore the social implications of atypical sensory processing with another group of individuals. Furthermore, by concentrating on the hypo-sensitivity, rather than hyper-sensory processing (as reported by participants in Chapters 3-5), we gained deeper insight into the potential ramifications of under-responsiveness to sensory stimuli. Another limitation is that this was a convenience sample of people who knew each other. However, this is not necessarily a negative, as using pre-existing groups can yield data not

available in newly formed groups (Kitzinger, 1994; 1995). Furthermore, it should be taken into account that this was a group of carers of individuals with Alzheimer's Disease (AD), and that we should be wary that the information gathered is to do with sensory issues, rather than dementia. However, the only sense that is known to deteriorate specifically in those with AD is olfaction, which received very little attention in the group. Furthermore, in 1991 it was reported that around 10% (visual) and 17% (hearing) of adults over the age of 65 suffer from some sort of sensory impairment (Raina, Wong, Dukeshire, Chambers, & Lindsay, 2000) – the fact that they could have AD does not negate the fact that they experience diminished sensitivity to sensory stimuli.

This chapter presents the data gathered from a group discussion among older adults on the topic of sensory impairment and the effect on both the individual and their family and friends. The data, both here and in the literature, show that sensory impairment can have profound effects on daily routines, communication and social relationships. The individual themselves, and their support system, often try to compensate for this in some way, in order to minimise feelings of isolation. This is an attempt to minimise the negative effects of sensory impairment. It is anticipated that individuals with sensory loss may benefit from adaptation to their environment in some way. In addition, it should be noted that changes in sensory sensitivity can have profound effects on the family and friends, and that information about the implications of sensory loss should be made available, alongside more support for carers. This is something that becomes ever more relevant, due to the aging population (Cracknell, 2010; World Health Organization, 2012) . Comparison between the findings presented here and those from the ASD groups will be discussed in Chapter 9.

Chapter 7 The relationship between autistic traits and olfactory performance in the general population

7.1 Introduction

The human olfactory system is remarkably sensitive to smells, with one study demonstrating that a single molecule of odorant can excite a single olfactory receptor (which is the most sensitive the system can be) (De Vries & Stuiver, 1961). However, the number of receptors in the human olfactory system is much smaller than in other animals (resulting in a comparative loss of sensitivity), e.g. humans have 10 million receptors compared to dogs, who have 1 billion (Goldstein, 2002). Furthermore, smell can have a profound effect on many aspects of perception and cognition. For example, our perception of flavour is strongly affected by smell, and a loss of the former can have a profound impact on the ability to taste (Goldstein, 2002). In addition, there have been studies demonstrating that smells can have significant effects on emotion (Lehrner, Eckersberger, Walla, Pötsch, & Deecke, 2000), social preferences (Li, Moallem, Paller, & Gottfried, 2007), moral judgements (Schnall, Benton, & Harvey, 2008) and even behaviour regulation (Holland, Hendriks, & Aarts, 2005).

As previously discussed, it has been well established that individuals with ASD tend to report experiencing over-sensitivity and/or under-sensitivity to sensory stimuli in a variety of questionnaire-based studies (Baranek et al., 2006; Crane et al., 2009; Leekam et al., 2007; Talay-Ongan & Wood, 2000) Indeed, the planned draft for the next version of DSM-5 has included the presence of sensory issues in the criteria for ASD (American Psychiatric Association, 2010), an aspect that is absent from the most recent version of DSM (DSM-IV-TR: American Psychiatric Association, 2000). A large proportion of those with ASD tend to report atypical sensory sensitivity. For example, Leekam et al. (2007) reported that 94% of their autism sample experienced increased levels of sensory atypicalities, compared with only 5% of typically developing children. However, it is also important to determine which mechanisms cause these different responses in ASD, so that greater insight into the causes and implications of ASD can be obtained.

Relatively few studies have experimentally investigated olfaction in ASD, with results being somewhat mixed. As was previously discussed in section 1.3.4, there is evidence that children with autism have raised detection thresholds for olfactory stimuli (Dudova et

al., 2011), although others have found no differences in thresholds for adults with ASD (Suzuki et al., 2003; Tavassoli & Baron-Cohen, 2012a). Furthermore, there are conflicting results in the identification abilities of those with ASD compared to TD comparison groups, with some finding no significant group differences (Brewer et al., 2008; Dudova et al., 2011), others finding impaired performance in an identification task (Bennetto et al., 2007; Suzuki et al., 2003) and one study finding impaired performance for only those with a diagnosis of autism, rather than AS (May et al., 2011).

As mentioned in the Introduction (Chapter 1), there is evidence to suggest that those with higher levels of autistic traits (often referred to as exhibiting the 'Broader Autism Phenotype') demonstrate similarities to those with an ASD. For example, it appears that brain structure and function are different in those with more autistic traits, with differences in the pSTS being identified (von dem Hagen et al., 2011). This brain region has been implicated in ASD, and is important in social and speech perception (Redcay, 2008). In addition, those with high levels of autistic traits have been shown to perform differently in both visual and auditory tasks compared to those with low levels of autistic traits, as discussed previously in Chapter 1. Furthermore, we recently found that self-reported sensory responsiveness to stimuli increased alongside an increase in autistic traits (see Chapter 2; Robertson & Simmons, 2012). However, as yet, there have been no studies reported which assess olfactory performance and the relationship with autistic traits.

It has been suggested recently that the atypical sensory responsiveness experienced by those with ASD could be a result of intra-participant variability caused by added noise in the neural system (Gowen & Hamilton, 2012; Milne, 2011; Simmons et al., 2009). The variability between those with ASD is often larger than observed in control groups (Milne, 2011), although few studies discuss the variance of responses observed in their samples. It may be that increased variance (both for responses given by each individual and for the group as a whole) could be indicative of increased noise in the perceptual system (see Simmons et al., 2009, for more detail).

In this study, we assessed various aspects of olfactory performance in the general population (threshold, discrimination and identification) and analysed the relationship with autistic traits. Furthermore, we administered the sensory questionnaire described in Chapter 2 to a sub-group of the sample, in order to a) determine whether the same, positive relationship between scores on the GSQ and AQ was observed and b) to observe whether perceived over- or under-sensitivity to olfactory stimuli was related to absolute thresholds.

Furthermore, we were interested in analysing intra-participant variability for the threshold test. Our main hypotheses were as follows:

- There would be no significant differences between high and low AQ scorers for the threshold, discrimination and identification tasks
- Those with high AQ scores would demonstrate higher intra-participant variability for thresholds compared to low AQ scores
- A positive, significant correlation between GSQ and AQ scores would be observed in the sample

7.2 Methods

7.2.1 – Participants

106 people (74 females; 32 males) participated in this experiment (mean age = 24 years 4.42 months ± 6 years 1.96 months). Those with the highest 15% (n = 17; mean score = 27.82 ± 5.64) and lowest 15% (n = 18; mean score = 6.33 ± 1.57) of scores in the AQ formed the 'high' and 'low' scorers groups (Low: AQ from 4 – 8; High: AQ from 22 – 45) and were compared in various aspects of their olfactory functioning.

A number (n=41) of participants were recruited by an undergraduate student (as part of her final year project), with the author obtaining the remaining participants (n=65). Both stages of data collection were carried out in the same way, apart from the inclusion of the GSQ in the author's collection of data (i.e. the GSQ was not included in the undergraduate student's study). Due to time constraints, some participants were not able to complete the GSQ during the session (n=3). Therefore, 62 of 106 participants completed the GSQ, with all 106 participants completing the olfactory experiments and the AQ. Participants were recruited using the University of Glasgow subject pool, which mainly consists of undergraduate and postgraduate students. Each session took approximately 1 hour, and participants were either paid £6 for their time (n=63) or given undergraduate course credits (n=43).

7.2.2 – Apparatus

7.2.2.1 – Sniffin' Sticks

The Sniffin' Sticks Extended Test (Burghart, Messtechnik) was used to measure the olfactory functioning of participants. This is a standardized, commercially available test that assesses three aspects of olfactory functioning (threshold, discrimination and identification) (Hummel, Sekinger, Wolf, Pauli, & Kobal, 1997).

Olfactory thresholds were established using the 'Threshold' section of the Sniffin' Sticks Extended Test. This test consists of 16 pens filled with varying concentrations of n-butanol diluted in propylene glycol (with pen 1 being the strongest and pen 16 being the weakest). Three pens are sequentially presented to the participant, with only one having an odour. The participant is asked to discriminate the pen that has an odour from the odourless pens. In the odour discrimination task, the experimenter presents triplets of pens (two with the same odour and a third with a different odour) to the participant. The participant is asked to determine which smell is different. Identification performance is assessed by the administration of sixteen common odours. The participant is asked to identify the odour from a list of four presented alongside each pen.

7.2.2.2 – Questionnaires

Autism Spectrum Quotient (AQ)

See section 2.2.2 for details of the AQ.

Glasgow Sensory Questionnaire (GSQ)

See section 2.2.2 for details of the GSQ.

7.2.3 – Procedure

Participants were asked to ensure that they did not eat or drink anything (apart from water) for 15 mins prior to the start of the experiment. As suggested in the Sniffin' Sticks manual, the tests were presented in the following order: Threshold – Discrimination – Identification. In addition, participants were not given feedback on their performance during any of the olfactory tasks. Questionnaires were presented in between olfactory tasks, with their order counter-balanced across the sample. The procedural details for the olfactory tasks were as follows.

Thresholds

Participants were blindfolded during the threshold task, in order to prevent visual information affecting performance. Odour thresholds were determined using an ascending staircase, triple-forced choice paradigm. Participants were presented with triplets of pens, with each pen presented for around 3 seconds and leaving a 5 second interval before the next pen was presented. As detailed in the manual, there was a minimum of 30 secs between the first pen of one triplet and the first pen of the next triplet being presented.

Pens were presented in the following repeating order across trials: TARGET – BLANK – BLANK; BLANK – TARGET – BLANK; BLANK – BLANK – TARGET. The task starts with either dilution level 16 or 15 (16: n=53; 15: n=53) and the concentration ascends in 2-dilution steps (e.g. 16-14-12 or 15-13-11) until the participant identifies the target pen in two sequential trials. The staircase then reverses and continues until the participant gives an incorrect answer. Seven reversals are determined for each participant, with the threshold being computed from the mean of the final four reversals. A visual illustration of this process is presented in Table 7.1 (Ticks are correct answers and crosses are incorrect answers).

Table 7.1	– Demonstration of identifying thresholds						
10	✔✔						
11		✔✔	✔✔		✔✔		✔✔
12	✔ X	✔ X		✔✔	X	X	
13				✔ X			
14	X						
15							
16	X						
Illustration of how thresholds are established using the Sniffin' Sticks task. The 'turning points' are coloured red: 13, 11, 12 and 11, which would indicate a threshold of 11.75.							

Possible scores on this task range from 0 (unable to detect any of the concentrations) to 16 (consistently able to detect the lowest concentration). As well as determining each person's threshold, we analysed the distance of the threshold from each turning point (as we were interested in whether this varied between participants) in order to assess intra-participant variability. This process can be illustrated using the data in Figure 7.1. The mean threshold is 11.75, and the distance of each turning point from the mean is computed (i.e. 1.25, 0.75, 0.25 and 0.75 respectively), with an overall mean of this distance computed from these values (which, in this example, is 0.75).

Discrimination

Participants were blindfolded during the discrimination task, in order to prevent visual information affecting performance. Discrimination ability was determined using a triple-forced choice paradigm. Participants were presented with triplets of pens, with each pen presented for around 3 seconds and leaving a 5 second interval before the next pen was presented. As detailed in the manual, there was a minimum of 30 secs between the first

pen of one triplet and the first pen of the next triplet being presented. Pens were presented in the following repeating order across trials: SAME – DIFF – SAME; SAME – SAME – DIFF; DIFF – SAME – SAME. Participants were required to determine which of the odours smelled different from the other two. Possible scores ranged from 0 (incorrect discrimination on all trials) to 16 (correct discrimination on all trials).

Identification

Participants were not blindfolded during the identification task. In order to assess their olfactory identification ability, they were asked to choose which odour they had been presented with from a choice of four. There were 16 odours in total and resulting scores ranged from 0 (incorrect identification on all trials) to 16 (correct identification on all trials).

7.3 Results

7.3.1 – Descriptive statistics

The AQ, threshold and identification scores were found to be normally distributed using the Kolmogorov-Smirnov test statistic (all $p > .05$). However, the discrimination scores did not follow a normal distribution, as they were negatively skewed and over half of the participants fell onto two of ten observed scores. In addition, the Kolomogorov-Smirnov test showed that there was a significant deviance from a hypothesized normal distribution ($p < .005$). Thus, non-parametric equivalents were used for comparison of the discrimination scores.

The main descriptive characteristics of the sample are included in Table 7.2, with Table 7.3 containing details of olfactory performance of the sample compared to established norms (Hummel, Kobal, Gudziol, & Mackay-Sim, 2006).

Table 7.2 – Descriptive characteristics of the sample			
	Mean	**Std. Dev.**	**Group Distributions**
Age	24 years 4.42 months	6 years 1.96 months	
AQ Score	14.82	7.32	
Gender (F:M)			74:32
Smoker (Y:N)			16:90
Native speaker (Y:N)			72:34

Table 7.3 – Characteristics of olfactory performance and established norms		Females		Males	
		Mean	**Std. Dev.**	**Mean**	**Std. Dev.**
16-35	**Threshold**	8.82 (9.39)	2.47 (2.56)	9.00 (9.24)	2.61 (2.99)
years	**Discrimination**	13.21 (12.91)	1.86 (1.92)	12.00 (12.61)	2.09 (1.95)
(n=99)	**Identification**	12.91 (13.68)	1.75 (1.62)	12.21 (13.48)	2.09 (1.73)
36-55	**Threshold**	6.38 (9.08)	1.16 (3.09)	7.50 (8.43)	0.25 (3.47)
years	**Discrimination**	11.75 (12.46)	2.50 (1.96)	12.00 (11.94)	2.65 (2.24)
(n=7)	**Identification**	14.00 (13.49)	0.82 (1.56)	14.33 (13.10)	0.58 (1.88)
Established norms (Hummel et al., 2006) are provided in brackets					

Thirty-four participants were non-native speakers. Independent samples t-test analysis showed that there were no significant differences between native and non-native speakers in their AQ score [$t(104)$ = .399, *ns, r*=.044] or olfactory thresholds [$t(104)$ = 1.179, *ns, r*=.122]. However, non-native speakers performed significantly better in the discrimination task [U=934.5, *p<.05, r*=.194] and significantly worse in the identification task [$t(104)$ = 2.082, *p<.05, r*=.210]. In addition, although the mean AQ score was higher for men than for women (16.16 compared to 14.24), this was not a significant difference [$t(104)$ = .218, *ns, r*=.129]. Although there were no group differences for olfactory threshold [$t(104)$ = .317, *ns, r*=.030] or identification [$t(104)$ =1.453, *ns, r*=.144], women performed significantly better in the discrimination task [U=747.5, *p<.002, r*=.297]. Lastly, smoking did not have a significant effect on any aspect of olfactory functioning [threshold: $t(104)$=1.22, *ns, r*=.139; discrimination: U=708.0, *ns, r*=.097; identification: $t(104)$ = .462, *ns, r*=.061].

7.3.2 – Relationship between autistic traits and olfactory functioning

7.3.2.1 – Thresholds

A Pearson's correlation analysis showed that there was no significant relationship between AQ score and threshold scores [r(104)=.012, *ns*, R^2=.014]. There was also no significant difference when the threshold scores of the highest and lowest AQ-scorers were compared [$t(33)$ = .509, *ns, r*=.086]. It should be noted that there was no difference in group variability when threshold was compared (Levene's Test was not significant (p>.05)). This indicates that there is no difference in inter-participant variability of thresholds.

As described in section 7.2, we were also interested in whether the relationship between the turning points and threshold (i.e. the intra-participant variability) was similar for those with high and low AQ scores. Figure 7.1 shows the mean distance from the observed

threshold score for the four turning points (larger values indicate greater intra-participant variability, with the minimum value possible being 0.5). A significant relationship was observed (r(104)=.266, *p<.01, R^2=.071*), with the variability increasing as AQ score increased.
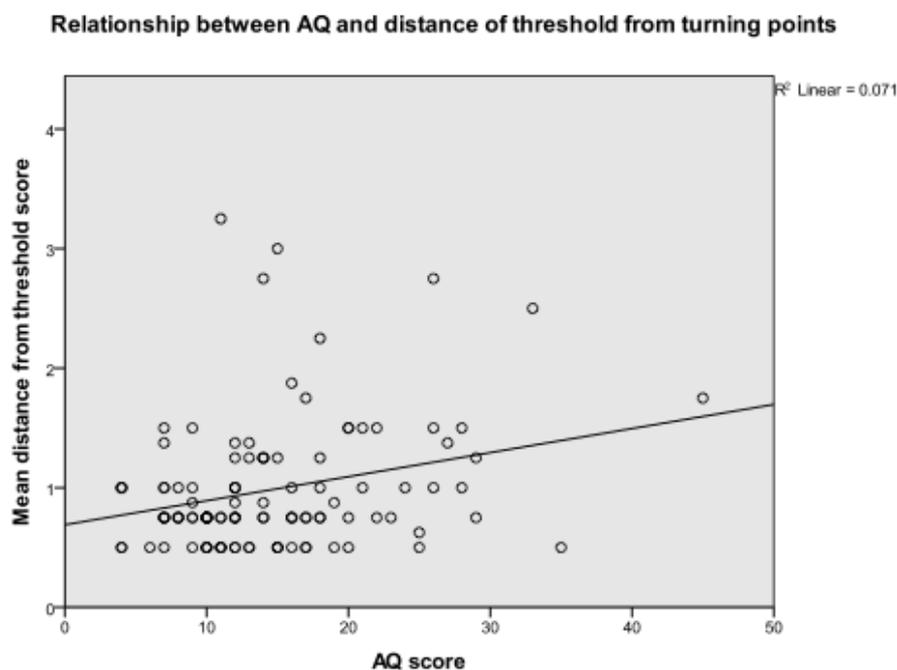
Figure 7.1 – Correlation between intra-participant variability in the threshold test (determined by calculating mean distance of the turning points from the threshold) and AQ score (measured by the Autism Spectrum Quotient; Baron-Cohen et al., 2001). Pearson correlation was positive (r = .266).

