

# INVESTIGATING AUTISTIC TRAITS, SENSORY EXPERIENCES AND PERSONALITY: A MIXED METHODS APPROACH

A Thesis submitted by

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#### Abstract

The relatively recent spectrum view of Autism Spectrum Disorder (ASD) with symptoms potentially varying from mild to severe, in combination with high rates of comorbid conditions, has raised the issue of heterogeneity among individuals with ASD. This has consequent challenges for obtaining consistent research findings and for the diagnosis of those with less severe symptoms or high-functioning ASD. Since evidence has suggested the presence of non-clinical levels of autistic traits within the general population, this thesis aimed to explore these traits in relation to personality and sensory experiences via a mixed methods design, comprising two parts. Part I consisted of two studies aimed at exploring the lived experiences of individuals with ASD and their caregivers, in relation to sensory experiences, in order to inform the subsequent studies. The focus of Part II was to explore autistic traits in the broader population and consisted of three studies.

In Part I, Study one comprised a systematic review of studies containing qualitative data from caregivers of individuals with ASD in relation to sensory experiences. Key sensory challenges reported related to: single senses (most commonly touch, taste, movement, and hearing), sensory issues embedded in certain situations, understanding the individual's sensory experiences, strategies to manage sensory issues, and the impacts of an individual's sensory issues on the family. A discrepancy between caregiver reports of the benefits of sensory based interventions and existing empirical evidence was identified. Study two involved qualitative analyses of sensory experiences, as described by three individuals with a diagnosis of ASD. Three main themes were identified: dominant types of sensory experiences including visual experiences, sounds, tastes and food preferences, tactile experiences, and less dominant senses including smells and movement, and multi-sensory experiences; management of sensory challenges; and participants' perceptions of change and difference.

The first study of Part II, study three, investigated the psychometric properties of the short form of the Autism Quotient (AQ-10) based on two separate non-clinical samples ( $N_1 = 194$ ;  $N_2 = 310$ ), via exploratory and confirmatory factor analyses. Results indicated a 7-item 3-factor solution for the AQ-10, with factors labelled social cues, intentions, and multi-tasking. Since the social cues factor accounted for the largest amount of variance (31%), and other factors together accounted for minimal explained variance (27%), only items comprising social cues were selected as a measure of autistic traits for subsequent analysis and studies. Structural equation modelling was conducted to analyse co-variate paths between social cues and selected personality traits, with findings indicating that social cue reading was not related to trait anger, introversion, or collecting. These results, therefore, challenged stereotypical associations between these constructs and ASD, and were consistent with existing evidence that social aspects of autistic traits are independent from repetitive behaviours, such as collecting. Study four extended these findings through exploration of social cue reading in relation to trait flexibility, anxiety, and sensory experiences. Consistent findings indicated positive associations between inflexibility, anxiety, and auditory and visual hypersensitivity, potentially suggesting that individuals with higher trait inflexibility and anxiety could experience greater sensory sensitivity or vice versa. Finally, study five involved a qualitative analysis of accounts of sensory experiences from a large combined sample (N = 504) of individuals from the general population. Content analysis of responses resulted in six main categories. Similar percentages of individuals scoring low and high on autistic traits (based on social cue reading difficulty) reported challenges relating to single senses (visual, auditory, tactile, and olfactory), people and crowds, and unexpected or unfamiliar stimuli. Unexpectedly, more individuals with low levels of autistic traits reported specific fears and anxiety responses to sensory stimuli, raising questions as to whether those with poorer social cue reading ability are more prone to report generalised anxiety (in line with trait anxiety) or are less aware or avoid reporting responses to sensory stimuli. Overall, the role of trait flexibility is highlighted across Parts I and II as being a central feature in individuals reporting experiences of sensory sensitivities. The collective findings of this program of research have implications for the further development of both clinical interventions and theoretical understandings, in addition to accommodations for individuals with sensory sensitivities and ASD traits.

*Keywords*: autism, autistic traits, ASD, social cues, sensory, inflexibility, trait anger, trait anxiety, collecting interests

### **Certification of Thesis**

This Thesis is entirely the work of Prasanthi Venugopalan except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

Principal Supervisor: Associate Professor Charlotte Brownlow

Associate Supervisor: Dr Erich C. Fein

Student and supervisor signatures of endorsement are held at the University

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#### **Chapter 1: Introduction**

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by difficulties in social communication and social interactions, and restricted, repetitive patterns of behaviour, interests, or activities (RRBIs) (Diagnostic and Statistical Manual of Mental Disorders [DSM-5], American Psychological Association [APA], 2013). This program of research focuses on exploring sensory experiences and personality traits of individuals with widely varying levels of autistic traits. These range from individuals in the general population with milder non-clinical levels of autistic traits (Bailey et al., 1995; Piven, Palmer, Jacobi, Childress, & Arndt, 1997), to those formally diagnosed with Autism Spectrum Disorder (ASD).

Atypical sensory perceptual experiences among individuals with ASD, have been widely documented since the earliest observations of autistic symptoms by Kanner (1943, p. 245) who noted children's aversions to "loud noises and moving objects". However, confusion about the role of sensory symptoms in relation to ASD is evident in the exclusion of reference to sensory symptomology in the fourth edition of the DSM-IV (APA, 2000) and then re-inclusion in the DSM-5, under the diagnostic criterion of restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). Since then, a growing number of studies have investigated sensory experiences in relation to ASD and autistic traits. However, a clear understanding of these experiences and underlying process is yet to be elucidated

A particular issue in terms of research into sensory issues and ASD has been the heterogeneity of individuals with ASD diagnoses. For example, the spectrum view of ASD means individuals vary in manifestation of symptoms from mild to severe. In addition, evidence has suggested that severity of symptoms in the social and RRBI domains vary independently (Frazier, Youngstrom, Kubu, Sinclair, & Rezai, 2008).

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Furthermore, mild levels of autistic traits have been shown to be present among nonautistic relatives of individuals and termed the 'broader autism phenotype' (Bailey et al., 1995; Piven et al., 1997). These milder features of ASD have been reported to be continuously distributed among the general population, leading to the development of screening tools such as the Autism-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), specifically designed to assess autistic traits in the general population.

Another factor contributing to heterogeneity of individuals with ASD is high rates of co-morbid conditions. Rates of co-morbid ADHD among children with ASD have been reported to be particularly high, ranging between 54% and 59% (Ghanizadeh, 2012; Goldstein & Schwebach, 2004; Stevens, Peng, & Barnard-Brak, 2016). A metaanalysis by van Steensel, Bögels, and Perrin (2011) estimated that approximately 40% of children and adolescents with ASD had at least one comorbid anxiety disorder diagnosis. Furthermore, pooled estimates of current and lifetime prevalence for anxiety and depressive disorder among adults with ASD were reported to be far higher than global estimates (Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha., 2018). This potentially suggests that anxiety and other neuroticism facet-level traits may present an area of inquiry in relation to autistic traits in the general population.

Some have suggested that a phenotypic characterisation of ASD, which includes factors additional to the core symptoms of autism, such as cognitive and adaptive function, language skills, and comorbidities, would improve identification of individuals with ASD, particularly those with less severe symptoms or high-functioning ASD (Grzadzinski, Huerta, & Lord, 2013; Romero et al., 2016). Kerekes et al. (2013) investigated phenotypical associations between ADHD, ASD, temperament, and character among 1886 twins aged between 9 and 12 years, in Sweden. They reported that neurodevelopmental conditions such as ASD and ADHD are specifically linked to particular temperament profiles. ASD was found to be correlated positively with harm avoidance (including greater worry, fear, and doubt), and negatively correlated with reward dependence, self-directedness, and cooperativeness (Kerekes et al., 2013). Other research into personality has reported associations between autistic traits and high neuroticism, low extraversion, and low agreeableness (Austin, 2005; Wakabayashi, Baron-Cohen, & Wheelwright, 2006). These factors, along with openness to experience and conscientiousness, are part of the five-factor model of personality (FFM) which provides a general model for personality (McCrae & John, 1992). Higher depressive and anxiety symptoms, as well as obsessional personality characteristics, have also been associated with higher levels of autistic traits (Kunihara, Senju, Dairoku, Wakabayashi, & Hasegawa, 2006). However, overall research into personality and autistic traits is limited. Austen (2005) suggested that since each trait of the five-factor model is comprised of a number of facets, further investigation of facet-level associations among the general population would provide more detailed understanding of personality structures in relation to the broader autism phenotype.

There has been a tendency for current representations of autism to have continued to be shaped by the earliest observational case study accounts of autism from the 1940s, which described aggressive behaviours, aloneness, and insistence on sameness (Draaisma, 2009). Since definitions of autism have changed in recent times to include a spectrum of symptom severity, it could be argued that early characterisations may not reflect current diversity among individuals with ASD. For example, there have been some reports of higher rates of aggression among children and adolescents with ASD based on caregiver reports (Hartley, Sikora, & McCoy, 2008; Kane & Mazurek, 2011), but little research into trait anger and autistic traits. In relation to introversion, existing studies have reported higher levels of introversion to be associated with ASD (Ozonoff, Garcia, Clark, & Lainhart, 2005a) and the broader autism phenotype (Dor-Shav & Horowitz, 1984; Li et al., 2017). However, reported findings of subsets of individuals with ASD traits who are more socially inclined and extraverted (Prior et al. 1998; Wing & Gould, 1979), including a group of children with a former diagnosis of ASD but who no longer met criteria (Suh et al., 2016) indicates the need for further research into introversion and the broader autism phenotype. Finally, references to collecting behaviours in relation to ASD have been described in case documentations (Chen et al., 2003; Skirrow, Jackson, Perry, & Hare, 2015; Wing, 1981), but collecting has not been investigated in relation to autistic traits in the general population. Therefore, further research into these areas is warranted, particularly with a view to building accurate characterisations of the broader autism phenotype and potentially challenging stereotypical associations.

In relation to sensory experiences, anxiety has been shown to be associated with sensory issues among children with ASD (Baker, Lane, Angley, & Young, 2008; Ben-Sasson et al., 2008; Lane, Reynolds, & Dumenci, 2012). Other studies have reported that autistic traits predict sensory over-responsivity which in turn produces higher levels of anxiety (Amos, Byrne, Chouinard, & Godber, 2018; Green, Ben-Sasson, Soto, & Carter, 2012; Horder, Wilson, Mendez, & Murphy, 2014; Robertson & Simmons, 2013). Horder et al. (2014) noted that even after controlling for autistic traits, atypical sensory experiences were still positively correlated with anxiety (as well as a history of mental illness, and migraines), raising the potential for misdiagnosis of ASD if these factors are not accounted for.

The persistent and rigid behavioural patterns and repetitive behaviours and/or interests associated with ASD have been thought to be associated with difficulties in

responding flexibly to situations, for example, resistance to change, the need for routines, and pre-occupation with certain objects (Gökçen, Petrides, Hudry, Frederickson, & Smillie, 2014; Leung & Zakzanis, 2014). Research has tended to focus on cognitive flexibility as a component of executive functioning (Pennington & Ozonoff, 1996). There have been mixed findings as to whether individuals with ASD exhibit differences in cognitive flexibility as measured in laboratory-based tasks (Geurts, Corbett, & Solomon, 2009; Leung & Zakzanis, 2014; Van Eylen et al., 2011). However, findings based on behavioural self-reports indicated that individuals with ASD had greater difficulty in transitioning between situations and activities in comparison to typically developing controls (Albein-Urios, Youssef, Kirkovski, Enticott, 2018; Leung & Zakzanis, 2014). Limited research has investigated trait flexibility in relation to sensory experiences and autistic traits.

In terms of qualitative data into sensory experiences and ASD, research has been relatively limited. A meta-analysis by Ben-Sasson, Hen, Fluss, Cermak, Engel-Yeger, and Gal (2009) revealed that the majority of existing qualitative research has been based on parent-based Likert-type response survey reports with results indicating issues related to under-responsivity, over-responsivity, and sensation seeking. In comparison, a small number of qualitative studies based on descriptive caregiver accounts (Dickie, Baranek, Schultz, Watson, & McComish, 2009; see also Muskat et al., 2015; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011) have reported more detailed sensory experiences of individuals with ASD relating to sensory modalities, and including caregiver perspectives and observations of these experiences.

Research based on first hand accounts of sensory experiences by individuals with ASD has also been relatively limited. Unusual experiences relating to sound, touch, vision, taste, smell, movement, and body position, occurring from childhood and continuing into adulthood have been described (O'Neill & Jones, 1997). Existing research has included participants' reports of experiencing general sensory overload, having strong stimuli preferences, and having to deal with the consequences of sensory reactions in daily life (Elwin, Ek, Kjellin, & Schröder, 2013; Robertson & Simmons, 2015; Robledo, Donnellan, & Strandt-Conroy, 2012; Smith & sharp, 2013).

Finally, a limited number of studies have investigated developmental changes in relation to autism and sensory experiences based on caregiver data (Fecteau, Mottron, Berthiaume, & Burack, 2003; Kern et al., 2006; Leekam, Nieto, Libby, Wing, & Gould, 2007). The findings from these studies report improvement of certain sensory difficulties with age, such as visual sensitivities, and worsening of aversions to touch (Kern et al., 2006; Leekam et al., 2007). However, little research has examined developmental changes in sensory experiences via first-hand accounts.

In summary, a greater understanding of variations and commonalities present in ASD populations and the broader autism phenotype is needed in order to gain greater understanding of the heterogeneity among individuals, which underlies much of the difficulty in obtaining consistent research outcomes in relation to areas such as sensory processing. It is argued that this could be achieved through further exploration of firsthand accounts of sensory experiences by individuals with ASD and caregivers, in order to elucidate key challenges related to sensory atypicalities, followed by research specifically into personality traits, sensory experiences, and autistic traits utilising nonclinical populations. Results could contribute to more accurate characterisations of ASD profiles which could then potentially lead to improved screening, diagnosis, and better outcomes for individuals, particularly those experiencing sensory challenges.

#### **Research Aims**

This program of research will be presented in two parts. Part I will comprise two studies, aiming to investigate accounts of sensory experiences from caregivers of individuals with ASD and individuals with a diagnosis of ASD. The purpose of this is to gain an experiential understanding of sensory experiences in relation to ASD, and to inform the studies in Part II. Since heterogeneity has been identified as being an issue that arises when researching and diagnosing autism, another aim of the project is to investigate the role of certain personality traits among the broader autism phenotype. Therefore, Part II will comprise three studies, aimed at investigating personality traits and sensory experiences in relation to autistic traits in the general population. Specific hypotheses and research questions will be posed in each chapter that follows. In order to achieve these aims, a mixed methods design will be utilised involving a combination of qualitative and quantitative methods (Creswell & Plano Clark, 2011).

With regard to terminology, the term ASD will be used throughout this thesis consistent with the latest DSM-5 diagnostic criteria for Autism Spectrum Disorder (APA, 2013). However, where a number of studies were conducted prior to the updated DSM or otherwise, have used other terms, results from these studies will be reported using the terms in the original studies. These terms include: autistic disorder, Asperger's syndrome or Asperger's Disorder (AS), and pervasive developmental disorder not otherwise specified (PDD-NOS). The term 'high-functioning' autism has been used where authors have reporting findings using the same term, in order to maintain consistency and clarity. It should be noted though that this term may been construed as misleading and simplistic, particularly by parents of individuals with ASD (Kenny, Hattersley, Molins, Buckley, Povey, & Pellicano, 2016). When referencing traits within the broader general population, the terms ASD traits or autistic traits will be used interchangeably. The term 'neurotypical' refers to individuals without a neurological or developmental condition such as ASD, and is widely used among individuals with ASD, clinicians, and researchers.

#### **Thesis Structure**

A review of literature will be first be presented in Chapter 2 in order to provide an overview of research in the field and present background information relevant to understanding current issues, gaps in the literature, and bases for the studies. Following this, Part I of the thesis will be presented, focusing on qualitative explorations of lived experiences in ASD. Study one (Chapter 3) will investigate key sensory challenges as reported by caregivers of individuals with ASD via a systematic literature review (SLR). Existing research has been focused almost exclusively on parent-based surveys with Likert-type responses, and results have been reported in terms of underresponsivity, over-responsivity, and sensation seeking. It is argued that a synthesis of qualitative research with caregivers as respondents, along with a critical evaluation of studies in this area, would add to these findings by revealing a deeper insight into the commonalities and variations among these sensory experiences as described by caregivers, and allow broader understanding of the area via examination of themes. Study two, involving qualitative analysis of accounts from children and adults with diagnoses of ASD in relation to sensory experiences will be presented in Chapter 4.

Part II, focusing on autistic traits in the broader population will be presented in Chapters 5 to 8. Chapter 5 will detail the methods utilised for the subsequent two quantitative studies, including participant details, measures. In relation to investigating autistic traits in the general population and personality factors, study three (Chapter 6) will aim to explore relationships between autistic traits and trait anger, introversion, and collecting interests in a non-clinical sample. Furthermore, in response to a relative lack

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of brief measures of autistic traits apart from the AQ-10 (a short form of the AQ) developed by Allison, Auyeung and Baron-Cohen (2012) and limited research into its validity, study three will investigate the internal consistency and factor structure of the AQ-10 via exploratory factor analysis and confirmatory factor analysis. Further analyses will be conducted through structural equation modelling (SEM) to analyse measurement reliability and pathways between factors.

Study four (Chapter 7) will explore sensory experiences and autistic traits among the general population in relation to the personality factors of flexibility and anxiety. This will be conducted through structural equation modelling (SEM) to analyse measurement reliability and pathways between factors. As discussed, anxiety has been shown to partially mediate the relationship between sensory experiences and autistic traits (Horder et al., 2014). However, little is known about the construct of trait flexibility in relation to sensory sensitivities, anxiety, and autistic traits. Furthermore, due to the high rates of co-morbidity reported among individuals with ASD, the relationships between co-occurring mental health diagnoses and these constructs will be investigated.

Study five (Chapter 8) will qualitatively analyse survey responses to open-ended questions on sensory experiences from individuals in the general population via content analysis and compare experiences among individuals with varying levels of autistic traits. The aim of this chapter will be to explore sensory experiences as described by individuals with milder non-clinical levels of autistic traits.

Finally, a review and discussion of study findings will be presented in Chapter 9 including limitations, implications, and clinical applications of findings. Contribution to the field of sensory experiences and autism will be discussed, in addition to recommendations for future research.

#### **Chapter 2: Review of the Literature**

The following literature review aims to provide an overview of research in the field, and background information relevant to understanding current issues, gaps in the literature, and basis for each of the studies in this program of research. This review will outline the significance of ASD, diagnostic changes over recent years, screening and diagnostic tools, and discuss issues pertaining to heterogeneity such as comorbidity, personality, and behavioural characteristics. A comprehensive overview of sensory experiences and autism will be conducted, including findings from empirical research and qualitative studies. Research into sensory experiences in relation to autistic traits among the general population will be examined, in addition to existing developmental research outcomes, and personality and behavioural factors related to sensory issues. Finally, theoretical frameworks that have been developed with a view to understanding ASD, perceptual processing styles, and sensory atypicalities will be discussed.

#### Autism Spectrum Disorder (ASD)

#### Significance of Autism Spectrum Disorder.

The average prevalence of ASD is currently estimated to be between 1% and 2% of the population of individuals ranging in age between 0 and 24 years, based on studies in Asia, Europe, and North America (Centers for Disease Control and Prevention [CDC], 2016) and appears to have risen considerably in recent decades. The 2015 Survey of Disability, Ageing and Carers (SDAC) showed that an estimated 164,000 Australians had ASD, which was a 42.1% increase from the 115,400 individuals (0.5% of the population) estimated to have ASD in 2012 (Australian Bureau of Statistics [ABS], 2017). However, this increase was lower than the 79% increase in cases of ASD between 2009 (64,400 people) and 2012 (ABS, 2014). Rises in rates are partially attributed to the broadening of diagnostic criteria, development of services,

and improved awareness (ABS, 2017; Fombonne, 2009). However, there has been uncertainty as to whether there has been an actual increase in prevalence rates (Rutter, 2005; Tsai et al., 2014). Baxter et al. (2015) conducted a systematic review of epidemiological data pertaining to ASD and reported that after accounting for variations in study methodology, prevalence rates for ASD appear to have remained stable between 1990 and 2010. Furthermore, there have been questions raised as to the prevalence ratios among males and females.

Currently, approximately four times as many males are diagnosed with ASD in comparison to females (CDC, 2016). However, there has been mounting evidence that these statistics do not reflect actual numbers of females with ASD. For example, some studies have reported male to female ratios in ASD ranging between 2.5:1 (Kim et al., 2011) to 1.8:1 (Mattila et al., 2011). There have been suggestions that ASD behaviours may present differently among females in comparison to males leading to cases of ASD among females being missed or misdiagnosed (Dworzynski, Ronald, Bolton, & Happe, 2012; Kirkovski, Fitzgerald, & Enticott, 2013; Rynkiewicz et al., 2016). Studies have shown that females with ASD tend to be better able to conceal social difficulties in comparison to males on the spectrum (Gould & Ashton-Smith, 2011; Lai et al., 2016). A recent study by Ormond, Brownlow, Garnett, Rynkiewicz and Attwood (2017) aimed to investigate sex differences in ASD characteristics, with a view to refining a parent report scale for female children and adolescents with ASD. Findings included that females with ASD were more likely to utilise social masking, imitation, and imagination than males with ASD. Further, Head, McGillivray, and Stokes (2014) reported findings that adolescent females with ASD scored significantly higher on levels of friendship quality, understanding, and empathy in comparison to males with ASD, but that these scores were significantly lower than their female neurotypical

peers. Similarly, research has indicated that peer relationships are particularly challenging for female adolescents with ASD (Attwood, 2007; Hartley & Sikora, 2009; Landa & Goldberg, 2005). Overall, this highlights the need for greater understanding of variability among ASD characteristics in order to improve diagnostic accuracy and maximise mental health outcomes for individuals.

#### **Diagnostic changes.**

Significant changes in the diagnosis of ASD and associated terminology have occurred in recent years. The Diagnostic and Statistical Manual of Mental Disorders (DSM) is widely utilised by health care professionals, as a guide for the diagnosis of mental health disorders according to clearly specified lists of diagnostic criteria (for example, Criterion A, B, etc.). The introduction of the latest version, DSM-5 (APA, 2013), introduced the term Autism Spectrum Disorder (ASD) as a single 'umbrella' diagnosis, which replaced the four separate pervasive developmental disorders (PDD) defined in the previous edition (DSM-IV-TR): autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) (APA, 2000). In the DSM-IV-TR (APA, 2000) symptoms had been classified into three domains based on the 'triad' of symptoms commonly associated with the core features of autism: social interactional difficulties, communication difficulties, and restricted and repetitive behaviours (e.g., Wing & Gould, 1979). However, in the fifth edition (DSM-5) (APA, 2013) these areas were recategorised into two domains: (1) the combined social interactional and communication domain, and (2) the domain of restricted and repetitive behaviours (Criterion A and Criterion B, respectively). This decision was based on evidence from research indicating support for two core autism symptom domains rather than three (see Frazier et al., 2008; Frazier et al., 2012; Norris, Lecavalier, & Edwards, 2012).

Criterion A lists three behavioural items which must all be met for a diagnosis of ASD. The first item refers to difficulty with social-emotional reciprocity, ranging from atypicalities in social approach to failure to initiate or respond to social interaction. The second refers to atypicalities in nonverbal communicative behaviour, ranging from poor eye contact to a lack of nonverbal communication. The third item refers to difficulty with social relationships, ranging from adjusting behaviours to suit social contexts to absence of interest in peers. Under Criterion B, four items are listed of which at least two must be met for diagnosis of ASD. These are: (1) stereotyped or repetitive motor movements, use of objects, or speech, (2) insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (such as adjustment difficulties or rigid thinking patterns), (3) highly restricted, fixated interests that are abnormal in intensity or focus (such as preoccupation with certain objects), and (4) hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (such as aversions to specific sounds or textures, or visual fascination with lights or movement) (APA, 2013).

In the DSM-5, symptoms no longer need to be evident prior to the age of three, with Criterion C instead indicating that symptoms must be present in the early developmental period. Criterion D specifies that symptoms must cause clinically significant impairment in functioning, while Criterion E allows specification of an accompanying intellectual impairment (if social communication is deemed to be below that expected for general developmental level) or language impairment. Other specifications under Criterion E are: having an associated medical, genetic condition, or environmental factor; another neurodevelopmental, mental, or behavioural disorder; or with catatonia. For individuals with social communicative difficulties but otherwise do not meet criteria for ASD, a new disorder was introduced: Social (Pragmatic) Communication Disorder (SCD).

Another significant change to the DSM-5 has been the removal from the diagnostic criteria of the requirement for a delay in or total lack of development of spoken language, due to limited evidence of the universality of speech difficulties among individuals with ASD (Grzadzinski et al., 2013). However, it is included as a specifier under Criterion E. Furthermore, the inclusion of sensory reactivity to list of diagnostic criteria, falling under the category of criterion B (restricted and repetitive behaviours), is a change from the DSM-IV-TR which did not include any reference to sensory symptomatology. Finally, when making a diagnosis of ASD, clinicians must specify one of three levels of impairment for major criteria A and B, ranging from the lowest severity (Level 1, Requiring support) to the highest severity (Level 3, Requiring very substantial support).

Similarly to the changes in the DSM, the latest schedule of the International Classification of Diseases (ICD-11) are expected to be released in 2022 (World Health Organization [WHO], 2018) and also combine several disorders under a single umbrella. The ICD-10 (WHO, 1992) currently specifies several pervasive developmental disorders (childhood autism, atypical autism, Rett syndrome, other childhood disintegrative disorder, overactive disorder associated with mental retardation and stereotyped movements, Asperger syndrome, other pervasive developmental disorders, and developmental disorder, unspecified), which will instead be incorporated under Autism Spectrum Disorder. The ICD-11 will also allow specification of severity along a spectrum, whereby individuals can exhibit a full range of intellectual functioning and language abilities.

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#### ASD screening and diagnostic tools.

There are a number of different tools utilised for ASD screening. Hirota, So, Kim, Leventhal, & Epstein (2018) conducted a systematic review of studies reporting the psychometric properties of a range of ASD screening tools for children (aged 4 years and above) and adults, including both clinical and general population samples, in comparison to two validated diagnostic tools: the Autism Diagnostic Observation Schedule (ADOS; Lord, 2002) and the Autism Diagnostic Interview, Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994). Hirota et al. found that among school age children and adolescents, the Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001), the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003), and the Social Responsiveness Scale (SRS; Constantino & Gruber, 2012) appeared to be effective in identifying ASD and in allowing differentiation from other neurodevelopmental and psychiatric disorders (Hirota et al., 2018). The SCQ is a 40item parent-report questionnaire about past and current autistic behaviours (scores of 15 and above are considered clinically significant). The SRS is a 65-item parent and teacher report questionnaire, which aims to identify and measure the presence and severity of autistic traits, as well as level of social impairment (T-scores of 60 or above are considered clinically significant). The Autism-Spectrum Quotient (AQ) is a 50-item self-rating questionnaire, which measures autistic traits in five domains including social skills, communication, imagination, attention to detail, and attention switching (Baron-Cohen et al., 2001). A score of 32 or above is considered clinically significant. Hirota et al. (2018) stated that recommendations for the use of other screening tools could not be made due to a lack of empirical research. They also noted that validity of tools may be impacted by factors such as the use of different clinical cut-off scores, or the type of report (e.g., self-report vs informant-report) (Hirota et al., 2018).

In terms of diagnostic tools, two commonly used measures are the ADI-R and the first and second editions of the ADOS (ADOS; Lord 2002; ADOS-2; Lord et al., 2012). The ADOS is a semi-structured, standardised observational assessment of communication, social interaction, play, and restricted and repetitive behaviours, for use with individuals ranging in age from 12 months to adulthood. The ADOS includes four modules, which the clinician selects for use depending on the individual's developmental and language level. The ADOS-2 includes an additional module for toddlers aged between 12 and 30 months with limited language. Administration time per module ranges from 40 to 60 minutes. Behaviours are assigned to predetermined categories and coded. Different cut-off scores allow diagnosis of autistic disorder (with higher severity of symptoms) or a broader autism spectrum disorder.

The Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) is a 93item structured interview conducted with parents/caregivers of the individual being assessed. It covers background history of the individual, developmental history, an overview of behaviours (including aggression, self-injury, and possible epileptic features), in addition to current functioning in core ASD domains (based on DSM-IV criteria): communication, reciprocal social interactions, and restricted and repetitive behaviours/ interests. It can be utilised for children and adults with a mental age above 2 years, and administration time ranges between 60 to 90 minutes. Clinicians follow standardised procedures to record and code informants' responses. Based on an algorithm for autism as specified in the ICD-10 and DSM-IV, if final scores exceed specified cut-off values in each of the three domains, a diagnosis of autism is indicated.

Both the ADOS and ADI-R have generally been considered 'gold standard' assessments in terms of being the best measures to diagnose ASD (Falkmer, Anderson, Falkmer, & Horlin, 2013; Ozonoff, Goodlin-Jones, & Solomon, 2005b). However, evidence from several studies has called this into question when applied to actual clinical practice in community settings. Kamp-Becker et al. (2018) argued that the highly complex level of administration and coding involved with the ADOS means that some subjective interpretation is necessary. They investigated the diagnostic accuracy of the original and the revised versions of the ADOS in a clinical setting via presentation of seven videotaped ADOS administrations to 235 clinicians. They found that accuracy varied according to the experience of the coder with the ADOS and the quality of the administration (Kamp-Becker et al., 2018). Baghdadli, Russet, and Mottron (2017) conducted a systematic review into the measurement properties of screening and diagnostic tools for adults with ASD with typical intelligence. They reported that none of the tools had satisfactory measurement properties and recommended that tools including the ADI-R and ADOS, should not be exclusively relied upon during the diagnostic process (Baghdadli et al., 2017). Matson, Beighley, and Turygin (2011) argued that realistically a 'gold standard' test for autism is not possible due to the variation of symptoms according to age group, gender, and intellectual level. They proposed that instead, measures should be selected with regard to the research question and in terms of whether the purpose of the assessment is for diagnosis, intervention goals, or monitoring of progress (Matson et al., 2011). Baghdadli et al. (2017, p. 122) also noted that when based on "categorical assumptions, applied to prototypical autistic phenotypes" diagnostic tools may result in an excessively high diagnostic threshold. Overall, recommendations are that standardised assessments such as the ADOS and ADI-R are administered by trained clinicians, and that results are integrated with information obtained from a thorough clinical evaluation (including multiple sources of observational information) in order to formulate an accurate diagnosis, based on either expert clinical judgement or decision-making by a

multi-disciplinary team (Baghdadli et al., 2017; Fusar-Poli et al., 2017; Kamp-Becker et al., 2018; Maddox et al., 2017). In addition, Baghdadli et al. (2017) stated that in adult populations without intellectual disability, self-report information can be reliably incorporated into a diagnostic formulation. They recommended use of the Ritvo Asperger and Autism Diagnostic Scale-Revised (RAADS-R) (Ritvo et al., 2008) self-report for this population due to their finding of it demonstrating good psychometric properties (Baghdadli et al., 2017). Kamp-Becker et al. (2018) suggested utilising the detailed information obtained from the ADOS beyond clinical cut-off scores, in order to determine whether DSM or ICD diagnostic criteria for ASD are met, with particular attention given to differential diagnoses for children and adolescents.

#### **Autistic Traits in the General Population**

Evidence from family and twin studies has shown that milder autistic traits are likely to be present among non-autistic relatives of individuals with autism, which have been referred to as the broader autism phenotype (Bailey et al., 1995; Piven et al., 1997). Evidence has indicated social and communicative difficulties among relatives of individuals with ASD (Piven et al., 1997). Also, among the general population, higher levels of autistic traits have been associated with higher neuroticism, lower extraversion, and lower agreeableness (Austin, 2005; Wakabayashi et al., 2006), as well as greater depressive and anxiety symptoms (Kunihara et al., 2006). Furthermore, these milder features of ASD, or broader autism phenotype traits, have been shown to be continuously distributed either normally or in a skewed unimodal distribution among the general population (Baron-Cohen et al., 2001; Constantino & Todd, 2003; Hoekstra, Bartels, Cath, & Boomsma, 2008; Hurst, Nelson-Gray, Mitchell, & Kwapil, 2007; Posserud, Lundervold, & Gillberg, 2006). In order to measure these traits many studies have utilised the Autism Spectrum Quotient (AQ) (Baron-Cohen et al., 2001).

#### The Autism Spectrum Quotient (AQ).

The AQ (Baron-Cohen et al., 2001) was developed with the aim of being a brief, self-administered instrument to measure where an adult of average intelligence was positioned on the continuum of the broader autism phenotype. The purposes of this were to establish a means of making scientific comparisons among individuals, and to serve as a screening tool to assist decision-making on whether to refer an individual for a full diagnostic assessment for ASD. The result was a 50-item self-report measure of autistic traits with five subscales: social skills; attention switching; attention to detail; communication; and imagination (Baron-Cohen et al., 2001). These dimensions were based on the 'triad' of symptoms commonly associated with the core features of autism, and which influenced the DSM prior to the 5<sup>th</sup> edition: social interactional difficulties, communication difficulties, and restricted and repetitive behaviours (e.g., Wing & Gould 1979), in addition to known areas of cognitive abnormality (Baron-Cohen et al., 2001).

Studies have shown that the AQ has acceptable predictive validity (Baron-Cohen et al., 2001; Booth et al., 2013; Woodbury-Smith, Robinson, Wheelwright & Baron-Cohen, 2005). Internal consistency has been found to range from moderate to acceptable ( $\alpha = .63$  to .77), and it has acceptable test-retest reliability (r = .70) (Baron-Cohen et al., 2001; Hoekstra et al., 2008; Lau, Kelly, & Peterson, 2013). However, some studies have reported far lower internal consistency values for the AQ subscales (below 0.70) (e.g., Austin, 2005; Hurst et al., 2007; Ingersoll, Hopwood, Wainer, & Brent Donnellan, 2011). This has led to a number of studies aimed at revising the AQ for increased reliability.

Some researchers have proposed and found improved consistency for a 3-factor structure, identifying domains pertaining to social skills, mentalising (mental-state

attribution)/communication, and detail orientation/patterns (Austin, 2005; Hurst et al., 2007; Ingersoll et al., 2011; Palmer, Paton, Enticott, & Hohwy, 2015). Most recently, Egito, Ferreira, Gonçalves and Osório (2018) investigated the Brazilian version of the AQ and also found inadequate support for a 5-factor model, instead proposing another 3-factor model (social skills, details/patterns, and imagination) based on 25 items. All of these studies were based on non-clinical samples. In contrast, Lau et al. (2013) included a large proportion of individuals with diagnoses of ASD in their sample (approximately 30%) and found support for a 39 item, 5-factor model of the AQ (Sociability, Social Cognition, Interest in Patterns, Narrow Focus, and Resistance to Change), and higher internal consistencies of subscales (all exceeding  $\alpha = .70$ ) than reported in other studies. In general therefore, past studies have found mixed results concerning the psychometric properties of the AQ.

Furthermore, Ruzich et al. (2015) conducted a meta-analysis of studies comprising a total of 6,900 non-clinical sample adults and 1,963 matched clinical ASD sample adults. Results indicated a mean score of 35 on the AQ among individuals with ASD, and a far lower mean score of 17 among the general population. Therefore, Ruzich et al. (2015) cautioned against using the AQ for diagnostic purposes, but rather as a descriptive quantitative measure of autistic traits or to divide the population into autism phenotypes. This also highlights the importance of more detailed investigation into the broader autism phenotype.

#### Short forms of the AQ: AQ-10.

In an endeavour to develop brief ASD screening tools, shorter versions of the AQ have been developed such as the AQ-28 (Hoekstra, Vinkhuyzen, & Wheelwright, 2011) and the 10 item AQ-10 (Allison et al., 2012), which includes an adult, adolescent, and child version. Allison et al. (2012) developed the adult AQ-10 based on a sample

of 449 adults with ASD and 838 controls which they randomly split into calibration and validation samples. Two items (evaluated to have had the highest discriminative power based on calibration sample participants) were selected from each of the five original AQ subscales (Allison et al., 2012). Sensitivity and specificity values were reported as 0.88 and 0.91 respectively, with internal consistency above 0.85 (Allison et al., 2012).

However, Sizoo et al. (2015) found lower sensitivity (27%) and specificity values (91%) for the AQ-10 (as well as the AQ-28 and Ritvo Autism Asperger Diagnostic Scale–Revised) based on a sample of 210 adults referred to outpatient clinics for assessment of ASD and 63 controls in the Netherlands. Furthermore, negative predictive values for the AQ-10 (39%), as well as the other measures, suggested that only half of the referred patients without ASD were correctly identified (Sizoo et al., 2005). Sizoo et al. concluded that none of these instruments had sufficient validity to reliably predict ASD in an outpatient setting. Nishiyama et al. (2014) also reported lower internal consistency for the AQ-10 (less than 0.70), as well as the full AO scale and other short forms, using a sample of 3,147 non-clinical and 60 clinical participants in Japan. However, Booth et al. (2013) reported that the AQ-10 performed similarly to the full AQ among 149 individuals with ASD and 134 controls in the UK, with sensitivity and specificity values of 0.79 and 0.87 respectively, and consequently recommended the AQ-10 as a brief screen for ASD. Internal consistency of items were however not reported by Booth et al. which is a limitation of the study. Overall, these mixed results indicate that further research into the AO-10 is necessary, particularly due to the ongoing need for brief and reliable screening tools to assist health professionals with initial assessments prior to further diagnostic follow-up for ASD.

#### **Co-morbidity and Personality Characteristics**

#### **Co-morbidity.**

Studies have shown high rates of comorbidity with ASD and a range of other disorders. A meta-analysis of studies investigating anxiety disorder among children and adolescents with ASD reported that 39.6% had at least one comorbid anxiety disorder diagnosis, the most common being specific phobia (29.8%), followed by OCD (17.4%) and social anxiety disorder (16.6%) (van Steensel et al., 2011). Another study reported that children with anxiety disorders (but without a diagnosis of ASD) scored higher on autistic traits than typically developing children (van Steensel et al., 2013). A recent systematic review and meta-analysis examining prevalence of anxiety and depression among adults with ASD reported that specific anxiety disorders, particularly social phobia and OCD, were also more common in adults with ASD (Hollocks et al., 2018). Pooled estimation of current and lifetime prevalence for any anxiety disorder among adults with ASD were reported to be 27% and 42% respectively, and 23% and 37% for depressive disorder (Hollocks et al., 2018). These are far higher than global estimates of 4.4% for depressive disorders, and 3.6% for anxiety disorders (World Health Organization, 2017).

There is also evidence of high rates of co-morbid ADHD among children with ASD, ranging between 54% and 59% (Ghanizadeh, 2012; Goldstein & Schwebach, 2004; Stevens et al., 2016). Furthermore, children with co-morbid ASD and ADHD have been reported to have more severe symptoms in comparison to those with a single diagnosis of either ASD or ADHD (Goldin, Matson, Tureck, Cervantes, & Jang, 2013; Jang et al., 2013). These include tantrum behaviours, conduct behaviour problems, worry/depressive symptoms, and avoidant behaviour (Goldin et al., 2013; Jang et al., 2013). Both Goldin et al. (2013) and Jang et al. (2013) utilised the Autism Spectrum

Disorders-Comorbidity Child Version (ASD-CC; Matson & Gonzalez, 2007) parent report scale. Diagnoses of comorbid ADHD were made according to participants meeting full criteria for each disorder based on the fourth edition of the DSM (DSM-IV-TR), even though this edition excluded diagnosis of ADHD if a diagnosis of ASD was present.

Changes in the fifth edition of the DSM (DSM-5), have enabled formal diagnosis of individuals with ASD with co-morbid ADHD. Romero et al. (2016) compared clinical comorbidities and psychiatric symptoms between individuals diagnosed with PDD according to the DSM-IV-TR criteria and those with a DSM-5 diagnosis of ASD. They concluded that those meeting DSM-5 criteria for ASD had more severe symptoms and were also more likely to meet criteria for co-morbid Obsessive Compulsive Disorder and eating issues (Romero et al., 2016). In order to improve identification of individuals with less severe symptoms or high-functioning ASD, Romero et al. (2016) and Grzadzinski et al. (2013) suggested a phenotypic characterisation of ASD, which includes factors additional to the core symptoms of autism, such as cognitive and adaptive function, language skills, and comorbidities. Furthermore, Lai and Baron-Cohen (2015) noted the importance of delineating differential diagnoses, comorbidities, and overlapping behaviours with other disorders, such as anxiety, depression, and personality disorders.

#### **Personality factors.**

In terms of personality, prior research has shown that autistic traits in the general population are associated with high neuroticism, low extraversion, and low agreeableness (Austin, 2005; Wakabayashi et al., 2006), which are major components of the FFM, the dominant non-clinical personality inventory in counselling psychology and work psychology. Higher levels of depression and anxiety, as well as obsessional

personality characteristics, have also been found to be associated with greater levels of autistic traits (Kunihara et al., 2006). Draaisma (2009) noted how the earliest observational case study accounts of autism from the 1940s described aggressive behaviours, aloneness, and insistence on sameness. These appear to have continued to shape representations of autism today. However, limited empirical research has been conducted into the relationships between autistic traits and constructs such as trait anger, introversion, and collecting.

*Trait anger*. Trait anger has been defined as a personality construct that refers to stable individual differences in frequency of or proneness to experiencing anger as an emotional state (state anger), which consists of "angry feelings, that may vary in intensity, from mild irritation or annoyance to fury and rage" (Spielberger & Reheiser, 2009, p. 273). Aggression, defined as verbal or physical behaviours towards others with the intention or likelihood of causing harm (Anderson & Bushman, 2002; Fitzpatrick, Srivorakiat, Wink, Pedapati, & Erickson, 2016), has been found to be positively related to trait anger (Wang et al., 2018). Trait anger has been reported to be a stronger predictor of aggression than state anger (Deffenbacher et al., 1996).

A number of studies have investigated aggression and autistic traits among nonclinical populations. Paul et al. (2015) utilised the Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999) to assess autistic traits among a sample of 331 adolescents receiving educational support, and found higher levels of autistic traits were associated with higher levels of aggressive behaviour, in addition to withdrawal and social problems. Pugliese, Fritz, and White (2015) found autistic traits were positively linked to anger rumination, facets of aggression, and social anxiety, with anger rumination being found to mediate the influence of social anxiety on hostility, verbal aggression, and physical aggression. Wang et al. (2018) also reported the mediating effects of anger rumination on this relationship. Caregiver report studies of children and adolescents with ASD have published variable rates of aggression. Kane and Mazurek (2011) reported a history of aggression among 1380 children and adolescents with ASD to be as high as 68% towards a caregiver and 49% to non-caregivers. Hartley et al. (2008) stated that 22.5% of young children with ASD were reported to have problems with aggression that fell in the clinically significant range. However, there is very limited research into trait anger itself in relation to autistic traits.

Introversion. In terms of the personality construct of introversion, two studies found higher levels of introversion among individuals with ASD compared to controls (Ozonoff et al., 2005a; Ramos et al., 2013). Ozonoff et al. (2005a, p. 91) compared 21 adults with ASD and 25 adult community controls utilising the Minnesota Multiphasic Personality Inventory-Second Edition (MMPI-2; Butcher et al., 2001) and described "discomfort in social situations, social reservation and introversion" as applicable to individuals with ASD. Similarly, findings from parent report studies, utilising clinical and non-clinical populations, have shown that internalising or withdrawn behaviours are positively associated with autistic traits (Hartley et al., 2008; Paul et al., 2015). In terms of the broader autism phenotype, studies have shown that parents of autistic children tended to be more introverted than those of typically developing children (Dor-Shav & Horowitz, 1984; Li et al., 2017). However, Prior et al. (1998) and Wing and Gould (1979) reported findings of subsets of individuals with high-functioning ASD who had a drive towards social engagement and wanting friendships, though they noted this did not necessarily translate to successful social interactions. Similarly, Suh et al. (2016) examined children termed 'optimal outcome', who no longer met diagnostic criteria for ASD due to achieving significant improvements in functioning, and reported that this group had higher levels of extraversion in comparison to typically developing peers and high-functioning individuals with ASD. Further investigation of introversion and autistic traits among the broader population would enable a better understanding of the relationship between these factors.

*Collecting.* Collecting behaviours have been described in a number of case documentations specifically in relation to Asperger Syndrome (AS) (Chen et al., 2003; Skirrow et al., 2015; Wing, 1981). Chen et al. (2003, p. 73) reported the case of a 21year-old male who developed stealing behaviours during adolescence, and was found to have collected large numbers of objects "such as paper, boxes, cups and plastic bags" in his living room. He was initially admitted to a psychiatric unit after being expelled from school due to the stealing, and was given a diagnosis of schizophrenia which was later changed to Aspergers Syndrome (AS). Chen et al. (2003, p. 73) noted that individuals with AS display a "variety of bizarre behaviours" in late adolescence, which creates the potential for misdiagnosis of schizophrenia or other similar disorders. Skirrow et al. (2015) documented the cases of three individuals (two males, and one female) ranging in age between 27 and 34 years, diagnosed with AS. They stated that all three displayed extreme collecting and/or hoarding behaviours. One individual had been "collecting, categorizing and storing a wide range of items in her two-bedroom apartment" since she was aged 16 years (Skirrow et al., 2015, p. 280). The 32 year old male was found to have "a vast number of CDs, cassette tapes and vinyl records" in his small flat, and had a collection of tickets from every live music concert he had attended (Skirrow et al., 2015, p. 281). Skirrow et al. (2015, p. 280) noted that the purpose of these behaviours seemed to be to maintain "a sense of personal continuity over time", for example, the concert tickets appeared to serve as 'anchor points' for the 32 year old male's life circumstance at different times. Skirrow et al. (2015) however also stated

that collecting or hoarding objects is commonly noted in individuals with ASD in clinical practice, but that there is limited research into the underlying processes of these behaviours.

Hoarding behaviour has been clinically defined as the accumulation of a large number of objects that clutter personal space, having difficulty discarding these objects despite them being of little use, and experiencing significant distress or impairment in general functioning (Frost & Hartl, 1996). Collecting behaviours may be less extreme and are not necessarily clinically significant unless they evolve into or meet the criteria for hoarding, but may be an aspect of restricted interests seen in ASD. The fact that existing case documentations all involved individuals with a diagnosis of AS, and towards the high-functioning side of the ASD spectrum, suggests that this trait could be evident in the broader autism phenotype. However, other than these limited case documentations there is little research into collecting behaviours, and no known investigation of collecting in relation to autistic traits in a non-clinical population has been conducted. Therefore, along with the limited existing research into trait anger and introversion, further research into these areas is warranted in order to provide further understanding of the broader autism phenotype.

### Sensory Experiences and ASD

Atypical sensory perceptual experiences have been reported to frequently occur among those with ASD, with as many as 90% of individuals with ASD demonstrating sensory perceptual difficulties (Leekam et al., 2007; Tomchek & Dunn, 2007). As discussed previously, this relatively high rate has been acknowledged by the recent reinclusion of sensory reactivity in the diagnostic criteria for Autism Spectrum Disorder (ASD) in the DSM-5 (APA, 2013), after being excluded from the previous edition. It is now listed as one of four possible manifestations under the diagnostic criterion B as: hyper- or hyporeactivity to sensory input, such as indifference to pain and temperature, adverse responses to certain sounds or textures, excessive smelling or touching of objects and visual fascination with lights or movement (APA, 2013).

Seven sensory systems have been defined: sound, touch, vision, taste, smell, movement, and body position (Dunn, Saiter, & Rinner, 2002). O'Neill and Jones (1997) stated that many first-hand accounts of people with autism contained references to unusual experiences relating to each of these senses, occurring from childhood and continuing into adulthood. These included hypersensitivities and hyposensitivities to stimuli, sensory distortions, overload, temporarily tuning out certain senses such as sound or vision, difficulties processing information from more than one sensory channel at a time, and experiencing multiple senses from a single source, for example perceiving colour and smell when hearing a sound (O'Neill & Jones, 1997). In the subsequent sections an overview of empirical research will be presented, in terms of measured abilities in a range of sensory domains, followed by a discussion of qualitative findings of sensory experiences based on first-hand account of individuals with ASD, and finally a summary of research findings based on sensory experiences in the general population.

### Overview of empirical research into sensory domains.

This section will overview existing empirical research in a range of sensory domains including: visual, auditory, tactile, olfactory, gustatory, vestibular and proprioceptive modalities. The aim of this is to understand the existing literature base in terms of measured abilities, prior to understanding reported sensory challenges as described in qualitative research findings (see O'Neill & Jones, 1997) which will be discussed in the subsequent section. *Visual.* A number of studies have investigated visual processing among individuals with ASD in a range of areas including, spatial vision, colour perception, motion perception, and visual search. Spatial vision is the ability to resolve or discriminate features that are defined spatially. Acuity (visual clarity) and contrast sensitivity (the ability to visually distinguish an object from its background) are the two primary measures of spatial vision.

Much of the empirical research on visual acuity has not indicated atypicalities among individuals with ASD (Albrecht et al., 2014; Anketell, Saunders, Gallagher, Bailey, & Little, 2015; Tavassoli, Latham, Bach, Dakin, & Baron-Cohen, 2011). Similarly, evidence has not shown that individuals with ASD have poorer contrast sensitivity than typically developing controls for identifying luminance (first-order) defined stimuli (Bertone, Mottron, Jelenic, & Faubert, 2003, 2005; Koh, Milne, E, & Dobkins, 2010a). Bertone et al. (2005) in fact reported that those with ASD displayed superior performance on a luminance defined task. However, individuals with ASD were found to have poorer performance than controls when stimuli presented were more complex and texture-defined (second-order) (Bertone et al., 2003, 2005).

In terms of colour perception, research has indicated that children with ASD have difficulties performing chromatic discrimination tasks (Franklin, Sowden, Burley, Notman, & Alder, 2008; Franklin et al., 2010; Heaton, Ludlow, & Roberson, 2008a). However, a review by Simmons, Robertson, McKay, Toal, McAleer, and Pollick (2009) noted that the diagnostic status of participants in these studies were not fully characterised, making it difficult to attribute these differences specifically to ASD. Also, Koh, Milne, and Dobkins (2010b) failed to find differences between the chromatic sensitivity of individuals with ASD and typically developing controls. Instead, they reported that siblings of individuals with ASD appeared to display superior chromatic discrimination ability (Koh et al., 2010b).

A number of studies have found that individuals with ASD have difficulties with motion perception (Milne et al., 2002; Pellicano, Gibson, Maybery, Durkin, & Badcock, 2005; Spencer et al., 2000), and biological motion perception (the ability to identify object information from partial inputs) (Annaz et al., 2010; Blake, Turner, Smoski, Pozdol, & Stone, 2003). However, other studies have not found differences between ASD and control groups on motion coherence tasks (Del Viva, Igliozzi, Tancredi, & Brizzolara, 2006; Jones, Quigney, & Huws, 2011) or in biological motion perception (Atkinson, 2009; Kaiser, Delmolino, Tanaka, & Shiffrar, 2010; McKay et al., 2012; Moore, Hobson, & Lee, 1997). The research therefore remains mixed in terms of conclusions that can be drawn in this sphere.

Many studies have reported on enhanced performances of individuals with ASD on visual search tasks, particularly the Embedded Figures Test (EFT: Witkin, Oltman, Raskin, & Karp, 1971), which involves detection of a simple shape within a complex figure (Jolliffe & Baron-Cohen, 1997; O'Riordan, 2004; Shah & Frith, 1983). Despite mixed results in the past, a more recent meta-analysis reported that individuals with ASD also display superior performance on the Block Design subtest of the Wechsler intelligence scales, in addition to the EFT, and exhibit a local processing bias toward letters on the Navon figures task (where a larger recognisable shape is composed of copies of a smaller different shape) (Muth, Honekopp, & Falter, 2014). Lindor, Rinehart, and Fielding (2018) found that children with ASD exhibited enhanced performance on complex visual search tasks, only if they possessed motor skills that met age expectations. Children with ASD and superior motor skills also displayed

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enhanced target discrimination on a visual crowding task, whereas those with poor motor skills performed poorly (Lindor et al., 2018).

Simmons et al. (2009) noted that overall, evidence for local superiority on visual search tasks has been relatively strong. This is in contrast to the inconsistent findings regarding other areas of visual processing, such as the processing of complex motion stimuli, facial recognition, and visual attention (Simmons et al., 2009). Little (2018) stated that methodological issues in visual research studies with individuals with ASD to date need to be addressed through cohort studies, larger sample sizes, clearly defined study protocols, and standardised diagnoses of autism among recruited participants. For example, investigations of visual search performances of the broader autism phenotype, as measured by the Autism Quotient, have also produced inconsistent results (Cribb, Olaithe, Di Lorenzo, Dunlop, & Maybery, 2016).

Cribb et al. (2016) conducted a meta-analysis of studies of EFT performances in the broader autism phenotype and reported that differences in findings depended on whether AQ scores were treated as a continuous variable or grouped into high and low. Studies which did not find significant relationships between the AQ and EFT performances (Carroll & Chiew, 2006; Carton & Smith, 2014; Valla et al., 2010) investigated continuous scores on the AQ, whereas those that did report enhanced visual performance among high AQ scoring individuals (Almeida, Dickinson, Maybery, Badcock, & Badcock, 2010a, b, 2013; Brock, Xu, & Brooks, 2011; Milne, Dunn, Freeth, & Rosas-Martinez, 2013) were quantile studies that compared extreme groups.

Gregory and Plaisted-Grant (2013) argued that inconsistent findings are due to the possible inclusion of individuals with undiagnosed ASD or relatives of individuals with ASD who have the autistic endophenotype (a quantitative and heritable biological trait associated with a disorder), for example, pertaining to visual search. They argued that equating high scores on the AQ to autism allows potential for spurious results (Gregory & Plaisted, 2013). However, the findings reported by Cribb et al. (2016) indicated that superior EFT performance has also been demonstrated among individuals scoring high on the AQ but below the clinical-cut-off (thus being likely to exclude cases of undiagnosed ASD), in comparison to low scorers. Therefore, the possibility that EFT performance varies dimensionally according to level of autistic traits in the general population cannot be discounted (Cribb et al., 2016). Research with far larger sample sizes may be necessary to detect this relationship when utilising using a continuous AQ design in order to increase statistical power (Cribb et al., 2016). This highlights the impact of methodological issues on study findings, and also the need for further research into the broader autistic phenotype.

*Auditory.* A number of studies have investigated auditory processing and ASD. O'Connor (2012) conducted a review of the literature and reported that overall findings have shown that individuals with ASD display superior performance than typically developing controls when processing simple, low level auditory information such as pitch. However, reduced performance has been reported when individuals with ASD are required to process more complex auditory stimuli, such as speech or during increased task demands (O'Connor, 2012). For example, a number of behavioural studies have investigated the ability to identify the pitch of pure tones through pitch categorisation and discrimination tasks, reporting that children with ASD exhibit greater accuracy than typically developing controls (Bonnel et al., 2003; Heaton et al., 2005; Mottron, Peretz, & Menard, 2000; O'Riordan & Passetti, 2006). Others have examined pitch contour (intonation) discrimination among children with ASD and controls. Heaton, Hudry, Ludlow, and Hill (2008a) reported that children with autism exhibited superior pitch contour discrimination for speech and non-speech stimuli. Other studies also reported superior performance on sentence pitch matching tasks, but poorer performance than typically developing controls on comprehension tasks (Järvinen-Pasley, Pasley, & Heaton, 2008a; Järvinen-Pasley, Wallace, Ramus, Happé, & Heaton, 2008b). There have been inconsistent findings regarding enhanced pitch perception among adolescents and adults with ASD (O'Connor, 2012).

*Loudness and intensity of sounds.* A limited number of studies have investigated loudness perception. Khalfa et al. (2004) reported that children with ASD had increased perception of loudness or hyperacusis (discomfort for sounds that would be tolerated by most individuals with typical hearing) in comparison to controls. In terms of intensity discrimination, behavioural studies have not shown significant differences between adolescents and adults with ASD and controls in terms of ability to discriminate intensity of tonal stimuli (Bonnel et al., 2010; Jones et al., 2009).

*Noise*. Difficulties in processing speech in the context of a noisy background have been reported among individuals with ASD, particularly when noise contained 'temporal dips' (Alcántara, Weisblatt, Moore, & Bolton, 2004; Groen et al., 2009). Temporal dips occur, for example, during brief pauses in the competing noise which allow for an individual to hear parts of the speaker (Peters, Moore, & Baer, 1998). Spectral dips occur when the spectrum of target speech differs from that of the background speech (Peters et al., 1998). Evidence suggests that spectral speech processing among children and adolescents with ASD is intact and similar to typically developing controls (Alcántara et al., 2004; Groen et al., 2009). However, difficulties in processing non-speech sounds in the presence of background noise have been reported among adults with ASD (Plaisted, Saksida, Alcantara, & Weisblatt, 2003; Teder-Salejarvi, Pierce, Courchesne, & Hillyard, 2005).

Mismatch Negativity (MMN). In terms of data from electrophysiological studies, findings of auditory atypicalities and ASD have been mixed. Mismatch Negativity (MMN) is a neural measure of auditory processing that assesses an individual's ability to detect a 'deviant' stimulus (for example differing in intensity, pitch, or phoneme) randomly presented among a standard sequence of regularly occurring auditory stimuli (Näätänen, Gaillard, & Mäntysalo, 1978). Some studies have reported findings of earlier MMN responses to deviant stimuli among individuals with ASD indicating increased sensitivity to auditory changes (Gomot et al., 2011; Lepistö, Nieminen-von Wendt, Wendt, von, Näätänen, & Kujala, 2007), whereas others have reported reduced sensitivity (Andersson, Posserud, & Lundervold, 2013; Jansson-Verkasalo et al., 2003; Yu et al., 2015) or mixed results depending on the deviant stimuli presented (Lepistö et al., 2005; Lepistö et al., 2008). A recent meta-analysis of 67 studies investigated auditory MMN and ASD and reported that though data was limited, young children with ASD appear to have greatest sensitivity to sound (Schwartz, Shinn-Cunningham, & Tager-Flusberg, 2018). However, Schwartz et al. (2018) stated that overall results were inconsistent due to variability in study designs, small sample sizes, and unrepresentative samples of individuals with ASD. They noted that examining group differences may not account for heterogeneity within the ASD population in relation to auditory change sensitivity, and that further research into this area is necessary (Schwartz et al., 2018).

*Tactile.* A number of studies have examined tactile sensitivity in ASD utilising psychophysical approaches (objective method of studying relationship between stimuli, specified in physical terms, and the sensations and perceptions evoked by these stimuli) (see Mikkelsen, Wodka, Mostofsky, & Puts, 2018 for a review). O'Riordan and Passetti (2006) and Cascio et al. (2008) investigated contact detection thresholds utilising von

Frey hairs, a device used to measure tactile sensitivity of the skin. Both studies reported no differences in contact detection thresholds between individuals with ASD and controls. However, Cascio et al. (2008) reported significantly lower detection thresholds (higher sensitivity to vibration) on the forearm among individuals with ASD in comparison to controls, and increased sensitivity to thermal pain on both the palm and forearm in comparison to controls.

Güçlü, Tanidir, Mukaddes, and Unal (2007) examined vibrotactile thresholds and masking tasks for low frequency flutter (40Hz) and high-frequency vibration (250Hz) stimuli and reported no differences between children with ASD and controls. A correlation between tactile and emotional sections of the Touch Inventory for Elementary-School-Aged Children (Royeen & Fortune, 1990) and Sensory Profile (Dunn & Westman, 1997) was found, which the authors suggested may point to an emotional basis for tactile sensitivities.

Blakemore et al. (2006) investigated detection thresholds for flutter (30 Hz) and vibration (200 Hz) stimuli among adults with Asperger's Syndrome (AS) and reported that the AS group had significantly lower detection thresholds for vibration but not flutter. Another finding was that while both the AS group and controls tended to perceive self-produced motion as less intense and 'tickly' than experimenter-induced motion, the AS group found both types of motion to be more intense and tickly than controls.

Puts, Wodka, Tommerdahl, Mostofsky, and Edden,(2014) reported findings that children with ASD had higher detection thresholds (worse perception) for static flutter stimulus (involving delivery of a static 25Hz stimulus to a finger) than controls, but no group differences were reported for dynamic stimuli (involving slow increase of stimulus from zero amplitude to 25 Hz). Similar results were reported by Tavassoli et al. (2016). Puts et al. (2014) suggested that these findings may indicate difficulties filtering sensory information leading to suppression of responses to certain stimuli, and the subsequent negative sensory responses seen in ASD. However, Cascio et al. (2008) found no group differences in vibrotactile detection thresholds at 33Hz on the palm. Further research into this area is therefore necessary. Additionally, Tavassoli et al. (2016) is one of the first studies to report positive correlations between tactile thresholds, AQ scores and the ASD core symptom of repetitive behaviours.

*Adaptation.* A few studies have utilised using neuroanatomical and neurophysiological measures to explore adaptation in vibrotactile processing, in terms of the ability to habituate to sensory stimuli. Studies have reported difficulties with adapting during amplitude discrimination tasks among adults with ASD (Tannan, Holden, Zhang, Baranek, & Tommerdahl, 2008) and children with ASD (Puts et al., 2014). The task utilised by Tannan et al. (2008) involved a portable vibrotactile stimulator with two probe tips placed above the participant's hand. In the adaptation condition, a 25 Hz tactile stimulus was delivered one second prior to the standard stimuli, and at the same location on the hand, which then allowed measurement of the effect of reduced perception of intensity (Tannan et al., 2008).

Tommerdahl, Tannan, Cascio, Baranek, and Whitsel (2007) investigated performance on short and long adapting stimulus tasks on spatial discrimination among four adults with ASD and four typical adult controls. Findings were that the ASD group exhibited superior spatial discrimination in short adaptation conditions, but comparable performance to controls on long adaptation conditions (Tommerdahl et al., 2007). Overall, Mikkelsen et al. (2018) noted that findings from these studies are inconsistent and this is reflective of differing methodologies, the descriptive language used, and the heterogeneity of ASD participants, meaning that results cannot be generalised to the ASD population more broadly.

*Olfactory.* Research into olfaction and ASD has examined olfactory identification, sensitivity, odour pleasantness, and odour discrimination (see review by Tonacci et al., 2017). Odour detection thresholds have been investigated in order to assess ability to discriminate between odours. Dudova et al. (2011) found that children with ASD exhibited reduced odour detection thresholds, indicating difficulties with odour detection in comparison to typically developing controls. Ashwin et al. (2014) reported that adults with ASD exhibited greater olfactory sensitivity, which was positively correlated with the level of autistic traits as assessed by the AQ. However, a number of studies have not found significant differences in odour detection thresholds between individuals with ASD and typically developing controls (Galle, Courchesne, Mottron, & Frasnelli, 2013; Suzuki, Critchley, Rowe, Howlin, & Murphy, 2003; Tavassoli & Baron-Cohen, 2012).

In terms of odour identification, a systematic review by Tonacci et al. (2017) found that 71.4% of studies reported that individuals with ASD had difficulties with identifying odours in comparison to controls. These results have been reported among adults with AS (Galle et al., 2013; Suzuki et al., 2003), and children with high functioning autism (Bennetto, Kuschner, & Hyman, 2007; May et al., 2011). Galle et al. (2013) reported reduced odour identification ability among individuals with autism and speech delay (which the authors noted may have been due to difficulties verbally labelling odours), in comparison to individuals with AS and controls. May et al. (2011) also reported poorer odour identification among children with high-functioning autism and ASD in comparison to children with AS. They noted that this contributed to evidence of high-functioning autism and AS being separate disorders. Though these were grouped together in the subsequent DSM-5, these findings again highlight the variability among individuals currently falling under the ASD spectrum. Two studies have not found odour identification differences between ASD participants and controls (Brewer, Brereton, & Tonge, 2008; Dudova et al., 2011).

A limited number of studies have investigated odour pleasantness. Two studies reported subtle differences between children with ASD and controls in odour pleasantness ratings (Hrdlicka et al., 2011; Legiša, Messinger, Kermol, & Marlier, 2013). Galle et al. (2013) reported no differences between odour pleasantness ratings of adults with ASD and controls.

*Gustatory.* A limited number of empirical studies have explored gustation among individuals with ASD (see review by Boudjarane et al., 2017). In order to assess gustation, one of two methods may be utilised. Chemogustometry involves different solutions (tastants) being applied to the tongue to evoke responses which allow assessment of perceptions of sweetness, saltiness, sourness, and bitterness. Electrogustometry involves the application of a constant anodal current to the tongue to stimulate perception of a metallic taste, which allows measurement of taste detection thresholds. Bennetto et al. (2007) and Tavassoli and Baron-Cohen (2012b) investigated taste identification among children and adolescents, and adults with ASD respectively. Findings from chemogustatory tests were that individuals with ASD were poorer overall at taste identification in comparison to controls. Bennetto et al. (2007) reported that children and adolescents with ASD found it particularly difficult to identify sour tastes in comparison to controls. Tavassoli and Baron-Cohen (2012b) reported that adults with ASD were significantly worse at identifying sour, bitter, and sweet tastes, but that there was no difference between the ASD group and controls in identification of salty tastes. Damiano et al. (2014) explored sweet taste sensitivity and liking for

sweet tastes (hedonic responses) among adults with ASD. They reported no differences between ASD participants and controls for either sweet taste sensitivity or hedonic responses (Damiano et al., 2014). However, increasing ASD symptom severity as measured by AQ scores, was associated with decreasing sensitivity for sweet tastes. Hedonic responses were unrelated to ASD symptoms (Damiano et al., 2014).

In terms of taste detection thresholds Bennetto et al. (2007) found no differences between ASD participants and controls. Overall, existing findings suggest difficulties in taste identification among individuals with ASD. Boudjarane et al. (2017) noted that all studies used variable gustatory assessments, for example, not all tastants were used in every study, which may have influenced findings. Therefore, further research is necessary.

*Food selectivity*. Food selectivity has been commonly reported among children with ASD and has been thought to be related to sensory processing difficulties, such as oral sensitivities (Schreck & Williams, 2006; Schreck, Williams, & Smith, 2004; Zobel-Lachiusa, Andrianopoulos, Mailloux, & Cermak, 2015). However, Chistol et al. (2018) argued that few studies have utilised quantitative measures to investigate this relationship. Chistol et al. assessed food selectivity among children with ASD and typically developing controls utilising direct measures of food intake, including a modified version of the Youth/Adolescent Food Frequency Questionnaire (Rockett et al., 1997) to measure food refusal, frequency of consumption, and number of unique foods consumed over 3 days (food repertoire). Sensory atypicalities were assessed using the Sensory Profile (Dunn, 1999). Findings were that atypical sensory processing was more common among children with ASD. Atypical oral sensory sensitivity (sensory hyper-sensitivity for taste and olfactory stimuli) among children with ASD was associated with higher levels of food refusal, more restricted food repertoire, and

lower consumption of fruits and vegetables (Chistol et al., 2018). In addition, a longitudinal study of children with ASD by Bandini et al. (2017) reported that between the ages of approximately 7 and 13 years, food refusal improved over time but there was no increase in food repertoire.

*Vestibular*. Vestibular processing refers to an individual's sense of balance and awareness of spatial orientation. It is a complex system involving structures in the inner ear, signals to neural structures controlling eye movements (vestibulo-ocular reflex) and muscles that allow upright posture and control of movement. Vestibular issues among individuals with ASD have been documented since early studies by Maurer and Damasio (1979). However, since then relatively few empirical studies have reported differences between vestibular processing between individuals with ASD and control participants (Kern et al., 2007; Ornitz et al., 1985; Ritvo et al., 1969; Siaperas et al., 2011). Children with ASD have been reported to have atypicalities in rotational vestibulo-ocular reflex, the function that allows maintenance of stable vision through eye movements in response to rotation of the head (Carson et al., 2017; Ornitz et al., 1985; Ritvo et al., 1969). Carson et al. (2017) suggested that this was indicative of dysfunction in cerebellar input to the brainstem among individuals with ASD. However, findings from other studies have not supported this (Furman, Osorio, & Minshew, 2015; Minshew, Luna, & Sweeney, 1999).

Difficulties with postural control among children and adolescents with ASD have been noted (Greffou et al., 2012; Minshew, Sung, Jones, & Furman, 2004; Molloy, Dietrich, & Bhattacharya, 2003). However, these atypicalities were not attributed to deficits in the vestibular system but rather to sensory integration issues (Minshew, et al., 2004; Molloy et al., 2003) and visual environment and developmental factors (Greffou et al., 2012). Therefore, vestibular processing appears to be a complex system dependent on multiple factors and other sensory systems. Though existing research point to atypicalities among individuals with ASD in this area, further research is necessary to elucidate understanding of underlying processes.

*Proprioception.* Research into ASD and proprioception, the sense though which the position and movement of our body is perceived, has been limited. Some studies have suggested that individuals with ASD tend to show increased reliance on proprioception in comparison to controls (Haswell, Izawa, Dowell, Mostofsky, & Shadmehr, 2009; Marko et al., 2015). On a task involving children learning to control a robotic arm to reach a target, Haswell et al. (2009) reported that children with ASD displayed stronger associations between self-generated motor commands and proprioceptive feedback and thus relied on proprioception, whereas the control group had greater tendency to integrate visual and proprioceptive feedback. Marko et al. (2015) utilised the same task but included random trials which included errors in the reach of the robotic arm, in order to assess learning. Findings were that children with ASD exhibited superior performance in comparison to controls when learning from errors that were sensed through proprioception, but poorer performance when learning from errors that were sensed through vision (Marko et al., 2015).

Izawa et al. (2012) also reported similar findings of a greater reliance on proprioceptive feedback among children with ASD. In contrast, Weimer, Schatz, Lincoln, Ballantyne, and Trauner (2001) reported that children with ASD displayed poorer performance than controls on certain tasks relying on proprioceptive feedback (for example, when require to balance on one leg with eyes closed). However, no significant group differences were found in performances on other tasks, such as visualspatial integration, and finger-tapping (Weimer et al., 2001). Fuentes, Mostofsky, and Bastian (2010) assessed proprioception of limb position among adolescents with ASD, on a number of tasks and reported no significant group differences in proprioceptive accuracy or precision. Similarly, Morris et al. (2015) reported similar performances between adults with ASD and controls on a postural illusion task indicating comparable proprioceptive processing between groups. However, they also reported evidence of visual processing differences, since the adults with ASD did not appear to utilise visual information to normalise their postural position whereas the control group did (Morris et al., 2015).

Paton, Hohwy, & Enticott (2012) investigated proprioceptive and sensorimotor differences among adults with ASD and controls, by assessing responses to the rubber hand illusion (when synchronous touch on a real, hidden hand and on a visible rubber hand tends to induce the experience of a touch located on the rubber hand). Findings were that adults with ASD and controls experienced the illusion similarly, and that the ASD group displayed more accurate proprioception but reduced sensitivity to visuotactile-proprioceptive discrepancy between the rubber hand and the real hand (Paton et al., 2012).

More recently, Riquelme, Hatem, and Montoya (2016) also reported that children with ASD had poorer upper limb proprioception and were less skilled in object manipulation than typically developing controls. Paton et al. (2012) suggested that proprioceptive precision and accuracy among individuals with ASD seem to be typical on simple tasks, but that these atypicalities could be more evident in more complicated, context-dependent scenarios. Therefore, further investigations are necessary.

### Summary of empirical research into sensory domains.

In summary, many of the findings pertaining to sensory processing are inconsistent. In relation to vision, evidence suggests that individuals with ASD display superior performance on visual search tasks such as the EFT, whereas findings in the broader autism phenotype have been mixed which has been attributed to methodological issues such as small sample sizes and participant heterogeneity (Cribb et al., 2016). In terms of auditory processing, there is evidence that individuals with ASD display superior pitch perception in comparison to typically developing controls (O'Connor, 2012). However, findings from electrophysiological studies on auditory change sensitivity have been inconsistent, with Schwartz et al. (2018) noting that examination of group differences may not account for heterogeneity within the ASD population. In relation to tactile processing, evidence suggests that individuals with ASD experience tactile atypicalities such as adaptation difficulties (Tannan et al., 2008). However, studies into tactile dysfunction in ASD are inconsistent with Mikkelsen et al. (2018) ascribing to the heterogeneity of ASD participants, and the diversity of tactile sensitivity measures. It is of note that the study by Tavassoli et al. (2016) was one of the first to report positive correlations between tactile thresholds, AQ scores, and the ASD core symptom of repetitive behaviours. In relation to olfaction, there is evidence that individuals with ASD have decreased odour identification ability in comparison to controls, however, findings from studies into olfactory sensitivity and odour pleasantness have been inconsistent (Tonacci et al., 2017). Studies examining gustation and ASD have been very limited. Though findings have suggested identification difficulties for certain tastes among individuals with ASD in comparison to controls, the use of variable gustatory assessments among studies limits the strength of findings (Boudjarane et al., 2017). Food selectivity has been reported to be more common among children with ASD in comparison to typically developing peers, and findings have suggested this to be associated with oral sensitivity (Chistol et al., 2018). However, little empirical research has been conducted into this area. Similarly, limited

research has been conducted into vestibular processing. Though research has suggested that individuals with ASD do experience vestibular atypicalities, these have been attributed to sensory integration issues (Minshew, et al., 2004; Molloy et al., 2003) and visual environment and developmental factors (Greffou et al., 2012) rather than to deficits in the vestibular system. Further research is therefore necessary. Finally, research examining proprioception and ASD has also been limited overall, with existing studies reporting mixed findings. Therefore, it is apparent that further research into sensory modalities is needed, particularly addressing the methodological limitations noted in reviews, which concern sample sizes, variable assessment measures, and heterogeneity of participants. Further investigation of the heterogeneity among individuals with ASD is therefore warrants further investigation.

## Qualitative research into sensory experiences.

The majority of research on sensory experiences has been based on parent reports, through the use of questionnaires, such as the Sensory Profile developed by Dunn (1999). Results from a meta-analysis of parent report studies indicated that the greatest difference between individuals with ASD and typical groups was in (1) underresponsivity, which refers to unawareness of or slow response to sensory input, followed by (2) over-responsivity, referring to exaggerated, rapid onset or prolonged reactions to sensory stimulation and (3) sensation seeking, in terms of craving specific sensory experiences (Ben-Sasson et al., 2009). A relatively small number of qualitative studies have been based on first-hand accounts of sensory perceptual experiences by individuals with ASD themselves.

*First-hand accounts of sensory experiences and ASD.* There is still a relative lack of understanding about underlying causes of symptoms in ASD and despite this many theories and definitions of autism have been propounded, while research into the

lived experiences of those with ASD has been quite limited (Robledo, Donnellan, & Strandt-Conroy, 2012). Temple Grandin (2009), a noted ASD self-advocate, described the highly debilitating impact of sensory sensitivities on her everyday functioning and emphasised the need to investigate this area, particularly via first-hand accounts. Existing research into first-hand accounts and sensory experiences has been based on data collected from: semi-structured interviews (Ashburner, Bennett, Rodger, & Ziviani, 2013; Elwin et al., 2013; Kirby, Dickie, & Baranek, 2014) including online messaging (Smith & Sharp, 2013), focus groups (Robertson & Simmons, 2015), published autobiographies and memoirs of ASD authors (Davidson, 2010; Elwin, Ek, Kjellin, & Schröder, 2012; Welch, Polatajko, Rigby, & Fitch, 2018), online written accounts (Jones et al., 2003), a combination of interviews and autobiographies (Chamak et al., 2008), interviews and autobiographies with the addition of observations and personal documents such as artwork and poems (Cesaroni & Garber, 1991; Robledo et al., 2012), and mixed method designs (Bertilsson, Gyllensten, Opheim, Gard, & Sjödahl Hammarlund, 2018; Gurbuz, Hanley, & Riby, 2018; Howe & Stagg, 2016). In this section an overview of sensory experiences reported in studies based on first-hand accounts of individuals with ASD will be presented, beginning with general sensory experiences followed by experiences related to each sensory modality.

## General sensory experiences.

*Attention to stimuli*. First-hand accounts have described sensory experiences such as becoming absorbed with certain details to the extent that individuals report becoming "stuck in the moment" and tending to "zone out" (Smith & Sharp, 2013, p. 903), finding it hard to divert attention away from a noticed stimulus such as low flicker rate in a light (Robertson & Simmons, 2015), or needing to avoid looking at certain objects in order to focus on an activity (Ashburner et al., 2013). Others have reported

having "narrowly focused and sharp" focus and attention to detail, leading to spending hours being absorbed in minute details such as upholstery fabric threads or air particles (Elwin et al., 2012, p. 424). Difficulty filtering out irrelevant stimuli has also been described, for example, being unable to shut out sounds and instead hearing all sounds merged together, with even faint sounds amplified (Elwin et al., 2012), or hearing all sounds at the same volume making it difficult to exclude sounds when attempting to hear someone speaking (Elwin et al., 2013).

Sensory integration and confusion. A number of individuals with ASD have described experiencing problems processing multiple stimuli (Davidson, 2010; Chamak et al., 2008; Jones, Quigney, & Huws, 2003; Robertson & Simmons, 2015; Smith & Sharp, 2013). For example, some have reported difficulty in listening to many sounds at the same time (Smith & Sharp, 2013), being unable to process "many things at once" (Jones et al., 2003, p. 116), having difficulty focusing attention on what one person is saying in the midst of several conversations (Elwin et al., 2013), or that hearing a small noise "shuts off your other senses" (Robertson & Simmons 2015, p. 579).