In addition, we compared the scores for high- and low-scorers on the AQ using an Independent Samples t-test. A significant difference was found, [$t(21.71) = 2.23$, *p<.05*, *r*=.277] with those who have high AQ scores having turning points significantly further away from their final threshold than those with low AQ scores. Inter-participant variability assesses the differences between the variability within various members of a group. The output for Levene's test was significant (*p<.05*), indicating that the variances of both groups were significantly different. The standard deviations for the AQ group were much larger than for the low scoring group, indicating that how far a person's turning points were away from the mean differed more in the high AQ group than in the low AQ group. The means for each group are illustrated in Figure 7.2.
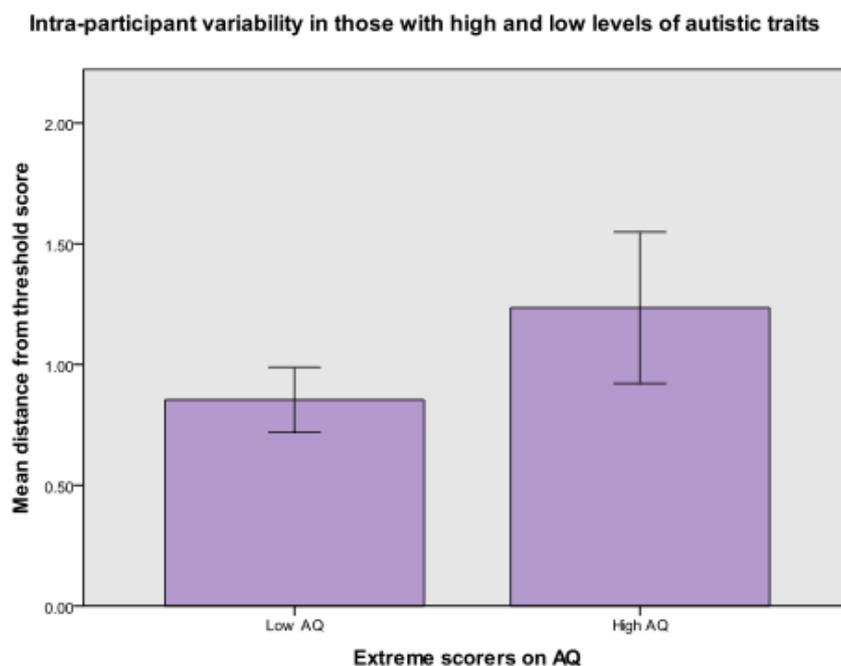
Figure 7.2 – Comparison of intra-participant variability (determined by calculating mean distance of the turning points from the threshold) of the highest and lowest 15% scorers on the AQ (Baron-Cohen et al., 2001). Error bars represent +/- 2 standard errors

7.3.2.2 – Discrimination

A Spearman's rho correlation analysis showed that there was no significant relationship between discrimination and AQ score [r_s (104) = -.101, *ns*, R^2 = .010].   There was also no significant difference when the top- and bottom-scorers on the AQ were compared [U = 117.50, *ns*, r = 0.127].

7.3.2.3 – Identification

As gender and whether a person is a native speaker were identified as possible confounds in section 7.3.2.1, a partial correlation was performed on these data (with gender and native speaker being held constant). Results showed that there was no significant relationship between AQ score and identification [r = -.117, *ns*, R^2=.014]. This was also true when the identification scores of high- and low-AQ scorers were compared using an ANCOVA, while controlling for gender and native/non-native speakers [F(2,31) = .866, *ns*, *r*=.224].

7.3.3 – Relationship between autistic traits, sensory sensitivities and olfactory functioning

As described in section 7.2, the GSQ (which was developed as part of the project described in Chapter 2) was given to a subgroup of the sample (n=62). As in the original study, a

positive correlation was observed [r(60)=.433, $p<.001$, R^2=.187] between total sensory score and AQ score (see Figure 7.3).
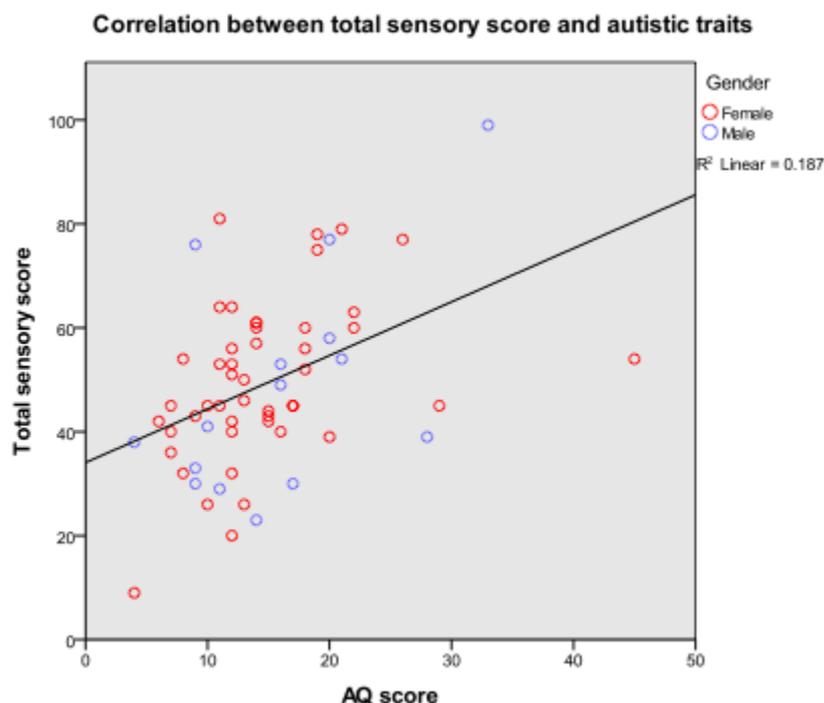
Figure 7.3 – Correlation between total sensory score (Robertson & Simmons, 2012) and AQ score (Baron-Cohen et al. 2001). Pearson correlation was positive (r = .433)

The relationship between reported sensitivity and olfactory threshold (both hyper- and hypo-sensitivity) was analysed. There was no significant correlation between either reported hyper-sensitivity to olfactory stimuli [r(60)=.173, *ns*, R^2=.030] or reported hypo-sensitivity to olfactory stimuli [r(60)=.021, *ns*, R^2=.0004] and threshold, as assessed by Sniffin' Sticks.

In order to determine the influence that threshold scores and intra-participant variability may have on sensory sensitivity (as measured by the GSQ), a regression analysis was computed (Figure 7.4).

Table 7.4 – Regression analysis of GSQ score, mean threshold and intra-participant variability

Variables	B	SE(B)	β	t	Sig. *(p)*
Constant	43.342	8.338		5.198	.000
Intra-participant variability	3.800	3.916	.126	.970	.336
Mean threshold	.289	.928	.040	.311	.757

R^2= .018

Although AQ scores (Figure 7.3) are significantly related to reported sensory sensitivity, neither intra-participant variability nor mean threshold scores contributed significantly to the GSQ scores.

7.4 Discussion

This chapter reports the relationship between autistic traits and different aspects of olfactory functioning (namely thresholds, discrimination and identification). Results showed that there were no significant differences in the olfactory threshold, discrimination or identification scores of those with high and low levels of autistic traits. However, we did find increased intra-participant variability in the threshold task, for those with high AQ scores. In addition, we replicated the correlational relationship between AQ score and sensory sensitivity, which was first reported in Chapter 2.

The finding that there was no difference in the threshold scores of those with high and low levels of autistic traits is consistent with similar olfactory studies conducted in adults with ASD. By not finding decreased olfactory thresholds in those with ASD (e.g. Tavassoli et al., 2012a) or in those with high levels of autistic traits (this chapter), there are implications for theoretical accounts of autism. The WCC (Happé & Frith, 2006) and EPF (Mottron et al., 2006) theories, in particular, posit that individuals with ASD have increased sensitivity to sensory stimuli. However, it should be noted that those with ASD (Baranek et al., 2006; Leekam et al., 2007) and higher levels of autistic traits (see Chapters 2 and 3; Robertson & Simmons, 2012) still report over-sensitivity to olfactory stimuli, even though this does not appear to be caused by lowered thresholds (Suzuki et al., 2003; Tavassoli & Baron-Cohen, 2012a; section 7.3). This has also been observed in the visual (Bertone et al., 2005), auditory (Jones et al., 2009; Khalfa et al., 2004) and tactile (Güçlü et al., 2007) domains. The disparity between direct measurement and self-report data mentioned in Chapter 1 has, thus, been mirrored here. It is possible that tests used to measure olfactory functioning may not be sensitive enough to capture true differences between the detection thresholds of those with ASD and TD controls. It may also be the case that the differences lie in the way the brain processes the stimuli, rather than how it is perceived. It must be, therefore, that something else causes this atypical responsiveness to sensory stimuli and further research is needed to determine the exact nature of atypical sensory processing in ASD.

The lack of correlation between thresholds and reported sensitivity to sensory stimuli has been reported elsewhere, for the general population. Doty et al. (1988) found that

individuals with multiple chemical sensitivities (MCS) (who often complain of an increased sensitivity to smells) did not have significantly lowered olfactory thresholds, compared to typically developing individuals. However, they did find several other differences for the MCS group (e.g. higher nasal resistances and respiration rates). This provides further evidence that there may be some other cause to the reported sensory sensitivity experienced by those with ASD, rather than lowered thresholds.

As far as we are aware, there have been no studies published which have looked at olfactory discrimination in individuals with a diagnosis of ASD. However, it appears that, like sensitivity and identification, there are no differences in the discrimination abilities of those with high and low levels of autistic traits. The identification abilities of those with ASD are also inconsistent, although this is most likely due to methodological and sample differences. There is evidence that adults with AS (Suzuki et al., 2003) and children with autism (Bennetto et al., 2007; May et al., 2011) are significantly worse at identifying smells compared to individuals with typical development, although a number of others have found no difference between clinical and control groups (Brewer et al., 2008; Dudova et al., 2011; May et al., 2011). In our study, we found that non-native speakers of English were significantly worse in the identification task than native speakers, although there was no difference observed between high and low scorers on the AQ. One reason for this could be because a) non-native speakers did not have the same breadth of English vocabulary as their British/Irish counterparts and b) they may have been brought up in a different culture, thus perhaps being exposed to different smells across their lifetime. It would be interesting to repeat this experiment using visual prompts (i.e. pictures) rather than words, as some did in their studies with those who have ASD (Bennetto et al., 2007; Brewer et al., 2008; Dudova et al., 2011; May et al., 2011; Suzuki et al., 2003), to see how this affects task performance.

Although there was no group difference observed for olfactory sensitivity, we did find a significant difference in the distance of the turning points (from which the threshold score was obtained) for the high and low scorers on the AQ. This means that, in general, those with a high AQ score performed more variably in the task (for example having turning points at 7, 11, 6 and 10 compared to 8, 9, 8 and 9, both of which would yield a threshold score of 8.5). The intra-participants variability was significantly higher in the high AQ scorers, and the standard deviations of this score were much larger in the high AQ group compared to the low AQ group (.648 compared to .285). These results provide further support for the hypothesis that added noise may be related to the sensory differences

observed in ASD (Gowen & Hamilton, 2012; Milne, 2011; Simmons et al., 2009), although another explanation is that there are higher-order influences that are contributing to the increased intra-participant variability (e.g. attention/distraction). However, it should be noted that we did not find any significant contribution to reported sensory sensitivity by either intra-participant variability or mean threshold score.

We also administered the GSQ (developed as part of the study reported in Chapter 2) to the majority of our sample, observing a positive relationship between AQ score and score on the sensory questionnaire. It should be noted that we did not make an effort to recruit those with an ASD diagnosis in this study, so finding a similar relationship in this sample provides support for our previous conclusions. It should be noted that the effect sizes for this correlation are smaller than in Chapter 2. One interesting point was that there was no association between reporting of either hyper- or hypo-sensitivity to smell and thresholds in our sample. However, this was to be expected, as there appears to be little association between reported sensitivity to olfactory stimuli and threshold levels (Doty et al., 1988).

In conclusion, the data presented in this study provide support for increased intra-participant variability in those with high levels of autistic traits (which, in turn, provides further support for the existence of an endophenotype in ASD). Furthermore, our data suggest that if there are differences in sensitivity, discrimination and identification in ASD, this may not be something that is shared by those with high levels of autistic traits. It seems apparent that differences in sensory perception that are experienced by those with ASD (and, to a certain extent, those who may have the Broader Autism Phenotype) are not caused by lowered thresholds *per se*, and that some other mechanism/s must be considered. It is therefore important that researchers investigate these possible causes experimentally, in order to elucidate the exact points in the sensory system at which differences arise.

Chapter 8   The Development of a Pilot Sensory Audit: Making Environments Safer for those with ASD

8.1 Introduction

The response of the human system to sensory input can vary greatly between typical individuals (Witkin, 1949). The extent of discomfort, or pleasure, in response to such input will depend on two factors: the properties of the stimulus itself (e.g. the intensity or frequency) and the subjective relationship the individual has with the stimulus (DeGagne & Lewis, 2009). The latter can be further dismantled into three separate components: the physiological sensitivity of a person (i.e. the level of their absolute thresholds), psychological or attitudinal factors (e.g. whether they already have negative connotations with a certain stimulus) and the environment that a person is habituated to (e.g. moving from a rural area to an urban environment may prove uncomfortable, at least initially).

Visually, there are specific physical properties that can make something unpleasant to look at (Wilkins, 1995). This is particularly applicable for individuals with a variety of medical conditions, as well as typically developing individuals. For example, it is known that a subset of individuals with epilepsy can suffer from induced seizures when looking at certain visual stimuli (including flickering light and or visual patterns). This is known as photosensitive epilepsy and affects approximately 4% of those who suffer from seizures (Wilkins, 1995). Furthermore, there is evidence to suggest that stripes can be one property of visual stimuli that is particularly irritating (Wilkins, 1995), and that the 'stripy-ness' of printed text can actually have an effect on reading (Wilkins et al., 2007).

In addition, there are various other visual conditions that may affect certain people negatively. Lighting is particularly important, with artificial lighting often causing discomfort. Wilkins (1995) suggests that this may be a result of the flickering quality of such light. In order to illuminate, an alternating current (AC) is used to either heat a wire conductor (incandescent lighting) or by causing the ionization of gas (gas discharge lighting). As an AC supply is typically used to power these devices, the light continuously and rapidly varies in brightness. This is not normally visible to the human eye, as once the frequency reaches a certain level (typically around 30 cycles per second: Macknik & Martinez-Conde, 2010) the eye perceives the light to be continuous. However, in reality, it is still flickering on and off. There is evidence that, although we do not consciously

perceive the flickering of the light, the visual system does not react the same way to intermittent light as it does to continuous (Berman, Greenhouse, Bailey, Clear, & Raasch, 1991; Brindley, 1962). Indeed, the visual system continues to resolve light stimulation at levels well above the critical flicker frequency threshold (Wilkins, 1995).

In terms of auditory stimuli, it has been reported that people experience increased distress and annoyance when listening to stimuli with particular properties. Indeed, it is possible for sounds of extremely high levels (i.e. over 120 dB) to cause pain, or even physical damage, to the auditory system (Nave, 2006). However, it should be noted that, in the acoustic literature, there is differentiation between the objective measurement of a sound (e.g. the sound level, measured in dB) and the subjective impression of a sound (e.g. the loudness, measured in phon). The latter is computed using the former while taking into account other acoustic properties, such as the critical bandwidth (Zwicker & Fastl, 1990).

Rasmussen (1979) investigated noise levels and annoyance in road traffic noise. Each noise condition lasted 30 mins and consisted of pink noise (where the energy is inversely proportional to the frequency) shaped to simulate cars and trucks passing by on a nearby road. The noise stimuli ranged from 40 to 70 dB. Results showed that annoyance was highly correlated with noise level measurement. Furthermore, studies using loudness measurements have also found that annoyance increases alongside an elevation of loudness levels (e.g. Nilsson, 2007). However, there is evidence that other factors are important, particularly in the perception of complex sounds. Berglund, Preis, & Rankin (1990) assessed the relationship between loudness and annoyance for community sounds (rather than meaningless sounds). They found that, while the loudness of a sound was most important in determining the annoyance of a loud sound, other factors had a considerable impact – especially in the perceived annoyance of quieter sounds.

This suggests that there are qualities other than the intensity of an auditory stimulus that are important. One example of this is frequency composition: sounds with high-frequency components are more annoying than lower-frequency sounds (Gray, 2000). This may be due to two reasons: a) that humans are more sensitive to high-frequency sounds than low-frequency sounds and b) the noise that we are surrounded by on a day-to-day basis is more likely to be low-frequency (Gray, 2000). The sharpness of a sound appears to be important in its perception. Sharpness is a measure of high-frequency content – the greater the proportion of high-frequency components, the 'sharper' it will sound (Cox, 2007). In Bergland et al. (1990)'s study, they found that sharpness was strongly related to how

'annoying' a sound was perceived to be, although this was much more important for the sounds with a lower sound level. However, there is also evidence that sounds with low frequencies (i.e. <250 Hz) can be particularly annoying. Persson & Bjorkman (1988) conducted a study using broadband fan noise centred at 80, 250, 500, and 1000 Hz at A-weighted comparable sound levels (where the dB level was altered depending on the frequency of the sound, so that all the sounds appeared to have the same loudness). They found that the noise centered at 80 Hz was found to be more annoying then the other three sounds.

Olfaction is the sense of smell, and has been found to affect flavour perception (Stevenson, Prescott, & Boakes, 1999), emotional states (Lehrner et al., 2000) and social preferences (Li et al., 2007). Humans are very sensitive to smells, and are able to detect some odours at very low concentrations (e.g. one drop of perfume in a three-bedroomed house) (Schiffman, 1990) in 50% of trials that the stimulus is present. There is evidence that olfaction systematically differs in humans – with studies finding that women are more sensitive to smells than men (Fillingim & Ness, 2000; Opatz, Soiffer, & Hummel, 2000). In addition, people become less sensitive to smells as they age (Evans, Cui, & Starr, 1995) and, in fact, loss of smell appears to be a reliable indicator of the onset of Alzheimer's Disease (Talamo et al., 1989). There are other factors that can affect olfaction detection thresholds, including prolonged exposure to highly odorous environments (Berglund, Lindvall, & Nordin, 1992), the menstrual cycle (Watanabe, Umezu, & Kurahashi, 2002), smoking (Liu et al., 1995) and injury to the head (Levin, High, & Eisenberg, 1985).