Others have described a kind of sensory "co-mingling", with one ASD author stating that a sudden bark from a dog could distort her sensory perception so that the dog appeared significantly larger than its actual size (Davidson, 2010, p. 307). Cesaroni and Garber (1991, p. 306) also reported two first-hand accounts of participants seemingly experiencing auditory, visual, and tactile stimuli from one source of stimulation, such as experiencing sound "often accompanied by vague sensations of color, shape, texture, movement, scent, or flavor". This experience of one sensory stimulus automatically inducing perception in other sensory areas has been termed synaesthesia (Baron-Cohen, Wyke, & Binnie, 1987).

Sensory overload. A number of first-hand account studies reported individuals' descriptions of becoming 'overloaded' in response to external stimuli (Chamak et al., 2008; Davidson, 2010; Elwin et al., 2013; Gurbuz et al., 2018; Jones et al., 2003). Elwin et al. (2013) noted participants described feeling overwhelmed by environmental stimuli, such as being in shops and noisy workplaces, as well as finding it difficult to be in crowds where their personal space was limited. Participants in the study by Smith and Sharp (2013, p. 900) also expressed that crowds were overwhelming, as well as being in social situations in which attempting to focus on "body language, speech and emotional cues simultaneously" caused overload. Gurbuz et al. (2018) investigated experiences of university students with ASD and reported that over half of the participants with ASD described experiencing sensory overload, which affected academic performance and participation in social activities, for example when faced with the noise and crowds at lectures. Jones et al. (2003) stated that overloading of the senses was reported as being due to having to use more than one or two senses at a given time. For example, one individual described that too much information came in through his eyes and ears at the same time if he was looking at and listening to something (Jones et al., 2003). Similarly, Chamak et al. (2008) reported an ASD author describing how sharp sounds and bright lights together would overload her senses.

*Hyposensitivity and hypersensitivity.* Davidson (2010) cited one author as describing some senses as either 'hypo' meaning they are at too low a level to be perceived, or 'hyper' meaning that they are at a heightened level which creates an overload. Elwin et al., (2013) used the terms hypo-reactive and hyper-reactive. Hyper-reactivity includes noticing small or unusual aspects of stimuli (Elwin et al., 2013).

In relation to hyposensitivities, a particular issue reported by individuals with ASD has been hyposensitivity to pain in terms of having high pain thresholds or insensitivity to pain (Chamak et al., 2008; Elwin et al., 2012; Robledo et al., 2012). Although, Robledo et al. (2012) also noted an instance of a participant being hypersensitive and over-reacting to painful stimuli. Elwin et al. (2013, p. 236) stated that the majority of participants were "long-term hypo-reactive to specific stimuli" and for example did not feel thirst or hunger, whereas a few individuals experienced "being temporarily hypo-reactive", for example shifting from being extremely sensitive to sounds to not hearing anything at all. Similarly, Elwin et al. (2012) reported instances of authors describing hyposensitivity to hunger or thirst and being temporarily hyposensitive to sounds. Another issue related to hyposensitivity is that of cravings for specific stimuli and has been expressed as the need for body pressure (Elwin et al., 2012; Chamak et al., 2008), preferences for deep pressure rather than light pressure (Robledo et al., 2012), and carrying a heavy bag to induce a sensation of heavy pressure (Smith & Sharp, 2013). However overall, studies based on first-hand accounts have noted considerably more reports of hypersensitivities than hyposensitivities, relating to multiple sensory modalities (Elwin et al., 2012; Elwin et al., 2013; Robledo et al., 2012). These will be discussed below along with data relating to each of the other primary sensory modalities.

## Single senses.

*Hearing*. High-pitched sounds have been reported to be particularly aversive to individuals with ASD. These have included: aversion to high-pitched electronic noises (Elwin et al., 2013); sudden, high-pitched sounds such as phones ringing, people whistling, hand driers, and crying babies (Ashburner et al., 2013); loud, high-pitched sounds, including sirens and whistles; and sudden noises such as car horns, doors shutting, and fireworks (Jones et al., 2003). Robledo et al. (2012, p.5) noted an instance of a participant with ASD disliking high-pitched noise along with certain people's

voices, describing it in terms of 'static' in the sound. A number of other individuals with ASD have also described human voices and the sounds of talking and conversation as aversive (Ashburner et al., 2013; Davidson, 2010; Jones et al., 2003). Other auditory experiences described have included experiencing discomfort when hearing deep sounds, which were sometimes perceived as extremely loud (Jones et al., 2003), and feeling frightened at the sound of low frequency notes and frequency shifts (Cesaroni & Garber, 1991). Many of the studies have also reported individuals describing certain sounds as being 'painful' (Ashburner et al., 2013; Chamak et al., 2008; Davidson, 2010; Jones et al., 2003; Robertson & Simmons, 2015; Robledo et al., 2012). Elwin et al. (2012) reported reactions to strong or unexpected stimuli, for example, one author who described hearing the sound of a foghorn as excruciatingly painful and subsequently covering her ears and screaming.

Experiencing 'premonitions' of intense auditory stimuli was noted by both participants in the study by Cesaroni and Garber (1991, p. 306), with one participant stating that loud noises were "not necessarily disturbing because they did not seem unexpected", and the other reportedly able to hear a train 5 to 10 minutes prior to it passing his home. Similarly, Smith and Sharp (2013) also noted one participant stating that he could hear trains which were passing 5 miles away, as well as a cockerel 2 miles away. The ability to hear very faint sounds has also been described in other accounts from individuals with ASD. Elwin et al. (2013) described a participant reporting she could hear noises or notice sounds that others did not seem to hear, such as the sounds from a fridge or other gadgets. Davidson (2010, p. 309) also noted one author hearing sounds such as the "hum of electrical apparatus" that others did not notice. Similarly, Elwin et al. (2012) stated that one author had a strong sensitivity to sounds, reportedly being able to hear his classmates at school calling his name from across the room, as softly as they could. In terms of pleasurable sounds, a number of individuals with ASD have expressed that listening to music was particularly enjoyable (Ashburner et al., 2013; Robertson & Simmons, 2015) or using enjoyment of music as a calming or grounding technique (Smith & Sharp, 2013).

*Vision.* A common finding among many of studies based on first-hand accounts is that participants reported being sensitive to light (Chamak et al., 2008; Davidson, 2010; Elwin et al., 2012; Jones et al., 2003; Robertson & Simmons, 2015; Robledo et al., 2012). Experiences described include having difficulty tolerating fluorescent lights (Chamak et al., 2008; Davidson, 2010; Robertson & Simmons, 2015; Robledo et al., 2012), and strong aversions to flashing and strobe lights (Chamak et al., 2008; Elwin et al., 2012). Instances were reported of individuals with ASD stating that certain bright colours, such as red, were "painful" to look at (Jones et al., 2003, p. 115) or "would hurt" (Robertson & Simmons, 2015). A number of individuals have described being adversely affected by sunlight, particularly in terms of walking outdoors into sunlight or having to adjust to bright light from darkness (Ashburner et al., 2013; Chamak et al., 2008; Elwin et al., 2012; Robertson & Simmons, 2015; Robledo et al., 2012), while others have expressed their need for bright, sunny days (Robledo et al., 2012).

Some participants have reported enjoying bright coloured lights such as traffic lights (Robledo et al., 2012; Smith & Sharp, 2013) and city lights (Ashburner et al., 2013). Elwin et al. (2012) also noted one author's strong positive reaction to colour and shiny surfaces. A fascination for visual patterns has been described, including various patterns in the general environment, as well as numerical patterns, though some individuals also found them to be distracting (Ashburner et al., 2013; Elwin et al., 2013; Robertson & Simmons, 2015).

*Touch.* A number of individuals with ASD have reported disliking the sensation of being touched, describing it as uncomfortable and overwhelming (Cesaroni & Garber, 1991; Chamak et al., 2008; Davidson, 2010; Elwin et al., 2012; Jones et al., 2003; Robertson & Simmons, 2015; Robledo et al., 2012). Many noted particular difficulties with being touched by those they did not know well or trust (Cesaroni & Garber, 1991; Robledo et al., 2012), with one individual describing having to hug strangers as "really nasty" (Elwin et al., 2013, p. 237), and another describing hugging as "painful" (Robertson & Simmons, 2015).

Chamak et al. (2008) reported that many ASD authors expressed having aversions to certain types of clothing. Similarly, other experiences narrated have included disliking wearing uniforms with plastic stitching (Ashburner et al., 2013), aversions to jewellery, metal buttons, and restrictive belts and ties (Davidson, 2010), and preferences for cotton fabrics and loose-fitting garments (Robledo et al., 2012). However, Ashburner et al. (2013) noted that individual preferences could be varied, with one participant disliking the feel of fabrics such as cotton and wool, and another enjoying the feel of wool and heavy blankets. In contrast to the findings of other studies, this particular participant also reported enjoying hugs (Ashburner et al., 2013), highlighting the variability among individuals.

Tactile sensitivity was also apparent in described aversions to being in the rain (Ashburner et al., 2013), and the sensation of water droplets while showering (Davidson, 2010). Chamak et al. (2008) reported that many ASD authors narrated a dislike of washing. However, Davidson (2010) noted that bathing preferences varied among ASD authors, citing one who enjoyed being surrounded by water in a bath, and another who disliked baths and preferred quick showers.

In the literature, a common finding was that many individuals expressed that the sensation of brushing or having their hair cut as being aversive (Chamak et al., 2008; Kirby et al., 2014; Robledo et al., 2012). One participant stated that brushing her hair was painful as her scalp was highly sensitive (Robledo et al., 2012). Kirby et al. (2014) also reported that some participants associated pain with hair brushing, in addition to brushing teeth and walking on sand.

*Smell.* A few studies have reported findings regarding olfactory issues. Davidson (2010, p. 309) stated that one ASD author described significant aversions to the smell of hair when it was "cooking" under electric curlers or a hair dryer in addition to hairspray, and cigarette smoke, while another could not tolerate the fragrance of perfume. Difficulties tolerating the smells of perfume, cleaning products and certain food smells have been noted (Ashburner et al., 2013; Elwin et al., 2013; Jones et al., 2003; Robertson & Simmons, 2015). Ashburner et al. (2013) stated that participants had wide ranging and differing opinions on what they found enjoyable: vanilla incense, animal smells, kitchen smells and barbeque smells. Smith and Sharp (2013) reported a participant's account of being so sensitive to smells, that she could recognise people by their fabric conditioner.

*Taste*. Both Chamak et al. (2008) and Davidson (2010) reported that food was a problem for many ASD authors, particularly with regard to taste, appearance, texture, and smell. Experiences ranged from finding tomato strongly aversive, to only being able to eat bland foods and having to take marinated chicken to the bathroom to wash off hot sauce (Davidson, 2010). Common dislikes voiced by two of the participants in the study by Ashburner et al. (2013), were the flavour of toothpaste and spicy foods, with one participant enjoying only a limited range of foods. Jones et al. (2003, p. 115) stated that one person found the texture of foods particularly aversive, describing

shrimp as "slimy", and jelly as "food that wiggles". Similarly, Robertson and Simmons (2015, p. 576) also noted certain participants who had difficulty with food textures, such as the "bursting" sensation of peas, grapes or mussels, as well as the mixing of food textures. They stated that some participants reported eating one type of food at a time as a coping strategy (Robertson & Simmons, 2015). Smith and Sharp (2013, p. 904) noted one participant voicing that when tasting olive oil he was able to taste "the olive and other fruit oils used to make it", and was able to make positive use of his sensitivities in his vocation as a chef.

*Movement.* Several studies have explored first-hand perspectives in relation to movement and ASD. Some of these have documented individuals' described difficulties with motor control (Bertilsson et al., 2018; Chamak et al., 2008; Elwin et al., 2013; Robledo et al., 2012). Difficulties reported have included an inability to stay still while feeling nervous or excited, and problems initiating or stopping movements (Robledo et al., 2012). Both Robledo et al. (2012) and Elwin et al. (2013) also noted that participants described challenges in co-ordinating and combining multiple movements or tasks, though Elwin et al. also stated that a couple of participants expressed having advanced motor abilities in terms of being particularly good at tasks involving precision and detail. Some participants reported paradoxical motor abilities, for example, being able to embroider but also "spilling and dropping things in everyday routines" (Elwin et al., 2013, p. 238). Bertilsson et al. (2018) investigated the perceived experiences of body and movements among young adults with ASD. They stated that participants expressed feelings of not being in control of their bodies, co-ordination difficulties, and sensing differences in function between the left and right sides of the body (Bertilsson et al., 2018). Similarly, Welch et al. (2018) reported that the written memoirs of minimally verbal youth with ASD indicated difficulties controlling their

bodies, for example starting and stopping movements, which they attributed to consequent social difficulties.

Ashburner et al. (2013) reported participants describing high levels of movement seeking and enjoyed movement sensations such as jumping on trampolines, riding roller coasters, rollerblading, and spinning around. Ashburner et al. also noted that the need for body movement was a coping strategy for all participants. Also, whereas Ashburner et al. (p. 176) reported instances of participants enjoying "balancing", both Elwin et al. (2013) and Robledo et al. (2012) stated that some participants expressed difficulties with balance.

*Proprioception.* A limited number of studies based on first-hand accounts have described experiences relating to proprioception. Robledo et al. (2012, p. 7), stated that some participants had issues with proprioception, with one reporting having difficulty "knowing where her body was in space". Elwin et al. (2012) also stated that one ASD author described being unable to feel where various body parts were in relation to each other. Bertilsson et al. (2018) reported that participants expressed difficulties being consciously aware of what was happening in their bodies and difficulties experiencing the body as whole. Welch et al. (2018, p. 5) noted one participant describing feelings of detachment from her body in terms of having "no clear sensation of where my arms and legs are attached."

*Summary of qualitative research based on first-hand accounts.* Overall, evidence from first-hand accounts suggests sensory hypersensitivities are most commonly described. This is in contrast to findings from parent survey report studies, which have indicated greater under-responsivities (Ben-Sasson et al., 2009). Also, a number of studies reported that hypersensitivities related to hearing, vision, and touch were described most commonly (Elwin et al., 2012; Elwin et al., 2013; Robledo et al., 2012). Fewer and more variable experiences were voiced in relation to taste, olfaction, proprioception, and movement, in comparison to reported visual, auditory, and tactile experiences. However, aversions to smells and foods that were noted, were described as being particularly strong (Davidson, 2010; Jones et al., 2003), and could cause physical discomfort (Robertson & Simmons, 2015). Also, studies investigating movement among individuals with ASD have commonly reported individuals describing difficulties controlling their bodies. Finally, multi-sensory experiences such as difficulties with sensory overload and integration have been described.

Overall, the reviewed studies based on first-hand accounts appeared to have varying methodological issues, including unverified ASD diagnosis (Jones et al., 2003), participant co-morbidities (Ashburner et al., 2013), the representativeness of samples such as published ASD authors (Chamak et al., 2008; Davidson, 2010; Elwin et al., 2012), or the need to ask probing questions or prompt responses during interviews when participants have had communication difficulties (Elwin et al., 2013; Kirby et al., 2014). However, the high rate of co-morbid conditions among individuals with ASD makes it difficult to access participants with a singular diagnosis of ASD and in order to ensure inclusion of less verbal participants, more defined interview questions may be unavoidable. However, the strength of findings from these studies has been increased when researchers have attempted to ensure verified diagnosis, the use of sufficient quotes, triangulation of data, and the researchers' engagement with reflexivity (Ashburner et al., 2013; Kirby et al., 2014; Smith & Sharp, 2013).

### Sensory experiences in the general population.

A number of studies, particularly more recently, have examined the relationship between autistic traits and sensory challenges in the general population. Grinter et al. (2009a) investigated global visual processing among neurotypical adults, and reported that individuals with high levels of autistic traits displayed greater accuracy and speed on the Embedded Figures Test (EFT: Witkin et al., 1971) and reduced performance on a global motion processing task. Grinter, Van Beek, Maybery, and Badcock (2009b) similarly found that individuals with high AQ scores had superior performance on the EFT and Block Design test in comparison to those with low AQ scores. Also in relation to visual processing, Sutherland and Crewther (2010) reported that individuals scoring high on the AQ had greater global visual perception difficulties. Bayliss and Kritikos (2011) investigated sensitivity to perceptual load, or ability to prioritise processing relevant sensory inputs. They reported that individuals with high levels of autistic traits experienced greater interference effects when the perceptual load was increased (Bayliss & Kritikos, 2011).

Stewart and Ota (2008) investigated relationships between auditory speech perception and autistic traits among 55 university students through testing of phonetic categorisation shifts (via presentation of stimuli on a word to non-word continuum). They reported that those with higher AQ scores were less infuenced by lexical information and more attuned to actual acoustic differences, whereas other participants were biased towards responding with real words. Furthermore, Stewart and Ota (2008) reported that this was related to the attention switching and imagination subscales of the AQ.

Stafford, Tsang, López, Severini, and Iacomini (2017) reported that food neophobia (reluctance to try new foods) was correlated with higher levels of autistic traits. However, autistic traits were not found to be related to olfactory sensitivity, suggesting that the correlation was unlikely to be mediated by olfactory sensitivity (Stafford et al., 2017). In relation to touch, an fMRI study by Voos, Pelphrey, and Kaiser (2013) reported that high levels of autistic traits among 19 neurotypical adult females, were correlated with aversions to social touch. Participants with higher levels of autistic traits also displayed reduced activation in the right superior temporal sulcus and right orbitofrontal cortex regions of the brain in response to slow, gentle touch. Voos et al. (2013) proposed that this indicated a diminished response to social stimuli, or disruption in 'social brain function'.

A number of studies have specifically investigated self-reported sensory processing in relation to autistic traits in the broader population. Robertson and Simmons (2012) found that among 212 individuals with and without a diagnosis of ASD (primarily from the UK), autistic traits, as measured by the AQ, were significantly correlated with the Glasgow Sensory Questionnaire (GSQ) (r = .78). Horder, Wilson, Mendez, and Murphy (2014) also found a significant positive correlation between the AQ and GSQ (r = .48) among a sample of 772 staff and students recruited from a London university. Significant correlations were also found between the AQ and two other sensory measures: the Adult/Adolescent Sensory Profile (AASP) (r = .34) and the Cardiff Anomalous Perceptions Scale (CAPS) (r = .33) (Horder et al., 2014). Similarly, Takayama et al. (2014) reported positive correlations between sensory atypicalities, as measured by a Japanese version of the GSQ, and autistic traits among 70 neurotypical adults in addition to 64 adults with ASD. Tavassoli, Miller, Schoen, Nielsen, and Baron-Cohen (2014) utilised a newly developed measure, the Sensory Perception Quotient, to assess sensory processing and also found that higher levels of sensory atypicalities were correlated with higher levels of autistic traits among both neurotypical adults and adults with ASD.

Amos et al. (2018) investigated relationships between sensory over-responsivity, anxiety, stress, and autistic traits, among 458 neurotypical adults. Autistic traits were assessed utilising the Broader Autism Phenotype Questionnaire (BAPQ; Hurley, Losh, Parlier, Reznick, & Piven, 2007). Amos et al. reported that higher levels of autistic traits were associated with greater sensory sensitivities, which resulted in increased levels of stress and anxiety. Similarly Mayer (2017) investigated autistic traits and sensory processing among 580 neurotypical adults and 42 adults with a diagnosis of high-functioning ASD from the UK, and reported that the level of sensory atypicalities positively correlated with autistic traits regardless of diagnostic status therefore providing further evidence of a similar pattern of sensory atypicalities were not significantly correlated with the attention to detail and imagination subscales of the AQ. Further, Taylor et al. (2018) examined associations between autistic traits and atypical sensory reactivity in a population of 12,419 Swedish twin pairs. They reported that the observed genetic overlap provided evidence of strong associations between autistic traits and atypical in a genetic link between the broader autism phenotype and sensory reactivity (Taylor et al., 2018).

Overall, results from these studies indicate that there is strong evidence for positive associations between sensory atypicalities and higher levels of autistic traits in the general population. Findings of superior performance on visual search tasks such as the EFT, difficulties in global visual perception, and increased susceptibility to interference effects among individuals with high levels of autistic traits, appear to mirror findings based on ASD populations. However, further research is necessary.

*First-hand accounts of sensory experiences among the broader autistic phenotype.* Robertson and Simmons (2018) conducted the first study investigating qualitative data in relation to sensory experiences among individuals within the general population with a range of autistic traits. They reported that overall, participants reported issues with visual, auditory, tactile, olfactory, gustatory, and proprioceptive stimuli (Robertson & Simmons, 2018). Hyper-reactivities to sensory stimuli, particularly in relation to auditory noise, were more commonly reported than hyporeactivities (Robertson & Simmons, 2018). In terms of problematic sensory experiences, individuals with high AQ reported more difficulties when in supermarkets or leisure centres, whereas low and medium scorers reported greater issues with crowds (Robertson & Simmons, 2018). Participants with medium to high AQ scores tended to have more problematic negative reactions due to sensory stimuli, and also differed in the coping mechanisms utilised, such as greater avoidance and increased preference for sensory based self-soothing strategies (Robertson & Simmons, 2018).

# Developmental changes in sensory experiences.

There are few studies that have been specifically aimed at understanding possible developmental changes in sensory experiences (Fecteau et al., 2003; Kern et al., 2006; Leekam et al., 2007). Leekam et al. (2007) investigated sensory experiences among children and adults with autism through interviewing carers, finding that 92.5% experienced sensory challenges, and that these persisted across age and ability levels. However, certain sensory symptoms were affected by age and intellectual ability (IQ). Significant group effects were found for dislike of 'gentle touch', which worsened with age, as well as for individual visual experiences (for example, getting 'unusually excited at seeing things spin'), which all improved with age and IQ (Leekam et al., 2007). Another finding was that the younger participants with lower intellectual ability tended to have difficulties across more sensory domains (Leekam et al., 2007).

Fecteau et al. (2003) also investigated developmental changes in symptoms of autism via interviewing carers of 28 verbal children and adolescents with autism aged between 7 and 20.4 years. Improvements were reported in the three diagnostically relevant domains for autism (social interactions, communication, and restricted interest and repetitive behaviour). In relation to sensory experiences, 78.3% of participants were reported to have sensory symptoms at the age of 5 years with approximately 39% reporting improvements over time, 61% reporting persistence of symptoms, and none reporting worsening of symptoms (Fecteau et al., 2003).

Kern et al. (2006) conducted a cross-sectional study of 104 persons with a diagnosis of autism aged between 3 and 56 years, matched to community controls. For participants with autism, the Sensory Profile (Dunn, 1999) was completed by someone known to the individual (such as a parent, carer, or familiar staff member), whereas 38% of the control group aged over 21 years completed the measure themselves (Kern et al., 2006). Findings included unusual auditory, visual, touch, and oral sensory experiences that were significantly different from controls (Kern et al., 2006). Similar to other studies, improvements in sensory difficulties were noted with age, apart from low threshold touch, which did not improve significantly (Kern et al., 2006). Another finding was a significant interaction between auditory and visual experiences, with auditory and visual sensitivity reducing with age for individuals with autism and increasing with age in the control group (Kern et al., 2006). Findings from these studies emphasise the need for further research into developmental shifts in sensory experiences and highlight the gap in literature in terms of data from first-hand accounts of both children and adults with ASD.

Sensory issues in relation to personality and behavioural factors: anxiety, intolerance of uncertainty, and inflexibility.

As discussed previously, a cross-sectional study by Amos et al. (2018) found that among the general population autistic traits predicted sensory over-responsivity which in turn produced higher levels of anxiety (Amos et al. 2018). Other studies have reported similar findings (Green et al., 2012; Horder et al., 2014; Robertson & Simmons, 2013). Lidstone et al. (2014) investigated the relationship between restricted and repetitive behaviours (RRBIs), a core feature of ASD, anxiety, and sensory experiences in children with ASD. RRBIs, as discussed earlier, are listed as the second major diagnostic criterion for ASD in the DSM-5, and symptom manifestations include stereotyped or repetitive motor movements, and/or insistence on sameness or inflexible adherence to routines (as well as restricted interests and hyper or hyporeactivities to sensory input) (APA, 2013). Findings were that anxiety was related to insistence on sameness, but not repetitive motor behaviours, and that this relationship was mediated by sensory avoiding and sensory sensitivity (Lidstone et al., 2014). Wigham, Rodgers, South, McConachie, and Freeston (2015) also reported that sensory sensitivities (both over and under responsiveness) were significantly associated with insistence on sameness and repetitive motor behaviours among children with ASD, and that these relationships were significantly mediated by anxiety and intolerance of uncertainty.

Intolerance of uncertainty has been defined as negative cognitive bias towards uncertainty, leading individuals to, for example, perceive situations such as unexpected events, as threats needing to be avoided (Freeston et al., 1994). Studies have shown that higher levels of intolerance of uncertainty, anxiety, and sensory sensitivities have been reported by caregivers of children with ASD than those of typically developing children (Boulter, Freeston, South, & Rodgers, 2014; Chamberlain et al., 2013; Neil, Olsson, & Pellicano, 2016). Neil et al. (2016) found that intolerance of uncertainty accounted for half of the variance in sensory insensitivities for children with ASD, with anxiety partially mediating this relationship, and that even after controlling for anxiety these factors remained significantly correlated. These findings suggest that intolerance of uncertainty and insistence of sameness have similar characteristics, such as aversion to changes and the need for predictability (Boulter et al., 2014; Chamberlain et al., 2013).

The persistent and rigid behavioural patterns and repetitive behaviours and/or interests associated with ASD have been thought to be associated with difficulties in responding flexibly to situations, for example, resistance to change, the need for routines, and pre-occupation with certain objects (Gökçen et al., 2014; Leung & Zakzanis, 2014). However, flexibility has been defined in various ways. Pennington and Ozonoff (1996) defined cognitive flexibility as a component of executive functioning reflected in the ability to shift between discrepant tasks and demands.

A literature review by Geurts et al. (2009) noted inconsistencies in findings of cognitive flexibility differences in individuals with ASD. Van Eylen et al. (2011) argued that studies utilising the Wisconsin Card Sorting Test (WCST; Grant & Berg, 1948) have consistently reported cognitive flexibility deficits, whereas studies that have used measures involving a higher level of explicit instructions have not found evidence of these deficits. Van Eylen et al. (2011) developed a task with similarly explicit instructions to the WCST, which focused on measuring switching (directly related to cognitive flexibility) and found that individuals with ASD did have difficulties with cognitive flexibility in comparison to typically developing controls. However, a quantitative review into the sensitivity of cognitive flexibility measures, by Leung and Zakzanis (2014), concluded that though the WCST had high sensitivity, none of the measures were reliable in differentiating between individuals with ASD and controls. Further, they noted that these measures may have limited ecological validity, particularly due to documented behavioural observations of inflexibility amongst individuals with ASD in everyday settings (Leung & Zakzanis, 2014). For example, studies utilising the Behavior Rating Inventory of Executive Function (BRIEF; Gioia et

al., 2000; BRIEF-A: Roth, Isquith, & Gioia, 2005), an informant response form with versions for both youth and adults that assesses behavioural executive functioning difficulties in the home environment, have indicated that individuals with ASD have difficulties being flexible in daily life (Gioia, Isquith, Guy, & Kenworthy, 2002; Mackinlay, Charman, & Karmiloff-Smith, 2006). Leung and Zakzanis (2014) indicated that the shift subscale of the self-report version of the BRIEF (assessing the ability to transition between situations and activities) demonstrated strong sensitivity in discriminating between clinical and normative populations, though they noted these results were based on a single study. However, a recent study by Albein-Urios et al. (2018) also found that the shift subscale of the BRIEF-A behavioural self-reports predicted cognitive flexibility difficulties in a non-clinical population whereas laboratory-based tasks produced mixed results.

Some have suggested that difficulties with cognitive flexibility are not limited to the domain of restricted and repetitive interests but may also underlie social interactional symptoms (Yoshida et al., 2010) such as problems adapting to social rules or adjusting social behaviours appropriately (Geurts et al., 2009). Gökçen et al. (2014) investigated the relationship between the ability to process socioemotional cues and cognitive flexibility in the general population. Findings indicated that participants with higher levels of autistic traits displayed poorer performance on both the cognitive flexibility task (WCST), and the social cognition task (Revised Reading the Mind in the Eyes Test (EYES; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001), and that performance scores on both tasks were positively related.

While existing research has focused on laboratory-based tasks and behavioural self-reports of cognitive flexibility, limited research exists into the relationship between personality-based measures of flexibility and ASD traits. Evidence has suggested that

ASD traits in the general population are associated with Five Factor Model (FFM) constructs: higher neuroticism, lower extraversion, and lower agreeableness (Austin, 2005; Wakabayashi et al., 2006). Other existing measures similarly assess these constructs. For example, the Hexaco Personality Inventory (HEXACO-PI: Lee & Ashton, 2004) includes the facet level Flexibility scale, which assesses an individual's willingness to compromise and cooperate with others. Individuals who score low on flexibility are characterised as rigid in their beliefs and tend to be argumentative, whereas those with higher levels of flexibility are more adaptive towards other's suggestions. The Flexibility scale is a subscale of the HEXACO agreeableness domain and includes items such as: 'Adjust easily', 'Am hard to convince', 'Get upset if others change the way that I have arranged things', and 'Am hard to reason with', which give an indication of an individual's ability to adjust to social rules. As discussed, evidence suggests that higher levels of autistic traits are associated with lower levels of agreeableness (Austin, 2005; Wakabayashi et al., 2006). Therefore, it could be hypothesised that scores indicating low levels of trait flexibility would be associated with higher levels of ASD traits. However, how the construct of trait flexibility relates to sensory sensitivities, anxiety, and autistic traits, and the interrelationships between these constructs along with co-occurring mental health diagnoses, is relatively unknown. Findings could have important implications for understanding sensory experiences in relation to ASD, and also in the potential development of evidence-based intervention strategies for individuals struggling with sensory challenges on a daily basis.

### **Theoretical Frameworks**

A number of theories have been developed in relation to autism, with a view to understanding core difficulties associated with ASD, and perceptual processing styles. The Theory of Mind hypothesis (Baron-Cohen, Leslie, & Frith, 1985) has been highly influential in terms of attempting to explain social interactional symptoms of autism through the proposition that individuals with ASD have difficulty making inferences about the mental states of others. However, criticisms have been that this theory does not account for autistic symptoms that become apparent in children earlier than the development stage at which 'theory of mind' develops, and also does not extend to providing explanations for other core areas of difficulty, such as in the domain of restricted or repetitive behaviour patterns (Tager-Flusberg, 2007). Other widely known theories are the weak central coherence theory (WCC) (Frith, 1989; Happé & Frith, 2006) and the enhanced perceptual functioning theory (EPF) (Mottron, Dawson, Soulières, Hubert, & Burack, 2006), both focused on non-social and perceptual cognitive aspects of autism.

The weak central coherence theory (WCC), also known as the central coherence theory, proposes that individuals with ASD have a perceptual processing style that gives preference to parts or details rather than the global picture (Frith, 1989; Happé & Frith, 2006). This leads to difficulties in being able to understand context, but also facilitates strengths such as higher performance than typically developing individuals on detail orientated tasks such as the Embedded Figures Test (involving detection of a shape within a larger figure) (Shah & Frith, 1993).

The enhanced perceptual functioning (EPF) theory (Mottron et al., 2006), also suggests that differences in non-social perceptual processing in ASD, are characterised by local processing of visual and auditory stimuli. However, Mottron and Burack (2001) stated that the EPF theory extended the WCC by accounting for common instances of relative strengths or enhanced performance by individuals with ASD on a wide range of tasks, such as pattern recognition or reproduction of shapes. In addition, the tendency towards local bias is explained as being a compensatory mechanism for difficulties processing higher order tasks rather than being indicative of deficits in global processing (Mottron & Burack, 2001). Lower level processes are defined as those processed by the senses in localised areas of the brain, for example physical parameters of visual perception such as colours (Mottron & Burack, 2001). Higher level processes are complex, not domain specific, and are able to be processed through multiple pathways, for example facial perception or semantic memory (Mottron & Burack, 2001).

Mottron et al. (2006) updated this theory to suggest that typically developing individuals engage in an automatic mandatory global bias even when it interferes with task performance, whereas higher-order control is not mandatory in individuals with ASD. Therefore, individuals with ASD are neither biased towards processing of local information nor global information. However, evidence for these theoretical frameworks has been inconsistent. Van der Hallen, Evers, Brewaeys, Van den Noortgate, and Wagemans (2015) conducted a meta-analysis of studies investigating local and global visual processing in ASD. Findings suggested that individuals with ASD are slower in global-order perception than typically developing individuals, especially when there is interference from incongruent information at a local level. Evidence did not support global processing deficits nor enhanced local visual processing among individuals with ASD (Van der Hallen et al., 2015). A recent overview of research into local versus global processing in autism by Simmons and Todorova (2018), suggested that though more rigorous studies have been conducted in the past few years, the debate on local versus global processing still largely remains unresolved. They stated that there continues to be a discrepancy between subjective accounts of perceptual experience and laboratory-based measures of perceptual

performance, and that further exploration of these differences at the individual level could provide greater understanding of perception in ASD (Simmons & Todorova, 2018).

Pellicano and Burr (2012) argued that there is a lack of evidence between theoretical constructs and the full range of actual sensory atypicalities reported, as well as other non-social symptoms experienced by individuals with ASD. Existing theories have not been able to account for the wide variation and fluctuations of these experiences among individuals (Pellicano & Burr, 2012). Therefore, Pellicano and Burr (2012) instead proposed that the ways in which individuals cope with the unpredictability of environmental events is central to understanding sensory perceptual atypicalities in ASD. This Bayesian inference approach refers to the probabilistic representation of beliefs, whereby existing beliefs (prior distribution) are updated with new information (likelihood distribution) to form a new belief (posterior distribution) (Palmer, Lawson, & Hohwy, 2017). Theories based on this approach are collectively known as predictive coding theories, which aim to understand cognition in ASD as a product of perceptual or learning errors thus taking a computational view from which testable models can be constructed (Haker, Schneebeli, & Stephan, 2016). Central to these theories is the idea that the predictions are continuously generated by the mind based on environmental input and prior learning, however prediction errors can occur when an individual's predictions do not match actual input (Evers, Van der Hallen, Noens, & Wagemans, 2018). Prediction errors may be relevant, thereby resulting in predictions being updated, or considered irrelevant, in which case an individual learns to ignore them (Evers et al., 2018).

A number of researchers have proposed that difficulties in this predictive coding process or Bayesian inference underlies sensory atypicalities in ASD (Lawson, Aylward, Roiser, & Rees, 2014; Pellicano & Burr, 2012; Van de Cruys et al., 2014). Pellicano and Burr (2012) suggested that atypicalities in the formation of 'priors' among individuals with ASD result in broader priors or 'hypopriors', resulting in atypical sensory experiences. Difficulty with generating precise top-down predictions (e.g., understanding context) (Lawson et al., 2014; Pellicano & Burr, 2012) or discriminating between relevant or irrelevant prediction errors (Van de Cruys et al., 2014), is thought to contribute to a tendency towards more local orientated processing in ASD. According to Pellicano and Burr (2012), this could result in a number of effects: (1) more accurate perception based on reality rather than past experiences, (2) difficulty in situations where priors resolve ambiguity, for example, when interpreting shadows, and (3) hypo-priors cause a mismatch between expectations and measurement leading to sensory overload.

Skewes and Gebauer (2016) applied Bayesian inference theory in an investigation of auditory localisation, based on the premise that individuals with ASD may not be utilising prior perceptual knowledge optimally to make inferences about the locations of sounds, which could explain sensory atypicalities such as difficulty perceiving the incoming direction of sounds. Findings confirmed that adults with ASD tended to display poorer integration of prior information when making judgments about the spatial sources of sounds, than neurotypical adults. However, Skewes and Gebauer (2016) noted that differences in the flexibility of individuals to modify responses according to rewarding feedback during the task may have contributed to the results.

Powell, Meredith, McMillin, and Freeman (2016) investigated the Bayesian proposition that individuals with autism have flatter prior distributions than neurotypical individuals, and that there is systematic variation in features of the priors among individuals. They examined motion perception in relation to autistic traits and sensory thresholds among the general population. Results supported the hypothesis, in that individual differences in perceived speed (during two tasks involving eye movement and low contrast) were predicted by differences in sensory thresholds and autistic traits. However, Powell et al. stated that models based on autistic traits or thresholds resulted in far poorer predictions, highlighting the importance of considering individual differences in priors and sensitivities, for example individuals with autism may display varying behaviours even if their priors are the same due to differing sensitivities. This suggests that the relationships between autism, priors, and perception and cognition are complex (Powell et al., 2016).

Pellicano and Burr (2012) stated that the advantage of a Bayesian framework is that it provides an explanation that encompasses non-social aspects of autism as well as sensory perceptual strengths and weaknesses, in addition to providing hypotheses that are testable. It also could account for an individual having both hypersensitivities and hyposensitivities, in that these sensory experiences depend on the predictability of context and an individual's prior knowledge (Pellicano & Burr, 2012; Van de Cruys et al., 2014). Therefore, sensory atypicalities in ASD are thought to be a result of how these environmental sensory inputs are interpreted rather than due to actual impairments in sensory processing (Pellicano & Burr, 2012).

The Bayesian framework is a promising approach to understanding sensory atypicalities in ASD. However, Palmer et al., (2017) noted that the theory is in its early stages and that other areas that need to be considered are developmental trajectories, the mechanisms underlying precision modulation, and the location of primary and secondary differences in the brain. There is currently insufficient operationalisation and definition of concepts such local and global visual processing among the literature (Simmons & Todorova, 2018; Van der Hallen, 2015) and moving forward, further clarification of these processes is necessary. Importantly, Tager-Flusberg (2007) emphasised that no single theory has been sufficient to account for the wide range of symptoms apparent in autism, and that an understanding of individual variability amongst those with autism is key to gaining further insight into ASD.

#### Conclusion

Overall, it is evident that a significantly high proportion of individuals with ASD experience sensory atypicalities. Despite this there seems to have been confusion regarding the impacts of these experiences, as seen in the exclusion and re-inclusion of sensory symptomatology in the DSM. The spectrum view of ASD, and evidence of the broader autism phenotype has led to investigations of autistic traits in the general population and development of screening tools such as the AQ. There has been renewed focus on sensory processing in ASD, since the re-inclusion of sensory symptomatology in the latest version of the DSM. Evidence has suggested that individuals with ASD display superior performance on tasks related to visual search, such as the EFT (Cribb et al., 2016), and pitch perception (O'Connor, 2012) in comparison to typically developing controls. Overall however, findings from empirical studies pertaining to sensory modalities in ASD, have not resulted in clear understandings of sensory atypicalities or underlying processes. Similarly, no singular theory has been fully able to explain sensory experiences in ASD, though the more recent Bayesian approach has appeared to be more promising. These issues have largely been attributed to high rates of heterogeneity among individuals with ASD. Therefore, it is argued that understanding individual variability through examination of trait level characteristics not widely researched, such as trait anger, introversion, collecting, and inflexibility, could assist to build a clearer picture of autism or the broader autistic phenotype. Furthermore, studies based on first-hand accounts thus far

have indicated that sensory atypicalities, particularly related to visual, auditory, and tactile difficulties, have substantial negative impacts on individuals with ASD (Elwin et al., 2012; Elwin et al., 2013; Robledo et al., 2012). Only one study has qualitatively investigated sensory experiences among the broader autism phenotype and general population (Robertson & Simmons, 2018). Therefore, further exploration of sensory experiences among individuals with widely varying levels of autistic traits, could allow greater understanding of the variations and commonalities among these experiences, as well as key challenges, and consequently the development of appropriate management strategies.