The majority of research into sensory issues in ASD has concentrated upon the personal sensory sensitivity of an individual to stimuli, either using parent/self-report (Baranek et al., 2006; Crane et al., 2009; Leekam et al., 2007) or direct measurement (Bertone et al., 2005; Cascio et al., 2008; Jones et al., 2009; Tavassoli & Baron-Cohen, 2012a; 2012b). However, the data in previous chapters (Chapters 3-6) show that certain aspects of an environment can be aversive too, and that if adaptations can be made, there is potential to increase accessibility for those with ASD (Chapters 4 and 5). Therefore, a pilot 'Sensory Audit' was developed, which was a small-scale project designed to determine the optimal ways to assess an environment for its suitability for those with ASD. The modalities highlighted for inclusion in the 'Sensory Audit' were visual, auditory and olfactory, which are the sensory modalities most frequently cited as being problematic for individuals with ASD (see Chapters 4-5) and are also the least likely to be under the direct control of the individual. The objective characteristics of various stimuli in an environment were of

interest, rather than an individual's self-reported sensitivity (which was assessed in Chapter 2). This chapter details the effort to apply the knowledge gained directly from individuals with ASD, by developing an objective method of measuring an environment for its 'sensory suitability' for those with ASD.

8.2 Methods

8.2.1 – Apparatus

8.2.1.1 – Visual

Overview of the visual environment

In order to assess the visual environment over the course of a day, the auditor took pictures, using a Sony Cybershot DSC-WX7 digital camera.

Luminance and Chromaticity

The luminance and chromaticity were measured using a Minolta CS-100 chromameter.

8.2.1.2 – Auditory

Sound level meter

The sound level was established using a CR:152B Optimus Yellow Sound Level Meter with Data Logging, which was calibrated prior to each measurement.

Field recorder

The auditory environment was recorded using a Roland R-09HR field recorder. Output files are uncompressed 16-bit .wav type, with a sample rate of 44.1kHz.

8.2.1.3 – Olfactory

Measurement of olfactory environment

There is no affordable, mobile technology currently available to measure olfactory environments. Thus, this portion of the Sensory Audit must be assessed using a human observer with typical or better-than-average olfactory threshold, discrimination and identification skills. The auditor's observations are noted on the form shown in Appendix G.

Verification of olfactory ability

In order to identify a suitable individual to fulfill the olfactory aspect of the Sensory Audit, the Sniffin' Sticks Extended Test is administered. This is a method of testing

chemosensory performance using 'pens', with various odorants diluted in propylene glycol (to a volume of 4 ml) (Hummel et al., 1997). See section 7.2.3.2 for more information. We required the auditor to be either more sensitive than or within one SD of the norms published in Hummel et al., 2006. The norms, along with the olfactory auditor's scores on each measure, are displayed in Table 8.1. Note that higher scores indicate superior performance, with the highest possible score being 16.

Table 8.1 – Details of olfactory performance of auditor and norms for male between 36 and 55 (Hummel et al., 2006)		
	Norms	**Auditor (male; 48 yrs)**
Threshold	8.43± 1.74	12.5**
Discrimination	11.94 ± 1.12	11.0*
Identification	13.10 ± 0.94	14.0*
* within norms for age group; **higher sensitivity than norms for age group		

8.2.2 – Procedure

8.2.2.1 – Visual

An overview of the procedural protocol for the visual Sensory Audit is given in Appendix H.

Overview of the visual environment

Multiple photographs were taken of the environment over the course of a working day. There were at least six viewpoints (ceiling, floor and all four walls) with extra photographs taken of any visual stimuli of interest (e.g. a colourful print/lighting/view from window etc). The reason for this was to a) assess whether we can identify any specific visual issues that may be present and b) to determine how the ambience in the room changes with time/weather/lighting etc.

Luminance and chromaticity

Luminance levels and chromaticity coordinates were recorded for 2-5 points of each viewpoint photographed, using the luminance and colour meter detailed in section 8.2.1.1. As with the photographs, these measurements were taken at multiple points over the course of a working day. Specific areas within each scene were identified and measured:

- the Macbeth colour checker reference white (included in the photograph)
- the natural bright point in the scene
- the darkest point
- any points of interest

- any particularly strong colours in the scene
- ambient colour
- ambient luminance

8.2.2.2 – Auditory

An overview of the procedural protocol for the auditory Sensory Audit was given in Appendix I.

Ambient noise

The ambient auditory environment was assessed by determining the sound level using the sound level meter detailed in section 8.3.1.2. In addition, the auditory environment was recorded in order to identify a) specific peaks and troughs in the sound level data and b) any particular noises that should be recorded in isolation and analysed. Snapshots of the ambient noise were recorded at multiple points over the course of a working day, and used to identify the specific noises which would be analysed in depth.

Specific noises

Noises to be recorded were identified by a) the information gathering session, b) disclosure of any pre-identified auditory issues and c) during the assessment of the ambient noise. The equipment detailed in section 8.2.1.2 was used to record the noise and determine the sound level simultaneously.   Efforts were made to isolate the noise from any ambient sound prior to recording, in order to assess the acoustic qualities.

8.2.2.3 – Olfactory

An overview of the procedural protocol for the olfactory Sensory Audit is included as Appendix J.

The designated auditor assessed the olfactory environment, by entering the designated area and focusing on any odours. Odours were named if possible, rating the intensity on a scale of 1-5 (very faint – faint – noticeable – strong – overpowering). If they could not name the odour, they attempted to describe it. These details were recorded on the form shown in Appendix G. After approximately 2 mins, the participant should not be able to identify any new odours (as they become quickly habituated to the odours in the environment). As a result, they removed themselves to clear air (a previously identified area or outside) and given a break for 10 minutes to clear their adaptation to the environment before reassessing

the area. Each room/space being assessed was done so in this manner. As in the visual and auditory audits, the olfactory audit was repeated multiple times over the course of a working day.

8.2.3 – Data Analysis

8.2.3.1 – Visual

Luminance

We were able to determine the amount of light that is emitted from a particular area by recording the luminance of certain points in a given environment. Luminance was measured in candelas per metre squared (cd/m^2), which enabled us to quantitatively assess the brightness of various stimuli in a given environment.

Chromaticity

An estimation of colour was obtained, using conversion from x, y and Y values to CIE 1931 colour space (Wysecki & Styles, 2000).

8.2.3.2 – Auditory

Ambient noise

Min, max and mean sound levels (in A-weighted decibels (dB(A): an expression of how loudly a sound is perceived by the human ear, by accounting for frequency as well as sound pressure)) were determined using the sound level meter and compared across a) different environments and b) time.

Specific noises

Specific sounds are analysed using the program Psysound 3 (Cabrera, Ferguson, Rizwi, & Schubert, 2008). Using a calibration file of a known sound level, the audio content from the field recorder was analysed for various acoustic properties:

- Loudness
  - This is an estimation of the subjective experience of sound intensity (rather than the objective sound pressure, measured by the sound level meter)
- 1/3 Octave Frequency
  - This details the frequency composition of the sound
- Sharpness
  - This is a measure of the high frequency composition of a sound (measured in acum)

- Roughness
    - This is a measure of the subjective impression of rapid amplitude change (measured in asper)

8.2.3.3 – Olfactory

Intensity and presence/absence of odours were charted across time.

8.3 Results

The pilot Sensory Audit was developed in order to help individuals with ASD by providing a method of objectively assessing sensory environments, as well as recommendations for the amelioration of such environments. In this section, the development of the Sensory Audit, as well as the results of the pilot Sensory Audit will be reported.

8.3.1 – Development of the audit

The first stage of the development of the Sensory Audit involved information gathering. The data from the qualitative questionnaire (Chapter 3), ASD focus groups (see Chapters 4 and 5), the elderly focus group (Chapter 6) and relevant literature (Dickie et al., 2009; Jones et al., 2003) were scrutinised for details of specific problematic stimuli and environments. We decided to restrict the pilot Sensory Audit to three senses (visual, auditory and olfactory), although it is anticipated that there is scope to assess other modalities with a full-scale Sensory Audit. This choice was reflected in the types of negative sensory examples found in the data, as people tended to report predominantly having problems with auditory stimuli, as well as visual and olfactory aspects of an environment.

8.3.1.1 – Visual

The specific qualities identified that appear to make visual stimuli more problematic are:
- Intensity
    - Either very high (e.g. bright lights, strong colours) or low intensity (e.g. dim lights) of stimuli
- Flickering
    - Visual stimuli which appeared to flicker (e.g. lights/visual equipment)
- High contrast
- Visual patterns
    - Items arranged in rows/busy visual patterns

- Fast-paced visuals

- Unpredictable visual stimuli

Some workplace-related examples of problematic visual stimuli include:

- Fluorescent lights

- Fast-moving crowds

- Fast-moving traffic

- Environmentally friendly lightbulbs

- Brightly coloured signs

- Dimly lit environments

- Bright sunlight

- Supermarket shelves

We then assessed the best ways to objectively measure the visual environment, taking into account common complaints in the data. As a result, we decided that the visual Sensory Audit would consist of the following:

- An overview of the visual environment

- An estimate of overall luminance

- An estimate of overall chromaticity

- Luminance measurements of specific areas of interest

- Chromaticity measurements of specific areas of interest

- A measure of the flicker of specific areas of interest

A visual Sensory Audit protocol was then developed, which defines how this aspect of the audit should be investigated, using the equipment in 8.2.1.1. The visual protocol is included as Appendix H. The protocol details a step-by-step procedure for a) measurement of the general visual environment, b) measurement of specific visual stimuli and c) analysis of the visual environment as a whole. By following this protocol, we are able to a) identify any problematic stimuli and b) quantitatively measure various visual aspects of them.

8.3.1.2 – Auditory

Problematic auditory stimuli were identified as particularly common during the information-gathering phase. The specific qualities identified that appear to make auditory stimuli more problematic are:

- Intensity
  - Either loud sounds in a range of background noise levels, or quiet sounds against minimal ambient noise.
- High-frequency sounds
- Low-frequency sounds
- Mixed sounds
  - Sounds which do not appear to go well together (e.g. are discordant)
- Repetitive sounds
- Unpredictable sounds
- Unidentifiable sounds
- Rapidly changing sounds

Some workplace-related examples of problematic auditory stimuli include:
- Fire alarm
- Noise of traffic/roadworks
- Echoing
- Multiple people talking at once
- Telephones ringing
- Sirens
- Microwave beeping
- People entering/leaving rooms

We then assessed the best ways to objectively measure the auditory environment, taking into account common complaints in the data. As a result, we decided that the auditory Sensory Audit would consist of the following:
- An overview of the ambient auditory environment
- A detailed analysis of specific noises highlighted as problematic

An auditory Sensory Audit protocol was then developed, which defines how this aspect of the audit should be investigated, using the equipment in 8.2.1.2. The auditory protocol is included as Appendix I. The protocol details a step-by-step procedure for a) measurement of the general auditory environment, b) measurement of specific auditory stimuli and c) analysis of the auditory environment as a whole. By following this protocol, we are able to a) identify any problematic stimuli and b) quantitatively measure various auditory aspects of them.

8.3.1.3 – Olfactory

The specific qualities identified that appear to make olfactory stimuli more problematic are:

- Intensity

    o   Particularly pungent odours can be an issue.

- A mixture of smells

- Particular types of smells

- Unpleasant smells

Some workplace-related examples of problematic olfactory stimuli include:

- Body odour

- Food smells

- Perfumes/colognes

- Air fresheners

- Alcohol-based hand disinfectant

- Cleaning products

- Cigarette smoke

We then assessed the best ways to objectively measure the auditory environment, taking into account common complaints in the data. Unfortunately, there is not an affordable, portable way to detect a wide range of odours in an environment. As a result, we have to use a human to audit the olfactory environment. We decided that the olfactory Sensory Audit would consist of the following:

- A detailed description of smells identified during the audit and an estimate of intensity

- A detailed description of smells which cannot be identified (i.e. aware of a smell, but too faint to identify) during the audit and an estimate of intensity

In order to ascertain whether an individual is suitable to assess the olfactory environment in the Sensory Audit, we must determine that they have a normal or superior odour detection threshold, discrimination abilities and identification abilities. The olfactory auditor for the pilot project (DS) was deemed to have a) superior threshold, b) typical discrimination and c) typical identification abilities. An olfactory Sensory Audit protocol was developed, which defined how this aspect of the audit should be investigated. This protocol includes the administration of the Sniffin' Sticks Extended Test (Burghardt,

Messetechnik), using the equipment in 8.2.1.3, as well as instruction for the olfactory Sensory Audit. The olfactory protocol and the worksheet for the auditor are included as Appendices E and B respectively. The protocol details a step-by-step procedure for a) assessment of the suitability of an individual for the olfactory aspect of the Sensory Audit, b) description of both identifiable and unidentifiable smells auditory stimuli and c) an estimation of their intensity. By following this protocol, we are able to a) identify any problematic olfactory stimuli and b) assess how their intensity changes throughout the course of a designated period of time (e.g. day/week).

8.3.2 – Results of the pilot audit

This section details the results of the pilot audit, which was carried out within an office (Rm 418) in the School of Psychology, University of Glasgow. This was not a full-scale audit, and thus measurements were not repeated as often as detailed in section 8.3.1.

8.3.2.1 – Visual

General décor and layout

The décor within Rm 418 is muted, with the walls painted a pale green-blue. A large desk sits in the centre of the room. There are two windows, fitted with vertical blinds, which look out onto the street. There are bookshelves on the right hand and left hand walls (from the door), with colourful books and folders sitting upon them. There are 4 filing cabinets, as well as another 2 desks and a variety of chairs.

RH wall (from door)

The right-hand wall is dominated by four long bookshelves filled with books and folders. For the most part, the bright colours are mixed. There is a block of black folders on the top right shelf, and a block of white books in magazine holders on the 2nd shelf. The brightest point was estimated to be the side of the computer screen sitting on the desk, and the 'typical' measurement was taken from the section of books falling over on the 3rd shelf.

Figure 8.1 – View of the right-hand wall from the door [photo]

Table 8.2 – RH wall (from door)		Luminance (cd/m^2)	Chromaticity		CIE (1931) colour
Session	**Area**		**x**	**y**	
2	typical	7.18	.370	.380	
	wall	17.6	.366	.387	
	shelf underside	1.66	.370	.392	
	white books	11.5	.365	.381	
	brightest point	37.5	.412	.419	

LH wall (from door)

There are four shelves near the window, with a block of brightly-coloured books taking up the whole of the second shelf. Five chairs sit against the wall. A whiteboard is situated near the door, with a disassembled desk partially in front of it.
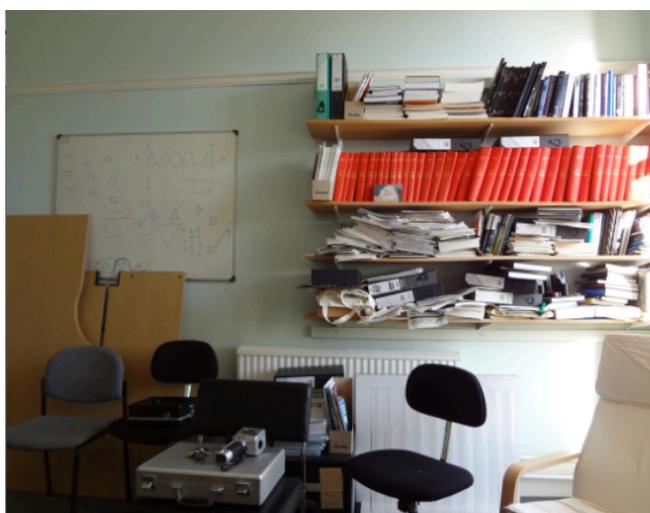
Figure 8.2 – View of the left-hand wall from the door [photo]

Table 8.3 – LH wall (from door)					
Session	**Area**	**Luminance (cd/m^2)**	**Chromaticity**		**CIE (1931) colour**
			x	**y**	
2	wall	73.1	.382	.385	
	books	60.6	.554	.364	
	brightest point	484.0	.370	.381	
	whiteboard	92.5	.365	.383	
	black books	19.2	.371	.365	

Floor

The light coming through the window created a distinction between the shaded and lighted areas of the floor. However, because the camera flash was on, it is not possible to see this in the photo. The shaded portion was the bottom right, with the lighted area in the top left.
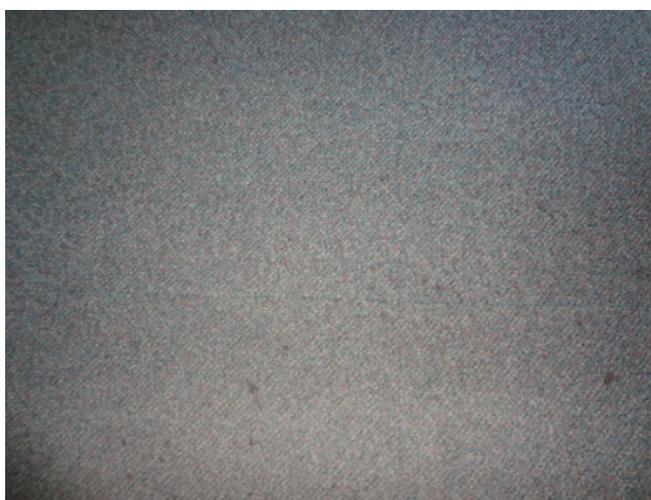
Figure 8.3 – View of floor [photo]

Table 8.4 – Floor					
Session	**Area**	**Luminance (cd/m^2)**	**Chromaticity**		**CIE (1931) colour**
			x	**y**	
3	lightest patch	5.78	.290	.328	
	darkest patch	0.44	.304	.344	

Wall with door

There is a large pinboard with drawings on it. There are two filing cabinets towards the left, with posters and two chairs under the pinboard.
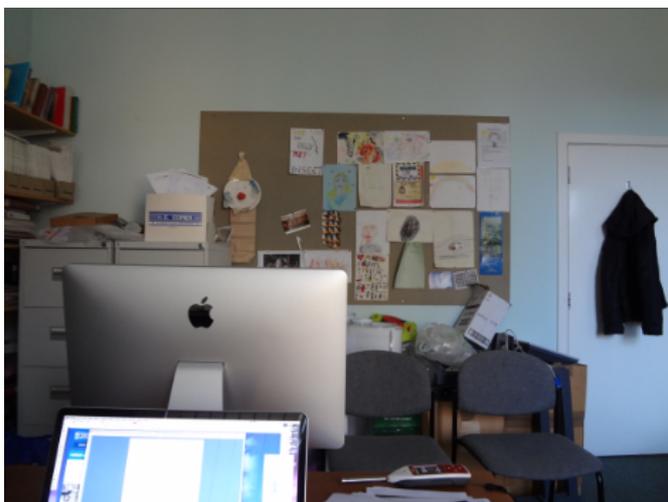
Figure 8.4 – View of the wall with the door [photo]

Table 8.5 – Wall with door					
Session	**Area**	**Luminance (cd/m^2)**	**Chromaticity**		**CIE (1931) colour**
			x	**y**	
3	wall	13.7	.359	.372	
	typical	6.44	.397	.358	
	pinboard	5.00	.366	.386	
	bk of computer	35.8	.336	.371	

Ceiling

There are 4 fluorescent lights on the ceiling, with a reflective grill over the tubes. There is also a decorative part of the ceiling, situated in the centre.