Part I of this program of research, aimed to gain an experiential understanding of sensory experiences and ASD and will be presented in the following two chapters. The next chapter presents study one, a systematic review of studies based on qualitative data from caregivers of individuals with ASD. Following this, the findings from study two, a qualitative examination of first-hand accounts from individuals with a verified diagnosis of ASD will be discussed. The aim of studies one and two were to provide a foundation to understanding sensory atypicalities, many of which have strong impacts on children with ASD and their families (Ashburner et al., 2013; Kirby et al., 2014; Smith & Sharp, 2013). Findings were expected to inform the three studies in Part II, which aimed to explore autistic traits in the general population in relation personality characteristics as well as sensory experiences. The purpose of this was to gain a clearer understanding of individual variability in the broader autism phenotype, and greater knowledge of associations between selected traits and sensory experiences. The results from Part II will be presented in the latter chapters of this thesis. The final chapter will review and discuss results including limitations, implications, and clinical applications of findings.

# Chapter 3: Part I – Study One, Caregiver Perspectives of Sensory Experiences and ASD

The current chapter will discuss the findings of study one, which comprised a systematic review of studies based on qualitative caregiver reports of sensory experiences. To the author's knowledge, a review of this nature had not previously been conducted in the academic literature. The purpose of synthesising qualitative data across studies along with a critical evaluation of studies in this area, was to gain an understanding of the types of sensory experiences observed by caregivers of individuals with ASD. It was also expected to indicate directions for future research and provide further information that could potentially be utilised to tailor effective management and environmental strategies. Therefore, this systematic review aimed to address the research question: 'What are the key areas of concern described by caregivers of individuals with ASD in relation to sensory experiences?'

#### Method

The systematic literature search employed databases encompassing psychological, medical, health, and behavioural science fields: PsycINFO, Psychology and Behavioral Sciences Collection, Health Source: Nursing/Academic Edition, PsycARTICLES, MEDLINE®, Current Contents Connect®, SciELO Citation Index, Web of ScienceTM Core Collection, Sage Journals Online, and ProQuest (for grey literature). Search terms used were broad and truncated, including combinations of the keywords 'sensory\*' AND 'autism\*' AND 'parent\*' AND 'qualitative' OR 'autistic\*' OR 'asperger\*'. Search results were refined to include only qualitative research using the Methodology option in EBSCO host, or by adding the search term AND 'qualitative'. All databases were searched from the date of inception until May 2016. After duplicates were removed, articles were screened according to title and abstract to assess relevancy and a full text review of articles was conducted. Reference lists were scanned for studies that may have been missed in the database searches. Google Scholar was utilised only as an additional check for any missed articles, since recent research has not recommended it for systematic reviews due to changing content, changing search algorithms, and issues related to span of coverage (Anders & Evans, 2010; Bramer, Giustini, & Kramer, 2016). The selection process, including the number of articles reviewed at each stage, is illustrated in Figure 3.1. All stages of the review (literature search, screening, and data extraction) were conducted by the author. The primary supervisor replicated the search and reviewed the screening and data extraction procedures to maximise analytical rigour.

# **Inclusion and Exclusion Criteria**

Inclusion criteria were that studies were (a) based on caregiver reports on the experiences of individuals with ASD, (b) contained qualitative data on sensory experiences, and (c) the data was speech based or textual. Studies were excluded if data was solely drawn from survey-based responses (for example, Likert scale responses), the article was a review paper rather than a study, or the majority of caregivers in the study were reporting on the experiences of individuals with co-occurring conditions or disabilities in addition to ASD (such as Down Syndrome).

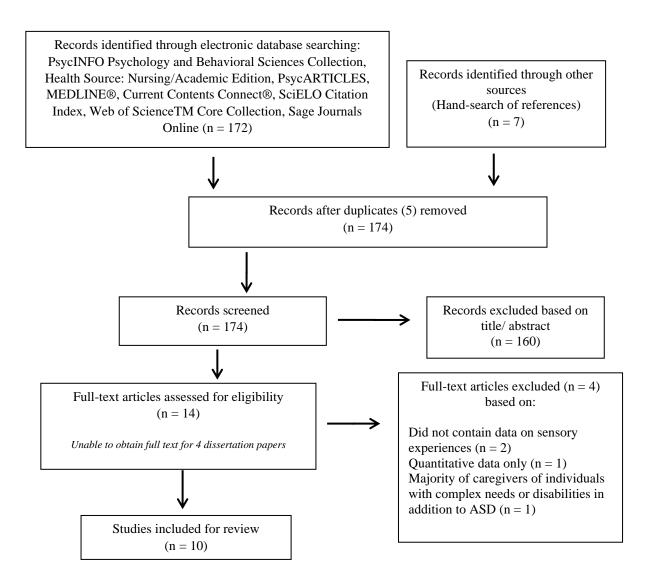


Figure 3.1. Flowchart of the literature selection process

#### **Data Extraction and Analysis**

Key information from each study including participant details, recruitment methods, qualitative methods, and findings, was extracted. The quality of each study was assessed independently by the research team using the 10-item Critical Appraisal Skills Program (CASP) Checklist for Qualitative Research (Public Health Resource Unit, 2013). Raters assigned one point for each criterion being met, with the highest possible quality rating score for a study being 10. Scores 9 and above were regarded as Excellent (7-8 Good; 5-6 Fair; < 5 Poor). Data analysis involved synthesising findings into themes, based on the principles of thematic analysis (Braun & Clarke, 2006). Findings were numbered lineby-line and sorted into categories based on common findings, which allowed identification of patterns in the data and the emergence of a final number of themes. To maintain analytical rigour, the research team critically discussed final themes to verify they reflected the original findings of studies.

#### Results

Ten studies were identified for inclusion in the review that met all of the inclusion criteria. Studies were conducted from 2008 onwards, with three being published in 2015. All studies utilised qualitative data collection methods, primarily semi-structured interviews, with two employing surveys with free response questions. The studies encompassed reports from over 270 primary caregivers of 243 individuals with ASD. Key features of the reviewed studies, including citation, study characteristics, sample description, strengths, notable limitations, and quality ratings are summarised in Table 3.1

Citation	Aim	Data Collection and Analysis	Sample and Recruitment	Strengths	Notable Limitations	Quality Rating
Bagby et al. (2012)	To explore how sensory experiences of children	Open-ended interviews	N = 7 (5 females, 2 males)	Diagnosis verified.	No notable limitations.	8.5-9.5 (Good to
	with and without autism affect family	(20 - 70 mins), via	*(6 parents of typically developing)	Clear form of data; type of interview questions		Excellent)
	occupations.	phone or face-to-face	12 children aged between 2 -8 years.	specified.		
			Autistic disorder (6), typically developing (6)	Triangulation; more than one analyst.		
		Grounded		-		
		theory	North Carolina, USA	Reflexivity; field notes throughout data collection,		
			Participants with autism recruited using a university based	journaling during coding process, and debriefing		
			state-wide research registry.	meetings with co-authors.		
			Convenience sampling of typically	6		
			developing subjects through university			
			mailing lists, and word-of-mouth.			
Bultas et al.	To (a) evaluate	Online parent	N = 59 parents (all female).	Diagnosis verified.	Diagnosis based on	8-9.5
(2015)	a tool designed to	surveys with	*(54 Health care providers)		parent report.	(Good to
	facilitate	free response		Triangulation; more than	X 1 C	Excellent)
	communication during health care encounters	and open- ended	ASD	one analyst.	Lack of parent demographics.	
	(b) to conduct a needs	questions	USA	Sufficient quotes.		
	assessment	(in addition to			Examples of open-	
	of the barriers and	multiple	Link to parent survey was posted to		ended questions not	
	resources that parents of children with ASD	choice and Likert scale	three local autism parent LISTSERV e- mail lists		included.	
	encounter during office- based	questions).				
	health care delivery.	Thematic				

# Table 3.1 Summary of the 10 Studies Included in the Review

Citation	Aim	Data Collection and Analysis	Sample and Recruitment	Strengths	Notable Limitations	Quality Rating
Farmer & Reupert	To describe and evaluate a six-session group	Open ended pre/post	<i>N</i> = 98 (63 females, 35 males)	Diagnosis verified.	No discussion of reflexivity or	7 (Good)
(2013)	parent education program provided to	questions included on	<ul><li>79 children (52 aged between 2 - 6 years.</li><li>27 aged over 6 years).</li></ul>	Depth of analysis.	triangulation.	
	parents of children with	self-		Sufficient quotes.		
	autism.	constructed Likert scale	ASD			
		questionnaire.	Rural Victoria, Australia			
		Inductive thematic analysis	Participants referred from educational and health providers.			
Dickie et al. (2009)	To describe the experiences of children with and without autism related to sensory	Open-ended interviews, via phone or face-to-face	N = 37 (29 parents of typically developing children)	Large sample size. Use of comparison group.	No notable limitations.	9.5-10 (Excellent)
	situations during their	1400-10-1400	66 pre-schoolers	Triangulation; more than		
	daily routines, to generate information	Thematic analysis	(37) Autistic disorder, (29) typically developing	one analyst.		
	about	2	1.0	Sufficient quotes.		
	how their parents		North Carolina, USA	Reflexivity; monthly		
	perceive and explain these "sensory		Participants with autism recruited using	meetings with research team		
	experiences", and to compare these sensory experiences.		a university based state-wide research registry. Convenience sampling of typically developing subjects through local day cares, university mailing lists, and word-of-mouth.	to discuss findings.		

Citation	Aim	Data Collection and Analysis	Sample and Recruitment	Strengths	Notable Limitations	Quality Rating
Schaaf et al. (2011)	To explore how sensory- related behaviours of	Semi- structured	N = 5 (4 females, 1 male)	Triangulation; more than one analyst.	No notable limitations.	10 (Excellent)
(2011)	children with autism affected family routines	face-to-face interviews	4 children aged between 7 - 12 years (6 males, 2 females).	Sufficient quotes.		(,
		Phenomenolo gical	ASD	Reflexivity; field notes throughout process,		
		approach	USA	independent coding, member checking, and audit		
			Purposive sampling from the clinical community via contact with parent groups, clinics, and word of mouth.	trail to track research activity.		
Robinson et al. (2015)	To provide an interpretive description	17 semi- structured	N = 13 (8 mothers, 5 fathers)	Diagnosis verified.	Setting of interviews not specified.	9-9.5 (Excellent)
	of parents' experiences of raising a child with Asperger's	interviews Interpretive	8 children aged between 11 - 19 years (6 males, 2 females).	Triangulation; more than one analyst.	-	
	syndrome (AS).	description (constant	Asperger syndrome	Sufficient quotes.		
		comparison)	Southern British Columbia, Canada	Reflexivity; field notes throughout process,		
			Convenience sampling through newspaper advertising, ASD service agencies and ASD family support group.	independent data analysis.		

lerstand the ences of youth itism in the t of health-care y in a hospital	and Analysis Semi- structured interviews Interpretive description	<ul> <li>N = 22 (19 females, 3 males)</li> <li>(14 health care professionals, and 6 youth)</li> <li>20 paediatric patients aged between 10 - 16 years (17 males, 3 females).</li> </ul>	Diagnosis verified. Triangulation; more than one analyst. Reviewing emerging themes with consultation group	No notable limitations	9.5-10 (Excellent)
		ASD Canada Purposive sampling through advertising and word of mouth.	<ul> <li>(including parents, health care providers and an individual with ASD), to ensure viability of experiences captured.</li> <li>Reflexivity; peer debriefing and negative case analysis.</li> <li>Depth of analysis.</li> </ul>		
lerstand the ctives of parents n with pervasive pmental disorders, ion to sensory tion 7.	22 questionnaire s, 9 semi- structured interviews Thematic analysis	<ul> <li>N = 9 (all female)</li> <li>9 children aged between 5 - 8 years (6 males, 2 females).</li> <li>Autism (7), cerebral palsy with autism (1), tuberous sclerosis (1)</li> <li>India</li> <li>Purposive sampling from 65 attendees at one of the workshops (run by the authors) for parents, on the topic of identifying sensory issues in their children.</li> </ul>	Triangulation; independent coding by more than one analyst. Sufficient quotes.	Sample; demographic details unspecified, but noted similar religious and socio- cultural backgrounds (further drawn from a single workshop) No discussion of possible interviewer bias; all children were receiving therapy from the authors.	6.5-8.5 (Fair to Good)
pn io tic	nental disorders, n to sensory	nental disorders, interviews n to sensory on Thematic	nental disorders, interviews n to sensory on Thematic analysis	nental disorders, interviews Sufficient quotes. n to sensory Autism (7), cerebral palsy with autism on Thematic analysis India Purposive sampling from 65 attendees at one of the workshops (run by the authors) for parents, on the topic of identifying sensory issues in their	nental disorders, n to sensoryinterviewsSufficient quotes.religious and socio- cultural backgrounds (further drawn from a single workshop)onThematic analysis(1), tuberous sclerosis (1)religious and socio- cultural backgrounds (further drawn from a single workshop)IndiaNo discussion of possible interviewer bias; all children were receiving therapy from the authors.

Citation	Aim	Data Collection and Analysis	Sample and Recruitment	Strengths	Notable Limitations	Quality Rating
Nickels (2010)	To investigate the perceptions of parents of children with ASD, special education teachers, and general	Semi- structured interviews (60- 90mins)	<ul><li>N = 7 parents (5 females, 2 males)</li><li>*(8 special education teachers, 6 general education teachers)</li></ul>	Diagnosis verified. Clear form of data; type of interview questions specified.	No notable limitations.	9 (Excellent)
	education teachers regarding educational interventions for children with ASD in a	Constant comparison analysis	6 children between pre-school and high school ages (5 males, 1 female). ASD	Maximum variation Reflexivity		
	Northeast Tennessee public school system.		Northeast Tennessee, USA Purposeful sampling			
Stickney (2010)	To explore the perceived benefits of a therapeutic riding program for children with autism spectrum	Semi- structured interviews (30 - 60 mins) onsite	N = 22 (16 females, 6 males) *(2 senior staff, 5 riding instructors, 5 volunteers)	Diagnosis verified. Sufficient quotes.	No discussion of reflexivity in terms of minimising researcher bias.	7.5 (Good)
	disorder.	Thematic analysis,	15 children aged between 4 - 23 years (2 females, 13 males). ASD		Only one researcher/analyst.	
			Kentucky, USA			
			Parents of participants in the riding program were contacted by the researcher.			

 $\overline{Note: N = \text{number of caregivers of individuals with ASD}}$  \* Additional participants included in the study.

Sample sizes varied, with larger samples utilised by the two survey studies (Bultas, McMillin, & Zand, 2015; Farmer & Reupert, 2013). Six of the studies were conducted in the USA, while others were conducted in Canada (2), Australia (1), and India (1). Two studies did not include caregiver demographics, other than gender. However, from the information available, caregivers were predominantly university educated Caucasian females, outnumbering males by a ratio of 3:5. Individuals with ASD were aged between 11 months and 23 years. One study did not specify the age range of individuals with ASD, while four studies did not specify gender. However, the remaining studies reported individuals with ASD as mostly males.

A range of qualitative data analyses techniques were utilised across studies: content analysis (40%), grounded theory (20%), with each of the remaining four studies covering critical discourse analysis, phenomenological analysis, constant comparative analysis, and thematic analysis.

#### **Critical Appraisal and Summary of Articles**

In terms of methodological quality, ratings were computed across all articles for each of the 10 attributes on the CASP checklist (Appendix A) (including clear aims, appropriateness of qualitative methodology, research design, recruitment strategy, data collection, potential researcher bias, ethical issues, data analysis, statement of findings, and discussion of applicability of findings) by two judges. These attribute ratings were then summed to give an overall rating of article quality. An intraclass correlation of .75 was computed for the summed article ratings, which indicates acceptable interrater reliability (Shrout & Fleiss, 1979).

Five studies were rated between 9.5-10 out of 10 (Excellent), indicating they were strong in terms of meeting criteria. Four studies achieved ratings between Good to

Excellent, and Good, with one study being Fair to Good. Studies with lower ratings commonly did not address issues of potential bias or discuss reflexivity (See Table 3.1).

Three of the studies specifically focused on investigating the sensory experiences of individuals with ASD via parent reports (Bagby, Dickie, & Baranek, 2012; Dickie et al., 2009; Schaaf et al., 2011). Bagby et al. (2012) and Dickie et al. (2009) included parents of typically developing children as a comparison group. Schaaf et al. (2011) explored the impact of sensory issues on family routines. Findings indicated that sensory issues restricted families' participation in a number of areas, and that strategies were utilised in order to accommodate the child's sensory needs in order to manage daily routines (Schaaf et al., 2011). Similarly, Bagby et al. (2012) reported that children's sensory experiences affected whether a family chose to participate in certain activities, how the family prepared for such activities, and the extent to which experiences, meanings, and feelings were shared. Parents of children with autism reported having to prepare considerably more for activities with sensory elements, than parents of typically developing children, and tended to avoid situations due to their children's sensory sensitivities (Bagby et al., 2012). Both Bagby et al. (2012) and Dickie et al. (2009) reported that parents of children with autism described difficulties understanding their sensory experiences. According to Bagby et al. (2012), there was a greater exchange of thoughts and feelings between typically developing children and their parents. However, Dickie et al. (2009, p. 11) reported that parents of children with autism were more likely to recognise the sensory aspects of their children's experience and were also "likely to attribute responses to aspects of autism". Dickie et al. (2009) also found that both parents of children with autism and typically developing children most commonly reported 'unpleasant' responses to sound, while touch and movement were commonly as described 'pleasant'. In contrast to typically developing children, the

sensory experiences of children with autism were described as extreme or unusual, and food related experiences tended to be negative (Dickie et al., 2009).

A strength of the studies by Dickie et al. (2009) and Bagby et al. (2012) was the use of a comparison group, which illustrated differences and similarities between the experiences of parents of children with autism and those of typically developing children. Other strengths were that both studies reported triangulation and reflexivity, in addition to detailing the coding process. Bagby et al. (2012) stated that multiple methods were employed to address validity issues, including clarification of participant statements during the interview process, the use of field notes, journaling during the coding process, and peer debriefing with other research members. Similarly, Dickie et al. (2009) reported that themes were developed through discussion at monthly research team meetings. The study by Schaaf et al. (2011) was also particularly strong in terms of reporting triangulation and reflexivity, via independent coding, member checking, and auditing to track research activity.

The seven other studies included in the current review explored a range of areas via parent reports of their children with ASD, but all included some reference to sensory experiences. Robinson et al. (2015) conducted semi-structured interviews with parents of eight children with Asperger's syndrome in Canada. Sensory sensitivities were described by many of the parents, in relation to touch, sound, taste, light and noise, and difficulties understanding their children's responses were also reported (Robinson et al., 2015). Strengths of the study were the reporting of triangulation and reflexivity via field notes and independent data analysis.

Muskat et al. (2015) and Bultas et al. (2015) explored experiences in health care settings. Muskat et al. (2015) interviewed 22 parents of paediatric patients at two specialised Canadian hospitals, out of a total of 42 participants, which included health

care providers and youth with ASD. Sensory issues reported by parents included difficulty understanding the location, nature, and level of pain experienced, and one parent reported dietary challenges (Muskat et al., 2015).

Bultas et al. (2015) aimed to evaluate a researcher-developed tool designed to improve office-based health care services for children with ASD, and to assess barriers and resources encountered during these services. A sample of 59 parents of children with ASD, in addition to 54 health-care providers, completed an online survey containing mostly free response questions (Bultas et al., 2015). Bultas et al. (2015) reported that 45 parents provided comments related to barriers during health care encounters, with 11 comments (24%) pertaining to environmental issues, which included sensory issues relating to vision and sound, as well as crowded waiting areas and waiting times.

Both studies reported triangulation with more than one researcher analysing data, and discussion of themes to ensure consensus. In addition, Muskat et al. (2015) reviewed emerging themes with a consultation group consisting of parents, healthcare providers, and an individual with ASD. Peer debriefing and negative case analysis were also conducted (Muskat et al., 2015). Muskat et al. (2015) also took measures to ensure that diagnosis was verified by file review, whereas Bultas et al. (2015) relied on parent reports of diagnosis. Other limitations of the study by Bultas et al. (2015) were that examples of the open-ended survey questions utilised were not specified, and parent demographics were not included.

The remaining four studies investigated experiences related to different programs or interventions: educational interventions (Farmer & Reupert, 2013; Nickels, 2010), a therapeutic riding program (Stickney, 2010) and sensory integration therapy (Joshi & Vaishampayan, 2008). Farmer and Reupert (2013) investigated the effectiveness of a six-session group educational program for parents of children with ASD in rural Australia. A questionnaire, including open-ended questions, was administered post intervention to 98 parents of 79 children aged between 2 and 6 years. One of the major themes that emerged regarding topics learned and valued from the program, with a total of 44 parent responses, was 'understanding sensory processing'. Many of the parents reported that understanding their child from a sensory perspective improved their overall understanding of ASD and significantly influenced "the way they related to and 'managed' their child", as well as assisted them to accommodate to the child's sensory needs (Farmer & Reupert, 2013, p. 24). A major strength of the study is the breadth of data collected. However, there was no discussion of triangulation or reflexivity in relation to the qualitative analysis, and it was unclear how the diagnosis of ASD was verified.

Both studies by Stickney (2010) and Nickels (2010) were doctoral dissertations. Stickney (2010) investigated the benefits of an 8-week therapeutic riding program based in Kentucky, USA for children with ASD. Stickney (2010) conducted semi-structured interviews with 22 caregivers of 15 children aged between 4 and 23 years. Two staff members were also interviewed and focus groups were conducted with staff and volunteers. Nine of the caregivers described choosing the program in order to assist children with sensory issues, by providing them with multi-sensory opportunities, for example "different sights and sounds and smells", being around new people, and the texture and movement of the horses (Stickney, 2010, p. 49). In response to children who were overwhelmed by excessive sensory stimulation, Stickney (2010) stated that staff would implement strategies according to individual needs, such as graduated exposure. Two of the caregivers reported that their children were eventually able to overcome their difficulty wearing a helmet due to sensory sensitivity (Stickney, 2010).

Nickels (2010) explored perceptions of parents of children with ASD, special education teachers, and general education teachers regarding educational interventions for children with ASD in a Northeast Tennessee public school in the USA. Seven parents of 6 children with ASD from a range of grades between pre-school and Grade 12, were interviewed, along with 8 special education teachers and 6 general education teachers. One of the nine themes identified related to sensory-motor interventions (Nickels, 2010). Parents strongly supported the effectiveness of sensory-motor interventions in decreasing atypical sensory responses and increasing calmness and focus in children with ASD, particularly occupational therapy, deep pressure, brushing, exercise or movement, and the use of sensory toys (Nickels, 2010). Parents of five of the six children in this study expressed that occupational therapy had assisted in addressing sensory problems and fine motor delays (Nickels, 2010). Sensory issues were one of the noted challenges and barriers to meeting the educational needs of children with ASD (Nickels, 2010).

In terms of limitations, Stickney (2010) mentioned previous experience volunteering in the riding program and the author was the only noted analyst, yet it was unclear what measures were taken to minimise possible researcher biases. In contrast, Nickels (2010) reported multiple measures to maximise reflexivity including journaling, a field log, and audit trail for review by an external auditor, which increases confidence in the findings.

Joshi and Vaishampayan (2008) utilised semi-structured interviewing to collect data from nine parents of children with pervasive developmental disorders (all mothers), who had been participating in a workshop run by the authors on sensory issues in children. Common themes reported were that parents' understanding of sensory issues assisted them to understand their child, and that occupational therapists' approachability and willingness to listen were important factors (Joshi & Vaishampayan, 2008).

Joshi and Vaishampayan (2008) initially constructed a questionnaire with both demographic and open-ended questions regarding parents' concerns and their understanding of sensory integration. This was distributed to 65 participants of one workshop, of whom 22 returned the questionnaire, and the authors reported that nine of these parents consented to be interviewed. It was unclear how the qualitative data from the questionnaires was utilised, as reference was only made to the analysis of interview data. In addition, the possibility of response bias was not addressed and there was no discussion of reflexivity or triangulation. These were particularly important to address since all participants' children were receiving occupational therapy or sensory integration therapy from the authors, in addition to attending workshops run by the authors.

Another limitation to the interpretation of the themes is that it is unclear whether all children had a diagnosis of ASD. While Joshi and Vaishampayan (2008) reported that seven of the parents in the study had children with autism and one child had cerebral palsy along with a diagnosis of autism, another child was only reported to have tuberous sclerosis. It was unclear whether the child also had autism or another pervasive developmental disorder, and this was not specified in the reporting of results.

# **Thematic Analysis**

Thematic analysis of data resulted in the identification of five themes: single senses, sensory issues activated in situations, understanding the individual's sensory experiences, strategies to manage sensory issues, and impacts of an individual's sensory issues on the family. These are presented below.

#### Single Senses

**Hearing.** Three of the studies specifically made reference to parent reports of sound sensitivities. Dickie et al. (2009) stated that 59% of the children with autism were reported to experience various sounds as being unpleasant, in comparison to 28% of the typically developing children. Loud and unexpected sounds were most commonly described as unpleasant (Dickie et al., 2009). Similarly, Nickels (2010) reported instances of loud noises as being a sensory issue for two children with autism. Both Schaaf et al. (2011) and Dickie et al. (2009) reported instances of caregivers of children with autism avoiding vacuuming due to the children's sound sensitivities. However, these issues did not necessarily remain constant, with one caregiver reporting her child's sensitivity to sounds varied (Dickie et al., 2009), and another stating her child was now able to manage a fire drill without headphones, as "he's gotten older some things don't bother him", (Nickels, 2010, p. 181). In contrast, Dickie et al. (2009) reported sound experiences were described as being positive for 24% of the children with autism, in comparison to 14% of the typically developing children.

**Touch.** A number of studies reported tactile experiences described by caregivers of children with autism (Dickie et al., 2009; Nickels, 2010; Schaaf et al., 2011; Stickney, 2010). Dickie et al. (2009) reported about a quarter of the caregivers of both children with autism and typically developing children described what they felt were positive tactile experiences for their children, most of which related to interpersonal touch. Five caregivers of children with autism reported their children responded positively to "deep pressure" (Dickie et al., 2009, p. 7; Nickels, 2010, p. 195). Deep pressure refers to tactile sensory input often in the form of firm touch, squeezing, or weighted backpacks. Negative tactile experiences were reported by four caregivers of children with autism in comparison to two caregivers of typically developing children in the study by Dickie et al. (2009). A child with autism reportedly did not like his head being touched (Dickie et al., 2009). Schaaf et al. (2011) also noted caregiver reports of tactile difficulties, with one child with autism appearing to find being dried with a towel aversive, while another had difficulty tolerating clothing.

**Taste.** Four studies noted caregiver reports of children with autism having sensory sensitivities related to food (Dickie et al., 2009; Muskat, 2015; Nickels, 2010; Schaaf et al., 2011). Muskat (2015) reported one caregiver describing her child's difficulty eating vegetables, while Nickels (2010, p. 196) described a child's dislike of 'food textures'. Dickie et al. (2009) found that eleven of the children with autism had negative food related experiences, in comparison to five of the typically developing children. Positive food related experiences were described for 28% of the typically developing children, in contrast to only 4% of the children with autism (Dickie et al., 2009). Dickie et al. (2009, p. 8) noted that caregivers of typically developing children reported negative food experiences as "simple preferences", whereas caregivers of children with autism provided detailed descriptions often with the child's behavioural responses to food (for example, gagging, vomiting, or having a 'melt-down'). Both Dickie et al. (2009) and Schaaf et al. (2011) reported accounts of mealtimes being stressful for caregivers of children with autism. Frustration and concern were expressed about the "quality of the family mealtime experience" (Dickie et al., 2009, p. 8), and the difficulty in "enjoying a full meal together" (Schaaf et al., 201,1 p. 381).

**Movement.** The apparent need for movement was described by a number of parents of children with autism (Dickie et al., 2009; Joshi & Vaishampayan, 2008; Nickels, 2010; Schaaf et al., 2011; Stickney, 2010). Schaaf et al. (2011) stated that one

child's frequent movement prevented him from staying at the dinner table for more than 10 minutes. Dickie et al. (2009, p. 7) noted that a quarter of the parents of both children with autism and typically developing children reported movement related experiences "which did not seem to vary across groups", including enjoyment of swinging and jumping. However, caregivers of children with autism particularly emphasised the experience of jumping, for example "he bounced and bounced and bounced", and "he jumps a lot" (Dickie et al., 2009, p. 7).

**Vision.** Seven of the eight parents who described visual experiences had children with autism (Dickie et al., 2009). Negative visual experiences for the children with autism included sensitivity to bright lights and sunlight, in comparison to one typically developing child's fear of watching certain images on video (Dickie et al., 2009). Three parents of children with autism described positive visual experiences, including "seeing everything", enjoying turning lights on and off, and watching flying objects such as bubbles and balloons (Dickie et al., 2009, p. 7). A number of other studies referenced visual issues, however, these were described in the context of environmental issues, as discussed later.

**Oral.** Three studies reported sensory issues related to the mouth (Dickie et al., 2009; Joshi & Vaishampayan, 2008; Schaaf et al., 2011). Two caregivers reported that their children with autism needed to "chew on things" (Dickie et al., 2009, p. 8). Schaaf et al. (2011) also noted one child reportedly chewing on a rubber device (P-chewy) for a minute after going swimming. Other oral sensory difficulties were described in relation to self-care issues as a whole. Oral hygiene and face-washing were reportedly difficult for two children with autism and one typically developing child (Dickie et al., 2009). Eight caregivers of children with autism reported 'negative' sensory experiences including having to brush teeth, brushing and cutting hair, and trimming nails (Dickie et al., 2009).

al., 2009). Another caregiver reported that oral massage prior to brushing her child's teeth resulted in "better tolerance" (Joshi & Vaishampayan, 2008, p. 52). Other studies made reference to children's sensory experiences but were described in relation to multi-sensory difficulties or situational factors rather than single sense experiences.

#### **Sensory Issues Activated in Situations**

Bultas (2016, p. 10) reported that 24% of the comments from caregivers of children with autism in relation to barriers during health care encounters referred to problematic environmental issues including "waiting times", "bright lights, loud televisions, and crowded waiting areas". Children with autism reportedly had difficulty regulating behaviour "in the light of multiple stimuli" and environmental challenges, for example, in large department stores, at restaurants, at movie theatres, or at sporting events (Schaaf et al., 2011, p. 379). Situations with "excessive stimulation" were described as difficult for children with autism, with some caregivers using the term "overload" (Dickie et al., 2009, p. 10). Nickels (2010, p. 217) also reported caregivers described their children experiencing sensory "overload", with one stating her child had to deal with "all the sights, sounds – everything". Other caregivers described their children's 'need' for multiple forms of sensory input, which they believed was provided by the multi-sensory environment of the therapeutic riding program being evaluated by Stickney (2010).

#### Attempting to Understand the Child's Sensory Experiences

Five studies reported caregivers' experiences of attempting to understand their child's sensory sensitivities. One caregiver of a child with autism attempted to understand the child's love of certain stimuli: "I have no idea why he likes things. I don't know if he's experiencing it in the same way I would?" (Dickie et al., 2009, p. 10). Another parent found her child's apparent need to jump and chew constantly,

"strange", and reported attempting to chew her child's 'chew tube' to understand his experience (Dickie et al., 2009, p. 10).

Robinson et al. (2015, p. 2314) reported caregivers' attempts to understand their children's sensitivities to "touch, taste, light, and noise", with one mother reporting "as parents we had no idea" what was happening. Other parents described their difficulties understanding their children's sensitivities at school, with one child refusing to attend school due multiple sensory issues (Robinson et al., 2015). Bagby et al. (2012, p. 83) also reported a mother describing her son's experience at school as "a waking nightmare" they were unable to "fix", resulting in him having to be home-schooled. Nickels (2010, p. 217) noted one mother's description of the impact "sensory overload" on her child's behaviour at school and her attempt at understanding his distress, stating "I would love to spend two minutes in that head. I probably wouldn't be able to handle it".

Bagby et al. (2012, p. 83) reported a number of caregivers of children with autism, found it difficult to form a "cognitive connection" with their children, in terms of being able to share understanding of their sensory experiences. Both caregivers of typically developing children and those of older children with autism described the importance of being able to discuss feelings about sensory experiences (Bagby et al., 2012). One mother of an older child with autism reported her sense of relief when her son learned to tell them about his sensory experiences, for example, "when loud noises hurt his ears" (Bagby et al., 2012, p. 82).

Farmer and Reupert (2013, p. 24) stated that caregivers reported that understanding their child "from a sensory point of view" assisted them to relate to their child as well as to understand the general nature of autism, and allowed them to use certain strategies or "accept and incorporate" certain behaviours to manage issues.

#### **Strategies to Manage Sensory Issues**

Schaaf et al. (2011) noted strategies were developed by families to assist them to participate in family activities. Some caregivers gave their children specific tasks to "decrease sensory over-responsivity" and provide focus, for example, pushing a grocery cart at a store (Schaaf et al., 2011, p. 383). Other strategies included the need for flexibility, establishing morning and bedtime routines to increase predictability of sensory stimuli, and structuring weekend activities (Schaaf et al., 2011). Bagby et al. (2012, p. 81) reported caregivers of children with autism reported a greater need for preparation in comparison to those of typically developing children, in terms of the "greater breadth and depth of alternative plans", for example needing "exit strategies" before going to sensory laden events such as parties or having to plan where to sit at an outdoor event.

Bagby et al. (2012) also reported three parents of children with autism aged between 7 and 8 years described intentionally exposing their children to situations with multiple sensory stimuli, to assist them to develop resilience. Similarly, Stickney (2010) reported nine caregivers of children with autism reported wanting to provide their children with a variety of sensory opportunities such as those provided by the therapeutic riding program. One mother stated she wanted to her child to experience "different sights and sounds and smells" and to "get used to being around some new people and some different sensations" (Stickney, 2010, p. 49).

Reported strategies used by caregivers of children with autism to specifically manage tactile sensory sensitivities included: developing a routine (e.g., laying the child's clothes out in the same order on a daily basis, and wrapping the child tightly with a towel rather than wiping) (Schaaf et al., 2011), using body brushing and weighting backpacks for deep pressure (Nickels, 2010), and gradual exposure (Stickney, 2010). Two studies reported parents' views of various sensory interventions for their children. Nickels (2010) stated parents, particularly of pre-school and elementary school aged children, were strong supporters of sensory motor interventions, including occupational therapy, deep pressure, brushing, exercise or movement, and the use of sensory toys. One mother reported her son had benefitted from weekly occupational therapy, exercise and movement in the classroom (bouncing and spinning), exposure to textures (touching shaving cream), deep pressure, and 'Wil Barger' protocol body brushing (Nickels, 2010, p. 195). Another mother also reported ongoing occupational therapy, along with a weighted backpack and other sensory therapies were useful for her son (Nickels, 2010, p. 196). Joshi and Vaishampayan (2008) reported five of the mothers in their study described incorporating equipment, including therapy balls, trampolines, swings, and textures into their daily home routines (Joshi & Vaishampayan, 2008).

#### Impacts of an Individual's Sensory Issues on The Family

Two studies reported the impacts of sensory experiences on families of individuals with autism (Bagby et al., 2012; Schaaf et al., 2011). These included the need to constantly monitor both the child and the environment to anticipate sensory issues or behaviours, and less attention provided to siblings of a child with autism leading caregivers to report feelings of guilt (Schaaf et al., 2011). Avoidance of certain places such as other people's homes was also reported due to fears that the child's sensory behaviours (e.g., touching or spinning) would cause disruption (Schaaf et al., 2011), or in anticipation of the child's sensory responses (Bagby et al., 2012). This not only impacted socialisation with other families, but also the extent to which a family could participate in activities together (Bagby et al., 2012; Schaaf et al., 2011). However, Schaaf et al. (2011) noted despite the reported challenges, families of children with autism and sensory sensitivities described making efforts to continue to engage in a variety of daily activities similarly to other families.

#### Discussion

The most commonly reported sensory challenges described by caregivers of individuals with ASD were in relation to hearing, touch, movement, and taste. Experiences related to vision and oral issues were also described but were reported more frequently along with multi-sensory issues as a whole. The hypersensitivities in multiple sensory domains described by caregivers of individuals with ASD in the current review is consistent with the "over-responsivity" to stimuli (e.g., distress from loud noises) noted by Ben-Sasson et al.'s (2009) systematic review of parent survey reports. Furthermore, studies based on first-hand accounts of individuals with ASD have also reported considerable hypersensitivities relating to multiple sensory modalities particularly in relation to hearing, vision, and touch (Elwin et al., 2013; Robledo et al., 2012; Smith & Sharp, 2013), thereby strengthening this finding. In relation to movement, caregivers of individuals with ASD commonly reported their children's apparent need to jump, bounce, and spin, which is consistent with caregiver survey report findings of "sensation seeking" among individuals with ASD (Ben-Sasson et al., 2009).

Caregivers made reference to their children's aversive experiences in multisensory environments, such as department stores, restaurants, and sporting events, and described difficulties with "sensory overload". This is consistent with findings from a number of studies based on first accounts of individuals with ASD, who reported becoming "overloaded" in response to external stimuli (Chamak et al., 2008; Davidson, 2010; Elwin et al., 2013; Jones et al., 2003). Based on parent survey data the greatest difference between ASD and typical groups was in under-responsivity or slow response to sensory input (Ben-Sasson et al., 2009). Findings from first-hand accounts of individuals with ASD have also described 'hypo' sensitivities or difficulties in relation to sensing pain (Chamak et al., 2008; Robledo et al., 2012), or hunger and thirst (Elwin et al., 2012). However, caregiver reports in the current review did not commonly reference under-responsivity in these terms. It is unclear whether the current finding of caregivers reporting their children with ASD apparently needing tactile stimulation (e.g., deep pressure), reflects underresponsivity to sensory input or instead sensation seeking, suggesting that further research is necessary.

Caregiver understanding of the individual with ASD's sensory experiences, strategies utilised to manage issues (the need for preparation and planning, intentional gradual exposure to multi-sensory environments, and sensory motor interventions), and the impact of the individual's sensory issues on the family (avoidance of certain situations and activities such as sporting events and social gatherings, the need to constantly monitor the child and the environment, and less attention able to be provided to typically developing siblings) were described. These reveal important insights into caregiver perspectives which are not evident from quantitative data from caregiver survey studies or first-hand accounts.

Overall limitations to the generalisability of results, include a notable northern hemisphere bias in terms of the location of studies and the individuals sampled, indicating the need for further research using more diverse populations to assess whether these experiences are shared similarly. Also, all studies sampled predominantly mothers of individuals with autism. Pertaining to the methodology of the current review, though steps were taken to ensure the search was rigorous (multiple databases, varied combinations of keywords, hand search of reference lists, independent search by a second researcher to check replication), it is possible that articles may have been missed. In addition, the aim was to synthesise qualitative data to obtain an understanding of the experiences of caregivers of individuals with ASD in relation to sensory issues via analysis and comparison of themes and concepts. Therefore, results cannot be taken as evidence for or against sensory interventions and therapies described.

In a systematic review of sensory interventions for children with ASD, Case-Smith, Weaver, and Fristad (2014) noted that existing studies have inconsistently defined these interventions and have also used the term referring to widely varying practices. Yet, sensory interventions are one of the most commonly requested services by caregivers of children with ASD (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006). Sensory based interventions (SBI) are adult-directed sensory strategies that are integrated into the child's daily routine, for example wearing a weighted vest, being brushed or rubbed, swinging, sitting on a bouncy ball, being squeezed between pillows (Case-Smith et al., 2014; Lang et al., 2012). These are based on the premise that specific forms and dosages of sensory stimulation may improve the nervous system's ability to process sensory stimuli (Lang et al., 2012). Sensory integration therapies (SIT), originally developed by Ayres (1972) are clinic-based interventions that provide sensory rich, play-based opportunities for children to engage in self-directed activities (Case-Smith et al., 2014). Case-Smith et al. (2014) reported positive effects for sensory integration therapies from small randomised controlled trials, and few positive effects for sensory-based interventions though they noted that these studies did not follow recommended protocols or target sensory processing problems. Therefore, findings from the current review pertaining to caregiver reports as to the benefits of sensory

based interventions are incongruent with existing evidence, and suggests further research is necessary to understand these discrepancies.

In conclusion, this review primarily contributes to the literature by revealing further insights into the experiences of caregivers of individuals with ASD in relation to sensory issues, and highlighting the impacts of these on family experience, as well as the strategies families develop in order to manage challenges. Findings potentially have clinical significance in terms of providing context for healthcare professionals, such as occupational therapists, when assisting individuals with ASD and their families with management and environmental strategies, in order to cope with sensory challenges at home, school, and in public settings. A secondary contribution to the literature, is the finding of discrepancies between caregiver reports of the benefits of sensory interventions and existing empirical evidence.

In summary, the findings highlight the need for further research into the development of sensory management strategies that are both caregiver supported and evidence-based. The variability among the types of sensory experiences described by caregivers of individuals with ASD, again suggests that heterogeneity in ASD populations may be contributing to inconsistent findings from research into sensory interventions. In order to explore this further, the next study aimed to explore first-hand accounts from individuals with ASD. This will be presented in the following chapter.

#### Chapter 4: Part I – Study Two, First-hand accounts of individuals with ASD

This chapter will report the findings from study two, which aimed to build on the results of the previous study through a qualitative investigation of first-hand accounts of sensory experiences from children and adults with ASD. Although a growing number of studies are examining first-hand accounts of sensory experiences by individuals with a diagnosis of ASD, research is still relatively limited particularly from the perspectives of children with ASD (Elwin et al., 2013; Kirby et al., 2014). Therefore, the aim of the current study was to obtain an experiential understanding of sensory experiences through in-depth explorations via interviews and analysis of written work, from individuals with a diagnosis of ASD. It was anticipated that the richness of qualitative data (Biklen, 2005; Smith & Sharp, 2013) could contribute to a deeper understanding of sensory experiences and challenges, which in conjunction with findings from the previous study could provide a fuller picture of these experiences in relation to ASD. Methods, findings, and a general discussion are presented below.

### **Methods**

### **Participants**

A total of three male participants aged 10, 13, and 53 years participated. All participants had a diagnosis of Autism Spectrum Disorder from a qualified professional (psychologist, paediatrician, or a psychiatrist), and were located in Australia. The 10 year old and 13 year old participants took part in face-to-face interviews of approximately 60 to 90 minutes duration, accompanied by their mothers. These were conducted in an interview room at the university, and were audio recorded. The 53 year old participant opted to submit a written account of his experiences. Data was also collected from the mothers of the child participants, in order to provide context for interpretation of findings. A summary of participant characteristics is presented in Table 4.1. The researcher assigned a pseudonym to each participant in order to protect privacy.

Pseudonym	Participants				
	Joey	William	Dave		
Location	Australia	Australia	Australia		
Gender	Male	Male	Male		
Age (years)	10	12	53		
ASD diagnosis age	5yrs (Paediatrician)	8yrs (Psychologist and psychiatrist)	Adult diagnosis (Clinical psychologist)		
Family	Eldest of three children. Lives with mother and two sisters.	Eldest of four children. Lives with mother, father, and siblings	Lives alone.		
Other mental health diagnoses	Intellectual impairment (severe), ADHD, OCD.	ADHD, Depression, Anxiety	Generalised anxiety, depression, OCD, social phobia schizophrenia		
Siblings with special needs	Younger sister - High functioning autism, OCD	No	-		
Education/job history	Special education class within a mainstream school.	Mainstream with special education support. Teacher aide helps 6-8 children in the class.	University – Masters. Currently completing PhD Previous occupations: Sales clerk, driving instructor, driver, research assistant, librarian, editor/disability pension. Current: Employed P/T Editing work from home		
Adjustment at school	Adjusted poorly.	Adjusted well.	Repeated Grade 2. Bullied.		
Friendships	Minimal. Engages in parallel play.	Minimal. Has difficulty making and maintaining friendships. Limited social skills.	-		
Medication	Ritalin	Lovan 30mg mane	Endep (Amitriptyline hydrochloride), Luvox (fluvoxamine), Minipress (Prazosin), Olanzapine, Somac		

		_	
Table 4.1 Chara	cteristics of Partic	rinants With a I	Diagnosis of ASD

#### **Materials and Procedure**

The study had full approval from the university's Human Research Ethics Committee (Ethical approval no: H17REA062). Participants were recruited over a period of six months via advertising through personal and community networks and posts to general social media sites (Facebook/Twitter links) as well as online autism specific community notice boards. The advertising posts and flyer included a brief description of the project, specified that participants needed to be aged 8 years or above and have a formal diagnosis of ASD, and would be required to either take part in an interview (face-to-face or online for approximately 60 mins) or submit a written account of sensory experiences. No payment incentives or otherwise were offered for participation.

On enquiring about the project via email, individuals were emailed either Participant Information Forms for Caregivers and Children (written in clear child friendly language) or a Participant Information Form for Adults. These outlined the project aims, participation requirements/options, and confidentiality statement. Informed consent was obtained from participants below 18 years and caregivers via signing of a consent form (see Appendix B) prior to the interview, at which time they were given the opportunity to ask any further questions. Caregivers were also requested to complete a brief demographic survey (see Appendix C). The adult participant provided informed consent via emailing a signed a consent form (see Appendix D), and subsequently a document containing a written account of experiences.

Interview participants were provided with a brief introductory description defining types of senses and examples of sensory experiences (see Appendix E). The 10 year old participant was guided and asked open ended questions related to each of the senses. The 12 year old participant was given freedom to talk about senses in whichever order he felt relevant. A question guide was used when necessary, and to cover any areas missed (Appendix E). The adult participant who chose to submit a written description of sensory experiences, was emailed a brief optional example question guide along with a demographic survey (Appendix F).

# **Data Analysis**

Data analysis involved synthesising findings into themes, based on the principles of thematic analysis informed by the work of Braun and Clarke (2006). Findings were numbered line-by-line and sorted into categories based on common findings, which allowed for identification of patterns in the data and the creation of final themes. To maintain analytical rigour, final themes were discussed with the principal supervisor to verify they reflected the original data.

### Findings

Three main themes and a number of subordinate themes were identified, all of which were considered relevant to understanding individuals' experiences of sensory processing and ASD (see Table 4.2).

 Table 4.2 Emergent Themes from Thematic Analysis of Accounts by 3 Individuals with

ASD

Superordinate Theme	Subordinate Theme
Theme 1: Sensory experiences	Visual.
	Sounds.
	Taste.
	Touch.
	Less dominant experiences: Smells &
	movement.
	Multi-sensory experiences.
Theme 2: Management of sensory	
challenges	
Theme 3: Perceptions of change and	Changes in sensory experiences.
difference	Unusual experiences and feeling different.

#### **Theme 1: Sensory Experiences**

Participants described experiences relating to specific senses, including vision, sounds, taste, and touch. Variable and less dominant experiences were described by both child participants in relation to smells and movement. Finally, in addition to singular sensory experiences all participants reported sensory challenges relating to multi-sensory environments. These are described in the following sub-themes.

#### Visual.

Visual sensory experiences were reported by all three participants. Adult participant, Dave, stated:

"I am sensitive to light. I don't like strong light at all. My eyes tire and start closing involuntarily".

He further stated that he had always been sensitive to light but felt he had greater sensitivity to sunlight as an adult. In contrast, ten year old Joey's mother noted that he appeared to be sensitive to sun shining into his eyes, for example, when in the car at certain times. This required him to have car window shades, and to swap car seats in order to avoid bright light. Interestingly, Dave noted that his parents did not give him sunglasses to manage his light sensitivities but attributed this to growing up in the 60s and 70s, when children did not commonly wear them. No issues pertaining to sunlight were reported by 12 year old William, with him instead stating that he could "stare at the sun", which illustrates the variability of these experiences among individuals.

Although, Joey did not articulate his sensitivity to light, he shaded his eyes with his hands at multiple times during the interview. When the researcher turned off the light (fluorescent bulb) and allowed some fluorescent lighting from the adjoining room to enter through an open door, Joey responded that this was better, and the interview continued. However, towards the end of the interview Joey began to shade his eyes again and when asked why, he responded "it's too bright". When questioned about this by his mother, he did not state if anything else was bothering him, but requested for the room light to be turned on again.

Both 10 year old Joey and 12 year old William, described visual experiences either in relation to what they 'did not like' or 'liked' to see, rather than in terms of visual sensitivities. When asked whether there was anything he could see that bothered him, Joey initially responded, "I don't like it when I see mean bullies". When prompted by his mother as to whether anything 'hurt' his eyes, Joey stated: "Things what hurt my eyes are when people chuck rocks at me," "I don't like when I'm at school", and "I don't like it when I see things that hurt my eyes". When asked about what types of things, Joey stated "When I close my eyes and it hurts".

In relation to enjoyable visual experiences, William stated,

"I like things to look nice. I like nature. It's looks very nice especially when you look at it from a height. See what I'm talking about over here [points to the large size poster scene of Japanese gardens covering a wall of the interview room]".

Joey also was also drawn to the poster scene, initially spending 3 to 4 mins looking at it after entering the room, and then again during interview. For William, this attraction towards the nature scene appeared to be a visual distraction at times as later during the interview he continued to look at the poster stating,

"I can't stop looking at that. I'm just going to swing this way now [swings chair around so picture is behind him]. [Whispered] It is still in my vision".

William also described liking things to be "a certain way especially when they don't look right", and that "sometimes things seem off, so I try and put them right". He stated for example that if he saw a messy ball of yarn, he would "want to untangle all that and roll in into a proper ball" or untangle string and "put it in straight lines." During the interview, Joey was also observed lining up pens on the table. His mother also stated that Joey liked things to be "visually pleasing", and that he would always roll up the toilet roll "until it's neat and flush". She felt that though this was partly due to his OCD, it seemed to be more about the visual aspects as there were no associated checking behaviours, and she stated "he doesn't care about it if he doesn't see it".

# Sounds.

Both child participants described sensory sensitivities to certain sounds.

William stated, while pointing to the wall clock in the interview room,

"I hate the sound of clocks. It's really annoying...It's like that annoying little background noise".

William also described certain sounds as "echoing" or reverberating in his head. He then requested whether the clock could be taken down as it was bothering him. Once the clock was removed from the room, William expressed that he felt "much better". However, he then remarked "Back to the ringing... it's either the clock or the ringing. I'll take the ringing any day". Neither the researcher nor William's mother had noticed any ringing sounds, and asked William where he believed it was originating from (fluorescent lighting or internal air-conditioning) but he could not identify the source. In relation to other unpleasant sounds, William stated,

"Certain sounds will send a shiver up my spine...Texters. I can't use texters. They really really annoy me...because of the sound they make, and it just sends shivers down my spine and makes the back of my head hurt. And then chalk on a chalkboard. If I'm hearing it from a distance I wanna go over there and snap the chalk piece in half and throw it."

Joey's mother reported that he had considerable auditory sensitivities which required him to wear sound cancelling headphones. He removed these once in the interview room. Similarly to William, Joey also reported challenges with sounds and stated,

"when things are noisy it's loud and I don't like it. When it's loud it hurts my ears".

He indicated that this is why he wore the headphones and that these helped him. Joey described a number of sounds that bothered him including:

"rain and storms...hail and ice, and when it gets heavy I don't like it...when the TV is loud...when movies are on it's loud... [and] noises at school are when people talk loud, and when people shout and scream".

Joey particularly expressed that hearing people shout physically hurt his ears:

"When people bang, when people yell. I don't like it when people bang and yell. It's too much cause my ears hurt and it's too loud for my ears to hear it, and I don't like it".

Joey's mother added that he would wake up screaming at the sound of "even gentle rain like pitter patter on the roof". She also stated that he would become distressed at the sound of the kettle boiling, unless reassured or prepared that the kettle would be turned on, and could not tolerate the sound of the lawn being mowed. Joey's mother also stated that if he had "had a big day at school" and the radio was turned on in the car, that he would tell her to "switch it off". Towards the end of the interview, when Joey was drawing and while his mother was speaking, he whispered "I want quiet time" and then repeated more loudly "I said I want quiet time." A little later, while his mother continued to speak, he whispered more urgently, "Quiet, quiet!" Therefore, it appeared that after experiencing certain amount sensory input Joey would make it clear that he required some quiet non-sensory time.

Sounds were however not only experienced negatively, and both William and Joey described sounds they enjoyed, particularly in relation to music. William stated,

"Well I really like the sound of a relaxing song, like something you would hear in a temple. Like something that would go along with the image of a forgotten temple and there's water dripping...and you can hear bird sounds. And I just love that."

He also expressed that he "really, really enjoyed" certain songs such as "Stairway to Heaven by Led Zeppelin", and that he if he already knew a song he could name the song "just by the music without the words". William also stated that he found classical music to be "really soothing", and that he was enjoying taking piano lessons. He described being able to easily pick out mistakes when someone was playing a piece, stating "it just sounds wrong."

In response to being asked which sounds he loved, Joey stated "music". His mother explained that Joey particularly liked music by Ed Sheeran and had even requested to attend his concert. However, Joey indicated that even if his favourite song was playing he still did not like it played loudly. In relation to music that Joey enjoyed, his mother stated,

"I don't think we ever do full loud with him in a car, but louder than normal...if it's Ed Sheeran ...I think he tolerates it because he loves a song so much...It's kind of yes he can but there's a reason behind it you know, whereas otherwise he wouldn't."

She stated that Joey appeared to like "soft calming songs" that had a beat and were repetitive. She reported that she had also observed him tapping complex beats on empty bottles in the house, and felt he had a strong sense of rhythm. Therefore, both William and Joey appeared to have an affinity towards music and found particular enjoyment in listening to favourite songs, while they both had auditory sensitivities to certain sounds. These aversions seemed to have a strong impact on daily functioning for Joey.

### Taste.

Experiences related to tastes and food preferences were described by both child participants. William expressed that he did not particularly like "bland" foods such as "cucumber, mushrooms, and tomato", though he would still eat them occasionally. However, in contrast, he stated "I really like hot sauce. I once drank half a bottle of hot sauce as a bet", adding that "If it's too hot I will spit it out, or more like try and wash the taste out", indicating that it was the taste rather than the heat of too much sauce that would bother him. William described not liking foods "all bundled into one," other than "gravy and mashed potato...or sausages and mashed potato", which he declared were "pretty nice". His mother elaborated that if she made a fried rice "where he likes every ingredient that's actually put in the fried rice" she has to "make it all separate and put it on the plate separately for him, so that he'll eat it all" due to his aversion to it being "mixed together". William explained,

"It's annoying and I feel like I have to pick through it to get what I want. Or to remove the things I don't want through eating and then enjoying what I do want as a whole."

However, William added that he would eventually still eat the parts he did not like,

"I mean I'll pick out the parts I don't like but I'll leave the parts I do like and once I finish all the parts I don't like, I will dig into those."

His mother noted that she could make him eat only a select few vegetables that "he has grown up with" such as "cauliflower, broccoli, carrot and peas", but that if she attempted to put any others, such "zucchini and squash", on his plate he would not eat it. She also added that William generally did not like soups and stews, and that even if they contained the few vegetables he did eat, stating "he won't touch it".

In contrast, Joey's mother reported that he had strong preferences for "cold and sloppy, pureed" food such as "apple puree", yet however did not like mashed potatoes. When asked as to why he did not like mashed potatoes, Joey stated "cause I don't like it". His mother stated that Joey refused to eat hot foods, and though he would "tolerate" chips from McDonalds, they needed to be just "warm". She also expressed that the majority of foods he ate tended to be "white", "flour-based" such as pasta, bread, or rice. She also stated that he preferred bland foods such as "margarine sandwiches" and plain boiled rice with "nothing in it, no herbs spices, nothing …bit of salt in the water". When asked about his favourite foods Joey stated he liked "apples, grapes…red grapes", "cheese", "water", "jelly", "Zaraffas" (his mother clarified that they visited a

café that served cold chocolate milk), and white "marshmallows". Joey also stated "I like apple puree because it's yummy, and it's healthy, and I like white 'parths' [sic]", and that he did not like eating watermelon especially "not with the seeds in it". Therefore, while tastes and food preferences varied between Joey and William, the boundaries placed around food selection were quite strong. Food selectivity, though seemed to have a far greater impact on the younger participant, Joey, who his mother stated was well below physical size and weight for his age.

### Touch.

All three participants described tactile sensitivities. Dave stated,

"I am sensitive to touch. I dislike high collars on shirts. I do not like the feel of sunlight on the skin. I dislike biting insects. Flies around my face are a problem."

William expressed that he hated "the feel of...a rubber glove", as it felt as though he was "marinating" in "sweat" and "excess body fluid". He also found wearing "safety googles" "really, really annoying". William also had difficulty tolerating certain fabrics such as polyester, instead preferring "cotton". His mother elaborated that finding bed sheets was an issue, and that they "took two and a half hours in the shops to find sheets that he actually would use" which "ended up being flannelette sheets". William described the feeling of polyester sheets as like being

"in a plastic bag with my head sticking out of the top, and then I've got to sleep in that and it feels like ...I don't hear it, but it feels like it's crinkling".

William also reported having difficulty with the feeling of clothing labels, and needing to have them cut off.

Joey stated that he did not like "spiky things" and instead preferred "soft things". He expressed that he did not like the feeling of grass when he was younger, stating,

"when I was little it felt, like, spiky...and that's why I weared [sic] my gumboots". However, he now liked the sensation stating that it "feels nice on the grass" and that it felt "soft". Joey's mother explained that this had been a recent change, since getting an autism assistant dog.

William reported particularly enjoying a number of extreme sensations within the realm of the sensory domain of touch. He stated,

"I touch my eyes because it's all gooey...I mean I've stuck my finger right down there [points to eye socket]".

He also expressed "I like to prick myself with screws", and "biting and eating the inside of my lip". When asked whether that was painful, William replied "No, not that much". Another tactile sensation William reported enjoying was chewing, stating that he liked to chew "string", "hair" and the ties in freezer bags as they had "a little bit of metal". He also reported eating "lead out of pencils" as it was "something to crunch". William's mother added that he had "chewed feathers, paper, foil at times" as well as "clothes". William noted that chewing clothes however, was "an old habit that I've started to grow out of".

Also in relation to tactile sensations, William's mother reported that he would wear shorts and a t-shirt in winter and "big parka" jacket, tracksuit pants and a tracksuit top to school in summer, in 35 degree heat, to the extent that "teachers have had to take it [the jacket] off him". William explained,

"I love to wear jackets in the summer, and I like to not wear jackets in the winter...I just like the heat in summer and then the cold in winter. It makes sense to me. I just really enjoy it".

Therefore, while all participants described tactile sensitivities and aversions both children also described enjoyable sensations. For William, this tended towards extreme sensation seeking and suggested a certain degree of hyposensitivity to pain. This is consistent with evidence that individuals may have both hypersensitivities and hyposensitivities within a sensory domain.

#### Less dominant experiences: Smells & movement.

Both child participants described experiences in relation to smells and movement, which appeared to be variable and less dominant than experiences in other sensory domains.

*Smells.* William stated "I really enjoy certain smells". However, he added that "sometimes I smell things that aren't really there...like today in school, I smelt lasagne", but "no lasagne was there". He stated that this happened "sometimes". His mother added that William seemed to have an ability to pick up smells that others could not, and recalled an incident when he could smell perfume when his grandmother had walked into the house even though "she hadn't put on a perfume for like 12 hours...and no-one else could smell it".

Joey also described particularly liking certain smells such as "flowers", "washing my hands", "Mummy's perfume" and "the bath bomb smell". However, his mother added that he had a specific aversion to fresh air when a window was opened. Joey explained that it smelled like "bird poo". His mother explained that he was fine when outside or playing in the garden, but if a window was opened he would request it to be closed, saying "it smells like bird poo in here". She believed the difficulty occurred "when he's in one smell and another smell enters it". Therefore, overall olfactory experiences for both child participants were quite variable and individualised, and were not reported to have a significant impact on daily functioning in comparison to auditory, visual and tactile experiences.

*Movement.* Both Joey and William described positive experiences related to movement. William stated, "I like rocking. I like hurtling towards the ground at high

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speeds". During the interview, William also spun himself around in the swivel chair at times, remarking "I'm really enjoying this chair...I enjoy the spinning sensation". William's mother added that at school, William had a particular type of seat called a "Hokki stool". William stated that this assisted him to "focus" on his "class work rather than rocking back and forth" on a chair. Similarly, Joey's mother stated that he could "spin and spin" and that "he doesn't really get dizzy at all". In response to being asked whether there were any places he loved to go to, Joey named a local indoor trampoline park. Therefore, both child participants appeared to enjoy spinning movements, though for William these tended towards extreme sensation seeking similarly to the taste preferences and tactile experiences he described.

#### Multi-sensory experiences.

In addition to the singular sensory experiences described above, all participants

reported sensory challenges relating to multi-sensory environments. Adult participant,

Dave, described his difficulty in multi-sensory environments,

"Large groups of people in a mall are a problem, especially if they criss-cross in my path etc. There seem to be too many colours, styles of clothing etc. I find it hard to have a conversation, listen and get on a train at the same time. I dislike facing people on a train."

Dave also found dealing with people "watching [him] and talking at the same time" to

be an issue, which could trigger a panic attack.

Similarly to Dave, 12 year old William also found shopping centres to be "too

much". He stated,

"There's too much sound. It's annoying, and there's too many people. It's like you've got a crowd and put it into one building. The crowd should be outside. It should be a market, it shouldn't be a big building. It should be a market where you can move away and take some time to sit down...my legs feel like they've been turned into jelly really, really slowly and that jelly is just way too weak. It's just I don't like the sound of people, continuously like all those people talking at once." William noted that not all multi-sensory environments made him feel this way. He stated, "I mean put me in a noisy environment like rainforest, I'd happily sit there".

When asked whether he liked going to shopping centres, and whether he was ok with the lights, sounds and smells, Joey answered "Yes". His mother agreed that smells did not seem to be an issue. She also added that they made sure to go to the toy section first. She reported they when they first enter a shopping centre, "He looks like it's gonna fall over but it's just disorientating", and that if they stayed longer than necessary, the "after-effects" were difficult to manage. She stated, "by the time he gets to car he could be having a meltdown and trying to kick the door in and stuff like that...and then when we get home, he goes into his room, tips all his toys out, and it's all because I've been in the shops too long". She stated he also had difficulties going to movie theatres, and crowded areas, such as school assemblies. Joey stated that what he did not like about the movies was "when it's too loud". His mother noted that in relation to Joey requesting to go to a music concert,

"He seems to think he can, but then he gets into a situation and he starts to mentally shut down. Either freak, like flips out and has a meltdown, or it's like his brain shuts off and then he just goes vacant because it's too many things"

She stated that he liked "the excitement of doing thing what other kids in his class are doing", but once there finds it difficult to stay or asks to leave. Overall, all participants reported considerable difficulties in certain multi-sensory environments, particularly those involving crowds of people and noise.

In summary, sensory experiences relating to visual, auditory, tactile sensitivities were described in addition to more nuanced taste preferences. Experiences that appeared to be less dominant were described by both child participants and related to smells and movement. Overall, however, these seemed quite individualistic in that while all participants reported sensory sensitivities, these manifested in varying ways. However, areas of commonality were aversions to noise, and considerable difficulty in multi-sensory environments such as shopping centres that involved many sights, sounds, and crowds. However, one participant, William, noted that he enjoyed certain multi-sensory environments such as being in a rainforest, so the context of the multisensory environment appeared to be key.

# **Theme 2: Management of Sensory Challenges**

All participants described strategies they utilised to manage sensory difficulties. Dave stated that he managed his sensory difficulties in a number of ways. He reported avoiding certain sensory stimuli that caused him difficulty, for example, the sun. He stated he tried to avoid the sun as much as possible, wore "sunglasses with a powerful tint" and had "a UV tint on my car windows". He avoided going to crowded areas, such as particular shopping malls. Dave also reported that he would "sit behind someone rather than facing someone".

When at cinemas Dave reported that he would "go when it is quiet and sit off to one side on my own", and "do things like a cinema visit the same way – park the same, drink the same, eat the same". When needing to do shopping he would go "at quieter times, keep left and walk quickly". Dave noted that he worked from home, which he found "good". He stated, "I have my TV brightness down and f.lux [light adapting software] on my laptop", though he at times found the "pinging" of emails at home "intrusive". Therefore, Dave appeared to have found specific ways of minimising the impact of his sensory sensitivities, through increasing predictability by developing routines, and making adjustments which allowed him to continue to engage in tasks and activities rather than avoid them altogether.

Dave felt that understanding "sensory overload - eyes and ears, talking, pressing buttons and walking etc - trying to deal with more than one sense at a time" has assisted him to manage, for example, "trying to talk and get on a train". He stated that he tried to "manage one task at time", and that "I now stop talking and concentrate on the job at hand".

Twelve year old William also described how he managed his difficulty in multisensory environments such as shopping centres,

"I try and block it out or I read. That's my go-to and that helps me. I'd like to take a book everywhere."

William's mother elaborated that his "safety is reading". She stated "he can immerse himself in that, so we can do the other shops...if he's got a book, he will read", and if he did not have a book she reported, "he will get frustrated and agitated...we'll get out as soon as possible so that he doesn't have a meltdown".

Ten year old Joey's mother stated that his headphones/ear muffs have been a major assistance for him to manage his sensory issues:

"Before that it was awful. For fifteen dollars each they've saved my life and his life because it's given us the ability to get out of situations... It's like it's so nice to be able to instantly cut it down [the noise] by half for him and then get out of the situation".

When asked whether he wore the headphones at school, Joey replied "Yes". His mother elaborated that he did not wear them all the time at school, but mainly "if he has to go to an assembly or the Anzac Day parade" and when leaving school. She expressed that they had multiple pairs, at home, school, and in the car, so that always had easy access. When at the movies Joey's mother reported that he would wear the headphones "for the whole movie and quite often sits on my knee for the whole movie as well". She expressed that he liked "a tight squeeze" and to be held firmly, which she believed made him feel "grounded" and better able to focus. Similarly, when at shopping centre she reported that he would immediately ask for the trolley, and that "as soon as he's in the trolley…he can sit and look around, because it's cut out everything else". She stated that this strategy currently worked as he was still very small for his age and able to fit into a trolley, but she was unsure what would happen when he grew larger.

Another major support for Joey, according to his mother, had been having an autism assistant dog for the past six months. She felt that since having the dog, Joey was now "more accepting of things", "has tried a few more foods", "can go to the shops for longer", "his language has picked up", now "walking on the grass", and is generally in "a calmer state". Therefore, overall all participants described actively utilising strategies to manage sensory challenges so that they could continue to complete required activities. Furthermore, the mothers of both child participants appeared to be key to assisting their children with this management by being aware of triggering situations, ensuring the children had access to tools to help them (e.g., in Joey's case, headphones and a therapy dog), and leaving situations when they believed their children were becoming overwhelmed.

### **Theme 3: Perceptions of Change and Difference**

All participants discussed both how their sensory experiences had changed over time and also their perceptions of themselves as being different from others.

### Changes in sensory difficulties.

Both child participants and their mothers described how their responses to certain sensory sensitivities had changed. William's mother stated that when he was younger, there were incidents where he had "stormed off" or "acted out", particularly when shopping, which she felt was due to anxiety, but she reported that he currently "doesn't tend to have meltdowns". William also noted that his tendency to chew clothes was "an old habit that I've started to grow out of".

In relation to his past reluctance to walk on the grass Joey reported, that it used to feel "spiky" whereas now it felt "soft". Joey's mother also stated that he had a strong aversion to squeezable jelly toys with nodules (designed for tactile stimulation) when aged two, but through continued exposure to them at the shops and buying one for him at home, he "eventually touched it" and then over a year progressed to playing with it so often "until it broke". However, when asked about whether he found the sound of the kettle any better now that he was older, Joey responded that it "still bothers me". Joey's mother stated,

"Even though things have improved, everything is still there that's always been there. He manages it...it takes a while and now, he can go to the shops. He's quite excited about going, he doesn't want to stay there for very long, he always wants to look at the toy section. But he's more happy to go because he knows we do this and this...and we leave, and we never stay there that long"

Adult participant, Dave, also noted changes in his sensory sensitivities since his childhood. He stated that he recalled "coming out of cinemas as a child and not knowing which way to walk home – disorientation - due to the sudden light, people etc.", but felt that this had improved as it did not happen anymore. However, he reported that as a child he was "more tolerant of biting insects" and "more accepting of sunlight". Therefore, for Dave, change was not necessarily in the direction of building tolerance. Being only recently diagnosed with ASD, Dave felt that he was in the "very early stages of understanding" his condition, and it had given him new knowledge about things he had faced as child, such as experiencing "sensory overload" when in the classroom. Overall, while all participants reported positive changes in certain sensory areas, these appeared to be about learning to be better able to manage responses and, in Joey's case, being in a calmer state.

## Unusual experiences and feeling different.

Perceptions of being different from others or having unusual sensory experiences were described by all participants. Dave expressed that he had a particularly strong long-term memory, particularly for visual information. "The sight ability to file an event, such as a dinner - who was there, mostly what was said - into long term visual memory is great. Friends can't believe I can recall most of what was said years ago. At times they say "you just take everything in" wondering what else I have in my head about them."

However, Dave noted that a "down side" to this was having to deal with "trauma

memories", stating "the image stays and you wish it did not."

Joey's mother also described his ability to remember specific details from many

years ago, which she could not. She stated,

"Like this now...in five years time he might say 'Mummy remember we went to be University and we were talking to that lady...that had the pink top on and the hair that was long and brown like yours."

Other unusual sensory experiences described were related to colour. William

reported a tendency to associate colours with objects. For example, if he saw purple he

stated "I think of a lilac or Mum or Mum's water bottle". When he saw red he

expressed,

"my first thought...the sun, because the sun is a ball of fire and I see instead of a yellow sun I see a red Sun because that's what it's true colour is...we just see it as yellow or white if you stare directly into it...because I associate red with fire or sun because sun is fire, and lots of it."

Also, in relation to colour, Joey stated that his favourite colour was blue. His

mother reported that he rarely ate coloured food, but that he would eat blueberries. She

stated,

"he's got a thing for the colour blue so all of his toys are blue...so food, it's always like I've got more chance of him eating it it's in a blue packet than any other colour. Because he's drawn to the colour, it almost doesn't matter what's in it."

Finally, all participants expressed instances of feeling different or being made to feel different by others. William reported that he did feel that his sensory experiences were different to others at times. In relation to others' perceptions he stated,

"Being called weird is like being called unique. It means you're something that people don't see every day...I feel that I'm annoying to certain people. People tell me that I am annoying and certain other things...I've had good days, bad days, everyone has those."

Joey spoke about not liking "mean bullies", and stated that it hurt his eyes when "people chuck rocks at me", also indicating his awareness of being perceived as different by others. Dave also expressed feelings of being different as a child, stating that he was "physically awkward looking" and had "low sport achievement". He also listed being bullied at school as one of the significant events that had a bearing on him. Therefore, negative experiences in relation to others' attitudes towards them at school regardless of age, appeared to have a strong negative impact on all participants.

## Discussion

This study aimed to explore sensory experiences as described by individuals with a diagnosis of ASD. In order to provide context or supplement information where necessary, data from caregivers was included. Themes that emerged related to: (1) sensory experiences related to vision, sounds, and tactile experiences, taste preferences, less dominant senses (smells and movement), and multi-sensory environments; (2) the management of sensory challenges; and (3) perceptions of change and difference, including perceived changes in sensory experiences, unusual experiences and feelings of being different.

Multi-sensory environments, such as shopping centres, movie theatres and areas crowded with people, were particularly difficult for all three participants. This is consistent with evidence from the systematic literature review (study one), as well as other studies based on first-hand accounts, which reported findings of participants having difficulty in similar multi-sensory environments (Elwin et al., 2013; Smith & Sharp, 2013). Interestingly, one participant, 12 year old William, noted that not all noisy environments were aversive, and that he would be happy in a rainforest. Little research has explored positive experiences relating to specific multi-sensory environments and ASD, which is an area for further investigation.

All participants described experiences related to vision. Two reported sensitivity to sunlight, whereas one went to the other extreme of staring at the sun. These findings are mirrored in existing literature, with the majority of reports by individuals with ASD describing aversions to sunlight (Ashburner et al., 2013; Chamak, Bonniau, Jaunay, & Cohen, 2008; Elwin et al., 2012; Robledo et al., 2012), with a few others indicating a need for bright, sunny days (Robledo et al., 2012).

Both child participants, appeared to interpret visual experiences as being beyond just sensitivities. They described things they found visually pleasing, such as objects being ordered or nature scenes. Furthermore, the youngest participant seemed to interpret upsetting incidents he experienced, such as bullying, as aversive visual experiences which physically hurt his eyes. Both child participants reported great enjoyment of music, which has been similarly reported by others with ASD as being particularly pleasurable and calming (Ashburner et al., 2013; Smith & Sharp, 2013). Both children also reported auditory sensitivities, though the younger participant seemed to have considerably more sensitivities which affected his daily functioning. Twelve year old William described being able to pick on sounds which others did not seem to notice, an experience noted in a number of other first-hand accounts in ASD (Davidson, 2010; Elwin et al., 2013; Elwin et al., 2012).

Hyperacusis (heightened sensitivity or exaggerated responses to particular sounds) has been documented among individuals with ASD (Danesh et al., 2015; Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). Jastreboff and Jastreboff, (2001) identified a form of hyperacusis (misophonia), in which individuals found specific patterns of sound aversive regardless of volume level (e.g. slurping, pencil tapping), and that these aversions varied among both individuals and environments. William's aversion to the sound of the clock ticking and Joey's distress in response to the sound of rain on the roof, appear to be consistent with misophonia. However, as described, these triggers are quite individualised. Ward (2019) noted that whether there are commonalities among cases is yet to be determined, but that a possible explanation is that those with higher sensory sensitivity generally find a wide range of sensory stimuli to be aversive and that specific triggers may be more similar to phobic responses. Further research is necessary.

Experiences related to taste and food preferences were reported by both children and their mothers. However, these appeared to vary between two extremes. The older participant, William, describing aversions to bland food, and foods that were mixed together. In contrast, the younger participant, Joey, preferred bland foods that were pureed, colourless, and at cold or just warm temperature. Again, impact on daily functioning was far greater for the youngest participant who was underweight and visibly much smaller in size for his age. Similarly, variable food preferences have been reported in the literature based on first-hand accounts (Ashburner et al., 2013; Davidson, 2010; Jones et al., 2003). Studies based on reports from caregivers have noted that individuals with ASD have more negative food related experiences than typically developing individuals (Dickie et al., 2009; Schaaf et al., 2011).

Mayes and Zickgraf (2019) also reported that atypical eating behaviours were significantly more common among children and adolescents with autism (70.4%) compared to those with other disorders such as ASD (13.1%) and typically developing children (4.8%). Among the children with autism, limited food preferences were the most common atypical eating behaviours (88%), followed by hypersensitivity to food textures (46%). Mayes and Zickgraf (2019) found that pica, the ingestion of non-

nutritive items such as crayons and paper, was only reported among participants with autism (12%). William's reporting of eating lead from pencils, and chewing hair and string, due to his 'enjoyment' of the textural sensation is of note as it raises questions for further research, in terms of the relationship between apparent sensation seeking behaviours in ASD and pica.

All three participants reported varying degrees of tactile sensitivity, with two reporting aversions to certain types of clothing. Aversions or preferences for particular clothing or fabrics have been described by participants with ASD in several studies (Ashburner et al., 2013; Chamak et al., 2008; Davidson, 2010; Robledo et al., 2012). William reported enjoying extreme sensations, such as touching his eyeballs and pricking himself with screws with apparent decreased sensitivity to pain. This appeared to extend into wanting to experience the extremes of temperatures, by wearing a jacket in summer and t-shirts in winter. Studies based on first-hand accounts have documented experiences relating to hyposensitivities in relation to cravings for specific stimuli (Elwin et al., 2012; Chamak et al., 2008), or having high pain thresholds or insensitivity to pain (Chamak et al., 2008; Elwin et al., 2012; Robledo et al., 2012).

Though less dominant in terms of issues described in relation to the impact of other senses, both children reported sensitivity to smells. William described ability to pick up on faint smells, in addition to reporting he sometimes detected odours with no identifiable source. The younger participant, Joey, reported aversions to certain smells that others could not detect. He also appeared to find enjoyment in a number of smells he found particularly pleasing. Variable olfactory experiences have also been reported in existing literature (Ashburner et al., 2013; Elwin et al., 2013; Jones et al., 2003). In relation to movement, both children reported a love of spinning with 12 year old William enjoying more extreme forms of movement. High levels of movement seeking,

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including spinning around, jumping on trampolines and riding roller coasters, were also reported by adolescent participants with ASD in the study by Ashburner et al. (2013). Overall, movement related sensory experiences are also less commonly described in the literature in comparison to other sensory domains.