Figure 8.5 – View of the ceiling [photo]

Table 8.6 – Ceiling					
Session	**Area**	**Luminance (cd/m^2)**	**Chromaticity**		**CIE (1931) colour**
			x	**y**	
4	Lights (on)	494	.414	.414	
	Ceiling (on)	15.7	.402	.406	
	Lights (off)	0.95	.331	.385	
	Ceiling (off)	8.75	.326	.349	

Wall opposite door

There are two windows in this wall, looking out onto the street below. A desk sits to the right, with two filing cabinets between the windows.

Figure 8.6 – View of the wall opposite the door [photo]

Table 8.7 – Wall opposite door		Luminance (cd/m²)	Chromaticity		CIE (1931) colour
Session	**Area**		**x**	**y**	
4	window w/ blinds	73.3	.388	.390	
	window w/o blinds	246.0	.336	.362	
	wall	7.26	.315	.341	
	LH filing cabinet	1.90	.397	.337	
	brightest point	434.0	.327	.345	

8.3.2.2 – Auditory

Ambient noise

Three 12-17 minute recordings were made. The data from the sound level meter for each is displayed below.

In session 2, the sound level ranged from 24.66 dBA to 76.56 dBA (Figure 8.7). When the office was quiet, the sound level maintained a range of 30-45 dBA, rising with external noise and speech. This appears to be a quiet environment, although because it backs out onto a street, extraneous noise may filter in.
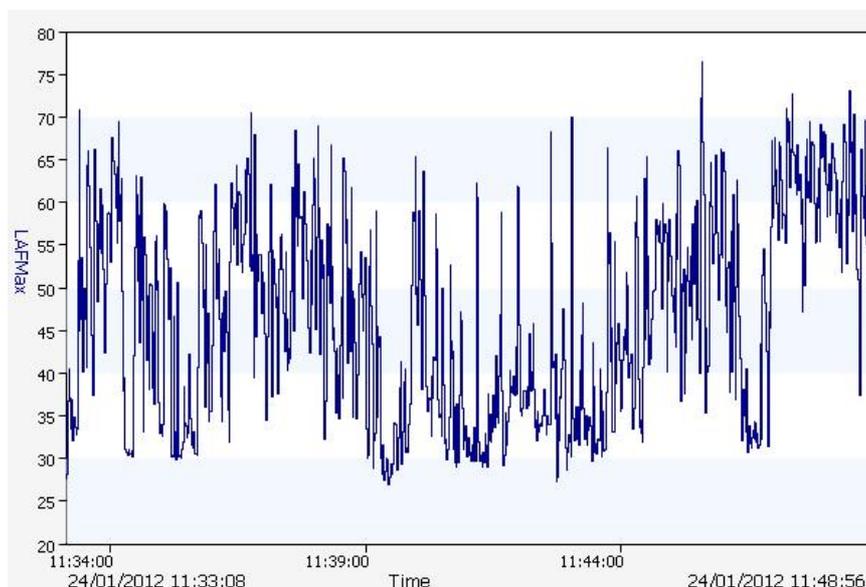
Figure 8.7 – Ambient sound level for session 2 of the pilot study

On the day of the recording, there were no sounds of building work/special circumstances that affected the recording. The following noises could be heard:

- People walking outside the office
- People walking inside the office
- Talking inside the office
- Traffic from outside the office
- Door opening and closing

In session 3, the sound level ranged from 26.05 to 75.64 dB(A) (Figure 8.8). Again, when the office was quiet, the sound level was maintained at 30-45 dB(A), and rose with external noise and speech.
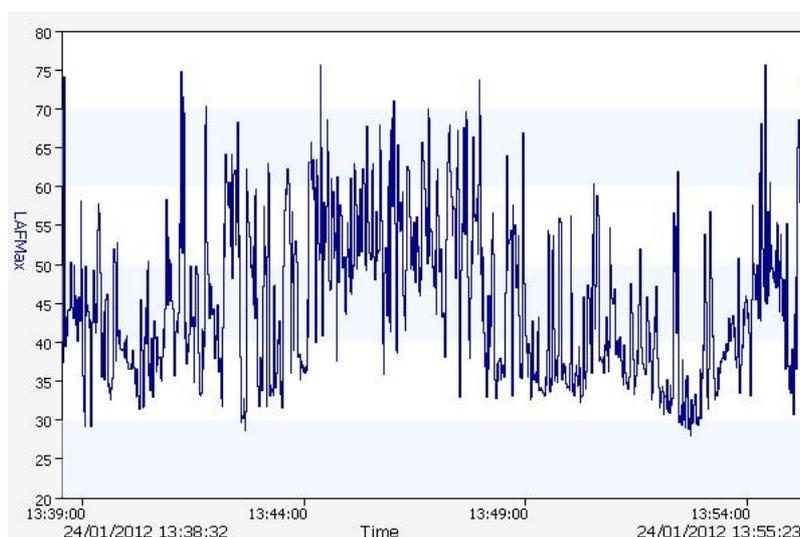
Figure 8.8 – Ambient sound level for session 3 of the pilot study

The following noises could be heard:

- People walking outside the office
- People walking inside the office
- Talking inside the office
- Talking from outside office
- Traffic from outside the office
- Noise of camera turning on
- Noise of chromameter being taken out of box
- Noise of writing results down
- Door opening and closing
- Lorry reversing

In session 4, the sound level ranged from 25.74 to 82.29 dBA (Figure 8.9).
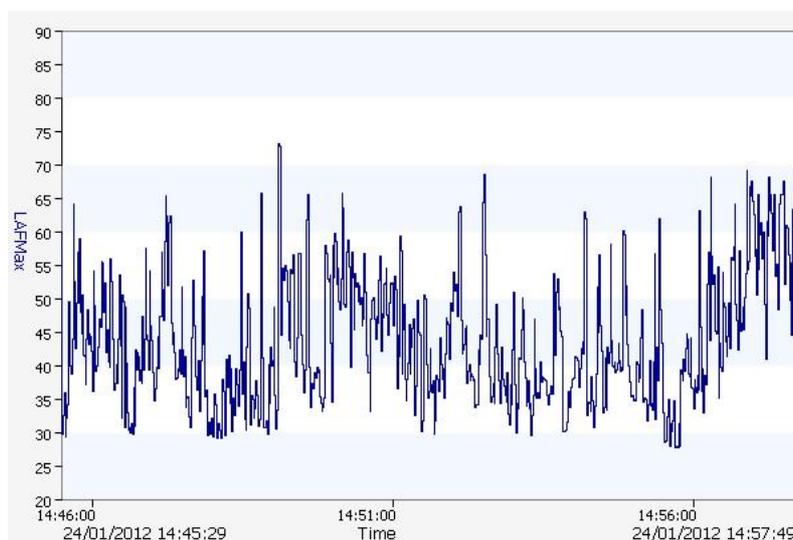
Figure 8.9 – Ambient sound level for session 4 of the pilot study

The following noises could be heard:

- People walking outside the office
- People walking inside the office
- The filing cabinet drawer being opened
- Talking inside the office
- Talking from outside office
- Traffic from outside the office
- Noise of camera turning on
- Noise of chromameter being taken out of box

- Noise of writing results down
- Door opening and closing

Specific noises

After listening to the audio recordings of the ambient environment, two potential problematic noises were identified: the phone ringing and the drawer to the filing cabinet being opened and closed. In addition, one potentially problematic noise was identified through discussion, which was the weekly testing of the fire alarm. These three noises were recorded and certain acoustic properties analysed, using PsySound3 (Cabrera et al., 2008).

Firstly, the A-weighted sound levels of the noises (dB(A)) were determined. These corresponded to the data from the sound level meter, which was used alongside the recorder. The phone (Figure 8.10) was the loudest of the three noises, with the fire alarm (Figure 8.11) being the quietest (although this was recorded with the door closed rather than open). The filing door cabinet (Figure 8.12) was recorded being opened and closed four times.
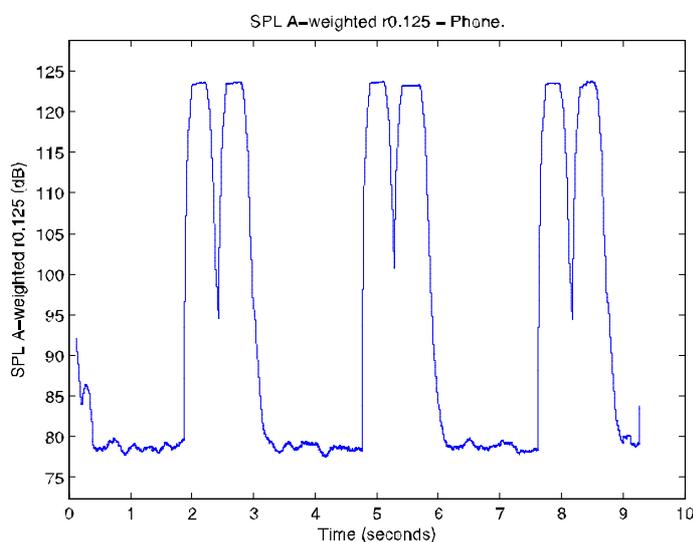
Figure 8.10 – The sound of the phone ringing, measured in dB(A).
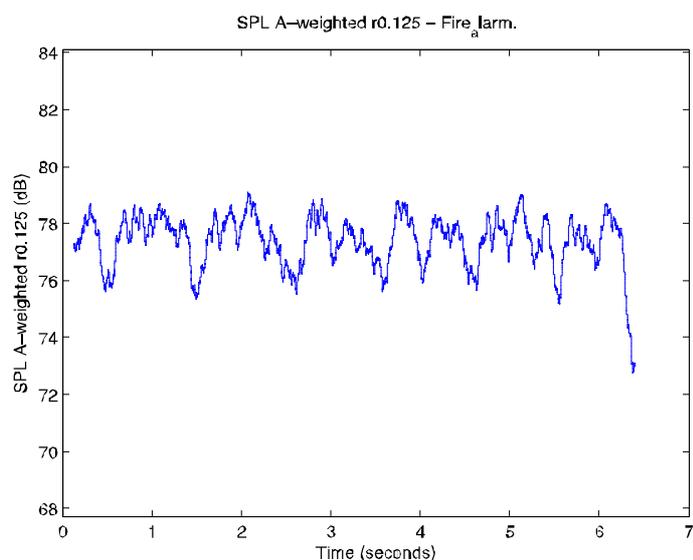
Figure 8.11 – The sound of the fire alarm, measured in dB(A).
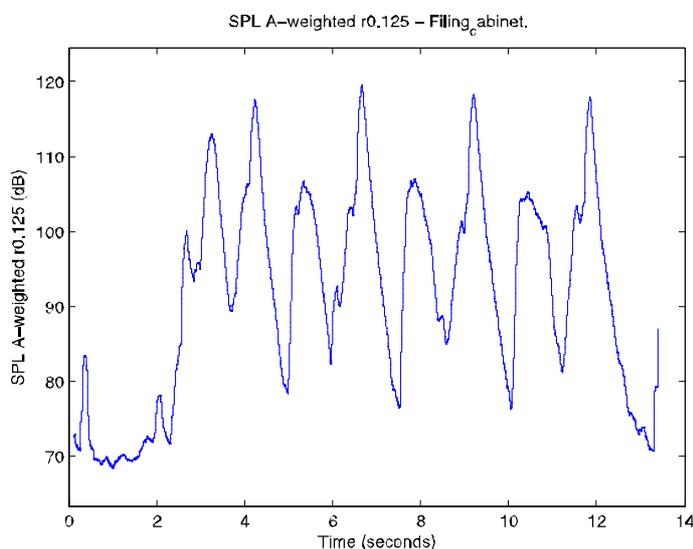
Figure 8.12 – The sound of the filing cabinet being opened and closed multiple times, measured in dB(A).

The pattern observed in Figure 8.10 (phone) is particularly interesting, as a very sharp increase and decrease in sound level during the 'ringing' phase can be observed. The sound of the filing cabinet drawer (Figure 8.12) shows the noise that specific parts of the process make. For example, the sound of the drawer being pulled open is slightly shallower than the sound of the drawer closing. In addition, the sound of the drawer closing tended to end in a 'bang' of sorts, which is also determined in the pattern of the sound level (there is a sharp peak for each of these occurances). The fire alarm (Figure 8.11) shows similarities to the phone ringing, as it has a modulating sound level (but without the sound level completely fading away).

Secondly, the frequency compositions of the sounds were determined. PsySound3 is able to split the audible frequencies into bands (1/3 Octave bands), which helps to identify the frequency content of the sound. There are around 30 possible bands that the sound can fall into, and this process is particularly helpful when investigating noises of high and low frequency. The output for the phone ringing (Figure 8.13), filing cabinet being opened (Figure 8.14) and fire alarm (Figure 8.15) are shown below.
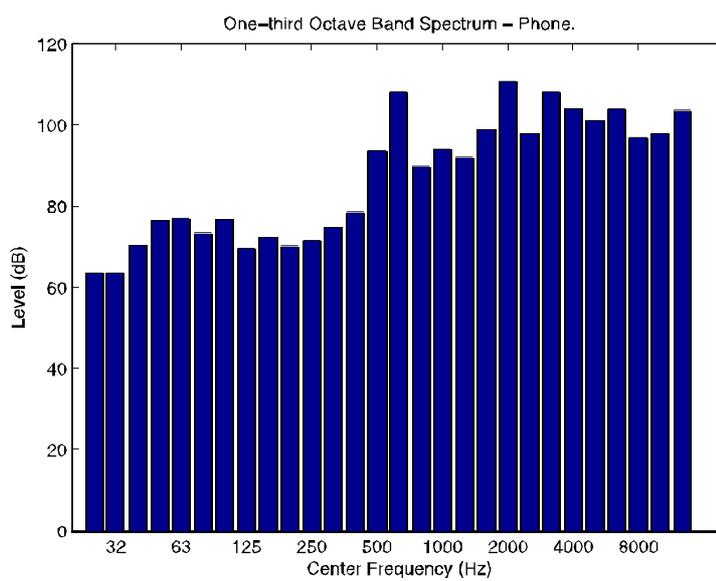
Figure 8.13 – The frequency composition of the phone ringing (in Hz) and the sound level in dB(A).
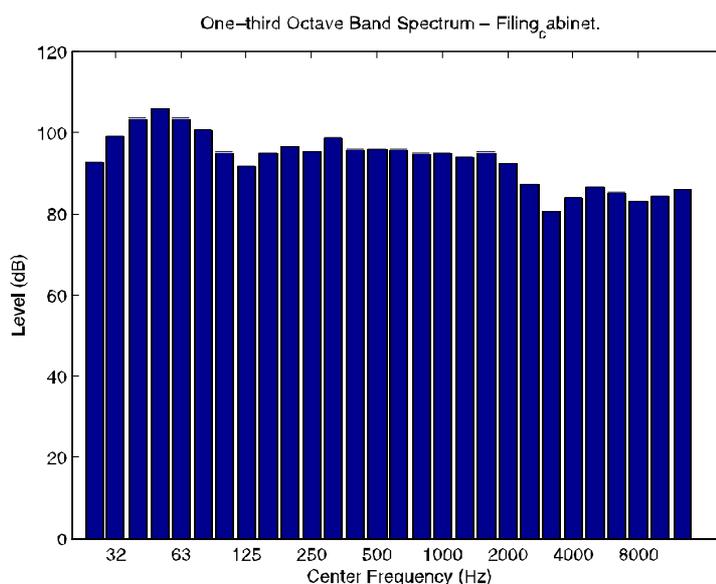
Figure 8.14 – The frequency composition of the filing cabinet opening (in Hz) and the sound level in dB(A).

One–third Octave Band Spectrum – Fire alarm.
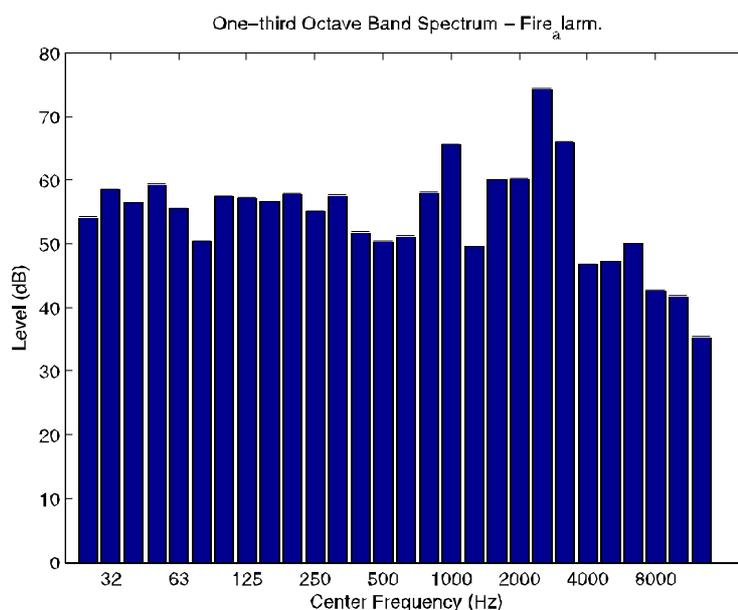
Figure 8.15 – The frequency composition of the fire alarm (in Hz) and the sound level in dB(A).

These data show that the filing cabinet has a much more even spread of high and low frequency components than the other two sounds. The loudest components of the phone are higher in frequency. For the fire alarm, the loudest aspects of the sound centre on 850-900Hz and 2750- 3500 Hz with a sharp drop off in the higher frequency components.

Thirdly, sharpness is a measure of the high frequency content of a sound (Cox, 2007) and is related to increased annoyance (Zwicker & Fastl, 1990). Sharpness was calculated for all three sounds, and are presented in Figures 8.16, 8.17 and 8.18 below.
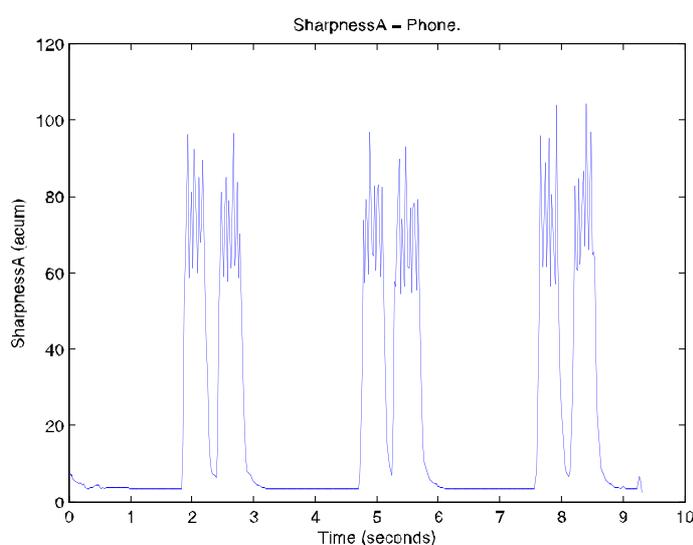
SharpnessA – Phone.