All three participants reported actively using strategies to manage sensory challenges. The adult participant, Dave, stated he would use tinted glass, avoid crowded areas, shop at quieter times and focus on one task at a time. Twelve year old William found that always having a book to read and focus on assisted him to block out external noise. The youngest participant, Joey, was reported to have been greatly assisted by sound-cancelling headphones which he was able to put on whenever necessary, and also more recently a therapy dog.

In terms of changes in sensory difficulties, all participants reported improvements in some areas. The youngest participant appeared to have the most severe sensory challenges, and his mother noted that they had found ways to manage rather than reduce these. The adult participant however reported worsening of sensitivity to touch, and greater visual sensitivities. Existing research conducted into developmental changes in sensory functioning and ASD, has similarly indicated worsening of aversions to touch with age, however reported improvements in visual sensitivities (Kern et al., 2006; Leekam et al., 2007). The adult participant also expressed that having a late diagnosis meant that he had only recently become aware of issues such as sensory overload and ways of managing this, but he felt this new found knowledge had assisted him to manage challenges. This highlights the importance of early diagnosis, in addition to improving access to resources among newly diagnosed adults with ASD.

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The final theme related to unusual experiences and feeling different. Two participants reported having particularly strong long-term visual memory for details. Experiences related to colour were also described, with the 12 year old participant indicating he tended to associate colours with objects. The mother of the youngest participant indicated that his colour preferences strongly influenced his food selectivity and play. There are select instances reported in the literature of participant reports of unusual experiences relating to colour, for example, perceiving colour and smell when hearing a sound (O'Neill & Jones, 1997), or that certain bright colours, such as red, were "painful" to look at (Jones et al., 2003, p. 115). As mentioned previously, this experience of one sensory stimulus triggering perception in other sensory areas has been termed synaesthesia (Baron-Cohen, Wyke, & Binnie, 1987).

A relatively recent prevalence study of synaesthesia and autism reported rates of 18.9% (31 out of 164) among adults with autism, three times higher than rates of synaesthesia reported among controls (7.22%, 7 out of 97) (Baron-Cohen et al., 2013). Neufeld et al. (2013) similarly reported a prevalence rate of 17.2% for grapheme-colour synaesthesia (when letters or numbers evoke colours), among 21 adults diagnosed with Asperger Syndrome. Subsequently, Ward et al. (2017) investigated the nature of the link between synaesthesia and autism, reporting that both individuals with grapheme-colour synaesthesia and individuals with autism similarly scored higher on sensory sensitivity (as measured by the Glasgow Sensory Questionnaire (Robertson & Simmons, 2013)) in comparison to controls, suggesting that sensory sensitivity is an important shared link warranting further investigation.

Finally, all participants reported negative experiences relating to feeling different or being made to feel different by others, specifically at school. In the analyses of writings by ASD authors conducted by Davidson (2010, p. 306), she noted

that authors often reported feeling excluded from "mainstream space", largely due to their sensory difficulties, and were particularly sensitive to the construction of this space by the actions and attitudes of the neurotypical majority. Some progress has been made in Australia, in terms of government run initiatives to promote implementation of classroom and teaching strategies to assist students with sensory processing difficulties (ASD Support Materials, 2018). However, much work needs to be done in terms of the active promotion and education of students on inclusiveness and acceptance of difference. This would assist to ensure that children who are already having to cope with challenges, are not further impacted by the behaviours and attitudes of others, which is also important to maximise positive mental health outcomes. This concludes the investigation of three in-depth accounts by individuals with ASD, and Part I of this program of research.

Key findings from Part I, were that sensory challenges overall were reported to have a strong impact on individuals with ASD, their caregivers, and family life. Auditory and tactile aversions appeared to be most commonly described, as well as difficulties in multisensory environments. A range of strategies were described as being implemented in order to cope with sensory challenges, including avoidance when sensory stimuli were deemed as overwhelming. Therefore, the process of needing to find adjustments was highlighted. However, the heterogeneity of experiences described across sensory domains was evident, and sensory management strategies were individualised according to each person's specific challenges. This suggests that the lack of empirical support for certain sensory interventions in contrast to beneficial reports from parents, could potentially reflect this heterogeneity, in that no singular intervention is likely to suit all children with ASD. Further research is therefore necessary. Furthermore, considering existing evidence for the broader autism

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phenotype (Bailey et al., 1995; Piven et al., 1997), a greater understanding of variations among non-clinical populations could assist to clarify issues of heterogeneity in relation to ASD traits. Therefore, Part II of this program of research aimed to investigate autistic traits in the general population in relation to personality and sensory experiences, via three studies: two quantitative and one qualitative. A discussion of the methods utilised for these studies will be presented in the next chapter, following which the findings from both studies will be discussed.

#### **Chapter 5: Part II - Methods**

The current chapter will detail the methods utilised for studies three, four, and five. Survey data was collected from two independent samples. This allowed validation of hypotheses and findings in studies three and four, which were quantitative in nature. Study five involved combining the two samples, in order to conduct a qualitative analysis of participant responses to open ended survey questions. This chapter will describe sample population details, recruitment procedures, measures utilised, and data screening and analyses procedures.

#### **Participants**

A total of 530 non-clinical participants aged between 16 and 82 years were recruited (297 females, 224 males,  $M_{age} = 36.9$  years, SD = 12.65). This was a combined total from two independently recruited non-clinical groups: Sample 1, a paid sample recruited via Amazon's Mechanical Turk (MTurk) (n = 328); and Sample 2, an unpaid community sample (n = 202).

Data were screened and outliers removed following examination of plots and illegitimate response patterns within cases. The remaining participants in Sample 1 (n = 310), ranged in age between 18 and 69 years (M = 38.57, SD = 11.13). One hundred and sixty-eight (54.2%) participants were male (44.2% female, 1% other (transgender, agender), 0.6% unspecified), and 86.1% of participants were located in the USA (11.0% India, 1.0% Canada, 0.6 % UK, 1.2% from other countries). The remaining participants in Sample 2 (n = 194) ranged in age between 16 and 82 years ( $M_{age} = 34.24$ , SD = 14.40). One hundred and forty-five (74.7%) participants were female (23.7% male, 0.5% other (transgender), 1% unspecified), and 79.9% of participants were located in Australia (10.8% India, 2.1% Canada, 1.5 % USA ,1.5 % UK, 1% UAE, 3% other countries). Full characteristics of the final two samples, and final total participant populations are presented in Table 5.1.

	Sample 1 (MTurk, $N = 310$ )	Sample 2 (Community, $N = 194$ )	Total ( $N = 504$ )
<b>Gender</b> ( <i>n</i> , %)	,	• • • • • • • • • • • • • • • • •	. ,
Males	168 (54.2)	46 (23.7)	214 (42.5)
Females	137 (44.2)	145 (74.7)	282 (56.0)
Other (transgender,	3 (1.0)	1 (0.5)	4 (0.8)
agender)			
Unspecified	2 (0.6)	2 (1.0)	4 (0.8)
Age (years, <i>M/SD</i> )	38.57 (11.13)	34.24 (14.39)	36.90 (12.65)
Location (n, %)			
USA	267 (86.1)	3 (1.5)	270 (53.6)
Australia	•	155 (79.9)	155 (30.8)
India	34 (11.0)	21 (10.8)	55 (10.9)
Canada	3 (1.0)	4 (2.1)	7 (1.4)
UK	2 (0.6)	3 (1.5)	5 (1.0)
UAE		2 (1.0)	2 (0.4)
Other countries	4 (1.2)	6 (3.0)	10 (2.0)
Level of Education (n,			
%)			
Less than High School	1 (0.3)	4 (2.1)	5 (1.0)
High School	32 (10.3)	46 (23.7)	78 (15.5)
Partial university degree	58 (18.7)	48 (24.7)	106 (21.0)
Technical college	33 (10.6)	17 (8.8)	50 (9.9)
Bachelors/3rd yr	83 (26.8)	19 (9.8)	102 (20.2)
Honours/4th yr	62 (20.0)	16 (8.2)	78 (15.5)
Masters	36 (11.6)	35 (18.0)	71 (14.1)
Doctorate	5 (1.6)	9 (4.6)	14 (2.8)
Mental Health	74 (23.9)	69 (35.6)	143 (28.4)
<b>Diagnosis</b> (n, %)			

Table 5.1 Participant Characteristics for Samples 1, 2, and Total Population Samples (After Screening)

*Note*: Numbers represent counts with percent of sample in parenthesis.

### Procedure

The studies had full approval from the University of Southern Queensland's Human Research Ethics Committee (Ethical approval no: H17REA247). The survey was hosted online via the host university's secure online survey platform. An explanatory statement at the beginning of the survey informed individuals of the participation criterion (minimum age requirement of 16 years), survey completion time of 20-25 minutes to complete, and confidentiality and privacy policies. Participants were informed that the survey would include a brief series of demographic questions followed by questions on personality scales for assessing autistic traits and personality. Demographic information collected included age, gender, country of residence, level of education, whether the individual had a diagnosis of a mental health issue, and whether the individual had a diagnosis of ASD (subsequently used as a screening question to ensure the final sample was non-clinical). Participants were also informed that the purpose of the survey was to enable a greater understanding of these factors among the general population. Participation was entirely voluntary, and respondents were informed that they could withdraw at any stage. Informed consent was indicated by ticking a box which then allowed access to the survey. All participants completed the survey online, at a time and location of their own convenience.

Participants were recruited over a period of 3 months via emailing the survey link to personal and community networks and posting the link to online community notice boards and general social media sites (Facebook/Twitter links). The survey also recruited students from the university, who were offered one percent course credit for participation. In order to obtain a large sample size, additional participants were recruited separately utilising MTurk. Participation was restricted to MTurk Masters workers (an Amazon rating/qualification indicating that a worker has a record of completing tasks consistently and accurately), and each MTurk participant received payment of \$USD 1.20 for survey completion.

### Measures

Autism Spectrum Quotient 10 (AQ-10 (Adult); Allison et al., 2012). This is a 10-item measure of autistic traits developed from the original 50-item Autism Quotient (AQ) (Baron-Cohen et al., 2001). Participants rate each statement (e.g., I often notice small sounds when others do not) with one out of four responses ranging from 'Definitely Agree' to 'Definitely Disagree'. Rather than using the dichotomous scoring method (1 point for Definitely or Slightly Agree on items 1, 7, 8, and 10, and 1 point for Definitely or Slightly Disagree on items 2, 3, 4, 5, 6, and 9), the study used continuous 1-4 point Likert scoring similarly to other studies (Lau et al., 2013; Palmer et al., 2015) in order to capture variability. Possible scores ranged from 10-40, with higher scores indicating greater levels of autistic traits. The researchers reported sensitivity and specificity values as 0.88 and 0.91 respectively, with good reliability for the AQ-10 (Adult):  $\alpha = 0.85$  (Allison et al. 2012).

International Personality Item Pool (IPIP; Goldberg, 1999). The IPIP is a collection of 3000 items representing various personality scales in the public domain (Goldberg, 1999). Scales selected included: Introversion (10 items) and Anxiety (10 items), representations of the Revised version of the NEO Personality Inventory (NEO PI-R: Costa & McCrae, 1992); Collecting (5 items), originally part of the Oregon Avocational Interest Scales (ORAIS; Goldberg, 2010), and Flexibility (10 items), originally a facet of the Hexaco Personality Inventory (HEXACO-PI; Lee & Ashton, 2004). Each item is rated on a 5-point Likert scale with scores for each item ranging from 1 point for 'Strongly Agree' to 5 points for 'Strongly Disagree'.

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Adequate to good Cronbach alpha reliabilities have been estimated for all scales; Introversion  $\alpha = .73$ , Anxiety  $\alpha = .83$ , Collecting  $\alpha = .84$ , Flexibility  $\alpha = .73$  (ipip.ori.org). Maples, Guan, Carter, and Miller (2014) also reported strong reliability and convergence of the IPIP-NEO scales with the NEO PI-R. Lee et al. (2007) reported satisfactory internal-consistency and reliability for the IPIP–HEXACO and moderately strong to strong convergent and discriminant correlations with the original HEXACO-PI scales.

The State Trait Anger Expression Inventory 2 (STAXI-2; Spielberger,

**1999).** The STAXI-2 is a measure of anger consisting of six subscales: State Anger, Trait Anger, Anger Expression-In (how often anger is felt but suppressed instead of expressing it), Anger Expression-Out (how often an individual outwardly expresses anger towards other people or objects either verbally or physically), Anger Control-In (how often an individual controls angry feeling by calming down), and Anger Control-Out (how often an individual controls the outward expression of angry feelings).

For the purposes of this project only the 10-item Trait Anger subscale was used, which measures dispositional anger. Respondents rate each item on a 4-point Likert scale with responses ranging from 'Almost Never' to 'Almost Always'. Possible scores range from 10-40. The STAXI-2 has been shown to have adequate to strong psychometric properties with internal consistency estimates for subscales ranging from  $\alpha = .73$  to .93 (Spielberger, 1999). Copyright requirements were met prior to use.

The Glasgow Sensory Questionnaire (GSQ; Robertson & Simmons, 2012). The GSQ is a 42-item tool which assesses sensory difficulties in daily life. Respondents rate each item (e.g., Do you find certain noises/pitches of sound annoying?) with one of five responses ranging from 'Never' to 'Always', each scored 0-4 points. Separate hyper, hypo and modality scores (Visual, Auditory, Gustatory, Olfactory, Tactile, Vestibular, Proprioception) may be calculated, as well as a total overall score. Possible scores range between 0 and 168.

Two open ended questions from the original version of the GSQ were included; 'Can you describe below which environments/situations, if any, cause you difficulty or cause you to panic?', and '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'?' A qualitative analysis of responses to these questions was conducted in study five.

The GSQ is a relatively new scale, however evidence to date has suggested that it has good reliability and validity. Significant positive correlations between GSQ and AQ scores in the general population (primarily in the UK) have been reported; r = .78(Robertson & Simmons, 2013), and r = .48 (Horder et al., 2014). Furthermore, Horder et al. (2014) found that in comparison to correlations between AQ scores and two other sensory scales, the Adult/Adolescent Sensory Profile (AASP; Brown & Dunn, 2002) and the Cardiff Anomalous Perceptions Scale (CAPS; Bell, Halligan, & Ellis, 2006), the correlation between the AQ and GSQ was strongest. Horder et al. therefore recommended the GSQ for use in both research and clinical work.

### **Data Screening and Analyses**

Prior to analyses the data were screened by analysing descriptive statistics. SPSS for Windows, version 25.0 was used for descriptive and inferential data analyses. There were no missing values, however, outliers at greater than plus or minus 2.67 standard deviations were detected. These were checked for abnormality and were noted as illegitimate outliers, due to response errors potentially due to inattention. These reflected less than 1% of cases and were subsequently removed. AMOS for SPSS, and MPlus software, were utilised to build and test hypothesised models in studies three and four. Goodness-of-fit indices were based on Pearson's Chi square values, the Root-mean-square-error of Approximation (RMSEA), the Comparative Fit Index (CFI), the Root Mean Square Residual (RMR) or the Standardized Root Mean Square Residual (SRMR), the Goodness of Fit Index (GFI), and the Tucker-Lewis Fit Index (TLI).

This concludes the current chapter on methods utilised for studies three and four, in addition to qualitative analyses conducted in study five. The following chapter will detail the findings of study three, which involved analysis of the factor structure of the AQ-10 followed by exploration of autistic traits in the general population in relation to selected personality traits.

### Chapter 6: Part II – Study Three, Investigation of Autistic Traits and Personality

This chapter will report the results from study three, which involved the investigation of personality in relation to autistic traits in the general population. As discussed, the widely varying symptom severity levels across the ASD spectrum, the identification of the broader autism phenotype in the larger population (Bailey et al., 1995; Piven et al., 1997), and high rates of comorbidity in ASD populations (Hollocks et al., 2018; Stevens et al., 2016) raise many complications when researching and diagnosing ASD. Some have argued that a phenotypic characterisation of ASD, which includes factors additional to the core symptoms of autism, would particularly assist to improve identification those with high-functioning ASD or milder features (Grzadzinski et al., 2013; Romero et al., 2016).

Existing research has reported associations between ASD traits and certain temperaments and personality traits such as higher harm avoidance and lower cooperativeness (Kerekes et al., 2013), as well as higher neuroticism and lower levels of extraversion and agreeableness (Austin, 2005; Wakabayashi et al., 2006). Limited research has been conducted into associations between traits such as anger, introversion, and collecting and autistic traits. Caregiver survey reports have indicated aggression to be an issue, particularly among young children with ASD (Hartley et al., 2008; Kane & Mazurek, 2011). Other studies investigating general population samples have reported positive associations between autistic traits and aggression (Paul et al., 2015) as well as anger rumination (Pugliese et al., 2015). Since evidence has suggested that trait anger is positively associated with aggression (Wang et al., 2018), study three aimed to investigate trait anger in relation to autistic traits.

Higher levels of introversion have been reported to be associated with ASD (Ozonoff et al., 2005a) and the broader autism phenotype (Dor-Shav & Horowitz, 1984;

Li et al., 2017). Similarly, collecting behaviours in relation to ASD have been described in a number of case documentations (Chen et al., 2003; Skirrow et al., 2015; Wing, 1981). However, overall research into these areas is limited. Therefore, study three also aimed to explore relationships between these constructs and autistic traits in non-clinical samples.

Firstly though, since the AQ-10 (Allison et al., 2012) was utilised as a measure of autistic traits, an investigation of the internal consistency and factor structure of the AQ-10 was conducted. This was deemed important due to it being one of few existing brief measures of autistic traits, with limited research into its validity. To our knowledge, this was the first study to: (1) conduct both exploratory factor analysis and confirmatory factor analysis on the AQ-10, utilising two independent non-clinical samples, with the aim of reaching an internally coherent and reliable factor structure for the AQ-10; and (2) to conduct structural equation modelling (SEM) to analyse pathways between autistic traits, trait anger, introversion, and collecting with the secondary aim to gain a greater understanding of the relationships between these constructs. Results are presented below, followed by a discussion of findings.

### Results

An exploratory factor analysis (EFA) of all 10 items of the AQ-10 was conducted on the Sample 2 (Community sample) (N = 202). Sample 2 was selected for the EFA so that the larger Sample 1 could be utilised for additional analyses requiring greater statistical power. Maximum likelihood extraction with oblique promax rotation, was used since the existing evidence base suggested potential correlations between the factors (Austin, 2005; Wakabayashi et al., 2006). Prior to conducting the EFA the data were screened by analysing descriptive statistics. There were no missing values, however, outliers at greater than plus or minus 2.67 standard deviations were detected. These cases were checked for abnormality and they were subsequently removed due to response errors. The remaining participants (n = 194) ranged in age between 16 and 82 years ( $M_{age} = 34.24$ , SD = 14.40). One hundred and forty-five (74.7%) participants were female (23.7% male, 0.5% other (transgender), 1% unspecified), and 79.9% of participants were located in Australia (10.8% India, 2.1% Canada, 1.5% USA ,1.5% UK, 1% UAE, 3% other countries). A summary of means and standard deviations for the AQ-10 items in Sample 2 is presented in Table 6.1.

Table 6.1 Means and Standard Deviations for AQ-10 items - Sample 2 (Community), *N* = 194)

	Mean	SD
AQ1 I often notice small sounds when others do not	2.41	1.01
AQ2 I usually concentrate more on the whole picture, rather than the small details	2.72	.88
AQ3 I find it easy to do more than one thing at once	2.81	.99
AQ4 If there is an interruption, I can switch back to what I was doing very quickly	2.70	.92
AQ5 I find it easy to 'read between the lines' when someone is talking to me	3.11	.92
AQ6 I know how to tell if someone listening to me is getting bored	3.51	.65
AQ7 When I'm reading a story I find it difficult to work out the characters' intentions	3.23	.85
AQ8 I like to collect information about categories of things (e.g. types of car, types of bird,	3.08	.98
types of train, types of plant etc		
AQ9 I find it easy to work out what someone is thinking or feeling just by looking at their	3.12	.84
face		
AQ10 I find it difficult to work out people's intentions	2.86	.81

Analyses of the AQ-10 showed that four factors had eigenvalues >1. However, examination of the point of inflexion of the Scree plot (see Figure 6.1) suggested the retention of three factors (with 56.87% of variance explained). In addition, the first factor accounted for well over 30% of variance explained).

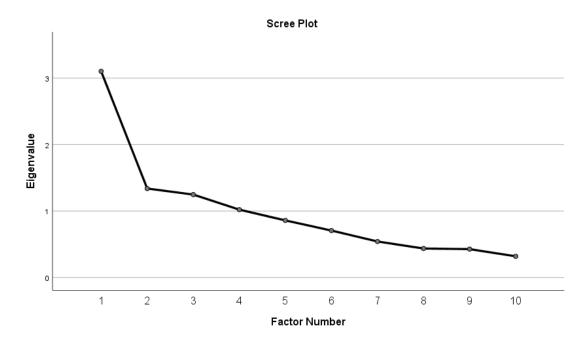


Figure 6.1. Scree plot for exploratory factor analysis of AQ-10

Items with loadings above 0.50 were examined for factor interpretation (see structure matrix in Table 6.2). This was to account for a higher percentage of variance in the variable and exceeds recommendations of minimum thresholds of 0.30 and 0.40 (Field, 2018; Stevens, 2002). Items 1 and 2 had loadings below the threshold, and although Item 8 had a high loading (0.89) on a potential factor (factor 5 in the structure matrix, which had a low eigenvalue (0.86), Item 8 failed to load onto any other factor. In addition, no other items loaded onto factor 5. Therefore, this potential factor and item 8 were excluded from further analyses. The resulting 7 items were grouped into the following factors and the meanings of these constructs were interpreted as follows (see Table 6.2): social cues (Items 5, 6, 9); intentions (Items 7, 10); multi-tasking (Items 3, 4). Having two items load on a factor may be an undesirable situation (Stevens, 2002). However, there were no other items not already retained for social cues that displayed acceptable loadings for intentions and multi-tasking.

			Fact	ors		
	1	2	3	4	5	6
AQ1 I often notice small sounds	.03	.11	.13	.07	.15	.29
when others do not						
AQ2 I usually concentrate more on	.20	.19	09	.16	11	.18
the whole picture, rather than the small details						
AQ3 I find it easy to do more than	.15	.83	.14	.36	.13	02
one thing at once						
AQ4 If there is an interruption, I	.22	.67	.15	.36	.20	.06
can switch back to what I was						
doing very quickly						
AQ5 I find it easy to 'read between	.58	.44	.23	.86	.19	.05
the lines' when someone is talking						
to me						
AQ6 I know how to tell if someone	.91	.24	.24	.57	.21	09
listening to me is getting bored						
AQ7 When I'm reading a story I	.22	.19	.98	.33	.25	10
find it difficult to work out the						
characters' intentions						
AQ8 I like to collect information	.17	.20	.20	.23	.89	01
about categories of things (e.g.						
types of car, types of bird, types of						
train, types of plant etc						
AQ9 I find it easy to work out what	.69	.18	.21	.66	.21	46
someone is thinking or feeling just						
by looking at their face						
AQ10 I find it difficult to work out	.40	.39	.50	.64	.36	45
people's intentions						

Table 6.2 Structure Matrix for AQ-10 Factors - S	Sample 2 (Community), $N = 194$ )
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Extraction Method: Maximum Likelihood.

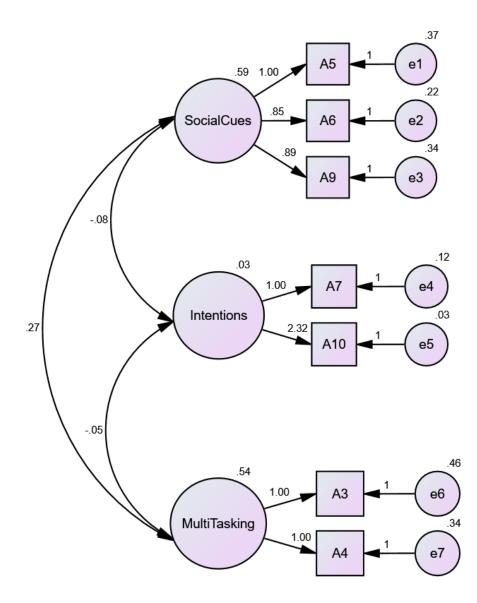
Rotation Method: Promax with Kaiser Normalization.

A CFA replicating the EFA was then conducted on Sample 1 (recruited via MTurk) (N = 328). Again, the data were screened, and outliers were removed (n = 18) using the same procedure used with the first sample. Participants ranged in age between 18 and 69 years (M = 38.57, SD = 11.13). One hundred and sixty-eight (54.2%) participants were male (44.2% female, 1% other (transgender, agender), 0.6%

unspecified), and 86.1% of participants were located in the USA (11.0% India, 1.0% Canada, 0.6 % UK, 1.2% from other countries). A summary of means and standard deviations for the AQ-10 items in Sample 1 is presented in Table 6.3. Results from the CFA indicated moderate fit (ChiSq = .00; GFI = .96; RMR = .03; RMSEA = .10; CFI = .95), demonstrating good reliability (see Figure 6.2).

Table 6.3 Means and Standard Deviations for AQ-10 items - Sample 1 (MTurk), N = 310)

	Mean	SD
AQ1 I often notice small sounds when others do not	2.38	.96
AQ2 I usually concentrate more on the whole picture, rather than the small details	2.81	.85
AQ3 I find it easy to do more than one thing at once	2.80	.96
AQ4 If there is an interruption, I can switch back to what I was doing very quickly	3.10	.90
AQ5 I find it easy to 'read between the lines' when someone is talking to me	3.17	.81
AQ6 I know how to tell if someone listening to me is getting bored	3.41	.67
AQ7 When I'm reading a story I find it difficult to work out the characters' intentions	3.22	.85
AQ8 I like to collect information about categories of things (e.g. types of car, types of bird,	2.60	.99
types of train, types of plant etc		
AQ9 I find it easy to work out what someone is thinking or feeling just by looking at their	3.15	.69
face		
AQ10 I find it difficult to work out people's intentions	3.04	.78



### Figure 6.2. CFA replicating three factor EFA Structure

In examining Figure 6.2, it is noted that in addition to overall fit, which was achieved without allowing error terms to covary, the three factors display significant correlations. In particular, social cues displayed a correlation of r = .27 (p < .01) with

multi-tasking and a correlation of r = -.08 (p < .01) with intentions. The first factor, social cues, accounted for over 30% of variance explained. This factor can be best conceptualised by the item content, which indicates social cues is measuring the ability to read non-verbal social cues. Although the other factors of multi-tasking and intentions showed relationships with each other and with social cues, these factors were excluded from further analyses due to lower eigenvalues, and also the reliance on only two items each, potentially making each factor unstable.

In order to address the second research question, pertaining to investigating the relationships between autistic traits, trait anger, introversion, and collecting in a nonclinical population, the CFA was extended. A non-recursive structural equation model (SEM) was developed and tested using the core AQ-10 factor identified in the previous CFA (social cues), which accounted for 31% of the variance in that model. SEM was conducted on Sample 2 and included covariate paths between social cues, trait anger, introversion and collecting with fully independent error terms. Adequate to good Cronbach alpha reliabilities were estimated for all scales: Social Cues  $\alpha = .76$ , Introversion  $\alpha = .81$ , Collecting  $\alpha = .90$ , and Trait anger  $\alpha = .90$ . Goodness-of-fit values indicated excellent fit for this model (ChiSq =.00; RMR =.04, GFI=.96; TLI=.98; CFI=.99; RMSEA=.05) (see Figure 6.3).

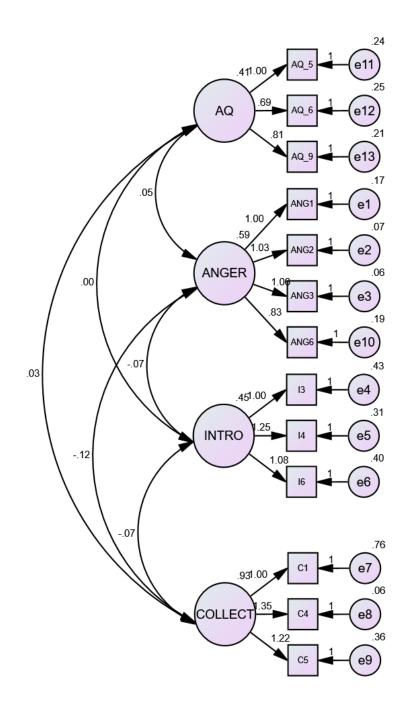


Figure 6.3. Social cues with anger, introversion, and collecting

In addition, analyses of the covariate paths between social cues, trait anger, introversion, and collecting indicated that social cues were not related to trait anger, introversion, or collecting. Introversion and collecting were both negatively related to

	AQ5	AQ6	AQ9	ANG1	ANG2	ANG3	ANG6	INT3	INT4	INT6	C1	C4	C5
AQ5 I find it easy to 'read between the lines' when	1												
someone is talking to me													
AQ6 I know how to tell if someone listening to me is	.52**	1											
getting bored													
AQ9 I find it easy to work out what someone is thinking or	.49**	.59**	1										
feeling just by looking at their face													
Trait anger 1	.02	.12	.09	1									
Trait anger 2	.05	.11	.08	.81**	1								
Trait anger 3	.02	.15*	.07	.76**	.79**	1							
Trait anger 6	03	.06	.05	.61**	.61**	.64**	1						
Introversion 3 Enjoy spending time by myself	00	01	03	.00	01	07	09	1					
Introversion 4 Seek quiet.	05	11	09	.01	.03	05	12	.60**	1				
Introversion 6 Enjoy silence	.03	04	06	.03	.04	02	01	.58**	.60**	1			
Collecting 1 Worked on my collection		19**	07	.02	04	07	.02	.11	.11	.05	1		
Collecting 4 Read a book about the things that I collect		19**	12	07	14	06	02	.06	.05	03	.66**	1	
Collecting 5 Bought a book about the things that I collect	28**	21**	13	06	11	08	03	.06	.08	.03	.68**	.91**	1

### Table 6.4 Correlation Matrix for SEM Factors – Sample 2 (Community), N = 194

\*\* p < .01 \* p < .05

Table 6.5 Sample 2, Community (N = 194) Factor Correlations

	-		•
			Estimate
COLLECT	<>	SOCIAL	.05
ANGER	<>	COLLECT	16**
INTRO	<>	COLLECT	11
ANGER	<>	INTRO	13*
INTRO	<>	SOCIAL	.01
ANGER	<>	SOCIAL	.11

\*\* *p* < .01 \* *p* < .05

#### Discussion

This study aimed firstly to investigate the factor structure of the short form of the widely used AQ, the AQ-10 (Allison et al., 2012). Results indicated that a more coherent and reliable model form for the AQ-10, at least in terms of studying relationships of other constructs in conjunction with autistic traits was a 7 item 3-factor solution comprised of social cues, intentions, and multi-tasking. Secondly, since the social cues category accounted for the greatest proportion of variance (31%), and because the other factors were unlikely to be reliably rendered with two items each, SEM was conducted to analyse co-variate paths between social cues as a distinct factor, and traits associated with autism yet not widely researched; introversion, collecting behaviours, and trait anger. Results indicated that social cue reading was not related to trait anger, introversion, or collecting. Our findings also indicated weak negative relationships between trait anger and introversion and trait anger and collecting, suggesting that those lower in trait anger are likely to be more introverted and more likely to engage in collecting.

The findings of a 7-item 3-factor solution for the AQ-10 suggest that this scale is measuring three separate constructs pertaining to: the ability to read non-verbal social cues (Social Cues), the ability to assess others' intentions (Intentions), and the ability to switch attention or focus on more than one task (Multi-tasking). Three AQ-10 items were excluded from the model, which allowed us to obtain best fit. Two of these related to detail orientation and one referred to collecting. This contrasts with past factor analytical studies of the full AQ, many of which reported the detail orientated construct emerging as a strong factor. A possible explanation for our findings, is that the brief AQ-10 only consists of two items relating to detail orientation and these were worded with opposite valences potentially contributing to a lack of consistency in responses (Conrad et al., 2004; Weems & Onwuegbuzie, 2001).

The excluded item relating to collecting had a high loading but did not load onto any other factors, and therefore did not fit the model. In the full 50 item AQ, this item was originally part of the 'Imagination' subscale. However, from our research it appears more likely that this item is a measure of repetitive behaviours. Also, the only other item from the original AQ 'Imagination' subscale (*When I'm reading a story I find it difficult to work out the characters' intentions*) correlated strongly with the item, *I find it difficult to work out people's intentions*, which was part of the AQ 'Social skill' subscale. Further research into the factor structure AQ-10 based on a clinical population would provide more clarity on its efficacy as a screening tool.

With respect to the trait anger construct, there is evidence that both high-angerprone and low-anger-prone individuals score similarly on measures of social problem solving skills knowledge, i.e., knowing how to respond to anger provoking situations (Conger, Conger, Edmondson, Tescher, & Smolin, 2003; Tescher, Conger, Edmondson, & Conger, 1999). However, those with higher levels of anger appear to have more difficulty executing these social problem-solving skills competently (Conger et al., 2003; Tescher et al., 1999). There is little research into trait anger and social skills pertaining specifically to reading non-verbal cues. It is unclear how or whether selfperceived ability to read social cues would differ from actual performance of social cue reading skills, and how these would relate to trait anger. Further research is therefore required. However, the results do suggest that social aspects of the broader autism phenotype may be unrelated to trait anger. Considering that trait anger has been associated with aggression, and that rates of history of aggression reported by caregivers of autistic individuals are relatively high (Kanne & Mazurek, 2011), it is important to explore other contributing factors to these reported rates. For example, Bronsard, Botbol, and Tordjman. (2010, p.5) investigated aggressive behaviours among autistic individuals and emphasised the key role of the environment in the expression of reactive aggression in terms of provoking an emotional overload "not regulated through cognitive skills such as social communication". Therefore, further research based on individuals with ASD, particularly adults, is necessary to clarify the relationship between autistic traits and trait anger. This is an essential step in not only developing effective management strategies, which has relevance in both clinical and educational settings, but also in challenging commonly held stereotypes about autistic individuals.

In terms of the links between introversion and ability to read non-verbal social cues, Akert and Panter (1988) found that extraverts demonstrated significantly higher accuracy in interpreting social cues than introverts. Most and Greenbank (2000) found that introversion only partially mediated the ability to perceive non-verbal social cues among adolescents with learning disabilities, suggesting the influence of other factors. However, an early study on the perception of social cues in relation to personality factors including introversion-extraversion (Thompson, 1978), did not find introversion to be related to sensitivity to social cues. Combined with our results, these findings suggest that the ability to read social cues is a complex construct which needs further exploration.

The current findings challenge the link between the social 'difficulties' associated with core autistic traits and introversion, and also highlight that these difficulties cannot be automatically associated with introverted personality traits or vice versa. Furthermore, Martin et al. (2015) conducted confirmatory factor analysis using a sample of 664 participants, to investigate the relationship between introversion and social anhedonia, the loss of interest in social interaction often seen in schizotypal personality disorders. They found both constructs to be distinct and separate from each other (Martin et al., 2015). This suggests that introversion needs to be defined and distinguished from other social interactional 'symptoms' warranting clinical diagnoses. In order to clarify the nature of the relationship between social difficulties and introverted personality traits in ASD, further empirical research needs to be conducted utilising a clinical population.

Other than two reports documenting cases of individuals with ASD displaying both collecting and hoarding behaviours and limited social skills (Chen et al., 2003; Skirrow et al., 2015), there is limited empirical research into this area. One study reported significant correlations between high scores on the social skills and communication subscales of the AQ adults and hoarding behaviours among adults with obsessive compulsive disorder (OCD) (Mito et al., 2014). Samuels et al. (2014) also reported that among adults with OCD hoarding behaviours were related to social and communication difficulties, as measured by the Pragmatic Rating Scale (Landa et al., 1992).

Wing (1981, p. 32) noted in her clinical account of Asperger's Syndrome that "all the features that characterise Asperger syndrome can be found in varying degrees in the normal population" and that this also applies to special interests such as collecting objects including "stamps, old glass bottles, or railway engine numbers". For Wing, what distinguishes individuals with Asperger's is that they are at the extreme end of the continuum and particularly have limited social skills and interaction. The current findings that social difficulties pertaining to cue reading and collecting do not covary, do challenge the notion of collecting being associated with high levels of autistic traits. It is unclear whether this would be the case if research was conducted utilising a clinical population. However, our findings also suggest that social aspects of autism could be an independent construct from repetitive behaviours and restricted interests, such as collecting. This is consistent with Palmer et al.'s (2015) findings that among a nonclinical adult population, autistic traits fell into two main domains: social characteristics and detail orientation, that varied independently. Similarly, Shuster, Perry, Bebko, and Toplak (2014) reviewed factor analytic studies examining ASD symptoms in clinically diagnosed ASD populations, and also found that the social/communication appeared to be distinct from the restricted and repetitive behaviours and interests domain. Palmer et al. (2015, p. 1299) suggested that these findings indicated the importance of assessing an individual's social and detail related traits independently rather than viewing ASD as a "unitary spectrum".

In summary, these findings have shown that structurally, the AQ-10 is measuring a series of factors rather than a singular factor (although new items may need to be generated for multi-tasking and intentions if these factors are to be reliably extracted in future research). Since the research question pertained to the relationship between the AQ-10 and traits found in the general population, we included trait anger, introversion, and collecting in the model. The fact that excellent fit was found between the AQ-10 factor that accounted for the largest amount of variance, social cues, and factors measured via non-clinical measures has important implications. Firstly, that autistic traits are distributed widely among the general population and secondly, that individuals with low levels of autistic traits (or neurotypical) could be just as likely to score highly on trait anger, introversion, and/or collecting. Finally, the findings of weak negative relationships between trait anger and introversion and trait anger and collecting were relatively small, but significant. This indicates the possible impact of other variables, which is another area for future research.

In conclusion, the present study provided an alternate 7 item 3-factor solution for the AQ-10 comprised of social cues, intentions, and multi-tasking. A subsequent SEM of the social cues and introversion, collecting, and trait anger constructs indicated that social cue reading was distinct from all three personality constructs. Further research utilising clinical populations is necessary. However, these findings are consistent with the current DSM-5 criteria, which independently classifies social interactional aspects of ASD and repetitive behaviours, such as collecting. A notable implication from these findings is that those with higher levels of autistic traits or ASD who have difficulties interpreting non-verbal communication are not necessarily also introverted, which also suggests that the construct of introversion needs to be distinguished from social interactional 'symptoms' warranting clinical diagnoses. Another implication with consideration of caregiver reports of aggressive behaviours among children with ASD, is the importance of investigating the contribution of other factors such as environment in the expression of anger among autistic individuals, particularly to challenge common stereotypes concerning associations between autism and anger, despite limited empirical evidence. Finally, the finding of excellent fit among the AQ social cues factor and non-clinical measures of trait anger, introversion, and collecting, highlights the difficulty in establishing a clear line between autistic traits and non-autistic traits among the general population. The next study will extend the exploration of personality traits in relation to autistic traits in the general population, in addition to investigating associations with sensory atypicalities. Findings will be presented in the following chapter.