Figure 8.16 – The sharpness of the phone ringing, measured in acum.
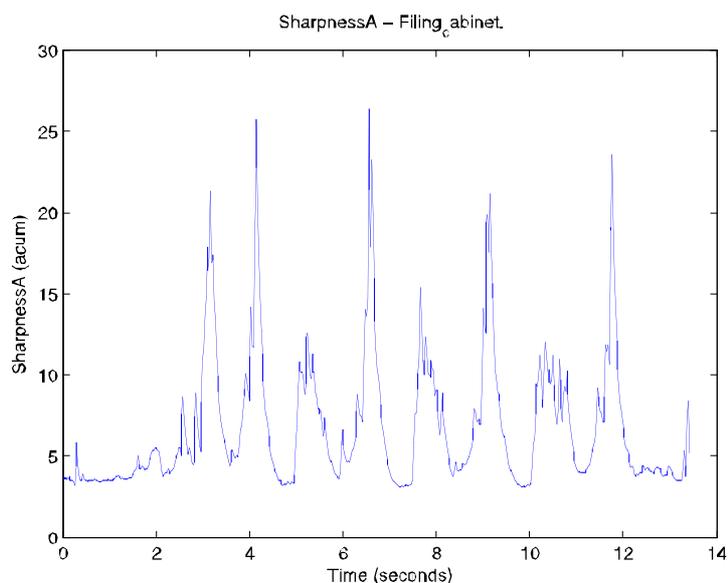
Figure 8.17 – The sharpness of the filing cabinet drawer, measured in acum.
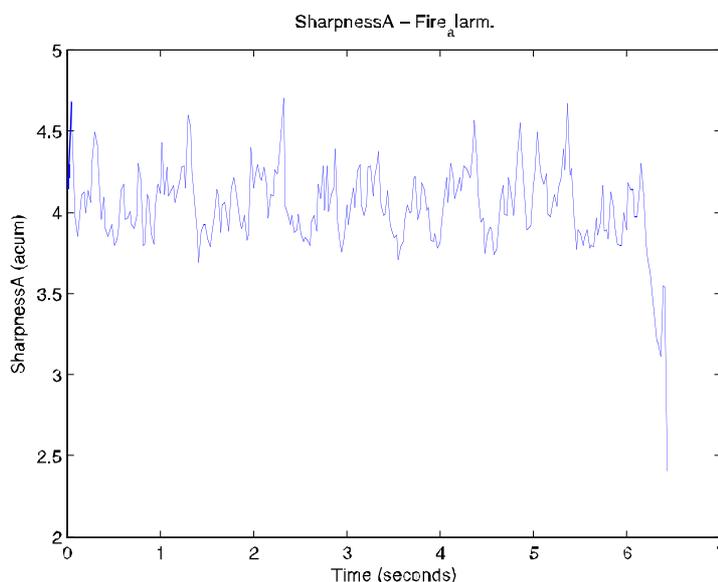
Figure 8.18 – The sharpness of the fire alarm, measured in acum.

The sharpness of the fire alarm is relatively low, centering around 4-4.5 acum, whereas the filing cabinet shutting peaks with the bang of the drawer shutting (around 20-25 acum). However, the phone ringing was a particularly sharp sound, as each ring reached between 80 and 100 acum.

The final analysis performed on these sounds was roughness. Roughness is a measure that quantifies rapid amplitude modulation and it is designed to emulate the subjective perception of a sound, rather than being an objective measure. As with sharpness, there is evidence that increased roughness contributes towards increased annoyance perception of a

sound (Zwicker & Fastl, 1990). Graphs illustrating the roughness of each of the three sounds are shown below in Figures 8.19 to 8.21.
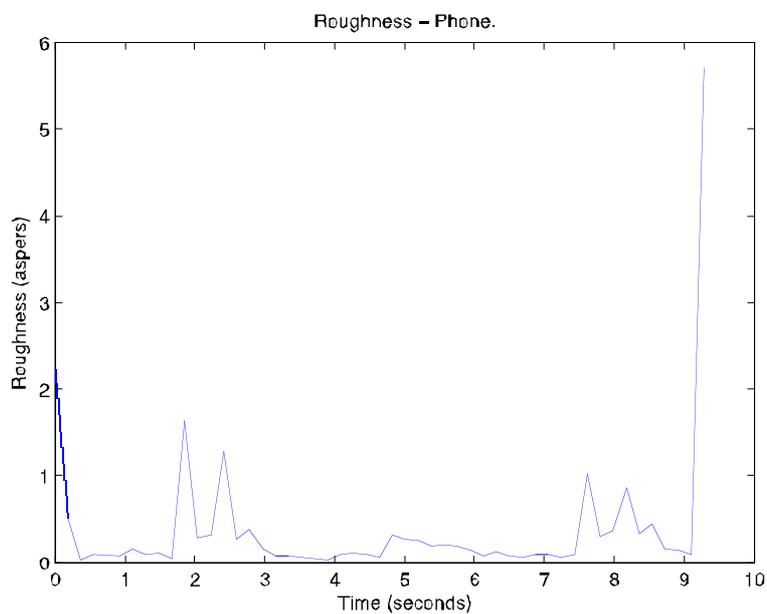
Figure 8.19 – The roughness of the phone ringing, measured in asper.
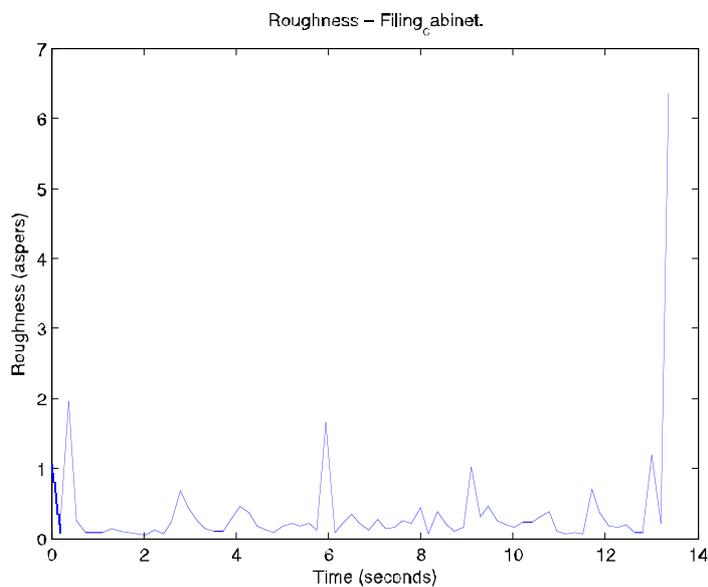
Figure 8.20 – The roughness of the filing cabinet drawer, measured in asper.
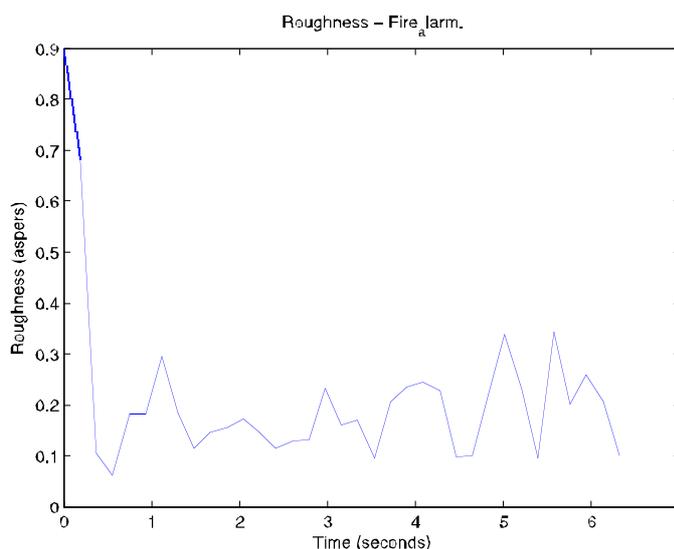
Figure 8.21 – The roughness of the fire alarm, measured in asper.

The graphs show that there is very little roughness to any of the sounds that were isolated for the pilot Sensory Audit, although the fire alarm appears to be slightly less rough than the other two sounds analysed.

8.3.2.3 – Olfactory

The protocol for this involves entering the environment and identifying the smells present and their intensity. The participant is then removed in order to become unaccustomed to the environment again (before assessing it a second time). The assessor is asked to describe the smells, whether they are able to identify them or not.

The olfactory audit showed that Room 418 was not a particularly odorous environment. Two smells were detected throughout the course of the day:

Satsumas – this was identified in session 1/2 and remained prevalent throughout the day. The intensity increased from 2 (faint) to 4 (strong) throughout the course of the working day. The cause of the smell was presumed to be the satsuma peel that had been left in the bin over the weekend.

Dusty/musty – the assessor identified a sort of dusty smell around the middle of the day (sessions 2/1 and 2/2) which then disappeared. This could not be identified and faded away by session 3/1.

8.4 Discussion

This chapter details the development of the Sensory Audit, as well as the results of a pilot assessment of the sensory environment. As described in section 8.2, the Sensory Audit assesses three different modalities – visual, auditory and olfactory. These were the most commonly reported as being problematic in the qualitative questionnaire (see Chapter 3) and the adult focus group (see Chapter 5). Children with autism, parents of those with autism and the elderly tended to concentrate on visual and auditory stimuli, with less of an emphasis on olfactory. Although the caregivers brought up issues with food, this was not reported as frequently in the self-report groups. This may be because the children interviewed were able to communicate effectively, as could the adults with ASD, and they would be able to communicate their dislikes to others. The parents of those with complex needs may be unable to communicate easily with their children and may be unaware of the reasons underlying challenging behaviour. Therefore, the three modalities chosen were done so because a) they reflected the most problematic issues in the information gathering phases and b) they could be objectively assessed (apart from the olfactory component).

The main benefit that those who use the Sensory Audit will gain is the recommendations for amelioration of the environment. For example, the recommendations given for the pilot Sensory Audit described in section 8.3.2 were as follows:

- If the testing of the fire alarm were a source of difficulty, it would be advisable to leave the premises between 9.20 and 9.50 am every Wednesday.
- Using door seals could reduce noise from the corridor outside.
- If concentration is affected by noise, noise reduction headphones or earplugs could be used.
- Using soundproofing curtains could reduce noise from the window.
- If the phone is bothersome, the University could be approached to purchase one with a variable volume/ring.
- Food waste left on a Friday afternoon could be taken to a bin on the street instead of being left in the office
- A shield could be purchased to cover the fluorescent lights.

These recommendations are based on a) close observation of the environment in question and b) discussion with those who have diagnoses of ASD (see Chapters 4 and 5). It should be noted that the pilot environment tested was relatively low-impact (a cellular office with a sole occupant), so whether these recommendations were followed up would depend on the personal sensitivity of the occupant.

This was developed in collaboration with the local company mentioned in Chapter 5 (through which we recruited our adult focus group participants). One of the predominant discussions arising in this group was the benefit that working at a place specifically designed for those with ASD could have. The participants were enthusiastic about the concept of the Sensory Audit and provided many examples of situations that they found intolerable. They agreed that the sensory environment at Specialisterne was much improved than in previous employment, and so it is our aim to identify what a 'good' sensory environment is, so that aspects of a 'difficult' environment can be highlighted and remediated somewhat.

It should be noted that, although an academic environment was chosen for the pilot Sensory Audit, the purpose of the study reported in this Chapter was predominantly to develop the protocols and procedure for administering the Sensory Audit. Indeed, data has been collected in other environments (e.g. the University of Glasgow gym and library) and these data will be used in the future to further develop the audit for use in the wider workplace. Furthermore, there is scope to develop the Sensory Audit to a variety of different environments, and target it at different populations. For example, many individuals have more severe forms of ASD and are far less able to communicate their distress and describe the issues that they have. This thesis (see Chapter 4), as well as the literature (Baranek et al., 2006; Dickie et al., 2009; Jones et al., 2003; Leekam et al., 2007), indicates that, despite often being unable to communicate verbally, these individuals frequently report difficulties with sensory stimuli. One way in which to expand the Sensory Audit to this subgroup of individuals with ASD would be to develop the sensory audit specifically for the long-term care environments of those with ASD (including residential schools). Furthermore, there is scope to expand the Sensory Audit beyond the ASD domain, by investigating elderly care homes, schools and hospitals. Indeed, it is not only those with ASD who report atypical sensory sensitivity to stimuli (Das-Munshi & Rubin, 2006), and a general Sensory Audit could be developed for this purpose.

However, one of the difficulties of the Sensory Audit is that it objectively assesses the environment without taking into consideration personal sensitivity. As demonstrated in Chapter 2, individuals in the general population report sensitivity to sensory stimuli in varying degrees. By developing a personal Sensory Audit to sit alongside the environmental Audit, we would be able to assess whether specific aspects of an environment might be problematic for those with certain sensitivities (therefore maybe

finding an individual solution, rather than making changes to the environment as a whole).
One example of this could be ambient noise level. The noise level in a typical open-plan
office is likely to be suitable for most people to work in (but perhaps not those with hyper-
sensitivity to auditory stimuli). Rather than disrupting the whole office by banning
speaking outside designated breaks, the company could provide earplugs for those who
need them. The personal Sensory Audit is scheduled for development in the near future.

Although the Sensory Audit is currently in development, it is anticipated that this project
could yield significant impact for individuals with sensory issues. With just over 1% of
people diagnosed with ASD (Fombonne, 2009) and an increasingly aging population
(Cracknell, 2010; ONS, 2012), it is increasingly important that environments are designed
to be low-impact. This could result in more pleasant working environments for all rather
than just those with ASD, especially with the impending development of the Personal
Sensory Audit.

Chapter 9   General Discussion

9.1   Summary of the findings

The studies presented in this thesis investigated the atypical sensory processing of individuals with a diagnosis of ASD, as well as those with varying levels of autistic traits. This thesis provides examples and interpretation, from both adults and children with diagnoses of ASD, of their sensory experiences. As far as I am aware, Chapter 4 reports the first qualitative study to investigate sensory processing directly with children who have autism, and Chapter 5 reports the first focus group study (on the topic of sensory sensitivities) with a group of adults diagnosed with ASD. Focus groups were also conducted with the caregivers of those with autism and other complex needs (Chapter 4) and an elderly control group of individuals caring for those with dementia (Chapter 6), in order to gain insight into the consequences of sensory issues (both hyper- and hypo-sensitivity) for carers. Furthermore, Chapter 2 reports the first significant positive correlation between autistic traits (Baron-Cohen et al., 2001) and self-reported sensory processing (Robertson & Simmons, 2012). These findings were expanded by the mixed method study reported in Chapter 3, which investigated differences in sensory experiences across three groups defined by AQ score (Low: < 19; Medium: 19-31; High: >31). In Chapter 7, we reported the first study examining the relationship between AQ score (Baron-Cohen et al., 2001) and olfactory performance (using Sniffin' Sticks; Berghardt, Messetechnik) of a large sample of adults (n=106). Lastly, we also report the development of the Sensory Audit (see Chapter 8), which consists of a set of implementable protocols (see Appendices C-E). These form the basis of a unique 'toolkit', which can be used to objectively assess the sensory suitability of an environment for individuals with ASD.

9.1.1 – What underlies atypical sensory responsiveness in ASD?

Although many studies have used parent report techniques and direct measurement paradigms to examine sensory differences between those with ASD and TD controls (see Chapter 1 for a discussion), there is a lack of replication and consensus among the research community. Parent report studies regularly show that those with ASD respond in an atypical way to sensory stimuli, compared to clinical and TD controls (Baranek et al., 2006; Leekam et al., 2007). Furthermore, evidence from self-report questionnaires shows that those with ASD report responding differently to sensory stimulation than controls (Crane et al., 2009). However, the results of experimental studies into sensory processing in ASD have not consistently found significant group differences (Bertone et al., 2005;

Güçlü et al., 2007; Jones et al., 2009), except in some aspects of visual processing (e.g. enhanced performance in some visual tasks: Jolliffe & Baron-Cohen, 1997; Plaisted, O'Riordan, Baron-Cohen, 1998a; Shah & Frith, 1983; 1993). There could be many reasons for this disparity, including: a) the experimental paradigms chosen by researchers not isolating the true perceptual differences in processing, b) that higher-order influences, rather than perceptual differences, are affecting the differences in response to sensory stimuli (e.g. attentional factors, affect) and c) that methodological differences or differences in clinical samples (or, indeed, control samples) can make interpretation of the results difficult.

Furthermore, there is evidence to suggest that sensory hyper-sensitivity is often related to factors other than the sensitivity of absolute thresholds. For example, Khalfa et al. (2004) investigated the auditory intensity perception of individuals with ASD and a TD comparison group. They found no group difference in detection thresholds; although there was an increasing disparity in perceived intensity as sound level increased (with the ASD group reporting sounds as more intense). In addition, there is also evidence that typically developing individuals with high chemosensory responsiveness (CR) (i.e. who report being particularly sensitive to olfactory stimuli) are more likely to experience odours as being less pleasant (Kärnekull, Jönsson, Larsson, & Olofsson, 2011), as well as avoiding situations where they might be exposed to certain smells (Nordin & Andersson, 2010). However, although those with high CR reported being more sensitive to olfactory stimuli (and perceived odours to be significantly less pleasant than their low CR counterparts), there was no evidence of a relationship between CR and olfactory detection threshold (Kärnekull et al., 2011). This indicates that increased responsiveness to sensory stimuli is not necessarily a by-product of decreased thresholds, but that they may be determined by other factors.