# Chapter 7: Part II – Study Four, Autistic Traits, Sensory Hypersensitivity, Inflexibility and Anxiety

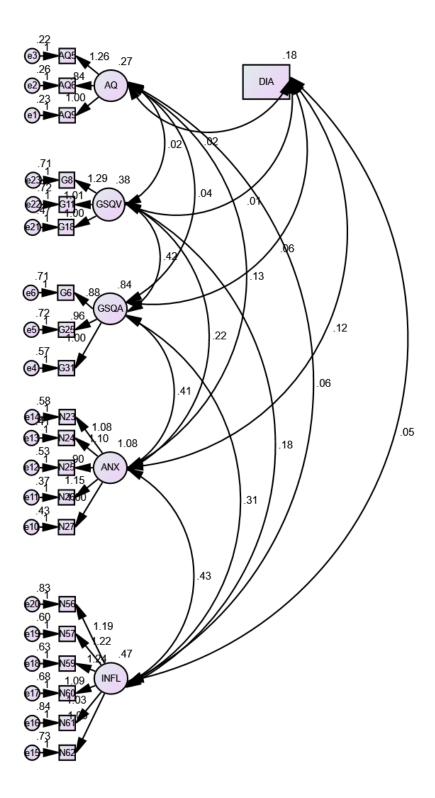
In the previous chapter, findings from study three indicated that the AQ-10 was measuring a series of factors rather than a singular factor, with the social cues factor accounting for the largest amount of variance. Therefore, autistic traits were assessed specifically as indicated by the social cues factor, which reflects the underlying construct of reading and understanding the emotions of others in the immediate social environment (social cue reading ability). Results showed that autistic traits were widely distributed among the general population and that trait level features of anger, introversion, and collecting were not significantly different between individuals with low social cue reading ability and those with higher levels of social cue reading ability. The current chapter will report the results of study four, which continued to focus on social cue reading as a measure of autistic traits in the general population, and aimed to explore this in relation to sensory experiences, trait flexibility, and anxiety.

As discussed, in previous literature anxiety has been shown to partially mediate the relationship between sensory experiences and autistic traits (Horder et al., 2014). In terms of flexibility, the persistent and rigid behavioural patterns and repetitive behaviours and/or interests associated with ASD have been thought to be associated with difficulties responding flexibly to situations, for example, resistance to change, the need for routines, and pre-occupation with certain objects (Gökçen et al., 2014; Leung & Zakzanis, 2014). Findings from Part I also indicated that in relation to coping with sensory challenges, caregivers of individuals with ASD reported needing to establish morning and bedtime routines and structuring weekend activities in order to increase predictability of sensory stimuli (Schaaf et al., 2011). Similarly, accounts from the participants with ASD in study two indicated that finding ways of adjustments were necessary in order to cope with sensory challenges. Furthermore, studies based on behavioural self-reports have stated that individuals with ASD reported greater difficulty in transitioning between situations and activities in comparison to typically developing controls (Leung & Zakzanis, 2014). Overall, however, research into trait flexibility is limited, and little is known about the relationships between trait flexibility in relation to sensory sensitivities, anxiety, and autistic traits among the broader general population. Therefore, it was expected that exploring these relationships would extend existing research, provide further understanding of the broader autism phenotype, and potentially reveal directions for further research in terms of the development of sensory management strategies. Furthermore, due to the high rates of co-morbidity reported among individuals with ASD (Hollocks et al., 2018; Stevens et al., 2016), the relationships between co-occurring mental health diagnoses and these constructs was also investigated.

### Results

A consistent narrative in existing qualitative literature has been that hypersensitivities relating to audition and vision are most commonly reported by individuals with ASD (Elwin et al., 2012; Elwin et al., 2013; Robledo et al.,2012). As discussed, evidence of associations between sensory sensitivities, anxiety, and mental health diagnosis have also been reported (Amos et al., 2018; Horder et al., 2014) along with some findings of self-reported behavioural flexibility difficulties among individuals with ASD traits (Albein-Urios et al., 2018; Leung & Zakzanis, 2014). However, there is limited research into trait flexibility in relation to sensory experiences. Therefore, the current study focused on investigating associations between these constructs in relation to autistic traits in the general population. The three AQ-10 items (Items 5, 6, and 9) identified as a social cue reading factor in the previous analysis (study three) were again used as a measure of autistic traits in the current analysis. A structural equation model (SEM) was developed utilising this social cues factor along with the following new constructs, selected based on the need for further investigation as indicated by the literature and findings from Part I of this thesis: auditory hypersensitivity and visual hypersensitivity items from the GSQ (GSQA and GSQV, 3 items each), inflexibility (10 items), trait anxiety (10 items), and mental health diagnosis (1 item) (See Appendix G for item descriptions). Two independent samples were utilised (Full details on methods including procedures, data screening, and descriptive statistics were presented in Chapter 5).

SEM was initially conducted on Sample 1 (collected via MTurk) (N = 310) and included covariate paths between these constructs with fully independent error terms. Adequate to good Cronbach alpha reliabilities were estimated for all scales: Social Cues  $\alpha = .78$ , GSQA  $\alpha = .77$ , GSQV  $\alpha = .68$ , Anxiety  $\alpha = .93$ , and Inflexibility  $\alpha = .90$ . Goodness-of-fit values indicated moderate fit for this model (ChiSq =.00; GFI=.88; CFI=.91; RMSEA=.07; SRMR =.06) (see Figure 7.1).



*Figure 7.1.* Social cues with visual hypersensivity, auditory hypersensitivity, anxiety, inflexiblity and mental health diagnosis - Sample 1 (MTurk) (N = 310)

Analyses of the covariate paths indicated that social cue reading difficulty was significantly and positively related to anxiety and inflexibility. However, these correlations were small (r = .13 and r = .06 respectively). Effect sizes were very small to small ( $R^2 = .02$  and  $R^2 = .01$ ) (Sawilowsky, 2009). Covariate paths between social cues, auditory hypersensitivity, visual hypersensitivity, and mental health diagnosis were non-significant. In addition to the non-significant path with social cues, visual sensory hypersensitivity was not significantly related to mental health diagnosis. However, auditory hypersensitivity was significantly related to mental health diagnosis (r = .13), in addition to anxiety (r = .41) and inflexibility (r = .31). Visual hypersensitivity was also significantly associated with anxiety (r = .22) and inflexibility (r = .18). Anxiety showed significant positive correlations with all other constructs, particularly inflexibility (r = .43) and auditory hypersensitivity (r = .41). As with anxiety, inflexibility showed significant positive relationships with all other constructs, the highest correlations being with anxiety (r = .43) and auditory hypersensitivity (r = .43).31). Auditory hypersensitivity was significantly related to visual hypersensitivity (r =.42). Finally, mental health diagnosis was significantly related to anxiety (r = .12), auditory hypersensitivity (r = .06), and inflexibility (r = .05), though these correlations were small. Pathways between mental health diagnosis, social cues, and visual hypersensitivity were non-significant. A correlation matrix for SEM factors and factor correlations is presented in Tables 7.1 and 7.2.

	Diag	AQ	AQ	AQ	GV	GV	GV	GA	GA	GA	Anx	Anx	Anx	Anx	Anx	Infx	Infx	Infx	Infx	Infx	Infx
		5	6	9	8	11	18	6	25	31	1	2	3	4	5	1	2	3	4	5	6
Diag	1																				
AQ5	.13*	1																			
AQ6	.00	.52**	1																		
AQ9	.00	.59**	.50**	1																	
GV8	.05	.00	.08	07	1																
GV11	04	04	.09	00	.39**	1															
GV18	.05	.08	.18**	.07	.41**	.47**	1														
GVA6	.08	.03	.06	.06	.46**	.30**	.33**	1													
GA25	.11*	.08	.07	.10	.38**	.24**	.25**	.50**	1												
GA31	.14*	02	.05	.04	.43**	.31**	.44**	.50**	.59**	1											
Anx1	.24**	.18**	.04	.05	.24**	.09	.15**	.31**	.24**	.27**	1										
Anx2	.20**	.22**	.09	.13*	.23**	.10	.17**	.26**	.27**	.25**	.73**	1									
Anx3	.19**	.27**	.20**	.21**	.22**	.11	.22**	.19**	.27**	.18**	.62**	.76**	1								
Anx4	.27**	.20**	.08	.09	.28**	.08	.21**	.30**	.25**	.25**	.75**	.76**	.68**	1							
Anx5	.28**	.21**	.11*	.11*	.28**	.09	.27**	.30**	.34**	.31**	.69**	.70**	.65**	.78**	1						
Infx1	.24**	.14*	.07	.12*	.18**	.11	.19**	.26**	.24**	.26**	.44**	.45**	.35**	.48**	.49**	1					
Infx2	.10	.08	.11	.09	.35**	.17**	.31**	.40**	.39**	.32**	.39**	.41**	.38**	.38**	.41**	.51**	1				
Infx3	.13*	.07	.10	.03	.17**	.03	.19**	.34**	.26**	.22**	.37**	.38**	.29**	.38**	.38**	.48**	.53**	1			
Infx4	.09	.06	.02	01	.19**	.04	.19**	.19**	.21**	.27**	.32**	.34**	.29**	.29**	.29**	.49**	.52**	.50**	1		
Infx5	.05	.11*	.12*	.02	.16**	.20**	.22**	.24**	.20**	.12*	.28**	.30**	.28**	.28**	.37**	.29**	.38**	.49**	.38**	1	
Infx6	.13*	.17**	.18**	.05	.07	.20**	.24**	.13*	.19**	.08	.21**	.26**	.30**	.24**	.30**	.37**	.42**	.46**	.41**	.63**	1

Table 7.1 Correlation Matrix for Items Representing SEM Factors (Sample 1, MTurk, N = 310)

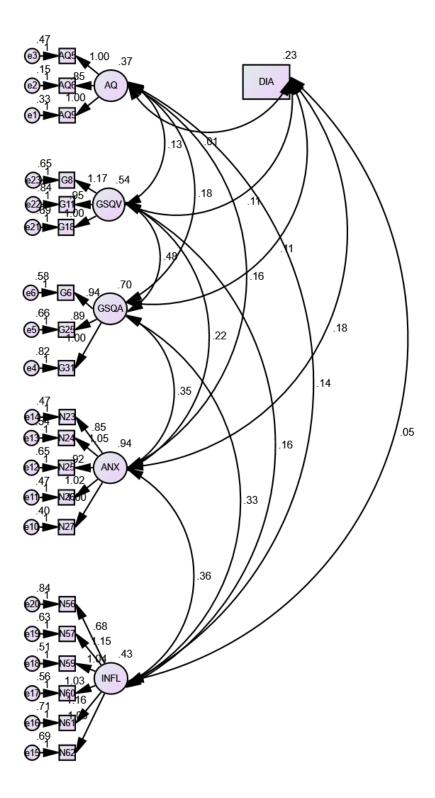
\*\* p < .01 \* p < .05

*Note.* Diag = Mental Health Diagnosis, AQ = Autism Quotient AQ-10, GV = Glasgow Sensory Questionnaire Visual Hypersensitivity, GA = Glasgow Sensory Questionnaire Auditory Hypersensitivity, ANX = Anxiety, INFX = Inflexibility.

			Estimate
AQ	<>	DIA	.08
GSQA	<>	DIA	.15*
ANX	<>	DIA	.28**
INFL	<>	DIA	.18*
AQ	<>	GSQA	.08
AQ	<>	ANX	.24**
AQ	<>	INFL	.16*
GSQA	<>	ANX	.43**
GSQA	<>	INFL	.50**
ANX	<>	INFL	.60**
DIA	<>	GSQV	.04
AQ	<>	GSQV	.07
GSQA	<>	GSQV	.75**
ANX	<>	GSQV	.35**
INFL	<>	GSQV	.42**
** <i>p</i> < .01 *	* <i>p</i> < .05		

Table 7.2 *Sample 1, MTurk (N = 310) Factor Correlations* 

The model was cross-validated utilising Sample 2 (N = 194). Again, adequate to good Cronbach alpha reliabilities were estimated for all scales: Social Cues  $\alpha = .76$ , GSQA  $\alpha = .73$ , GSQV  $\alpha = .70$ , Anxiety  $\alpha = .90$ , and Inflexibility  $\alpha = .80$ . Goodness-offit values also again indicated acceptable fit for this model (ChiSq =.00; GFI=.87; CFI=.91; RMSEA=.06; SRMR =.06) (see Figure 7.2).



*Figure 7.2.* Social cues with visual hypersensivity, auditory hypersensitivity, anxiety, inflexiblity and mental health diagnosis - Sample 2 (Community) (N = 194)

Analyses of the covariate paths indicated that social cue reading difficulty was significantly related to anxiety (r = .16), inflexibility (r = .14), and both auditory and visual hypersensitivity (r = .18 and r = .13 respectively). Overall, these correlations were small. Social cue reading ability, representing level of autistic traits, was not related to mental health diagnosis. In addition to the non-significant path with social cues, mental health diagnosis was not significantly related to inflexibility. However, inflexibility was significantly related to all other constructs, particularly anxiety (r = .36) and auditory hypersensitivity (r = .33). Anxiety and both auditory and visual hypersensitivity were also was significantly related to all other constructs. Anxiety was most strongly correlated with both inflexibility and auditory hypersensitivity (r = .48). Finally, mental health diagnosis was significantly related to anxiety (r = .11), and visual hypersensitivity (r = .11), though these correlations were small. A correlation matrix for SEM factors, and factor correlations are presented in Tables 7.3 and 7.4.

	Diag	AQ	AQ	AQ	GV	GV	GV	GA	GA	GA					Anx5	Infx	Infx	Infx	Infx	Infx	Infx
		5	6	9	8	11	18	6	25	31	Anx1	Anx2	Anx3	Anx4		1	2	3	4	5	6
Diag	1																				
AQ5	.14	1																			
AQ6	.00	.52**	1																		
AQ9	07	.49**	.59**	1																	
GV8	.19**	.14	.17*	.09	1																
GV11	.17*	.12	.23**	.08	.46**	1															
GV18	.27**	.18*	.22**	.07	.48**	.39**	1														
GA6	.21**	.16*	.13	.03	.41**	.34**	.40**	1													
GA25	.19**	.20**	.20**	.26**	.36**	.23**	.31**	.52**	1												
GA31	.19**	.18*	.24**	.23**	.44**	.38**	.37**	.43**	.49**	1											
Anx1	.30**	.16*	.07	.05	.159*	.00	.15*	.28**	.20**	.26**	1										
Anx2	.33**	.32**	.18*	.17*	.16*	.10	.18*	.31**	.22**	.24**	.67**	1									
Anx3	.30**	.23**	.18*	.14*	.17*	.07	.24**	.26**	.22**	.21**	.60**	.71**	1								
Anx4	.30**	.26**	.13	.11	.26**	.12	.22**	.28**	.28**	.23**	.63**	.59**	.56**	1							
Anx5	.34**	.25**	.13	.12	.20**	.11	.19**	.21**	.21**	.13	.61**	.65**	.54**	.79**	1						
Infx1	.10	.07	02	05	.08	01	.08	.15*	.11	.05	.32**	.34**	.23**	.30**	.36**	1					
Infx2	.10	.17*	.18*	.16*	.03	.13	.17*	.28**	.24**	.26**	.23**	.26**	.31**	.27**	.28**	.35**	1				
Infx3	.01	.33**	.27**	.21**	.24**	.075	.29**	.41**	.38**	.31**	.18*	.28**	.22**	.25**	.28**	.26**	.54**	1			
Infx4	.13	.20**	.22**	.17*	.15*	.125	.19**	.36**	.24**	.17*	.32**	.39**	.38**	.36**	.40**	.31**	.47**	.43**	1		
Infx5	.16*	.19**	.18**	.17*	.11	.047	.20**	.29**	.23**	.30**	.31**	.30**	.31**	.35**	.34**	.26**	.43**	.47**	.41**	1	
Infx6	.13	.13	.16*	.05	.17*	.24**	.16*	.34**	.23**	.26**	.18*	.23**	.28**	.29**	.31**	.28**	.40**	.35**	.44**	.52**	1

Table 7.3 Correlation Matrix for SEM Factors (Sample 2, Community, N = 194)

\*\* p < .01 \* p < .05

*Note.* AQ = Autism Quotient AQ-10, GV = Glasgow Sensory Questionnaire Visual Hypersensitivity, GA = Glasgow Sensory Questionnaire Auditory Hypersensitivity, ANX = Anxiety, INFX = Inflexibility.

			Estimate
AQ	<>	DIA	.02
GSQA	<>	DIA	.29*
ANX	<>	DIA	.39**
INFL	<>	DIA	.16
AQ	<>	GSQA	.34*
AQ	<>	ANX	.26*
AQ	<>	INFL	.36**
GSQA	<>	ANX	.43**
GSQA	<>	INFL	.61**
ANX	<>	INFL	.57**
DIA	<>	GSQV	.31**
AQ	<>	GSQV	.30*
GSQA	<>	GSQV	.79**
ANX	<>	GSQV	.31*
INFL	<>	GSQV	.34*
** p < .01	* p < .05		

Table 7.4 Sample 2, Community (N = 194) Factor Correlations

p < .01 \* p < .05

### Discussion

This study aimed to investigate the relationships between trait anxiety, inflexibility, sensory experiences, and autistic traits among a non-clinical population. It also aimed to examine relationships between having a mental health diagnosis and these factors. Since analysis of the AQ10 in the previous study indicated that social cues were the strongest of the three factors identified, items pertaining to social cue reading difficulties were selected as a measure of autistic traits for this study. Sensory experiences specifically pertaining to auditory hypersensitivity and visual hypersensitivity, as measured by the GSQ, were selected due to consistent evidence from first-hand accounts by individuals with ASD that these areas are most commonly reported as being challenging (Elwin et al., 2012; Elwin et al., 2013; Robledo et al.,2012).

Consistent findings across samples were positive relationships among and between inflexibility, anxiety, auditory, and visual hypersensitivity. Social cue reading difficulties were also associated with inflexibility and anxiety, though these associations were weaker. Prior research has indicated links between anxiety, mental health diagnosis, autistic traits, and sensory sensitivities (Horder et al., 2014). This study did not find an association between social cues and mental health diagnosis. Furthermore, results indicated an association between social cue reading difficulty and auditory and visual hypersensitivity in one sample only and this correlation was small.

However, results provided consistently strong evidence that individuals with higher trait inflexibility tended to have higher levels of auditory hypersensitivities. In the analyses association can be inferred, but as a cross sectional study, causality cannot be inferred from the results, which raises questions about whether trait inflexibility leads to individuals being more adversely affected by auditory stimuli, or whether having a higher level of auditory hypersensitivity and associated anxiety leads to greater inflexibility is uncertain. This may have important implications for assisting individuals to manage sensory hypersensitivities, for example, utilising strategies to promote increased flexibility and anxiety management. Further research targeted at exploring this relationship, for example via longitudinal developmental research, is warranted.

Both anxiety and auditory hypersensitivity were associated with having a mental health diagnosis. However, these correlations were small and not entirely unexpected due to anxiety being a symptomatic feature of multiple mental health conditions (APA, 2013), and existing evidence of associations between anxiety and sensory hypersensitivities (Amos et al., 2018). Further research could be directed at exploring whether certain types of mental health diagnoses are more likely to be associated with auditory hypersensitivities, and whether these mental health diagnoses are associated with an overall heightening of senses paralleling generalised or specific anxiety states. This could also contribute to developing targeted strategies to manage these sensitivities.

Finally, the lack of consistently strong associations between social cue reading difficulties and auditory and visual hypersensitivities is interesting, particularly since Robertson and Simmons (2013) reported consistently strong and significant, positive correlations between total sensory score and each of the full AQ sub-scales, including the 10-item 'Social' subscale. In the present study, positive associations between social cues and both auditory and visual hypersensitivities were only found in Sample 2, which was predominantly female. Therefore, it could be that gender effects may account for these differences between samples. However overall, correlations were relatively small in comparison to those found by Robertson and Simmons (2013). Considering that current DSM-5 (APA, 2013) diagnostic criteria for ASD reference sensory symptomatology specifically under the RRBIs criterion, results from the current study are consistent with this and may provide further evidence that sensory hypersensitivities are less likely to be associated with social difficulties, such as cue reading. Furthermore, this argument is strengthened by the significant positive relationships found between inflexibility and sensory hypersensitivities, since reference to inflexible behaviours is also categorised under RRBIs in the DSM-5 (APA, 2013).

Though significant relationships were found between inflexibility and social cue reading, the strength of these associations were relatively small in comparison to inflexibility and sensory hypersensitivities and differed between samples, again suggesting that other factors may be influencing these relationships. It is interesting to note that though literature has reported evidence of links between self-reported cognitive inflexibility on a subscale of the BRIEF-A and higher levels of autistic traits (Albein-Urios et al., 2018; Leung & Zakzanis, 2014). Albein-Urios et al. (2018) noted

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that these positive associations may have been due to similarities between several items of the BRIEF-A shift subscale and ASD symptoms such as "I get disturbed by unexpected changes in my daily routine" reflecting an insistence on sameness. Therefore, links between flexibility and autistic traits pertaining to social cue reading specifically, have thus far not been reported in the literature. Additional research exploring these relationships is important, particularly utilising clinical ASD populations. Furthermore, findings are consistent with the current DSM-5 specification of independently varying social and RRBI core domains Frazier et al. (2008). This suggests that an individual could have high levels of sensory sensitivities and high levels of trait inflexibility, yet relatively good social cue reading ability. However, as discussed in the previous study, ability to read social cues is a complex construct, and whether perceived ability to read social cues translates to demonstrated ability in social situations requires further exploration. The following chapter details the findings of study five, which extended this research through qualitative analyses of accounts of sensory experiences among the broader general population.

## Chapter 8: Part II – Study Five, Qualitative Exploration of Sensory Experiences in the General Population

This chapter will report the findings from study five, which aimed to build on the results of the previous studies through a qualitative investigation of accounts of sensory experiences from individuals in the broader population. To date, only one known study has conducted a qualitative investigation of sensory experiences among the general population (Robertson & Simmons, 2018). Robertson and Simmons (2018) reported that two themes emerged from their analysis, "problematic sensory experiences" and "calming sensory experiences", and that coping mechanisms and certain sensory experiences varied according to level of autistic traits as measured by scores on the full version of the AQ. For example, individuals with high levels of autistic traits reported increased avoidance and greater sensory-based self-soothing coping mechanisms in comparison to those with low or medium levels of autistic traits (Robertson & Simmons, 2018). Therefore, the aim of the current study was to understand sensory experiences of individuals with wide ranging levels of autistic traits in the general population. Differing from Robertson and Simmons (2018), the current analysis pertaining to the general population focused specifically on social cue reading difficulties as a measure of autistic traits (consistent with the previous studies within this program of research), and included only two of the four open-ended questions on the GSQ in order to specifically focus on types of sensory experiences and severity of responses to sensory stimuli. Methods, findings, and a general discussion are presented below.

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#### Methods

### **Participants**

530 non-clinical participants aged between 16 and 82 were recruited (297 females, 224 males,  $M_{age} = 36.9$  years, SD = 12.65) to participate in an online survey (see Chapter 5 for detailed Methods). This was a combined total from two independently recruited non-clinical groups: Sample 1, a paid sample recruited via Amazon's Mechanical Turk (MTurk) (n = 328), and Sample 2, an unpaid community sample (n = 202). Characteristics of the final community, MTurk and total participant population (after removal of outliers) are presented in Chapter 5, Table 5.1.

### **Materials and Procedure**

While studies three and four (discussed in the previous two chapters) examined quantitative data in order to investigate trait level characteristics, sensory experiences, and history of mental health diagnosis across among individuals in the general population broader autism phenotype, study five aimed to analyse the qualitative data elements of the instruments to gain a deeper understanding of these experiences. Therefore, two open ended questions from the original version of the GSQ were included in the online survey: 'Can you describe below which environments/situations, if any, cause you difficulty or cause you to panic?', and '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'?' These items were specifically selected in order to focus on obtaining textual data specific to areas of sensory difficulty for individuals, and the strength of responses to sensory stimuli. These questions were open text and specified as optional.

Scores on the AQ-10 were calculated in relation to the Social Cues factor, items 5, 6, and 9, which were identified in Study 2 as accounting for the largest amount of

variance among the three factors identified (see Chapter 5 for a detailed discussion of this). Accordingly, responses to the open-ended GSQ questions were divided into two groups: individuals with low scores on the Social Cues factor, ranging between scores of 3 and 6 (indicating greater social cue reading ability); and those with high scores, ranging between 7 and 12 (indicating greater difficulty with social cue reading). Examination of a stem leaf plot suggested that a score of 7 was an appropriate split point. Overall, scores on social cues ranged between 3 and 11. Among low scorers a total of 214 out of 389 participants (55.0%) provided responses. Among high scorers a total of 55 out of 115 participants (47.8%) provided responses.

Content analysis, based on Krippendorff's (1980) framework, was utilised to categorise responses. Responses were first independently coded into items based on content by the first author and principal supervisors. Areas of difference were explored via keyword searches and frequency counts, and subsequently discussed and resolved. Items were then subsumed into categories to allow meaningful interpretation.

### Results

Analyses of responses resulted in the coding of 50 content areas. These were then subsumed into six main categories: singles senses (visual, auditory, tactile, and olfactory); people and crowds; multi-sensory situations; unexpected and unfamiliar stimuli; specific fears; and responses to sensory stimuli. Categories, sub-categories, and frequencies and percentages of responses for participants scoring low and high on autistic traits (based on total scores on social cue reading items identified in study three) are presented below in Table 8.1.

### Table 8.1 Comparison of Frequencies and Percentages of Responses Between

## Individuals Scoring High and Low on Autistic Traits

Category	Level of autistic traits							
¥ ;	Low		High					
	(n = 38)	89)	(n = 1)	15)				
	Frequency	(%)	Frequency	(%)				
	of		of					
	responses		responses					
Single senses	78	20.0	23	20.0				
Visual	20	5.1	5	4.4				
Auditory	39	10.0	12	10.4				
Tactile	5	1.3	2	1.8				
Olfaction	14	3.6	4	3.5				
People & crowds	86	22.1	28	24.3				
Multi-sensory environments	11	2.8	7	6.1				
Specific fears	92	23.7	15	13.0				
Small spaces/lift	24	6.2	6	5.2				
Heights	11	2.8	1					
Spiders	2		-	-				
Phones	5	1.3	-	-				
Flying	2		-	-				
Doctors	5	1.3	-	-				
Isolation	5	1.3	-	-				
Agoraphobia	3		-	-				
Public speaking	14	3.6	4	3.5				
Exams/meeting	5	1.3	-	-				
Criticism	3		-	-				
Lose something	1		1					
Pressure/time/late	9	2.3	2					
Cars	3		1					
Responses to sensory stimuli	121	31.1	26	22.6				
Physiological/headache/dizzy/breathing	12	3.1	3	2.6				
Anxious/panic/nervous/stressed/can't	64	16.5	9	7.8				
concentrate/on edge								
Overwhelmed/crying/shutdown/dazzled	19	4.9	4	3.5				
Irritated/annoyed/angry	10	2.6	-	-				
Aggressive	-	-	2					
Self-harm	-	-	1					
Exhaustion	2		1					
Meltdown	9	2.6	-	-				
Worse response when tired	5	1.3	-	-				
Cope better now/trained self to cope	-	-	6	5.2				
Unexpected or unfamiliar situations	14	3.6	3	2.6				

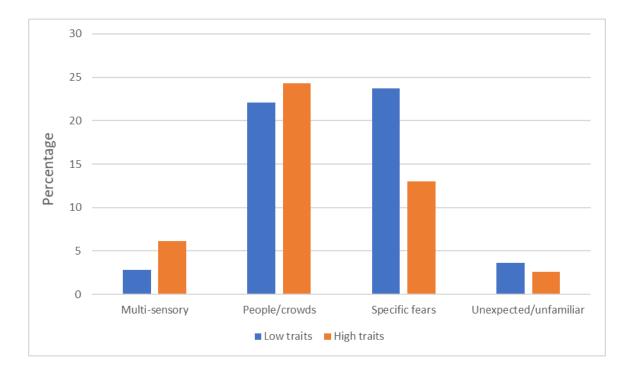
### **Single Senses**

Twenty percent of both the high scoring and low scoring autistic trait groups provided responses describing sensory difficulties related to specific sensory modalities. Similar percentages of individuals in the high scoring and low scoring autistic trait groups described issues relating to vision, audition, touch, and olfaction. Approximately ten percent of individuals in both groups described challenges related to sound, the majority of whom found loud noises aversive. Some indicated awareness of over-sensitivity to loudness of sounds ("even noises that most people would not consider loud upset me a great deal and make me feel as if I am going to crack", "Loud noises really bother me, sometimes even not so loud noises"). A number of others reported that it was loudness of sounds related to people that bothered them ("being in a room with too many loud people"), or caused feelings of claustrophobia ("being in loud crowds makes me feel anxious and claustrophobic", "loud crowds with loud music or noise with an exit hard to find or get to").

Approximately five percent of high scorers reported visual sensitivities in comparison to 3.5% of low scorers, with 96% of all visual issues reported across groups being related to light, particularly bright lights or fluorescent bulbs ("bright lighting makes me feel dazzled and I cannot concentrate on what people are saying. I just want to shield myself from the light", "fluorescent lights bother me in a way that is inhumane. I have quit a job before because I couldn't combat the lighting"). Similar percentages of individuals in each group reported finding certain smells aversive (approximately 3%) ("when others are wearing too much perfume, I cannot stand the smell and have to leave"). Finally, 1.3% of individuals scoring high on autistic traits reported touch to be aversive ("the thought of people touching my body makes me really uncomfortable like hair-cuts or going to the dentist", in comparison to 1.8% of low scoring individuals ("I get easily overwhelmed by any touch").

#### **People and Crowds**

Similar percentages of individuals in the high and low autistic trait scoring groups, reported finding being around people and in crowds difficult (24.3% and 22% respectively) ("Crowds make me feel panicky", "when it's very crowded, I tend to get very nervous"). A number of people noted that not being able to leave the situation bothered them ("Crowds make me feel panicky. Anywhere hot and crowded with no exit in site", "large groups of people, places where points of entry/exit are not well defined"). See Figure 8.1.



*Figure 8.1.* Comparison of percentages of responses between individuals with low and high levels of autistic traits (as measured by social cue reading difficulty).

# **Multi-Sensory Environments**

A greater percentage of individuals scoring high on autistic traits had difficulties in multi-sensory environments and situations (6.1%), in comparison to low scorers (2.8%). The majority of responses from both groups related to finding shopping centres aversive ("shopping centres because there is lots of background noise and people going different directions which can cause them to accidentally run into you").

# **Unexpected and Unfamiliar Stimuli**

Approximately 4% of individuals scoring low on autistic traits found dealing with unexpected or unfamiliar situations, events or people difficult, in comparison to approximately 3% of high scorers ("In unfamiliar environments, I get overwhelmed more quickly").

# **Specific Fears**

A relatively high percentage of individuals scoring low on autistic traits indicated they had specific fears (23.7%), with small confined spaces and lifts being most commonly listed (6.2%), followed by public speaking (3.6%), heights (2.8%), and being late or meeting deadlines (2.3%). Thirteen percent of high scorers indicated that specific fears were an issue, and similarly listed small confined spaces and lifts (5.2%), public speaking (3.5%), and heights (1.7%) as being problematic. A greater variety of specific fears were named by low scorers in comparison to high scorers.

# **Responses to sensory stimuli**

Thirty-one percent of individuals scoring low on autistic traits and approximately 23% of high scorers, provided descriptions on how they responded when dealing with too much sensory input. A relatively high percentage of low scorers indicated that they experienced feelings such as anxiety, panic, nervousness, stress, and difficulty concentrating (16.5%), in comparison to high scorers (7.8%). Approximately 5% of high scorers and 3.5% of low scorers indicated feeling either overwhelmed or tended to cry of 'shut down'. A small percentage of individuals in both low and high scoring groups (3.1% and 2.6% respectively) reported physiological responses, such as headaches, dizziness, or difficulties breathing. Interestingly, 2.6% of low scorers reported feelings of irritation or annoyance ("too much stimulation does irritate me"), whereas 1.7% of high scorers instead reported stronger feelings of anger ("want to yell, attack people"). Also of note is that 5% of high scorers, in comparison to no low scorers, indicated that they had trained themselves to cope with sensory challenges ("I used to reach meltdown quite a lot between the years of 13 to 17, however, I've noticed I rarely become panicked when I go out nowadays"; "over the years I have learned to suppress the panicky feeling and follow others' leads").

# Discussion

The current study aimed to explore sensory experiences among the general population with varying levels of autistic traits, as measured by social cue reading ability. An interesting finding was that a far larger percentage of individuals with lower levels of autistic traits (less difficulty in social cue reading) listed specific fears and phobias as being issues, though similar percentages of individuals across groups listed the same fears as being most problematic (confined spaces, public speaking, and heights). Also, almost double the percentage of low scorers, in comparison to high scorers, indicated that having to deal with too much sensory input led to anxiety, panic and associated responses, with slightly more individuals with lower levels of autistic traits also reporting feelings of being overwhelmed, and physiological responses such as headaches. This is surprising, since specific phobia has been reported to be the most common anxiety disorder among children and adolescents with ASD (van Steensel et al., 2011). However, Hollocks et al. (2018) reported that rates of specific phobia seemed to be lower among adults with ASD, though pooled estimates of anxiety were still much higher than general population estimates. Also, as discussed earlier, Robertson and Simmons (2018) reported that 40% of general population individuals

scoring high on autistic traits (as measured by the full AQ) reported avoidance in response to the GSQ question "How do you calm yourself down if you start to panic?" (not included in the current study). Whether the unexpectedly lower reports of anxiety and specific fears among high scorers in the current study reflects this avoidance is unclear.

In addition, findings from study four indicated that social cue reading difficulties were associated with higher levels of trait anxiety. Therefore, as this study measured autistic traits solely as a function of social cue reading difficulty, and since more low scorers (indicating better social cue reading ability) in this study indicated experiencing anxiety in response to sensory stimuli or overload, this raises a number of other questions. Firstly, whether anxiety 'responses' to sensory input are an independent construct from trait anxiety. Secondly, whether those with higher levels of autistic traits are more likely to have more generalised anxiety (in line with having higher trait anxiety) rather than specific fears. Thirdly, whether those with lower levels of autistic traits, in terms of better social cue reading ability, are more aware of their own specific triggers and responses in comparison to those with higher levels of nonclinical autistic traits and lower social cue reading ability (who may also engage in greater avoidance in terms of reporting of responses to sensory difficulties). Fourthly, whether adults with higher levels of autistic traits have learned to be better able to cope with sensory difficulties, which is plausible, since 5% of high scorers, in comparison to 0% of low scorers, indicated that they had 'trained themselves' to cope with sensory challenges.

Findings from this study also indicated that the percentage of individuals with higher autistic traits (indicating some social cue reading difficulties) having difficulty with multi-sensory environments, though small, was double that of those who had lower

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levels of autistic traits. Therefore, being able to manage multiple stimuli, particularly crowded environments, appeared to be a greater issue for those with higher levels of autistic traits (and greater social reading difficulty). This is also consistent with the results from the first part of this program of research which showed that all three participants with a diagnosis of ASD reported considerable difficulties in multi-sensory environments involving crowds of people.

Also, regardless of social cue reading ability, a considerable percentage of individuals across groups in this study found crowds and people aversive. This suggests that a dislike of crowds is common across the general population. Similarly to the findings from study three, which did not indicate an association between introversion and social cue reading ability, this challenges stereotypical characterisations of individuals with autism as having less inclination towards social interaction than neurotypical individuals.

Furthermore, whereas the current study specifically focused on social cue reading difficulty as a measure of autistic traits, Robertson and Simmons (2018) utilised the full AQ (which included all subscales). They reported that when in multi-sensory environments such as supermarkets, individuals scoring high on autistic traits were more likely to report interaction with sensory stimuli as the main source of discomfort, whereas low and medium scorers reported greater difficulty with crowds. Descriptions of aversions to the 'noise' and visual aspects of crowded environments by all participants with ASD in Part I of this study (e.g., "too many colours", "all those people talking at once"), are consistent with this. Combined with findings from the previous studies in this project, these results are consistent with DSM-5 specification of two independent core domains (social interactional and RRBIs), and suggest that difficulties experienced in multi-sensory environments could potentially be more related to other features of autism such as multi-tasking/attention switching rather than social difficulties. However, further research targeted at investigating relationships between sensory difficulties and multi-tasking difficulties is necessary.

Finally, 10% of individuals across groups, regardless of level of autistic traits as measured by social cue reading difficulty, reported auditory issues, mainly related to loud noises or noises related to people. Similar percentages of individuals across groups reported issues pertaining to visual and olfactory challenges (approximately 5% and 3% respectively). This is consistent with findings from study four which indicated that social cue reading was not consistently associated with auditory and visual hypersensitivities. Since this is in contrast to the existing strong evidence base that individuals with higher levels of autistic traits experience greater sensory challenges, this could suggest that sensory difficulties in ASD are associated with an aspect of autism other than social cue reading difficulty. Therefore, an area for further research is the exploration of auditory and visual sensitivities in the general population in relation to high and low levels of autistic traits as measured specifically in relation to RRBIs or multi-tasking ability (the distinct construct identified in study three), rather than social difficulties. This could provide answers as to whether a higher percentage of individuals with greater difficulties in the RRBI domain would report auditory and/or visual issues, or whether these difficulties are in fact distributed evenly among the general population and are not limited to those with autistic traits or ASD. A general discussion of key findings from all studies in this project will be presented in the following chapter, along with limitations, implications and areas for future research.

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#### **Chapter 9: General Discussion and Conclusion**

This program of research utilised a mixed-methods design in order to gain a fuller understanding of autistic traits, personality, and sensory experiences. The overarching purpose of this was to obtain further insight into the issue of heterogeneity, which evidence has suggested has led to inconsistencies when researching sensory experiences in ASD and the broader autism phenotype, as well as difficulties in the screening and diagnosis of ASD. Therefore, the research was divided into two parts. The aim of Part I was to explore the lived experiences of individuals with ASD and their caregivers in relation to sensory experiences in order to provide a foundation for understanding these experiences and to inform development of the subsequent studies in the program of research. Part II aimed to investigate autistic traits in the general population, in relation to personality traits and sensory experiences, with a view to exploring heterogeneity and the broader autism phenotype.

Part I comprised two studies, beginning with a systematic review of studies based on qualitative data from caregivers of individuals with ASD, and followed by qualitative exploration of reports from individuals with a diagnosis of ASD. Part II comprised three studies, with the first two focused on investigating autistic traits in the general population in relation to personality traits and sensory sensitivities. The final study involved qualitative exploration of sensory experiences among individuals in the general population. This chapter will discuss the key aims and findings from each study, the implications of findings, limitations, and directions for future research.