By designing qualitative studies in which we find out details about the sensory experiences of those with ASD, we have been able to isolate certain aspects that could affect the perception of sensory stimuli in those with ASD. It should be noted that these qualitative data are purely exploratory, and the primary function of these data are to provide ideas about the potential direction of future research in sensory functioning in ASD. Firstly, there seems to be an attentional component to sensory processing. In the adult focus group (Chapter 5), participants described fixating on a single sensation to the exclusion of others (mono-channel processing) and also described being unable to tear their attention away from an unwanted stimulus once they had noticed it (difficulty shifting attention). This

concurs with the findings of Jones et al. (2003), who extracted examples of mono-channel processing in their qualitative study of sensory processing in adults with self-disclosed HFA. In addition, Liss, Saulnier, Fein, & Kinsbourne (2006) previously found a relationship between sensory and attention abnormalities in a sub-sample of individuals with autism. They found that sensory over-reactivity (hyper-sensitivity), under-reactivity (hypo-sensitivity) and over-focusing (sensory-seeking) were related to difficulties in shifting attention. However, although there may be some sort of relationship between attention and sensory sensitivities, there is currently little evidence that this would be a causal relationship (and if it were, whether sensory sensitivities cause the increased attention or whether attention differences modulate response to sensory input).

One of the strongest themes to be extracted from the adult focus group (Chapter 5) was that control over sensory stimuli was important – this was also an important concept in the children's data (Chapter 4). These data showed that having control over the sensory stimuli meant that normally problematic stimuli were far less likely to cause distress. These findings are mirrored in Jones et al.'s (2003) study, with their sample reporting that unpleasant sensory experiences could become pleasant once the discomfort produced by them was under control. Furthermore, the concepts of unpredictability and control are linked: it is difficult to control something that is unpredictable. JJ in the children's qualitative study (Chapter 4) discussed how the unpredictable nature of the school bell made it difficult for her to cope with it ('I just don't like it when [the bell] goes off unexpectedly'). Kärnekull et al. (2011) found similar results in their study of TD individuals with varying levels of CR. They suggested that there were certain characteristics of a stimulus that caused it to be perceived as more unpleasant in those with high CR. These included instances where the exposures were a) unpredictable, b) sustained and c) difficult to control.

Another potential influence of sensory perception is affect. Affect is a term used to describe emotions and comprises both positive and negative valences. Furthermore, affect can be considered to be either a stable part of a person's personality (trait) or can indicate transient mood fluctuations over short periods of time (state). In Chapter 5, we discussed how negative emotions were reported to affect sensory perception (as well as being a result of discomfort arising from problematic sensory interaction). For example, AB mentioned how her anxiety could affect whether she was able to attend social gatherings, such as a music gig ('if I was very anxious before going into that gig, and you know, if I was already having a pretty bad … sensory day, then I wouldn't be able to walk into the place'). As

mentioned in Chapter 5, there is evidence that emotions can affect the perception of sensory stimuli (e.g. Laretzaki et al., 2010; Malow, 2003). For example, one study found that women with high levels of trait anxiety perceived both negatively and positively emotionally valenced odours as significantly more intense (Chen & Dalton, 2005). In addition, men with high levels of anxiety were quicker at detecting the emotionally valenced stimuli compared to the neutral stimuli. This provides some evidence that anxious individuals are both quicker at detecting positive and negative olfactory stimuli, and perceiving it to be more intense, than calm individuals (Chen & Dalton, 2005). In addition, there has been a suggestion that tactile hyper-sensitivity observed in ASD is emotional in origin, rather than perceptual (Güçlü et al., 2007). However, as discussed in Chapter 1, there are some concerns with this study due to the small sample size. The potential for an influence of affect on sensory perception is important, particularly when working with a clinical group like ASD. There is evidence that those with ASD demonstrate greater rates of anxiety and depression than typically developing individuals (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000) and it could be argued that it is important to screen for both state and trait affect in future studies.

9.1.2 – The impact of atypical sensory processing on caregivers

The original purpose of the caregiver focus group (Chapter 4) was to provide examples about the sensory behaviour of those with autism and other comorbidities – it should be noted that the participants in the caregiver and child groups were not related. As people are typically unable to retain memories of events prior to around 3 years of age (Usher & Neisser, 1993), we felt that the main carers of those with ASD (normally parents) would be in the best position to relay the atypical sensory interactions of their children. The participants did provide such information, but when we compared the descriptions to that from the first-hand data of unrelated children and adults with ASD (Chapters 4 and 5), it was apparent that the caregivers often found it difficult to determine the specific precipitant of challenging behaviour. This was demonstrated through the frequent use of qualifiers such as ('I don't know what it is', 'I'm assuming that's what it is' and 'I don't know if it was the lights'). However, as the analysis of the focus group progressed, it became apparent that the richest, most vivid descriptions centred around the impact of the sensory behaviours on both the child and the caregiver themselves. This was also observed in the older adults group, who had been recruited predominantly to give first-hand accounts of their experiences with sensory stimuli. Although this did occur, the group became most animated when discussing the effect that the sensory loss experienced by

their loved ones (all of whom have dementia) can have. As a result, Chapters 4 and 6 detail the consequences of atypical sensory responsiveness, for both those with sensory differences and their caregivers.

In the caregiver focus group, the majority of the children that our participants looked after had other complex needs, as well as a diagnosis of autism (see Chapter 4.2.2). This included those with Down syndrome (n=3), Angelman's Syndrome (n=1) and visual impairment (n=1). Studies have investigated the contribution that raising a child with disabilities can have on parental stress levels (Hassall, Rose, & McDonald, 2005), with results indicating that the severity of the disability and the extent of the behaviour problems can have a profound impact (Sanders & Morgan, 1997). However, in our study, we were specifically interested in the events that appeared to be caused by problematic sensory stimulation. This is difficult to determine using third-party report, particularly as most of the children described by the sample had very little verbal ability, so we were often wholly dependent upon interpretation of the event. However, the participants clearly explained their reasons for suspecting a particular cause of challenging behaviour, making sure to qualify when they were unsure of the underlying precipitant.

For this group, problems with sensory processing have traumatic effects for both the child with ASD and their caregivers. The experience of seeing their child so upset because of a stimulus in the environment (e.g. the sound of hair clippers, the lights in a shop etc.) was difficult for the participants to deal with. For the older adults focus group, much of the discussion centred around changes in relationships that sensory impairment brought. The participants discussed how, in group situations, their relative tended to 'opt out' of taking part in the discussion as they found it increasingly difficult to understand what others were saying. They also found that other family members had begun to avoid including the person in their discussions, as it became increasingly difficult for them to communicate. This caused distress for the caregivers, as they observed the person they cared for becoming increasingly isolated ('Just shut them out - just like that! They used to … say it was children that did that sort of thing but it's every age group … they will shut an individual out because they don't respond instantly').

One particular concern for the caregivers of those with ASD was that they had to be constantly alert, as their child might react negatively at any given time. This was highlighted by the experience of GH in Chapter 4.3.2, as she described how her daughter became upset by the sound of bagpipes streets away ('she can hear the guy playing the

bagpipes streets away and she will not go in that direction, and she will do anything to get away from it – run in front of cars – the lot') . Furthermore, she mentioned that she was often oblivious as to *why* her daughter was running away, and had to make specific effort to try to detect the cause ('you've to stop and listen to hear what she's listening to') in order to avoid it in the future. A similar sentiment of constantly having to be aware of the surroundings was shared in the older adults group. NN described taking her father-in-law for a walk and having to be aware of his positioning in relation to the roadside ('we've now got to make sure that we walk to the edge of the kerb, and he's got to be on our right-hand side because otherwise he will just walk off the kerb'), highlighting that if she and her family were not careful, her father-in-law could hurt himself by falling onto the road.

Another theme which arose from these data was that of the social implications of atypical response to sensory sensitivities. For caregivers of those with autism and complex needs, the challenging behaviour caused by hyper-responsiveness to particular aspects of an environment meant that they found it difficult to return to certain places in the future. This is an example of using avoidance as a coping mechanism, and seems to be effective for these participants and their children. OP mentioned that, after she had taken her son to the hairdressers and he exhibited acute distress, she decided never to take him back again. Furthermore, after a difficult experience in an airport with her daughter a few years previously, EF had not attempted air travel since. However, a by-product of this approach is that the daily routines that the majority of society take for granted are compromised for these individuals. In an ideal scenario, environments could be adapted somewhat, in order to make them more comfortable for those with ASD and other sensory sensitivities. For the group of older adults (Chapter 6), sensory loss meant that their daily routines also became limited. For example, when participants were asked about how they managed to read menus in restaurants, they replied by saying they just 'didn't go anymore'. Furthermore, RR described how her partner's hearing loss had affected his ability to use the phone – this meant that a) he was unable to have a conversation with his daughter when she phoned and b) RR was then called to the phone every time the phone rang, in order to speak to the caller. This is another example of the kind of simple, day-to-day tasks that are impacted with increasing sensory loss. These findings support the literature, by highlighting that vision and hearing loss can impact profoundly on the ability to carry out typical, daily tasks (such as shopping, cleaning or cooking), in turn affecting the quality of life that an individual has (Dargent-Molina et al., 1996; Raina et al., 2004). Furthermore, it echoes the data from the ASD caregivers group, as their children's quality of life is also affected by their sensitivity to the environment.

The final important concept to emerge from both the ASD caregiver and older adult focus groups was of compensation by carers. The process of trying to minimise the disruption caused by sensory atypicality in those that they cared for was apparent for participants across both focus groups. In the ASD caregiver group (Chapter 4), this typically involved finding other ways to do something that didn't result in challenging behaviour from sensory issues. For example, OP mentioned that she was planning to have a hairdresser come to the house in the future to cut her son's hair, rather than taking him to the hairdresser. Other techniques to help cope with problems with the hairdressers included only going when the shop was completely empty (EF) and cutting her grandson's hair in the bath (UV). Furthermore, EF mentioned that, when her daughter had started taking her clothes off in public, she made this more difficult by restricting the clothes her daughter wore ('for about three years, she had to wear dungarees') in order to compensate for this behaviour. Lastly, OP and UV mentioned that they had to mash foods, as this was the only way their son and grandson would eat solid food. In fact, UV went on to describe that her grandson's health was affected by this diet, and she would try different ways of getting him to eat solid foods (e.g. putting chips in a McDonalds paper bag).

Compensation for sensory issues was a major theme in the data from the older adult focus group. Both first- and second-hand examples were provided, showing that people would a) compensate for sensory loss on the behalf of others, as well as b) making their own compensations for the differences in their sensory sensitivity as they aged. OO described how she had started to plan every event that her father was a part of, so that his sensory loss had minimal impact ('You can't go anywhere spontaneously – everywhere you go you're planning ahead, or if you're going somewhere new you're thinking will there be this'). In addition, OO discussed how she and her sister had had to start taking responsibility for her father's finances, as he was unable to see the pinpad when in a shop or at an ATM ('he's had to tell my sister and I what his PIN numbers are … his card … gets passed to us and, you know we- we have to do the- [mimes typing on a keypad]'. This highlights the importance that close friends and family are to those with sensory differences, as the caregivers appear to automatically adapt to situations in order to minimise the disruption for their loved ones.

9.1.3 – The relationship between sensory processing and the BAP

As previously reported, both parent- (Baranek et al., 2006; Dickie et al., 2009; Kern et al., 2007b; Leekam et al., 2007; Rogers et al., 2003) and self-report (Crane et al., 2009) studies have shown consistent group differences between the reported sensory sensitivities of those with ASD and clinical or typically developing controls. The main strength of the study reported in Chapter 2 is that we extend this finding to the general population. These results concur with the findings of several visual perception (Grinter et al., 2009a; 2009b; Stewart et al., 2009; Sutherland & Crewther, 2010) and language (Stewart & Ota, 2008; Yu, 2010) studies investigating the relationship between perceptual tasks and the broader phenotype. However, the results reported in section 2.3 are particularly interesting as they demonstrate that there appears to be a strong, linear correlation between level of autistic traits and atypical sensory sensitivity throughout the general population (rather than a discrete difference between high- and low-scorers on the AQ). Furthermore, the findings in Chapter 3 reinforce the concept that sensory issues are present, to a greater or lesser degree, throughout the general population. However, frequency analysis demonstrated fundamental differences in the most prevalent themes drawn from each of the three groups (low-, medium- and high-scorers on the AQ).

The findings from Chapters 2 and 3 provide support for the argument that differing levels of autistic traits are present in the population at large. Evidence from studies investigating the 'broader phenotype' of autism has found that a) many first-degree relatives of those with ASD exhibit similar, but muted, personality traits to those who have a diagnosis of ASD (Piven et al., 1994) and b) that this appears to extend continuously throughout the population (Constantino & Todd, 2003). The implications of this are that ASD may be an endophenotypic disorder (i.e. that relatives of those with ASD may share a subset of the genes responsible for autism) (Pellicano, 2008). This is a potentially profitable line of enquiry in the effort to identify underlying genes, particularly as autism has been shown to be a highly heritable disorder (Bailey et al., 1995).

Although we found no difference in the olfactory thresholds, discrimination and identification abilities of those with high and low levels of autistic traits, we did find increased variability in the distance between the turning points used to determine threshold, and the threshold itself (Chapter 7). This provides evidence that there is increased intra-participant variability in sensory processing in those with higher levels of autistic traits, something that has been suggested elsewhere for those with a diagnosis of

ASD (Gowen & Hamilton, 2012; Milne, 2011; Simmons et al., 2009). This suggests that there may be common mechanisms underlying the sensory differences observed in ASD and in those with high levels of autistic traits, and provides support for the observation that it would be beneficial to investigate those with a possible endophenotypic expression of autism. It would be interesting to determine whether increased intra-participant variability is common in ASD, and what the implications of this could be.

9.2 Integration across studies

In this section, links between studies presented in this thesis will be considered. Firstly, broadly similar themes were elicited across Chapters 3-5, with examples of both 'problematic sensory stimuli' and 'enjoyable sensory stimuli' being discussed. Within the data from those with varying levels of autistic traits (Chapter 3), the focus was on 'calming techniques', rather than enjoyable stimuli per se. Secondly, descriptions of pain and discomfort as a result of atypical sensory perception were common throughout all chapters, although were most prevalent in the descriptions by children and adults with ASD (Chapters 4 and 5). Thirdly, the adults with ASD deemed control as being highly important, which was also reflected in the children's group. It was particularly interesting to note the 'coping methods' in Chapter 3, with 40% of examples in the high AQ group being related to avoiding a difficult situation, which is one method of exerting control. Fourthly, although sensory-seeking behaviour was commonly reported in the ASD chapters, under-sensitivity to stimuli was not. However, it should be noted that it is arguably more difficult to elicit examples about 'not feeling' stimuli than being over-sensitive or actively engaged in seeking it, and this is perhaps something that should be addressed in future studies. Finally, the concept of mood and perception was another theme that emerged throughout all three studies. The link between these was very clear for adults with ASD, for both negative (see Figure 5.1) and positive stimuli (see Figure 5.2). There were far fewer examples in the children's group (Chapter 4) and in the questionnaire study (Chapter 3), although there were some instances of note. For example, JJ in the children's group discussed how she really liked bright colours as they made her happy, but they also "hurt" her eyes. Furthermore, one participant in Chapter 3 discussed how someone bumping into them at the supermarket made them "unreasonably" angry, although there is the implication that this could be a result of unwanted social rather than sensory interaction.

It is also important to consider the link between the questionnaire data (Chapter 2) and the threshold data (Chapter 7), as it would stand to reason that those with high levels of autistic traits would exhibit lowered olfactory thresholds, especially if hyper-sensitivity to olfactory stimuli is reported using the GSQ. However, we found no significant relationship between GSQ score and olfactory threshold (Table 7.4). Furthermore, studies with participants who have ASD have found either no difference in threshold sensitivity or elevated thresholds (Dudova et al.,2011; Suzuki et al., 2003; Tavassoli & Baron-Cohen, 2012a), despite self-report and parent-report questionnaires consistently demonstrating increased issues with sensory stimuli, including olfactory (Baranek et al., 2006; Crane et al., 2009; Leekam et al., 2007). Although consistent with the olfactory literature (e.g. Doty et al. 1988), this raises further questions of the relationship between thresholds and reported sensitivity, which I will discuss further in section 9.3.

Another important point, already discussed in section 4.4.3, is the similarities and differences in first-hand and second-hand data. The experiences of the children and adults tended to center around what sensory atypicality meant for them on a daily basis – i.e. the nature of the negative or positive stimuli, what the implications and consequences were, and how they dealt with it. This meant that we were able to gain insight into the causes of discomfort and enjoyment, and what factors were likely to play a role in this. Conversely, the parents' accounts were more likely to consist of the social, physical and emotional implications of sensory issues, for both themselves and their children. Although the caregivers did attempt to provide reasons for the challenging behaviour of their children, they were often unsure of the underlying causes. In addition, it was interesting to discover the variety of compensatory techniques that parents employed when their child demonstrated sensory-related (or otherwise) distress (e.g. avoidance, compensation, distraction), which mirrored many of the techniques that individuals with high levels of autistic traits (Chapter 3) or adults with ASD (Chapter 5) used for themselves, as well as how carers of elderly individuals dealt with the ramifications of their loved ones' sensory loss (Chapter 6). By using focus groups from a variety of viewpoints, we were able to increase the range of information on the implications of sensory atypicality in ASD, which will hopefully inform the design of future experimental research into ASD.

9.3 Relationship between self-report and direct measurement

Much of the data from behavioural studies is heterogeneous, which makes it extremely difficult to determine whether any differences found (or not) between those with ASD and

TD individuals/clinical controls are real and replicable. Differences in the clinical participant groups used (e.g. whether they have a diagnosis of ASD, HFA or AS and whether they are children, adolescents or adults), control groups (e.g. whether controls are matched on verbal or non-verbal IQ and chronological or mental age) and experimental tests (e.g. using Sniffin' Sticks Identification task vs. UPSIT) make it very difficult to compare results.

However, one issue that has been highlighted throughout the thesis is the limited consistency between parent- or self-report data and direct measurement. Indeed, parent-report (Baranek et al., 2006; Leekam et al., 2007) and self-report (Crane et al., 2009) studies in ASD, as well as our self-report study looking at autistic traits (Chapter 2; Robertson & Simmons, 2012), show consistently that those with a diagnosis of ASD (or high level of autistic traits) experience elevated levels of atypical sensory processing, compared to both TD controls (Baranek et al., 2006; Crane et al., 2009; Leekam et al., 2007) and those with low levels of autistic traits (Robertson & Simmons, 2012). It is important to consider the underlying reasons for this disparity, as it could help inform future research directions in this field.

Within the adult focus group, participants discussed adaptation to sensory stimuli. Many of them described experiences where they had difficulty adapting to stimuli (particularly olfactory), with one individual saying that he could smell alcohol-based disinfectant gel on his hands for two days after he first put it on. This is another example of self-report data being inconsistent with the experimental literature, as a recent study (Tavassoli & Baron-Cohen, 2012a) found no significant difference in the olfactory adaptation of individuals with ASD. However, there were other existences of difficulties adapting to sensory stimuli within the group (e.g. adjusting to the change in light levels when exiting a building), and there is evidence that individuals with ASD adapt differently to visual (Pellicano et al., 2007) and tactile (Tommerdahl et al., 2007) stimuli. It would be particularly interesting to explore adaptation in ASD further, by expanding upon the research already conducted in the visual, tactile and olfactory domains, as well as expanding to other modalities.