# Part I - Study 1 (Chapter 3) Systematic Literature Review of Caregiver

#### Perspectives of Sensory Experiences in ASD

The purpose of study one was to investigate key sensory challenges as reported by caregivers of individuals with ASD via a systematic literature review. It was argued that since the majority of qualitative research into sensory experiences and ASD has been focused on caregiver survey (Likert scale response) studies, a synthesis of qualitative research based on textual data from caregivers would provide a deeper insight into the commonalities and variations among these experiences.

A number of themes were identified following review of the final sample of studies. The first related to single senses, with the most commonly reported sensory challenges described by caregivers of individuals with ASD being in the domains of hearing, touch, movement, and taste. Experiences related to vision and oral issues were also described but were reported more frequently within a broader conceptualisation of multi-sensory issues as a whole. Sensory issues that were activated in certain situations were frequently reported, with caregivers making reference to their children's aversive experiences in multi-sensory environments, such as department stores, restaurants, and sporting events, and difficulties with 'sensory overload'. Other themes identified related to caregiver understandings of the individual with ASD's sensory experiences, strategies utilised to manage issues (the need for preparation and planning, intentional gradual exposure to multi-sensory environments, and sensory motor interventions), and the impact of the individual's sensory issues on the family (avoidance of certain situations and activities such as sporting events and social gatherings, the need to constantly monitor the child and the environment, and less attention able to be provided to typically developing siblings). Overall, the systematic review provided insights into caregiver perspectives which were not evident from existing caregiver studies based on survey scale responses, and particularly highlighted the impact of the sensory challenges of the individual with ASD on families and the varying strategies utilised in order to better manage these sensory difficulties.

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A major finding was the discrepancy between caregiver reports of the benefits of sensory based interventions and existing empirical evidence. These interventions were described as widely varying and included sensory based interventions (SBI) (adult-directed strategies integrated into the child's daily routine, body brushing and body pressure, as well as sensory integration therapies (SIT) (clinic-based provision of sensory rich, play-based opportunities for children to engage in self-directed activities) (Case-Smith et al., 2014; Lang et al., 2012). Small randomised controlled trials suggested positive effects for sensory integration therapies but there was little evidence for sensory-based interventions, though Case-Smith et al., (2014) noted that not all studies followed recommended protocols. Despite this, sensory interventions have been reported to be one of the most commonly requested services by caregivers of children with ASD (Goin-Kochel et al., 2007; Green et al., 2006). Therefore, the current findings suggested that further research is necessary to understand these discrepancies, particularly through a more thorough understanding of sensory challenges. Consequently, the subsequent study aimed to explore this further via investigation firsthand accounts of sensory experiences by individuals with ASD.

# Part I - Study 2 (Chapter 4) First-Hand Accounts from Individuals With ASD

Study two aimed to build on the findings of the previous study by qualitatively investigating first-hand accounts from children and adults with ASD. Three main themes were identified, the first relating to types of sensory experiences which included descriptions of visual experiences, sounds, tastes and food preferences, tactile experiences, less dominant senses including smells and movement, and multi-sensory experiences. The second theme related to management of sensory challenges, while the third referred to participants' perceptions of change and difference.

All participants described experiences related to vision, with both child participants describing visual experiences that they found pleasing, such as objects being ordered and nature scenes. All three participants also reported varying degrees of tactile sensitivity, with two reporting aversions to certain types of clothing. Both child participants also reported auditory hypersensitivities, though the younger participant was more severely impacted by these to the extent it affected daily functioning, and both also reported enjoyable auditory experiences in relation to music. Experiences related to taste and food preferences were also reported by both children and their mothers, and appeared to vary between two extremes, with the youngest participant preferring bland, colourless, or pureed foods, and in contrast the older participant, describing aversions to bland food, and foods that were mixed together. Again, impact on daily functioning was far greater for the youngest participant. Sensitivity to odours was described by both children, though olfactory experiences were less dominant overall and individualised. Both children described enjoyable movement seeking experiences, with the older child enjoying more extreme forms of movement similarly to the extreme experiences he described relating to the domains of touch, taste, and vision. Multi-sensory environments, such as shopping centres, movie theatres, and areas crowded with people were particularly difficult for all three participants.

All three participants reported actively using strategies to manage individual sensory challenges, such as tinted eyeglasses or sound cancelling headphones, or avoided situations that could provoke sensory overload. In terms of changes in sensory difficulties, all participants reported improvements in certain areas, whereas the adult reported worsening sensitivity to touch and greater visual sensitivities. Relating to the final theme of unusual experiences and feeling different, a particularly strong long-term visual memory for details was reported by two participants, and both child participants

reported differing experiences related to colour: associating colours with objects, and having very strong colour preferences which influenced food selectivity and choice of play activities. Finally, all participants reported negative experiences relating to feeling different or being made to feel different by others, specifically at school.

# Part II - Study 3 (Chapter 6) Investigation of Autistic Traits and Personality in Two Non-Clinical Samples

Study three aimed to explore relationships between autistic traits (in two independent non-clinical samples), as measured by the AQ-10, and personality traits which had not been widely researched in relation to the broader autism phenotype, namely anger, introversion, and collecting. The AQ-10 is one of the few existing brief measures of autistic traits, however there is limited research into its psychometric validity. Therefore, this study initially sought to explore the internal consistency and factor structure of the AQ-10. Results indicated that a more coherent model for the AQ-10 was a 7 item 3-factor solution comprised of Social Cues (the ability to read nonverbal social cues), Intentions (the ability to assess others' intentions), and Multitasking (the ability to switch attention or focus on more than one task). Since social cues accounted for the largest proportion of variance, and due to this factor being extracted with three items, the social cues items were specifically utilised as a measure of autistic traits in the subsequent analyses.

Structural equation modelling (SEM) was conducted to analyse co-variate paths between social cues and selected trait level characteristics, with results indicating that social cue reading was not related to trait anger, introversion, or collecting. These findings may have important implications for further research into ASD, which are discussed below. Furthermore, the finding of excellent fit in the SEM model as indicated by goodness of fit statistics (Brown & Cudeck, 1993; Hu & Bentler, 1995), among the social cues factor and non-clinical measures of trait anger, introversion, and collecting, highlighted the difficulty in establishing a clear line between autistic traits and non-autistic traits among the general population.

# Part II - Study 4 (Chapter 7) – Sensory Experiences, Autistic Traits, Inflexibility, And Co-Occurring Mental Health Diagnosis

The fourth study extended these findings through exploration of social cue reading in relation to trait flexibility, anxiety, and sensory experiences in the general population. Building on the findings of study three, study four continued to focus on social cue reading as a measure of autistic traits among the two independent general population samples. The aim was to explore social cue reading in relation to trait flexibility, anxiety, and sensory experiences. Sensory experiences specifically pertaining to auditory hypersensitivity and visual hypersensitivity were focused on due to evidence that challenges in these areas were most commonly reported by individuals with ASD (Elwin et al., 2012; Elwin et al., 2013; Robledo et al., 2012). Consistent findings across samples were positive relationships among and between inflexibility, anxiety, auditory, and visual hypersensitivity. Social cue reading difficulty was not found to be associated with a co-occurring mental health diagnosis. Weak but significant correlations were found between a co-occurring mental health diagnosis and both anxiety and auditory hypersensitivity. A significant association between social cue reading difficulty and auditory and visual hypersensitivity was found in one sample only and this correlation was small. The main finding of this study was consistently strong evidence that individuals with higher trait inflexibility and anxiety tended to have higher levels of auditory and visual hypersensitivities. This indicates possible links between adaptation abilities, anxiety, and the severity of sensory challenges experienced among individuals in the general population.

# Part II - Study 5 (Chapter 8) Qualitative Exploration of Sensory Experiences in the General Population

Study five aimed to build on the results of the previous studies by qualitatively investigating accounts of sensory experiences from the broader population. This involved content analysis of responses to two open ended questions from the GSQ, collected from the two broad samples of individuals (detailed in Chapter 5). For this analysis, samples were combined, and consistent with previous studies, level of autistic traits were assessed based on social cue reading. Content analysis resulted in responses being sorted into six main categories: single senses (visual, auditory, tactile, and olfactory); people and crowds; multi-sensory situations; unexpected and unfamiliar stimuli; specific fears; and responses to sensory stimuli. Frequencies and percentages of responses in categories and sub-categories, were compared between participants scoring low and those scoring high on autistic traits.

A higher percentage of general population individuals scoring high on social cue reading difficulty, indicative of ASD traits, (approximately 6% in comparison to low scorers 2.8%) indicated that multi-sensory environments were an issue, particularly due to noise and seeing crowds. However, similar percentages of individuals in the general population, regardless of autistic trait levels, described issues relating to single senses, with the most commonly described issues related to sound (loud noises) and vision (light). A far larger percentage of individuals with lower levels of autistic traits (less difficulty in social cue reading) listed specific fears and phobias as being issues, though similar percentages of individuals across groups listed the same fears as being most problematic (confined spaces, public speaking, and heights). Unexpectedly, double the percentage of low scorers, in comparison to high scorers, indicated that having to deal with too much sensory input led to anxiety, panic, and associated responses, with slightly more individuals with lower levels of autistic traits also reporting feelings of being overwhelmed and invoking physiological responses such as headaches. However, interestingly 5% of high scorers described learning to cope with challenges whereas no low scorers indicated this. Finally, a considerable percentage of individuals across the low scoring and high scoring groups in the general population (10%) found crowds and people aversive, suggesting that a dislike of crowds is common across the general population regardless of social cue reading ability.

## **Unique Contributions to Knowledge**

This program of research makes several contributions to knowledge within the area of autistic traits, personality, and sensory experiences, and findings have implications for clinical interventions and practice. In terms of furthering knowledge and understanding, the following key elements are important contributions from the work: (1) the discrepancy between caregiver reports of the benefits of sensory based interventions and existing empirical evidence; (2) the strong impacts of sensory challenges on individuals with ASD yet individual variability of experiences across sensory domains; (3) evidence for an alternate 7-item, 3 factor structure for the AQ-10 consisting of social cues, multi-tasking and intentions (although the addition of new items is recommended); (4) the lack of an association between autistic traits (as assessed by social cue reading difficulties) and trait anger, introversion, and collecting; (5) positive associations between trait inflexibility, anxiety, and auditory and visual hypersensitivities; (6) the relatively similar percentages of individuals scoring low and high on autistic traits (based on social cue reading difficulty) reporting difficulties relating to single senses (visual, auditory, tactile, and olfactory), people and crowds, and unexpected or unfamiliar stimuli; (7) the substantially higher numbers of individuals with low levels of autistic traits reporting specific fears, and anxiety

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responses to sensory stimuli; and finally (8) common findings across studies one, two, and five, of the need to adjust and use strategies (including avoidance) in order to cope with sensory difficulties highlighting the need for further research into the role of trait inflexibility.

In terms of theoretical frameworks, these findings are in line with Pellicano and Burr's (2012) Bayesian inference approach which proposes that the ways in which individuals cope with the unpredictability of environmental events is central to understanding sensory perceptual atypicalities in ASD. Caregivers and individuals with ASD described processes of learning and needing to adjust to sensory difficulties, through management strategies or avoidance of situations which provoke sensory overload. In combination with the findings that higher trait inflexibility and anxiety are associated with greater auditory and visual hypersensitivities, this is consistent with the idea that sensory difficulties are a result of how an individual interprets environmental sensory inputs rather than to actual impairments in sensory processing (Pellicano & Burr, 2012). This would also account for the individual variability in sensory atypicalities described.

## **Clinical Implications and Future Directions**

The findings from the studies in the current program of research have substantial clinical implications. Furthermore, these are far reaching in terms of encompassing several major fields of psychology. Firstly, the finding that a more internally coherent structure for the AQ-10 consisted of 7 items measuring three distinct constructs: social cues, multi-tasking, and intentions, raises questions as to the validity of using the full AQ-10 as a screening tool for ASD traits. Further research into the development of brief ASD screening measures is therefore necessary.

Since social cues emerged as the strongest of the three constructs, subsequent analyses of general population data (studies three, four, and five) specifically focused on social cue reading as a measure of autistic traits (with high social cue reading difficulty reflecting high ASD traits). A key finding from study three was that social cue reading was unrelated to introversion, trait anger, and collecting. This challenges existing evidence that those with higher levels of autistic traits also have higher levels of introversion. Findings of subsets of individuals with ASD and the broader autism phenotype, who are more extraverted, are consistent with this (Prior et al., 1998; Suh et al., 2016; Wing & Gould, 1979), and suggest that the construct of introversion may need to be distinguished from social interactional 'symptoms' warranting clinical diagnoses such as anhedonia, as suggested by Martin et al. (2015). This is an important diagnostic consideration for clinicians. An area for further research is whether introversion is related to other aspects of ASD, such as attention switching and/or sensory sensitivity in the broader autism phenotype.

The finding that trait anger was not related to autistic traits (as measured by social cue reading) in the general population, is an important step towards potentially challenging societal negative stereotyping of individuals with ASD as having tendencies towards aggressive behaviours, particularly considering recent media trends towards the sensationalist reporting of crimes in relation to autism (Gunasekaran & Chaplin, 2012). Investigating the contribution of other factors such as the environment, which Bronsard et al. (2010) noted played a key role in the expression of reactive aggression (or emotional overload) and was not regulated by social communicative skills, is warranted in consideration of caregiver reports of aggressive behaviours among children with ASD. Further research exploring relationships between trait anger, sensory sensitivities, and attention switching (since multi-tasking was identified

as a distinct construct in study two), in both non-clinical and ASD populations could also elucidate these links. The lack of an association between collecting and social cues also contributes to challenging stereotypes of individuals with ASD traits being more inclined towards collecting. However, considering that collecting behaviours have been linked with 'insistence on sameness' and RRBIs, further exploration of collecting in relation to multi-tasking or attention switching in the broader autism phenotype and individuals with ASD is necessary.

In relation to sensory experiences, a consistently strong finding from study four was that individuals with higher trait inflexibility tended to have higher levels of auditory and visual hypersensitivities. Associations between higher levels of anxiety and auditory and visual sensitivities were also found. This has important implications and clinical applications, in terms of the development of targeted management strategies, for example to promote increased flexibility and anxiety management to assist individuals to manage sensory hypersensitivities. Further research and longitudinal developmental studies targeted at exploring directional relationships between inflexibility and sensory sensitivities among individuals with ASD, is necessary.

Findings from Part I indicated that overall sensory experiences among individuals with ASD are quite variable, highlighting the heterogeneity within ASD populations. However, the strong impacts of challenges, particularly related to auditory and tactile sensitivities in addition to multisensory environments, were consistently described. Findings from Part II indicated that auditory sensitivity, particularly related to noise and crowds, was also reported to be an issue for 10% of general population participants regardless of social cue reading ability (indicative of level of autistic traits), suggesting that this can be an issue for many people. Furthermore, though relatively small percentages of individuals in the general population reported difficulties in multisensory environments, a greater number of individuals with higher levels of ASD traits reported these difficulties (6%), in comparison to those with lower levels of ASD traits. Whether this percentage would increase if autistic traits were assessed as a function of multi-tasking/attention switching rather than social cue reading needs further investigation. This could have important implications particularly since coping in multisensory environments such as shopping centres, crowds, and movie theatres, appeared to be a key challenge reported by individuals with ASD and caregivers. Therefore, whether this is a sensory integrational issue related to multi-tasking difficulties needs further exploration. Furthermore, investigation of perceptions of pleasantness and unpleasantness in relation to sensory stimuli in multi-sensory environments among both the general population and individuals with ASD is warranted. This could provide a better understanding of sensory stimuli and multisensory environments described by some individuals with ASD as being positive (e.g., rainforests) as well as individual variabilities. Findings could then be incorporated into environmental modifications which could extend to work and educational settings.

The higher percentage of general population participants scoring low on autistic traits (indicating better social cue reading ability) reporting anxiety responses to sensory stimuli in comparison to high scorers was unexpected. Noting that 5% of high scorers described utilising strategies or training themselves to cope with sensory issues, in comparison to no low scorers, could be suggestive that those with ASD and high levels of autistic traits have had to be more focused on finding ways to manage sensory difficulties. Therefore, they may more readily provide descriptions of coping strategies rather than responses to sensory challenges. This is consistent with findings from the individuals with ASD in study two, which indicated that strategies were actively utilised to manage sensory challenges, whereas responses to sensory difficulties did not

emerge as a major theme. There could be a possibility that those with higher levels of autistic traits may avoid spontaneously describing responses such as anxiety unless specifically prompted, or find ways of avoiding stimuli that provoke sensory overload in order to manage their responses. For example, findings from both caregivers and individuals with ASD in studies one and two, indicated either the complete avoidance of certain situations that would aggravate sensory issues, or the use of strategies such as leaving situations when necessary or shopping at quieter times.

Furthermore, the fact that a far larger percentage of individuals in the general population, with lower levels of autistic traits (less difficulty in social cue reading) listed specific fears and phobias as being issues than high scorers is surprising due to high rates of comorbid anxiety (including specific phobias) among individuals with ASD (Hollocks et al., 2018; van Steensel et al., 2011). In combination with the previous finding that a greater percentage of general population participants scoring low on social cue reading difficulty reported anxiety responses in comparison to high scorers, as well as findings from study four, indicating an association between social cue reading difficulties (higher autistic traits) and higher trait anxiety, a number of questions arise: (1) whether anxiety 'responses' to sensory input are an independent construct from trait anxiety, (2) whether those with higher levels of autistic traits are more likely to have more generalised anxiety (in line with having higher trait anxiety) rather than specific fears, and (3) whether those with better social cue reading ability have more awareness of their own specific triggers and responses in comparison to those with lower social cue reading ability (higher levels of non-clinical autistic traits). Further research into these areas is therefore warranted.

In terms of the effective management of strategies for sensory issues it appeared that from the individuals and caregivers interviewed in study two, they had all developed individualised ways of coping with difficulties (for example, one wore headphones and had access to a therapy dog, another had tinted glasses, while the third always needed access to a book to focus on when in environments such as shopping centres). The caregivers of the children with ASD interviewed also played an active role in assisting with these strategies. Findings from study one, that some caregivers of individuals of ASD reported the benefits of utilising strategies such as sensory based interventions, despite a lack of empirical evidence for these interventions highlights the need for further research. Potentially, the individual variability of sensory experiences among individuals could mean that consistently positive outcomes from a single intervention is unlikely and that assisting individuals to manage specific issues of concern to them may be more appropriate. Furthermore, the current findings suggest that inflexibility, along with anxiety, is a key trait associated with auditory and visual hypersensitivities. This is consistent with the reports from caregivers and individuals with ASD of needing to find ways to adjust rather than being able to eliminate sensory issues. Therefore, it could be that trait flexibility, in addition to anxiety, modulates whether an individual obtains benefits from sensory interventions rather than the intervention in itself, which may account for inconsistent research findings. This could potentially suggest that strategies aimed at assisting individuals to both improve flexibility and manage anxiety could be beneficial in managing sensory challenges.

In a review of anxiety and ASD by Rodgers and Ofield (2018), the authors suggested that despite various intervention programmes being developed, the underlying mechanisms of anxiety in ASD populations are still unclear and that further research is necessary, particularly in relation to adults with ASD as well as those with co-occurring intellectual disability. Joyce, Honey, Leekam, Barrett, and Rodgers (2017) investigated anxiety and restricted and repetitive behaviours among youth with ASD via self-report measures and parent questionnaires. They reported a significant positive relationship between restricted and repetitive behaviours and anxiety (Joyce et al., 2017). Furthermore, a significant positive relationship was found between parent reported levels of intolerance of uncertainty and between restricted and repetitive behaviours among individuals with ASD (Joyce et al., 2017). As a result of the emerging data on the potential interconnectedness of anxiety, restricted and repetitive behaviours, intolerance of uncertainty and sensory difficulties in ASD, Rodgers et al. (2019) developed protocol for the first parent group intervention programme (Coping with Uncertainty in Everyday Situations) specifically targeting intolerance of uncertainty in children with ASD. Therefore, a key area for continuing future research, which would enable more evidence based programs to be developed, is investigation of the directional relationships between trait inflexibility, anxiety, and sensory atypicalities among individuals with ASD. Considering the previous findings, exploration of the relationships between these constructs and attention switching ability is also warranted.

Finally, similarly to the findings from Robertson and Simmons (2018), the current findings indicate that many individuals in the general population, regardless of social cue reading ability, were reporting sensory issues, finding crowds difficult, and also having aversive responses to sensory stimuli (particularly anxiety). This is a strong indication that there is a need for environmental and societal change as well as greater awareness of stress management. For many individuals with a clinical diagnosis of ASD, these difficulties are clearly amplified and impact daily functioning, yet they have had to find their own ways of coping in environments that are most often catered to the majority (Shankar, Smith, & Jalihal, 2013).

It is evident that in recent times there has been greater awareness of sensory issues, particularly in schools, where accommodations have been made to assist students with ASD (ASD Support Materials, 2018). Transitioning to the workplace has also been highlighted as an area of difficulty for many individuals with ASD (Hendricks, 2010; Taylor & Mailick, 2014). A qualitative study by Pfeiffer et al. (2017) reported that adults with ASD voiced that the physical or sensory environment impacted job satisfaction and performance. Furthermore, Pfeiffer et al. (2018) investigated relationships between social and sensory aspects of person-environment fit and job satisfaction among working adults with ASD. They reported that those with with greater sensory atypicalities, in terms either Sensory Sensitivity or needing more sensory input (Low Registration) as measured by the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002), had significantly lower scores on physical comfort in their work environments, while those with higher sensation avoiding responses reported significantly lower job satisfaction (Pfeiffer et al., 2018). They highlighted the need to consider an individual's unique characteristics in relation to the environment in order to increase job satisfaction and improve person-environment fit (Pfeiffer et al., 2018).

Finally, the issue raised by all three participants with ASD regarding bullying and being made to feel different at school, which appeared to have a strong impact on all of them, is again an indication of the need for societal change in terms of greater acceptance and appreciation of differences. In summary, the findings from this program of research have substantial implications which are far reaching in terms of encompassing the fields of clinical, personality, and developmental psychology. They also impact educational, organisational, and assessment spheres.

### **Limitations and Methodological Issues**

In terms of limitations, it is acknowledged that the research was potentially overly focused on a single factor: socials cues. However, as discussed, this has provided important insights which indicate that future research needs to be directed at investigating other dimension scores. Relating to the quantitative studies, differences in effects were noted between the independent samples potentially signalling Type II errors due to differing sample sizes. Therefore, where effects were observed in Sample 1, there may not have been sufficient data in Sample 2 to detect these effects, potentially reflecting a lack of statistical power. Furthermore, whereas relatively even percentages of males and females were present in Sample 1, the gender ratio was skewed in Sample 2 (approximately 75% female), which may also account for these differences.

In relation to participant selection for the studies utilising general population data, a potential limitation is the use of Amazon's paid recruitment service, Mturk, particularly in terms of the majority of MTurk workers being from the USA. For example, 86% of Sample 1 (MTurk) were based in the USA. However, MTurk is a widely used tool which allows access to a large research participant pool at a low cost (see Paolacci & Chandler, 2014). The low cost also minimised coercive risk. Also, our inclusion criteria specified that workers needed to be MTurk Masters (an Amazon qualification for workers who have a demonstrated record of completing work accurately) as prior research has indicated these workers had higher reliability scores and higher attentiveness to tasks than regular MTurk workers (Peer, Vosgerau, & Acquisti, 2014). Despite these potential limitations, our use of an independent sample from a separate population pool (with the majority of participants being from Australia) increases the validity of findings, and does indicate some replicability across national boundaries. Approximately 11% of both samples were from India indicating our samples were relatively diverse.

Another limitation is the use of self-report measures, which could be subject to response bias and social desirability responding. For example, McEwan, Davis,

MacKenzie, and Mullen (2009) found that the STAXI-2 was vulnerable to social desirability response bias. Foley Hartman, Dunn, Smith, and Goldberg (2002) reported similar findings utilising the original STAXI (Spielberger, 1988). However, both studies were conducted on clinical forensic populations, in comparison to broader non-clinical population samples contributing to this program of research. Taking these limitations into consideration, future research needs to be directed towards replicating findings utilising clinical ASD populations, while incorporating other types of measures in addition to self-reports. Finally, it is acknowledged that there is the possibility that those individuals who consented to participate in the survey may have been particularly interested in the topic.

In relation to the exploration of first-hand accounts of individuals with ASD, a limitation of the study was the small sample size of three participants which limits generalisability, but the rich content provided unique insights into individual experiences of sensory sensitivities from a broad sample of individuals with ASD. Also, for the youngest participant (aged 10 years) with intellectual disability, a greater reliance on caregiver responses and prompting was required in order to clarify meaning and provide context for responses at times. However, final transcripts were analysed by both the researcher and principal supervisor independently, and critically discussed to maximise accuracy of themes. Furthermore, all participants had multiple comorbidities, which may have influenced findings. However, rates of comorbidity and ASD have been reported to be generally high (Ghanizadeh, 2012; Goldstein & Schwebach, 2004; Stevens et al., 2016). Additionally, consistency of findings from study two with existing literature contributes to increasing confidence in the contributions of this data. A strength of study two is the age span and ability range of the participants. Limited research has investigated first-hand accounts of sensory

experiences by young children, particularly with intellectual disability. Although caregiver input was necessary to supplement responses from the youngest participant with intellectual disability, this exploration highlighted the importance of including individuals whose opinions are not always included in the narrative of sensory processing. Strategies that facilitated rapport building and engagement with this particular participant, included incorporation of drawing materials and scented marker pens towards the end of the interview when focus seemed to be waning.

# Conclusion

This thesis aimed to explore autistic traits, sensory experiences, and personality via a mixed methods design. The five studies conducted collectively provided further understanding of the commonalities and variations in trait level characteristics and sensory experiences in relation to ASD and ASD traits. Findings indicated heterogeneity of sensory experiences both across the ASD population and the broader autism phenotype, however, the strong impact of sensory challenges on daily functioning of individuals with ASD was apparent. Additionally among those with ASD, there were consistent reports of needing to adjust and actively use individualised coping strategies, which included avoidance of particularly aversive stimuli. Along with findings that trait inflexibility and anxiety were consistently associated with higher sensory sensitivities in the broader general population, this highlights the need for further research into these relationships. Furthermore, unexpectedly, similar percentages of general population participants indicated sensory difficulties regardless of autistic trait levels. As autistic traits were specifically assessed as a function of social cue reading ability, and since multi-tasking was found to be a distinct construct from social cues, an investigation of multi-tasking ability (or attention switching) in relation to sensory challenges, trait inflexibility and anxiety is strongly urged. Further

exploration of directional relationships among these constructs, in addition to the role of environmental factors, could provide greater understanding of the heterogeneity in sensory atypicalities evident among the ASD population. This could improve individual experiences through tailored management strategies and clinical interventions, positively impact workplace and educational outcomes, and as a whole promote broader acceptance of neurological diversity within societies.

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# Appendix A

	CRITICAL APPRAISAL (CASP) TOOL	YES / NO COMMENTS
1	Was there a clear statement of the aims of the research?	
	Consider: what the goal of the research was, why it is important and its relevance (this	
L	should be explicitly stated in the abstract or introduction).	
2	Is a qualitative methodology appropriate?	
	Consider if the research seeks to interpret or illuminate the actions and/or subjective	
	experiences of research participants (because of the nature of the studies we are including, it	
	is very likely that the answer for this question will always "YES". Only in case of clear	
	doubts we will answer "NO")	
3	Was the research design appropriate to address the aims of the research?	
	Consider: if the researcher has justified the research design (e.g. have they discussed how	
	they decided which methods to use?). We will answer "YES" only in the case we can find in	
	the text the justification of the research design.	
4	Was the recruitment strategy appropriate to the aims of the research?	
	Answer "YES" only in the case the researchers provide information enough to conclude that	
	there is no selection bias. In case you identify a selection bias OR authors don't provide	
	information about the recruitment strategy, we will answer "NO".	
5	Were the data collected in a way that addressed the research issue?	
U	3 aspects need to be reported in order to answer "YES":	
	□ if the researcher has discussed saturation of data AND	
	□ if the researcher has made the methods explicit (e.g. for interview method, is there an	
	indication of how interviews were conducted, did they used a topic guide?) AND	
	□ if the form of data is clear (e.g. tape recordings, video material, notes etc).	
	i fine form of add is clear (e.g. tape recordings, video material, notes etc).	
6	Has the relationship between researcher and participants been adequately considered?	
Ū	Consider whether it is clear: if the researcher critically examined their own role, potential	
	bias and influence during: formulation of research questions, data collection, including	
	sample recruitment, and choice of location.	
	In case information is reported by the authors either in the methodology section (how they	
	avoided this bias) or in the limitations (acknowledging the bias)we will answer "YES".	
	Otherwise we will answer "NO".	
7	Have ethical issues been taken into consideration? Consider: if approval has been sought	
,	from the ethics committee	
8	Was the data analysis sufficiently rigorous?	
0	4 criteria need to be addressed:	
	□ Sufficient data are presented to support the findings (i.e., authors include in the paper the	
	quotes) AND	
	□ Report the type of analysis used (thematic analysis, grounded theory)AND	
	There is an agreement between primary data and secondary data (the results of the	
	authors has to correspond with the information they extracted).	
	<i>Report of triangulation (more than one analyst)</i>	
9	Is there a clear statement of findings? Consider:	
,	2 criteria need to be addressed in order to answer "YES":	
	Summary of the results presented at the beginning of the discussion.	
	Adequate discussion of the evidence both for and against the researcher's arguments	
	D Aucquure discussion of the evidence both for this digunist the researcher's digunents	
10	How valuable is the research?	
10	Answer "YES" only if they report the possible implications of their paper for research OR	
	for practice OR for policy.	
	Critical Appraisal Skills Programme (CASP). Making sense of evidence, 10 questions to help v	1

Critical Appraisal Skills Programme (CASP). Making sense of evidence. 10 questions to help you make sense of qualitative research. Oxford: Public Health Resource Unit, 2006.

## Appendix B



# University of Southern Queensland

# Consent Form for USQ Research Project Interview (Under 18 years)

### **Project Details**

Title of Project: Human Research Ethics

Approval Number:

Investigating Sensory Experiences among Individuals with Autism Spectrum Disorder H17REA062

## **Research Team Contact Details**

## Principal Investigator Details

Ms Shanthi Venugopalan Email: Shanthi.Venugopalan@usq.edu.au Mobile: 0407 640 376

#### Dr Charlotte Brownlow Email: Charlotte.Brownlow@usq.edu.au Telephone: (07) 4631 2982

Dr Erich Fein Email: Erich.Fein@usq.edu.au

### Statement of Consent

### By signing below, you are indicating that you:

• Have read and understood the information document regarding your child's participation in this project.

Supervisors Details

- You and your child have had any questions answered to your satisfaction.
- Understand that if you or your child have any additional questions you can contact the research team.
- Understand that the interview will be either audio or video recorded.
- Understand that you will be provided with a copy of the transcript of the interview for your perusal and endorsement prior to inclusion of your child's data in the project.
- Understand that you, or your child, are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email <u>ethics@usq.edu.au</u> if you do have any concern or complaint about the ethical conduct of this project.
- Are the legal guardian of the child that will participate in this project.
- Agree for your child to participate in the project.

If your child would like to review a transcript of the completed interview (to verify comments) and/or receive a summary of key findings from the study, please provide an email address for it to be sent to:

Child or Young Person's (under 18 years) Agreement to Participate	Parent's (or Legal Guardian's) Consent for a Child or Young Person to Participate	
Name	_ Name	
Signature	_ Signature	
Date	_ Date	
	m member prior to your child participating in the terview.	

## Appendix C

## CAREGIVERS OF INDIVIDUALS WITH ASD SURVEY

FIRST NAME OF CHILD (Names will not be included in final writeup): DATE OF BIRTH: AGE: SEX: Age at which Autism Spectrum Disorder was diagnosed: Who made the diagnosis? Living Arrangements: How many people / children are in the family?

Where does this particular child fit in (e.g. eldest, middle, youngest)? Do any of the other children have any particular needs or similar/other diagnoses?

What educational arrangements do you have for your child with ASD diagnosis (e.g. mainstream, home schooling, special ed.)?

How well does your child adjust to school situations?			
Poorly	Fairly well	Well	Excellently
How would yo	u describe your child's f	riendships?	

Is your child involved in any extracurricular activities?

Are there any medical conditions that you think have an impact on your child?

Is your child currently taking medication? Yes / No

If yes, please describe:

Do you have any other comments about your child's sensory experiences? (optional)

# Appendix D



# University of Southern Queensland

# **Consent Form for USQ Research Project** Interview: Adults

### **Project Details**

Investigating Sensory Experiences among Individuals with Autism Spectrum Title of Project: Disorder Human Research Ethics H17REA062 Approval Number: **Research Team Contact Details Principal Investigator Details** Supervisors Details Ms Shanthi Venugopalan Dr Charlotte Brownlow Dr Erich Fein

Email: Shanthi.Venugopalan@usq.edu.au Email: Charlotte.Brownlow@usg.edu.au

Email: Erich.Fein@usg.edu.au

#### **Statement of Consent**

#### By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you will either talk about your experiences in an interview, or instead submit a written description of your experiences.

[Understand that if you participate in an interview, it will be either audio or video recorded. (Understand that you will be provided with a copy of the transcript of the interview for your perusal and endorsement, prior to inclusion of this data in the project.)]

- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email <u>ethics@usq.edu.au</u> if you do have any concern or complaint about the ethical conduct of this project.
- Are over 18 years of age. •
- Agree to participate in the project.

If you would like to review a transcript if completing an interview (to verify comments) and/or receive a summary of key findings from the study, please provide an email address for it to be sent:

Email:

Participant Name	
Participant Signature	
Date	
Date	

Please return this sheet to the Principal Investigator prior to undertaking the interview.

## Appendix E

Interview format for Individuals with Autism Spectrum Disorder (aged 8 - 17)

Interviews will be semi-structured and questions will be utilised flexibly.

A brief introduction (also included in participant information statement) will be provided.

What are sensory experiences?

We have five main senses which we use to observe and understand the world around us; sight (using our eyes), touch (using our fingers or feelings on our skin such as heat, cold, pain, pressure, itchiness), smell (using our nose), taste (using our tongue) and hearing (using our ears). Sensory experiences may also involve movement such as swinging, bouncing or jumping.

Sample questions:

Which sense would you like to talk about?

Are there any [sounds, sights, smells, etc] that you find difficult? What do you do to make it better?

What types of [insert sense] do you enjoy?

Additional questions may include:

How do sensory issues affect you in different places, for example, at home, at school, in shopping centres, at movie theatres?

*Do you feel you have sensory experiences that are different or unusual from those other people have?* 

Do you think your sensory experiences have changed since you were younger and if so, how?

### Appendix F

Title of Project: Investigating Sensory Experiences among Individuals with Autism Spectrum Disorder Ethics Approval Number: H17REA062

### DEMOGRAPHICS

FIRST NAME (Names will not be used in final write-up):

DATE OF BIRTH: AGE: GENDER:

COUNTRY OF ORIGIN: CURRENT LOCATION/COUNTRY/CITY:

Age at which Autism Spectrum Disorder was diagnosed:

Who made the diagnosis - no names required (E.g. paediatrician?)

Current living situation (please circle/describe):

Living alone / With others (Please describe)

### MEDICAL HISTORY AND HEALTH STATUS

List any significant illnesses or mental health diagnoses you have had in the past:

Are you currently taking medication? Yes / No

If yes, please describe:

EDUCATIONAL HISTORY Highest level of education completed? : Primary School / Secondary School / Technical College / University / Other

If currently studying: Full-time / Part-time? Type of course/field:

How would you describe your academic performance/grades?

List any significant events relating to schooling/education that you think have a bearing on you:

WORK HISTORY Are you currently employed? (please circle): N / Y

If yes: Full-time / Part-time? Occupation

Have you been employed previously? (please circle): N / Y

(Optional) Provide details of previous employment e.g field/industry – identifying names/details are not required:

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### Guide for write-up on sensory experiences: Adults with Autism Spectrum Disorder

The purpose of this study is to collect information from adults and children with autism spectrum disorder (ASD) on their sensory experiences, in order to better understand key sensory challenges, for example in the realms of hearing, vision, touch, taste, smell and movement and/or other. These may impact individuals differently in various settings (e.g. at home, at a shopping centre, in a movie theatre, at work).

Please feel free to write as much or as little as you like about about any sensory experiences you feel are relevant to you. The following questions are a guide (*What sensory experiences are relevant to you (hearing, vision, touch, taste, smell and movement and/or other), Would you describe these experiences as being positive or negative, and why? What do you do to manage negative experiences? How do sensory issues impact you in different environments, for example, home, shopping centres, movie theatres, work, university? What types of things do you think would help you to manage difficulties in certain environments? Are there any sensory experiences you enjoy or would describe positively, and what are they? Do you feel you have sensory experiences that are different or unusual from those other people have? Think back to when you were a child. Do you think your sensory experiences have changed and if so, how?)* 

# Appendix G

Item descriptions - SEM (Social cues, sensory sensitivity, anxiety, inflexibility, mental health)
AQ5 - I find it easy to 'read between the lines' when someone is talking to me
AQ6 - I know how to tell if someone listening to me is getting bored
AQ9 - I find it easy to work out what someone is thinking or feeling just by looking at their face
GSQ8 Visual Hyper - Do bright lights ever hurt your eyes/cause a headache?
GSQ11 Visual Hyper - Do you find yourself fascinated by small particles (for example, little 'bits' of dust in the air)?
GSQ18 Visual Hyper - 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)?
GSQ6 Auditory Hyper - Do you find certain noises/pitches of sound annoying?
GSQ25 Auditory Hyper - Do you dislike loud noises?
GSQ31 Auditory Hyper - Do you react very strongly when you hear an unexpected sound?
(Anxiety) 1 - Worry about things
(Anxiety) 2 - Fear for the worst
(Anxiety) 3 - Am afraid of many things
(Anxiety) 4 - Get stressed out easily
(Anxiety) 5 - Get caught up in my problems
(Inflexibility) 1 - React strongly to criticism
(Inflexibility) 2 - Get upset if others change the way that I have arranged things
(Inflexibility) 3 - Am annoyed by others' mistakes.
(Inflexibility) 4 - Can't stand being contradicted.
(Inflexibility) 5 - Am hard to satisfy.
(Inflexibility) 6 - Am hard to reason with.

Mental health diagnosis - Have you ever been diagnosed with a mental health issue?

Note. AQ = Autism Quotient AQ-10 (Allison et al., 2012), GSQ = Glasgow Sensory Questionnaire (Robertson & Simmons, 2012), Anxiety (IPIP (Goldberg 1999) Public domain representations of the NEO PI-R (Costa & McCrae, 1992)), Inflexibility (HEXACO-PI: Lee & Ashton, 2004).