Finally, another interesting point that was elicited from the group discussions (Chapters 4 and 5) was the relationship that attention plays in the role of perception in ASD. All of the individuals in the adult group (Chapter 5) discussed incidents in which they had found it difficult to divert their attention from a stimulus (e.g. a flickering light) once they had noticed it. However, this deeply focused attention could also result in them being

completely unaware of sensation in a different modality (e.g. an inability to feel pain or an inability to hear anything). In fact, it was possible to use this in a positive way (e.g. by wearing earphones in a crowded street, which dulled the visual, tactile and olfactory stimuli). It is possible that, at least some of the time, mono-channel processing (as reported by Jones et al., 2003), where attention is focused on a single sensory modality to the exclusion of others, could be misconstrued as hypo-sensitivity, and it would, again, be a potentially fruitful avenue of research in the future.

9.4   Theoretical perspectives

The current theoretical accounts of autism, as reported in section 1.5, explain the results presented in this thesis to varying levels of success. As the Extreme Male Brain (Baron-Cohen et al., 2002) does not account for sensory sensitivity, it will not be discussed here. The Executive Dysfunction theory ((Hill, 2004; Ozonoff et al., 1991; Russell, 1997) posits that differences in the executive functioning system are responsible for the core cognitive signs and symptoms observed in ASD. The concept that attention may play a role in sensory sensitivity (see Chapter 5) is consistent with this theory, although it has little explanation for the hyper-sensitivity experienced by individuals with ASD. The Central Coherence theory (CC) also provides limited explanation for the findings of this thesis. The adults in the focus group did discuss becoming incredibly focused on local detail, rather than global percepts, which is also consistent with the Enhanced Perceptual Functioning theory (Mottron et al., 2006). However, the CC theory does not provide an explanation for the hyper- and hypo-sensitivity reported by the individuals with ASD in our focus groups (Chapters 4 and 5).

The neural theories (see section 1.5.2) are more consistent with the findings of the qualitative data (Chapters 4 and 5). EPF (Mottron et al., 2006) does explain the hyper-sensitivity of individuals with ASD and the focus on local detail, both of which emerged from the groups of those with ASD. However, the potential influence of higher-order processes (e.g. attention) is not explained by EPF, although it should be noted that the role of attention in ASD perception and sensation has not yet been investigated fully in the literature. Furthermore, EPF does not provide a full explanation of hypo-sensitivity in ASD, which was an important component of the group discussions. Finally, the neural noise hypothesis has been used as a potential explanation for ASD in multiple publications (Belmonte & Yurgelun-Todd, 2003; Dakin & Frith, 2005; Franklin et al., 2010; Rubenstein & Merzenich, 2003; Sanchez-Marin & Padilla-Medina, 2008; Simmons et al., 2009;

Thornton, 2006). This concept is the best 'fit' for the data provided in the thesis, as it explains hypo-sensitivity and, through the concept of stochastic resonance, hyper-sensitivity. However, currently, there is no explanation for the potential impact of higher order processes on perception in ASD.

9.5   Practical applications of the research

There are potential practical applications of the GSQ as well as the Sensory Audit, both of which were developed for inclusion in this thesis. In Chapter 8, we presented the development and pilot results of the 'Sensory Audit'. The concept of the audit evolved from discussions with those who have ASD (Chapters 4 and 5), caregivers of those with autism and complex needs (Chapter 4) and descriptions of the impact of problematic stimuli from those with medium- and high-AQ scores (Chapter 3). This resulted in a set of protocols, which could be used in a multitude of environments to assess whether there are a) any potentially problematic sensory stimuli and b) whether there are any steps that can be taken to ameliorate such problems. Although there have been sensory audits developed for use in autism (e.g. Jones & Attfield, 2012) these do not consist of objective measurement. In addition, these Sensory Audits are designed for use in schools, with children, rather than for use in multiple environments with adults who have ASD. Furthermore, the protocols will be made freely available on our lab website (http://autism.psy.gla.ac.uk) in the future, alongside details of the equipment and software used for analysis and potential recommendations for problematic environments. It is our hope that companies, as well as individuals with sensory sensitivities, find this output useful and use it in order to increase accessibility for those with ASD (as well as others with atypical sensory experiences).

Furthermore, the sensory questionnaire we have developed (Chapter 2) adds to the battery of tests that can be used to establish the precise sensory processing difficulties of individuals on the autism spectrum. In addition, we recently found that sensory sensitivities can affect productivity and concentration of those with ASD, and that low-impact sensory environments are essential for these individuals (see Chapter 5). It is anticipated that, in the future, the sensory questionnaire could be used in conjunction with the sensory audit, in order to screen environments for specific problems highlighted by the sensory questionnaire. By using both tools, those responsible for providing a comfortable working environment would be able to pinpoint the most common issues for a certain individual, and work with them to reduce any problems.

9.6   Limitations of the research

One of the main limitations of the research presented in this thesis is that we were unable to confirm the diagnoses of those with ASD using 'gold-standard' methods (such as ADI and ADOS). The reason for this is that it would have greatly increased the difficulties that we had with recruitment. However, we did take steps to ascertain that our participants for the child group interviews (Chapter 4) and the adult focus groups (Chapter 5), as well as those participating in the caregiver focus group study described in Chapter 4, all had medical diagnoses of ASD. For the children with autism, the following steps were taken: a) both schools were asked to only invite participants who had a confirmed diagnosis of autism, b) parents were told that our interest was in recruiting those with a diagnosis of autism and c) parents were asked to complete the SCQ on their child's behalf. For the adult focus group, all participants worked (or were trainees) at a local company that hires individuals with ASD as software testers. All employees must have a confirmed diagnosis of ASD in order to gain employment with this company unless they are in a managerial or support role. In addition, all participants confirmed during the course of the focus group that they had received ASD diagnoses prior to participation. Lastly, for recruitment of the caregiver focus group the following steps were taken: a) the gate-keeper involved in the research was asked to recruit those who cared for those with a diagnosis of ASD, b) all participants were asked to complete a demographics questionnaire indicating the diagnoses received for their child (n=8 had autism) and c) parents were told that the purpose of the group was to discuss sensory issues in autism.

A second limitation is that we were unable to confirm IQ scores for the participants in Chapters 2 and 3. A previous study has found a modest negative correlation between autistic traits and IQ ($r = -.27$), although this was mainly explained by communication problems (Hoekstra et al., 2010). However, the authors stressed that autistic traits and IQ are mostly independent. It should be noted that we asked participants to disclose any difficulties they had with understanding the questionnaire, with very few indicating comprehension difficulties with any of the questions (n=2). For these participants, the responses to the problematic questions were removed and the algorithm used to compensate for missing responses was applied. It should be noted that the questionnaire was piloted on an adult with a confirmed diagnosis of autism (and changes subsequently made to improve comprehension) prior to recruitment of the experiment proper.

A final potential limitation of the research is that, with the exclusion of the children's groups, we were not able to complete multiple focus groups with each type of participant. As with the first limitation, the primary reason for this was due to recruitment difficulties. However, in qualitative research, the size of the sample is not the major concern that it is in quantitative research (Marshall, 1996). This is because we are more interested in the saturation of themes emerging from these data (which is where we reach a point at which no new information can be extracted) rather than the quantity of descriptions (although the latter is somewhat important in mixed methods research). An important point to make here is that similar themes were apparent throughout all three ASD groups (children, adults and caregivers), e.g. that sensory issues can cause discomfort and pain, that control is important and that some sensory stimuli can have hugely positive effects. This is particularly striking given the differences between each group (including age, ability, communication skills and perspective (i.e. first- vs. second-hand)).

9.7   Future directions

I would argue that future research into the sensory experiences of those with ASD should be mindful of the first-hand experiences described in this thesis, as they provide insight into what it is like to live with ASD. The overarching theme of this thesis is that it may be necessary to investigate the effect of other psychological mechanisms when attempting to determine the differences between the sensory experiences of those with ASD and TD individuals. In particular, the data presented in Chapters 4 and 5 suggest that it may not be that there are purely perceptual differences in the way that those with ASD and TD individuals experience sensory stimulation. It may be that attentional factors and affect, for example, play an important role in the modulation of sensory information.

When revisiting the diagrams of how the themes from the adult focus group were connected (Figures 5.1 and 5.2), I feel that it would be important to consider these concepts in future studies. These illustrations provide one interpretation of how those with ASD may perceive the world, and some of the potential influences on perception. I think that it would be an important future step to consider whether these reported effects on perception are borne out in direct measurement data. In particular, I believe that it would be important to conduct experiments investigating the roles of attention, control, expectedness and affect in perception, as these concept emerged as part of the discussion in both the groups with children and adults (Chapters 4 and 5). I also think it is important to research the neural noise hypothesis of ASD as there is evidence to suggest that those with

ASD have increased levels of noise (Milne, 2011) and further experimentation in this field could be an exciting avenue for autism research. Theoretically, none of the theories considered in section 1.5 are fully consistent with the data presented here, and it will be interesting to see how they, and other theories develop as further research is undertaken in this area.

Furthermore, I would argue that it would be beneficial to expand research into the broader phenotype of autism – logistically it can avoid potential difficulties with recruitment and may provide greater insight into the mechanisms underlying atypical sensory processing, and potentially other aspects, of ASD. In addition, I think that the findings presented here indicate the importance of screening controls for autistic traits when conducting research in ASD. It could be that some of the mixed results observed could be, in part, due to differences in the autistic trait levels of controls. Lastly, it appears from the research presented in this thesis that group differences are not necessarily expressed in the ways that we may expect. It is important that, moving forward, we determine whether differences arise in other aspects of these data (e.g. in intra- or inter-participant variability) and the implications of this.

9.8 Conclusions

The thesis presented here has explored the nature of sensory sensitivities in ASD, as well as in those with varying levels of autistic traits. Firstly, we found that there is a significant relationship between atypical sensory responsiveness (both hyper- and hypo-) and autistic traits in the general population (Chapter 2). We also found significant group differences in the frequency of responses to various qualitative questions. One particularly interesting finding was that those with ASD tend to use either sensory soothing techniques or avoidance, whereas those with low levels of autistic traits tend to stay in a difficult situation and use non-sensory soothing techniques. The qualitative studies in Chapters 4 to 6 showed that sensory sensitivity has a profound effect on both individuals with ASD as well as those close to them. We also found greater intra-participant variability in high AQ scorers (when compared to low AQ scorers) for an olfactory threshold test, indicating that it may be fruitful to assess whether variability is consistently different in those with ASD. Lastly, we developed a Sensory Audit, which was a practical application of the work presented in the earlier chapters.

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Appendix A

Glasgow Sensory Questionnaire (GSQ) (ver. 1.0)

What is your Date of Birth?   _____

What is your postcode?   _____

Are you male or female?

   Male   *Female*

Do you live in the UK at the moment?

        Yes   *No*

If *Yes*, would you like to be entered into a draw to win an HMV/Amazon UK voucher? (worth £10). Please note that I have no affiliation with any of these companies.

If so, please enter your email address.

_____

SAMPLE QUESTIONS (please read to make sure you know how to answer the questionnaire but **do not answer** these sample questions).

These sample questions (and answers) have been included to make it as easy as possible for you to fill out the questionnaire.

A. Do you find it difficult to concentrate on visual information (for example, reading a book) when there are noises in the background?

In this question, an example is given which helps to explain the question further. Examples are only given to help prompt you (if needed).

Sample answer to question A:

If I experience problems (most of the time) in concentrating while watching a movie when there is background noise, I would answer '*Often*'. This would be regardless of whether I experienced the exact issue detailed by the example.

Never   *Rarely*   *Sometimes*   (*Often*)   *Always*

B. Do you find it difficult to look people in the eyes?

It can be hard to answer questions like this as the amount that eye contact (or something else) is a problem for you is likely to have varied throughout your life-time. For this reason, we ask that you choose the option that corresponds best with your experience over the last 12 months.

Sample answer to B:

If I found it difficult to have eye contact with someone all of the time at the age of 7, but as an adult I find it easy <u>most</u> of the time, I would answer 'Rarely'.

Never   (*Rarely*)   *Sometimes*   *Often*   *Always*

1. Do you really like foods that are very strong-tasting (for example chillis and very spicy foods)?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

2. Do you think you have a strong sense of smell – are you able to smell odours very well?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

3. Do you dislike sudden flashes of light?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

4. Do you dislike the **physical** sensation you get when people hug you?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

5. Do you ever seek out bright lights to look at?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

6. Do you gag when you are eating certain foods, perhaps feeling as if you are going to be sick)?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

7. Do you find it difficult to manipulate your hands when completing a delicate task (for example, picking up small objects or transferring objects from one hand to the other)?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

8. Do you ever run your hand around the outside of an object before picking it up?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

9. Do you stand very close (for example, less than 1 metre/3 feet away) or very far (for example, more than 3 metres/9 feet away) when you are talking to someone?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

10. Do you find yourself fascinated by strong visual stimuli? Examples of this would be sparkling lights, mirrors and bright colours.

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

11. Do you find certain noises/pitches of sound annoying?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

12. Do you smell your food before you eat it?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

13. Do you drop objects a lot?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

14. Do bright lights ever hurt your eyes/cause a headache?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

15. Do you enjoy swinging upside-down (perhaps hanging by your legs)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

16. Do you avoid wearing certain types of clothes (for example, ones made from 'scratchy' material like wool)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

17. Do you like to listen to the same piece of music/part of a DVD over and over again?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

18. Do you feel ill/dizzy/peculiar if you have to reach up high or bend down low for something?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

19. Do you find yourself fascinated by small particles (for example, little 'bits' of dust in the air)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

20. Do you like to spin yourself round and round?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

21. Do you ever feel ill just from smelling a certain odour?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

22. Do you find it difficult to hear what people are saying?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

23. Do you dislike having a haircut (for example, because little bits of hair go down your back)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

24. Do you notice that you have hurt yourself but did not feel any pain?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

25. Are you ever told by others that you wear too much perfume/after-shave?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

26. Do lights ever seem to flicker when you look at them? ('Flickering' in this question means appearing to turn on and off very quickly instead of appearing constant).

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

27. Do you particularly enjoy the feeling you get when moving your body quickly (for example going on a rollercoaster or swinging on a swing-set)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

28. Does it irritate you when others wear perfume/after-shave?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

29. Do you like to bang objects or doors as you like the sound that they make?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

30. Do you feel pain very easily?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

31. Do you like lining objects up?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

32. Do you rock yourself backwards and forwards?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

33. Do you find it difficult to go into a strong-smelling shop (for example "Lush" and "The Body Shop")?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

34. Do you cut the labels out of your clothes?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

35. Do you wake up often during the night or find it very difficult to get to sleep?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

36. Do you dislike being turned upside down, perhaps because it makes you feel ill?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

37. Do you hate the feel or texture of certain foods in your mouth?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

38. Do you avoid going to restaurants because you can smell a certain odour?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

39. Do you like the feelings of vibrations against your skin?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

40. Do you play music on an MP3 player/iPod so you can drown out external noise?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

41. Do you think you have a weak sense of smell – are you unable to smell odours very well?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

42. Do you always sit with your feet planted firmly on the ground?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

43. Do you dislike loud noises?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

44. Do you use the tip of your tongue to taste your food before eating it?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

45. Do you really like certain strong smells?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

46. Does your body ever feel 'numb' - like you can't feel anything against your skin?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

47. Do you look down at the ground most of the time?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

48. Do you think you have a weak sense of taste? One example of this would be if most food taste of 'nothing'?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

49. Do you find that you are unaware of your body's signals (for example, don't often feel hungry/tired/thirsty)?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

50. Do you like feeling different textures in your mouth at the same time (for example, both solids and liquids in your mouth together)?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

51. Do you ever feel dizzy/ill when playing fast-paced sports, for example basketball or football?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

52. Do you react very strongly when you hear an unexpected sound?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

53. Do you dislike walking on uneven surfaces?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

54. Do you really like listening to certain sounds (for example, the sound of paper rustling)?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

55. Do you find yourself bumping into people/objects?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

56. Do you like the feeling when someone presses forcefully into your muscles/back? This could be likened to deep pressure massage.

Never   *Rarely*   *Sometimes*   *Often*   *Always*

57. Do you like to run about – perhaps up and down in straight lines or round in circles?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

58. Do you chew and lick objects that aren't food (for example pen lids or bottle tops) because you like the way they feel in your mouth?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

59. Do you find it very difficult to thread a needle?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

60. Do you enjoy wearing very strong perfumes/after-shaves?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

61. Do you turn your whole body (rather than only your head) when you look at something or someone?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

62. Do you find that you position your body in a way that is different to most people (for example, lie on your back on a sofa with your legs straight up in the air at a 90° angle)?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

63. Do you find it difficult to tie your shoelaces or button up your clothes?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

64. Do you eat objects that are not food (something that is known as pica) as you like the taste?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

65. Do you find that you are able to go outside without a coat or a jacket when other people think that it is too cold?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

66. Do you like the sound of echoing (words or sounds repeating)?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

67. Do you eat the same foods most of the time?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

68. Do you like to wear something/hold something (for example, a hat or a pencil) so that you know where your body 'ends'?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

69. Do you flick your fingers in front of your eyes?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

70. Do you find it difficult to swallow pills?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

Additional Questions

71. Have you ever had your hearing medically tested?

   Yes   *No*   *Not Sure*

If Yes, can you explain why and, if you feel comfortable, share the results?

_____
_____
_____

72. Can you describe which environments/situations, if any, cause you difficulty or cause you to panic?

_____
_____
_____
_____

73. Do you ever find yourself reaching "meltdown" due to too much sensory input – for example feeling like too much noise/lights/smells cause an 'overload')?

_____
_____
_____

74. How do you calm yourself down if you start to panic?

_____
_____
_____

75. Do you find going to leisure centres/supermarkets difficult? If so, what makes it difficult?

_____

_____—

_____

Do you have any other comments you would like to add?

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix B

Principal Components Analysis (70 items)								
	Components							
	1	**2**	**3**	**4**	**5**	**6**	**Hyper/Hypo***	**Mod.****
Q19	.656				.279		*Hyper*	*Vis*
Q63	.644				-.295		*Hyper*	*Pro*
Q23	.642						*Hyper*	*Tac*
Q68	.630						*Hyper*	*Pro*
Q8	.623						*Hypo*	*Vis*
Q62	.611						*Hyper*	*Pro*
Q26	.605						*Hyper*	*Vis*
Q24	.599						*Hypo*	*Tac*
Q14	.595	-.273					*Hyper*	*Vis*
Q38	.592					.264	*Hyper*	*Olf*
Q10	.588	.342					*Hypo*	*Vis*
Q55	.587				-.390		*Hypo*	*Pro*
Q32	.587						*Hypo*	*Ves*
Q69	.585						*Hypo*	*Vis*
Q31	.584						*Hypo*	*Vis*
Q52	.583						*Hyper*	*Aud*
Q49	.571						*Hypo*	*Pro*
Q54	.570	.309					*Hypo*	*Aud*
Q37	.563						*Hyper*	*Gus*
Q34	.558			-.264			*Hyper*	*Tac*
Q20	.555		-.317				*Hypo*	*Ves*
Q9	.549						*Hypo*	*Pro*
Q64	.544						*Hypo*	*Gus*
Q6	.542				-.332		*Hyper*	*Gus*
Q11	.541						*Hyper*	*Aud*
Q16	.540			-.319			*Hyper*	*Tac*
Q47	.529						*Hyper*	*Vis*
Q46	.528						*Hypo*	*Tac*
Q33	.527	-.322					*Hyper*	*Olf*
Q22	.521					-.330	*Hypo*	*Aud*
Q13	.500					-.483	*Hypo*	*Pro*
Q7	.498				-.254		*Hypo*	*Pro*
Q21	.498						*Hyper*	*Olf*
Q57	.497	.353	-.287				*Hypo*	*Ves*
Q51	.491	-.284	.319				*Hyper*	*Ves*
Q44	.491						*Hyper*	*Gus*
Q66	.489				.312		*Hypo*	*Aud*
Q28	.482	-.310	-.317				*Hyper*	*Olf*
Q53	.479	-.287					*Hyper*	*Ves*
Q4	.476						*Hyper*	*Tac*
Q29	.448	.341					*Hypo*	*Aud*
Q43	.448	-.318					*Hyper*	*Aud*
Q35	.447						*Hyper*	*Aud*
Q17	.444						*Hypo*	*Aud*
Q3	.431	-.419	-.269				*Hyper*	*Vis*
Q58	.430	.283			-.325		*Hypo*	*Gus*
Q61	.425				.312		*Hyper*	*Pro*
Q12	.421			-.339			*Hypo*	*Olf*
Q67	.412						*Hyper*	*Gus*

Q48	.401			.323		.287	*Hypo*	*Gus*
Q45		.551	.311				*Hypo*	*Olf*
Q27	.269	.483	-.341			-.258	*Hypo*	*Ves*
Q39		.379					*Hypo*	*Tac*
Q5	.301	.339					*Hypo*	*Vis*
Q36		-.393	.533				*Hyper*	*Ves*
Q18	.418		.433				*Hyper*	*Ves*
Q15	.365	.307	-.428				*Hypo*	*Ves*
Q60		.363	.425		-.293		*Hypo*	*Olf*
Q42			.380				*Hyper*	*Ves*
Q2				-.701			*Hyper*	*Olf*
Q41		-.265		.682			*Hypo*	*Olf*
Q50		.252			.396		*Hypo*	*Gus*
Q25	.352				-.367		*Hypo*	*Olf*
Q70	.340					.367	*Hyper*	*Gus*
Q1						-.342	*Hypo*	*Gus*
Q65	.436						*Hypo*	*Tac*
Q59							*Hyper*	*Pro*
Q40	.350						*Hyper*	*Aud*
Q56		.280					*Hypo*	*Tac*

Appendix C

Principal Components Analysis (42 items)

Components

	1	2	3	4	5	6	Hyper/Hypo*	Mod.**
Q19	.665			-.410			Hyper	Vis
Q63	.664						Hyper	Pro
Q68	.649					.260	Hyper	Pro
Q23	.645						Hyper	Tac
Q8	.615					-.282	Hypo	Vis
Q26	.615						Hyper	Vis
Q38	.615				-.330		Hyper	Olf
Q62	.610		-.319				Hyper	Pro
Q14	.609	.256					Hyper	Vis
Q69	.602		-.260				Hypo	Vis
Q31	.595			-.275			Hypo	Vis
Q32	.587		-.261				Hypo	Ves
Q24	.586						Hypo	Tac
Q52	.585						Hyper	Aud
Q37	.570						Hyper	Gus
Q20	.567		-.278				Hypo	Ves
Q49	.566						Hypo	Pro
Q34	.564				-.288		Hyper	Tac
Q54	.557	.318					Hypo	Aud
Q6	.555			.353			Hyper	Gus
Q46	.542					-.479	Hypo	Tac
Q11	.541					.295	Hyper	Aud
Q9	.541					-.301	Hypo	Pro
Q33	.529	-.309					Hyper	Olf
Q21	.519	.280	.355				Hyper	Olf
Q51	.511		.460				Hyper	Ves
Q7	.505						Hypo	Pro
Q53	.503						Hyper	Ves
Q22	.502	-.316					Hypo	Aud
Q44	.494						Hyper	Gus
Q57	.492	.317	-.443				Hypo	Ves
Q4	.479	-.383					Hyper	Tac
Q43	.453	-.357				.427	Hyper	Aud
Q67	.420						Hyper	Gus
Q48	.418					-.315	Hypo	Gus
Q12	.403				-.360		Hypo	Olf
Q58	.424	.573					Hypo	Gus
Q60		.563			.394		Hypo	Olf
Q18	.423		.434	-.361			Hyper	Ves
Q17	.453	.265		-.475		.307	Hypo	Aud
Q25	.349	.291		.363	.506		Hypo	Olf
Q65	.420		-.393		.433		Hypo	Tac

Appendix D

Glasgow Sensory Questionnaire (GSQ) (ver 1.1)

What is your Date of Birth? _____

What is your postcode? _____

Are you male or female?

Male   *Female*

Do you live in the UK at the moment?

Yes   *No*

SAMPLE QUESTIONS (please read to make sure you know how to answer the questionnaire but **do not answer** these sample questions).

These sample questions (and answers) have been included to make it as easy as possible for you to fill out the questionnaire.

    A.   Do you find it difficult to concentrate on visual information (for example, reading a book) when there are noises in the background?

In this question, an example is given which helps to explain the question further. Examples are only given to help prompt you (if needed).

Sample answer to question A:

If I experience problems (most of the time) in concentrating while watching a movie when there is background noise, I would answer '*Often*'. This would be regardless of whether I experienced the exact issue detailed by the example.

Never   *Rarely*   *Sometimes*   (*Often*)   *Always*

    B. Do you find it difficult to look people in the eyes?

It can be hard to answer questions like this as the amount that eye contact (or something else) is a problem for you is likely to have varied throughout your life-time. For this reason, we ask that you choose the option that corresponds best with your experience over the last 12 months.

Sample answer to B:

If I found it difficult to have eye contact with someone all of the time at the age of 7, but as an adult I find it easy <u>most</u> of the time, I would answer 'Rarely'.

Never   (*Rarely*)   *Sometimes*   *Often*   *Always*

1. Do you dislike the **physical** sensation you get when people hug you?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

2. Do you gag when you are eating certain foods, perhaps feeling as if you are going to be sick)?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

3. Do you find it difficult to manipulate your hands when completing a delicate task (for example, picking up small objects or transferring objects from one hand to the other)?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

4. Do you ever run your hand around the outside of an object before picking it up?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

5. Do you stand very close (for example, less than 1 metre/3 feet away) or very far (for example, more than 3 metres/9 feet away) when you are talking to someone?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

6. Do you find certain noises/pitches of sound annoying?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

7. Do you smell your food before you eat it?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

8. Do bright lights ever hurt your eyes/cause a headache?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

9. Do you like to listen to the same piece of music/part of a DVD over and over again?

   Never   *Rarely*   *Sometimes*   *Often*   *Always*

10. Do you feel ill/dizzy/peculiar if you have to reach up high or bend down low for something?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

11. Do you find yourself fascinated by small particles (for example, little 'bits' of dust in the air)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

12. Do you like to spin yourself round and round?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

13. Do you ever feel ill just from smelling a certain odour?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

14. Do you find it difficult to hear what people are saying?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

15. Do you dislike having a haircut (for example, because little bits of hair go down your back)?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

16. Do you notice that you have hurt yourself but did not feel any pain?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

17. Are you ever told by others that you wear too much perfume/after-shave?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

18. Do lights ever seem to flicker when you look at them? ('Flickering' in this question means appearing to turn on and off very quickly instead of appearing constant).

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

19. Do you like lining objects up?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

20. Do you rock yourself backwards and forwards?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

21. Do you find it difficult to go into a strong-smelling shop (for example "Lush" and "The Body Shop")?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

22. Do you cut the labels out of your clothes?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

23. Do you hate the feel or texture of certain foods in your mouth?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

24. Do you avoid going to restaurants because you can smell a certain odour?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

25. Do you dislike loud noises?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

26. Do you use the tip of your tongue to taste your food before eating it?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

27. Does your body ever feel 'numb' - like you can't feel anything against your skin?

    Never   *Rarely*   *Sometimes*   *Often*   *Always*

28. Do you think you have a weak sense of taste? One example of this would be if most food taste of 'nothing'?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

29. Do you find that you are unaware of your body's signals (for example, don't often feel hungry/tired/thirsty)?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

30. Do you ever feel dizzy/ill when playing fast-paced sports, for example basketball or football?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

31. Do you react very strongly when you hear an unexpected sound?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

32. Do you dislike walking on uneven surfaces?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

33. Do you really like listening to certain sounds (for example, the sound of paper rustling)?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

34. Do you like to run about – perhaps up and down in straight lines or round in circles?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

35. Do you chew and lick objects that aren't food (for example pen lids or bottle tops) because you like the way they feel in your mouth?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

36. Do you enjoy wearing very strong perfumes/after-shaves?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

37. Do you find that you position your body in a way that is different to most people (for example, lie on your back on a sofa with your legs straight up in the air at a 90° angle)?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

38. Do you find it difficult to tie your shoelaces or button up your clothes?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

39. Do you find that you are able to go outside without a coat or a jacket when other people think that it is too cold?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

40. Do you eat the same foods most of the time?

       Never   *Rarely*   *Sometimes*   *Often*   *Always*

41. Do you like to wear something/hold something (for example, a hat or a pencil) so that you know where your body 'ends'?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

42. Do you flick your fingers in front of your eyes?

Never   *Rarely*   *Sometimes*   *Often*   *Always*

Additional Questions

43. Have you ever had your hearing medically tested?

Yes   *No*   *Not Sure*

If Yes, can you explain why and, if you feel comfortable, share the results?

_____

_____

_____

44. Can you describe which environments/situations, if any, cause you difficulty or cause you to panic?

_____

_____

_____

_____

45. Do you ever find yourself reaching "meltdown" due to too much sensory input – for example feeling like too much noise/lights/smells cause an 'overload')?

_____

_____

_____

46. How do you calm yourself down if you start to panic?

_____

_____

_____

76. Do you find going to leisure centres/supermarkets difficult? If so, what makes it difficult?

_____

_____

_____

Do you have any other comments you would like to add?

_____

_____

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Appendix E

((Appendix removed due to intellectual property rights))

Please contact:

Ashley Robertson (ashleyerobertson@me.com) or
David Simmons (David.Simmons@glasgow.ac.uk)

for more information or if you would like a copy of the GSQ and coding sheet

Appendix F

Questions asked in children's group interviews

Visual
- Do you ever have to close your eyes because you have a sore head/eyes? If so, what hurts you?
- What is your favourite TV show? What was it when you were little?
- Do you enjoy going to school discos? What do you like/not like about them?

Auditory
- What are your favourite sounds?
- What sounds don't you like?
- Do you like listening to music? If so, what kind is your favourite?

Tactile
- How does it make you feel if someone hugs you when you are not expecting it (e.g. from behind)
- Do you have any clothes you don't like to wear? Why not?
- Do you like going to the hairdressers? Why/why not?

Olfactory
- What smells do you like?
- What smells do you dislike?
- Are there any places that you find smelly to go into?

Gustatory
- What tastes do you like?
- What tastes do you dislike?
- Are there any foods that you think taste very weak?

Overall
- Do you like or dislike crowds? Why?
- When upset, how do help to calm down? Why does it help you?
- Do you have any particular habits (expand if necessary). Why do you do this?
- What makes you happy?
- What makes you sad?
- Are they any places you don't like going – why?

Appendix G

Olfactory audit: recording smells

1. Enter room/area to be audited
2. Name all the smells you can identify and rate their intensity
3. If you detect a smell that you cannot identify, describe it and rate its intensity
   a. Intensity is scored on a five-point scale
   b. Very faint = 1; Faint = 2; Noticeable = 3; Strong = 4; Overwhelming = 5
4. Leave the room after 2 minutes (for a 10 minute period), before returning and repeating steps 1-3.

Session (1-5)	1st/2nd testing?	Smells identified	Description of identified smells	Description of unidentified smells	Intensity (1-5)

Appendix H

Visual protocol

General measurement of the sensory environment
1. Still photographs will be taken of the environment
    a. A digital camera (Sony Cyber-shot DSC-WX7) (16.2 MP, 5x optical zoom) will be used to photograph the environment.
    b. Multiple photographs will be taken of the same environment, charting the ambience of each room over a certain period of time.
        i. The following angles will be photographed:
            - View of room from the door
            - Each of the walls (from the office chair)
            - View outside window(s) (if applicable)
            - Floor
            - Ceiling
            - Light sources
            - Anything unusual/of interest
        ii. Photographs will be taken at five timepoints:
            - Typical starting time
            - Midmorning
            - Lunchtime
            - Midafternoon
            - Typical leaving time
    c. As each photo is taken, the photo and the chromaticity and luminance levels will be recorded on the provided sheet
2. Chromaticity will be measured
    a. A chroma meter will be used to investigate chromaticity (Minolta CS-100)
    b. Readings will be taken at the same time as the photographs, luminance measurements, flicker measurements and flicker levels.
    c. 1-3 readings will be taken per photograph, with details recorded
        i. stand away from the subject (global as possible)
        ii. record most colourful points
3. Luminance levels will be measured
    a. A light level meter will be used to investigate luminance in the environment (Minolta CS-100).
    b. Readings will be taken at the same time as the photographs, chromaticity measurements, flicker measurements and flicker levels.
    c. 2-5 readings will be taken per photograph, with details recorded
        i. stand away from the subject (global as possible)
        ii. record brightest and darkest points plus up to 3 other points

Outcomes
1. Most problematic visual stimuli identified
2. Specific properties identified (i.e. chromaticity/luminance levels/patterns)
3. Hints and tips for amelioration given

Appendix I

Auditory protocol

<u>Step-by-step procedure</u>
Information gathering
1. Research most annoying noises in general population and in those with ASD.
2. Ask those who work in the area what the most annoying noises are.
3. Record snapshots of the ambient environment in each area (20-30 min recordings) alongside the sound level meter
    a. 5 timepoints
        i. typical starting time
        ii. mid-morning
        iii. lunchtime
        iv. mid-afternoon
        v. typical finishing time
4. Listen to ambient files – are there any noises identified which could be problematic? If so, add to list of specific noises to record and analyse

Recording of specific noises
1. Assess when the noises are likely to occur (i.e. the microwave beeping will be more likely at lunchtime, the front door banging will be more common at 9am/5pm).
2. Draw up a schedule of noises to record and when.
3. If miss any, schedule another day to record.
4. Ensure that all settings on the recorder are correct
5. Use the calibrated sound level meter in conjunction with the recorder
    a. Record the sound/loudness level of the problematic sound
    b. Note the min, max and mean values
6. Upload the data from the recorder and sound level/loudness meter.

Analysis of noises
1. Run the PsySound3 analysis, assessing:
    a. Loudness
    b. 1/3 Octave Frequency
    c. Sharpness
    d. Roughness

<u>Outcomes</u>
1. Most problematic noises identified
2. Specific properties of noises determined
3. Hints and tips for amelioration given

Appendix J

Olfactory protocol

<u>Participants should adhere to the following criteria</u>
- Non-smokers
- Have typical sense of smell
  - Detection
  - Identification
  - Discrimination
- Do not currently have an upper respiratory tract infection (e.g. cold, flu)
- Are below a certain age limit (e.g. 55 years, as sensitivity to smell changes as we age)
- Do not eat or drink anything apart from water for 30 mins before start of study
- Have not been in a particularly strong-smelling environment for prolonged period of time in the last 24 hours

<u>Step-by-step procedure</u>
Testing the olfactory system
1. Participant should be placed in a well-ventilated (i.e. little to no odour) room. The experimenter should not wear any perfume/aftershave and should also wear odourless gloves (i.e. cotton).
2. Threshold test (using the Sniffin' Sticks). This involves the administration of different concentrations of butanol.
   a. Participants are familiarized with the odour of butanol using pen number 1.
   b. Participants are instructed that one pen of three will contain butanol in small quantities (the other two have solvent). 3AFC task.
   c. Participants are blindfolded
   d. Pen is placed 2cm below nose
   e. Once cap is removed, participant given verbal command to sniff
   f. All three presented then participant chooses one with butanol.
   g. This is repeated in sets of three (one butanol pen/two solvent pens). Order of presentation changes for each set of three pens.
   h. Triplets of pens have intervals of 20-30 secs between them.
3. Rest for 3-5 mins
4. Discrimination task
   a. Two pens will contain the same smell, with one having a different smell.
   b. Participants are blindfolded
   c. Pen is placed 2cm below nose
   d. Once cap is removed, participant given verbal command to sniff
   e. All three presented then participant chooses one that is different.
   f. This is repeated in sets of three (one butanol pen/two solvent pens). Order of presentation changes for each set of three pens.
   g. Triplets of pens have intervals of 20-30 secs between them.
5. Rest for 3-5 mins
6. Identification task
   a. Participants given 16 pens (one at a time)
   b. They are asked to identify the smell.
   c. They are given 4 scents to choose from.
   d. Even if they do not do, they should still choose an answer (4AFC).
   e. Participants do not need to be blindfolded for this task.

Assessing the sensory environments
1. The auditor enters the area and focuses on any odours that they are able to detect. They write their observations of the sheet provided in Appendix G.
2. After 2 mins, they remove themselves to a neutral environment (e.g. outside)
3. They will be given a break for 5 mins to clear their adaptation to the environment.
4. The participant will enter the second area to be assessed.
5. Each area will be assessed in the same way, taking care to include a 5 min rest period between areas being assessed.

Analysis of environments
1. Analysis involves looking at the pattern of smells over the course of a day in different environments. Particularly intense smells are noted.

Outcomes
1. Most problematic smells identified
2. The intensity of smells across a full day is tracked
3. Hints and tips for amelioration given